

Adolescent Nutrition

Assuring the Needs
of Emerging Adults

Yolanda N. Evans
Alicia Dixon Docter
Editors



Springer

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Preface

Adolescence is a time full of growth, opportunity, and potential in addition to risks. As health care providers, we have the unique privilege of playing a role in navigating health behavior. This developmental stage of youth sets the stage for future health over the lifetime. Nutrition is part of every aspect of development, from puberty to cognitive maturity, from growth to self-esteem.

Experts from the Society for Adolescent Health and Medicine stated in the Position Paper on Addressing Nutritional Disorders in Adolescents published in the *Journal of Adolescent Health* (2018):

Adolescent-specific recommendations for nutritional intake differ significantly from adult to child recommendations...factors contributing to nutritional disorders in adolescence include poverty, child maltreatment, political upheaval, socio-cultural influences, and inequitable access to education and health care. Nutritional behavior may be affected by expected developmental and behavioral changes of adolescence, including increased influence from peers and media, evolution of sociocultural beliefs, and body consciousness.

Nuance in communication is critical in all realms given the complexity of providing care to adolescents combined with social determinants of health, necessity to mature, and family dynamics.

We are excited to share this book as a guide for offering developmentally and culturally appropriate nutrition care that respects the autonomy and developing independence of

the adolescent and young adult and at the same time, involve the family and caregivers whenever appropriate. Ultimately, our goal of this publication is to empower the adolescent towards health with an underlying objective to improve outcomes by effectively engaging with each individual. Some of the areas included in this book are new and changing, thus evidence-based approaches to care may be limited. However, we have included authors from an array of disciplines, with extensive clinical expertise in the care of adolescences who bring with them case studies, research where applicable, and future research endeavors in each chapter. As editors, we grew more and more excited as we read each well-written chapter; learning as experts in adolescent health ourselves, from the unique perspective and expertise of each author. We are even more thrilled to share this book with you.

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Part I
General Adolescent Nutrition

Chapter 1

General Adolescent Development



Andrea M. Landis

“The teen years are a time of opportunity, not turmoil”
– McNeely & Blanchard, JHU [15]

There is no consensus about the age range that defines adolescence. Most people agree that the developmental phase of adolescence includes individuals roughly between the ages of 12–19. Conveniently, adolescence can be conceptualized by dividing the process into four psychosocial development phases [17]:

1. Early adolescence or “tweens” - approximate 10–14 years of age; or middle school years
2. Middle adolescence – approximate 15–16 years of age; or high school years
3. Late adolescence – approximate 17–21 years of age; college or employment
4. Young or “emerging” adults – approximate 18–25 years of age.

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Each stage comprises various physical, social, emotional, and behavioral development and tasks. For example, compared to late adolescence; youth in early adolescence experience lower self-esteem due to their preoccupation on physical attractiveness [20]. Important physical, cognitive, and social differences across the different stages will be discussed further in this chapter.

Physical Development

Overall, adolescents are generally healthy. Eighty-three percent of adolescents aged 12–17 years are in excellent or very good health [21].

Both male and female adolescents undergo tremendous growth. They experience an intense 2–3 year growth spurt where females may grow 6–7 in. and males may grow 9 in. [17]. This rapid growth velocity is dependent primarily on hormones such as pituitary growth hormone, thyroid, and sex hormones (estrogen and testosterone). During these growth spurts, bones and muscles get longer and stronger. After the growth spurt, adolescents add height and weight slowly until they reach adulthood. Girls attain most of their height by age 17, while boys lag behind and continue to grow until they are 18–20 years. By then, the majority of adolescents have reached 98% of their adult height. Prediction of the adolescent's adult height is a difficult task. Yet, health care providers can calculate a general estimate or mid-parental target height if both mother's and father's heights are known [17].

Mid Parental Target Height :

For girls : $(\text{father's height} - 13\text{cm (or 5 inches)}) + \text{mother's height} / 2$

For boys : $(\text{mother's height} + 13\text{cm (or 5 inches)}) + \text{father's height} / 2$

Children and adolescents who are smaller than their peers or are not growing at the normal rate according to the CDC Stature-for-age growth charts (<https://www.cdc.gov/growth->

[charts/clinical_charts.htm](#)) may have delayed growth. A growth delay may be caused by an underlying health condition, such as growth hormone deficiency or malnutrition. These individuals need to be evaluated and managed.

Children's body composition changes as they age and varies by natal sex. Providers determine weight status by calculated body mass index (BMI). BMI is an indirect measure of body fat based on weight in relation to stature. BMI is determined by the following formula:

$$\text{BMI} = \text{weight in kilograms} / (\text{height in meters})^2$$

Or

$$\text{BMI} = \text{weight in pounds} / (\text{height in inches})^2 \times 703.$$

BMI measures among children and adolescents need to be expressed relative to other children the same age and sex. Health care providers are recommended to determine weight status by calculating BMI and identifying BMI percentile for age and sex at every encounter [22]. The CDC BMI-for-age charts are the most commonly used indicator to assess and track growth patterns of children and adolescents ages 2–20 in the US. BMI transformed into age- and sex-specific percentiles are also used to determine weight status as defined per the guidelines by the CDC: underweight (less than the fifth percentile), normal or healthy weight (fifth percentile to the less than 85th percentile), overweight (85th to less than 95th percentile), and obese (95th percentile or greater) (Fig. 1.1) [5].

Different parts of the body grow at different rates during this growth spurt. In contrast to the progression of an infant's growth or cephalocaudal direction; adolescent's hands and feet are the first body parts to grow to full adult size, followed by the arms and leg bones; the trunk is the slowest-growing part. As the body gets taller, its shape changes. The composition of the natal female body changes during puberty include the accumulation of fat mass at an average annual rate of 1.14 kg/year [18]. The natal female develops breasts and a soft

adults. At younger ages, boys continue to lag behind girls. In early adolescence, girls achieve complete development of their joints, enabling them to outperform boys of the same age on a variety of athletic skills that require coordination (e.g. gymnastics). However, by age 17 or 18 joint development is more similar. Both males and females show an increase in muscular strength but it is much greater in boys. This difference in strength reflects the underlying difference in muscle mass and distribution between sexes. In adult males, about 40% of total body mass is muscle; compared to only 24% in adult women [17].

Puberty

The growth spurt is one of the first signs that a child is beginning puberty; but it is only part of the story. Puberty is a collective term that encompasses all the changes, both inside and out, that are needed for reproductive organ maturity and capability of reproduction. For the most part, these changes are controlled by the glands of the endocrine system. The mechanisms by which this system is activated are not completely understood, but puberty begins when the hypothalamus starts to release gonadotropin-releasing hormone (GnRH) in pulses. GnRH travels to the anterior portion of the pituitary gland in the brain signaling the release of two more puberty hormones - luteinizing hormone (LH) and follicle-stimulating hormone (FSH) – to the ovaries and testes. These glands secrete hormones that cause the reproductive organs to enlarge and mature - testosterone in males and estradiol in females. Testosterone is the primary hormone responsible for voice changes and attainment of a male body physique. While estrogen plays a key role in growth and the monthly release of an ovum. These hormones are released/inhibited by the central nervous system and enables a positive feedback loop that results in pubertal maturation. This loop is known collectively as the hypothalamic-pituitary-gonadal (HPG) axis (Fig. 1.2). Pubertal changes typically

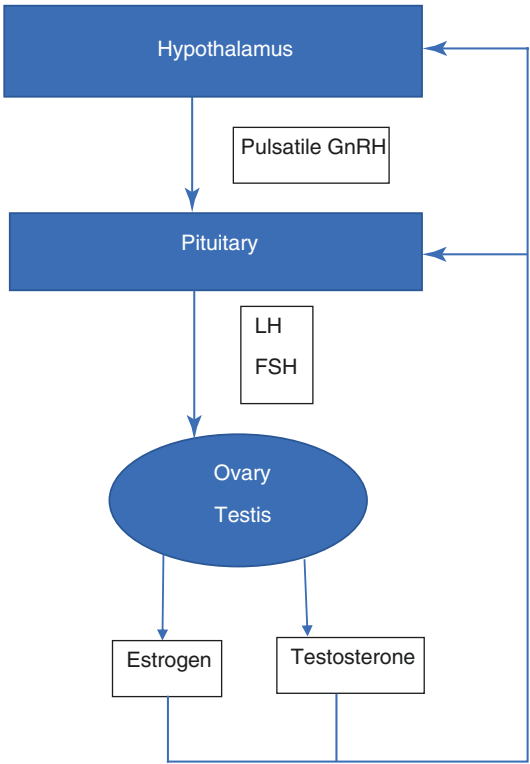


FIGURE I.2 Hypothalamic-pituitary-gonadal axis (HPG Axis)

occur between ages 10–14 for girls and 12–16 for boys [17]. The reproductive organs targeted by hormones, are enlarging and maturing in preparation for future reproduction. The changes experienced by both females and males can be labeled as primary and secondary sex characteristics. Primary sex characteristics include growth of reproductive organs present at birth (testes, penis, ovaries, uterus, and vagina). Secondary sex characteristics emerge during puberty and include breast development in females; deeper voice and beard growth in males. Body hair, acne, body odor occur in both males and females.

For females, the first sign that puberty has begun is enlargement of the breasts, or thelarche. The breasts first appear as breast “buds” with a small mound of glandular tissue beneath the nipple. Females will also see changes in fat distribution around their hips before age 11–12 years and then pubic and underarm hair growth. Females experience their first menstruation (or menarche) approximately 3 years after the growth spurt and approximately 2 years after breast buds appear [17]. Normal range of onset of menarche varies anywhere from 9–15 years and depends on such factors as age of thelarche, race and ethnicity, BMI and parent reported age of menarche. The average age of menarche in the US is 12.4 years [17]. For the first year, periods can be erratic. In one longitudinal study, compared with black participants, Hispanic girls were more likely to have menarche earlier, whereas white and Asian girls were more likely to have menarche later. Parental and adolescent reports of menarche age are highly correlated. BMI had a greater effect on age at menarche than did race and ethnicity; higher the BMI earlier younger the age of menarche [2].

The first sign that a male is entering puberty usually is an enlargement of the testes and sprouting of pubic hair. The volume of each testis will grow from <4 ml to >25 ml. Next the scrotum becomes reddened, thinner, and larger and the phallus begins to grow in size. Genital development and pubic hair development precede the end of the growth spurt. Sperm production in the testes begins between ages 12 and 14. First ejaculation, the action of ejecting sperm from the body, can occur at age 13 or 14. Development of a beard and voice changes occur near the end of the sequence [17].

As with any aspect of human development, the physical changes that adolescents experience happen to everyone, but the timing and order of these changes will vary from person to person. There is no precise timetable, but there is a fixed sequence for the physical changes of adolescence (Fig. 1.3). Chronological age correlates poorly with biological maturity so health care providers use the Sexual Maturity Rating (SMR) scales or Tanner Staging developed in the 1960s to

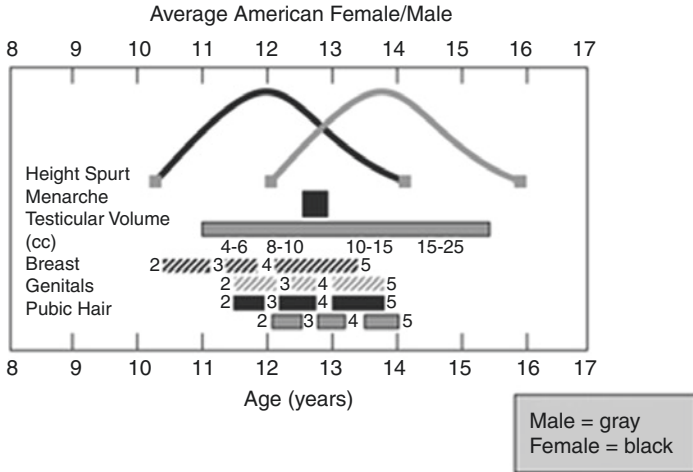


FIGURE 1.3 Puberty sequencing for average American males and females [10]

classify and track physical pubertal maturation. The stages for both sexes are categorized into five stages beginning at pre-pubescent (Stage 1) to adult (Stage 5) [14] (Fig. 1.4). The stages are based on secondary sexual characteristics – breast size and pubic hair for females and penis and testes size and pubic hair for males [17].

The cause of precocious (early) puberty is not fully understood, but it is treatable. Males with an increase in testicular and penile size before age 9 or females with breast development before age 8 are considered “early bloomers.” The opposite is true for late pubertal development or “late bloomers.” Males who have not started having penile and testicular enlargement (>4 ml) by age 14 and girls who have not started having breast enlargement by age 13 or menarche by age 16 are delayed as well [17]. These children need to be evaluated and managed by a health care provider. Delayed puberty could be caused by anorexia, nutritional deficiencies or hormonal insufficiencies. To determine if bone growth is normal, hormone, thyroid, chromosome blood tests and a body-age

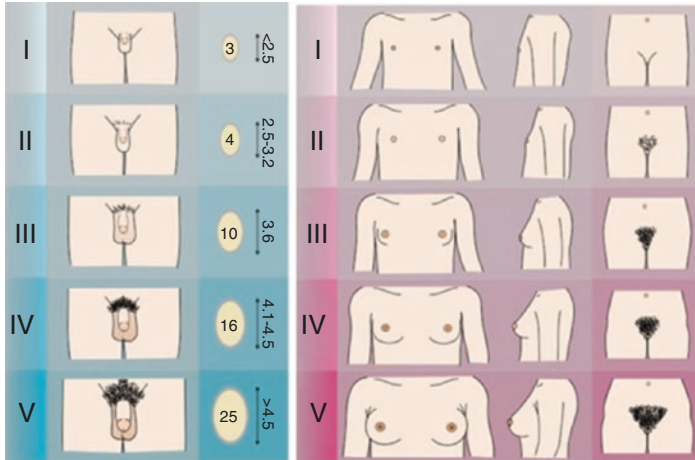


FIGURE 1.4 Tanner staging for boys and girls [23]

radiography of the hand are available to determine if there are other reasons for early or delayed puberty. Early or late pubertal development may just be a normal variation of puberty, or it could be the result of a medical condition that should be treated. Disorders of puberty can hugely impact the adolescent's physical and psychosocial well-being [12].

Just like early childhood, the adolescent brain undergoes a lot of growth and development. But what makes adolescence unique is how the brain undergoes a remodel. The brain grows and strengthens in three ways: generating new neurons, pruning some of the extra neuron growth, and strengthening connections [3]. Adolescence is one of the few times in which the brain produces a large number of neurons at a very fast rate. In fact, many more cells are made than are needed. The extra neurons give adolescents more places to store information, which helps them acquire new skills. The brain trims down or "prunes" the existing neuron growth based on the parts of the brain the adolescent actively uses. This pruning process creates a more differentiated brain structure that enables adolescents to easily access the information they use most. Lastly, the connections between neurons are what

enable the information stored in the brain to be used on a daily basis. The brain strengthens these connections by wrapping myelin sheaths around the axons to protect and insulate them. These changes help adolescents recall information and use it efficiently. Different sections of the brain develop at different times in adolescence. These changes in the brain shape a young person's thinking and help prepare adolescents for adult decision-making. The part of the brain, the prefrontal cortex, responsible for abstract thinking, logic, planning, and decision-making develops last. In the meantime, the part of the brain responsible for emotion, motivation, and impulse control, the limbic system, seems to be in overdrive. The limbic system is a set of brain structures located mid-brain including the amygdala, hippocampus, and hypothalamus. This system overrides the prefrontal cortex, which doesn't mean adolescents aren't rational. It just means that what they feel in the moment may outweigh their logic. The focus on the limbic system in the developing brain leads to heightened risk-reward seeking behavior and poor impulse control. Health risk behaviors, such as substance use and sexual risk-taking, are commonly initiated during adolescence [13]. National data report young people age 15–24 years acquire half of all new STDs, and that one in four sexually active adolescent females has an STD [4]. While the deeper subcortical areas have done most of their development by adolescence; the prefrontal cortex does not fully mature until the mid-twenties or even later [11].

Cognitive Development

The maturational changes in the brain coupled with trying new experiences result in new thinking capabilities, such as enhanced learning, abstract thinking, advanced reasoning, and improved absorption of new information. Children move from a concrete to a more formal logical structured thought process and capacity for abstract thought and reason in adolescence. Dr. Jean Piaget, a Swiss developmental psychologist, developed a blueprint that describes four stages of normal

intellectual development and learning based around mental development, language, play, and comprehension from infancy through adulthood. The four stages are Sensorimotor stage: birth to 2 years; Preoperational stage: ages 2–7; Concrete operational stage: ages 7–11; and Formal operational stage: ages 12 and up. This Formal Operational Stage of cognitive development emerges between age 12–16 [3].

In addition to brain growth and cognitive changes allowing them to think in new ways, adolescents are struggling with the formidable but crucial task of forming an identity. During adolescence, connections with peers are valued as never before and they develop via friendships, romantic relationships, and affiliations with adolescent “crowds” [3]. Emotional support from friends can exceed that from family members. Adolescents are influenced by outside factors such as: parents, peers, community, culture, religion, school, world events, and social media. Survey data from 2018 revealed 95% of adolescents reported having a smartphone and 45% of adolescents age 13–17 say they are online on a “near-constant” basis [1]. Despite the nearly universal presence of social media in their lives, there is no clear consensus among adolescents about the ultimate impact on people their age. Forty-five percent of adolescents believe social media had neither positive nor negative effect on people their age. Meanwhile, 30% reported social media has had a mostly positive impact. Among those who reported it as positive stated the top three reasons were: feeling connected to their friends, help adolescents interact with a more diverse group of people, and have people who will support them through tough times [1]. These responses emphasize how social media has made it easier to communicate with family and friends and to connect with new people. Adolescents value loyalty, intimacy and faithfulness in their friends and typically form friendships with peers who share their interests. Building new connections and establishing identities outside of the family is a normal part of development. Interacting with people outside of the family circle can teach adolescents how to maintain healthy relationships in different contexts and identify roles they can play in the broader community. Erik Erikson, a German-born

American developmental psychologist and psychoanalyst, theorized an identity and psychosocial development theory [8]. According to Erikson's theory, each stage of life is associated with a specific psychological struggle that contributes to a major aspect of personality. The central crisis for adolescents age 13–19 is “identity vs. role confusion.” Erikson posited the development of a sense of identity is the central developmental task of adolescence. He argued that the child's early sense of identity comes partly unhinged in early adolescence because of the combination of rapid body growth and the reproductive changes of puberty. The younger/immature identity will no longer suffice; a new identity must be forged, one that will equip the young person for the myriad of roles of adult life – occupational roles, gender roles, religious roles, and other possibilities. Confusion about all these role choices is inevitable and leads to a pivotal transition Erikson called the identity crisis, a period during which an adolescent is troubled by their lack of identity. Erikson believed that adolescents' tendency to identify with peer groups was a defense against the emotional turmoil that exists in the identity crisis. Ultimately, each adolescent must achieve an integrated view of himself, including his own pattern of beliefs, occupational goals and relationships.

Despite these conflicts, adolescents' underlying attachment to their parents remain strong on average. An adolescent's sense of well-being or happiness is more strongly correlated with the quality of parent or caregiver than peer attachment. Parent support and parental involvement is associated with positive self-esteem, self-efficacy, and academic well-being [19]. Parents or guardians of adolescents are encouraged to provide physical, cognitive, social, and emotional development [6].

Summary

Adolescence is a critical transition from childhood to adulthood. Male and female adolescents experience tremendous physical, pubertal, cognitive, and social development all at

different rates. Brain and pubertal changes enable young people to venture out into the world, learn about their limits and form social identities separate from their families, paving the way for independence.

Case Study

A male age 14 comes into your office. You detect upon walking into the room that he has pungent body odor. You also note that he has some mild facial acne and some axillary hair.

1. Should you conclude that he is going through puberty normally?
2. What hormone causes these changes?

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Chapter 2

Confidentiality



Alana K. Otto and Do-Quyen Pham

Introduction

Case 1

A 16-year-old young woman presents with her mother to a registered dietitian for an initial visit. She was referred by her primary care provider (PCP) for evaluation of possible malnutrition. The young woman is an elite competitive swimmer. She swims 2–4 hours per day, 5 days per week. At a recent well child visit, her PCP noted the patient's last menstrual period was 4 months ago. She had previously had regular monthly periods since menarche at age 12. She otherwise had no complaints, such as acne, hirsutism, or other skin changes. Physical exam was notable for a normal heart rate and a BMI of 22. There was no history of weight loss; in fact, the patient had gained two kilograms since her most recent visit 4 months prior. Laboratory evaluation for possible hormonal etiologies

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of irregular menses was normal. The PCP was concerned the patient was developing the female athlete triad and referred her for nutrition counseling.

At the beginning of the visit, the dietitian explains to the young woman and her mother that she offers all teenage patients a chance to speak with her privately and notes that state laws afford teenagers the right to confidential care for some specific complaints. Later in the visit, the dietitian asks to speak to the young woman alone. After the mother steps out, the provider asks the patient if she has any questions or concerns she would likely to discuss with the provider privately. The patient asks the dietitian if the depot medroxyprogesterone acetate injection she is using for birth control might be the reason her period went away. She reports she started using the medication to prevent pregnancy approximately 6 months ago when she started dating her boyfriend. She does not want her parents to know she is sexually active, so she goes to a free community family planning clinic on her own to get injections. She remembers the family planning provider telling her the medication might cause her periods to be irregular or go away all together.

The dietitian thanks the young woman for sharing this information and notes there is no mention of the medication in the patient's primary care records. She asks the patient if her PCP is aware she is using the medication. The young woman says no, stating "she never asked."

As children grow into adolescents and young adults, their cognitive abilities, independence, and autonomy increase [20]. Although many adolescents assume some responsibility for healthcare-related decisions as their cognitive and social development progress, in most jurisdictions in the United States, parents are legally responsible for medical decisions involving minors, and parental consent is generally required for children to receive health care until the age of 18 [8, 20]. Over the last several decades, however, states have enacted a variety of minor

consent and privacy laws, which allow adolescents to receive healthcare services confidentially, i.e., without parental consent or notification [8, 31].

Confidentiality refers to an agreement to limit or restrict access to private information. In a healthcare context, confidentiality refers to an agreement to keep information shared between the patient and provider private [20]. Minor consent and privacy laws allow adolescents to receive certain types of care without their parents' consent and with the assurance that potentially sensitive information disclosed to their healthcare providers will not be shared with others, including their parents, unless the adolescent explicitly gives her or his provider permission to share [2, 20]. The types of confidential services available to adolescents vary by state. Commonly available confidential services include sexual and reproductive health, mental health, and substance use services [20].

Numerous studies have demonstrated benefits of allowing adolescents to receive confidential care. Adolescents are more likely to seek health care and to discuss sensitive topics when confidentiality is assured [12]. Additionally, studies have found parents think it is important for their teenage children to spend time alone with their medical providers [14, 17, 26]. Professional medical organizations representing pediatric and adolescent medicine providers have long supported adolescent access to confidential healthcare services [1]. Despite consensus among adolescents, parents, and providers about the importance of confidentiality, obtaining and providing confidential services can be challenging for young people and their medical providers, respectively, for a variety of reasons. Furthermore, adolescents, parents, and providers report limited knowledge of adolescent consent and confidentiality laws [6, 22, 29]. For providers, familiarity with regulations regarding adolescents' access to confidential care, along with consideration of common obstacles to confidential care, may facilitate the provision of quality care for adolescent patients.

Legal Considerations

Confidentiality laws determine “who has the right to control the release of confidential information about [health] care, including medical records, and who has the right to receive such information” [10]. Laws and regulations related to confidentiality are shaped by various statutes, regulations, precedents, and court decisions at both the federal and state levels and thus may vary by state [2, 10].

As noted above, in the United States, parental¹ consent is generally required for children and adolescents to receive health care until the age of 18, and parents typically have the right to access their children’s medical records. However, since the 1970s, states have adopted various minor consent laws, which allow minors to consent to certain types of healthcare services without parental consent. Additionally, all states have enacted laws allowing minors who meet certain criteria, such as emancipation from their parents or those who are parents themselves, to consent to their own health care.

In general, when minors have the right to consent to healthcare services, they also have the right to receive those services confidentially, i.e., to control the release of related healthcare information. Practically speaking, this often means that minors may receive such services without the consent, notification, or involvement of their parents and that healthcare providers may not disclose related information to parents without the minor’s permission. However, there are some important exceptions to confidentiality requirements. Generally, providers are required to disclose information an adolescent wishes to keep confidential if a specific law or regulation requires disclosure to parents, a mandatory reporting regulation applies (e.g., in cases of abuse or suspected abuse), or if the adolescent poses a significant danger to her- or himself or to others [10].

¹ Throughout this chapter, the word “parent” is used broadly to refer to biological parents, related caregivers, or other adults who have legal custody or guardianship of an adolescent.

The types of services adolescents may consent to, as well as the types of minors granted the right to consent, vary by state. Familiarity with state and federal regulations specific to one's practice environment is therefore essential for providers who care for adolescents. It is important to note there is no universal age of consent for confidential services; for example, in some states, confidential contraceptive services are available to adolescents 12 and older, while in other states, confidential contraceptive services are available to those 14 and older. Furthermore, age restrictions may vary even within a given state; for example, state law may provide for confidential mental health services for minors 13 and older but confidential contraceptive services only for minors 14 and older.

Common Confidential Topics

Care commonly available confidentially includes sexual and reproductive health, mental health, and substance use services. Laws regarding confidential sexual and reproductive health care for adolescents vary considerably by location; depending on the state, adolescents may have access to confidential testing and treatment for sexually transmitted infections, contraception, abortion, and/or prenatal care.

In some instances, adolescents may present specifically seeking confidential services, e.g., a young woman who presents alone to request birth control. In other cases, confidential topics may come up during preventive visits or acute encounters for unrelated (or seemingly unrelated) medical complaints, e.g., an adolescent with abdominal pain who discloses recent unprotected intercourse and is ultimately diagnosed with pelvic inflammatory disease. Alternatively, providers in a variety of settings may choose to ask adolescent patients about one or more confidential topics in order to perform a complete psychosocial assessment or to assess a patient's risk for morbidity, such as sexually transmitted infections or suicide. In all cases, the laws governing consent and confidentiality apply, i.e., information protected by confi-

confidentiality laws should not be disclosed to parents or caregivers without adolescents' explicit permission unless there is an exception to the adolescent's right to confidentiality.

Providers who care for adolescents commonly use a structured template for psychosocial assessment called HEEADSSS [15, 16]. The HEEADSSS assessment guides conversation about a number of psychosocial topics, some of which may be confidential. It is designed to progress from generally non-threatening topics, such as where an adolescent lives or goes to school, to more sensitive topics, such as whether an adolescent is sexually active or at risk for suicide. For providers, the use of such a template may increase comfort with discussing potentially sensitive topics by providing a standard script and making such conversations routine; it also facilitates the collection of a complete psychosocial history rather than the piecemeal assessment that might result from an unstructured conversation. For adolescents, the use of a standardized template may provide reassurance that questions about sensitive information are routine and not targeted at the specific adolescent, i.e., that they do not reflect judgment on the part of the provider about a patient's behavior. Providers who use the HEEADSSS template may therefore find it helpful to preface the assessment by informing adolescents that these questions are asked of all adolescent patients. For example, a provider might start the assessment by telling an adolescent patient, "*There are some questions I ask all my teenage patients. None of these questions are specific to you, so if any of them don't apply to you or you don't feel comfortable answering, please let me know, and we can skip them and move on to the next question.*" Additionally, assuring adolescents prior to beginning the HEEADSSS assessment that their responses will be kept confidential – and explaining any potential limits to confidentiality – is critical to facilitate open, honest communication during the assessment [15]. See Box 2.1 for more examples of language that may be used to discuss confidentiality with adolescent patients and their families.

Benefits of Confidential Care for Adolescents

Allowing adolescents to spend time alone with their medical providers supports adolescents' emerging autonomy; it also allows for the development of knowledge and skills needed to support one's own health as an adult [26]. Developmentally-appropriate opportunities for medical decision making offer adolescents graded opportunities to develop and hone important skills, including receiving and synthesizing information, asking critical questions, and making important or even difficult decisions.

Confidentiality is essential to this process [5]. The assurance of privacy is paramount to adolescents' trust in their healthcare providers, and this trust affects a young person's willingness to seek medical care and to communicate honestly with their providers. Adolescents describe confidentiality as highly important to them [30, 35]. In several studies, adolescents report they would delay or forgo care because of concerns about privacy [11, 19, 28]; additionally, adolescents report they may not be honest with their providers if confidential care is not available [35]. On the other hand, adolescents' willingness to seek care increases when confidentiality is assured [12, 35], and adolescents are more likely to discuss sensitive topics, including sexuality, mental health, substance use, and self image [12, 14], as well as to be honest with their providers [35], when confidentiality is assured. Furthermore, discussing sensitive topics with a medical provider is associated with adolescents having more positive perceptions of their care; in one study, adolescents were more likely to report their providers understood their problems, eased their worries, allowed them to make decisions, gave them some control over their care, and allowed them to take responsibility over their care when encounters involved discussion of one or more sensitive topics [4].

The Role of Parents and Caregivers

Although parents of adolescents also generally describe confidential care for adolescents as important [14, 17, 26], their views on the topic are more complex, and their attitudes about confidential care for their children may be conflicting [2, 26]. For example, in a nationally representative survey of parents of adolescents, an overwhelming majority (89%) believed their teenage children should be able to speak with medical providers alone, yet a majority (61%) still preferred to be in the room with the adolescent and provider for the entire visit [14]. Furthermore, although parents are able to identify many of the benefits of confidential care for adolescents, many expect providers to disclose sensitive information to them, even if such disclosure is against their child's wishes [9, 24]. Moreover, some parents fear that confidential care promotes risky behavior or undermines their ability to protect their children [25]. Providers should be mindful of the potential for these concerns among parents and ensure that both adolescents and their parents understand the rationale behind giving adolescents opportunities to speak with providers alone. It is also essential for patients, parents, and providers to be on the same page about what information will or will not be kept confidential and for this understanding to be established prior to an adolescent speaking with a provider alone.

Of note is that negative parental perceptions of confidential care for adolescents may be amenable to change through parent education. One study found that providing parents with information about the benefits of confidential care and legal limits to confidentiality was associated with increases in the proportions of parents who agreed with the notions that there are good reasons for teens to receive confidential care and that teens should be able to speak with their providers alone; additionally, provision of this information was associated with significant increases in parental knowledge of confidentiality and consent laws [17].

Importantly, obtaining confidential care does not appear to be associated with secrecy or deception between adolescents and their parents: in one study, adolescents seen at an urban teen clinic for confidential services were equally likely as those seen for non-confidential services to inform their parents they'd been to the clinic and to tell them all the reasons for their visit, with the majority of both groups reporting that their parents knew about their visits and the reasons for them. There was also no difference between those seen for confidential vs non-confidential services in willingness to tell their parents about a serious or sensitive health problem, such as pregnancy, a sexually transmitted infection, or substance abuse [21]. Additional studies suggest many, although certainly not all, adolescents tell or would be willing to tell their parents about their use of confidential health services [18, 36]. Providers should therefore not assume that all adolescents who receive confidential services do so without the knowledge or support of their parents. Providers may find it helpful to ask adolescent patients whether their parents are aware of confidential information, and if so, if their parents are supportive of the adolescent seeking care. Furthermore, if providers plan to interact with parents after discussing a confidential topic with an adolescent patient, they may find it beneficial to have frank conversations with adolescents prior to these interactions in order to delineate the specific details of what will or will not be shared with the parents.

In some cases, adolescents may be willing to share sensitive information with their parents but feel uncomfortable doing so. In these situations, providers may serve as valuable resources for facilitating communication between adolescents and their parents. Again, the provider should first have a candid conversation with the adolescent about what information is to be shared and about the adolescent's preferences for the conversation. In some instances, the adolescent may ask the provider to share sensitive information on her or his

behalf; in others, the adolescent may ask a provider to initiate a conversation about a sensitive topic and allow the adolescent to take over the conversation when she or he feels comfortable; in still others, a provider's presence alone may help an adolescent feel comfortable disclosing sensitive information to a parent.

Communicating with Adolescents and Families

Confidentiality is a complex topic, and the nuances of consent and confidentiality laws may not be well understood by adolescents or their families. In a study by Lyren et al. [24], adolescent patients and their parents had drastically different expectations about whether providers could or would tell parents information the adolescent wanted to keep private. Thus it is critical that providers who care for adolescents ensure adolescent patients and their parents understand the types of information that may (or must) be kept confidential as well as the limits of confidentiality.

As noted above, it is recommended that providers outline expectations for confidentiality at the outset of a visit. Some centers also inform families to expect an adolescent to meet with a provider alone prior to a visit via letter or online notification. Setting the expectation that the provider will speak with the patient alone prior to or at the beginning of the visit normalizes the process and eliminates the possibility of the perception that the provider is requesting to speak to the patient alone in response to information that arises during the visit; the latter may be perceived by the adolescent as judgmental or by parents as a sign the provider has specific concerns about the adolescent's behavior that she or he has not shared with the parents. Furthermore, outlining the applicable protections and limitations of confidentiality at the beginning of a visit, before the adolescent is

asked about potentially sensitive topics, allows the adolescent to make an informed decision about the types and extent of sensitive information they wish to share with the provider.

Whenever possible, providers should speak with adolescents and their parents together about the applicable protections and limitations of confidentiality to minimize the potential for misunderstanding. The following is one example of a strategy for structuring an appointment when an adolescent patient is accompanied by a parent:

- The patient and parent are roomed together.
- With both the patient and parent in the room, the provider informs the patient and parent that it is standard practice in the center for all adolescent patients to have an opportunity to speak to their providers alone. The provider briefly explains the rationale behind and benefits of confidential care for adolescents, the expectation that information discussed privately will be kept confidential, and the limits of confidentiality in the state. The provider checks for understanding and answers any questions the patient and/or parent may have.
- At an appropriate point in the encounter, the provider asks the parent to leave the room so she may speak with the patient alone.
- Once the parent has left the room, the provider briefly reiterates that information discussed privately will be kept confidential, except when limitations apply. The provider may reiterate any limitations applicable in the state and then check for understanding, answering any questions the adolescent may have.
- The parent may then be brought back into the room, if appropriate, to finish the visit.

Box 2.1 provides examples of language that may be used when discussing confidentiality with adolescents and their families.

Box 2.1 Recommended Language for Discussing Confidentiality with Adolescents and Their Families

With patients and parents together at the start of the visit

An important part of adolescence is starting to take ownership of your own health. For this reason, we spend some time at each visit talking with adolescent patients alone. The information we talk about during this time is private. This means that I'm not going to tell parents – or anyone else – what we talk about, unless the patient gives me permission to do so, or unless I think it's necessary for the patient's immediate safety to share certain information. Does anyone have any questions about this?

With patients alone

Just to remind you of what we talked about before – the information we talk about during this time is private. I might tell other providers involved in your care about what we talk about, if I think it's important for them to know in order to take care of you, but otherwise, the information stays between you and me unless you give me permission to share it with someone. There are times I have to share information patients want to keep private, if I think it's necessary in order to keep someone safe or if the law requires me to share it. For example, if a patient tells me they're thinking about hurting or killing someone else, or thinking about hurting or killing themselves, or using drugs or alcohol in a way that puts anyone in danger, I need to do everything I can to help keep that patient and others safe, and that usually involves telling their parents what's going on. Also, the law requires me to notify the authorities if I learn that someone is being abused. I would always tell you if I needed to share private information with someone else, and we would talk through what that would look like before I actually shared any information. Do you have any questions about this?

To introduce the HEADSSS assessment to a patient

There are some questions I ask all my adolescent patients privately. Although it may not seem like it, each of the things I ask about gives me important information about your health and helps me figure out how I can support your health and safety. None of the questions are targeted at you, specifically, so if there are any you don't feel comfortable answering, let me know, and we'll move on to the next question.

Practical Considerations

The presence of minor consent laws does not guarantee access to confidential healthcare services, as the realities of the healthcare system often limit the feasibility of confidential care for adolescents. Factors intrinsic to the healthcare system, such as electronic health records (EHRs) and third-party billing and payment systems, may present logistic challenges to confidentiality. Additionally, factors extrinsic to the healthcare system may limit adolescents' ability to obtain confidential care; for example, adolescents with limited access to transportation or private modes of communication (such as their own personal cell phone) may find it difficult or impossible to receive truly confidential care.

EHRs have allowed for improvements in continuity of care, communication, and transparency [3, 33]. However, increases in transparency come with the potential for breaches of confidentiality. For example, EHRs often incorporate OpenNotes or other access to patient information via online patient portals [3, 33]. EHRs may or may not include functionality to restrict parental access to adolescents' medical information via patient portals. Providers must be aware of the EHR functionality, as well as organizational policies regarding patient access to medical information, at their respective institutions and make thoughtful decisions about how to document confidential or potentially sensitive infor-

mation for adolescent patients. For example, providers should understand who – patient, parents, or both – has access to an adolescent’s patient portal. Providers should also be familiar with the types of information – such as entire notes vs visit diagnoses – that are available via their institutions’ patient portals. Parental access to confidential documentation should be restricted whenever such functionality exists. If parental access to visit notes or other potentially confidential information cannot be restricted, providers should inform patients of the potential for inadvertent disclosure and use their discretion to adjust documentation accordingly.

Providers should also be aware of the types of information included on patient-facing materials that may be generated during a visit. For example, at many institutions, after-visit summaries printed after a patient encounter include a list of the patient’s current medications; this may lead to inadvertent disclosure of information an adolescent patient wishes to keep confidential, e.g., an after-visit summary generated after a well-child visit may include birth control pills that were prescribed confidentially at a previous encounter. Some EHRs allow providers to mark certain medications “confidential” or to print after-visit summaries without medication lists. If such functionality is not available, providers may choose not to provide printed visit summaries for adolescent patients.

The widespread adoption of EHRs has also raised concerns about the longevity of such records and the persistence of potentially sensitive information. For example, documentation of an adolescent’s single experimentation with drugs can become a permanent part of her health record. In one study, providers reported often omitting potentially stigmatizing information from EHRs to promote privacy for the patient [33]; however, incomplete documentation may decrease quality of care for an adolescent who relies on an extensive care team to know and communicate specific aspects of her or his health.

Payment and billing systems also pose challenges to providing confidential care. Under third-party payment and bill-

ing systems in the United States, detailed bills and/or explanation of benefit (EOB) forms containing diagnoses and other health information are typically sent to the primary insurance holder. For many adolescents, the primary insurance holder is a parent. Thus information about confidential services may be inadvertently disclosed to parents via bills or EOBs. In addition, in the United States, young adults over 18 – who have full legal responsibility for their own medical care and generally have the right to receive any and all health services without parental consent or notification – are increasingly covered by their parents' health insurance, as the Patient Protection and Affordable Care Act of 2010 (commonly called the Affordable Care Act) allows young adults up to the age of 26 years to remain on their parents' insurance plans. While this provision has the benefit of expanding access to private health insurance for many young adults, it has also created the potential for inadvertent disclosures of confidential health information via bills or EOBs sent to parents [32]. Notably, the potential for such breaches of confidentiality may make young adults less likely to seek care for potentially sensitive issues. For example, a study by Loosier, Hsieh, Cramer, and Tao found that young women insured through a parent were less likely than self-insured young women to receive reproductive health services, and sexually active young women insured through a parent were less likely than self-insured young women to receive chlamydia testing [23]. States have implemented different mechanisms to address this concern, and individual institutions may use specific billing codes for sensitive procedures or diagnoses to promote privacy for the patient [32]. While non-medical providers, such as dietitians and social workers, may be unlikely to order specific tests or conduct procedures that may be considered sensitive, their care may be indirectly affected by breaches in confidentiality, e.g., if a patient loses trust in her care team after an inadvertent disclosure via an EOB. All providers should therefore be aware of protocols in their respective states and institutions and strive to approach documentation and billing in a way that is sensitive to adolescents' unique needs.

Providers should also be prepared to navigate situations in which logistic challenges limit or restrict adolescents' access to confidential care. For example, while an adolescent with depression may have a right to receive confidential mental health services, it may not be feasible for her to attend and/or pay for psychotherapy sessions without the assistance of a parent, particularly if she is too young to drive or would need to leave school in order to attend sessions. In such cases, the provider may have a discussion with the adolescent about these challenges and attempt to partner with her to establish a plan to disclose only the information necessary to facilitate needed care.

Cultural Considerations

Cultural influences can add complexity to the provision of confidential care for adolescents. Culturally-influenced stigma around common confidential topics and fear that confidentiality may be breached are commonly reported by racial and ethnic minority adolescents, while concerns that confidentiality may limit a parent's ability to take optimal care of their children have been reported among racial and ethnic minority parents [13, 25, 27, 34].

Among adolescents, stigma associated with confidential topics may limit adolescents' comfort discussing these topics with their healthcare providers. For example, in many Asian cultures, sexual and reproductive health are considered inappropriate topics of discussion [13, 27]; such stigma contributes to Asian-American adolescents having the lowest rate of discussion with healthcare providers regarding sexual health topics of any racial/ethnic group [13, 37]. Additionally, adolescents' concerns about potential breaches of confidentiality may be influenced by culture. For example, a study by Frost et al. found many Asian-American adolescents feared their primary care providers would breach confidentiality about sexual and reproductive health topics because of their community connections to the adolescents' parents; adolescents

in this study chose to seek this type of care at a clinic unknown to their parents, rather than with their primary care providers, to maintain anonymity and privacy [13]. Likewise, a study of Latina and African-American adolescent girls found that these adolescents avoided needed reproductive health care because of “fears of being stigmatized or rejected by their mothers” [25]. Latina adolescents, in particular, mentioned the stigma associated with sexual activity and the importance of maintaining one’s standing in the community as a virgin as reasons to avoid needed sexual and reproductive health care [25]. Overall, fears about breaches of confidentiality were more prominent among African-American than Latina adolescents [25]. These findings highlight the importance of respecting adolescents’ emerging autonomy and protecting their right to confidentiality while simultaneously maintaining respect for their cultural norms, their parents, and their communities.

Limited studies of parents of adolescents have found that Latina and African-American mothers fear confidential care promotes risky behavior and limits their ability to protect their children, especially their daughters [25]. The mothers in McKee et al.’s study described distrust of the medical system as contributing to their discomfort with confidential care for their adolescent children; distrust was particularly common among African-American mothers [25]. Mothers also described concerns that information provided to adolescents without parents present would be developmentally inappropriate or overly sexualized. Despite discomfort with the idea of confidential care for the adolescent children, Latinx parents in a study by Tebb et al. indicated they would rather their children receive confidential care than to forgo needed care because of worry their parents would find out [34]. In this study, parental comfort with confidential care for adolescents was primarily influenced by their trust in the clinician. Trust, in turn, was influenced by the parent’s relationship with the provider, the parent’s perception of the provider as a partner in their child’s care, and the provider’s clinical and communication skills. Parents were also more likely to trust a provider

who was the same gender as their child [34]. These findings emphasize the importance of building trust and rapport with parents and involving parents as partners in adolescent health care when appropriate.

Breaking Confidentiality

Case 2

A 17-year-old young man presents for an initial visit with a social worker. He was referred by his PCP for psychotherapy for a new diagnosis of anorexia nervosa. His PCP sent over medical records that document a history of trauma prior to the development of the eating disorder as well as ongoing symptoms of depressed mood, anhedonia, and poor sleep. Records indicate that parents are aware of the patient's trauma; the case was addressed by authorities and child protective services, but the patient has not received psychotherapy in several years.

The social worker meets with the patient and his parents to provide an overview of mental health treatment for anorexia nervosa and to learn more about the patient. Prior to reviewing a care plan, the social worker asks to meet with the patient alone, stating the clinic provides all adolescents opportunities to discuss concerns with their providers privately. The social worker states that such discussion is confidential, but that confidentiality may be broken in situations where the patient's safety is in danger. The patient and parents express understanding.

Shortly after the parents leave the room, the patient becomes tearful. He shares that over the last 2 weeks, his mood has worsened, and he has been having thoughts of suicide. He has not told anyone about these thoughts. He is afraid that sharing this with his parents would worry them. He has thoughts that everything would be better if he were "gone" and has a plan to kill himself by overdosing on pills when his parents are not home the next day. When asked directly, he shares that there are several psychotropic medications in the home, and he has easy access to these medications. The social worker thanks the

patient for sharing this difficult information with her and tells the patient she must inform other adults, including the patient's parents and other members of his care team, because she is worried about his immediate safety. The patient is distraught, firmly stating he does not want his parents to know what is going on. The social worker reminds the young man that she has a responsibility to disclose information the patient wants to keep private if she thinks it is necessary to keep him safe. The patient states he can't bring himself to tell his parents how he feels because he doesn't want to upset them. He would prefer to have someone else break the news to his parents. He agrees to have the social worker disclose the information to his parents with a child life specialist present for emotional support.

As the social worker tells the young man's parents about her concerns, the patient becomes increasingly comfortable with the conversation and is ultimately able to open up to his parents about his frequent thoughts of suicide. After the conversation, he is transported to the emergency department for further evaluation. Later, the social worker informs the patient's PCP and dietitian of what happened in order to coordinate ongoing care.

As noted above, in some circumstances, providers may need to break confidentiality and disclose information adolescents wish to keep private. In most jurisdictions, providers are required to report certain information, even if an adolescent patient wishes to keep the information confidential; for example, providers are generally required to report child abuse or suspected child abuse to local authorities and to report sexually transmitted infections to local departments of public health. In other cases, providers may determine that disclosing information a patient wishes to keep private is in the best interest of the patient and/or others; for example, if a patient plans to intentionally harm herself or another person or is engaging in behaviors, such as driving under the influence, that put others at risk of harm.

When a clear-cut legal requirement to break confidentiality, such as a reporting mandate, does not exist, providers must use their judgment to determine when to disclose

information an adolescent wishes to keep confidential. Such decisions may be influenced by the provider's knowledge of the legal environment in which they practice, the requirements of their employer or institution, and the principles of medical ethics, including autonomy, beneficence, and non-maleficence. Generally, it is appropriate to break confidentiality if the patient poses a "significant risk of serious harm" [7] to her- or himself, another person, or the community. As Diekema [7] notes:

a breach of confidentiality is not justified simply because you think it would be better for the patient if others knew about a certain condition or problem... Confidentiality should only be violated if what the adolescent has revealed suggests there is a strong likelihood of serious harm...; that the harm will most likely be prevented by breaking confidence; that all alternatives have been exhausted; that they have been given the opportunity to make the revelation themselves; and that they have been notified of your intention to break confidentiality.

A provider who determines they must break confidentiality should inform the adolescent patient of their decision and the reason(s) for it, apologize to the adolescent for breaking their confidence, and offer the adolescent the opportunity to disclose the information her- or himself with the provider present. Information should be disclosed only to those who need to know in order to prevent or reduce the risk of harm [7].

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Chapter 3

Communication and Adolescents



Establishing Rapport: Building a Relationship of Trust Through Accessible Nutrition Education and Counseling

Alicia Dixon Docter and Elena Ralph

Case Study

Mandy is a 17 year old who has been coming to see you for nutrition counseling and her medical provider for a year for help with behavior changes related to higher weight. She has been making gradual changes each month, but her weight has not stabilized. In fact, it has rapidly increased. You spend time speaking with Mandy confidentially at each visit. Today, after her family leaves the room, you reflected on the past year with her and all of the positive changes she has made. On review of weight trends, you ask if something may be impacting her life. Though you have asked about binge eating in the past, today you ask if she has eaten more than others around

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her and felt any guilt or shame with it. After exploring her current life stressors a bit more, she discloses that she is attracted to females and hasn't felt comfortable sharing this information with anyone. In order to cope with feelings of stress, she has been eating at night and sneaking food into her room. You encourage her to establish care with a mental health provider. She returns to see you a few months later, after seeing a therapist weekly, and updates you that she was able to come out to friends and family. Her weight trend has stabilized.

Introduction

We've chosen to work with adolescents and so can be surprised when colleagues or friends voice that they could never work with this population for a variety of reasons. Reasons may include teens are scary; teens don't talk to me; teens remind me of my own roller-coaster of an adolescence; they'll never listen to what I have to say; they are so "big"; they are confusing; etc. With these opinions in mind, we've written this chapter to provide guidance for those of you who are new to working with teens, those who currently work with teens and want to learn more, or who simply have an interest in gaining more skills in working with this unique population.

As practitioners, as women who were teens at one time and even now as mothers, we recognize and empathize with the complex landscape facing all disciplines working with teens. We've written this chapter to share the evidence-base to our approach to working with adolescents so others can have the incredibly satisfying experiences we've had watching teens and families open up, "get it" in terms of how we are supporting them, and be empowered to move forward with their lives. While there isn't a lot of evidence on effective interventions for adolescents on specific "conditions," we have gathered together what there is, along with evidence from scientific literature. We have also included "textbook" knowledge of nutrition plus anecdotal and empirical experience from our years of clinical work.

Firstly, we want adolescents and their families and caregivers to feel successful in meeting their healthcare goals, whatever they determine them to be. Additionally, we want clinicians to have the same experience we have had over the years that helps keep us engaged and growing personally and professionally. For example, we feel it is an incredibly rich experience to empower teens and have the privilege to affect and support sustainable change. This can help prevent stress and feelings of being burnt out. A physician we work with recently said at a workshop that we were co-leading that we want to provide advice about weight concerns with love and trust. While we're not prone to talking about love in a clinical setting, we realize this approach is based on the desire to provide nutrition care in a *nurturing* way – the way that the feeding process is meant to be from day one. The approach that feeding a child is *nurturing* them to grow is one we need to take after seeing so many teens and families struggle with how to understand and apply the myriad of nutrition messaging in our culture. With a constant barrage of messaging that bodies must look a certain way (see chapters on social media, eating disorders, supporting and promoting health equity, Health at Every Size, gender diverse youth), teens are influenced and may see themselves negatively. Extrapolating from an article on what an adolescent expects of their healthcare providers, we note the five over-arching themes: talk with me not at me; accept me; respect my privacy and confidentiality; show me you are a professional; and give me a trusted relationship [1]. This chapter is designed to help those providing nutrition guidance to be able feel comfortable in these five realms.

Adolescent Development

Adolescents are in the middle of the most significant change in growth since their first year of life. While this is a theme throughout the book, Chaps. 1 and 4 discuss this in-depth and provide fundamental knowledge and background on developmental aspects and milestones that the clinician needs to

constantly have in the forefront of their minds when working with and advocating for teens in any setting. In addition, we urge clinical leaders, administrators and educators to develop a similar knowledge base so that adolescents and their caregivers can have an optimal experience, regardless of the setting or diagnosis. Adolescent minds and bodies are changing rapidly, their relationship with their families is changing and their peers are very important to how they see the world. All of these affect how teens interpret and participate in the interaction with you, the clinician. Moreover, adolescents tend to view themselves as actors in an intense drama, one in which they occupy center stage and events take on a heightened importance. A calm approach, and a sense of humor, can counterbalance the urgency they feel [2].

Setting the Stage for a Successful Visit/ Interaction

In order to manage boundaries with patients and clients, the Academy of Nutrition and Dietetics recommends that we recognize the important position of the food and nutrition expert (or any professional working with a teen in this capacity), and the dependency of the patient/client on the care and services provided by the professional. This is a good first step in establishing boundaries in a clinical setting [3].

Recommendations for establishing solid boundaries include the following. Avoid revealing personal contact details, including social media information. Refrain from self-disclosure regarding personal issues including work-related concerns. Avoid acting or feeling possessive of a patient/client or student. Maintain an awareness of patients who have the potential to form unusual emotional attachments. Recognize when you feel overwhelmed by a potential boundary violation and seek support. Maintain a satisfying work-life balance to ensure personal fulfillment and prevent burnout [3].

Fundamental to setting professional boundaries is careful structuring of time limits in your appointments. Careful tend-

ing of time limits reminds you, the teen and family members (and team members!) that all professional boundaries are important. If you set up good time boundaries, this goes a long way in terms of setting expectations. Keep in mind, some patients will naturally respect boundaries and others will push the limit. On a note of self-preservation, don't expect gratitude, even if those who push the limit and benefit from stretching your boundaries end up getting more time or information from you. This philosophy and approach is simply part of your clinical practice. If you have a hard time setting boundaries, seek help to understand why and then improve upon what you have in place [4].

Other Considerations for a Successful Visit

- **Information prior to visit:** Develop a script for any staff that may have patient contact. This includes administrative assistants or schedulers so patients and parents know what to expect regarding visit length and importance of follow up visits. If you have written information available via your website or brochure, include information on confidentiality and health rights by age. During the first visit, be sure to review a policy on how to respond to missed appointments and cancellations. Maintain the expectation that the patient and family see all members of the treatment team.
- **Outside communication:** Communication boundaries are equally as important to set. Patients and families should know in advance, the appropriate way(s) to communicate with you between visits. For example at our institution, we avoid sharing our email address or direct telephone number and instead funnel questions through our program nurses to triage the questions or concerns. The electronic medical record has recently expanded the options for communication between patient or caregiver and provider. Age-dependent confidentiality rules may vary by state. Currently in the state of Washington, adolescents age 13 and older may have their own personal and confidential

account to communicate with medical providers. Teens can grant their legal guardians “proxy access” which allows the parent to see limited information.

- **Learners and Mentoring in Clinical Settings:** As an expert in adolescent nutrition, you may be called upon to teach and mentor others. The best way to support a positive interaction with learners is to have ground rules for any observer. For example, if a student is supposed to be observing your interactions in a clinical setting, but is trying to connect with the patient over having a similar background or being of similar age, it is important to intervene and redirect. Once you are outside of the room and in a private space, remind them of the ground rules.

Developing Rapport

Developing rapport is a necessary component of a successful visit. There are multiple components to successful development of rapport and these include: physical setting, focusing your mind, etc. The remainder of this section will expand upon these themes and how a provider can further develop rapport through clinic visits.

Physical setting The physical setting in which you conduct visits plays an essential role in rapport building. The room should be well lit and the patient should be seated in a position that facilitates discussion. Consider having armless chairs so that body habitus does not impede the adolescent’s ability to feel comfortable while seated. If possible, the computer or desk should be located in a place that your back is not to the patient while typing. At the same time, be sure you have access to the door in the event a quick exit (for a quick consult or even an emergency) is necessary.

Focus Your Mind It is essential to center one’s self before entering the room. Be sure to clear any expectations you may have for the session regarding how it will go, etc. Be mindful

of implicit biases you bring to the interaction (subconscious reactions or thoughts to the patient name, gender, age, body size/weight, native language, ethnicity, insurance status), and consider how they may affect your interaction and ability to provide equitable care. Spending a moment on self-care and mindfulness can bring a heightened awareness to who is in the room, how they are feeling, how you are feeling/thinking and provide insight as to how to proceed in the appointment. This can help ensure you interact in real time instead of relying on pre-set messages of what you think you should be saying [5].

Avoid pre-conceived agendas and messaging You may have a general sense of what topic you'd like to discuss or a plan you would like to put in place, but it is imperative you be prepared to accept the teen and caregiver where they are in regards to behavior change. We are there to support and nurture. Throughout our visit, we can ask questions and facilitate conversations around what they have been able to accomplish, even if it is the very act of getting to the appointment. Other accomplishments may include, making one incremental change in eating or activity; going to school more regularly; progress with a feeling or attitude about making a change in any of the areas you have been discussing. The acknowledgement of meeting a patient where they are is a vital part of nurturing; this is an area where the patient may have previously missed getting support from other health care professionals or family along the way.

Build trust A good and trusting relationship is built over time and cannot be expected to be accomplished in one visit [6]. Always, introduce yourself and ask about preferred names or nicknames. Try to determine intent of the visit. For example, you could say "I'd appreciate it if you can tell me what brings you in today and what you expect to get out of our visit?" Try to avoid asking the patient directly about "goals" when you first meet them as it can be inferred as "pass/fail" "right/wrong" or simply put them on the spot and can diminish rapport building.

It is important to verbally outline the structure of the visit so both the adolescent and parent/caregiver know what to expect. Start the assessment together and acknowledge parents' input, but let parents know you will begin education and individualize a plan with the adolescent on their own. You may need to remind parents that you will spend time alone with the teen. This gives the adolescent space to speak freely without their parents present, helps develop a sense of autonomy over their health, and allows parents to begin the process of planning for transition to adult care.

Be inclusive Once alone with the adolescent, review and reinforce confidentiality, provider gender affirming care, and use nonjudgmental language to gain trust. Teenagers need reassurance most things discussed will be confidential. Talk with them about times when confidentiality would be breached (such as concern for their safety). See Chap. 2 (Confidentiality) for more detailed information on confidentiality. Gender affirming healthcare supports a true sense of identity and allows the adolescent to feel fully accepted. Ask about preferred name and gender pronouns during the initial visit. When providers used non-inclusive language, adolescent participants felt unaccepted, as opposed to feelings of “relief or elation” when their chosen name or pronouns were used [7]. Please also see Chap. 26 on Gender Diverse Youth for more information on gender-affirming care.

Meet them where they are and emphasize strengths The objective of a first visit is to get to know the patient. Be prepared to make a comment about something neutral that you can both relate to – “beautiful weather out there today” or “what are your plans for the rest of the day?” If this falls flat, do not worry about it – at least you have made the effort to connect. It can be important to ask again about their hopes for the visit when you are alone. If a teen appears particularly put off by the visit, acknowledge where they may be. Did they know about the appointment? Are they upset they have missed school? Are

they missing other activities to be here today? As you continue the session, try to weave specific questions around getting to know your patient into your nutrition assessment. Be sure to ask about interests and hobbies. Use this time to probe a little further around comments that came up during your time with parent(s). Plan to reflect on teen's feelings and thoughts around their interaction with parent/caregiver. Be sure to reassure the teen that you are on their side; that you will advocate for them. As you gather more information, remind the teen it is a safe environment with no "right" answers. Let them know you are not judging their answers and only trying to better understand their day-to-day life.

Choose the language and teaching methods you use Be sure to use language the patient can understand and avoid unnecessary medical jargon. Teens do not like being talked down to because of age or difference in education levels. A nonjudgmental style conveys respect [1].

In order to create behavior change, teens need to feel educated and empowered to make changes. Spend time reviewing and discussing concepts. You can do this via pen and paper or through the internet. Work to create small achievable goals between visits. It can be helpful to write these goals down together. Some teens like using tools such as a log or journal. These should be created together and can be used to track progress. If time permits, do a summary at the end of the session with parents back in the room. This is known as a 'teach back'. Teach backs have been found to be associated with more patient-centered communication and increased affective engagement of patients [8]. Share with parents what the teen is doing well (make sure the teen knows you will discuss this ahead of time), either by letting the teen share (preferable) it or if they feel uncomfortable, you assist in doing it. Provide printout copies of the goals set forth for the next visit if you have decided it would be effective to write them out for a particular teen and/or family.

Be relaxed and pace your messaging This skill takes time to master. Remember you are the expert and this level of confidence shines through to the adolescent. Let conversation flow naturally and avoid having a set agenda. Welcome silence. Be prepared to change course multiple times throughout a visit. Leave room for spontaneity. Try to steer away from dichotomous thinking. Allow the teen to see that two opposite things can be true at the same time as opposed to thinking something is good or bad. For example, a teen may say “chips are bad” and “fruit and vegetables are good.” You could rephrase this dichotomous thinking by saying “all foods work. All foods provide energy for the body.” And then either at the moment it comes up or, during the education section of your visit, take the time to describe the concept of metabolism and how it applies to the patient. See the chapter on Wellness and Excessive Weight Gain for how to review metabolism during the clinical encounter.

Don't assume that patients will share ideas openly right away. Providers should be patient with their adolescent clients. When teens feel comfortable, they will be more willing to talk and open up. In the meantime, if an adolescent is not answering questions the provider should respect this and move on. Giving the adolescent space to speak freely is essential, but pushing them to talk is not conducive or necessary. It can sometimes be helpful to acknowledge if she/he is not focused on what you are talking about or simply not interested in being at the visit at all. Adolescents want health care providers with compassion and understanding, an ability to communicate with adolescents, a willingness to be straightforward and honest, and, who are competent, kind and warm [9].

Avoid changing providers within the same discipline In adolescent focus groups, participants identified that they strongly preferred a relationship with a consistent provider [10]. They feel more comfortable opening up to someone who is familiar with them. If a provider switch has been determined to be necessary by the care team, make every effort to ensure there is a warm handoff between providers.

Use of Motivational Interviewing (MI) to Develop Rapport

Motivational interviewing (MI) is an empirically supported approach to patient-provider communication that is characterized as “a therapeutic conversation that employs a guiding style of communication geared toward enhancing behavior change and improving health status” [11]. MI has recently been cited as a component of effective management for nutritional disorders in adolescence [12].

In the past several years, we’ve noticed that members of the inter-disciplinary team appear to be more familiar with MI after completing professional degrees though there appears to be great variability based on the institution attended. Therefore, while we will review essentials of MI in this chapter, it should be considered an introduction and then the reader should consider additional in-depth reading and training [4]. Once training is completed, it is essential to begin to weave concepts into your practice, and utilize until it becomes natural. For example, on a return visit with a patient you could ask “what do you remember from last visit” versus saying “do you remember what we talked about last visit?”

It may be tempting to skim an article on MI or attend a one-hour workshop and then begin using MI tools such as the confidence ruler or develop a list of pros and cons around making change and call this MI and feel you’re “doing MI”. Instead, we have found asking permission and using OARS (open-ended questions, affirmations, reflections and summary statements) are considered to be the core, and most helpful, MI skills [13]. Underlying all of this is recognizing the right of autonomy of the adolescent (as well as adults) to make their own decisions.

Asking permission Clinically, the authors of this chapter agree that the essential MI skill a clinician needs to be aware of, and be able to employ on regular basis, is asking permission (at the beginning of a session and then throughout the conversation if the patient has shown an interest in acquiring more information or indicated an interest in making changes).

Furthermore, as we've taught this to clinicians of varied professions, we've come to realize that the most important place to start is asking permission (e.g. "I'd like to take a few minutes to talk about what activity you like; is that OK?") and asking an open-ended question. Asking permission sets the stage that the patient is in charge and has ultimate control of the session. Next, being able to ask a good open-ended question will almost guarantee that the clinician will have plenty of material to affirm or reflect upon which will help develop the conversation and keep it going to help develop the relationship.

Open-ended questions An open-ended question is one that invites a person to think a bit before responding and gives them plenty of latitude on how to answer [13]. Typically, these are questions that can't be answered with a yes or no or a very short answer.

Affirmations Affirmations comment on something that is good about the person. They involve noticing, recognizing and acknowledging the positive. An affirming comment can be about something specific such as intentions or actions. It's possible to affirm by re-framing the teen or parent's actions or situation in a positive light. In general, avoid affirmations starting with I. I statements put the speaker in a one-up position and can come off with parental overtones [13].

Reflections The essence of a reflective listening response is that it makes a guess about what the person means. The reason for responding with a statement rather than asking a question is practical: a well-formed reflective statement is less likely than a question to evoke defensiveness and more likely to encourage continued exploration [13].

Summary statements Summaries are essentially reflections that pull together several things that the person has told you. They can be affirming because they imply "I remember what you tell me and want to understand how it fits together?"

Summaries also help clients to hold and reflect on the various experiences they have expressed. They not only hear themselves describing their experiences, but they also hear you reflect what they have said in a way that encourages them to continue [13].

A simple rhythm is to ask an open-ended question and then reflect upon what the person says, perhaps two reflections per question but do avoid using a rigid formula. The key is to rely more on reflections than questions [13].

Remember, all of these skills will require courage to try and then practice because they are essentially different from the traditional medical model of asking questions to get needed information to make a diagnosis or tell a patient what they need to do. We have provided Table 3.1 for your reference so that you can review where you are and then try a new approach using MI principles (adapted from [13]).

Rolling with Resistance A less-mentioned concept in MI that is important to keep in mind is rolling with resistance. Resistance is a natural response by patients to the idea of change and is seen by those of us working with adolescents and parents as common and certainly not full of malevolence. On the provider side, we need to be aware of and cautioned against using one's own righting reflex. The righting reflex is natural reflex to try and "fix" or make something better for the patient and set them on a better course [13]. The righting reflex is natural and while not intended by providers to be top down yet can get in the way of identifying desire for change and developing rapport.

Time Concerns It may seem to you that using an MI-informed approach this will add a lot of time to your clinical sessions. We have heard this from providers we are training in MI. We encourage you to keep open to the idea of trying OARS or even an element of OARS such as open-ended questions in your clinical conversations. As you become more practiced, it will feel more natural and take less time.

TABLE 3.1 Description and Practice of OARS

Techniques	If you currently say or do...	Try this...	Practice
Open-ended questions	Closed-ended		Try re-writing these as open-ended questions:
- Cannot answer yes or no	- Did you...	- Rephrase so that the answer provides more information	- Are you making sure your child is physically active every day?
- Creates impetus for forward movement to help individual explore change	- Can you...	- Get them to tell you more – how often, to what extent	- Do you fix your child breakfast every morning?
	- Will you...	- Explore what they think – Tell me about, why might you want to make this change?	- Do you have professional goals for this year?
	- Is it...	- See what they already have in mind – How might you go about it, in order to succeed? What are three reasons to do it?	- Can you stop spending money?

Affirmations			
- Ask open-ended questions in order to uncover something positive & then affirm it.	- Were you successful or unsuccessful?	- Point out strengths where the person only receives failure	- I see that you were able to eat breakfast this week.
- Statements of recognition about individual strengths	- Were you able to follow the plan?	- Consider effort, intentions, partial successes	Nice work!
- Helps individual feel change is possible	- Did you do anything this week?	- Be genuine	- Sounds as if you were able to get in by 8 AM several times this week.
- Be aware of “cheerleading” – can be patronizing	- I’m so worried about you	- Be specific and personal	- The last time we met, you talked about classes that might interest you. You must have done some research – that’s a good first step.
	- You don’t seem to be making any progress	- Use resistance as the source for affirmation	- Sounds like you are delaying your remodel to save money.
	- I know you can do it		

(continued)

TABLE 3.1 (continued)

Techniques	If you currently say or do...	Try this...	Practice
Reflective listening			
- Listen carefully to patient	- Clearly, you're not doing well.	- Statement, not question – Voice should go down	- It sounds like you are feeling tired in the morning and can't get up to make breakfast.
- Vary level of reflection. Avoid only comments at the emotional surface.	- Everyone seems really mad about something in this room.	- Takes hard work to practice	- So, you are saying you are having trouble understanding the bus schedule.
- If you are right, emotional intensity of session will deepen. If wrong or patient not ready to deal with, the patient corrects you and the conversation moves forward	- I'd like you to work on ... - Uh huh (looking around the room)	- Starts with: So... Sounds like... You... So, one hand...but on the other...	- So, you're saying that you are confused about how to develop a savings plan.
	- Eye rolling, sighing heavily - Looking at the clock, phone or computer - Multi-tasking		

<p>Summary statement</p>	<p>- Communicates interest in individual and helps develop rapport</p>	<p>- Can shift direction if necessary</p>	<p>- I gotta get going, see you next time.</p> <p>- Gosh, you have a lot to do but it's going to be fine.</p> <p>- So that's it.</p> <p>- You've got everything you need, right?</p>	<p>- Begin with announcement that you are about to summarize</p> <p>- Be selective and concise</p> <p>- Note ambivalence</p> <p>- Invitation to correct anything</p> <p>- End with an open-ended questions</p>	<p>- I see you want to use teach backs to help your patients demonstrate what you've shared, yet I hear that you are struggling with the time it takes away from giving them more info. What could you eliminate? Can you try it once later today?</p> <p>- To summarize, you're going to start by setting aside \$50/week and see how that impacts your budget. How will you know if that feels okay for you?</p>
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When Providing Information is Imperative Our experience and the literature indicate that using OARS helps develop rapport, trust, and ultimately develop a relationship from which the adolescent will benefit. We recognize that initial visits and return visits are designed to check progress, labs, and provide additional support in terms of problem-solving and goal-setting. That being said, the patient may need information right away. For example, at a return visit, if a teen says, “I am going to cut carbs to lose weight” it will be important to provide information and educate. As with OARS, start by asking permission. “I hear you have an idea of what you would like to do to feel like you have more energy. Are you okay if I ask you a couple of questions to understand this more?” Then, utilize Elicit, Provide, Elicit (EPE) [14].

- Elicit: Ask an open-ended question to focus your informing. What do you already know about “carbs”?
- Provide: “Carbs” (carbohydrates) are your body’s main energy source. They help your brain, heart, lungs and muscles work. Without them, you break down muscle that gives you strength and shape. (This example provides information in simple, easy to understand terms).
- Elicit: Elicit the patient’s response to the of information you just provided. “What might this mean for you?”

Promoting Satisfaction/Preventing Burnout

In addition to some of the guidance listed above and below to help promote satisfaction with your work and thus prevent burnout, it is important to develop self-compassion and show grace to self and others. Allow time for self-care, in the type and amount that works best for you. Burnout can manifest in different forms: emotional fatigue, cynicism, lack of empathy, etc. Recognize your limits and signs that you may be emotionally fatigued. Another important aspect of care to consider is our own implicit biases. Many times, having a different perspective and goals than the patient can lead to emotional

exhaustion. Our own implicit biases may be involved when this occurs. It is important to recognize bias so that we can work to remove it. For more information please see the Chapter on Supporting and Promoting Health Equity.

Additionally, experts have written about how to cope with challenging interactions and suggest that recognizing the physical or emotional responses triggered by challenging patients/families may allow the provider to effectively partner with, instead of confront, the patient or the family [15].

Reflection is a key competency in working with adolescents and it can be used clinically or in leadership [16]. In order to work with teens and their families it important to be aware and reflect upon one's own experience as an adolescent and in family/caregiver interactions. This way, you can be prepared for reactions you may have in a session and then be able to reflect upon them further either on your own, with a trusted confidant or one of your team members. These reactions are normal and can be considered countertransference. Counter-transference is defined as the complex of feelings of a psychotherapist toward the patient [17].

Working with an inter-disciplinary, inter-professional team has many benefits that can promote satisfaction and prevent burnout. The team allows the sharing of responsibility of caring for teens. As a provider, you can obtain perspective and guidance on next steps via care conferences and team meetings. You can use case management to work through complex cases and identify recommendations for next steps. A team allows providers to relay a unified message. One way to ensure consistent messaging amongst team members is a warm hand-off. A warm hand-off helps set expectations for the next clinician's interaction and reinforces the importance of the team approach. It also can instill confidence in the family that the team is working together.

Supervision and mentoring can also provide support to help promote satisfaction and ultimately prevent burnout. Meeting regularly (realistically no more than once a month) with a trusted colleague, manager or mentor is suggested and

can provide perspective. Additionally, supervision is the perfect place to get validation that you are still providing value for patients even when there appears to be little or no change taking place [4].

Food and Nutrition Approach

While the authors have been working with adolescents for many years using the approach outlined below, we were pleasantly surprised to get support for our approach when the Academy of Nutrition and Dietetics (AND) published a new position paper stating that the total diet or overall pattern of food is the most important focus of healthy eating. Focusing on variety, moderation and proportionality in the context of a healthy lifestyle, rather than targeting specific nutrients, foods or calories can help reduce consumer confusion [18]. Additionally, the Society for Adolescent Health and Medicine (SAHM) recent new position paper [12] takes the following position that furthers this approach: providers should have a balanced and unified approach for counseling all adolescents with nutritional disorders – regardless of weight – about healthy patterns of eating and activity.

Make It Accessible and Individualized

In order to help make nutrition education accessible for the teen and caregivers, make sure the information and conversation is:

- Developmentally appropriate and based on normal adolescent development [12]. Consider the developmental stage for each individual you see. As stated in the chapter on adolescent development (Chap. 1), younger teens are more concrete in thinking about ideas and older teens are more capable of abstract thinking.
- Limited in technical language and jargon – use scientific terms but be prepared to explain them and use a more

appropriate word using the teen's vernacular. If a teen is not responding or is looking worried, blank, or overwhelmed, reframe your language to simplify words and try again. Conversely, try to avoid public health "bullet points" messaging because they aren't tailored to the patient's needs. Our clinic's youth advisory board is requesting clinicians provide even more in-depth science-based education about how the body responds in various conditions such as anxiety, etc.

- Strengths-based and grounded off a good nutrition history and informed by Motivational Interviewing (MI) [12]. Additionally, be sure to base education on what the teen is already doing well. It may be a change in practice for the provider to emphasize what is going well but it is essential to build trust.
- Based on a thorough nutrition history – (please see the chapter on Bulimia Nervosa, for an excellent review of how to do this). If a patient is restricting (regardless of weight status), they may not have the glucose on-board in their brain to be able to understand and process your input. Simplify input if needed and make sure the patient has return visits scheduled so that you continue to build on topics. This can take multiple visits until the patient demonstrates understanding and is applying it to their behavior. Of note, sometimes a full history will take several visits to obtain if the teen is compromised nutritionally or if the psychosocial situation is complex.
- Informed by team input (or your own observation) regarding emotional status. As you communicate regularly with team members, if you hear that the teen is overwhelmed by pressing social issues, it is okay to slow down the rate at which you are imparting information.
- Individualized for each adolescent. It can be tempting to make assumptions based on too little information or even a visual assessment in the interest of time available in clinic, standard work, etc. See Chaps. 8, 10, 11, 12, 26 etc. for why assumptions are counter-productive and even damaging to the teen.

Ground Nutrition Advice in the Science of Nutrition as Well as Evidence in Order to Avoid Promoting Dichotomous Thinking (“Good vs. Bad”)

As stated earlier, the total nutrition approach has been suggested by the Academy of Nutrition and Dietetics and provides a much-needed paradigm from which to base recommendations [18].

We’ve identified and woven together evidence-based key themes to offset negative messaging about food, body image and weight bias in our culture. Moreover, our aim for these themes is they support non-judgmental messaging that normalizes balanced eating and promotes growth and development. They can be used as nutrition education or as part of a clinical treatment. This approach includes three guiding principles:

- Food works to support the body;
- Restriction doesn’t work to support the body;
- A supportive environment helps support the body.

Our goals for nutrition sessions are to promote self-regulation so that a child/teen grows and attains his/her genetically determined body type; establish or reclaim (through education, counseling, and experimentation) self-regulation to normalize weight, body composition, food relationship; and enjoy food and eating— eat when hungry and stop when satisfied, most of the time [19].

Nutrition Education Tools

While non-nutrition professionals can introduce the concepts (e.g. eating breakfast or adding a snack mid-afternoon), the nutrition professional is essential to be able to effectively provide the appropriate level of information based on a thorough nutrition assessment. A certified nutrition professional

has both a breadth and depth of understanding of the sciences behind nutrition – physiology, biology, anatomy, chemistry, food science, etc. to provide these tools and concepts.

- Describe metabolism verbally and visually – please see the chapter on Wellness, for an excellent description on how to do this.
- If needed, put the concept of calories in perspective – define a calorie for what it is and then put the caloric value of a food into perspective in terms of a portion of the total value that is needed to keep a person alive, growing and active.
- Describe foods and the nutrients they provide, including micro and macronutrients.
- Visualize patterns of eating that support a person.
- Describe energy use during various types of activity.
- Keep guidance positive and realistic – resist the temptation to provide a long list of to-do's. Through an MI-informed approach, determine 1–2 steps the teen is willing and able to take over the next 1–2 weeks!
- Provide a written meal plan for visual guidance only after 3–4 visits of discussing the above and if you do, be sure it is based on what the patient is already doing well and is individualized based on their history and preferences. Be sure to let the patient and family know that this is only a road map and not intended to add rigidity to eating. Help them know that eventually they will be able to plan, prepare and eat meals more intuitively.

Concluding Thoughts

Never underestimate the value of a team in supporting adolescents and emerging adults. Putting in the time and energy towards developing an approach to support evidence-based food and nutrition messaging amongst all types of providers presents many opportunities. These include but aren't limited to: strengthening the roles of a multi-disciplinary team members; decreasing the burden that one provider type is solely

responsible for nutrition messaging and behavior change; developing new interdisciplinary working relationships; strengthening health messaging for adolescents and families, and ultimately our patients and the public.

We hope this chapter has provided you with insight on how to communicate with adolescents. From our experience, we have found these approaches to be satisfying and helpful for teens. We encourage you to work on applying some of these strategies in your own work, recognizing that it takes courage to try these practices, themes and messaging. Be patient. At the core, remember we are trying to provide nutrition care in a *nurturing* way – the way that the feeding process ought to be for every child. Let this message guide your work.

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Chapter 4

Developmental Nutrition



Holly Anderson

Case

Kelsey is an 11-year-old girl who comes in with her mother for a nutrition appointment. The registered dietitian (RD) learns there has been increasing discussion and concern at home related to Kelsey gaining weight over the last year. Mom drives the visit and is the primary person providing information. She states that Kelsey has always been “bigger-bodied” compared to her friends, but this has become more pronounced in the last year since she has gained about 10 pounds while her height has stayed the same. The RD learns Kelsey is very active with track and basketball. She has practice for one of the two sports every day after school. Kelsey eats three meals a day plus two snacks – one mid-morning and one before practice. Mom shares she is proactive in packing Kelsey healthy lunches and “low-calorie” snacks for before practice so that her daughter “is not tempted by the junk in the school’s vending machine, which might cause her to gain even more weight.” Meals appear to be appropriately portioned and balanced in carbohydrates, protein, and fat, but snacks are typically small and primarily carbohydrate. Kelsey declines feeling particularly concerned about her weight and becomes tearful during the visit.

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The information collected during the visit paints a reasonably clear picture for the RD: Kelsey's dietary and activity patterns are consistent with a healthy adolescent lifestyle. The RD takes the opportunity to provide education around and normalize the body composition changes that occur during adolescence due to the massive growth and development that comes with this period. She explains how sometimes, especially in adolescent girls, weight gain occurs earlier than linear growth, which simply reflects the body preparing itself for the pubertal growth spurt. The RD affirms Kelsey's meal balance and composition as well as her physical activity patterns. She also identifies snack composition as an area Kelsey could work on. Together, the RD and Kelsey come up with the goal of pairing a protein food with a carbohydrate for her snacks to provide more energy and satisfaction to support her during her activities.

The visit with Kelsey and her mother provides an example of a common concern that arises during adolescence. The physical and physiological changes occurring during this period present emotional challenges that can cause individuals and their families to grow confused or concerned. An understanding of adolescent growth and development processes and their accompanying nutritional implications is important for healthcare providers to grasp to optimally guide and counsel this group through this stage.

Introduction

Adolescence is a distinct and important maturational period beginning with puberty. In the same way that the first few years of life are a significant period of rapid physical growth and cognitive development, adolescence is recognized as a second stage of rapid growth and change. The surge in growth and development that occurs during adolescence creates increased nutritional and metabolic demands that are important to understand. Adolescence poses a unique window during which linear growth, establishing one's lifelong metabolic rate, bone mineral deposition, and development of the body

systems occur and can be optimized. Inadequate energy, macronutrient, and/or micronutrient intakes during this period can have adverse long-term effects [1]. Establishing positive nutrition and lifestyle behaviors early on carries great importance, given the evidence suggesting dietary patterns and habits established during childhood and adolescence tend to carry over into adulthood [2]. Improper nutrition during adolescence may also contribute to disordered eating patterns related to dieting or restriction, poor body image, or a disrupted relationship with food [3, 4].

Adolescent caregivers and healthcare providers should recognize nutrition as an important contributor to normal adolescent development [5]. Reaching full growth potential, including timely and optimal linear growth as well as proper organ remodeling, depend upon adequate nutrition [6]. Additionally, a clear understanding of these developmental changes as well as their accompanying nutritional implications is imperative in order to prepare providers to distinguish between normative and non-normative changes and to properly support adolescents and their families mentally, emotionally, and physically through this period of growth and maturation [1].

Definitions

Definitions of several terms commonly used in the context of developmental nutrition will be helpful for use throughout the course of this chapter:

Calorie: A calorie is a unit of energy, used to measure the energy level of foods [7].

Body Mass Index (BMI) is a measurement index used to assess weight status. BMI is calculated from dividing a person's weight in kilograms (kg) by their height in meters (m), squared as shown in the equation below:

$$\text{BMI} = \left[\text{weight (kg)} \right] / \left[\text{height (m)} \right]^2$$

In adolescents, a normal BMI falls between the fifth and 85th percentile curves on a sex-specific BMI-for-age growth chart. A BMI below the fifth percentile on the chart may indicate underweight or malnutrition, unless an individual has trended that low their entire life. At or above the 85th is defined as overweight, and obesity is defined as at or above the 95th percentile for age and sex [7, 8].

Weight gain velocity (weight velocity) refers to the rate of weight gain during adolescence, while **height gain velocity** (height velocity) refers to the same for height. **Peak height velocity** is the maximum rate of longitudinal growth [3].

Energy expenditure (EE) refers to the sum of the energy requirements throughout the body. This includes both physical processes to survive (i.e. breathing, digesting food, hormonal activity, etc.) as well as calories burned by way of physical movement (i.e. walking, emptying the dishwasher, lifting weights, etc.) [7]. **Metabolism** refers to the physiological processes by which the body breaks down food to be used for energy. Once an individual reaches adulthood, his or her peak metabolic rate is set for life. Adolescence is a key window during which the individual can influence his or her metabolic rate through factors like diet and activity [9].

Macronutrients provide all of the energy supplied by food and are broken down into three categories: carbohydrates, protein, and fat. **Micronutrients**, such as vitamins and minerals, are required in trace amounts for a variety of key functions that support growth, development, and survival throughout the body [7].

Key Developmental Considerations

Adolescence is a period marked by significant physical, psychological, and emotional development and change [10]. Nutrition is highly intertwined in this transitional period between childhood and adulthood from a physiological development perspective as well as a behavioral one. Energy intake during adolescence directly influences physical growth

outcomes, and teens take on new social and financial independence that puts them in position to make decisions related to their eating patterns and behaviors [6]. Establishing positive behaviors during adolescence not only helps to facilitate optimal growth and development but also equips individuals with dietary patterns and habits that support chronic disease prevention, positive body image, and overall health.

Assessing Growth

Growth charts are a clinical tool used to assess a child's growth through comparison to age-appropriate norms. Periodic and accurate measurements provide reference points over time to ensure a child is growing appropriately for his or her age [11]. For children and adolescents ages 2–20 years in the United States (U.S.), Centers for Disease Control and Prevention (CDC) growth charts are used. The body measurement charts include one each for males and females: stature-for-age, weight-for-age, BMI-for-age, and weight-for-stature. The charts contain a series of percentile curves to provide an illustration of the normal distribution of the various body measurements among children in the U.S. [12].

When a child's measurements are plotted on charts over time, his or her growth trends become apparent. Each individual's growth tends to trend along or around a consistent percentile curve. This curve becomes that child's "normal." Normal physiologic growth is defined as growth within two standard deviations of the 50th percentile for a given population. Depending where an individual's trends fall, growth will be considered average, a variant of normal, or pathologic [11]. Pathologic growth is a growth pattern greater than two standard deviations from the 50th percentile growth curve for the designated group [11]. This range leaves room for variability across different body builds [3]. In the event of pathologic growth trends, healthcare providers should conduct further investigations appropriately, as it may be an indicator of nutrition risk [11]. Clinical growth charts are not intended for

use as a stand-alone diagnostic tool but rather as an instrument to contribute to developing an overall clinical picture [12]. A minimal to a significant degree of deviation from an individual's "normal" is expected during adolescence, especially given the variation of timing and the rate of changes during the growth spurt. In other cases, departure from the normal trend line may suggest an abnormality regarding the child's health and warrant further evaluation [11].

Puberty

Puberty is a period of sexually dimorphic, biological changes beginning during late childhood. The changes are marked by sexual maturation, significant brain development, and physical growth. Hormonal changes in the brain trigger the onset of a series of other dynamic and transformational changes in the body [1, 10]. Adolescents grow in height and body weight, bone and muscle mass increase, and the heart, liver, kidneys, lungs, and brain grow and develop [6].

On average, puberty begins by about ages 11 in females and 13 in males [11]. Delay in pubertal onset and/or progression is most frequently associated with chronic disease, stress, or undernutrition [10]. Pubertal maturation occurs at widely varied rates, dependent upon factors such as genetics, energy intake, and energy expenditure. Moderate physical activity is known to confer positive benefits to cardiovascular health and body composition; however, excessive physical activity during this period can have harmful effects related to supporting normal adolescent growth and development [11].

Important brain changes occur before, during, and beyond puberty. Gonadal hormones released during puberty affect a variety of neuronal processes, such as neurogenesis, synapse formation, neurotransmitter receptor sensitivity, dendritic growth, and apoptosis. Stressors during adolescence, such as suboptimal or inadequate nutrition, may lead to disruption of key brain development and increase an adolescent's vulnerability to unfavorable psychopathologies [10].

Pubertal Growth Spurt

Adolescence marks the only time besides birth when height velocity increases [3]. This phenomenon is known as the “pubertal growth spurt” [1]. Body size, shape, and composition change rapidly and, in some cases, dramatically [11]. Upstream neuroendocrine changes cause increased secretion of growth hormone (GH), which correlates with increased gonadal sex hormones. These endocrine changes lead to concurrent sexual maturation and skeletal growth [6, 13]. Other accompanying changes include alterations to muscle and fat distribution; changes to metabolic rate; breast, genital, gonadal, and adrenal development; and changes to sleep and circadian rhythm patterns [1]. These changes necessitate increased energy requirements during and following this period, putting adolescents at risk for delayed or abnormal growth or even protein-energy malnutrition if needs aren’t met [13, 14].

Prior to the growth spurt, there tends to be a pre-pubertal slow in height velocity in both males and females. Height velocity can be calculated using measurements taken every 6 months to 1 year. At about mid-puberty, height velocity sharply increases, with girls averaging a peak height velocity of about 9 centimeters per year at age 12, and boys averaging a peak height velocity of about 13 cm per year at age 14 [11]. In adolescent males, peak height velocity tends to coincide with peak weight velocity; however, in females, peak weight velocity often occurs about 6–9 months before peak height velocity, causing weight gain without concurrent longitudinal growth in pubescent girls. Weight gain and changes to body shape and size often cause parents and teens to grow concerned. Such concern may lead to unnecessary and potentially harmful behaviors such as weight-loss diets or restriction [3, 11]. It is important to underline the normalcy of these physiological changes in adolescent girls to help minimize their engagement in these types of behaviors. Weight loss during this key period of growth and development could adversely affect ultimate adult height or cause

disruption to the menstrual cycle. Given that bone mass accrual during puberty is highly predictive of one's bone mineral density moving forward through the rest of his or her life, disruption to normal menstruation and bone density accrual during this life stage poses the risk of permanent complications, such as osteoporosis, later in life [6]. Additionally, weight-control behaviors during this stage, such as dieting, may threaten one's body image and/or relationship with food [4].

Weight gain during puberty constitutes 50% of the ideal adult weight. There are also accompanying alterations in relative proportions of fat, muscle, water, and bone. These changes in body composition occur purposefully in order to support adolescent bodies going through the pubertal growth spurt [3]. The rate and type of these changes occur differently in males versus females [11]. During the pre-pubertal period, boys and girls tend to exhibit relatively similar proportions of lean body mass to fat; however, differences in body composition between the sexes become dramatically evident during puberty and carry forward throughout the rest of the lifespan [7].

Androgens, or male sex hormones, stimulate a growth-promoting effect during puberty [3]. Boys and girls alike experience elevated androgen levels; however, serum testosterone, the anabolic androgen hormone, increases up to ten times as much in adolescent boys as compared to adolescent girls. This causes a significant increase in lean body mass with an accompanying decrease in percent body fat, resulting in a disproportionate ratio of muscle tissue over body fat in boys. Boys gain on average 33–35 kilograms (kg) of lean body mass between the ages of 10 and 20. Girls experience an increase in lean body mass as well, but it's significantly less in comparison, at about 16–18 kg during the same age span. By age 15, the male-to-female ratio of lean body mass is 1.23:1 and by age 20 that ratio has increased to 1.45:1. To add to the growing distinction between male and female body compositions, female hormones, estrogen and progesterone, cause deposition of proportionately more body fat than lean

body mass [3]. This accretion of essential sex-specific fat mass constitutes the greater proportion of the weight gain that occurs during the pubertal growth spurt in girls [7]. Healthcare providers should help educate on and normalize these body composition changes occurring through adolescence so that teens and their families can welcome the change in a positive manner.

The timing and duration of body composition changes correlate with sexual maturation, so nutritional requirements correspond better with degree of sexual maturity than with age [6]. The discrepancy in lean body mass between boys and girls is the primary reason behind the difference in nutrition requirements [7]. For example, the disproportionate gain in bone and lean body mass in boys warrants higher energy, protein, zinc, and calcium needs when compared with the needs of adolescent girls [3].

Nutritional Considerations During Puberty

The rate of growth during adolescence is second only to the rate of growth during infancy [6]. Tissue expansion occurs to accommodate this significant pubertal growth. Blood volume expands, bone and muscle mass increase, and the liver, heart, kidneys, lungs, and brain grow and develop [6]. The extent of this growth and expansion creates an increased demand for energy and specific nutrients, qualifying adolescence as a nutritionally vulnerable stage [11]. Adolescents need to eat often and in substantial amounts to support growth, especially during peak growth velocity [3]. Sufficient calcium and vitamin D intake become highly important to support bone growth, iron needs increase to accommodate expanding blood volume, and adequate protein is crucial with significantly increasing lean body mass. As physical activity increases, so do energy and protein demands. Amino acids, which are the building blocks found in protein, are needed in increased amounts during exercise in order to support striated muscle growth [6].

Globally, the leading cause of growth delay is malnutrition related to poverty. In the U.S., self-induced energy restriction, which can lead to nutritional growth retardation, also contributes to undernutrition. Undernutrition can lead to delayed sexual maturity, including a later age onset of menarche in girls. Secondary amenorrhea, or absence of menstruation, may also occur as a result of suboptimal nutritional status. Conversely, there may be an association between a moderate degree of obesity and early onset sexual maturation in adolescents [11].

Growth spurts and increased sleep demands appear to be co-occurring; thus, facilitation of optimal sleep should go hand in hand with providing adolescents with robust nutrition. Inadequate sleep may contribute to disturbances to neuroendocrine and metabolic hormones, which will have adverse implications for dietary patterns [15].

Metabolic Demands of Adolescent Growth and Development

Metabolism refers to the physiological processes by which the body breaks down food to be used for energy. The speed of metabolism is known as the metabolic rate, or the rate at which the body uses energy [9]. Three components make up the body's energy requirements: basal metabolic rate (BMR), energy cost of growth (ECG), and activity energy expenditure (AEE) [6]. BMR composes the most significant source of energy needs (60–70%) and refers to the rate at which the body uses energy for basic cellular and tissue maintenance [9]. BMR is approximately the sum of the energy expenditures (EE) of all organs and tissues in a fasted, resting state in a thermoneutral environment [16]. Energy is expended to support blood circulation, respiration, gastrointestinal and renal functions, cell and tissue metabolism, and food digestion, which is referred to as the thermic effect of food (TEF) [17]. ECG and AEE refer to any added energy requirements beyond those needed for basic survival. ECG constitutes the

energy required for basic human growth and development, such as that which occurs during adolescence. AEE encompasses any additional energy requirements from physical activity [6].

Supporting consistent metabolism is considered optimal for overall health. Gender, age, and other predisposed genetic factors, such as ethnicity, all contribute to determining an individual's metabolic rate [16]. These are influencing factors outside of the individual's control. For example, REE appears to decrease with age [9]. Nutrition and physical activity also play a role in determining metabolic rate, but they *can* be controlled [16]. Engaging in routine exercise and eating regular meals and snacks throughout the day helps to support a fast and active metabolism [18]. The body slows its metabolism during periods of calorie restriction or starvation. This is a survival tactic in an effort by the body to preserve energy. Adolescence is a critical window during which individuals can influence their metabolic rate through engaging in positive nutrition and activity patterns. Optimizing metabolic rate during this window pays off, as it becomes the peak metabolic rate that will remain with the individual for the rest of his or her life [19].

The unique mass and metabolic rate of different tissues and organs cause each to influence BMR differently, given that fat free mass (FFM) is more metabolically active than fat mass (FM). Put another way, muscle mass has a higher EE than fat tissue. This also explains why males tend to have faster metabolisms than females: They have a much higher proportion of FFM to FM [9]. Regular physical activity helps to increase lean body mass, which contributes to raising one's metabolic rate [20].

The increased energy demands during adolescence can be attributed to the sum of the needs created by the immense growth occurring and any added physical activity. Adequate intake of energy and nutrients is essential to support survival and human development. If energy intake is insufficient to meet BMR, then ECG and AEE will be compromised, and complications related to pubertal delay, menstruation, stunt-

ing, and bone mass density can result [6]. Figure 4.1 below provides a depiction of how BMR, ECG, and AEE add up to result in a total energy requirement [6].

Energy balance refers to the dynamic relationship between food and beverage intake (energy intake) and daily activities and physical activity (energy expenditure). A positive energy balance occurs when calorie intake exceeds energy expenditure, resulting in energy storage as fat [9]. A

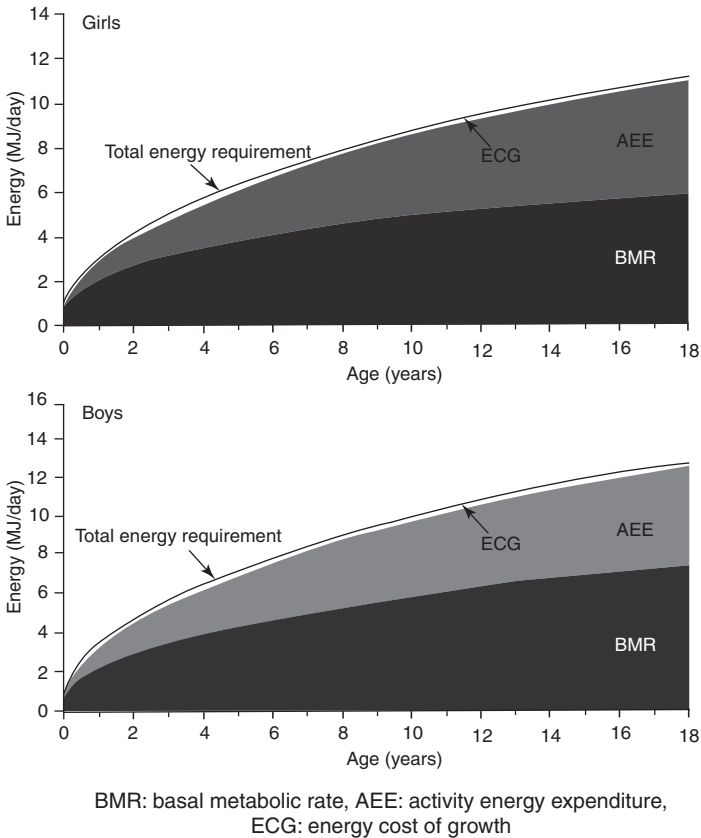


FIGURE 4.1 Energy requirements of girls and boys from birth to 18 years of age. (Reproduced from Das et al. [6])

negative energy balance occurs when energy and nutrient intake is insufficient for the body to carry out its daily activities or exercise. In this case, the body turns to stored energy from muscle or fat. The body is adept at tolerating and adapting to some variation in energy balance, primarily through gains and losses of body fat; however, promoting energy balance over time is important for maintaining a healthy weight [17]. A consistent positive energy balance contributes to weight gain [18, 21], while a consistent negative energy balance causes depletion of tissue, leading to weight loss [9]. In children and adolescents, the goal is to achieve an energy balance sufficient to support growth and development without encouraging excess weight gain or weight loss [21].

Metabolic Demands of the Body Systems During Adolescence

ECG encompasses the energy requirements needed to support growth and development of each of the body systems. As tissues expand and organ systems develop, energy and nutrients are allocated throughout the body to support these processes [11]. Energy is required both to synthesize the new tissue and to be stored in the newly made tissue [9].

Maturation of the sexual organs is often thought of as the hallmark of puberty [6, 13].

A variety of hormonal activities stimulate development of the reproductive organs. The dynamic growth and change of the reproductive system constitutes one of the numerous sources of heightened energy and nutrient demands. If energy supply is insufficient, the body may prioritize other systems. In females, this could result in delayed onset of menarche or secondary amenorrhea. Low estrogen levels in the event of disruptions to the menstrual cycle have direct implications for building up bone mineral density, especially during puberty, although bone mass accrual continues for years beyond menarche. Disruption to normal menstruation and

bone density accrual during puberty can lead to permanent complications, such as osteoporosis later in life [6].

Linear growth serves as an important indicator of the general health of an adolescent, hence the importance of regular and accurate height measurements. Deviations from physiologic growth trends may indicate nutritional insufficiency and/or other health concerns [11]. The immense linear skeletal growth and increase in bone mass during puberty create significant metabolic demands [6]. In fact, peak energy and nutrient needs tend to correspond with peak height velocity in adolescents [3]. Bone mineralization depends on nutrition, sex hormones, and physical activity [11]. Both male and female sex hormones promote increased bone mineral deposition. All people have a genetically predetermined peak bone mass, and adolescence is a critical window during which to optimize bone mineral deposition. Establishing healthy bone density during adolescence is preventative against injuries and osteoporosis later in life, since bone mass in adulthood depends on the peak mass attained during adolescent skeletal growth [1, 22]. In adolescents who undergo normal pubertal development, an estimated 45% of skeletal mass is added during puberty [3] and by age 18, at least 90% of skeletal mass is present [11]. Although bone mineral density increases to a smaller degree during the years following the growth spurt, optimizing the bone mass accrual that occurs in the years following puberty is equally as important [23]. To support attainment of each individual's unique predisposed bone mass, adequate energy, dietary calcium, and vitamin D are crucial. Additionally, physical activity is instrumental, as weight bearing exercises support higher bone mineral density [3].

Growth and development of muscle mass during adolescence is paramount. GH and sex steroid hormones trigger muscle mass synthesis in both males and females. Insulin-like growth factor 1 (IGF)-1 interacts with GH to influence muscle tissue synthesis. Interaction of these hormones promotes glycogen storage and protein synthesis through transfer of amino acids into cells. As noted previously, high concentrations of testosterone cause males to experience a more sig-

nificant increase in muscle mass than is seen in adolescent females. By adulthood, males have on average 50% more lean body mass when compared with females [23]. Individuals with a higher percentage of FFM are likely to have a higher energy requirement [9].

Around the time of peak height velocity, adolescents experience maximal increase in muscle mass and decrease of fat. Optimizing energy and protein needs at this stage is important to fuel the significant hormonal activity and protein synthesis required for building muscle. Growth and development of muscle is particularly vulnerable to undernutrition, [23] because when energy intake is insufficient, dietary protein is used to meet energy needs rather than for repairing or synthesizing new tissue [3]. Supporting muscle strength and function has implications for growth and maintenance of bone density, as muscle contractions provide a load on bone that helps build bone mass and strength. Growth and development of muscle during adolescence thus not only has implications for body composition and metabolic rate, but also for promoting optimal bone health [24].

Adolescence constitutes a critical period of brain development, and nutrition is an important element of normal and optimal neurodevelopment [8]. Undernutrition, including anything from suboptimal nutrition, certain micronutrient deficiencies, or protein-calorie malnutrition, during childhood and/or adolescence are linked to adverse outcomes that negatively impact cognition, behavior, and brain development. Academic performance, behavior, and mental health outcomes all have been shown to be adversely impacted as a consequence of insufficient energy and nutrient intake [25].

Increased energy demands to support growth and development also create increased demands of certain nutrients, such as thiamin, riboflavin, and niacin, all of which are necessary for carbohydrate metabolism [3]. These nutrients are found in foods like whole grain cereals, pastas, and breads. Riboflavin is also found in milk and dairy products. Vitamins B-6 and B-12 are important for supporting new tissue growth, which can be consumed in fish, and meat products. By consuming a varied and balanced diet complete with fruits, veg-

etables, whole grains, meat, and fish, adolescents can ensure they are obtaining ample amounts of these nutrients to support tissue growth across all the body systems [26].

Increased Energy and Nutrient Demands Due to Physical Activity

In general, adolescents tend to be on the move and engaged in a variety of recreational activities. AEE encompasses the increased energy needs attributable to physical activity and should be factored in when considering adolescent's dietary patterns. Adequate and balanced food and hydration provide the energy needed to support activities as well as muscle mass enlargement [6]. The degree of energy expenditure due to movement varies considerably among adolescents, depending on each individual's balance of active and sedentary behavior, including both sport and activities of daily living [9].

Excessive exercise during adolescence may adversely impact growth. One such instance where this is commonly observed is amongst teens who participate in high-intensity sports that encourage strict weight control, such as wrestling, gymnastics, or endurance running. Delayed or impaired growth in developing boys and girls as well as delayed menstruation in teen girls can result in the event that energy and nutrient intake are insufficient to support high intensity training [23]. On the other hand, a more sedentary individual with a disproportionately high energy intake will be in a positive energy balance, leading to increased energy stored as fat tissue. A positive energy balance over time leads to weight gain and is a risk factor for overweight or obesity [9].

Meal Patterns to Support a Healthy Metabolism

To support a healthy and active metabolism, adolescents should eat meals and snacks in a routine and structured manner throughout the day. Eating balanced, satisfying meals at

regular intervals throughout the day helps to promote adolescents' ability to identify hunger and satisfaction signals and to reduce overeating or eating unrelated to hunger but rather to boredom or emotions [18]. In fact, research has shown an inverse association between meal frequency and obesity among adolescents. One explanation may be that an even distribution of energy intake throughout the day could be associated with increased dietary thermogenesis and energy expenditure [27]. Routine eating intervals also ensure energy is readily available to fuel brain function, basic movement, and physical activity throughout the day. Meal pattern and snack recommendations depend on one's growth and development stage and degree of physical activity [18].

Adolescents, especially females, are prime targets for media surrounding thinness, dieting, and various other messages promoting a so-called ideal body weight. Because weight-control behaviors are prevalent in the media and among adolescents, it is important that health care providers understand the potential associated physiological and psychological risks. Studies reveal associations between adolescent weight-loss behaviors and a variety of other adverse outcomes, including delayed linear growth, delayed menarche, as well as an increased risk of long-term weight gain. Studies have also shown an association between calorie restriction and significant reduction in resting energy expenditure among adolescents classified as obese. Decreased resting energy expenditure may help to explain subsequent challenges to lose weight among this group. Dieting behavior among adolescents is also associated with negative self-esteem [28].

Meal Composition

The body requires a combination of the three macronutrient groups: carbohydrate, protein, and fat. Each group serves distinctly unique roles throughout the body, and each contributes differently to the experience at eating times, with respect

to satiety and satisfaction [17]. Satiety refers to the sensation of fullness that persists until hunger returns, playing a role in when a person stops eating and how long he or she will wait before eating the next meal or snack. Satisfaction refers to the feeling of pleasure derived from foods, which can help to reduce eating in the absence of hunger [29].

Carbohydrates (sugar, starch, and fibers) are the body's preferred energy source, and the brain is dependent on glucose for energy. They are the most rapidly digested of all the macronutrients, making them the quickest and most readily available energy source. Enzyme activity and digestion of carbohydrates begin in the mouth and continues in the intestines, where sugars are then absorbed and transported throughout the body to be used by cells as energy. Carbohydrate-containing foods provide an immediate sense of satisfaction but only a limited duration of satiety due to their rapid digestion. Carbohydrates as a group produce a relatively rapid rise and fall of blood sugar; however, blood sugar response varies depending on the type of carbohydrate ingested. Simple carbohydrates are simple in molecular structure and complex carbohydrates have a more complex molecular structure. Simple sugars (honey, cane sugar, fruit juice, etc.) produce the most rapid rise and fall of blood glucose concentration, while more complex carbohydrates (fruits, sweet potatoes, whole grain breads and pastas, etc.) contain fiber that slow the blood sugar response and help extend satiety [17].

Amino acids (protein) are the main structural and functional element of all cells in the body. The body depends on sufficient protein to operate and survive. Amino acids are either non-essential, which means they can be produced by the body, or essential, meaning they must be ingested in the diet. Consuming a wide variety of protein to ensure consistent intake of all essential amino acids is crucial for performance of many functions throughout the body and for survival. Digestion, muscle and tissue growth, immune health, enzyme function, hormonal production and activity, and virtually all other functions throughout the body depend on the

availability of sufficient protein. During adolescence, rampant synthesis of new tissue utilizes significant amounts of protein on a daily basis. Protein digestion is focused in the stomach and intestines. Due to the complex structure of protein, the digestive processes are more complex and take more time than carbohydrate metabolism. As a result, gastric emptying occurs more slowly, and the postprandial glucose response is reduced. There is also evidence to suggest meals and snacks consumed with adequate protein trigger the release of hormones that signal satiety. Protein, thus, is not as immediately satisfying during a meal but better contributes as a lasting energy source [17, 30].

Of the three macronutrient groups, fat is the most calorically dense, containing nine calories per gram (protein and carbohydrates each contain four calories per gram). The body depends on fat for insulation, neural conductivity, cellular and hormonal health, and digestion of fat-soluble vitamins (vitamins A, D, E, and K). During adolescence, fat provides a significant and important source of calories as well as key nutrients. Fats are subdivided into categories based on their structure. The two basic categories of fat are saturated and unsaturated fats. Within the unsaturated fats category, there are two sub-classifications: monounsaturated (MUFA) and polyunsaturated (PUFA) fatty acids. PUFAs are further subdivided into omega-6 PUFAs or omega-3 PUFAs. Unsaturated fats are often considered the “healthy fats,” given their numerous beneficial utilities in the body, and should be emphasized in the diet. Foods rich in MUFAs include olive oil, avocado, nuts, and seeds. PUFAs are considered *essential*, meaning they are not made in the body and must be consumed in the diet. Common PUFA-containing foods include salmon or other fatty fish, walnuts, and flax and chia seeds. Insufficient omega-3 PUFAs contribute to poor growth and adverse neurological outcomes, given these fats support cell membrane integrity as well as hormone and immune system support [17].

Due to its insolubility in the blood, fat digestion requires a more involved, alternate route. Consequently, fat digestion

and absorption take the longest of the three macronutrients [17]. Fat triggers the release of hormones that slow gastric emptying and send signals to the central nervous system (CNS), communicating a sensation of fullness [30]. Consuming fat and protein with carbohydrates has also been shown to lessen or slow the postprandial blood glucose response. For these reasons, fat functions as a more long-term energy source, which contributes to lasting satiety. Fats also contribute desirable texture and palatability that add to satisfaction during eating times [17].

A diet complete with a variety of foods is the best way to ensure adequate intake of macro- and micronutrients. By consuming a combination of carbohydrate, protein, and fat, a meal or snack provides the spectrum of nutrients the adolescent body requires for growth and development. Aiming for this balance at eating times also promotes satiety and satisfaction [17].

Breakfast

It is often said that breakfast is the most important meal of the day. In young people, eating breakfast has been associated with overall improved diet quality and nutritional adequacy [27]. Studies show that compared with breakfast skipping, breakfast consumption is linked with positive metabolic health outcomes, such as lowered risk of developing type 2 diabetes mellitus (T2DM) and metabolic syndrome. Skipping breakfast has also shown an association with weight gain, including an increased risk of overweight and obesity in young people [27, 31].

Several behavioral and metabolic mechanisms have been proposed to help explain the benefits of eating breakfast. From a behavioral perspective, skipping breakfast may contribute to overeating during the rest of the day to make up for the energy deficit established at the missed morning meal. This overeating appears to occur mostly at dinner or during a late evening snack and is referred to as “catch-up hunger.”

Energy consumed later in the day may be more likely to be stored as glycogen or fat, rather than used up during basic movement or physical activity. Missing breakfast may also lead to increased snacking, particularly on energy-dense, nutrient-poor snacks [27].

Eating breakfast kickstarts one's metabolism after a night's sleep. Following a period of fasting, free fatty acids (FFA) mobilize from cells and serum FFA levels become elevated. It has been proposed that skipping breakfast may contribute to prolonged elevated FFAs throughout the morning hours. Elevated concentration of FFAs have shown an association with insulin resistance, so it may be that breakfast skippers experience an increased glycemic response at lunch time [31].

In addition to fueling metabolism, breakfast serves as an important opportunity for adolescents to increase their total daily nutrient intake and ensure they are meeting their energy needs. While they may replace the missed morning meal with energy-dense snacks due to catch-up hunger, those who skip breakfast do not appear to make up the nutrient intake they miss at breakfast through the remaining meals of the day [27]. Breakfast consumption has been linked with greater likelihood of meeting micronutrient recommendations due to higher micronutrient intakes, most notably vitamins A and C, calcium, riboflavin, zinc, and iron. Given the significance of childhood and adolescence as key periods for increasing bone mineral density, optimizing calcium intake is key. Breakfast consumers tend to demonstrate higher milk and calcium intakes than breakfast skippers [27]. Additionally, energy, protein, carbohydrate, and fiber intake all appear to be higher among adolescents who eat breakfast [27]. Many common breakfast foods, such as whole grain cereals, toast, oatmeal, and fruits and vegetables, are high in antioxidants and dietary fiber. Dietary fiber exerts beneficial effects on carbohydrate metabolism by slowing the rate of glucose absorption and promotes slower gastric emptying, which helps individuals feel full for longer [18, 32].

Typical Nutrition Patterns Among Adolescents

As adolescents explore new social contexts and responsibilities, independence and autonomy increase [1, 14]. With new autonomy comes increased decision-making power related to food choices. Adolescents tend to eat more meals away from the home, and percentage of calories obtained from snacking and grazing increases [14, 33]. Other common nutrition patterns among teens include missed meals, high frequency of fast food, and dieting (especially among females) [6]. A host of factors come into play that influence choices and behaviors related to dietary patterns. These influences include parent modeling, food preferences, food cost and convenience, media and marketing, body image, peer environment, and cultural influences [6]. Often, this can lead to a pattern of less healthy food choices, such as high frequency of fast food and processed, energy-dense snacks [14].

Intake patterns among adolescents tend to be inconsistent with the Dietary Guidelines for Americans [4]. National surveys and population-based studies among youth have identified the following nutrition-related concerns among adolescents: low consumption of fruits and vegetables, whole grains, and calcium-rich foods like dairy; excess consumption of sugar-sweetened beverages; and frequent intake of fast foods [34]. These patterns further lend themselves to concerns such as inadequate intake of vitamins and minerals and increasing prevalence of overweight and obesity among adolescents [6].

Meal Patterns

Adolescents' schedules tend to be busy with school, social activities, sports, and other extracurricular activities. This can lead to chaotic meal patterns, including fewer meals at home and skipped meals [3]. While the majority of the U.S. population consumes three meals and at least one snack per day, surveys illustrate that only half of adolescent females

and young adult males eat three meals per day. This group does, however, appear to eat at least two snacks in addition to meals [35], so snacks can become a substantial source of adolescents' nourishment. In fact, current survey data suggests children and adolescents obtain at least one third of their calories from snacks [33]. This places importance on the choice and quality of foods eaten at snack time. Nutrient density through foods like fruits, vegetables, healthy fats, and optimal protein choices should be encouraged over energy dense foods found in convenience stores or vending machines [3].

Adolescents often find themselves with increased autonomy around breakfast. Whether in an effort to reduce overall calorie intake for weight loss or as a consequence of increased sleep demands that lead to a state of rush in the morning, many adolescents choose to forgo eating breakfast [18]. In fact, studies and surveys have shown that breakfast consumption among adolescents has declined. In particular, there appears to be a decline in breakfast consumption during the transition from childhood to adolescence [27]. Teens should be reminded of the important and beneficial role that breakfast plays in maintaining a healthy weight, academic performance, and appetite management throughout the day [18].

Dietary Composition

Dietary surveys, such as the National Health and Nutrition Examination Survey (NHANES), reveal adolescent diets to be heavy in calorically-dense, nutrient-poor foods and low in nutrient-dense foods [8]. Foods like sweetened beverages, fast food entrees, and high-fat, sugary snacks are prevalent in adolescent diets and appear to contribute to a consequential lack of recommended foods like fruits, vegetables, whole grains, dairy, and fish [2, 33]. The overall nutritional profile of the diet suffers as a result of these patterns [33]. Less parental supervision, more influence from peers at eating times, and

mass media promotion targeted at adolescents may help explain these trends [8].

Vegetable consumption in the U.S. is inadequate across all age and sex groups, but adolescent boys ages 9–13 and adolescent girls ages 14–18 lead this statistic, consuming the lowest amount of vegetables as a percentage of recommended intakes. Fruit intake among adolescent girls in the 14–18 age group also ranks as the lowest percentage of recommended intakes in their age and sex group. As a byproduct of low fruit and vegetable intake, adolescents' diets are on average low in fiber, antioxidants, vitamins, and minerals [35].

The dietary guidelines recommend half of all daily grains consumed be whole grains. Adolescent diets tend to be higher in simple, refined carbohydrates, such as white breads and pastas, bagels, pizza, white rice, and refined cereals. Concurrently, average whole grain intakes in both adolescent boys and girls is significantly below the recommended amount, at less than one ounce per day [35].

Dietary surveys reveal average protein intakes among adolescents to be sufficient. In fact, according to the NHANES study from 2005 to 2010, protein was the only dietary component among adolescents that scored significantly higher on the Healthy Eating Index (HEI), a system developed by the United States Department of Agriculture (USDA) to assess a group's adherence to the dietary guidelines [2].

Dietary survey data demonstrate fat intake among adolescents reflect high intakes of saturated fats, obtained from foods like french fries and snack chips. At the same time, this group appears to consume inadequate amounts of unsaturated fats and oils in the forms of nuts, avocados, seafood, and plant oils [35].

During the transition from childhood to adolescence, milk consumption declines while soda consumption increases [8]. This is problematic for two reasons: first, milk products are the primary source of calcium for adolescents. Second, calories from added sugars contribute no nutritional value and are stored as fat. Adolescents appear to consume a relatively high proportion of added sugars as a percent of daily calories.

Soft drinks, energy drinks, sweetened teas, and fruit juices are common sources, as beverages constitute 47% of all added sugars in the U.S. diet. Other sources include convenience foods like snack mixes, cookies, candies, and pastries [35].

Convenience and Fast Foods

In the context of activity-filled lives and new independence, convenience and fast foods become popular choices among adolescents. Foods in this category tend to be high in saturated and trans fats, added sugars, and calories and low in essential micronutrients [3].

Research shows adolescents spend over \$5.4 billion on fast food and \$9.6 billion on convenience store snacks annually. Vending machine purchases among adolescents amount to \$736 million each year, with 78% of those sales occurring in schools. Foods from these sources tend to be energy dense and low in key nutrients [3]. Foods available when dining out tend to be higher in calories, saturated fat, sodium, and sugar. While parents, caregivers, and healthcare providers should encourage a limited frequency of dining out, equally important is to educate teens around how to make positive food choices when eating away from the home. Education around balanced meals, portion sizes, and hidden sources of excess sugar and calories may be beneficial [18].

What Micronutrients Are Shown to Be Inadequate in Adolescent's Diets?

Nutrition deficiencies occur among adolescents for a variety and combination of reasons stemming from the individual, household, and population levels [14]. Micronutrient deficiencies tend to occur in the context of an overall unhealthy eating pattern. Low intakes of foods rich in micronutrients, such as fruits, vegetables, whole grains, and dairy, result in insufficient micronutrient intakes [35].

Dietary surveys consistently reveal calcium to be inadequate in adolescent diets. Adolescent girls in particular appear to be at risk for low calcium intake. This may be reflective of common food choices among this group, such as sugary snacks, convenience foods, and fast foods. Further, it may be that increased consumption of soft drinks in this age group ends up substituting for milk intake, contributing to insufficient calcium intake. Mechanistically, excess soft drink consumption may interfere with bone mineralization given that caffeine causes increased calcium excretion in the urine [3].

Vitamin D is considered a nutrient of public health concern in the U.S. across all age groups, including adolescents, given the health risks associated with low vitamin D status. Vitamin D is necessary for supporting bone growth and bone mineral density, vital processes for adolescent growth. Exposure to UV rays from the sun enable the body to synthesize vitamin D, and good food sources include salmon, tuna, and vitamin D-fortified milk, beverages, and cereals [35].

Iron intake is consistently shown to be inadequate in adolescents' diets. Adolescent girls in particular under consume iron. This may be reflective of popular food choices among adolescents, such as convenience, snack, and fast foods, which are not good sources of iron. Suboptimal iron status puts individuals at risk for iron-deficiency anemia [35], which is the leading cause of years lived with disability among children and adolescents [6]. Poor iron status may limit adolescent growth and hinder the immune response [3].

Many adolescents fail to meet zinc needs during puberty due to poor overall diet quality [36]. Adequate zinc intake is especially important in adolescents given its role in immunological, neurological, and reproductive health as well as in supporting optimal growth patterns. Given there is no body store or functional reserve of zinc in the body, routine dietary zinc intake is essential to prevent deficiencies which can lead to impairments in linear growth, delayed sexual and bone maturation, among other adverse health effects. Physiological requirements for zinc during adolescence are

high, which can present a risk factor for zinc deficiency in this population. Key dietary sources for zinc include meat, poultry, and fish, so adolescents with diets low in animal protein may be at risk for zinc deficiency. Zinc supplementation provides an option for individuals on a vegetarian or low animal protein diet [37].

Nutritional Recommendations

Current nutrition recommendations are based on national dietary guidelines, research in adolescent populations, and current practice [34]. The 2015–2020 Dietary Guidelines for Americans provide a set of nutrient-based reference values known as the Dietary Reference Intakes (DRIs). The Recommended Daily Allowance (RDA) refers to the average daily intake sufficient to meet the needs of 97–98% of healthy individuals in a given age and sex distribution. The Estimated Average Requirement (EAR) is the average daily intake estimated to meet the needs of half the healthy individuals in a given life stage and sex group. Adequate Intake (AI) is a reference value believed to meet the needs of all individuals in a particular group [35]. Acceptable Macronutrient Distribution Ranges (AMDRs) are estimates based on epidemiological evidence that suggest intake levels of essential nutrients within these ranges may reduce chronic disease risk while providing essential nutrients [17].

Determining nutrient requirements for adolescents presents many challenges due to the significant variability in stages of growth, growth rates, activity levels, and metabolic rates across the group [3]. Estimates are provided for energy and nutrient requirements for this age group to serve as a reference point but should be individualized accordingly. Energy needs, for example, vary widely among adolescents. Height, weight, sex, and physical activity level all influence needs [35]. Disproportionately larger gains in lean muscle mass and bone density and greater rate of growth in adolescent boys as compared to girls create higher energy demands [3]. Given the

rapid use of energy due to added demands of growth and development, appetite tends to be persistently heightened in adolescents [6, 35].

The RDA for carbohydrates in adolescent boys and girls ages 9–18 is 130 grams (g) per day, which is based on an estimate of the average minimum amount of glucose utilized by the brain. The recommended intake may also be estimated using the AMDR, which for carbohydrates is 45–65% of daily energy needs. Further, the recommendation is for as at least half of carbohydrates in the form of grains (pastas and breads) to be whole grains. Whole grains are in preference to simple carbohydrates like white breads and pastas or sweet treats. Fruits, vegetables, and legumes are other examples of recommended carbohydrate sources. Each individual's ultimate recommendation will vary greatly depending on factors such as physical activity level, appetite, and stage of growth [17]. There is also a recommendation to limit added sugars to less than 10% of calories per day [35].

Protein requirements increase during adolescence to support growing muscle mass [8]. The RDA for protein in relation to height is often considered a good option when estimating protein needs for adolescence. For girls, this ranges from 0.27 to 0.29 g/centimeter (cm) height, and for boys, the range is 0.29–0.32 g/cm height. In children and adolescents ages 4 to 18, the AMDR for protein is 10–30% daily energy needs. Inadequate dietary protein during adolescence may interfere with linear growth and cause decreased lean body mass [3].

Due to a lack of evidence, there is no RDA for fat intake in adolescents. The AMDR for fat is 25–35% of daily energy for children and adolescents ages 9–18 [35]. The 2015–2020 Dietary Guidelines recommend limiting saturated and trans fats while emphasizing mono- and polyunsaturated fats in the form of vegetable oils, dairy, nuts, seeds, and fish [35].

As highlighted previously, calcium, vitamin D, and iron, are commonly shown to be inadequate in adolescents' diets. The AI for calcium in adolescents ages 9–13 years old is 1300 mg. Common examples of calcium-rich foods include milk, yogurt,

cheese, fortified cereals, and tofu. Adequate vitamin D is equally as important to support rapid skeletal growth. The DRI for adolescents is 600 international units (IU) per day. Salmon, fish oil, mushrooms, fortified orange juice and nut milks, and dairy products are examples of foods providing vitamin D. Obtaining sufficient vitamin D from food sources can be challenging, so a supplement may be warranted for some adolescents [35].

Iron requirements increase during adolescence to support blood volume expansion in boys and girls and menstruation in girls. Boys and girls ages 9–13 are recommended to consume 8 mg/day. The requirement increases to 11 mg/day in boys between ages 14 and 18 to accommodate the growth spurt. To replace iron losses through menstruation, the recommendation increases to 15 mg/day in girls ages 14–18 [14, 17, 35]. Iron is available in foods in two forms: heme iron and non-heme iron. Heme iron is more readily absorbed by the body and found in animal sources such as poultry, lean meats, and seafood. Sources of non-heme iron include legumes, fortified breads and cereals, and dark leafy vegetables. Consuming vitamin C-rich foods alongside iron-containing foods improves non-heme iron absorption [35].

Conclusion

Adolescence is a critical period of growth and development during which the body is changing in size, shape, and composition. Establishing and maintaining positive nutritional patterns through adequate intake of energy and key nutrients is of vast importance for supporting optimal growth and development. Barriers to adolescents attaining these patterns are present in the form of increased social freedoms and new autonomy over choices related to food, exercise, and health. Consequently, the average adolescent engages in less than optimal eating patterns. Adolescents' diets tend to be low in nutrient-dense foods like fruits, vegetables, whole grains, fish,

healthy oils, and dairy, while instead reflecting higher proportions of energy-dense foods high in saturated fats, salt, and added sugar.

Decisions made during adolescence have momentous implications for present and future health. Obtaining adequate calories and key nutrients play directly into outcomes such as linear growth, bone health, and a healthy metabolism. Establishing eating and physical activity habits that support a consistent energy balance is important for preventing under- or overweight, which is relevant for health during adolescence and adulthood, since lifestyle preferences and habits developed during adolescence often carry over into adulthood. This is a key window during which adolescents require education, support, and guidance around making positive lifestyle choices and developing lasting, beneficial behaviors.

The breadth and magnitude of the changes occurring during adolescence often present a multitude of questions, concerns, and mental and emotional challenges. Healthcare providers are in a unique position to help guide, educate, and support adolescents and families through these changes. With an understanding of the developmental processes and key physical and social changes occurring during this life stage, healthcare providers, adolescents, and their parents can work together to positively influence the nutritional well-being of the adolescent in a way that optimally supports growth, development, and emotional success.

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Chapter 5

Wellness and Excessive Weight Gain



Carley MacRae

Wellness in health is a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity [1]. Obese adolescents are at particular risk for low wellness due to weight stigma, weight-based teasing/bullying and increased risk of social isolation, avoidance of health care, depression, anxiety, substance use, low self-esteem, self-harm, poor body image, and suicide [2–5].

Prevalence, Diagnosis Criteria, Complications

Approximately 21% of adolescents are obese [6, 7] and 7–9% of them are considered at the highest levels of obesity (Class II and Class III obesity) [6]. The prevalence of obesity is higher in African American and Hispanic youth compared to non-Hispanic whites and non-Hispanic Asians [6, 7]. Obesity is also higher in less educated households and in youth living in rural settings [8].

$$\text{BMI} = \text{weight (kg)} / \text{height (m)}^2$$

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TABLE 5.1 Overweight and obesity classification

≥ 85 th percentile for BMI for age	Overweight
≥ 95 th percentile for BMI for age	Class I Obesity
$\geq 120\%$ of the 95th percentile for BMI for age	Class II Obesity
$\geq 140\%$ of the 95th percentile for BMI for age	Class III Obesity

Body mass index (BMI) is the tool most frequently used to estimate degree of obesity. The Center for Disease Control (CDC) produces weight, height, and BMI growth charts for children and adolescents. These are used to plot trend lines in a patient's height, weight, and BMI over time. Table 5.1 shows how an adolescent's BMI is categorized.

One barrier to working with adolescents diagnosed with Class II and Class III Obesity is that historically growth charts have only shown up to the 97th percentile for BMI for age. With the development of these categories new growth charts have been developed to show percent of the 95th percentile above the 95th percentile (Fig. 5.1) [6, 9].

Identification of adolescents with elevated BMI, particularly those with class II and class III Obesity, is important as these individuals are at a higher risk of developing numerous weight related comorbidities [9–11] Table 5.2 categorizes common obesity related comorbidities by organ system [12–15].

Identification of Overweight and Obese Adolescents

While BMI is a helpful screening tool, it is important to recognize its limitations given that it is a population-based assessment tool. It does not account for individual variances due to genetics, ethnicity, or body habitus. As such, it is essential to evaluate an adolescent's current BMI in the context of their individual growth history.

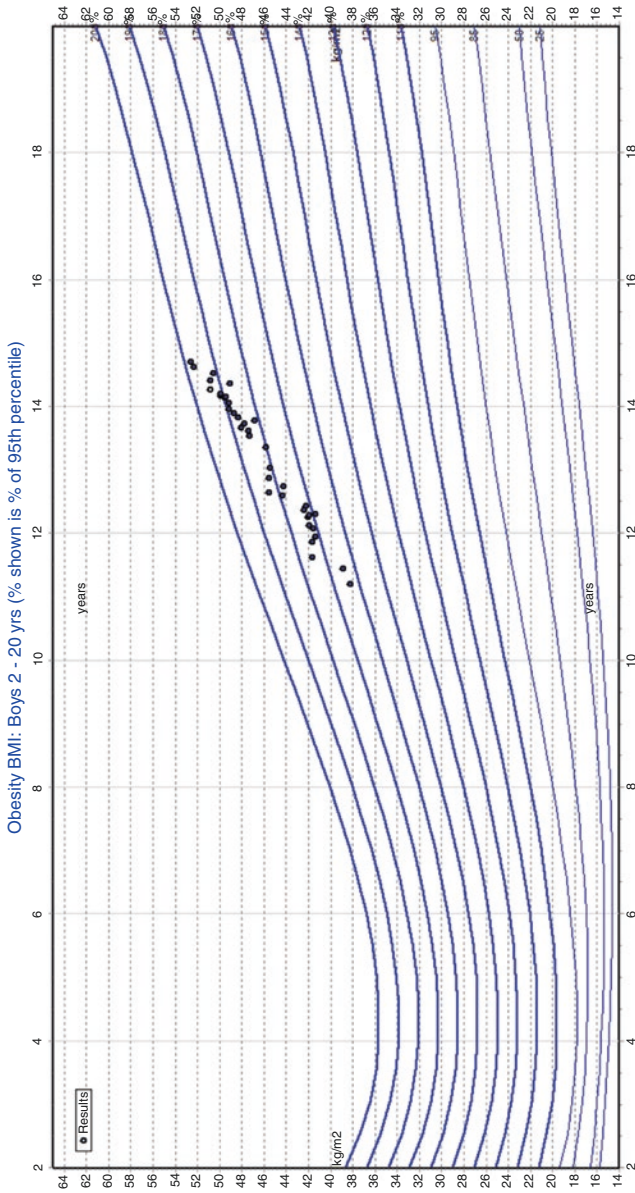


FIGURE 5.1 Obesity BMI growth charts

TABLE 5.2 Obesity related comorbidities by organ system

Organ System	Comorbidities
Cardiovascular	Hypertension Elevated total cholesterol Elevated low-density lipoproteins Decreased high-density lipoproteins Elevated triglycerides Metabolic syndrome
Endocrine	Impaired glucose tolerance Insulin resistance Type 2 diabetes Polycystic ovary syndrome (PCOS)
Respiratory	Abnormal respirator muscle function and central respiratory regulation Difficulty with ventilation during surgery Sleep apnea Pickwickian syndrome Frequent, severe upper respiratory infections Asthma
Orthopedic	Coxa vara Slipped capital femoral epiphyses Blount disease Legg-Calve-Perthe disease
Dermatologic	Acanthosis nigricans
Gastrointestinal	Transaminitis Non alcoholic fatty liver disease Gallstones Gastroesophageal reflux disease (GERD) Constipation
Immunologic	Impaired cell-mediated immunity
Neurological	Pseudotumor Cerebri

TABLE 5.2 (continued)

Organ System	Comorbidities
Psycho-Social	Low self-esteem Bullying Teasing Discrimination/weight bias Reduced quality of life Anxiety Depression Eating disorders
Other	Low vitamin D

Adapted from Kleinman [12] with additions taken from Barlow [13]; BeLue et al. [14]; Zakharova et al. [15]

Figure 5.2 presents an example of a 16 year old male who despite having a BMI classifying him as obese is likely tracking at a healthy BMI for his body. Further assessment of his health is warranted, but given that he has been trending along the 95th–97th percentiles for BMI since age 2 he is likely at a healthy weight for his height and body habitus.

Figure 5.3 presents an example of a 16 year old male who is likely healthy at a BMI around the 97th percentile for age, but given his current BMI has exceeded his early childhood BMI curve he is at a weight that puts him at risk for poor health outcomes.

Figure 5.4 presents an example of a 16 year old male who is overweight per his BMI, but given his historical BMI curve being around the 50th percentile is at increased risk for poor health outcomes.

In 2005, the Institute of Medicine (IOM) recommended:

Schools should measure yearly each student's weight, height, and gender- and age-specific BMI percentile and make this information available to parents and to the student (when age appropriate).

They acknowledged that current systems and services might now be inadequate to support students and their families in resolving these concerns and so encouraged the development of:

...protocols that are not only reliable and useful but that sensitively collect and communicate this information [16].

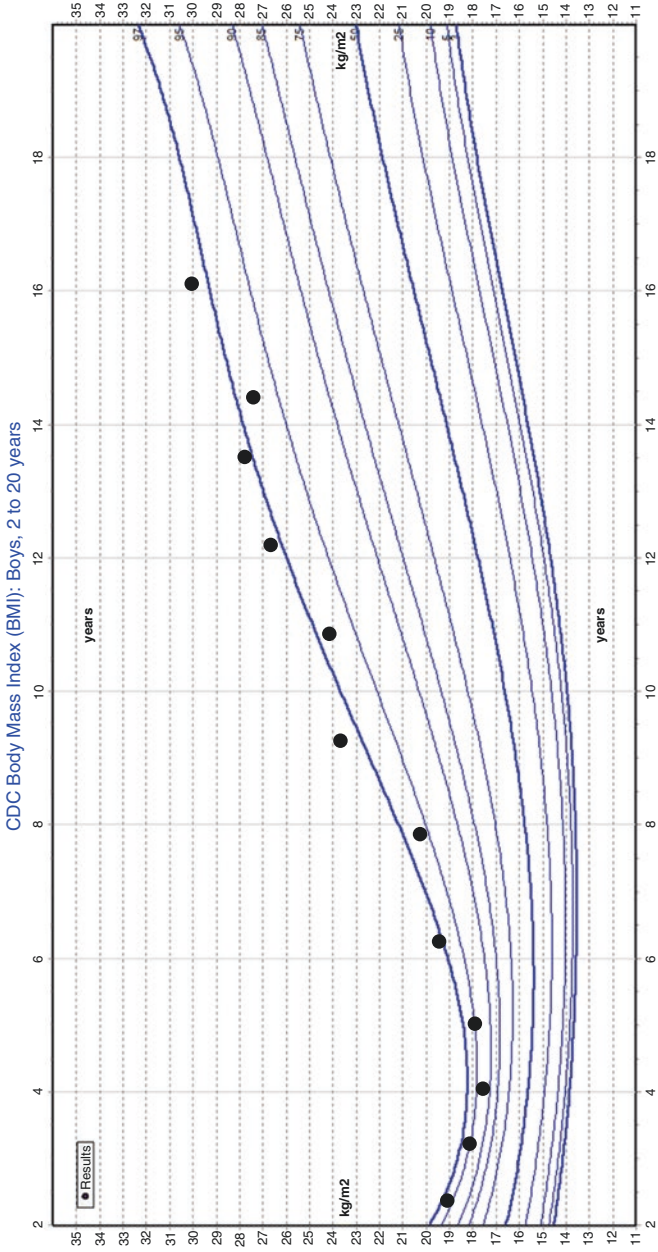


FIGURE 5.2 Growth chart showing appropriate growth

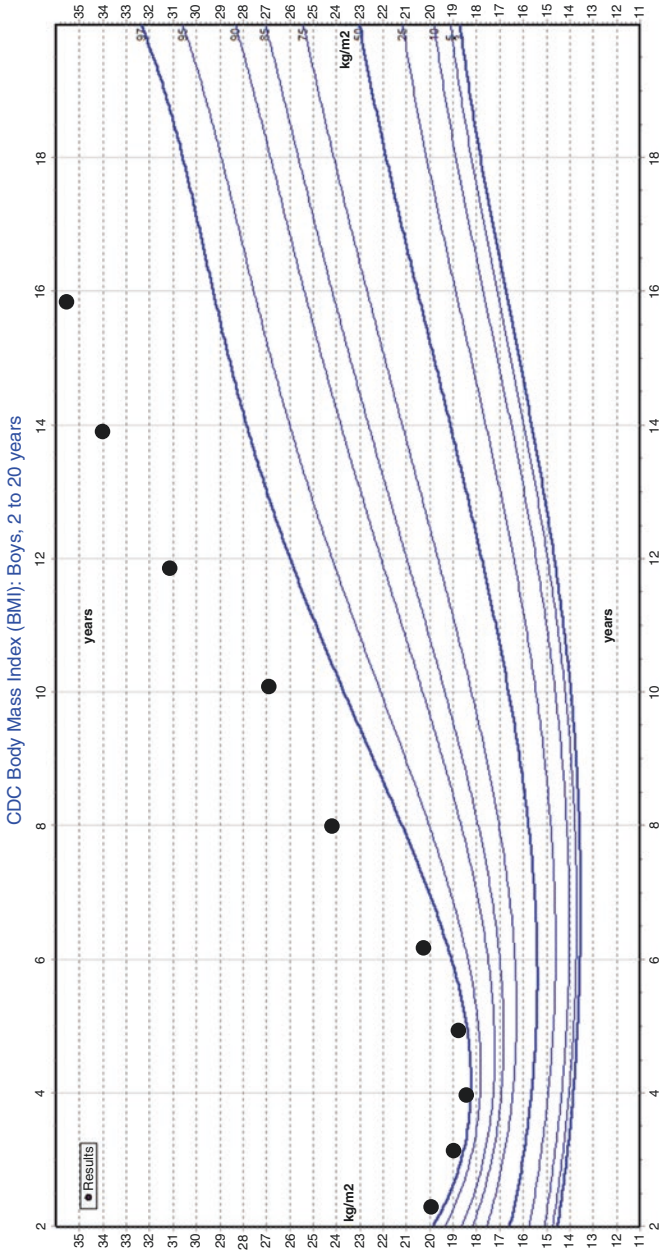


FIGURE 5.3 Growth chart showing excessive weight gain

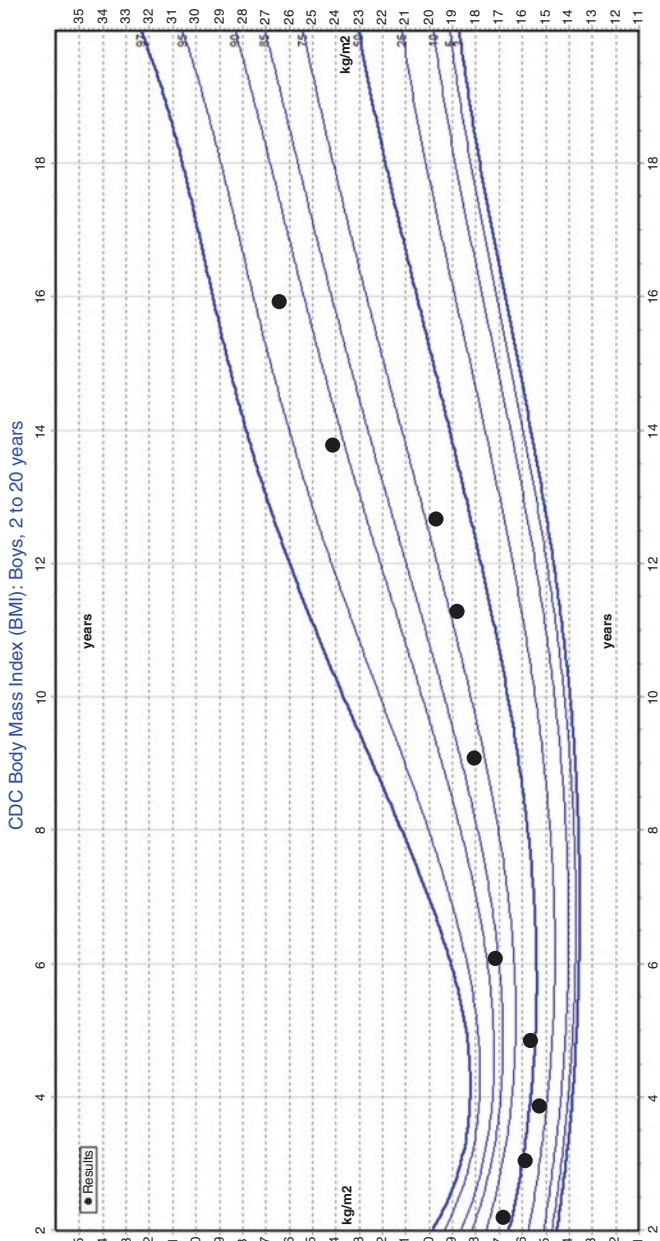


FIGURE 5.4 Growth chart showing excessive weight gain

Since 2005 numerous studies have been conducted on what are commonly referred to as “BMI Report Cards.” Results have been mixed as to whether these are helpful or harmful and so caution should be used when considering these as a tool [17–21].

Other tools commonly used in nutrition focused physical exams that are not recommended for use in overweight and obese adolescents include waist circumference, waist to hip ratio and triceps skin fold tests [13, 22]. This is largely because of a need for clinically useful cut off points based upon age, gender, and sexual maturity prior to their routine utilization in a clinical setting [22, 23]. It is also worth noting that there are psycho-social risks with the use of these measures in the adolescent population.

Assessment of Weight Related Comorbidities and Risk Factors

Biochemical Laboratory Assessment

Some obesity related comorbidities cannot be detected without the use of laboratory data. The 2007 Expert Committee recommended that adolescents with a BMI between the 85th–94th percentiles without risk factors have fasting lipid profiles assessed [13]. Lipid profile laboratory tests include total cholesterol, triglycerides (TG), high-density lipoprotein (HDL) cholesterol, and low-density lipoprotein (LDL) cholesterol. Patients of the same BMI, but who also have other risk factors such as elevated blood pressure and acanthosis nigricans should have a fasting lipid profile along with fasting glucose and liver enzymes aspartate aminotransferase (AST) and alanine aminotransferase (ALT) repeated biannually [13]. Adolescents with a BMI at or above the 95th percentile should have all previously noted lab values repeated biannually regardless of risk factors [13].

Assessment of vitamin D level is an area of emerging research. Adolescents with elevated BMIs are at a higher risk

TABLE 5.3 Recommended laboratory levels

	Borderline abnormal	Abnormal
Total Cholesterol [28]	170–199 mg/dL	≥200 mg/dL
Triglycerides [28]	90–129 mg/dL	≥130 mg/dL
HDL Cholesterol [13]		≤40 mg/dL
LDL Cholesterol [28]	110–129 mg/dL	≥130 mg/dL
ALT [29]		>26 U/L (boys) >22 U/L (girls)
Fasting Glucose [30]	100–125 mg/dL	≥126 mg/dL
Vitamin D		<20 ng/mL [24] <30 ng/mL [25]

of vitamin D deficiency [15]. This is a concern as inadequate vitamin D in the body may place individuals at higher risk of diabetes, hypertension, cancer, auto immune disease, and inflammatory diseases [15]. Current practice is for these patients to be screened for vitamin D deficiency by looking at 25(OH)D, the circulating form of vitamin D [24, 25]. Unfortunately, there is a lack of consensus around what constitutes a low 25(OH)D serum level. The IOM recommends vitamin D levels above 20 ng/mL. Others have recommended levels above 30 ng/mL and 50 ng/mL [24–27]. Factors such as sun exposure, latitude, and skin pigmentation also impact vitamin D levels [24] (Table 5.3).

Clinical Assessment

Sleep and Nutrition

Adolescent sleep habits also impact health. Obstructive sleep apnea is more common in children who are severely obese [31]. Symptoms include loud snoring, momentary pauses in breathing, restless sleep, and daytime sleepiness. Identifying patients who struggle with sleep is imperative as obstructive sleep apnea can result in right ventricular

hypertrophy, pulmonary hypertension, poor attention, and poor academic performance [13]. Even without obstructive sleep apnea, adolescents are notorious for poor sleep habits [32]. This is concerning as short sleep duration is associated with obesity [33]. Poor sleep is also linked to less healthy food choices that are higher in glycemic load, higher in glycemic index, more calorically dense, and higher in carbohydrates with more consumption of sweets and treats [34, 35].

Psychiatric Influences on Nutrition

Patients with ADHD, particularly those taking stimulant medications, are at a higher risk of excessive weight gain due to these medication's impact upon appetite. Adolescents who take these medications will often notice that their appetites' are minimal during the active states of these drugs. Often this is during the school day. This appetite suppression usually leads to inadequate energy intake throughout the day and leads to excessive levels of hunger once the medication's active state wears off. This can lead to excessive food intake, grazing, and bingeing in the afternoon and evening [36]. Patients being treated for mental health concerns should also be screened for use and history of use of second-generation antipsychotics as these have also been associated with weight gain [37].

Nutrition Assessment

Healthcare professionals have historically been trained to focus upon dietary intake when conducting nutrition assessments. Such an assessment typically includes information about a patient's intake of calories, protein, carbohydrates, fat, sodium, fruit, vegetables, sugar, fiber, dairy, portion sizes, and variety. While these are important factors influencing an adolescent's health, focusing solely upon them is short sighted and can leave patients and families feeling ashamed

and hopeless. Other variables such as eating behaviors, family food environment, and adolescent high risk behaviors should be assessed as well.

Adolescent Eating Behaviors

Providers must be careful to avoid weight bias from impacting their assessment of restrictive disordered eating in obese patients. Patient's carrying excessive weight still need to be evaluated for excessive restriction of calories, restriction of food groups and/or food types, unhelpful calorie counting, unhelpful weighing of self, abuse of laxatives and/or diuretics, purging, spitting of food, and binge eating in addition to eating frequency, eating patterns, frequency of thoughts about food and eating, eating in the middle of the night, meal skipping, emotional eating, bored eating, picky/avoidant eating, ability of an adolescent to self-regulate their food intake (identification and response to hunger and fullness), eating speed, and dieting behaviors (e.g. Paleo diet, gluten free diet, vegetarian, vegan, dairy free, ketogenic diet, weight watchers). It is critical that when disordered eating practices are present, helping a patient overcome these concerns should be the priority over helping a patient lose weight. For additional information about disordered eating please reference Sect. 3 of this book.

Family Food Environment

Assessing the family food environment involves a conversation with the parent and teen about who carries the cooking and grocery responsibilities, how often food is consumed that is prepared outside the home, use of electronics while eating, frequency of family meals, family forbidden foods, parental restriction of an adolescent's preferred food or food amounts, parental catering to an adolescent's preferred foods ("short-order cooking"), food/eating related conflict between a teen and their family members, and parental food relationships [13].

High Risk Behaviors

Adolescent high risk behaviors that should be asked about in a nutrition assessment include alcohol use (amounts and frequency of use), tobacco and nicotine, marijuana, and illegal substances. Along with safety concerns, many of these impact the appetite and caloric consumption.

Physical Activity and Sedentary Behaviors

Providers should also take into account an adolescent's activity level. This should include questions about level of intensity, frequency of activity, routine activity patterns, and sedentary behaviors. Many obese patients face barriers to engaging in physical activity and providers must evaluate these prior to making recommendations to increase activity. Socially, youth may be subject to bullying or may feel ashamed and/or self-conscious about their body and/or abilities during an activity. Financially, many families may struggle with equipment costs, registration fees, transportation costs as well as the provision of transportation to/from events given work responsibilities. The built environment can also present barriers to safe recreational areas such as sidewalks, parks, schools, playgrounds.

Treatment of the Obese Adolescent

Treatment Intensity

There remains a lack of consensus around the best treatment approach for adolescents with a BMI greater than the 95th percentile for age. The United States Preventative Services Task Force (USPSTF) stated in 2010 that these individuals are best served using an intensive behavioral intervention that is age-appropriate, culturally sensitive and family-centered [35]. Such treatments should not just focus upon weight, but also help develop life-long healthy behaviors [38].

Barlow, et al. recommended that weight management in the pediatric population be addressed in a four stage approach assuming that the more intense the intervention, the greater the long term impact [13, 39].

The USPSTF found in 2010 that interventions of more than 26 contact hours were the most likely to be effective in reducing excess weight after 6–12 months of treatment. This was based upon a reduction of BMI z score by 0.2 or more compared to little or no reduction in control groups [39]. Weight management interventions with patient contact hours at or above 52 hours were even more impactful with decreased BMI z-scores. These z-scores decreased between 0.22 to 0.34 compared to control groups that noted a small to moderate increases in z-scores. A multidisciplinary/interdisciplinary approach is also recommended which involves medical, nutrition, fitness, and behavioral to address topics about eating, physical activity, sedentary behavior, parenting techniques, family eating, and medical comorbidities [13].

Although high intensity treatment programs involving a multidisciplinary team may be ideal, this type of treatment can place a high burden on an adolescent and their family. Attrition rates are high in obesity treatment with studies reporting between 27% to 73% [40]. Barlow noted in 2007:

[a patient's] motivation is the most important but also the most challenging aspect of obesity care.

Understanding an adolescents' expectation of treatment as well as their parents' expectation of treatment can influence motivation and engagement in long-term treatment [41]. Also accounting for how accessible an intensive behavioral obesity treatment programs is to a patient and family is important. Unfortunately many obese adolescents do not have access to these programs due to living in rural communities or poor insurance coverage [42]. Even families living near children's hospitals may not have access to research-based weight management programs. In 2013, only 60% of children's hospitals offered programs with the recommended intensity and most didn't even last an entire year [42].

Adolescent Focused Treatment

When overweight and obese teens and their parents seek professional help to support weight loss it is valuable to have open and honest conversations with families around realistic weight management goals. When having this conversation, providers should use neutral terms such as “weight” and “body mass index” rather than more stigmatizing words such as “overweight,” “obese,” “extremely obese,” “fat,” or “weight problem” [2]. Regardless of weight, the primary focus of intervention should focus upon making healthy lifestyle changes which will support on-going health. This should be shared with families in conjunction with the weight recommendations (Table 5.4).

Given the developmental needs of an adolescent, most teens benefit from providers meeting one-on-one with them for a portion of the visit [22]. Targeting both parents and teens throughout treatment is likely beneficial as well [43, 44].

Nutrition Interventions

Eating Behaviors

Meal and Snack Patterns, Timing and Balance

As previously noted, while it can be tempting to initially target an adolescent’s food choices, it is often more produc-

TABLE 5.4 Adolescent Weight Loss Recommendations (Barlow et al. [13])

Age	BMI category	Long term goal
12–	5–94th	Support growth along patient’s growth line.
18 years	85–94th (with health risks)	Age appropriate weight and height velocity maintenance.
	95th–99th	Gradual weight loss no greater than 1#/mo.
	>99th	Gradual weight loss no greater than 2#/week.

tive and supportive to first address an adolescent's unhelpful eating behaviors. While this should be individualized based upon findings in the nutrition assessment, typically the first line of intervention is around eating patterns. This is in the early stages of research, but for now the primary goal is to help patients develop a plan for regular meal and snack timing to avoid "grazing" behaviors (eating more frequently than every 3 hours) [35]. Adolescents should nourish their body about every 3–4 hours during waking hours. Using phone or watch alarms can be helpful to cue adolescents of these eating times when adults are unable to do so. The development of a regular eating pattern is critical as an irregular intake of main meals has been shown to lead to poorer food choices and impact the quantity of food consumed [45].

One of the most common causes of irregular food intake is breakfast skipping. About a third of adolescents skip breakfast [46]. When an adolescent is skipping breakfast, starting a breakfast routine is the best starting point for a nutrition intervention. This is because breakfast skippers are more likely to consume food between meals as well as more likely to consume snack-type foods which tend to be more calorically dense [45, 47]. As such, helping a teen eat breakfast can result in positive nutrition changes later in the day without directly addressing those concerns. Consumption of breakfast has also been associated with a lower risk of obesity and improved cardio-metabolic risk factors [46, 48].

Start by helping adolescents identify their barrier to having breakfast and using motivational interviewing techniques to help them develop solutions to overcoming these barriers [13]. Common barriers are a perceived lack of time, lack of hunger in the morning, lack of perceived good food at home or school, and competing morning priorities. Once a daily breakfast routine has been established as part of an adolescent's eating pattern, it can be helpful to address breakfast composition. Preliminary research is beginning to highlight the value of having a higher protein breakfast to help with satiety [47] although helping adolescents understand the

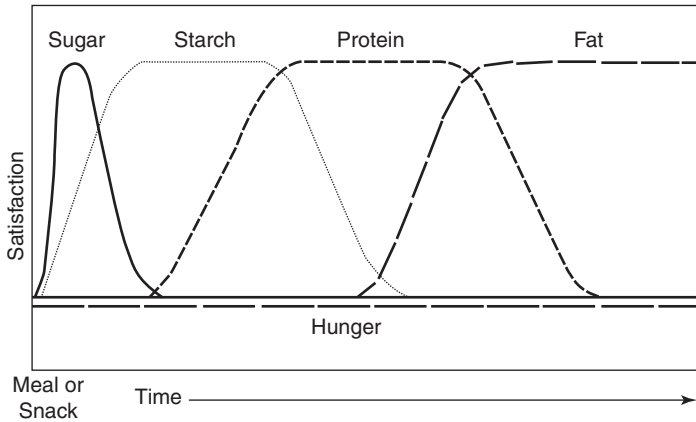


FIGURE 5.5 Satisfaction from consuming sugar, starch, and fat. (Reproduced with permission from Elynn Satter MS, RD, LCSW, BCD)

value of starches and fruits/vegetables along with protein at breakfast is also important.

Teaching and motivating adolescents to consume balanced meals and snacks in addition to breakfast can further assist teens in spacing their eating evenly throughout the day. As noted in Fig. 5.5 helping teens consume a food with a natural sugar (fruit/vegetable) along with a starch, protein and fat can help an adolescent maintain satisfaction until the next eating time [49]. Teens should include a protein, fat, starch, and fruit and/or vegetable at meals. Snack should include a protein with either a fruit/vegetable/starch. Once teens are successfully including each group of food into their meals it is important to help them consume healthy portions of these foods [35]. The United States Department of Agriculture's (USDA) MyPlate can be a helpful resource for introducing this [50]. In the United States, often the starch group is the largest portion of food on the plate. Helping patients mimic the healthy eating plate so that one-half of their plate is fruits and vegetables while only one-fourth of it is starch and one-fourth of it is protein can help with satisfaction as well as decrease the likelihood of excessive caloric intake at a meal.

Responding to Hunger and Fullness

Whitlock recommends that adolescents learn how to practice mindful eating [35]. Among other things, this skill can help teens navigate their natural urges to eat in the absence of hunger to handle emotional needs and boredom. Research suggests that eating in the absence of hunger may be associated with adiposity [51, 52].

Telling patients about mindful eating and teaching them how to practice it are distinctly different. Tools that are helpful to teach teens how to practice mindful eating are Jan Chozen Bay's Eight Hungers (Table 5.5 [53]) and the Hunger Meter (Fig. 5.6). These tools can also help teens learn to slow their rate of eating, although other cues can also be helpful such as placing the eating utensil down between bites, avoiding electronics while eating, and increasing conversation while eating. Reducing the speed of eating is important as rapid eating is associated with increased energy intake [54]. Fast eaters consume 75% more calories than slow eaters and rapid eating is associated with higher BMI [54].

TABLE 5.5 Jan Chozen Bay's eight Hungers [53]

Type of hunger	Description
Stomach hunger	Stomach growls or rumbles
Ear hunger	Hearing sounds of cooking or food packages or talk about food
Eye hunger	Food looks so good to eat
Nose hunger	Food smells so good
Mouth hunger	Food tastes so good
Mind hunger	Eating out of boredom or habitual eating
Heart hunger	Emotional eating
Cellular hunger	Eating when thirsty

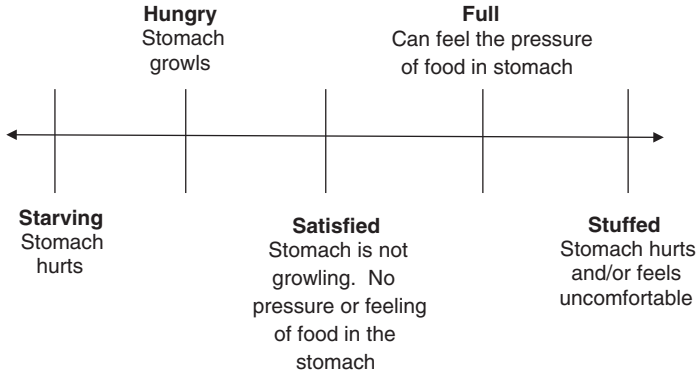


FIGURE 5.6 The hunger meter

Assessment and Treatment Goal for Family Food Environment

Adolescents do not have full control over the food available to them thus the assessment of the family food environment is critical as is the involvement of parents/caregivers buying, cooking, and serving of food. Understanding who does the cooking, who does the grocery shopping (where and how often), and presence/level of food insecurity are all-important. Understanding parental/family expectations around meal times can be enlightening. Are families eating together? Is the TV on? Are people eating whenever they want to or are eating times organized? Is the teen eating frequently in their room? How often are families getting food at restaurants? How often is the teen eating out? It is important to help families decrease their fast food consumption although understanding the reasons a family has resorted to fast food/restaurants is critical to long-term success in decreasing the frequency of these establishments. For example, families will utilize these resources due to lack of cooking skills, children's picky eating, lack of time or perceived time to cook, lack of skills to quickly menu plan, perceived lower costs and as a way to express love to their child(ren) particularly when

other resources are scarce. Regardless of the reason, eating out can lead to an excessive intake of calories [35].

Parents often complain that their teenager is a picky eater. While this may be true, it can be helpful to understand both the parent and teen's perspective. Parents often hear their adolescent complain "there is nothing to eat" at home. The dialogue about what the teen likes and what is available at home frequently occurs in clinic visits. While this may seem silly it is valuable to teach families by modeling this dialogue, so that they can begin doing this at home. Helping parents know a teen's food preferences can help a parent increase the availability of preferred healthy foods in the home [55]. Alternatively, it is important to make sure frustrated parents do not over-adjust and begin to cater to a teen's food preference. This is equally unhelpful.

Reminding parents the importance of not forbidding food is important as teens in particular will help themselves to food outside of the home. Similarly, parental restriction does not work well with adolescents. Parental restriction can result in adolescents doing more sneaking and hiding of food as well as increasing stress and shame around food, which can exacerbate overeating. Understanding the conflict occurring in the home is important as well as understanding unequal or unfair household restrictions or "guidelines" around food and eating. For example, sometimes a heavier child is restricted from foods that their thinner sibling is allowed to eat. This is rarely helpful.

Dietary Modifications

Calorie and Macronutrient Restriction

Traditional dietary interventions for overweight and obese patients focused upon caloric restriction. While a caloric restriction of 300 to 400 kcal per day below a patient's daily caloric needs for weight maintenance may mathematically lead to a weight loss of 1 pound per week. In practice, this approach often does not lead to a long-term loss of weight without significant work in the areas of eating behaviors and family food environment. This is because restriction alone

can diminish self-regulation, disrupt hunger and satiety cues, and lead to restrict-binge cycles as well as even weight gain [13, 56–58]. Nutrition interventions focused upon long-term behavior change can be more helpful. As Savoye noted:

Dietary interventions emphasizing selection of healthier foods are more likely to be sustained [59].

Such approaches are considered “non-diet” interventions (no calorie restriction) and may focus on lower fat intake, increase of nutrient dense foods, and/or moderation of portion sizes. At the same time, there continues to be some evidence for the short-term benefit of aspects of a less restrictive modified stoplight-type diet and the low glycemic load diet to help adolescents begin to have success at reducing their intake of high energy-dense foods [22, 60, 61]. This type of approach should only be considered after a thorough history has been completed to rule out history of disordered eating that may be exacerbated by any type of restriction, perceived or otherwise.

Dietary Fat, Dietary Protein, and Dietary Carbohydrates

Providers can help adolescents and their families by helping them understand both the positive and negative role of dietary fat in the body. Current recommendations are for teens to consume dietary fat as part of a balanced macronutrient diet ($\leq 30\%$ of kcals) keeping saturated fat in particular at 7–10% of total calories [28]. Trans fat should be limited and the remaining 20% of calories from fat should be from mono-unsaturated and polyunsaturated fats [28]. Recommended intake of cholesterol is ≤ 300 mg/dl [28, 62]. See Chap. 4, Developmental Nutrition, for guidelines on dietary protein and carbohydrates.

Sodium and Fiber

General recommendations are for all adolescents is to decrease their intake of high sodium foods so that their maximum intake of sodium does not exceed 2300 mg per day [35, 63]. Adolescents often are consuming inadequate amounts of

whole grains [63]. Nutrition recommendations are currently to help teens make at least half of their grains whole and generally increase their fiber intake [35, 63]. Helping teens and their families decrease consumption of processed foods can help decrease sodium and increase fiber intake [35].

Beverages

Adolescents consume high amounts of added sugar. Half of their added sugar intake is in the form of sugar-sweetened beverages (SSBs) [63]. Asking open-ended questions is helpful in determining how much soda, sweetened teas, sweetened coffees, energy drinks, and sport drinks are consumed daily/weekly. Current recommendations around SSBs range between limiting them [64] and eliminating them [35]. One useful strategy to help adolescents reduce their intake of SSBs is to guide them in replacing sugar with high intensity sweeteners. This reduces caloric intake and can be helpful in the short-term, but concerns remain about their effectiveness and safety when used long-term [63, 65].

Evaluating juice intake can be difficult as what patients and their families' think of as juice is often different from what the assessing provider considers juice. As such, it can be helpful to specifically ask about 100% fruit juice, homemade juice, "natural juices," and juice smoothies. Current recommendations are to drink 100% juice when consuming juice and to limit juice to 8 ounces or less per day [66]. In practice, it is helpful to encourage the removal of juice from the home. A common nutrition intervention is to encourage the substitution of fruit for juice, however such a recommendation should be made with caution. It is common for this recommendation to be heard by patients and their families' that fruit is *always* okay to consume. Thus, a provider can accidentally set the stage for a patient grazing on fruit throughout the day.

Adolescents typically consume inadequate amounts of dairy [63]. Asking questions about how many times a day a teen consumes milk, cheese, and/or yogurt is valuable as well as understanding the typical fat content of the dairy foods consumed. This helps determine areas of excess saturated fat

intake as well as assessing for risk of vitamin D and calcium deficiency. Current recommendations for adolescents are 3 cup equivalents of dairy a day and choosing nonfat or 1% dairy foods [63]. Adolescents should be meeting the minimum requirements of 1300 mg/day of calcium and 600 IU/day of vitamin D daily [24]. While research has demonstrated that teens are at risk of inadequate amounts of dairy, it is important to assess for excessive intake of dairy. Excessive intake of dairy and/or drinking of milk between eating times can lead to excessive weight gain.

Physical Activity and Sedentary Behaviors

The 2010 Dietary Guidelines recommend adolescents participate in at least 1 hour of physical activity a day. Ideally, such activity should be at either a moderate or vigorous intensity level [63]. This can be a challenge for many overweight and obese adolescents due to the barriers previously mentioned above. Prior to making changes in the area of physical activity, youth should have a medical evaluation to ensure participation in more strenuous activity is safe, to discuss discomfort in muscle and/or breathing, and to evaluate for other co-morbidities that could limit participation. Once this is completed, a good starting point is to work with the teen to identify activities that they can truly enjoy or learn to enjoy. Many have had a negative experience with exercise and will need to be supported through this in order to find something they can envision themselves doing. Once such an activity is identified, it is recommended to support teens increase their overall activity level in 20-minute increments towards 60 minutes a day [35].

In addition to increasing activity, many teens need support and structure to help them limit their non-academic screen time. The current recommendation is a maximum of 1–2 hours a day [35]. Engaging the family in making these changes can additionally support the teen. Examples of this might include a family walk, taking the family pet outside to play or something more advanced such as family hiking or joining a local recreation center with a sibling.

Clinical and Laboratory

Many overweight and obese adolescents have dyslipidemia, most commonly in the form of moderately-to-severely elevated TG, normal-to-mildly elevated LDL cholesterol, and low HDL cholesterol [28]. It is important to clarify that lab results were drawn in a fasting state to prevent falsely elevated results.

When triglycerides are elevated, helping patients increase their physical activity has been demonstrated to positively impact these levels [13] as has decreasing the intake of simple carbohydrates and weight loss [28].

Patients with elevated LDL cholesterol that does not respond to the general population recommendations of saturated fat and cholesterol should be taught to further decrease their saturated fat intake to less than 7% of daily calories and decrease cholesterol intake to less than 200 mg/d [28, 62].

Preliminary research has shown some evidence that increased physical activity improves HDL cholesterol levels in the pediatric population, however not enough to draw conclusive evidence [13, 62]. The use of omega 3 fatty acids on HDL and TG has not been widely studied, but it has been recommended to increase HDL and decrease TG while improving insulin resistance [62, 67]. Research also remains limited in the areas of fiber, soy-based proteins, stanols and sterol esters [28, 62].

As previously noted, many adolescents struggling with obesity will have low vitamin D levels. Current recommendations are for patients with low vitamin D levels to be treated with supplements. Appropriate vitamin D supplementation is debated. The IOM recommends supplementation with 600 IU/day to maintain healthy vitamin D levels [24]. The Endocrine Society agrees, but suggests that those with a BMI >30 kg/m² may need supplementation of up to three times that amount [25]. The current upper limit (UL) for vitamin D in the adolescent age group is 4000 IU/day [24]. This is also debated. Supplementation should continue for 1–3 months prior to rechecking levels.

Special Considerations

Unique Situations

Teens with low muscle tone and diseases/conditions that impact muscle development frequently have significantly lower caloric needs compared to typically developing teens. These include teens with trisomy 21, hypothyroidism, Prader-Willi syndrome and those who are wheel chair bound. These teens usually only need about 9 to 11 kcals per centimeter in height to maintain healthy growth and avoid excessive weight gain. To slow these patients' excessive weight gain or support weight loss these patients may only need about 7–9 kcals per centimeter in height [68].

Pharmacotherapy and Bariatric Surgery

The gold standard for treating adolescent obesity remains lifestyle and behavior change due to the risks of more extreme treatment in growing and developing bodies. Occasionally, pharmacotherapy and/or bariatric surgery may be warranted, but only after a teen has completed an intensive lifestyle modification program that has been unsuccessful in leading to weight loss or resolving comorbidities [35].

There can be serious health consequences associated with diet pills and weight loss supplements including dehydration, chronic diarrhea, chronic constipation, metabolic acidosis, hypokalemia, fluid and electrolyte abnormalities, cardiac arrhythmias, stroke, hepatic failure, renal failure and death [69]. In fact, at this time the only weight loss medication approved for adolescents is Orlistat (Xenical) [13, 35]. Rebound weight gain is common with the discontinuation of it and patients frequently do not consistently use it due to the unpleasant gastrointestinal side effects [70]. This field is evolving and the Food and Drug Administration makes changes regularly. It is recommended that providers review

TABLE 5.6 Common Bariatric surgery criteria [35]

Bariatric surgery criteria
Achieved Tanner stage 4 or 5 and near final adult height
BMI > 40 or BMI > 35 with significant comorbidities
Comorbidities persist despite compliance with lifestyle modification program
Psychological evaluation and the absence of untreated underlying psychiatric illness
Patient able to adhere to dietary and activity changes

the recommendations of national societies when clinically caring for obese adolescents.

Roux-en-Y gastric bypass and laparoscopic gastric sleeve surgeries are both approved for use in severely obese adolescents. To be considered appropriate for bariatric surgery, adolescents must meet the goals set forth by their treatment team and insurance company. The current recommended criteria are noted in Table 5.6, however it is notable that this can vary from institution to institution and between insurance companies. A short-term very low calorie diet along with calorie counting is warranted. Such diets should never contain less than 1200 kcals per day.

While surgical intervention can result in weight loss, it is not without risk. Post-surgical complications include iron deficiency anemia, folate deficiency, vitamin D deficiency, thiamine deficiency, protein-energy malnutrition, and dehydration. It is also a non-reversible option and should be considered very carefully with teens, their parents/caregivers and treatment team.

Clinical Pearls

It is a privilege to work with adolescents and their families as they tackle the vulnerable topic of weight and health. Providers must be careful to check their own weight bias when treating these patients [2]. While there are many areas

TABLE 5.7 Prochaska and DiClemente's stages of change model

Pre-contemplation	Lack of awareness of a need to make a change
Contemplation	Aware of the need to make a change, but not ready to make that change.
Preparation	Decision is made to make a behavior change
Action	Change behavior is initiated
Maintenance	Change behavior is maintained
Relapse	Return to a previous level of change

in which weight bias can present itself, one that is often overlooked is a provider's desire for a patient to lose weight in order for the provider themselves to feel successful. Providers need to check their own discouragement to prevent it from blinding them from identifying health risks, barriers to change, and a patient's movement within different stages of change (Table 5.7).

Taking a chronic disease approach to treatment can be helpful when determining a time to discontinue treatment. A "lack of progress" in terms of weight loss is typically not a valid reason for stopping care. Instead, it is an opportunity to look deeper into the presenting barriers. Using tools such as the stages of change and motivational interviewing can be helpful. Signs that discontinuing or pausing care may be appropriate include normalized labs, weight stabilization, appropriate weight loss, and teen burnout in treatment. When the time comes to discontinue or pause care, it is helpful to do so in a staged way that makes sure a teen and their family are able to maintain lifestyle changes with less support. For example, when meeting with a patient monthly is no longer deemed necessary (or sustainable for a patient/family) it can be helpful to follow up in 3 months, then 6 months, then 12 months prior to discharging to a teen's primary care provider. It is recommended that all such decisions be discussed within the greater treatment team and that teen's and their parents/caregivers be coached on identifying when it may be helpful to return to specialized weight management care.

Case Study: An Adolescent Female with Obesity Interested in Bariatric Surgery

Description: 17 year old female with obesity, sleep apnea, diabetes insipidus, impaired fasting glucose, back pain, knee pain. She began working with a full wellness treatment team of social work, fitness, medical, and nutrition. At age 19, patient becomes interested in surgical intervention to assist in weight loss.

Physical Assessment:

- Initial Weight: 148.4 kg (>99th percentile)
- Initial Height: 167.9 cm (~75th percentile)
- Initial BMI: 53 kg/m² (>99th percentile)
- Initial Labs: Elevated triglycerides, elevated HbA1c (5.8%).

Family Medical History: Patient's mother diagnosed with gestational diabetes during pregnancy then was later diagnosed with type 2 diabetes. Family history is also significant for early strokes, hypertension, and substance abuse.

Social History: Complicated social history. Mother died unexpectedly during wellness treatment. Patient lives with grandparent. There is significant food insecurity and intermittent housing insecurity.

Nutrition Assessment: Patient shares that she cannot remember a time when she had a good relationship with food. She endorses emotional eating, binge eating, and eating in the middle of the night when she is unable to sleep. Her eating pattern is notable for cycles of eating too often and too much throughout the day as well as cycles of eating too little and infrequently throughout the day.

Initial 24 Hour Diet Recall:

Lunch – sandwich and granola bar

Multiple snacks throughout the day – granola bar/fruit/yogurt/cheese/nuts

Dinner – Included a meat, vegetable, and starch

One or more snacks after dinner

Physical Activity Assessment: Physical activity is low.

Patient's Stage of Change: Patient notes that she is motivated to make changes for herself. In the past she primarily made changes to please others.

Commentary: Patient was well-engaged in treatment. She began a weekly, 3 hour evening wellness program 4 months after initiating one-on-one treatment with medical, nutrition, social work, and fitness providers. She continued to follow up routinely with all providers for 3 years. During this time she was able to develop and follow a daily eating routine despite varying daily schedules for school, work and social activities. She rarely ate for emotional reasons and rarely endorsed binge eating at the end of treatment. She resolved her habit of eating in the middle of the night when sleep was challenging. She was also more aware and responsive to her hunger and satiety cues. After 1 ½ years of treatment, HbA1c was within normal limits having decreased from 5.8% to 5.3%. Weight had decreased 4 kg and BMI had decreased 2 kg/m².

24 Hour Diet Recall (post intervention):

9 am – Breakfast – Eggs, snow peas.

12 pm – Lunch – beef stew.

3 pm – Snack – granola bar.

6 pm – Dinner – stir-fry.

8:30 pm – Snack – chocolate covered almonds.

After 2 ½ years of working with the treatment team she began pursuing gastric sleeve surgery. Nutrition interventions reinforced previous work, but began to incorporate a greater focus on self-monitoring, calorie counting, caloric restriction, removing carbonated beverages, and high protein diet. Gastric sleeve surgery was performed after 6 months of preparation for the life changing surgery. Patient transitioned to adult care 4 months after surgery, however at that time weight was 110 kg, and BMI decreased to 39 kg/m².

Clinical Pearls: This was a highly motivated patient with excellent family support. Despite this she had many challenges to overcome in her work to improve her health. There were four clinical pearls to note from this case:

1. Long-term, frequent follow up: This patient was engaged in regular wellness care for 3 years and due to her pursuit of bariatric intervention will likely have some sort of medical, nutrition, and/or social work intervention throughout her life. This patient's example is difficult for many patients and families to implement due to competing priorities.

2. Adolescent centered care: This patient worked with two dietitians pre and post bariatric surgery. One dietitian was an expert in bariatric surgery and the other in adolescent nutrition. The combination was valuable as one professional provided the recommendations while the other would follow up more frequently to help the patient implement those recommendations in the adolescent/young adult world.
3. Self-Monitoring: This patient was ultimately able to be successful in self-monitoring her food intake via a food journal application. However, this success was not achieved until it was necessary to achieve preliminary goals for surgery. Interestingly, self-monitoring goals were previously addressed with this patient but with little success. This change was discussed and patient noted she was more motivated with the thought of bariatric surgery than just working to make health-related changes. This was a fascinating revelation from a highly motivated patient.
4. Body Image: Patient did not report improved body image 4 months post bariatric surgery.

Case Study: A 12-year-old Male with Obesity Delaying Surgical Intervention

Description: 12 year old male with obesity and sleep apnea that are delaying surgical intervention of idiopathic scoliosis. Surgeon recommends a 50 pound weight loss prior to surgery.

Physical Assessment:

- Initial Weight: 126 kg (> 99th percentile)
- Initial Height: 175 cm (> 99th percentile)
- Initial BMI: 41 kg/m² (> 99th percentile)
- Initial Labs: Elevated ALT, low vitamin D.

Family Medical History: Both parents struggle to manage their weight. Mother reports history of repeatedly losing and regaining 50 pounds. She endorses her own experience of shame with food and eating. Father is currently dieting. Family history is significant for depression.

Social History: Patient's parents divorced when he was 7 years old. He resides with his mother during the school year and his father during the summer. He alternates living with the opposite parent on weekends. He has been the recipient of significant weight and height related bullying/teasing in the school setting.

Nutrition Assessment: Patient endorses routinely skipping breakfast and lunch on school days and then bingeing on food after school. Also endorses boredom eating, sneaking food from the kitchen, and emotional eating. He will wake in the middle of the night to eat. He has trouble describing a hunger sensation and a fullness sensation. Fast food intake can be excessive. There is a family history of family weigh-ins. Portion sizes are large as family uses quite large plate ware. Fruit and vegetable intake are minimal.

Initial 24 Hour Diet Recall:

4:30 pm – Snack – whole bag of chips + leftovers from the previous night's dinner, ¼ of a cake.

7 pm – Dinner – pancakes, bacon.

Physical Activity Assessment: Physical activity is minimal.

Patient's Stage of Change: Patient communicates a wavering stage of change between preparation and action.

Commentary: Patient is moderately engaged in treatment. Followed up twice with medical, three times with nutrition, and did not meet with fitness or social work providers. Patient was eventually lost to follow up despite numerous attempts by the clinic to contact the family. During nutrition treatment, the patient and family were educated on metabolism, meal/snack timing, meal/snack balance, mindful eating, increased physical activity, and realistic rate of weight loss.

24 Hour Diet Recall (after 2 visits):

8:15 am – School Breakfast.

11 am – School Lunch.

3 pm – Snack – bowl of Cheerios with milk.

5 pm – Dinner – Grilled cheese sandwich and soup.

Clinical Pearls

1. Due to the history of weight shaming or “fat shaming”; establishing a good rapport with patient and family is imperative in order to gain better insight as to what eating, and experiences of food, have taken place or are currently taking place.
2. Different disciplines may have different expectations around how fast a patient can and should lose weight. Multi-disciplinary communication is important to promote when caring for adolescents and their families.

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Chapter 6

Ensuring Nutritional Adequacy in the Adolescent and Young Adult Athlete



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Introduction

The intent of this chapter is to outline the needs of adolescent and young adult athletes to ensure nutritional adequacy in both general populations and those with additional health concerns. Adolescent athletes have unique considerations, in that, they have higher baseline needs due to continued growth, development and maturation in addition to higher energy requirements with training and competition. For all athletes, it is necessary that they achieve

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their baseline nutrient requirements before they can gain performance benefit from additional modifications, some of which may not be appropriate or have added benefit.

Needs of Active Youth and Athletes

Energy

Recommendations for total energy needs are based on predictive equations to achieve proper growth and development in both healthy children and those with illness, plus additional requirements for sports and exercise, which is predominately extrapolated from recommendations and research applied to college aged, middle aged and older adult populations. Thus, the practitioner often needs to adapt adult recommendations to the young adult based on their unique considerations.

Estimating total energy requirements for the pediatric, adolescent, and young adult factors energy required to maintain basal metabolic functions, thermic effect of food, level of physical activity, as well as additional requirements to support age-appropriate growth and development, and can be estimated based on the practitioner using a variety of predictive equations and methodologies.

Predictive Equations:

- Dietary Reference Intake (DRI) and the Dietary Guidelines provides estimated energy requirements (EER) based on energy expenditure, requirements for growth, and level of physical activity. Most youth athletes will be at active or very active level
- Basal metabolic rate: sports dietitians will also commonly use the Harris-Benedict equation to determine basal metabolic rate (BMR) and multiply by activity factor. In adults, this factor is multiplied by 1.8-2.3 for moderate to very heavy physical activity [1]

Other Considerations:

- Stages of growth and development: Tanner stages or Sexual Maturity Rating (SMR) identifies the stage of growth and development on a scale of 1 (prepubertal) to 5 (maturity). Please refer chapter “[Developmental Nutrition Needs](#)” for nutritional considerations during puberty and consider additional points published through 2002 Supplement to the *Journal of the American Dietetic Association* for tailoring specific recommendations for youth athletes [2].
- Physical activity: most variable component, and should consider training or exercise schedule, competition schedule, sport type, exercise frequency, duration and intensity, as well as seasonal changes to exercise schedule

Energy Metabolism

During exercise, the body powers its movement by converting stored energy from muscle glycogen, liver glycogen, oxidation of free fatty acids, and exogenous carbohydrate sources. The fuel source, either carbohydrates or lipids, can vary depending on the individual in their stage of development, as well as the intensity and duration of the exercise.

In adults, muscle glycogen can store limited amounts of carbohydrates, and consequently, is used to power brief, but intense exercise, as well as intermittent aerobic activity. Typically for endurance athletes, they use glycogen during the initial phase of their exercise, then convert to stored body fat for energy. Lipids are predominantly used during low and moderate intensity exercise. During the start of non-endurance exercise in adults, energy is predominantly derived from muscle glycogen, and with training, mitochondrial adaptations favors lipid metabolism [3].

There is evidence to suggest that young athletes’ glycolytic capacity is still developing and thus, they have lower glycogen stores than adults and are better able to utilize fat

as a fuel source than adults. Also, in comparison to adult athletes, young adults are not able to sustain similar duration of exercise and experience earlier onset of fatigue, which is believed to be attributed to their reduced glycogen stores. Consequently, it is thought that youth athletes require more exogenous carbohydrate sources during exercise to maintain exercise intensity, and some research has shown improved sports performance [4]. More research is needed to better understand carbohydrate utilization and requirements in youth athletes, as it is also thought that youth athletes utilize exogenous carbohydrates at a reduced rate than adults [4].

Energy Deficiency

Inadequate energy intake can manifest as:

- weight loss
- loss of muscle mass
- loss of strength
- increased fatigue
- increased injuries or stress fractures
- low bone density
- delayed and/or stunted growth
- menstrual dysfunction
- inability to and/or prolonged recovery from activity
- low heart rate and/or low blood pressure

It should be noted that youth athletes may be in negative energy balance, but may not experience weight loss, and may maintain their weight or an appropriate weight for their body. Often this is achieved by metabolic changes and adaptations in body composition with decreased lean muscle mass.

When assessing potential etiologies for negative energy balance, practitioners should also assess for adequate access to nutritious foods. Food insecurity is an issue for an estimated 40 million people and 12 million children in the United

States, and may be an ongoing challenge for young athletes, especially in providing adequate energy and nutrient-dense foods to fuel their physical activity and support appropriate growth and development [5]. Food insecurity also impacts relationship with food and is associated with binge eating and food hoarding behaviors.

RED-S Relative Energy Deficiency in Sport/ ExMD Exercise-Related Menstrual Dysfunction

Case Study

Your next patient is a 15-year-old female who is coming to see you because her parent is concerned that she stopped menstruating. Menarche occurred at age 13 and patient was having regular cycles until 6 months ago. She has not lost any weight but on chart review has always been lean with BMI of 19.6. She became a vegan 8 months ago to be “healthier”. She plays year-round basketball and has just made it to an elite team that travels about 6 times a year to different regions of her state. She also plays for her high school basketball team and is practicing on average about 18 hours per week.

- Considerations:
 - How would you approach the visit? What questions would you ask and whom would you ask? How would you establish rapport and trust with the patient?
- Assessment:
 - Menarche – has the patient started OCPs or birth control that would account for amenorrhea? Do we suspect secondary amenorrhea due to inadequate calorie intake?
 - Energy balance – does she still require an additional energy factor for ongoing physiological growth and development? How do changes in her exercise program affect energy requirements? How would changes to her

eating effect energy balance, if at all? How do you interpret her weight stabilization?

- Patient/team/family attitudes/beliefs/motivators – what are the motivators for following a vegan diet?

In 2014, the International Olympic Committee (IOC) convened an expert panel to replace the 2005 IOC Consensus Statement on the Female Athlete Triad. The new Consensus Statement includes guidelines to guide risk assessment, treatment and return-to-play decisions. The IOC expert working group established a more comprehensive term for the condition previously known as ‘Female Athlete Triad’. The term “Relative Energy Deficiency in Sport” (RED-S), points to the complexity involved and the fact that male athletes are also affected, as outlined in Fig. 6.2.

RED-S refers to impaired physiological function including metabolic rate, menstrual function, bone health, immunity, protein synthesis, and cardiovascular health caused by relative energy deficiency. The cause of REDS-S is energy deficiency relative to the balance between dietary energy intake and energy required for health and activities of daily living, growth and sporting activities. Psychological consequences can either precede RED-S or be the result of RED-S. The clinical phenomenon is not a ‘triad’ of the three entities of energy availability, menstrual function and bone health, but rather a condition or syndrome that affects many aspects of physiological function, health and athletic performance. This consensus statement, ‘Sport Risk Assessment and Return to Play Model’ categorizes the syndrome into three groups and translates these classifications into clinical recommendations [6].

The underlying problem of RED-S is an inadequacy of energy to support the range of body functions involved in optimal health and performance. Energy availability (EA) is calculated as Energy intake (EI) minus the energy cost of exercise relative to fat-free mass (FFM) and in healthy adults, a value of 45 kcal/kg FFM/day equates energy balance.

Low EA, which occurs with a reduction in EI and/or increased exercise load, causes adjustments to body systems to reduce energy expenditure, leading to disruption of an array of hormonal, metabolic and functional characteristics.

Disordered eating (DE) is the major offender in those with low EA, but other situations such as a poorly managed training program with an extreme exercise commitment, may occur without disordered eating.

Although the literature on low EA has focused on female athletes, it has also been occasionally reported to occur in male athletes. There are few prevalence studies of low EA in male athletes, yet it appears in the weight sensitive sports (including dance) in which leanness and/or weight are important due to their role in performance, appearance or requirement to meet a competition weight category.

DE may begin with efforts to eat “healthier” often changing portions or meal balance in an effort to achieve a prescribed goal, sometimes extending to eliminating food groups or short term restrictive diets. This could look like “eating clean”, decreasing or eliminating a food group in an effort to improve “bloating” or athletic performance, removal of snacks or skipping certain meals.

The continuum can end with clinical eating disorders (EDs), abnormal eating behaviors, distorted body image, weight fluctuations, medical complications and variable athletic performance.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) diagnostic classifications for EDs include anorexia nervosa, bulimia nervosa, binge ED and other specified and unspecified feeding or ED.

These EDs have many features in common, and athletes frequently move among them. The pathogenesis of EDs is multifactorial with cultural, familial, individual and genetic/biochemical factors playing roles. Please see other chapters for additional ED information.

In addition, factors specific to sport such as dieting to enhance performance, personality factors, pressure to lose weight, frequent weight cycling, early start of sport-specific training, overtraining, recurrent and non-healing injuries, inappropriate coaching behavior and regulations in some sports have been suggested. The prevalence of DE is about 20% and 13% among adult and adolescent female elite athletes, and 8% and 3% in adult and adolescent athletes (Figs. 6.1 and 6.2).

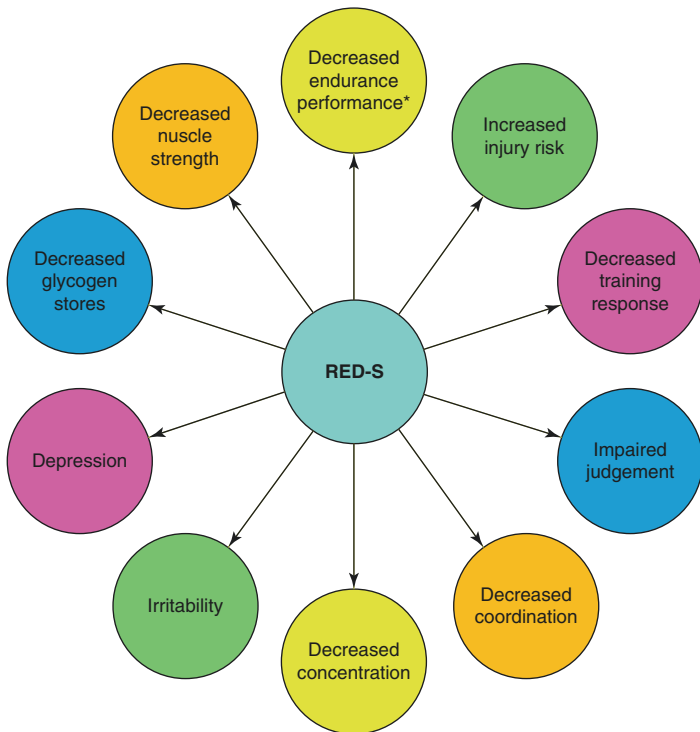


FIGURE 6.1 Potential performance effects of relative energy deficiency in sport (*Aerobic and anaerobic performance). (Reproduced from [6, 7])

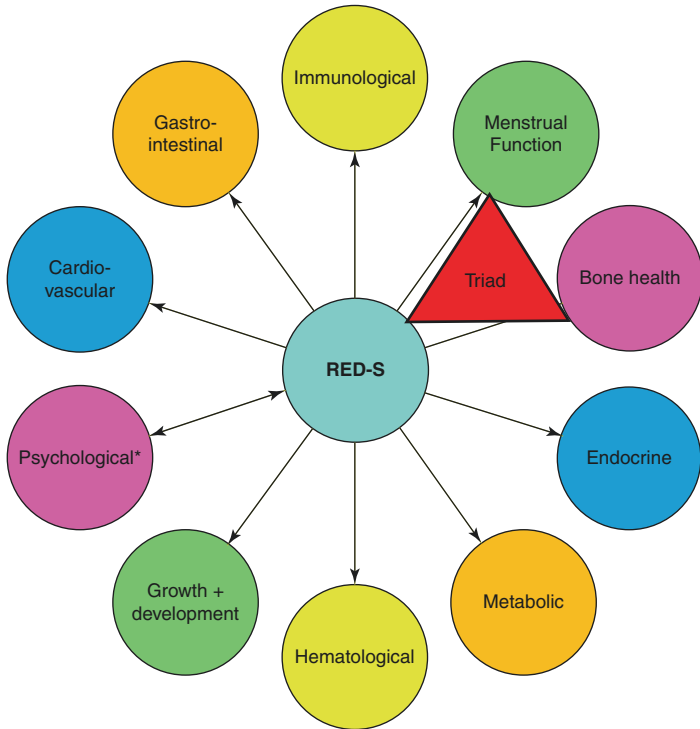


FIGURE 6.2 Health consequences of relative energy deficiency in sport (RED-S) showing an expanded concept of the Female Athlete Triad to acknowledge a wider range of outcomes and the application to male athletes (*Psychological consequences can either precede RED-S or be the result of RED-S). (Reproduced from [6, 7])

Macronutrient Composition

In recent years, there has been increased focus in both adult and pediatric worlds to modify the distribution of calories from different macronutrient groups (carbohydrates, proteins and fats) with the purpose of improving health, athletic performance and achieving a certain physique. For athletes who are still growing and developing, manipulating the distribution of calories can impact their muscle recovery, risk of

injury, growth potential, as well as their attitudes, behaviors and relationship with food. For athletes in adolescence, a minimum of 55% of daily calories from carbohydrates, 15–20% from protein and 20% from fat is recommended, and ranges are parallel to those recommended in the Dietary Guidelines for Americans, but adjusted accordingly based on the nutritional assessment and unique needs of the athlete. DRI for Americans recommends: 45–65% energy from carbohydrates, 10–35% protein and 20–35% fat.

Carbohydrates

Carbohydrates or glucose are the brain and muscle's primary source of energy, and help to meet overall total daily calorie requirements. In regards to exercise, carbohydrates, as well as lipids, supply skeletal muscle ATP production, and maintain blood glucose levels. Exogenous carbohydrate sources during exercise can also help maintain blood glucose levels. Post exercise, carbohydrates are used to replace muscle glycogen, a stored carbohydrate source in the body [1, 4].

Those who advertently or inadvertently restrict calorie or energy intake, in particular of high-carbohydrate food sources, may experience increased risk of injury. In this state of negative energy balance, there are inadequate energy sources to meet the body's physical demands, which includes replenishing depleted energy stores, repairing exercised muscle, and building lean body mass (depending on stage of growth and development). Consequently, amino acids are used to help meet energy needs. This depletes substrates available for the primary role of amino acids, repairing and building tissue. This may result in reduced growth rate or growth potential, decreased lean body mass, and increased risk of injury [2].

From a general health perspective, selecting high-carbohydrate, whole foods, like fruits, vegetables, beans, legumes and whole grains are recommended as these supply nutrient-rich vitamins, minerals, and high fiber food sources.

Ultimately, these choices aid in overall health and reduced risk of chronic diseases. The use of simple or refined carbohydrates, like sports drinks; however, can be beneficial in improving performance in adult populations. This has been less studied in children and/or adolescent athletes.

Protein

Protein, in particular amino acids, are predominately used for repairing, maintaining, and building muscle and tissues in the body. Protein requirements may be increased depending on stage of growth and development, as well as if the individual is beginning a training program, as protein needs are initially increased due to higher levels of protein turnover with exercise (i.e. skeletal muscle catabolism) and nitrogen loss, and require additional substrates for protein synthesis. However, protein intake should not be excessive, as this can also increase the risk for dehydration, renal load, placing extra stress on the kidneys and liver, and can also provide excessive energy above what the body needs.

Contrary to popular belief, an excess of protein intake does not equate to additional accrual of lean body mass. Instead, if excess protein contributes to overall excess energy intake, then this will be stored in the body as adipose tissue. Another common misconception is that increased protein intake aids sports performance, but this has not been demonstrated in research in adults or youth [4]. In general, youth athletes often exceed protein requirements of a non-athlete youth or adolescent of $\sim 0.71\text{--}0.76$ g/kg/day EAR (estimated average requirement) with adolescent athletes reporting intake of $\sim 1.2\text{--}1.6$ g/kg/day [3]. Thus, intake of lean, high-quality protein sources will likely meet their demands, and consequently, additional protein supplementation is often not required [4]. For those following a vegetarian or vegan diet, an additional $\sim 10\%$ protein is advised to factor for decreased digestibility and utilization, and should include a wide variety of protein sources [1].

Protein metabolism before, during and after exercise is affected by many factors, including: age, development, sport/type of exercise, intensity and duration. Recommended protein intake based on sport type has mostly been anecdotal, as the DRI does not recognize the unique needs of the individual if they are routinely active and/or competitive athlete.

In general, optimal distribution of high-quality protein throughout the day can help recovery after exercise, and can provide timely substrates to be used in the development of lean body mass. Consuming ~20–25 grams of high-quality protein throughout or immediately after strength training workouts enhances muscle protein synthesis [3, 8]. This can be achieved through normal refueling, and there may not be additional benefit from protein supplementation or exceeding this threshold of protein.

In post-exercise recovery, the body works to replete energy in the form of adenosine triphosphate (ATP), rebuild muscle glycogen stores, and repair and build skeletal muscle. With adequate balance of macronutrients in the diet, especially carbohydrates and protein, individual amino acids will be spared to rebuild skeletal muscle, and exogenous carbohydrate will be directed towards ATP and muscle repletion. For the athlete who restricts total calories or has inadequate carbohydrate intake, individual amino acids will be diverted to also restore ATP, and thus, the muscle is not repaired nor built to its complete capacity. This can be detrimental to the athlete, as this increases risk for fatigue and injury.

Fat

Fat supplies energy, essential fatty acids, and assists in the absorption of fat-soluble vitamins, A, D, E and K. With training, metabolic adaptations occur in both adolescents and adults. There is less reliance on the conversion of stored carbohydrates to provide energy to fuel exercise, and more effective utilization and oxidation of free fatty acids from adipose tissue and triacylglycerol [3]. After exercise, repletion of “lost” fat stores is not necessary, as it is with muscle glyco-

gen repletion, because the body has ample adipose stores. Consequently, the recommendations for total calorie intake of fat in adolescent athletes mirrors the dietary guidelines for Americans to reduce chronic disease risk. Recommendations are 20–35% of total calories, with saturated fat and trans fat to provide no more than 10%. Dietary surveys of adolescent athletes show fat intake is typically at least 30% [3].

Fluids and Electrolytes

Maintaining appropriate body fluid balance, including both fluids and electrolytes, during exercise is important for medical stability and safety, as well as performance. Dehydration, defined in adults as a loss of >2% of body weight, can potentially cause exertional heat illness, including heat stroke or heat exhaustion, as well as impaired cognitive functioning, impaired performance with muscle cramps, fatigue and electrolyte alterations. There can also be an increased perception of effort [9]. Signs and symptoms of dehydration to monitor for include: decreased urination; more concentrated or dark colored urine; fatigue and weakness; dizziness; confusion; listlessness or irritability; increased thirst; headache; muscle cramping; chills; stomach pain; difficulty paying attention; and decreased performance [21].

Youth athletes are typically more prone to hypohydration, the state of body water deficit, than hyperhydration; however, more research is needed to better understand the degree to which hypohydration effects sports performance and health in youth [9]. There may be greater risk of heat illness if the youth athlete starts their activity poorly hydrated, which research has demonstrated commonly occurs, but also with vigorous activity in warm, hot or humid weather, insufficient cooling, and inappropriate choice of uniforms and clothing [3, 9]. The goal for the athlete is to maintain euhydration before, during and after exercise (Table 6.1). Overhydration or water intoxication does not confer additional sports performance advantages, and can also place the athlete at medical risk with hyponatremia ranging from mild to severe [10].

TABLE 6.1 Fluid recommendations based on age and physical activity

	Before exercise	During exercise	After exercise
9–12 year old		100–250 mL (3–8 ounces) at every 20-minute intervals	
Adolescents		Up to 1–1.5 L (34–50 ounces) per hour	
Adult	5–7 mL/kg or ~2–3 mL/lb. of water or sports beverage at least 4 hours prior to exercise 10–20 ounces of cool water 10–15 minutes before event	100–200 mL (3–6 ounces) of fluid at 15 to 20-minute intervals. Practically, this equates to 2–4 gulps per 15–20 minutes Water for activities lasting less than 60 minutes Beverages with 6–8% carbohydrate and electrolytes are recommended for exercise >1 hour	Normal meals and beverages. With excessive dehydration, 450–675 mL (16–24 ounces) of fluid for every lb. (0.5 kg) body weight lost during exercise. Rehydration and salty foods help replete fluid and electrolyte losses

Adapted from Rodriguez and DiMarco [1], and Bergeron et al. [11]

Research previously concluded that youth are less effective in regulating body temperature and have lower exercise tolerance in heat; however, more recent research suggests that youth and adults have similar exercise tolerance in the heat, but the methods of heat dissipation differ. Youth ath-

letes use radiative or conductive cooling, dissipating heat by redistributing blood flow, and with maturation, sweating rate increases so that by reaching adulthood, body thermoregulates by sweating and evaporative cooling [3].

The choice of fluids can vary depending on clinical judgement and circumstance, and should factor type of sport or exercise, including sport duration, but should also factor environmental concerns, like temperature, humidity and altitude. Youth have less sweat sodium losses than adults, and consequently, the use of sports beverages or drinks with electrolytes in place of water is not necessarily needed, especially for routine physical activity [3]. Unnecessary intake of sports drinks is also discouraged to minimize providing excessive calories that may increase risk for overweight or obesity. However, use of sports drinks may be warranted in hot, humid environments or for competitive adolescent athletes during periods of prolonged, vigorous sports activity, and/or recovery between events within close proximity to stabilize blood glucose levels and promote fluid and electrolyte balance [3]. The American Academy of Pediatrics suggests the use of electrolyte-supplemented beverages when the young athlete participates in ≥ 1 hour of activity or repeated same-day sessions of strenuous exercise, sport participation or other activity [11]. Milk is another beverage offering carbohydrate, fluid, sodium and protein that may also be used as recovery between events occurring in close proximity [3].

Micronutrients

Micronutrients serve a multitude of functions in the body, including: coenzymes in energy metabolism; scavenging free radicals produced by oxidative stress; and supporting bone health. During adolescence, there are additional needs to support growth and development, including the development of lean body mass, expansion of red blood cell volume, and peak bone growth and mineralization. Additionally, in exercise there are extra demands placed on the body for energy metabolism, muscle repair, oxidative damage, and thus, it is

suspected that micronutrient needs are higher. In particular, for adult athletes, the most common vitamin and mineral deficiencies are: calcium, vitamin D, B vitamins, iron, zinc, magnesium, vitamin C, vitamin E, selenium and antioxidant beta-carotene [1].

School-age children typically have low dietary intake of calcium, iron, vitamins A, C, D, E and B-6, and in adolescence, dietary intake is typically low in calcium, Vitamins A, C and B-6 [1].

Additional vitamin and mineral supplementation may not be indicated for healthy youth if the diet is adequate and balanced; however, special consideration can be applied for individuals with chronic disease, food insecurity and/or unbalanced/inadequate diet.

Calcium and Vitamin D

Calcium is utilized in the body for bone mineralization and growth, maintaining blood calcium levels, blood clotting, nerve innervation and supporting muscular contractions. Vitamin D aids calcium absorption, and special attention to adequate levels of Vitamin D, both from foods and from sunlight exposure, should be considered. The needs for calcium increase starting at 9 years of age accounting for rise in bone density. In adolescence, about 50% of bone mass is accumulated, and 90% is gained by the time one reaches 18 years of age. Consequently, the recommended dietary allowance of calcium increases at 9 years from 1000 mg or 3–4 servings a day to 1300 mg a day or the equivalent of 4–5 servings a day. Vitamin D 600 IU/day is advised for those ages 1–18 years of age, but additional supplementation may be indicated for those with limited sun exposure or Vitamin D insufficiency and/or deficiency with 25-OH Vitamin D concentration <30 ng/mL [12].

Despite the greater need for high-calcium food sources, it has commonly been shown that US children and adolescents do not meet their dietary needs, and fall below minimum recommendations [4]. In addition to growth concerns, this

specifically places the athlete at increased risk for stress fractures and/or osteopenia/osteoporosis.

It is also common for calcium intake to be inadequate if total calorie or energy intake is restricted. If the athlete is amenorrheic or oligomenorrheic, adult needs increase further to 1500 mg [13].

Iron

There are increased iron needs in adolescence to support increases in hemoglobin production, expansion of blood volume, and accrual of muscle mass, and needs are increased further in females at onset of menses. Low iron is one of the most common nutritional deficiencies in adult athletes, especially in women, and in adolescents, low iron can be attributed to a diet inadequate in calories, or a vegetarian diet with poor iron availability. Low iron may also occur during periods of rapid growth [1]. Iron deficiency with or without anemia can diminish sports performance, especially in athletes involved in endurance activities that have higher aerobic demands [4]. For adult endurance athletes, it is suggested that their needs are increased ~70% [1], but there has not been research to support increased requirements in youth athletes participating in endurance sports.

Depleted iron stores are often first seen with changes in serum ferritin, then early iron deficiency by changes in transferrin saturation, and lastly iron deficiency anemia with changes in hemoglobin and mean cell volume [3]. It should be noted that some adult athletes experience an adaptation with expansion of plasma volume at the start of an aerobic training program, and thus experience a transient decrease in serum ferritin and hemoglobin [1]. This can also be applicable for the young adult athlete initiating an exercise program.

Recommended intake:

- 9–13 years, boys and girls: 8 mg/day
- 14–18 years, boys: 11 mg/day
- 14–18 years, girls: 15 mg/day

- 19–50 years, males: 8 mg/day
- 19–50 years, females: 18 mg/day (excluding requirements for pregnancy and lactation)

Iron-rich food sources include meat (beef), chicken, fish (clams, oysters, shrimp, sardines), some vegetables (spinach, baked potato with skin), fruits (dried prunes) and grains (iron-enriched or fortified oatmeal and cereals). Iron is better absorbed from animal-based sources than plant sources, and absorption may be enhanced if paired with foods high in Vitamin C (fruits, melons, dark-green leafy vegetables, citrus juices) [4]. Iron-enriched or fortified cereals including breads, breakfast cereals and fortified grains can provide up to 18 mg of iron or equivalent to the daily dietary needs for females ages 19–50, and although they may not be as bioavailable as other sources, they also support other nutritional needs of the athlete, by supplying a high-carbohydrate fuel source.

Nutrient Timing

In addition to ensuring that athletes are achieving their essential nutrient needs to maintain growth, support physical activity and get adequate amounts of macro and micronutrients, concepts of meal pattern and timing of nutrition can provide additional benefit. How food is distributed in the day impacts metabolism, athletic performance, energy, and recovery. At a basic level, having eating distributed throughout the day to meet basic nutritional needs is essential, and from there, the individual can gain added benefit from specific distributions of foods at specific times surrounding and during activity for sports performance.

Typical adolescent eating patterns often reflect skipped meals, particularly breakfast, and tend to be loaded towards the end of the day, with heavier dinners and afternoon and evening snacking. This pattern presents challenges to the adolescent in general, but as an adolescent athlete, having adequate intake earlier and throughout the day to support

activity, particularly with after school practice, is necessary. If athletes are participating in morning practices in addition to afternoon practices then the need for adequate intake and appropriate nutrient timing increases.

Pre-exercise Nutrition

It is optimal that the athlete be adequately fueled prior to participating in their exercise, practice or competition for performance, as opposed to competing or practicing in a fasted state when they are hungry. This ensures that there are adequate blood glucose levels, but that enough time has passed to allow for proper digestion, so that the athlete doesn't feel ill during exercise. In general, one should allocate 2–4 hours to allow for proper digestion of meals [14].

For activities that are ≤ 60 minutes, assuming the athlete had appropriate meals/snacks or fueling preceding the practice, the athlete should ensure they are maintaining adequate hydration and fluid intake, but otherwise, pre-practice snacking is not necessarily required [1]. However, it is common for adolescents to often have irregular meals and snacks throughout the day, especially in the earlier part of the day. Adolescents frequently skip breakfast for sleep and feel rushed to get out the door, and for some, may also miss or have inadequate mid-day fueling at lunch, not caring for school lunch offered, forgetting to pack lunch or not having adequate time. Consequently, many teen athletes arrive to their practice hungry. For these individuals, pre-practice snacking will ensure that they have energy for their practice.

In general, pre-exercise fueling should ensure there is adequate time for gastric emptying so that the athlete doesn't experience a variety of gastrointestinal symptoms, like stomach cramps, vomiting or urgency. Thus, high-fiber, high-fat foods are discouraged prior to their activity, as these foods slow digestion and delay gastric emptying. Foods that are high in carbohydrates, lower in fiber, contain moderate

amounts of protein and provide adequate energy prior to activity are ideal fuel items. It is common for many athletes to have select few foods that are best tolerated prior to their workout, and many individually initially go through a period of experimenting with different foods.

Nutrition During Exercise

The primary goals for fueling during exercise are to maintain adequate hydration and provide a stable source of carbohydrates to maintain blood glucose levels to sustain energy levels and prolonged exercise. Fueling during exercise is especially important for the athlete who is engaging in exercise greater than 60 minutes. Current adult recommendations are to consume 30–60 grams of carbohydrate per hour of exercise, ideally from simple carbohydrate sources, like sports drinks, sports gel or carbohydrate-based snack to help athletic performance. Recommendations for youth are not established, as the use of exogenous carbohydrate sources needs to be researched further. It is known that youth athletes are not able to store as much glycogen as adults, placing them at higher risk for fatigue during prolonged exercise and exercise at higher intensity. This may suggest a higher need for fueling during exercise; however, the adolescent athlete is not able to utilize exogenous carbohydrate sources as well as adults. Despite this, some youth research is showing some performance enhancement for carbohydrate fueling during exercise [4].

The carbohydrate fuel source should be easily digested, absorbed, and utilized quickly in the body, and prevent abdominal discomfort. The source of carbohydrate should ideally be glucose or a mix of glucose and fructose. Fructose-based sources may cause more gastrointestinal distress, like diarrhea [1].

There are mixed recommendations for exercise that is less than 60 minutes. However, special considerations

could be applied for the athlete whom has early morning practices or competitions and generally does not have adequate time prior to their practice for a meal or snack. For these individuals, their liver glycogen stores have been depleted overnight, and they would benefit from a simple, high-carbohydrate fuel source, like a sports drink with 6–8% carbohydrate concentration, during exercise to provide a quick form of energy. Gastric emptying has been shown to reduce when hypertonic fluids with carbohydrate concentration is greater than 8%, like in soda or fruit juice, and may cause stomach cramping [1].

Post-exercise Fueling

Much like fueling during activity, the need for immediate post-exercise meal or snack depends on the degree of glycogen depletion, length, type and intensity of activity, but also, special considerations are made to help the athlete achieve their total daily energy requirements.

Ideal recovery foods will have adequate carbohydrates as well as moderate amounts of protein to help replete energy used, restore muscle glycogen, and repair and build catabolized skeletal muscle tissue. For optimal nutrient recovery, it is recommended to time meals or snacks within 30 minutes after a workout to take advantage of the “muscle recovery window” that occurs the first 2–4 hours after exercise. Of which, it is recommended to include 1–1.5 g carbohydrate/kg of body mass 30 minutes after exercise for performance enhancement [4]. During this time, muscles are most receptive to storing muscle glycogen, muscle repair and synthesis, but timing the meal or snack up to 30 minutes after exercise factors for time needed for adequate digestion and absorption of these nutrients. Adult athletes that have had maximal glycogen depletion can repeat this every 2 hours for a total of 6 hours [1].

Sports and Activity

Table 6.2 provides insight into the exercise demands of various sport types, and consequently will help inform the nutritional assessment and intervention.

Nutrition for Team Sports

Nutritional considerations for those participating in team sports can widely vary given the range of sports that fit within this classification. Each sport and position within the team has its own exercise physiology, and this too may fluctuate

TABLE 6.2 Classification of different sports and activities and their considerations for care

Sport classification	Types	Unique sport considerations
Team sports	Basketball, football, hockey, rugby, volleyball	Involves short bursts of high-intensity activity, followed by low intensity exercise or pauses for moderate to long duration Variability between sports, positions, playing styles and from game-to-game variation Preseason training often includes double workouts
Power sports	Middle distance running, kayaking, cycling, rowing, swimming	Frequent, high-intensity workouts, often to exhaustion in adults, that require starting the exercise well-fueled Competitions that require fueling between events and post-recovery fueling

TABLE 6.2 (continued)

Sport classification	Types	Unique sport considerations
Sports emphasizing looks and weight	<u>Emphasizing lean physique</u> Dancing, gymnastics, cheerleading, cross country/distance running, cycling, figure skaters, wrestlers, rowers, divers, swimming <u>Muscular physique</u> Basketball, football, baseball, powerlifting, rugby, track <u>Weight classes</u> Crew, wrestling, boxing, martial arts, horse racing	Athlete may feel pressure to achieve a certain weight class or aesthetic look and may engage in weight loss, either appropriately pre-season, or through disordered eating

Adapted from Carl et al. [15]

from athlete-to-athlete, as well as individual variability in the athlete with training and player adaptation.

Despite this, team athletes commonly experience cycles of heavy practice or training schedules, followed by periods of reduced activity during competition and/or offseason times. During preseason training, athletes can find it challenging to take in adequate energy, and can easily lose weight, become dehydrated and depleted. Some may notice weight fluctuations in the competitive and/or off seasons when double practices are reduced. Also, the practitioner should recognize the influence some athletes feel to achieve a certain weight or physique during their season, and support the athlete appropriately. Additional considerations regarding weight and physique are listed below.

Within the individual practice or game, the athlete can be supported by ensuring adequate fueling and hydration, especially in recovery between events. Given the nature of team sports games or play, athletes have an opportunity to hydrate during various game breaks; however, gastric emptying of fluids

may be reduced during brief intermittent, high-intensity exercise, and needs may be greater if they began the play at a fluid deficit, are playing in hot conditions, wearing heavy, protective garments, have high physical activity patterns and have repeat matches [10]. Failure to adequately hydrate has been shown to increase perception of effort, decrease exercise capacity, deteriorate mental stamina and performance, and overall decrease sports performance [10]. Athletes may also be at increased risk of muscle glycogen depletion, especially in youth athletes, and hypoglycemia with high stop-and-go movement, and if there is insufficient pre-workout fueling and post-workout recovery between games. This may warrant appropriate use of sugar-containing beverages, as previously discussed.

Nutrition for Endurance Athletes

For both swimming and running, these sports can begin in early childhood, and once started, both sports types often run longer throughout the year than other sports with swimming often being yearlong. Because of the often intense sports training, these athletes are at increased risk of overtraining syndrome, overuse injuries, and RED-S. These athletes are encouraged to follow a high-calorie, balanced diet with adequate intake of macronutrients to support energy balance and sports performance.

Nutrition for Sports that Emphasize Weight and Looks

There are no current measures of desired weight, BMI and/or body composition with sports performance; however, noting disruptions in a player's sports performance may indicate that the athlete is either at an optimal or suboptimal weight at their developmental stage. Despite this, some athletes believe that achieving a certain weight will enhance performance, allow them to compete at a certain weight class and/or will provide more favorable critiques by judges, and may engage in either weight loss or weight gain strategies. Some weight loss practices can pose medical risk to the athlete, as well as impair athletic

performance and increase the risk of injury. Consequently, The American Academy of Pediatrics has issued guidelines for practitioners to gauge the safety and appropriateness of weight loss, and offers a screening tool, Preparticipation Physical Examination, to assess unhealthy weight loss through disordered eating. For certain sports, like wrestling, there are also set rules set by NCAA and National Federation of State High School Associations to minimize unhealthy weight loss practices. Also, some states have additionally set their own standards, often more strict than national standards to ensure weight loss still supports appropriate hydration [15].

Healthy Weight Loss

Considerations:

- Not encouraged in those skeletally immature
- Preferable to occur in off-season
- Gradual weight loss no more than 1 lb./week in growing athlete with excess body fat or 2 lbs./week in mature athlete. It should be noted that there are no established recommendations regarding body composition, including body fat percentages, in neither children nor adolescents, and the minimum allowable body fat percentages set by many associations and/or federations are under the fifth percentile in general adolescent population

Achieved by:

- Adequate calorie intake that meets energy demands for growth, development, activities of daily living and sports; and diet is adequately balanced
- Preservation of lean body mass
- Appropriate amount of exercise
- Maintain adequate hydration

Unhealthy Weight Loss

- Weight loss >2 lbs./week and muscle mass is lost
- Excessive exercise

- Stimulants, laxatives use, diet pills, dehydration techniques and vomiting

High rates of “weight cutting” or dehydration for acute weight loss are reported in high school and college wrestlers [15].

Other sports, however, promote weight gain and building lean muscle mass to improve strength, performance, and power; however, this may be limited or influenced depending on stage of development, sports training/regimen, genetics and nutrition.

Healthy Weight Gain

- Achieved by a combination of both increased calorie intake, as well as strength training to support development of lean body mass. Those whom are skeletally immature should avoid powerlifting and bodybuilding
- Female athletes and prepubertal male athletes can gain strength through strength training, but will not achieve considerable lean muscle mass
- Gradual weight gain and increases equating to >2 lbs./week may result in increased adiposity
- Male athletes may gain 0.5–1.0 lb. of lean mass per week and women ~0.25–0.75 lb./week
- Increased calorie intake, ~300–500 calories/day above estimated calorie requirements, and strength training with increased protein intake of ~1.5–1.8 g/kg/day that supports gradual weight gain through development of lean body mass

Unhealthy Weight Gain

- Rapid and/or excessive weight gain, resulting in increased adiposity rather than increased lean muscle mass
- Use of anabolic steroids or supplements

In regards to specific nutrient needs based on sports type, Table 6.3 outlines general recommendations or considerations.

TABLE 6.3 Comparison of macronutrient requirements and recommendations in the adolescent athlete versus adult athletes, as well as additional factors depending on sport [3, 12]

Requirements	Adult athlete	Adolescent athlete	Endurance	Strength/power
Carbohydrates (g/kg)	Daily recovery: Low intensity or skill-based activity: 3–5 g/kg/day; moderate exercise program (training 1 hour/day): 5–7 g/kg/day During exercise: not required if short duration of 0–75 minutes; 30–60 g/hour for 75 minutes – 2.5 hours Immediate recovery after exercise: 1–1.2 g/kg/hour	Daily recovery: 5–7 g/kg/day	Additional 1–3 g/kg before exercise Daily recovery: 5–7 g/kg/day for moderate training program; 6–10 kg/day for endurance program (1–3 hours/day); and 8–12 g/kg/day for extreme exercise program (4–5 hours/day) Immediate recovery after exercise: 1.5 g/kg 30 minutes after	1.6–1.7
Protein (g/kg)		1.2–1.7	1.2–1.4	
Fat (% of diet)	25–30			
Additional considerations			Iron requirements increased by ~70%, especially in distance runners (adults)	

Performance Enhancing Substances

Case Study

Your next patient is a 17 yo football player who wants to “bulk up” before the football seasons starts. He wants to add creatine and protein powder to his daily intake but wants your opinion before making any changes. He eats three meals and three snacks per day, and usually has red meat at dinner three - four evenings per week. He works out in the weight room at the gym 2 hours per day in addition to his football team practices that occur 5 days per week. How can you counsel him?

Over the last 3 decades, the availability of performance enhancing substances (PESs) has increased with access to the Internet and over the counter retailing, and hyper marketing of stimulant containing beverages, and increasing use of topically applied anabolic androgenic steroids. Although the overall use of many PESs may have declined over the past 15 years, reviews of multiple studies have prompted concern that the onset of use may be occurring increasingly in the pediatric/ adolescent / young adult population [16, 17].

For many adolescent and young adult (AYA), use of PESs may be an attempt to enhance their appearance rather than actual performance: many users are not actively involved in any organized athletic activity. Terms such as “performance- and image-enhancing substances” and “appearance- and performance-enhancing drugs” emphasize their broader appeal.

A Minnesota study evaluating various muscle-enhancing behaviors revealed that in an urban high school population, 38.8% of boys and 18.2% of girls reported a history of protein supplement use [18].

Interestingly, this number was also concerning in that middle school youth used 29.7% (males) and 24.7%, (females) respectively. Although students participating in team sports were more likely to use protein supplements (24.2%), it is worth noting that use of protein supplements still was high in students who were not involved in sports (18.2%).

In addition to sports participation, other correlates of PES use include body dissatisfaction, higher BMI, training in a

commercial gym, and exposure to appearance-focused media. The latter was particularly true for the genre of “fitness” media, which tends to have a large focus.

on muscle development, as opposed to the genre of more traditional sports-reporting media. Multiple studies have revealed correlations between PES use and alcohol and drug use, as well as other risk-taking behaviors.

The term nutritional supplement generally refers to substances such as protein/amino acid preparations, trace elements, vitamins, minerals and herbal preparations. Creatine, a complex, non-essential amino acid, is the most popular supplement used as a PES. It is thought to increase muscle mass and strength, shorten recovery times during workouts and increase training load overall. It does appear to improve strength and performance in short-duration, anaerobic events but has little effect on endurance activities. Up to 30% of people seem to be “non-responders” to creatine, likely because they have already maximized creatine stores in the body through dietary intake. Creatine has been shown to increase myofibrillar protein synthesis; these increases in whole body nitrogen retention, protein synthesis, and water retention allow muscle cells to become larger and heavier. Athletes and weightlifters undergo tremendous muscle breakdown in anaerobic exercise, and the addition of creatine presumably helps achieve zero or positive nitrogen balance. Athletes supplementing with creatine have lower body ammonia levels, which suggests less protein degradation. Creatine cannot work without strength training; those who do not lift weights do not achieve the measured benefits compared with those who do lift. Creatine does not increase strength; rather, it increases an athlete’s ability to train. Its greatest benefit seems to be in repetitive, short-burst sports (anaerobic) such as power lifting and wrestling rather than swimming and long-distance running (aerobic) activities. Side effects include weight gain through water retention, muscle cramps, diarrhea and rarely impaired renal function [19].

The larger problem with nutritional supplements is that the FDA does not regulate them. This means that manufacturers do not have to prove the safety or efficacy of their products. Multiple studies have shown that stated ingredients

are often missing or present at levels much higher than what has been reported on the label. In addition, steroids and stimulants have been shown to be present in up to 25% of nutritional supplements.

Any potential ergogenic effects of PESs can be contrasted to the great improvements in strength and athletic performance often observed in child and adolescent athletes attributable to the combined effects of training and development. Typical strength gains of approximately 30% are reported in youth resistance training programs of 8–20 weeks' duration. Supplements or nutritional interventions that are currently available and legal cannot rival this rate of gain. The best advice for performance-related concerns in young athletes is to focus on the basics of appropriate training and nutritional practices. PESs are not substitutes or shortcuts to a higher level of athletic performance or appearance. Athletes who do not adhere to the basic principles of good training and adequate nutrition will not benefit from PESs.

Athletes with Health Conditions

Table 6.4 outlines other diagnoses or health concerns that might influence nutritional needs or adaptations to nutrition intervention.

TABLE 6.4 Nutritional considerations for athletes with health conditions

Health condition	Nutritional considerations
Cancer	Vary depending on the cancer diagnosis, treatment and outcome
Special needs Olympic participants	Special needs Olympics suggests participants may have existing challenges with appropriate oral hygiene, maintaining physical activity patterns and vision concerns

TABLE 6.4 (continued)

Health condition	Nutritional considerations
Type 1 diabetes	Nutrient timing and insulin adjustments to maintain euglycemia (see Type 1 diabetes)
Crohn's/ ulcerative colitis	Considerations for GI tolerance, nutrient timing and ensuring adequate energy intake
Trisomy 21/ Down's syndrome	Atlanto-axial instability Unclear inherent differences in metabolism Potential for co-occurring diagnosis (hypothyroidism)
Athletes in wheelchairs	Nutrient needs: Paraplegia: 28 kcal/kg Tetraplegia: 23 kcal/kg No additional protein requirements, unless there are pressure wounds and activity is encouraged [20]
Seizure disorders	No known considerations.
Cerebral palsy	Many report feeding or digestive difficulties: self-feeding, food preparation, timing modifications to allow time for swallow or to meet medication needs, reflux, pneumonia, asphyxiation. Therefore, feeding during activity would be challenging, partially related to swallow risks, but as well as dental hygiene and food selection Additional supplements may be required for those with malabsorption or whom tire with eating
Celiac	Compliance with a gluten-free diet to aid proper digestion and absorption of nutrients to support adequate fueling.

Diets

It is common during adolescence and young adulthood for eating habits to vary, not only driven by social changes that occur from school age to adolescence, i.e. transition of eating predominantly at home to eating with peers or on campus, but also as a form of identity exploration during this time. For the athlete, in particular, there are also beliefs that dieting may improve athletic performance.

Dieting poses challenges for getting adequate calories and nutrients. Restriction of any one food group, regardless of intention, has the potential to impact caloric intake, macronutrient composition and micronutrient intake, and as such, may impact growth, development and athletic performance.

Off Season Nutrition and for those Experiencing an Injury and Life Transitions

Case Study

Jimmy is a current 3-season college athlete – track in the spring, cross-country in the fall and triathlon in the summer – and is transitioning to his first professional job at a startup tech company where he will primarily be coding. He will be working in an office setting from 8 am-5 pm, and socializing afterwards. What are some considerations for Jimmy as he goes through this life change?

Considerations: How would you approach the visit? What questions would you ask and whom would you ask? How would you establish rapport and trust with the patient?

Assessment:

- What changes do you anticipate with Jimmy's daily nutrient/energy needs?
- What skills would be important to assess and ensure are in place prior to transition (i.e. meal preparation, budgeting, meal planning, etc.)?
- What challenges could Jimmy encounter?

For those who transition from periods of high activity to subsequent periods of limited or no activity, they may experience challenges with maintaining physical health and nutritional patterns established during the sports season. For those decreasing their activity, their in-season meal pattern and intakes would exceed their current energy needs. Making this transition likely includes a shifting relationship with food as well as a modified relationship with activity. For athletes who are habituated to multiple hours of activity per day, a shift to more typical amounts of activity may be challenging (i.e. the athlete who completed 2 hours of primary practice with a 30 minute optional workout may feel that a 30 minute run as an entire workout is drastically different). The change in activity level can also impact hunger cues and signaling, which in conjunction with decreasing activity result in changes to metabolism. The behaviors that many athletes may develop around food, outside of athletics, are not appropriate. A view that many people have, both within athletics and outside of athletics, is that activity “makes up for” or “cancels out” “overeating” or “cheat days.” If a former athlete maintains this perspective, their previous opportunities for “making up” for food are limited and there could be an increase in restrictive eating behaviors or a challenging relationship with food, body and activity. Changes in meal pattern and composition, whether that be restriction of food or disinhibited eating can affect caloric and nutritional adequacy.

The end of athletic careers, often lining up with the end of high school or college also results in an overall change in daily pattern and structure, energy needs and change in relationship with food, body and physical activity. For those injured with the intent to return to play, ensuring adequate intakes to support recovery as well as activity as possible without exacerbating injuries is recommended. Their energy needs will likely decrease with a decrease in activity, however maintaining adequate needs and meal pattern for repair and recovery is recommended. The end of athletic careers may also reflect a change in location, access to community and support systems. Former athletes may benefit from connecting to a variety of resources including establishing with a

primary care provider, mental health counselor, sports medicine physician or physiatrist to assist with long-term injury treatment, and referrals to a nutrition professional to support changes in daily activity and nutrient needs.

Conclusion

The intent of this chapter is to outline the needs of adolescent and young adult athletes to ensure nutrition adequacy in both general populations and those with additional health concerns. Adolescent athletes have unique considerations in that they have higher baseline needs due to continued growth, development and maturation in addition to higher energy requirements due to training and competition. For all athletes it is necessary that they achieve their baseline nutrition requirements before they can gain performance benefit from additional modifications, some of which may not be appropriate or have added benefit.

Adolescent and young adult athletes require their energy needs to be met in order for their participation in activity to not negatively affect their growth and health. These energy needs change with pubertal status, type of activity, and level of participation. Once they are getting adequate calories, meal pattern and composition as well as nutrient timing can be modified for additional benefit. For athletes with additional considerations, such as chronic illness, physical or developmental disability, preferred diet, food insecurity, injury or seasonality of sport, these key components may require further adjustment.

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Chapter 7

Media Influences on Body Image & Eating Behaviors in Adolescents



Mya Kwon

Introduction: Why We Should Care about Body Image

Patient Case #1: Jamie

Jamie, a senior in college, was referred to me by her therapist due to rapid weight loss from restrictive eating and overly obsessive thoughts about food and body. Although she had always been “normal” in size, she had become more aware of “healthy eating” after training for a half-marathon that led her to increasingly to cut more foods and food groups (i.e., carbohydrates, added sugars, dairy, gluten, etc.) from her diet—even though she did not have any intolerances or other medical reasons—and subsequently to lose a significant amount of weight. She was now “underweight” by definitions of the BMI, had lost her period for more than six months, and displayed thoughts and behaviors of both

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anorexia and orthorexia.¹ However, even at this significantly low body weight and smaller body size, she still felt extremely dissatisfied with her body and herself overall, particularly as she compared herself to her friends or the influencers² she followed on Instagram. Even though most of her food choices were “healthy” in terms of nutritious value, she would feel guilty if she ate anything remotely considered “unhealthy” by her own standards. She would find herself comparing what she ate to the attractively arranged salad bowls by such Instagram “fitness/health experts” who often would have no health credentials. The obsessive and controlling thoughts about food and her body were taking a toll on her physically as well as mentally. She stated she could no longer stay focused since much of her time and energy were consumed with food and body thoughts. However, even with this awareness, she had extreme difficulty letting go of the control due to fear of gaining back the weight. She also reported that how others viewed her would change as she felt that being known as the “skinny and healthy girl” was a significant part of her self-identity.

Patient Case #2: Ella

Ella was a 19 year-old theology student who started seeing me in hopes of weight loss. She was a driven, ambitious, and bright young woman with big goals in life. One of those goals was to achieve a very specific body size and shape. She

¹ Although not yet formally part of the DSM (Diagnostic and Statistical Manual of Mental Disorders), orthorexia nervosa is increasingly recognized clinically and in research. It is manifested as an obsessive and excessive focus on “healthy eating” with severe dietary restrictions, often leading to clinical impairments such as malnutrition, social isolation and increase in anxiety and guilt associated with food choice.

² A Social Media Influencer is a user on social media who has established credibility due to having a large number of followers which allows them to reach a wide audience with their messages.

showed me pictures of several Instagram influencers she followed who had “perfect bodies and inspiring messages” she aspired to emulate. Ella also had a compelling story of overcoming personal difficulties and mental health challenges in her younger adolescence and would say she was now proud to be who she was due to those experiences. However, she stated her remaining challenge was that: “I need my outer image to reflect who I am inside.” She made it clear that her current larger body classified in the “overweight” category, by definition of the BMI, simply would not suffice. Although she was already being highly controlling and restrictive with her caloric intake and spending at least two hours in the gym every day, she was perplexed why she was not losing further weight and wanted to know what she was “doing wrong” even though she was also chronically tired and hungry. Despite that she already had a lot going as a successful and popular student, her levels of self-worth and self-esteem were largely influenced by her own perception of her appearance and size. In session, she would share how she felt held back by her body with high degrees of internalized weight stigma.³ She truly believed that she was simply “not good enough” and could not be a positive role model to other women unless she was “fit and skinny” like the other Instagram and YouTube influencers. Such weight-stigmatized beliefs were also reinforced through her personal relationships where her dad would often comment that she “should eat cleaner and become slimmer”, and a past boyfriend who said she would be “prettier at a lower weight.” Therefore, she highly equated appearance with success and confidence and was afraid no one would take her seriously even though her greatest role model was Oprah (who ironically has also been seen in the public eye as struggling with weight issues and weight cycling over many years throughout her career).

³ Also known as weight bias or weight-based discrimination, is discrimination or stereotyping based on a person’s weight and is highly correlated with body dissatisfaction, a leading risk factor in the development of eating disorders.

Body Dissatisfaction: A Public Health Issue with Negative Health Outcomes

These scenarios are probably not a surprise to anyone working with adolescents and young adults. As a clinician primarily working with college-age and young adult population on the spectrum of disordered eating, as well as clinical eating disorders, I encounter similar stories almost every day. Many of my patients say and believe “my body is not good enough” or “I am not worthy enough unless _____” where the blank is often filled with either a specific body size/weight, or an unsustainable strict dietary pattern that often leads to negative consequences across the physical, mental and emotional realms.

A meta-analysis of 66 studies concluded that negative body image (or “body dissatisfaction” as a more clinical term) plays a key role in the development of eating disorders [1], and is also associated with a wide range of negative mental and physical health outcomes such as depression, low self-worth, suicidality, extreme weight control behaviors, and decreased quality of life, even in those who do not develop clinically acute level of eating disorders [2–6]. Although such outcomes would be dire to individuals across any life stage, it is even more critical to the adolescent and young adult population, considering the unique aspects of their cognitive and physical developmental stages. Evidence shows that body dissatisfaction is often established before age 14 and often even evident among 7–11 year-old girls [147]. Adolescence is also a high-risk period for developing disordered eating and clinical eating disorders: Up to 13% of females experience a clinical or subclinical eating disorder in their lifetime including anorexia nervosa, bulimia nervosa, binge eating disorder, and other specified feeding or eating disorders [156]. Although causes of eating disorders are complex and symptoms vary, common to all eating disorders are body dissatisfaction, weight concerns, overevaluation of shape and weight [157]. Alarming, by elementary school, 40–60% of girls are found to be concerned about their weight or becoming “too fat” and by the time females reach college, the rates of body dissatisfaction and the “desire to be thinner” have been reported to be as high as 88% regardless of their

actual size [7, 8]. Although much research and attention on body dissatisfaction has focused on females, the prevalence and negative impact in males is showing to be increasing as well. Research shows that, once established during adolescence, body dissatisfaction “does not appear to go away simply through development” and will likely carry through the adult years, especially without proper interventions. This is alarming given the potential array of negative consequences [9].

Despite body dissatisfaction being regarded as a key risk factors that can lead to short- and long-term adverse mental and physical health outcomes, many clinicians and school-based providers do not feel they have a comprehensive understanding of the influencing factors that lead to “negative body image,” nor that they have the sufficient tools to work with these issues in adolescents and young adults. Although body image development is complex and multidimensional, media is often pointed to as the biggest culprit leading to body dissatisfaction. However, the impact of media should be noted as part of the bigger socio-cultural context where it serves as one of the strongest channels to spread values, norms and standards of a particular society and culture [10].

With this understanding, the objectives of this chapter are:

1. To provide a framework for the mechanisms and messages of various media and explain its role in disseminating cultural and societal constructs of the “ideal body,” often leading to body dissatisfaction, a key predictor of adolescent eating disorders and mood disorders;
2. To highlight why adolescence is a particularly susceptible period to media influences and resulting body dissatisfaction that can lead to an array of negative mental and physical health outcomes;
3. To provide tools and strategies drawn from research and intervention practices related to media that clinicians and school-based providers can utilize to support better body image development and positive health outcomes.

The Fig. 71 is my attempt to put together a comprehensive model that captures the essence of what is discussed in this chapter.

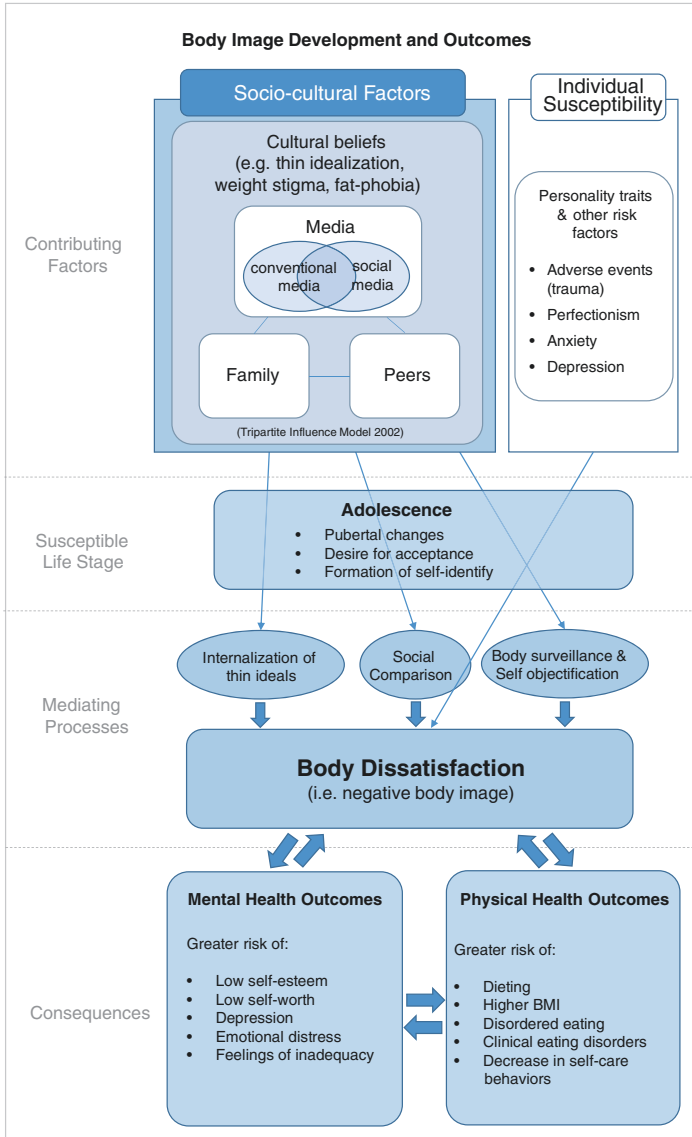


FIGURE 7.1 Media influences on body image & eating behaviors in adolescents

Body Image: What Is it and What Does Media Have to Do with it

Although there are various technical definitions of “body image,” Thomas Cash, an established scholar on the subject refers to it as how one personally experiences their own body [11]. In other words, it can be understood as how someone sees their own body, how they feel in their own body, and how satisfied and comfortable they are in their own body. The key is “how one experiences their own,” meaning it is not objective and is more about someone’s own perceptions, beliefs, thoughts and feelings about their body [11]. Therefore, the actual size, weight or BMI (although greater BMI is a known risk factor for greater body dissatisfaction) is not the governing factor here, because how someone experiences their own body fully depends on the individual’s own perception. We saw this in the case of Jamie, who had never actually been “overweight” according to the BMI, nor had experiences of being criticized by others about her body. Yet she still had a highly negative body image, or body dissatisfaction, and continued to compare herself to others whom she thought had “better bodies.” In fact, body dissatisfaction has been documented to be so prevalent across the population, particularly in adolescent girls and young women, to the point that weight has often been described as “a normative discontent” [12]. This is alarming because many studies confirms that body dissatisfaction is a key predictor of disordered eating, eating disorders, lower levels of self-esteem and greater depression [6, 13–15].

In terms of what informs the concepts of “better bodies” and perception of one’s own body image, the socio-cultural model, the dominant theoretical framework for explaining body image development, proposes how Western society’s strong emphasis on appearance and continued promotion of ideal physical qualities, for males and females, have prevailed as important constructs in our society [16, 17]. Especially for females throughout centuries, there has been a particular “look” that defined female attractiveness, with

examples such as: the flat-chested slender flapper figure of the 1920s; Marilyn Monroe's hourglass figure in the 1950s; and the waif-thin model figure popularized in the 1990s [8]. Although this is evidence that the society's idea of the "physical ideal" can change, it is difficult to argue that current society continues to primarily prefer smaller size, or the "thin ideal," over larger size in both females and males [18, 19]. Recently there has been an emerging emphasis on "fitness," in addition to "thinness" that is still a central component of what is generally regarded as the "ideal body." Conversely, "larger size" is generally regarded as less desirable, or even as fearful, with various negative associations (otherwise known as "weight stigma"), although "ideal body" variations persist depending on different populations and cultures.

Prevailing messages of the thin ideal and appearance ideals are reinforced through multiple channels. The well-known and widely accepted Tripartite Influence Model points to media, family and peers as the biggest influencers that reflect cultural beliefs and reinforce and impact ideas of ideal body image development in individuals [16, 17]. Of the three, media has garnered the most attention due to its pervasiveness and impact. In other words, media exerts tremendous influence on body image by reinforcing ideas of what we "should" look like to be desirable or successful. Both of our patients, Jamie and Ella, were clearly impacted by the pervasive influence of social media and its emphasis on the "thin and fit" ideal messages. They internalized such messages to the point of believing that thinness and fitness were a prerequisite for social, personal and professional success, so much so that they were willing to compromise physical, emotional and mental health.

Impact of such media messages can be devastating to adolescents as during their ongoing physical and emotional self-evaluation. They are in critical stages of developing a sense of self as their bodies go through rapid physiological change

during puberty. Meta-analysis studies on media and body image reveal that exposure to thin-ideal media has an immediate negative effect on adolescent girls' body image [158]. When the evaluation of oneself does not match the standards of the "ideal body" of which they have internalized, this discrepancy can lead to feeling of dissatisfaction with one's body and oneself overall and could further lead to disordered eating habits, clinical eating disorders, and mood disorders [13–15].

Even though media exerts a powerful role in impacting body image perceptions through disseminating sociocultural appearance norms, of course not everyone will be impacted to the same degree. There are mediating mechanisms and individual factors (e.g., low self-esteem, depression, perfectionism, trauma, and importance of appearance to self-worth, etc.) that can increase or decrease an individual's vulnerability and susceptibility to these messages [20]. Therefore, it is important to understand body image as a multidimensional concept and that media influences do not occur in isolation.

Media Influences on Body Image and Eating Behaviors

Mass Media: A Powerful Influencer of Ideal Physical Standards

Media not only spreads information, but also spreads values, standards, concepts and ideas that largely represent cultural and societal ideals. This includes the "cultural stereotypes about the aesthetics of body image" [20]. Several theories support this idea including Social Cognitive theory [10], the mass communication-focused cultivation model [21], and the sociocultural perspective previously mentioned [16, 22]. In referring to media messages, this includes messages from both television, advertisements, magazines, radio as well as

the newer forms including the internet and social networking sites (SNS) often referred to collectively as social media. We will discuss the effects of both although more emphasis will be placed on social media as there are already abundant resources and research on the effects of conventional forms of mass media and how they influence adolescent body image perception. Also important to note is how the prevailing media messages regarding ideal bodies and wellness have evolved.

Changes in Media Forms and Messages: Past to Present

90s: Conventional Mass Media and Emphasis of the “Thin Ideal”

One of the core traits of the ideal body that has prevailed and continues to be reinforced through media messages is the “thin ideal.” Not only do various media forms repeatedly present images of unrealistically thin body ideals, but also provide information on ways to accomplish them [23]. The influence of magazines, television, advertisements and film, in the depiction of unrealistic body shape and size standards peaked in the 90s [23, 24]. It continues to be difficult to not notice messages glorifying thin bodies, advertisements of products that promote how to “lose the extra pounds,” and the commercial diets promoted, not to mention the rise of social media that has created a new platform for these messages especially for younger audience.

Weight Loss at the Center of Media Messages: Continued Dissemination of the “Thin Ideal”

Pursuit of weight loss to achieve the “thin ideal” continues to in the media, but peaked in the 90s. Research during that decade showed that the ideal female beauty in the U.S. con-

tinued to shrink as models in Playboy centerfolds were 13–19% below average body weight and that the BMI of Miss America contestants declined from 22 in 1922 to 18 (considered underweight) in 1999 [25–27]. Teen magazines more than tripled during this time and a majority of 15- to 18-year-old girls reported reading these magazines daily [28]. Television, music videos, films were also popular media forms. The rise of the internet through the decade present new opportunities for media influence to lead adolescents to internalize the ideals imposed by society and increased risk for body dissatisfaction and disordered eating behaviors [29, 30]. Conventional mass media also perpetuated weight stigma as 50–70% television shows geared towards children and adolescents were found to include weight stigmatizing content including negative stereotypes of larger size characters while depicting thin characters more desirable [31]. The British Medical Association in 2000 stated, “evidence is increasing that there are tremendous pressures on today’s girls and young women to try to attain body shapes that are unhealthy, unnatural and dictated by media norms” [32].

It is not a surprise that in the 90s, the diet industry tripled from 10 to 36 billion dollars [33]. It has increased in the U.S. in 2018 to a 68 billion dollars industry [34]. This shows that media continues to sell and our society continues to buy into the elusive idea that anyone can achieve the “thin ideal” solely by means of individual will power: More than two-thirds of weight-loss diets result in little to no success especially when looked at long-term results [35]. Research also has shown that the human body has a host of physiological and psychological mechanisms that kick in to defend a certain weight range [36]. Furthermore, substantial evidence supports that dieting during adolescence is actually a consistent predictor of higher weight status in adulthood, disordered eating, clinical eating disorders, lower self-esteem, and increased emotional distress [37–39]. However, despite the host of physical, psychologi-

cal and emotional outcomes that show such attempts to change body size are not only ineffective, but result in more harm than good, the unattainable thin ideal continues to be reinforced through different channels across our society including mass media. All of this is despite accumulating evidence that shows weight is not a proxy for health [37, 40].

Again, it is important to remember that body image is complex and media impact likely operates in conjunction with other societal channels (such as peers and family) as well as individual factors that can affect each person's susceptibility [17, 20]. Nonetheless, media influences on body image is far from negligible, even more so with the rapid rise of the internet and social media to exert its potency to promote a "media-led appearance culture" [41].

90s–2000s: Rise of the Internet and "Thinspiration"

The usage of internet-based media platforms increased dramatically since the 1990s. By 2007, 94.9% of U.S. adolescents between age 13 and 18 reported having access to the internet and spending an average of 1.5 hours on-line per day outside of schoolwork [42]. The rise of internet and social media drastically changed how adolescents consume media. While conventional use decreased, the internet became the dominant socio-cultural medium with interactivity and community-seeking that was not present in conventional media [43]. Although there can be positive effects to this "community seeking," through the 1990s and 2000s, there was a huge proliferation of pro-anorexia ("pro-ana") and pro-bulimia ("promia") websites (approximately 400) directly promoting eating disorder behaviors and endorsing messages—commonly referred to as "thinspiration," a combination word of thin and inspiration—to achieve a thin body at all costs [44, 45]. Supermodel Kate Moss's well-known quote "Nothing

tastes as good as skinny feels”⁴ exemplifies the web messages at the time. These pro-eating disorder websites would use positive descriptions of eating disorder behaviors by reinforcing an extreme version of thinness as “perfection,” endorsing eating disorders as a way of “transformation” from “ugly and fat” to “thin and beautiful” [46, 47]. Such pro-anorexia website emphasis on “thinspiration,” or highly fat-phobic content is more extreme and direct compared to the subtle messages in other media outlets [48]. Studies show that users of pro-ana (pro-anorexia nervosa websites experience lower self-esteem, greater negative affect, increased desire for disordered eating and exercise behaviors [49]. Although usage and impact of such pro-ana websites might have decreased recently with the further emergence and popularity of Social Networking Sites (SNS), the prevalence and impact of “thinspiration” content continues.

2000s-Present: Changes in the Media Landscape with Social Media

Media has always been a powerful socio-cultural medium of relevance to body image development. However, in recent years, the rising use of mobile devices and various social media platforms have drastically changed the media landscape and consumption pattern.

Social Media, by definition, is “the collective of online communications channels dedicated to community-based input, interaction, content-sharing and collaboration” [50]. This would include any on-line communication, including websites, forums, blogs and Social Networking Services (com-

⁴ In a 2018 interview, 9 years after the original quote, Kate Moss spoke about her regret of having shared the quote, that she no longer believes in the mantra, and is pleased to see more embrace of body diversity today.

monly referred to as SNS). SNSs are online platforms and apps “which people use to build social networks or social relationship with others who share similar personal or career interests, activities, backgrounds or real-life connections” [51]. FaceBook, Twitter, Instagram, SnapChat are among the most widely known.

The proliferation of social media impacts almost everyone’s life, but its usage and impact is unmatched in adolescents and young adults, commonly referred to as “Digital Natives.” They have never known a world without instant access to the internet and social networking platforms [52]. In Pew Research Center’s 2018 report on “Teens, Social Media & Technology,” 95% of teens reported having access to a smartphone and 45% of them said they are on-line “almost constantly” [53]; 97% reported using at least one social media platform at nearly three hour per day on average [53]. Indeed, the age group 16–24 are by far the most active social media users and social media addiction is thought to affect around 5% of this age group. It has been described to be “more addictive than cigarettes and alcohol” [54, 55]. Although Facebook was the most popular and widely used social media platform by adolescents until 2017, the social platforms that adolescents reported using the most since 2018 are YouTube (89%), Instagram (72%) and Snapchat (69%) [53].

The implications of easy access and high usage of social media on adolescents’ mental health, physical health and emotional wellbeing is a relatively new area of research. There are positive aspects such as providing a space to connect with friends and family, form new connections and communities, explore self-expression and learn about the world [54]. However, considering that the adolescent years are crucial for emotional and psychosocial development, there are also significant concerns for possible detrimental effects, particularly in areas of mental health, including impact on self-esteem, self-worth and increased risks for mood disorders and body image issues [54].

Unique Aspects of Social Media and the Implications on Body Image

Interactivity & Ubiquitous Access:

Interactivity is the biggest distinguishing factor social media has from conventional mass media. In conventional forms of mass media, the direction of content is mostly one-way. However, with social media, users can be both creators and receivers of content meaning anyone can view, create, edit, and most importantly share content. Users are no longer merely passive mass media receivers, but “full-fledged communicators with enhanced autonomy, self-efficacy and personal agency” [56]. Coupled with the highly accessible nature of mobile phones and other handheld devices, consuming and creating media messages can be instantaneous and constant. Over 3.2 billion new photographs are being uploaded to social media platforms every day, which creates exponentially more opportunities for appearance-based social comparisons—one of the key mediating mechanisms leading to body dissatisfaction [20].

Community Forming & Selective Exposure: Another important aspect of social media is that it allows for selective exposure by allowing users to actively seek or filter out the type of content and messages they want to expose themselves to [57]. Thus, when one has a greater degree of internalizing the thin ideal or other appearance-related ideals, they will likely gravitate towards type of content that they already agree with and find appealing (i.e., place high importance on appearance and size), which would further reinforce such values. Also, platforms like Instagram suggests new accounts to follow based on the type of accounts and content the user frequently consumes, therefore if one follows and “likes” a “thinspiration” content, Instagram will suggest more that are similar. This can create an “echo-chamber effect,” where users perceive their values to be more common than they actually are as a result of selec-

tively and repeated viewing contents of other, similarly minded people [58].

Personalized Media and Peer Comparisons: Compared to conventional forms of media that was much more impersonal out of reach celebrities and models, social media are more personal outlets. To those seeking appearance-based comparisons, the comparison targets are no longer primarily models and celebrities, but often friends, family or influencers⁵ who have many followers and status similar to traditional celebrities, but seemingly still “normal people.” Studies on YouTube, currently one of the top three social media platforms popular with adolescents, found that the emotional attachment adolescents feel for YouTube stars—usually similar aged “peers”—is often greater than toward a Hollywood celebrity [59]. Also, when it comes to body comparisons, research has indicated that adolescent and adult men and women are more likely to compare their physical attributes (i.e., weight, shape, height) to peers than to celebrities [60, 61]. However, even though they may be comparing themselves to manipulated photos (via filters, or other photo-altering tools), they may not be aware of these manipulations and end up feeling negative about themselves as a consequence [62].

Image/Appearance-Based Content and Messages: There is one commonality among the currently most popular social media platforms that adolescents currently use the most: Instagram, YouTube and Snapchat are all visual story applications that prioritize image and video content, unlike Facebook or Twitter that is often text-oriented. This is an important aspect that aligns with the mediating mechanisms—thin ideal internalization and social comparison—of how body dissatisfaction develops. In some research of social media and thin ideal internalization, researchers found a lack of association when

⁵ A Social Media Influencer is a user on social media who has established credibility due to having a large number of followers which allows them to reach a wide audience with their messages.

social media use was measured in terms of overall use instead of content-specific use [63]. However, when studies looked at social media usage specifically related to appearance (such as viewing, posting, commenting on photographs related to appearance), they found it to be more strongly correlated with thin ideal internalization compared to simple utilization of any social media content [63, 64]. In short, the type of content and messages users exposed to, as well as the level of engagement with such content is what matters. It may then not be surprising that Instagram and Snapchat, which are highly image and video-based, also happen to be the platforms with “the greatest and second-greatest negative net impact on adolescent well-being” [52].

Patient Case Application

For instance, Jamie was an active user of Instagram. She would often comment on the appearance and lifestyle of popular individuals she followed on Instagram. Even though most of these people were not celebrities, but “normal people” often similar in age to Jamie, their curated posts portraying thin physiques and certain diet patterns, they had great influence on Jamie especially when such influencers had massive number of followers. By regularly accessing this type of content which she curated for herself, her internalized value of the “thin ideal” was reinforced and she continued to engage in “upward comparisons” (comparing self to those who are perceived to be closer to the “thin ideal”), which led to experiencing more instances of feeling negative and “not good enough” about her own body.

New Media Messages in the SNS Age: #Fitspiration to #Clean Eating

Even with the shift in media use from conventional forms of media to social media, the “thin ideal”—or “thinspiration”—

is still prominent as a major part of the body ideal. Existing research analyzing thinspiration content on SNS platforms such as Facebook, Instagram, Twitter and Pinterest found the content often depict extremely thin or underweight figures and messages endorsing eating disorder-like behaviors and extreme exercise behaviors [65, 66]. Criticism of thinspiration content has emerged for its detrimental effects on body image and eating behaviors and other mental health problems such as depression, suicidality and self-harm in adolescents [66]. Such criticism may have in part fueled the emergence of more subtle "thin ideal" messages that have infiltrated the internet and social media in the name of "fitness" "health" and "wellness."

#Fitspiration #Fitspo: As Damaging if Not More than "Thinspiration"

"Fitspiration," or "fitspo" in short, is a combined word of fitness and inspiration [67]. Fitspiration posts on social media, images and text that are designed to inspire people to pursue a "healthy lifestyle" through exercise and eating well, are now promoted as a healthy alternative to thinspiration. Its rise in popularity can be confirmed by searching fitspiration content on any online and social media platform: a search (August 13, 2019) of the #fitspiration hashtag⁶ on Instagram returned over 18 million images compared to 5 million in 2015. However, despite the positive intentions of promoting a "healthy lifestyle," there are many elements of "fitspiration" that warrant concern as much as, if not more than "thinspiration" messages.

Continued Focus on Appearance: Content analysis studies of fitspiration on various SNS platforms found repeated representation of only one body type—lean and toned, and the emphasis on appearance and attractiveness rather than

⁶ Instagram enables users to use hashtags (# symbol) to add keywords to the photos they post and make them searchable.

health benefits [67,68]. 45% of fitspiration images were posed to look thinner or smaller than reality emphasizing looks rather than function, 42% promoted weight loss, 36% depicted body objectifying messages and 26% induced body-related guilt [68].

Increased Risk for Body Dissatisfaction: Studies comparing thinspiration and fitspiration content found that fitspiration showed “problematic image content similar to thinspo in emphasizing a fit and thin body ideal”. These studies concluded that fitspiration might be more detrimental than thinspiration as it makes the ideal image even more unattainable by adding a fitness aspect to the existing thin ideal [68]. Another study comparing 50 fitspiration and thinspiration websites found that even though thinspiration had a greater emphasis on weight loss and thinness, both types of content emphasized objectification of the female body, focus on appearance, and weight bias, ultimately leading to body dissatisfaction and restrictive eating [69]. Yet another study suggested that fitspiration content could be “even more damaging than thinspiration” as they found that fitspiration content displayed more messages of body guilt and shame, and found that women viewing fitspiration images reporting greater body dissatisfaction than those exposed to just thin-ideal images [70].

Condoning Extreme Exercise and Dietary Restriction: Elements of fitspiration that promote extreme attitudes toward exercise (e.g., “Crawling is acceptable, puking is acceptable, tears are acceptable, pain is acceptable. Quitting is unacceptable.”) is highly problematic as excessive and compulsive exercise often occurs together with dietary restriction, purging, and other unhealthy weight control behaviors [71]. In a study aiming to investigate compulsive exercise and disordered eating among women who post fitspiration posts on Instagram, the authors found that despite the proclaimed “healthiness” of fitspiration, these women scored higher on

measures of disordered eating and levels of compulsive exercise attitudes than those who post other type of content [72]. Although regular physical activity is beneficial to health, such levels of excessive and compulsive exercise attitudes is associated with fatigue, injury proneness, and social withdrawal that can have detrimental effects on both mental and physical health [73]. A particularly troubling finding was that almost 20% of the women who post fitspiration images were at risk for a clinically significant eating disorder. The researchers expressed concern that even though at the surface such content may present as healthy and harmless, it could actually be “a culturally sanctioned way of rationalizing dietary restriction, disordered eating, and over-exercising [72].”

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Ella followed many popular fitness and health influencers on Instagram and YouTube. She would regularly speak about the “fit and skinny” influencers—often with no formal training or credentials in the area of fitness and/or health—who would post pictures of working out or mirror selfies showcasing their abs with captions of “fitness tips” or describing their “hard work.” Instead of feeling positive or inspired, Ella increasingly displayed even higher degree of body dissatisfaction as she would express frustration about why her body didn’t look like theirs despite the hours she spent at the gym every day at the expense of minimizing her social life. This is in line with studies suggesting viewing fitspiration images on Instagram is associated with higher body dissatisfaction and greater drive for thinness among young women [159] and also that exercising primarily for appearance-related reasons has been found to be linked to disordered eating, depression, and negative body image [160–162]. She used to enjoy her time working out and was able to recognize the other benefits of physical activity aside from “becoming skinny and fit,” such as feeling stronger, as she continued to force herself to do more

with the increasing desire to change the body. Then she started noticing exercise becoming less enjoyable and expressed concerns that it was becoming “unsustainable.” With frustration that her body was not changing in the way she wanted it to, she compensated more by further restricting her food intake, increasingly contributing to uncontrollable binge eating episodes that would worsen her confidence and self-worth even more as she felt like “a failure.”

#Clean Eating (i.e. Orthorexia): Healthy Eating that Is Not Healthy?

Another trend worth noting on social media is the growing healthy eating community [74]. Although striving to incorporate more fruits and vegetables and less processed foods in the diet could be a positive endeavor, there are concerns around it triggering disordered eating and eating disorders especially among adolescents [75]. One concern is with the growing popularity of “clean eating.” The British Dietetic Association named “clean eating” as the number one “worst celebrity diet to avoid” in 2017 and 2018 [76]. Although there is not much established research or a clear definition for clean eating in the scholarly literature, it has been highly popularized via social media platforms (Instagram noted as the most popular one), wellness blogs and books written by non-experts, often with little to no formal science or nutrition training [77, 78]. Clean eating typically includes elements such as choosing whole foods (“free of chemicals, additives, preservatives, etc.”) and often involves further elimination of processed foods or food groups such as added sugar, gluten, grains, dairy even with the absence of any clinical necessities [76, 79]. In more extreme cases, it may also involve “cleanses” or “detoxes” with purported benefits to health and weight loss, but without credible evidence to support such claims.

Although sometimes used interchangeably with “clean eating,” a clinically meaningful term that refers to a patho-

logical level of obsession with strict adherence to eating only “healthy” and “clean” foods is called Orthorexia Nervosa [78]. Although not yet a formal eating disorder diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (DSM), it is increasingly being documented both in literature and in the clinical realm of eating disorders. With Orthorexia, individuals frequently restrict intake to a limited type of foods that they believe are “clean” and “healthy,” such as raw vegetables. Over time, the extreme restrictive eating behaviors can escalate to a time-consuming obsession and isolation where individuals spend tremendous time and energy to find foods they “can eat,” and will avoid social eating situations because they are afraid to eat in any other way. Although it can exist in absence of other eating disorders, Orthorexia is often a comorbidity with both Anorexia and Bulimia and can significantly worsen development of eating disorders [80, 81]. It also can delay detecting eating disorders when a patient proclaims they are “not restricting,” but “just eating healthy.”

Disordered Eating in Disguise of Health: It is well established that dietary restraint is related to a host of negative outcomes such as body dissatisfaction, low body-esteem, negative attitudes toward eating, and eating disorders [82, 83]. What should be clear is that dietary restraint does not apply solely to diet patterns based on low caloric intake for the purpose of weight loss, but there is evidence that even following special diets with elements of elimination (i.e., vegetarian, vegan, paleo, gluten-free) is also linked with higher rates of eating disorders [84]. A diet adhering to “clean eating” is also a form of dietary restraint, especially with increased elimination of different foods and/or food groups, which is often the case in an attempt to become “cleaner,” but unintentionally may lead to many adverse health consequences.

The problem is that in many cases, a decision to start “clean eating” may be informed by social media, with a benign motivation to just become “healthier.” Accumulating evidence indicates more people are turning to social media platforms to seek information about food and diet [85–87]. There are statistics that 42% of American social media users

report that finding information on social media affects their health decisions related to diet and exercise, and nearly 90% of young adults aged 18–24 indicated they trust medical information found on social media [88]. Further, a study exploring characteristics of consumers of health and fitness-related social media content found that nearly 48.7% of consumers seeking health and fitness-related social media content were teenage girls and that those with eating disorders were two to three times more likely to consume such type of social media content [88]; meaning adolescents, who are already at higher risk of eating disorders and body dissatisfaction are becoming even more vulnerable by seeking such information on social media. Instagram viewers have been shown to have a staggering prevalence of orthorexia symptoms (49% of users as supposed to 1% in the general population). No other social media channel was shown to having this effect [89].

Patient Case Application

This was the case with Jamie, who said nutrition was not something often on her mind until she determined to eat “healthier” when she decided to prepare for her first marathon. She turned to the internet and social media to seek information about “healthy eating,” but soon started following influencers preaching the values of “eating clean” and how “sugar is the enemy,” “carbs are fattening,” “all foods with preservatives should be avoided.” She started to eliminate more and more foods from her diet. However, she soon found herself becoming more afraid of eating foods, feeling stressed and unable to enjoy her time when going out to eat with friends. On a date she would sometimes cancel plans altogether; she increasingly felt more tired and cold; she found it difficult to concentrate in class, and she was rapidly losing weight even when she no longer intended to, all the while becoming even more unhappier with her body and herself.

Harmful Messages in Disguise of Health: Similar to what was found with “fitspiration” content on social media, a content analysis study of “healthy living blogs”—blogs devoted to supposedly sharing individual’s healthy lifestyles including eating and exercise habits—found that much of the promoted content included problematic messages endorsing thin ideals, fat-phobia/weight-stigma and disordered eating messages in the name of “health” [87]. The content analysis revealed that 20% of the blog authors self-identified as having had an eating disorder, over 50% referenced currently being on a particular diet, 23% indicated using some form of dietary restraint, and over half included some form of guilt-inducing messages about certain foods [87]. The researchers discussed that although these blogs may seem less explicit than the messages of pro-eating disorder websites, they could potentially be even more problematic as they may reach a wider audience in a way that normalizes disordered eating thoughts and thin idealization messages.

The significant concern here is that there is great potential for harmful and non-evidence-based dietary advice to be circulating among vulnerable adolescent users, especially those who may have an eating disorder or are at risk of developing one. As one clinician put it, “at best, clean eating is nonsense dressed up as health advice. At worst, it is embraced by those with underlying psychological difficulties and used to justify an increasingly restrictive diet, with potentially life-threatening results [90].”

Negative Consequences of “Clean Eating”: Clean eating and orthorexia poses potential harm to the health of adolescents in many ways. First, due to the increasingly restrictive nature and elimination of many foods, it can lead to unbalanced diets and nutrient deficiencies. This can result in further adverse physical consequences that resemble those of restrictive eating disorders (i.e. anorexia), such as reproductive issues, chronic fatigue, amenorrhea (absence of a period for more than three consecutive months), osteoporosis, irregular heart-beat, difficulties concentrating, and depression [78, 79, 90].

Second, similar to the effect of other eating disorders, “clean eating” can create a dysfunctional relationship with food by adopting an overly simplified “good vs. bad” framework regarding food. The notion of “clean” eating suggests that some foods are then “dirty” or bad, which does not align with the Academy of Nutrition and Dietetics’ position on advocating for the *Total Diet Approach* emphasizes focus on balance and variety, not elimination and rigidity that can lead to distress, fear, and a dysfunctional relationship with food [91]. Although there can be healthy and unhealthy quantities of any type of food, no food in itself is inherently bad. Third, it thus further enhances the confusion around food and nutrition with proliferation of information that is not evidence-based. There are often far-fetched benefits claimed with “clean eating”, ranging from weight loss, radiant skin, and reduced cholesterol, to eliminating diabetes, skin rashes, and migraines, even though, as with any other fad diet, there is no “magic bullet” when it comes to diet and health [92]. However, social media influencers with little or no credible expertise in these areas are able to use their images and personal stories to engage users, who then feel more personal connection and perceive them as “authorities” in their food and health messages [74, 75, 89].

Why the Adolescent Stage Is Most Susceptible to Media Impact

Although everyone living is subject to the influence of the cultural beliefs and media messages and could be at risk for body dissatisfaction at any stage of life, adolescence is a unique period that further increases such risks due to a combination of factors: Physically, rapid changes to the body through puberty create heightened awareness of one’s own body, and it is a key period for developing norms related to health behaviors and body image [93]; Cognitively, there is increased awareness of societal norms and values

regarding appearance and size [94]; Developmentally, this is a unique stage for exploring one's own individuality and self-identity [95]; Socially, peer relationships become more important and there is also increased need for peer acceptance. Media has the potential to influence each of these areas. Given the pervasiveness of media and how much time adolescents today spend on social media, it is not a surprise that vulnerability to body dissatisfaction and disordered eating behaviors can substantially increase during this life stage.

Disorienting Period of Physical Development

Puberty is physiologically a dynamic developmental period marked by body size, shape and body composition changes, with the average weight gain ranging between 40–50 lb in females and 50–60 lb in males [96]. Body composition also changes dramatically with increased fat deposits, especially in the areas of breasts and hips with the start of menstruation in females and with increase in lean body mass in males [96]. Many young adult female clients I have worked with shared how they wish they knew that it was “normal” to gain so much weight during puberty. Without that understanding, such rapid change can feel disorienting and “out of control” in this sensitive developmental stage. With changing bodies to make sense of, adolescents' views of their bodies significantly contribute to their body image as well as overall sense of self [97, 98]. Such rapid physical changes can alter how adolescents perceive and experience their own bodies as they might start to develop weight consciousness and start to become more aware the socio-cultural ideas of “ideal bodies” through various channels, especially through media and peers. This is also a time of increased self-awareness, and preoccupation with self-image [99]. Through combinations of these factors, they may come to realize how their body does not align closely with those standards and images. These can significantly contribute to body dissatisfaction and low self-esteem. By the early adolescent years, 20–50% of girls “feel too fat,”

and 40% consider themselves overweight even though many are normal by standards of the BMI [100, 101].

Vulnerable Time of Emotional and Social Development

Exploring Self Identity and Self Expression

Adolescence is also developmentally a period where there is increased desire for autonomy, exploration of self-identity and self expression [59]. Social media is saturated with content related to appearance ideals, dieting, fitness, and health and as adolescents are bombarded with these messages. The amount of time they spend on these platforms puts them at greater risk of internalizing such messages, in part dependent on how much they internalize the messages and incorporate them into their own values and self-identity. For instance, those partaking in fitspiration or clean eating, “fitness” or “health” might have been internalized to a high degree and an important part of self-identity. Once such values become an integral part of one’s self identify, increased engagement with such content creates more exposure and reinforcement in a manner of a feedback loop. There is evidence that more time spent engaging with such content on social media may be associated with elevated internalization of problems [59, 102]. Therefore, there is increased risk for greater internalization of messages from sociocultural channels during the adolescent stage when there is less assurance and balanced components contributing to a healthy self-identity and sense of self.

Increased Desire for Peer Acceptance and Social Identity

As adolescents place increasing importance on peer relationships, and developing their own social identity, social media spaces become appealing platforms where they can manage

to do both. In fact, one of the key benefits of social media is that it can help adolescents feel less lonely and connected through on-line interactions [59]. However, with the rapid physical changes during puberty, increase in self-consciousness about appearance as an increasing part of self-identity, and now coupled with the desire for peer acceptance, interaction with peers on-line as well as off line would mean there are more opportunities for social comparisons. As previously mentioned, social comparison is a well-documented mediating mechanism between media exposure and body dissatisfaction, and in line with Social Comparison theory, adolescents are more likely to compare themselves to peers than celebrities for physical attributes [60, 61]. Also, if appearance and size take up a significant portion of an individual's self-identity, that would increase the need to scrutinize one's own body from an external observer's standpoint. This process is referred to as "self-objectification" and individuals who have repeated self-objectification experiences through social comparisons are more likely to endorse the unrealistic body ideals; in other words, show greater degree of thin-ideal internalization [103]. Research supports that both self-objectification and social comparison are strong predictors of body dissatisfaction [41, 103, 104]. It is not a coincidence that uploading one's own photographs and looking at others' is a common activity on these platforms. In this way, social media, centering around images, creates increased exposure to unrealistic appearance/body ideals coupled with misinformation. This provides more opportunities for social comparisons, and in turn greater risk of internalizing such messages, all of which are predictors for negative outcomes such as mood disorders, body dissatisfaction and pathological eating behaviors [105].

Patient Case Applications

Both Jamie and Ella clearly displayed high degrees of thin ideal internalization, and they valued appearance and size as important parts of self-identity. To Jamie, being known as "the

skinny girl” was an important part of her own self-identity such that she was terrified of gaining weight even though she was “underweight” in classification of the BMI. She was increasingly feeling the negative health consequences ranging from low energy, amenorrhea and low heart rate. Even when she received compliments about her size from friends who had no idea that she was struggling from body image and food issues, she would feel triggered and stressed saying “Just the fact that people take notice of my body and feel free to comment on it makes me terrified of what they would notice and say if I gained weight.”

Ella, through her past experiences, personal relationships, and media messages, also felt immense pressure to conform to societal standards of the “thin and fit ideal,” both by her own internalized beliefs and through the reinforced messages she received from external sources. With appearance and ideal body size internalized as important values, she frequently engaged in body checking behaviors throughout the day (signs of self-objectification), as well as social comparisons to other peers on campus and to those she followed on social media. She realized these comparisons were bound to make her “feel awful and not good enough.” However, it was difficult for her to consider that her self-worth, identity, success and happiness would not depend on her body and size.

Another Complicated Layer: Gender, Sexuality and Ethnicity

Body Image and Media across Gender and Sexuality

In Adolescent Males

Body dissatisfaction among males has been understudied compared to the vast amount of research with females, even though it is an area that applies to males as well. There are an increasing number of studies showing that body dissatisfac-

tion is common among men [106, 107]. Adolescent males also experience body dissatisfaction and eating disorders symptoms and are impacted by similar sociocultural factors, including messages and appearance ideals presented by media [105, 106]. Similar to the effects in females, body dissatisfaction has been shown to be associated with unhealthy weight-control behaviors, eating disorders, and lower self-esteem in males [105, 108].

Media can strongly influence boys' and young men's body image concerns. Research shows that both genders aim toward body ideals dictated by the media [109]. The male body ideal includes several features such as leanness, athletic muscularity, and height. One researcher asserted that such "male body ideal is becoming more and more muscular and therefore unattainable" [110]. Although there is less research available existing research found associations between consumption of media, such as magazines emphasizing health and fitness, and both body dissatisfaction, and use of muscle-enhancing supplements [45]. A meta-analysis by Barlett et al. suggested that the exposure to muscular ideals were associated with lower levels of body esteem and body satisfaction and with increased levels of negative behavioral and psychological outcomes [111]. Experiments on the effects of exposure to muscular media images on male undergraduate participants showed less satisfaction with their bodies [112]. Studies have also found that in image-based social media platforms, fitspiration posts featured images of men more frequently than thinspiration posts [68]. In fact, in a review of six studies examining the potential differences of social media impact on male and female body image and disordered eating, only one study found significant difference between genders. All other studies found that the relationship between SNSs and body image or disordered eating was not significantly different between adolescent girls and boys [113].

Similar mediating mechanisms between exposure to appearance/body ideals and development of body dissatisfaction applies to males as to females. More exposure to body

ideals presents more opportunities to internalize such ideals, and engaging in social comparisons, easily done on social media platforms, has been correlated as a central contributor leading to low body esteem and body dissatisfaction in both adolescent girls and boys [60]. Taken together, evidence indicates that adolescent males are certainly not immune to body dissatisfaction and its consequences, and that the mediating mechanisms between exposure to media messages and body dissatisfaction are similar to those in females.

In Sexual Minorities

Sexual minorities are another subpopulation that received minimal attention in research of media and body image even though there is evidence that they constitute a highly vulnerable subgroup for body dissatisfaction that often leads to disordered eating. For example, in a study comparing 112,000 heterosexual and 4400 sexual minority men on different aspects of body image, greater levels of muscularity dissatisfaction, self-objectification, and more frequent appearance-based social comparisons were observed in sexual minority men [114]. Another study, though it did not directly measure the levels of body dissatisfaction, found that in a sample of 24,591 U.S. high school students across diverse ethnicities and gender orientations, female and male sexual minorities had substantially elevated risk—in some cases as much as a sevenfold increased risk—of disordered weight-control behaviors [115]. As many as 1 in 3 lesbian and bisexual girls engaged in these behaviors in the past month compared with fewer than 1 in 10 heterosexual girls. Similarly, 1 in 5 gay and bisexual boys reported disordered weight-control behaviors in the past month compared with 1 in 20 heterosexual boys [115]. Considering that body dissatisfaction is one of the strongest predictors of eating disorders and disordered eating behaviors, there is need for increased attention and research regarding potential risk factors, including media use, for body dissatisfaction and eating behaviors among sexual minority adolescents.

Body Image and Media across Ethnicity and Race

Ethnicity and Race

Body image research up to the mid 2000s not only heavily focused on females, but primarily of Western societies in samples of predominantly white females, with little focus on ethnic differences [116]. Although still limited, research into body dissatisfaction among ethnic-minority women has increased. The majority of the study results suggest that rates of body dissatisfaction tend to be lower in Black women compared to white women, with potential explanations including less thin-ideal internalization and less narrow appearance values observed in Black women [117, 118]. However, it is illogical to assume that Black women are without body dissatisfaction. In fact, more recent research suggests body dissatisfaction and disordered eating is becoming increasingly similar across cultures. Studies have highlighted the influence of media as one of the primary reasons [116]. In a meta-analysis of 98 studies investigating ethnicity and body dissatisfaction in the U.S., researchers found only a small difference in the average White-Black comparison, and in comparisons of white to other ethnicities (Asian-American and Hispanic), the differences were even smaller, closer to zero [116]. The researchers concluded that these “findings directly challenge the existing notion that there are large differences in body dissatisfaction between white and other non-white women” and suggested that body dissatisfaction may be more universal across ethnicities than previously believed.

There is evidence that this Westernized “thin ideal” is not only widely disseminated and impacting appearance ideals among different ethnic minority groups in the U.S., but also globally. Media is believed to have played a huge role in the global diffusion of the thin ideal. Studies of Argentine, Malaysian-Chinese, and Fiji women found considerable levels of body dissatisfaction, and internalization of Western-style thin ideals correlated to Western media exposure [119]. The case in Fiji especially highlights the impact of media as

the rates of eating disorders in female adolescents were almost non-existent until the mid 90s. However, when Western television programs were introduced, researchers started to see a rapid rise in the level of eating disorders and weight control behaviors in this population. By 2007, four of ten girls reported “vomiting to lose weight” [120]. Although a compelling case to highlight the potential impact of media on proliferating the “thin ideal,” there are complexities. Women in Belize seemed to have rejected the Western-style thin ideal, as body shape was found to be more valued than body size in general. Therefore, as the researcher noted, it is important to remember that “the ways culture and media interact to influence body disturbances is a complex issue” [119].

However, the popularization of social media across the globe definitely adds a powerful mechanism for such Western-style body ideals in both male and females to penetrate cultures and nationalities. In a cross-cultural survey of body ideals and body dissatisfaction among 7434 individuals in 41 sites across 26 countries, one of the major findings was that greater exposure to Western media was associated with a preference for a thinner figure, implicating the powerful influence of media on perception of appearance ideals [121]. All of the types of social media messages and images previously discussed now have the potential to reach and influence non-Western culture adolescents to rethink their concepts of ideal bodies and attitudes about their own bodies.

Overcoming Negative Media Influences and Facilitating Positive Body Image

Body image development is complex and there is an array of socio-cultural and individual factors that can impact its formation. However, it would be difficult to argue that media is not one of the most powerful channels communicating the cultural and societal beliefs of unrealistic and unattainable

appearance ideals. Levels of body dissatisfaction reported in children and adolescents steadily increase with age and are known to be over 80% by the time they reach college. This is alarming due to the numerous mental and physical health outcomes that are associated with body dissatisfaction including depression, anxiety, low self-esteem/self-worth, disordered eating, extreme dieting, and clinical eating disorders. Therefore, body dissatisfaction warrants attention as a public health priority for adolescents. Anyone working with this population should have a comprehensive understanding of the factors and media influence leading to body dissatisfaction development, practice prevention efforts against such influences, be able to identify and assess high-risk individuals, and provide appropriate interventions when detected.

Promoting Body Positivity: A Protective Factor Against Harmful Media

Practicing ways to help adolescents establish a healthy and positive view of one's body would be key to protect them against the negative forces during this vulnerable period. In the past decade's emerging research of positive body image, there have been strong indications that positive body image may serve as a significant protector against negative influences detrimental to body image [122]. Some of the key components of positive body image that have emerged from such research include: Appreciating the body's appearance and function with a broader conceptualization about beauty; being aware of and attentive to the body's experiences and needs, and possessing a positive cognitive style for processing body-related messages in a self-protective way, which would include rejecting harmful media messages [123, 124].

These key components of positive body image could be extremely helpful in supporting adolescents navigate the socio-cultural pressures of appearance ideals and harmful media messages that reinforce them. The increasing time teens are

exposed to idealized images on social media represents a challenge for them. It may be unrealistic to expect adolescents' social media use to decrease anytime soon. However, what can be done is to understand the factors that can build positive body image and use the positive characteristics of social media to shift its use in a way that can support a healthy and positive view of one's body and sense of self.

Media Use Supporting Positive Body Image

When considering the risks of body dissatisfaction, what we now know is that it is the type of content and how consumers engage with that content that is more important than merely the amount of time spent on media [63, 64]. Increasingly more studies are finding high correlations between image-based media and higher risks of body dissatisfaction [62–64, 70]. The fact that the most popular social media platforms among adolescents today (Snapchat, Instagram and YouTube), referred to as HVSM (Highly Visual Social Media), are correlated with higher internalization of appearance ideals and social comparisons to other people's bodies and seeking health/fitness information aligns with such facts. However, the good news is that we can guide adolescents to create that “chamber effect” by curating their social media feeds with positive body image messages that focus on body appreciation and body function, messages and images that reject the “thin ideal,” “fitspiration,” and “clean eating.” The fact that the user-generated nature of social media allows for more diversity in representation of body shapes, sizes and appearances that were less visible on conventional forms of media is also a positive feature of social media. For example, both in the YouTube and Instagram community, there is a surge of popular influencers with millions of followers who do not fit the dominant thin-ideal (e.g., larger bodies), communicate messages of body positivity not dependent on “thin” or “fit”

ideals or gender stereotypes of femininity or masculinity, and are vocal in their own self expression and self-identity not conforming to societal norms [125, 126]. Studies confirm that demand for greater diversity representation and messages countering the thin or fit ideal in media is increasing in young consumers [127]. Popular search terms on Instagram such as #bodypositivity (over 10 million posts as of August 2019) and #effyourbeautystandards (over 4 million posts as of August 2019) speak to that new paradigm. In contrast to “thinspiration” or “fitspiration”, images and messages that feature specific body attributes with messages inducing body shame or guilt, body positive messages revolve around self-care not dependent on appearance ideals such as “Exercise is a celebration of what your body can do, not a punishment for what you ate,” or “Hating your body will never get you as far as loving it.” Such messages are compatible with ideas of self-compassion, which means engaging in self-kindness instead of self-criticism. Correlational research found higher self-compassion to predict less body shame and body surveillance, fewer body comparisons, less emphasis on appearance as an indicator of self-worth, and also to act as a buffer between media thinness-related pressure and thin-ideal internalization [128–131]. Experimental evidence also confirmed that subjects who viewed self-compassion posts on Instagram showed greater body satisfaction, body appreciation, self-compassion, and reduced negative mood compared to women who viewed fitspiration posts [132].

Focusing on Physical and Emotional Self-Care over Weight and Appearance

As research shows, body dissatisfaction is one of the most consistent and strongest predictors to a wide array of negative outcomes. It must also be understood that “body shaming” (essentially a form of displaying weight-stigma) and using body dissatisfaction as a motivator for health-promoting

behaviors is not effective. Stigmatizing larger bodies and using shame as a way to motivate people to lose weight are shown to contribute to negative behaviors such as binge eating, social isolation, avoidance of healthcare services, and decreased physical activity—in other words, an overall decline in health-promoting behaviors [31].

Awareness of and attentiveness to the body's experiences and needs is another key component of positive body image. We can help by prioritizing and focusing on taking care of the physical and emotional needs instead of focusing on weight or appearance. Focusing on controlling food intake or engaging in obsessive and extreme exercise to change the body is often a coping mechanism for emotional difficulties. That is why positive body image is often discussed in the context of “embodiment,” which sees positive body image as a state of “body-self integration” that allows better attunement to one's physical and emotional needs and responding to it through kind, self-care behaviors [124].

Evidence-based practices focusing on self-compassion based self-care include mindfulness and non-diet approaches such as Health at Every Size® (HAES)⁷ and Intuitive Eating (see Chap. 12). Essentially, these approaches advocate for making decisions about food, exercise and self-care in the absence of a weight-focused mindset. Intuitive Eating is a self-care eating framework that honors both physical and mental health. The program, created by two dietitians, has been the subject of more than 100 studies to date [133]. Governed by 10 principals not centered around changing body size or weight, the program is instead based on evidence that demonstrates greater physical and emotional health for people who attend and respond to physiological hunger and satiety cues to determine when and how much to eat,

⁷ Health at Every Size® (HAES), founded by the Association for Size Diversity and Health (ASDAH), is a continuously evolving social justice movement and evidence-based treatment approach offering an alternative to the weight-centered approach to patients of all sizes. The core principles are: Weight Inclusivity, Health Enhancement, Respectful Care, Eating for Well-being, and Life-enhancing Movement.

who to pay attention to for nutritional advice, and when and how food might come into play for non-hunger reasons (e.g., cravings, emotional needs, stress, etc.) [134–137]. HAES® also advocates for pleasurable movement based on evidence that exercising for pleasure in lieu of weight loss is linked to well-being and positive body image [70–72, 138].

These philosophies and practices are often what effective body image intervention programs center around [40]. An evaluation of a 10-week intervention program for women with a variety of body image or eating concerns that incorporated mindfulness and intuitive eating showed significantly increased mindfulness, body appreciation, and intuitive eating immediately post-intervention compared to a wait-list control group [139].

Early Detection and Screening of Body Dissatisfaction and Risk Factors

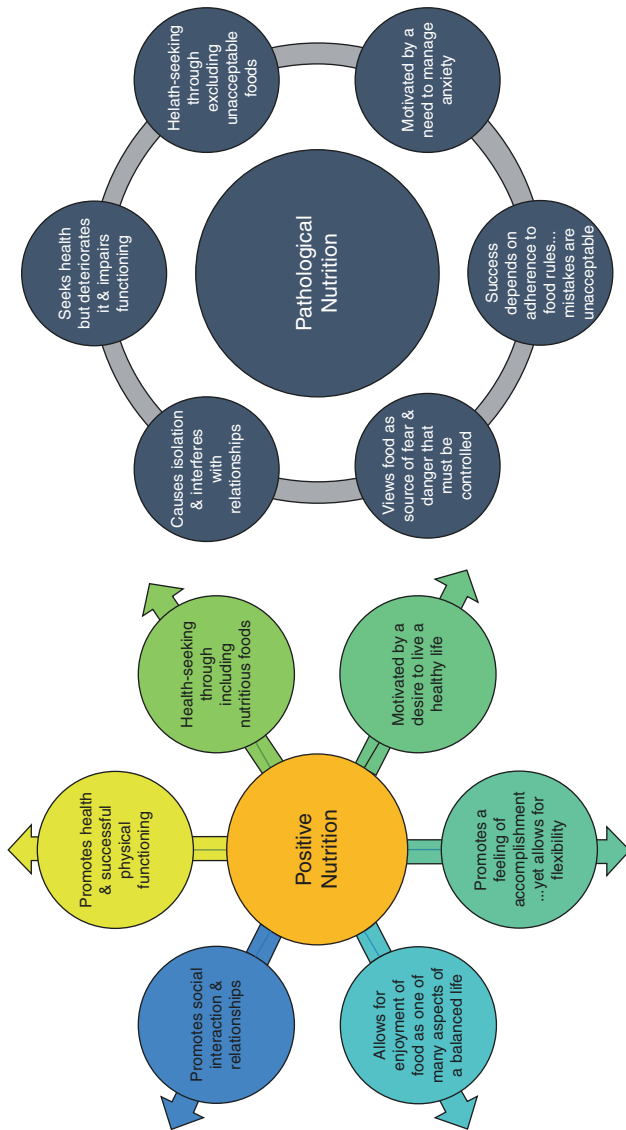
As body dissatisfaction is highly prevalent among adolescents and is a key predictor for eating disorders, early detection and appropriate intervention is needed. It is important for anyone working with adolescents to remember that body dissatisfaction and its negative effects do not discriminate between gender, ethnicity or sexual orientation. Although typically it has been thought to mostly impact young, white females, there is evidence for continued increases in males and a significantly elevated risk in sexual minorities. Therefore, proper assessment and detection of signs of body dissatisfaction, excessive and compulsive exercising, and disordered eating behaviors would be important and necessary for all adolescents of concern.

As body appreciation is inversely related to body dissatisfaction, body shame, body surveillance, and body checking behaviors, a screening tool such as The Body Appreciation Scale-2 can be a helpful tool for providers. It is a widely-used measure of positive body image which assesses several components of body image, including body appreciation, body acceptance, attention to bodily needs and a protective cognitive mindset to reject harmful media messages about appear-

ance. [123]. The measure has been validated for consistency among both male and females of different ages and of various countries [123, 140–142]. With just 10 items, it can serve as a helpful screening tool for assessing the levels of body dissatisfaction and body appreciation in adolescents.

Also, in order to understand the impact of media influences in each adolescent's body image, it would be important to ask questions regarding total time spent on social media, platforms used, type of content they follow, level of engagement with such content, reasons of following such content (e.g., to seek information, to engage in comparisons, etc.), and most importantly, the prevailing messages (e.g., thin ideal, fit ideal, clean eating, etc.) they are receiving and have internalized as their own values.

Equally important would be to assess the adolescent's current eating and physical activity behaviors and the motivations behind the behaviors, especially with the rise of "clean eating" trends and "fitspiration". Their prevalence on social media platforms may make it more difficult to gauge the level of disordered thoughts and behaviors when adolescents assert they are being "healthy." Certified Eating Disorder Registered Dietitian Jessica Setnick's Positive Nutrition vs. Pathological Nutrition chart (Fig. 7.2) is a valuable tool in assessing whether a proclaimed health behavior may be in fact pathological. Essentially, a positive eating behavior that enhances physical and mental health is based on balance, variety, joy, connection and flexibility, not on elimination, fear, isolation and rigidity. Although depicted in the context of nutrition, these elements could similarly apply in assessing healthy vs. excessive and compulsive exercise behaviors. In other words, it would no longer benefit physical or mental health when physical activity is compulsive or rigid, leads to physical harm and pain, causes more distress than joy, and results in isolation and interference with other areas of life. Research also shows that when the primary motivation for physical activity is to change appearance or size, body appreciation and body acceptance decreases [138]. Therefore, it is important to not just explore the behavioral symptoms, but attitudes and beliefs underlying the eating and physical activity behaviors.



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FIGURE 7.2 Positive vs. Pathological Nutrition

Efforts to Increase Body Appreciation and Challenge the Thin Ideal

Body appreciation is positively related to favorable appearance evaluation, body esteem, proactive coping, positive affect, life satisfaction, self-compassion, Intuitive Eating (i.e., eating according to physiological hunger and satiety cues), and physical activity not motivated by appearance reasons [137, 138, 140, 143]. Additionally, research shows that not only do women who appreciate their bodies critique unrealistic appearance ideals in the media [144] and resist consuming appearance-focused media [145], they also protect their body image when exposed to appearance-based media [146]. Considering that “possessing a positive cognitive style for processing harmful messages” is one of the key components of what can lead to greater body appreciation [124], “protective filtering” [147], or the cognitive ability that allows negative messages regarding food or body to be rejected and positive information to be accepted, would be a valuable tool for protection against the harmful media messages and increasing body appreciation.

Tylka, an established researcher in this field, proposes media literacy as an effective component of protective filtering [148]. Media literacy involves critical evaluation of media’s depiction of appearance ideals, such as being conscious of the unattainable and narrow portrayals of beauty and size, the fact that presented images may be highly altered, and understanding that substantial time and professional assistance is required for models to look the way they do [147, 149]. Positive body image and protective filtering of media messages are proposed as better strategies to protect against the impacts of harmful media messages [147, 148].

That is why cognitive dissonance-based interventions are emerging as effective eating disorder and body dissatisfaction prevention programs. A good example is The Body Project (<https://www.bodyprojectcollaborative.com>), a widely implemented and successful cognitive dissonance-based program that was originally designed as an eating disorder prevention program. It targets three key risk factors for the development

of eating disorders: thin-ideal internalization, body dissatisfaction, and negative affect [150, 163]. It implements a peer-facilitated curriculum with interventions that involve a series of verbal, written, and behavioral exercises to challenge ideas of the thin-ideal. Meta-analysis reviews have found that the most effective cognitive dissonance-based programs targeted interventions girls aged 14 and above, and therefore promising as an intervention geared toward adolescents [151, 163]. For girls with pre-existing body image issues, interventions led to significant reductions in thin-ideal internalization, body dissatisfaction, negative affect, psychosocial impairment and risk for onset of eating disorders with effects maintained up to three years post-intervention [152]. Another 1-hour dissonance-based intervention significantly increased body appreciation among adolescent girls immediately post-intervention, compared to a control group [153]. This intervention involved participants defining and critiquing the thin-ideal, discussing the costs of pursuing the thin-ideal, challenging “fat talk,” completing a top-5 body activism list, and ended with a self-affirmation exercise.

Although less extensively implemented and studied, there are also adaptations of The Body Project designed for males and sexual minority males called The Body Project: More than Muscles, and The PRIDE Body Project, respectively. These are based on the similar dissonance-based model as the original The Body Project where participants in groups discuss and identify culturally-based body ideals, then challenge these ideals through activities and homework. Experimental evidence has shown promising results with decreases in body dissatisfaction, drive for muscularity, self-objectification, body-ideal internalization, and dietary restraint compared to controls [154, 155].

Understanding elements of such effective programs will be helpful for schools and communities to note in creating programs aimed at enhancing positive body image and preventing eating disorders and body dissatisfaction. Programs should be multifaceted, incorporating dissonance, psychoeducation (“myth busting”), media literacy and behavioral components such as: Engaging participants in

counter-attitudinal activities that require them to speak out against the thin ideal or other appearance ideals; encouraging participation in embodying activities that emphasize the function, as opposed to the appearance; fostering on-line and off-line peer communities and social networks that focus on positive non-appearance related qualities, and do not engage in body shaming and “fat-talk.” These strategies may assist in creating a healthy environment that fosters respect and appreciation for all bodies and lead to decreased body dissatisfaction and improvement in mental health.

Patient Case Epilogue

Interventions with Client Case #1: Jamie

In Jamie’s case, a multidisciplinary treatment team that supported her with a consistent message was extremely helpful in her recovery from body dissatisfaction and eating behaviors. Her therapist and I helped her understand that her underlying fear of weight gain was due to the fear of “losing control” and with education about the body’s physiological needs, metabolism, and set-point weight, we slowly helped her overcome her fear that the body would indefinitely gain weight if she did not practice restraint. We also helped her explore how her food eliminations and orthorexic beliefs of “bad foods” did not serve her mental or physical health. We then slowly introduced the previously eliminated foods back into her diet while trying to shift her food beliefs towards variety, balance and joy. She found it quite helpful to be able to discuss with her therapist the pressure she felt around “needing to be thin” as part of her own self-identity and became open to exploring other ways she could secure a sense of self that did not have to do with appearance. She had a supportive family system that did not discuss weight and the thin ideal as important values in the home. This was an important source of reassurance and a “safe place” in her recovery. However, as she was often comparing herself to peers and people she followed on social media and blogs, her therapist and I spent much time

challenging the social media messages. In time, she was able to recognize that the frequent social comparisons were not beneficial to her health. Eventually she chose to take a break from engaging in any social media, which she found immensely helpful in not constantly being exposed to triggers of clean eating and thin-idealization.

Interventions with Client Case #2: Ella

With Ella, the greatest challenge and barrier in recovery was that not only did she have high thin ideal internalization, but that such messages were reinforced externally through her personal relationships and social media. Her beliefs of happiness and health were strongly intertwined with size, at the expense of her emotional, mental, and physical health. She worked with our team comprised of me, a therapist, and a medical provider. Our team helped her broaden her perspective about weight, beauty and health, and she was slowly able to shift her perspective to where she could still work on “health” without tying her weight and body size to it. She was also able to understand her underlying needs of wanting to feel confident, accepted, and worthy of love and care that was being manifested in trying to “control the body.” A pivotal point in her recovery was in re-curating all of the social media accounts that she followed. Instead of the thin-spiration and fitspiration accounts and messages that she began to identify as “toxic,” she started following accounts that reinforced body positivity, size diversity, Health at Every Size and self-compassion. These new sites helped her to engage less in social comparisons and say “I am starting to feel my body more as a vessel than an ornament.” Another turning point for Ella was in joining the “Body Image Group” that I co-facilitated with a therapist colleague. This was a six-week group therapy program with college-aged females who were experiencing body dissatisfaction and disordered eating. Because Ella did not otherwise have a supportive community, this weekly group was the only place where she could connect with others with similar struggles

and safely share fears and concerns about the body and eating. Being able to discuss issues such as society's weight stigma and challenge the thin ideal. Her participation in the program helped her feel less of a need to conform to the "thin ideal" pressure and need to incorporate it as a major part of her self-identity. This shift also led to less-destructive coping behaviors and away from excessive exercise and restrictive eating. To the group she would previously say that "having any positive thoughts in my now-body or confidence with who I am without losing weight seems impossible." However, after the six weeks, she shared that she felt "I never thought my mindset could change in such a short period of time, but it has, and I feel empowered."

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Part II
Caring for Diverse Populations

Chapter 8

Supporting & Promoting Adolescent Nutritional Health Equity



Julia Wignall

Introduction

Healthcare providers may observe a range of behaviors or engagement from adolescents when creating nutritional care plans and recommendations. Teens may present in ways often described as: noncompliant, difficult, having ambivalence, acting uncooperative, appearing anxious or depressed, not coming to scheduled visits, or lacking progress in treatment goals around diet or exercise. Yet there may be health inequities at play, inhibiting adolescents from fulfilling their health care needs. Health disparities or “differences *between* groups in status and outcomes” have been increasingly studied to understand how social status and circumstances can alter long-term health outcomes ([1], p. 839; [2]). Status differences have been defined as economic, social and environmental disadvantages that arise from the unjust treatment of people especially within certain racial and ethnic groups [3]. In addition to race and ethnicity, the American Academy of Pediatrics [1] states that disadvantages also stem from socioeconomic

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position, geography, gender and age. These status differences facilitate social sources of inequity and can lead to poverty, discrimination, racism, historical trauma and their consequences, often “including powerlessness and lack of access to quality education, housing, safe environments and health care” ([1], p. 839; [4]). These social circumstances can significantly impact health outcomes and lead to the development of chronic conditions that disproportionately affect certain groups [5–8]. Thus, health disparities are multi-factorial and can be impacted by various lived experiences, from individual perceptions and behaviors to interactions with their family, community, environment, and policy [9, 10].

Healthy equity is “everyone having a fair and just opportunity to be healthier” and thus requires removing sources of inequity that are avoidable, unnecessary, and unjust [3, 4, 11]. Most literature focuses on risk factors that cause health disparities and how providers can identify and treat such factors. This chapter will highlight why a focus on protective factors is critical for health equity and what providers can do to support and promote nutritional health equity among adolescents.

The Shifting Landscape of Adolescents

The U.S. population is anticipated to shift dramatically by 2050, with adolescents becoming more ethnically diverse than ever [12]. The U.S. Department of Health and Human Services expects the population of White, Non-Hispanics to drop by 13.8% by 2050 while Hispanic and Asian adolescents will increase by 11.1% and multiracial adolescents will double from 3.4% to 7% [13]. This rapid shift in demographics of U.S. youth requires a “new paradigm to conceptualize and address the health and well-being of children” [1, p. 840]. If not addressed, this demographic shift could widen existing health care inequities that disproportionately affect certain groups. Additionally, adolescents of today are experiencing more pronounced health disparities unimaginable in the last gen-

eration due to dramatic shifts in social and environmental conditions [14, 15]. Obesity is now one of the most common adolescent health disparities, disproportionately affecting African-American, American Indian/Alaskan Native and Latino youth [12, 16]. Yet one-third of adolescents in a recent study are also reporting food insecurity [14]. Meanwhile, Type 2 diabetes in youth has more than doubled in the last decade [14, 17]. These contrasts signify a remarkable change in the experience of U.S. youth and require innovative approaches to health promotion.

Adolescence is an important time in a person's life, marking a shift to independence in decision-making, and identity solidifies into patterns of behavior [18, 19]. This process is compounded by the fact that youth are "particularly sensitive to influences from their social environment" [12, 20]. A study of Mexican-American adolescents in Texas found that male and female participants relied to varying degrees on teachers, family, coaches, peers, and online resources for information and influence regarding diet and exercise [21]. While societal politics and policies continue to reinforce health inequities, adolescents are at a critical stage to envision, be influenced, and develop useful health behaviors that can have lasting effects on their health outcomes. Many studies have shown that adolescence is a critical time to prevent or exacerbate chronic illness [14, 15, 22, 23]. Providers focused on nutritional health can help shift behaviors for an increasingly diverse group of adolescents amidst changing social factors by focusing on their assets and encouraging developmentally appropriate health independence and autonomy.

Eco-Bio-Developmental Model of Support

The eco-bio-developmental framework was developed for public health and illustrates how early social and environmental experiences (ecology) and genetic predispositions (biology) can influence the development of adaptive

behaviors that are important for lifelong physical and mental health. Adaptive behaviors such as resiliency, agency, and learning capacities are imperative to all aspects of life and can be predictors of health and even future economic productivity [24]. Prolonged negative social and environmental challenges such as family dysfunction, abuse, or poverty can cause “toxic stress,” a response from multiple factors that can alter brain functioning and culminate in maladaptive coping patterns, fragmented social networks, and unhealthy lifestyles [25]. Because adolescence is a developmentally critical time for establishing life-long patterns, it is an important stage to influence an individual’s illness trajectory [14]. Moreover, health care providers must recognize that each youth has resiliency and capital but there are lived social and environmental experiences as well as limited access to resources that impact one’s ability to fully realize their health agency [26].

In October 2019, the California state legislature passed a bill to change “at risk” youth to “at promise” in all education code [27]. Importantly, healthcare providers seeking to create health equity will need to consider how they frame narratives about their patients from youth with deficits to youth with assets. Most literature about adolescent nutritional health focuses on risky behavior and populations who are high risk, putting the onerous for equity on the patient rather than status differences and societal controls. At an encounter level, providers are able to support the health equity of adolescents by seeing them as individuals with assets and agency amongst a milieu of external circumstances. How providers “personally view, interact with, and advocate for young people” is an important shift to supporting health outcomes [30]. Indeed, given opportunity, access to resources, and a supportive environment, adolescents are adaptable and can engage in positive health behaviors. As the American Academy of Pediatrics [1] states, providers can support fair distribution of resources through social justice as well as promote forms of capital and agency amongst youth (p. 840). Finding ways to support a teen’s environment and social circumstances as well as their individual coping skills and behaviors will mitigate

stress and increase their capacity for resilience, hope for the future, and positive health outcomes [26, 31].

Each adolescent's ecology or sociocultural and environmental experiences, including what health disparities they face, can be completely unique and individual. Providers cannot assume which disparities are impacting an adolescent's health—or even what intervention would be most successful, given such differences in social circumstances, including: family functioning, access to resources, environmental qualities, and cultural beliefs and values. Therefore, providers must also be armed with the acceptance that adolescents and communities experiencing health disparities are “not people with problems but people with the answers” [28]. Health care providers must shift their focus from problems and shortfalls to developing individual agency, promoting health knowledge and shifting policy [26, 29].

ACES, Health Equity, & Nutritional Care

Adverse Childhood Events (ACEs) have been well documented to significantly impact long-term health outcomes leading to chronic illnesses later in life [25]. Having multiple ACEs increases the chance for poorer self-rated health amongst adolescents [32, 33]. ACEs include forms of neglect, abuse, and household dysfunction such as parental drug or alcohol abuse, mental illness, domestic violence, divorce, or incarceration [26, 34]. ACEs also exist on a community level in neighborhood violence, lack of safety, and poverty [35]. Toxic stress has been directly attributed to experiencing multiple ACE events in childhood and lower resilience has been found to correlate with a higher number of reported ACEs [32, 35–37]. Several studies have identified how ACEs impact adolescent nutritional health in a variety of ways, including a lack of access to healthy food or exercise, unhealthy weight management behaviors, and minimal social support [34, 36, 38]. Davis et al. [39] found that adolescents who reported an ACE were 1.2–1.5 times more likely to be overweight, obese

or severely obese compared to their peers. More research needs to be done to understand the impact of ACEs and health disparities such as food insecurity on underweight adolescents.

While ACEs are “experienced universally across all sectors of population, some groups are more likely to experience multiple ACEs” leading to increased health disparities among certain groups [40]. Those who are already likely to experience health disparities for status differences are also disproportionately affected by ACEs. Identified groups that more commonly experience disparities include persons of low socioeconomic status as well as Black, Hispanic, and LGBTQ individuals [40]. One study found that experiencing racism has the strongest negative effect of all ACE variables [41]. ACEs have also been studied to understand how they affect youth by gender. Isohookana [34] found that adolescent females exposed to trauma have an increased likelihood of obesity and/or engaging in unhealthy weight control behaviors. Consequently, nutritional health can be significantly impacted by factors not traditionally associated with nutritional treatment plans. Additional factors that could be critical to supporting nutrition in adolescents include: family functioning, social networks, cultural beliefs and values, and access to mental and physical health services [26, 42].

Increasing evidence suggests that “a person’s zip code may be the biggest determinant of health” given the socioeconomic factors at play [35]. Community level ACE events disproportionately affect ethnic minorities who are more likely to live in violent and low-income neighborhoods. Neighborhood safety is a significant barrier to a healthy lifestyle, affecting health promotion interventions and behaviors [38]. While community-level health disparities are typically studied in urban areas, youth living in rural communities are also impacted. Rural youth, particularly youth of color, are more likely to experience food insecurity than their urban or suburban counterparts due to reduced access to school food wellness programs and health care [43]. The relationship between community ACEs and health disparities are inter-

woven through experiences of violence, abuse, discrimination, and lack of access to resources. Adolescents in both urban and rural environments may experience a lack of access to resources such as: a safe school environment, healthy foods, community health programs, safe parks or playgrounds, recreation, extracurricular activities, community centers, and libraries [10, 35].

In addition to experiencing ACEs and health disparities, teens may have additional reasons for displaying hesitancy in trusting their medical providers. Disempowerment and a lack of trust in the medical system for ethnic minorities were born out of discriminatory treatment and dehumanizing practices [44]. Feeling empowered by and trusting of the medical system is difficult given the exposure to this historical trauma. In addition, access to health care itself may be limited. The Center for Disease Control (CDC) estimates that one-third of adolescents ages 10–17 have not had a wellness check-up in the last 12 months [45, 46]. Thus, “relying on [and screening for] conventional ACEs alone could considerably underrepresent the prevalence of adversity experienced by some populations” [41, 47].

While ACE studies rely on generalizing poor health outcomes and historical trauma between social groups (e.g., ethnic minorities), how youth experience and react to such events are based on their individual ecology and coping skills. Providers seeking to engage youth in their nutritional health must consider an adolescent’s social and environmental supports, perceptions, and experiences in addition to their individual agency and resilience. Given the multitude of life factors that create and sustain health disparities and ACEs, promoting and supporting health equity for adolescents is not a simple task; however, it is possible.

Biases & Self-Awareness

In order to support adolescents with their nutritional health, providers should consider their explicit and implicit biases. Explicit biases are beliefs a person is aware of while implicit

biases are beliefs, attitudes, or stereotypes a person can have without knowing it. No one is immune to implicit biases, which have been found even amongst “individuals who report egalitarian beliefs” ([48], p. 457; [49, 50]). A 2015 study of providers who serve many obese American Indian/Alaska Native children took a Weight Attitude Implicit Association Test, which found that there was an implicit bias favoring thin people and a weak bias favoring White youth. These biases existed even among long-term Indian Health Services providers [48].

Providers seeking to support adolescents with their nutritional health should also consider the role of sociocultural biases such as toxic masculinity that can impact diagnoses and treatment plans. Toxic masculinity is a set of behaviors and beliefs that can include suppression or masking of emotions and using violence or toughness to maintain power [51]. Few empirical research studies of eating disorders have focused on males, highlighting the belief that males are tough and eating disorders signify weakness, femininity, or lack of control [52, 53]. Further research is working to expand the definition of eating disorders. For example, one study found that males who more strongly conform to traditionally masculine norms had an increased chance of muscularity-disordered eating [54]. Yet, few males present in clinics for eating behaviors and often experience several misdiagnoses and inappropriate referrals that lead to delays in care for treating the eating disorder [52, 55–57]. Another study looking at stereotypes and shifting standards by gender, found that when interacting with the appropriate provider, a male might be more easily recognized as having anorexia nervosa because of gendered ideas of what a male diet and nutrition should look like [64]. Providers can also consider how gender and other biases are at play when treating gender-diverse adolescents.

Weight stigma can significantly impact disordered eating, appropriate diagnosis, and underutilization or avoidance of seeking health care [58–62]. In fact, being labeled as “fat” or

“overweight” as young as 14 can predict the likelihood that teens will have disordered eating later in life [63]. In addition, certain individuals may experience “thin privilege” where they are not subject to body biases because they meet societal expectations of body type and are therefore less likely to suffer from an eating disorder or associated psychological factors. Consequently, weight bias from social circles and health care providers can have a long term impact on a teen’s health. Brochu [60] recommends shifting towards weight inclusive approaches with adolescents that acknowledge weight stigma as well as other social biases and stereotypes.

Biases can take the form of many beliefs, attitudes, or microaggressions towards youth and can play out in how providers establish relationships, form assumptions about attitudes and behavior, and craft decision-making processes including rationing of care, rates of referrals, screenings, diagnosis and pain management [67, 68]. As an adolescent provider, it is important to reflect on and consider potential biases that could impact care decisions. Implicit biases can cause negative interactions with health care providers, and may impact a teen’s engagement in their care [9].

Some researchers have developed a set of reflective questions to reframe adolescent encounters and aid in identifying potential biases in care. The following questions were developed for providers to address biases against “difficult” patients but can be modified to reflect on how such biases can affect health equity (Table 8.1).

In addition to the questions developed by Edgoose, it may be helpful to recognize that adolescents who are considered difficult, ambivalent, or noncompliant are actually individuals with unmet needs [66]. To explore what these needs might be and to support health equity, consider asking yourself: “what needs are unmet?” and “what biases am I bringing?” Asking reflective questions such as those by Edgoose and Olszewski can be a starting place for providers to recognize their biases and address them to provide equitable care.

TABLE 8.1 Questions to reflect on biases and assumptions

Questions to ask	Example thoughts
Checking biases: Why do you consider this adolescent difficult, non-compliant, or unmotivated to change?	They've "no showed" several times—they don't really want treatment. They keep questioning me or disagree with my plan. He is quiet and doesn't seem interested.
Checking biases: What biases or assumptions do you have?	He doesn't care about this health. She's a good kid. They're not going to like what I recommend. He's bored. She has mental health issues. They need to watch their diet. They don't trust my expertise. She's overweight so she doesn't have anorexia.
Checking biases: What are potential implicit biases that may be impacting my assumptions or biases?	Race, gender, ethnicity, sexual orientation, insurance type, mental health, socioeconomic status, body size, age.
Shifting biases: What is your agenda today?	I want to discuss her dietary habits. I want to wean the miralax. I want to refer them for mental health support. I want to help this teen lose weight. I want to explain the seriousness of their condition.
Shifting biases: What is the adolescent's agenda?	She wants to discuss bullying at school. He wants to know why he feels tired. They want to talk about breakfast.
Shifting biases: What social history could you gather that would enable you to further explore your assumptions?	Who provides meals at home? Tell me about your family. What does "being healthy" mean to you? How do you get to appointments? What food or activity options are near your home?

Adapted from Edgoose [65]

Training & Exposure

Another way to mitigate negative effects of biases is through training and exposure to youth from communities which experience health inequities and have exposure to chronic illness. Community-based training programs can help with developing sensitivity to and an awareness of diverse healthcare and individual experiences. One such program is the Stanford Youth Diabetes Coaches Program that pairs family medicine residents with healthy adolescents from low-income, ethnic minority communities [69]. While the program's goal is to train adolescents to become self-management coaches for family members with diabetes, it also trains primary care physicians to better partner with adolescents. The program has been implemented in remote locations where practitioners wanted to support local, underserved schools or communities and connect with teens outside of the exam room. High school students who participated in the program reported increased diabetes knowledge, self-worth, problem solving and self-efficacy. By engaging in the health of their family members, youth became empowered to improve their own health behaviors, potentially altering their health outcomes.

Another community-engaged research study in Richmond, Virginia asked adolescent participants to complete photography assignments focused on barriers and facilitators to healthy eating and physical activity [38]. The research team partnered with an afterschool weight management program that sought to assist weight loss while increasing personal knowledge on healthy eating and physical activity. Findings from the study revealed opportunities to influence everything from individual health knowledge and empowerment to policy-level changes including access to safe physical activity throughout the inner city neighborhoods. All adolescents who participated in the study felt that the weight management program shared positive health knowledge such as food demonstrations, supermarket tours, and opportunities for

hands-on cooking. Clinicians should consider what opportunities they may have to partner with community members to best understand barriers to the adoption of healthy activities [38, p. 308]. Ultimately, training programs that are interactive and allow clinicians to examine their assumptions, perceptions, and biases of adolescents support the incorporation of such learnings into their practice [30].

Screening for Strengths & Resilience

Given the historical trauma of interacting with the medical system for ethnic minority communities in the United States., engaging and empowering youth from underrepresented communities is particularly important [69, 70]. One way to involve youth in their health is through strength based screenings that help build trust and rapport while promoting the capabilities and positive behaviors of the teen. While there are many ACE-based screenings, use of such comprehensive screenings by pediatricians is minimal (only 4%), possibly because screening for ACEs or disparities on a first clinic visit or before establishing rapport, may reinforce such negative experiences with the medical system [71, 72].

However, several strength based screenings focused on resilience have been established. Resilience is defined as “the capacity to respond or adapt in the context of a stressor” [10, 73] and focuses on strengths that individuals possess both internally (coping skills) and externally (family and community supports). Rather than focusing on risks and deficits, these screenings emphasize how individual and social strengths can mitigate exposure to traumatic experiences [26].

One example of such strength based screening is the “7 C’s” resiliency screening (competence, confidence, connection, character, caring, coping and control) created for the outpatient visit [36, 74]. This resiliency measurement tool was found to correlate with responses to the Health Survey for Adolescents (HSA) that assesses participation in risk behav-

iors. Adolescents who had low resiliency were more likely to partake in risk behaviors [36]. A focus on resiliency and other protective factors could change outcomes. Interestingly, the study also found a high correlation between increased resilience and participation in exercise or activities. A teen's level of physical activity could be an indicator of resilience. The "7 C's" screening should be used for "surveillance of resilience in the context of risk-taking behaviors" and help adolescents focus on areas they excel [36, p. 206].

Another screening tool is SSHADESS which is a modification of a psychological assessment developed to focus on an individual's strengths [74, 75]. This screening relies on open-ended questioning that includes risk behaviors but starts and ends with their strengths. It is recommended that these types of screenings are a part of an annual checkup. Before conducting any type of screening, Soleimanpour [37] urges that providers should first ensure that appropriate services and referrals are identified for youth who need any level of support. Screening alone cannot provide the assistance an adolescent needs; but, screenings can facilitate health equity by providing access to evidence-based interventions and resources.

Motivational Interviewing: A Trauma-Informed Approach

One evidence-based intervention is motivational interviewing (MI), a communication approach useful for building trust and rapport with adolescents. This method shows sensitivity, while acknowledging and assessing engagement with health and interest in changing [76–78]. Key to mitigating health disparities, providers must continue to navigate "individualized, strengths-based conversations for adolescents to use in future decision-making" [36, 74]. Several studies have found that clinician communication strategies can promote resilience in youth [71, 74]. In order to support health equity, nutritional health providers need to carefully communicate

their intent and navigate building relationships with teens. Originally developed to help substance abuse patients make positive behavior changes, motivational interviewing has been adapted to support a wide variety of health behaviors in adolescents [79, 80]. Research shows positive behavior change amongst adolescents engaged in MI [30, 81]. One study showed that adolescents with Type 1 diabetes who report positive patient-provider communication and collaborative approaches have higher competence in managing their care [79].

To engage in MI, clinicians must first establish an authentic, trustworthy relationship. For adolescents, assuring confidentiality and having time alone with a provider is key for them to disclose sensitive information [82]. In addition, one study found that using MI increased confidentiality assurances and “the likelihood of providers spending time alone with adolescent[s]” ([37], p. S110; [83]). Consequently, MI can support positive teen-provider communication practices including confidentiality.

Secondly, healthcare providers must show interest and open-mindedness to a teen’s experiences, thoughts, and ideas. Although building trust and rapport with adolescents takes time, it should not be overlooked. Providers cannot make assumptions about the adolescent experience. MI relies on strength-based interviewing that helps the rapport-building process. Table 8.2 illustrates simple yet effective tools that support the development of trust.

The impact of an MI approach can be seen in a study by Pollak et al. [80] which found that an adolescent whose providers used more consistent MI-informed techniques had greater weight loss, greater physical activity, and reductions in screen time.

A key to strength-based interviewing and communication is allowing teens to identify their own solutions or ideas about what they would like to try to change. Similar to a health equity mindset, MI approaches youth as individuals not with problems, but with answers. This method gives them a sense of control and autonomy over their health and refo-

TABLE 8.2 Motivational interviewing tools that support strength-based interviewing and rapport-building

Ask permission: To start a conversation or steer the direction, ensuring their agreement to continue

Open-ended questions: Ask questions about their life or health, focusing first on what's going well

Acknowledge: Recognize and affirm efforts or positive choices, even if small, acknowledge their experiences both positive and negative

Reflect: Show them you're listening by restating what you've heard

Summarize: Bring the conversation to a close by reviewing the discussion and what came out of it, possibly stating solutions or ideas the youth identified themselves

Adapted from Rollnick et al. [84, p. 91]

cuses their efforts on positive behavior changes. MI can also encourage humility by leveraging “reflection” as a time for providers to summarize what they are hearing and for teens to correct any assumptions or mistakes. One study that looked to increase African-American adolescent engagement with psychiatric treatment by overcoming biases and disparities to care incorporated cultural elements to the MI process like striving over obstacles and attending to individual and family perspectives [78]. Healthcare providers may want to consider how they engage adolescents in positive communication through leveraging their ideas, language and perspectives.

Medical anthropologists Arthur Kleinman & Peter Benson [85] studied how to operationalize cultural competency in a medical setting. Culture is not simply a person's ethnicity or background but “a process [or lens] through which ordinary activities and conditions take on an emotional tone and a moral meaning for participants” ([85], p. 1674; [86]). Motivational interviewing skills that are used with *all adolescents* are critical to an inclusive approach. Kleinman [87] recommends reconstructing a youth's illness narrative to bet-

ter understand their perception of suffering and healing without stereotyping or making assumptions. Fitting with MI's use of open-ended questions, the approach outlined in Table 8.3 might help a provider support adolescents by understanding their perception of their condition. Providers could start with a specific symptom (i.e. what do you think has caused your lack of appetite?) or a new diagnosis (i.e. what do you call your health condition to friends or family? What do you think caused it?). This approach can be particularly helpful in understanding and creating a plan that incorporates a youth's cultural values, beliefs, and behaviors. This method could also identify opportunities for health education and skill development ranging from cooking to personal agency.

Reflecting on the experience of caregiving, Kleinman [88] notes that the standardizations and emphasis on process and productivity in healthcare have limited a provider's ability to focus on what really matters to individuals and have often reinforced stereotypes. He states that the most important thing for medical students to remember is not how to put these questions into their system or process, but that "the expression of kindness, the enactment of decency, and the commitment to presence" are what matter most (p. 1377). To

TABLE 8.3 Kleinman's 8 questions (1988)

What do you call this problem? What do you think has caused it?

Why do you think it started when it did?

What do you think your problem does inside your body?

How severe is this problem? Will it have a short or long course?

What kind of treatment do you think you should receive?

What are the most important results you hope to receive from this treatment?

What are the chief problems this illness has caused you?

What do you fear most about this illness/treatment?

successfully implement MI in practice, providers must focus more on the relationship being developed than simply an exchange of information.

In addition to managing assumptions and creating agency, motivational interviewing can also help to process, acknowledge, and manage trauma. A trauma-informed approach is necessarily person-centered, demonstrates cultural humility, and provides emotionally supportive care [37]. Since certain populations are more likely to experience neighborhood violence and poverty, a trauma-informed approach is critical to mitigating health disparities and supporting diverse adolescents. While not all nutritional health providers need to be experts in trauma-informed care, they can leverage MI as an approach to navigate conversations and encourage youth to seek additional support. It is critical that adolescent providers have resources and referrals available to support teens. For example, having information about community or after school programs, mental health resources, housing, or food resources could be helpful to provide awareness and access to needed services. While MI has been shown to improve provider communication and adolescent health, more research needs to be done to understand its impact on improving adolescent health equity.

Adolescent Health Education & Empowerment

There are a wide variety of studies and programs seeking to promote resiliency, health equity, and positive health outcomes for adolescents. Often, successful programs target health knowledge and education while increasing connectedness with a youth's family or community [38]. A study looking at racial differences in obese youth's perceptions of health care and weight loss found that minority youth may have health knowledge and behavior gaps around weight comorbidities and risky behaviors in comparison to white youth [89]. Another study of Canadian adolescent perceptions and

knowledge about social determinants of health found that students attributed their health primarily to physical determinants rather than social determinants and 44% of students did not attribute their health to any social determinants [90].

Some studies have taken a more individualized, psychological approach to amassing coping skills for resiliency. Chandler et al. [26] developed a 4-week intervention focused on increasing resilience and positive health behaviors while decreasing symptoms and negative behaviors with the goal of interrupting the ACE to illness trajectory. The young adult participants met once a week for an hour with a facilitator who gave lectures and guided group activities focused on mindfulness and resilience with the goal of creating a sense of control, agency, and safe space. Qualitative interviews after the intervention showed the importance of starting with strengths, reframing resiliency in past behaviors, and the benefits of social connections [26]. While the study could not show a decrease in risk behaviors, it did promote positive health behaviors. Increasing health knowledge while focusing on youth empowerment could decrease disparities.

Support the Family

Adverse experiences within a family, such as divorce, loss of a parent, incarceration, addiction, and abuse can lead to poorer health outcomes in youth who may be less able to successfully navigate the adolescent transition to adulthood [37]. How a family functions with or without experiencing adverse events can be “particularly protective” of an adolescent’s health ([37], p. S109; [92–94]). Soleimanpour et al. [37] finds that more interventions need to be studied to understand what can best support family dynamics given the critical role of the family in adolescent development, health knowledge and decision-making.

Despite the significant role family and parents play in informing health knowledge, some parents may struggle to feel that they can contribute to their child’s well-being.

Health providers may experience that a parent's sense of control over their adolescent's eating and activities vary. A study comparing communication about food and health between high and low-socioeconomic status (SES) adolescents and their parents found that high-SES parents emphasized healthy food and quality over price and prioritized dialogue and expectations around diet [95]. Low-SES parents felt they had less control over their children's choices, that they were not modeling their own ideals of healthy eating, and were more concerned about other aspects of their child's life such as walking home from school safely. Consequently, when a family is experiencing an ACE event or disparity, it may be harder to prioritize positive health behaviors. Adolescent healthcare providers should encourage small changes to diet or exercise that a parent feels they can support since they determine access to foods [38, 95]. Supporting the parent in positive discussions around food choices and physical activity could help with adolescent health outcomes. Providers should also consider how they can support a family by advocating for safer neighborhoods, economic equity, and social justice to shift the root causes of health disparities.

Leverage Community and Culture to Foster Health Equity

An adolescent's community and culture can play significant roles in their adoption of healthy behaviors. Adolescents are influenced and directed by social and cultural norms that they must navigate when considering changing behaviors. Culturally, food is both a "substance and a symbol for social life" whereby individuals communicate their cultural identity and perspective [96, 98]. Diet is an effective way to express and "embody sociocultural significance" including individual identity, social status, nationalism, medicinal practices, and religion [96, p. 86]. The social implications of diet and food choices are important to understand when navigating discussions about nutrition. For example, foods brought to social

engagements such as a celebration or potluck can be expected to include culturally-relevant foods. Items that are perceived as “healthy” by providers may be actively rejected if they do not comply with cultural expectations. Studies looking at Mexican-American adolescents found that familial and cultural norms define what foods are considered “healthy” and interventions that do not address culturally-based health knowledge may be less successful [21, 91].

In fact, treatment plans that do not include culturally-based foods can be interpreted as ineffective or incomplete. For example, a study looking at the perceptions of alternative medicine among Chinese immigrant parents of children with cancer found a heavy reliance on food to restore health and create balance in their bodies [97]. The study also found parents felt that recommendations of typical “Caucasian” foods such as cheese or dairy were not useful or relevant for their child [97]. Another study looking at pediatric cancer patients from diverse cultural backgrounds in Hawaii found that when youth are hospitalized for other reasons, the ability to access a traditional diet, including a space to make and prepare their own food, is believed to lead to better outcomes in healing and health [99]. Consequently, limited access to traditional foods, preparation methods, or a lack of integration into a treatment plan could impact the nutritional health of adolescents. Limiting access to traditional foods and resources can be felt as a rejection of their social identity, making it harder to support positive health changes.

Nutritional recommendations that focus solely on individual improvement may feel socially isolating and leave those who cook food feeling devalued and unable to maintain critical social connections through food [100]. In fact, Yates-Doeer and Carney [100] argue for demedicalizing nutritional health through recognition that health can be created in the kitchen and through social connections. While clinically easy to focus on a teen’s health improvement, having an “awareness of how and where prescriptive dissonances arise” including other factors that determine why and how food is made are key to navigating an adolescent’s nutritional health (p. 316).

Finally, community-based and culturally-situated programs that partner with organizations that incorporate humility into their development could be critical to supporting adolescents [78, 101, 102]. Culturally-situated programs and perspectives can help rebuild trust of the medical system in disenfranchised communities and cultural groups [78]. For example, Fleischhacker [101] has provided recommendations for registered dietitians to work in collaboration with a tribal community to promote healthy eating. Dietitians need to show sensitivity to tribally-led efforts that must address the co-existence of food insecurity and obesity, identifying both prevention and treatment strategies while being culturally-situated to ensure adoption [101]. The tribally-led efforts must foster community ownership, food sovereignty, healthier food choices, and place an emphasis on the family while combining traditional approaches with Western medicine interventions. Healthcare providers working with diverse populations can consider how engaging an adolescent's family, community, and cultural views into their treatment plan could increase adoption and improve health outcomes.

Conclusion

Adolescents who have experienced health disparities have the power to identify and implement nutritional health solutions. An awareness of health inequities and ACEs can help healthcare providers understand that health is about more than how an adolescent presents in clinic or on test results. Exploring implicit biases through a reflective practice can help facilitate a provider's understanding of how they view adolescents and consequently treat them. Healthcare providers can expose themselves to youth of diverse backgrounds and social circumstances to expand their awareness and sensitivity to health disparities as well as their own assumptions. By focusing on strength-based screenings, providers are able to determine a youth's assets and positive health behaviors.

Motivational interviewing and trauma-informed communication and practices can facilitate behavior change and emotional support. By understanding illness and symptoms within the context of a teen's cultural and personal views, providers can develop useful and meaningful treatment plans. By leveraging youth health literacy, providers can actively engage them in their health knowledge and agency. Through partnership with adolescents' families and communities and engagement in culturally-informed solutions, providers can support positive social connections and environments that promote youth healing. Engaging in advocacy at the community and policy levels can help address deep-rooted social problems that cause inequities. As gatekeepers to referrals for evidence-based interventions and support, providers can help decrease inequities by providing access to such resources.

While this chapter provides many examples of studies focused on specific ethnicities or demographics, it is important to consider that providers should promote health equity by asking questions and having curiosity about all adolescents. Ultimately, providers cannot assume what youth have experienced but can find the best in them, helping adolescents leverage their resiliency and agency to support health equity.

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Chapter 9

Food Insecurity Among Adolescents and Emerging Adults



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Introduction

Food insecurity is the lack of consistent access to adequate food to maintain a healthy lifestyle. Food insecurity can affect the mental, physical, and emotional well-being of adolescents and emerging adults. One may not consider that emerging adults, particularly those in college, are at risk for food insecurity. However, more research emerges each day about the scope of food insecurity among college students and emerging adults. So much so that in 2019, the U.S. Government Accountability Office issued a report so that universities

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could provide better support to college students struggling with food insecurity [1].

Defining Food Insecurity

The U.S. Department of Agriculture has formal definitions of food insecurity (see Table 9.1) [2]. There are two categories of food insecurity: food secure and food insecure. Food

TABLE 9.1 Food security terms and definitions

Food security category	Term	Definition
Food secure	High food security (old label = food security)	No reported indications of food-access problems or limitations
	Marginal food security (old label = food security)	One or two reported indications – typically of anxiety over food sufficiency or shortage of food in the house. Little or no indication of changes in diets or food intake
Food insecure	Low food security (old label = food insecurity without hunger)	Reports of reduced quality, variety, or desirability of diet. Little or no indication of reduced food intake
	Very low food security (old label = food insecurity with hunger)	Reports of multiple indications of disrupted eating patterns and reduced food intake

Adapted from USDA

security and food insecurity each have two categories. Within food security, there is high food security – no indicators of limited access to food, and marginal food security, which includes up to two indications around access to food. Within food security, there is low food security and very low food security. Low food security indicates lower quality diets; those that report low food security may have to choose between healthier foods like fruits and vegetables and paying for medications. Very low food security is a result of many indications of decreased access to food to the point of cutting meals, and even going hungry because there wasn't enough money for food. There is emerging evidence that the profiles of people reporting marginal food security may appear much more like food insecurity rather than food security, which may also suggest that food insecurity is underreported across the US [3, 4]. Further, while these are government-defined terms, practitioners in the field are still using older terms such as “hunger” because it is more intuitive to what families, and youth, may be facing.

Food security often – even typically – operates as a cyclical phenomenon. In agricultural societies, it tracks wet versus dry seasons and pre- versus post-harvest that directly affect local food supply [5]. In urban and rural settings alike, food security also tends to follow economic cycles that shape household income. The cyclic aspects of some nutrition assistance programs can also create or aggravate cyclic patterns of food insecurity. For example, in the U.S. household caloric intake and nutrition can shift dramatically in the weeks following monthly disbursements – the so-called “the food stamp cycle” where food intake and nutrition peak in the first few days after disbursement and hits a nadir right before the next one [6]. For U.S. adolescents dependent on free-lunch and similar school-based nutrition programs, school breaks create hunger peaks [7, 8]. This cycle may also be present among college students [9].

Measuring Food Insecurity

The U.S. Department of Agriculture has provided practitioners and researchers with formal tools to measure food insecurity. Most of the time, food insecurity is measured at the household level using an 18-item questionnaire: the U.S. Household Food Security Survey Module (HSFFM) (<https://www.ers.usda.gov/media/8271/hh2012.pdf>). This module can be asked of households with and without children (Fig. 9.1). There are 10-item and 6-item versions of the 18-item questionnaire. There is also a youth module for adolescents 12 and older. In college students, most use the 10-item adult survey. In 2010, a 2-item screener was developed and tested with families with young children and was found to have high sensitivity and specificity against the 18-item HFSSM [10]. The American Academy of Pediatrics now recommends that all youth be screened for food insecurity at well-child visits, using the 2-item screener [11]. Given the high rates of food insecurity among college students (see below) [12], one could argue that emerging adults should also be screened for food insecurity at doctors' visits as well. In addition, schools including nurses offices, may want to consider using the 2-item screener to assess for food insecurity.

- "Within the past 12 months we worried whether our food would run out before we got money to buy more."
- "Within the past 12 months the food we bought just didn't last and we didn't have money to get more."

FIGURE 9.1 Two-item screener to assess food insecurity. Affirmative response to either question suggests a struggle with food insecurity. (From Hager et al. [10])

A Note on Measurement of Food Insecurity Among College Populations

Emerging evidence suggests that some youth, particularly emerging adults in university settings, may not respond to the above USDA food insecurity modules as expected, despite seeing differences among food secure and food insecure students. Future research is forthcoming on how best to measure food insecurity with this population.

Prevalence of Food Insecurity Among Adolescents

Households with children experience higher rates of food insecurity compared to households without children. In 2017, 15.7% of families with children reported not have adequate food. Studies indicate that parents try to protect their children from food insecurity; in some households, only the adults are food insecure. However, according to USDA, 7.7% of children in the use report food insecurity [13]. Youth Risk Behavior Survey data suggests that 12.8% of adolescents report food insecurity [14]. The National Health and Nutrition Examination Survey also collects data on food insecurity; those data indicate that 31% of adolescents reported food insecurity [15, 16]. The acute and chronic cycles of food insecurity among adolescents is unknown.

It is well understood that parents attempt to protect their children from the effects of food insecurity, often by cutting back on their own food intake [17]. Adolescents living in food insecure households report lower prevalence of food insecurity as compared to their parents [18]. However, the effects of food insecurity still trickle down to most food insecure youth [18].

Food Insecurity Among Emerging Adults and College Students

University campuses, particularly those serving a diverse student base, have been revealed recently as sites of surprisingly high levels of food insecurity [12]. The transition to college creates new challenges related to growing independence that impact food security, including living away from family, developing new social support networks, sourcing and preparing meals, and managing finances. Studies have identified food insecurity as a rising and sometimes serious issue for college students. A review of peer-reviewed and grey literature found average rate of food insecurity of 35–42%, including 32.9% for U.S. studies in particular (range = 14.1–58.8%) [12]. Risk in the U.S. appear to be elevated among U.S. Black, Hispanic, and Pacific island compared to white or Asian students [19–21]. Food insecure students are reported to be more likely to live away from home (including on campus), be working while attending classes, and receiving financial aid. Rates of severe (very low) food insecurity had an average prevalence of 18.1% (range = 8.9–26%). These high numbers make sense, given that in the last several years' universities have become both accessible to diverse (e.g., first generation) students and that the costs of attending (especially tuition) have risen dramatically [22].

Food insecurity for college students has been shown to peak at the end of the semester [9], although only first-year students have been followed. For many, leaving home for the first time means new challenges to feed themselves, manage loans and finite cash resources, gain and manage part-time employment, engage new social networks and forms of peer support, and learn new social norms (including around food and eating). Those living on a semesterized campus in the US, they also now newly inhabit a world shaped by regular cycles of resources and academic and social expectations and stressors. They arrive in fall to start the school year, when Pell grants and other financial aid are

dispersed. Academic workload and financial stresses tend to converge at the end of semester. They then typically return homes over winter break. The same cycle then repeats again through the spring.

In considering campus health, the findings also need to be considered in terms of a recent USDA report proposing that food insecurity may better reflect chronic disease among adults than income [23]. Food insecurity was associated with ten chronic diseases, whereas income was associated with only three of the same diseases assessed. Campuses have complex algorithms that predict students' success; food insecurity may be another indicator that can be measured to fully understand the likely trajectories of student well-being.

Food Insecurity and Mental Health

A recent review concludes food insecurity is associated with worse mental health, independent of SES, in consistent ways across the globe [24]. Worry and stress over how to get enough food can trigger mental illness [5, 25], as can the feelings of shame and stigma that come with not being able to provide the right amounts and types of food to meet social expectations. Associations have been demonstrated between food insecurity and worsened mental health especially for those living in poverty [26, 27], including adolescents and emerging adults [12, 28, 29]. The effect of food insecurity on mental health cannot be understated. Youth who report food insecurity are also more likely to report suicide ideation [30–32]. The stress and anxiety of not knowing where your next meal is coming from, and stigma associated with poverty are the most consistent adverse effects documented in relationship to food insecurity [12, 29]. When adolescents and emerging adults are screened for mental health, food insecurity should be assessed in addition to mental health resources, food assistance may be needed.

Food Insecurity and Eating Behaviors

The behaviors practiced among youth set the stage for behaviors later in life [33, 34]. Research indicates that adolescents and emerging adults are known to have poor eating behaviors [35–42], consuming high amounts of fast food, sugar-sweetened beverages, and low amounts of fruits and vegetables. On average, less than 10% of adolescent youth meet the dietary guidelines for fruit and vegetable consumption [43]. Despite the already poor eating behaviors characteristic of this age group, adolescents and emerging adults who report food insecurity also report poorer eating behaviors as compared to their food secure counterparts [19]. Specifically, research has shown that food insecure youth tend to report higher levels of fast food, higher fat intake, lower frequency of breakfast and family meals [5, 19, 44–47]. Beyond that, food insecure youth are less likely to report lower positive perceptions of healthy eating. These patterns of poorer eating behaviors are also reported among parents of adolescents [48], suggesting a need to intervene with both parents and their adolescent and/or emerging adult offspring.

Food Insecurity, Weight Change, and Overweight

Food insecurity and weight change are inextricably linked. In western culture settings, food insecurity and obesity have been proposed to work paradoxically, in that those who are less food secure accrue elevated risk of being overweight/obese over time. The most often cited example of this is adult women receiving U.S. nutrition assistance [49, 50]. Some studies have also linked food insecurity among adolescents to weight gain and risk for obesity [51–53], although the overall literature is mixed [50]. For recipients, food insecurity is observed to operate in monthly cycles that track aid dispersal.

In the first few days, food availability and quality peak, and then across the month some foods decay so that food insecurity peaks in the last few days. Here it is not just about quantity or even number of calories consumed [54], but rather the proposed downstream effects of such factors as reliance on higher calorically-dense, low-nutrient foods to fill a hunger gap, different eating patterns (like snacking) on weight gain through time, and perhaps appetite changes related to living with stress.

A trend toward overweight has long been identified as a characteristic of university students, starting from their arrival on campus. Conventional wisdom is that entering college students tend to gain large amounts of weight, the so-called “freshman 15.” Although really often more of a “freshman 5,” the first year of university is one in which weight change is the norm [55, 56]. Few studies have directly linked food insecurity with weight change in college populations. Given that the college student population is known to be on a weight-gain trajectory overall, it makes sense that food insecurity could in itself potentially operate as an unrecognized driver of this phenomenon. However, findings from one study suggest no relationship between weight gain and food insecurity [9].

Food Insecurity and Academic Performance

Consistent evidence links food insecurity to lower academic performance among both adolescents and emerging adults [12, 44, 57–60]. Research has shown that food insecure youth have lower self-reported and GPAs, lower reported course attendance, and higher levels of drop-outs compared to food secure youth. For example, van Woerden et al. reported that food insecure freshmen had significantly lower GPAs after one year [58]. The long-term effects of lower academic achievement among food insecure youth has yet to be stud-

ied. Retention in school and within universities, as well as post-graduation job placement, are of significant concern.

Interventions to Address Food Insecurity

National School Lunch Program and similar food assistance programs in schools offer an important safety net for adolescents who are food insecure, providing foods at free or reduced price for students in need. Students participating in school meal programs have healthier dietary intake and report lower levels of food insecurity [61–63]. Summer feeding programs provide a free meal to any youth ages 2–18 years at eligible sites. Emergency food networks through food banks, pantries, and shelves, provide free food to families in need. Food pantries on college campuses are becoming more and more common; the College and University Food Bank Alliance has created a network of university-based food pantries. Adolescents who are food insecure may also benefit from their parents or guardians participation in the Supplemental Nutrition Assistance Program (SNAP), a federal program that provides a cash equivalent for food. This program has also shown important benefits, including lower levels of food insecurity. Some studies have shown healthier eating behaviors and outcomes among SNAP recipients [64–66]. Emerging adults in college can apply for SNAP benefits; however, in order to be eligible for and receive SNAP benefits, enrolled college students have additional requirements, including working at least 20 hours per week, participation in a financed work-study program, have dependents younger than age 6 years (or do not have adequate child care that inhibits their ability to work 20 or more hours), and/or receive benefits under a Title IV-A program [67]. Part-time students and students who receive most of their meals from meal plans are not eligible for SNAP. The 2019 GAO report emphasized the need for the SNAP program to be more visible to college students, and encouraged USDA to examine and explore flexibly to enrollment requirements in SNAP for college students [1].

Food Insecurity Case Study

Jason is a first-generation college student and a junior in the chemistry department at a large public university. His parents were laid off from a factory three years ago. He lives off campus with two roommates. Jason's student loans just don't seem to be enough this year. To meet the needs of living expenses, Jason has decided to add another part-time job to his schedule: one as a research assistant in a chemistry lab and another as a server at a pizza restaurant. With the new job, Jason has been skipping class, and not doing well on exams. After midterms, Jason's organic chemistry professor, Dr. Johnson, referred Jason to his academic counselor because of his poor performance. Because of his jobs and class schedule, Jason was only able to get an appointment with his academic counselor two weeks after Dr. Johnson sent the original request. Jason shares with his academic advisor that his responsibilities at his jobs are making it difficult to get to class and complete homework. He has little energy and sometimes finds that he sleeps through class. He also mentions that he's feeling overwhelmed most of the time and having a hard time dealing with the stress. Jason's academic advisor counsels Jason on time management and refers Jason to the on-campus student counseling center. Jason drops by the student counseling center after his appointment with the academic advisor: there's nothing available until later in the day, and the available times conflict with his lab job. Jason leaves, feeling defeated. Jason tries to get an appointment two more times, and there is finally an opening on his third try, three weeks after his appointment with his academic advisor. There, the counselor completes a full assessment, including a stress and depression screening, for which Jason tests positive. The counselor is able to spend more time building rapport with Jason, asking questions, and learning of all the tasks he is attempting to manage. During this appointment, the counselor discovers that Jason also is struggling to get enough food. Jason's only consistent meals are those at the pizza restaurant where he receives an employee discount. The

counselor knows that you, as the dietitian at the student health clinic, have more experience with helping students access healthy food. The counselor refers Jason to you, and Jason is able to set up an appointment for the next day.

1. Quantify the time and the number of people that Jason had to go through to meet with you. In what ways could the barriers to care impact his physical health, future academic success, and mental health?
2. What aspects of Jason's mental health should you explore with him? Are there other co-morbidities (aside from anxiety and/or depression) to screen for?
3. You have the sense that Jason is food insecure. What steps do you take?
4. What other health issues may Jason be facing? How might his access to consistent meals be impacted by physical health concerns?
5. What are the social determinants of health that are impacting Jason? What are the multifactorial root causes to Jason's problems?
6. In what ways do Jason's past experiences, background as a first generation college student, and possible circumstances prior to attending college, impact his current state? How can you, as his current provider, address those issues?

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Chapter 10

Culturally Appropriate Care



Maya Michelle Kumar

Introduction

Culture refers to a shared collective of beliefs, values, practices, and norms in a social group. It influences our language and communication, interpersonal relationships, family dynamics, sense of purpose, spiritual beliefs, and the most fundamental elements of how we perceive the world and each other. Culture is what makes us human, and cultural interconnection is what brings us together.

It can be no wonder, then, that culture is a critical determinant of the nutritional health of every human being. Cultural influences more than merely *what* we eat; it affects *how* we eat, *when* we eat, *where* we eat, *who* we eat with, and (perhaps most importantly) *why* we eat. It also influences our beliefs and behaviors about obtaining food, food preparation, and physical activity.

It is well known that adolescence is a time of great nutritional risk. Adolescence is a period of rapid growth and development, both physical and socioemotional. Eating disorders, obesity, and micronutrient deficiency frequently

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begin or worsen in adolescence, leading to increased morbidity and mortality in adulthood [17]. But cultural differences may significantly influence which adolescents are most at risk.

Health care providers have the privilege of caring for adolescents from a broad array of cultural backgrounds and practices. Health care providers who treat nutritional disorders must recognize that nutrition-related practices may be some of the most important elements that define a culture. Cultural practices may be deeply personal and steeped in traditions that have lasted for many generations. To make matters more complex, culture is always changing and adolescents are often the key drivers of these changes. Therefore, adolescents may hold cultural identities that are different from those of their families and communities; this may make it difficult for adolescents and their caregivers to agree on what nutritional health entails. If health care providers ignore cultural influences when counseling adolescents about nutritional health, then at best they will be unable to facilitate acceptable and sustainable improvements, and at worst they will destroy their therapeutic relationships with adolescents who might be in dire need of help.

It is a common fallacy among providers that a knowledge of “traditional foods” is sufficient to provide culturally informed nutritional health care. While this knowledge may be helpful, it only scratches the surface of how culture shapes nutritional health and risks incorrectly assuming that all families from certain cultural backgrounds include traditional foods in their diets. In this chapter, we will explore the many cultural considerations that may influence nutritional health and behaviors among adolescents and their families, and how culture-related barriers to effective nutritional health care may be overcome.

Traditional Beliefs About Nutrition

Individuals all possess explanatory models that constitute the foundation of their understanding of how their bodies work [16]. These explanatory models often lead to strong beliefs

about nutritional health, which may be highly variable across cultural groups.

For example, in many Western societies, it is believed that overweight youth are ‘unhealthy’ while thin youth are ‘healthy,’ regardless of other aspects of their nutritional health. However, in many other countries around the world, it is believed that an overweight youth, or a youth with chubby cheeks or a ‘glow,’ is ‘healthy’ while a thin youth is ‘sickly’; it may also be believed that overweight children and adolescents just have ‘baby fat’ that they will eventually out-grow [11]. Ghee, oils, and butter may be considered ‘strengthening’ and beneficial for growth, and may be preferentially encouraged among children, adolescents, and menstruating girls and women [11, 14]. Fats are also believed to improve lubrication and facilitate and easier delivery among pregnant girls and women [14]. In many Eastern cultures, certain foods are considered ‘heating’ while others are considered ‘cooling.’ An imbalance in the body between hot and cold is often believed to lead to illness states, and so choosing foods to restore the desired balance may be considered necessary to treat or prevent illness.

Caregiver beliefs about nutrition is a critical determinant of their children’s nutritional health. For example, among 8–12 year olds in Greece (where thin children are traditionally considered less healthy), researchers found a positive association between obesity and living in a household where the grandmother cooks [15]. On the other hand, parents with a history of eating disorders are far more likely to have negative interactions with their children related to feeding and eating, and their children are more likely to have extremes of weight and disordered eating [28]. As another example, a European study found that teenaged girls were three times as likely to demonstrate clinically significant disordered eating attitudes if their mothers did too [29].

Other traditional beliefs that are not specifically about food and weight may still impact nutritional health. In many cultures, it is strongly believed that food should not be wasted and that children should ‘clean their plates.’ Declining food or drink that has been offered by others may be considered offensive. Belief that children and adolescents can get sick if

they play outside, or fear their safety if they leave their homes, can result in more indoor and sedentary behavior.

Health care providers may be unaware of the traditional beliefs and explanatory models held by their patients, and therefore may misinterpret or fail to understand their patients' nutritional behaviors. Worse yet, they may simply presume that patients and their families are acting unintelligently. Providers should assume that patients and their families always have a reason for their behavior, even if they don't know what it is, and should make an effort to ask patients about the beliefs that guide their decisions. The patient's explanatory models of nutrition and health can be influenced by information from a provider, just as they are influenced by culture; if the provider acknowledges the patient's beliefs, the provider can then engage the patient in an open discussion and provide new information that may change the patient's beliefs [16].

Gender Roles

Gender roles may be central to cultural practices. While girls and women have more opportunities than ever before, gender equality is not a reality in the majority of societies in the world.

In many cultures, the presence of gender inequality affects food allocation within a household [12–14]. Richer or more expensive foods may be reserved for the males of a household. It is also common for more food to be allocated to family members with the highest potential for income generation; traditionally, this results in males and/or those who engage in physical labor to receive the most food, while 'women's work' at home may be considered to require less energy. Even as women take on more responsibilities outside of the home, traditional gender-based household practices of food allocation may persist. Social hierarchy affects eating order in many cultures, with men and older family members usually being served first and younger women (e.g., daughters-in-law or younger female children) serving themselves last, which is

associated with smaller nutritional quantities and/or poorer diet quality. During periods of food shortage, women tend to have larger decreases in their nutritional intake than men.

Many traditional food beliefs, such as those discussed earlier in this chapter, specifically relate to menstruating and/or pregnant young women. For instance, 'eating down' (i.e., eating less) is a common cultural practice during pregnancy to avoid having to birth a large baby, and it is commonly believed that a full stomach is harmful to a fetus [14, 18]. On the other hand, butter and oil may be believed to increase lubrication and consequently an easier delivery, and may be considered 'strengthening' during menstruation [11, 14].

Gender inequality may affect adolescent nutritional status through changes in physical activity. Over the course of adolescence, girls appear to become less physically active than boys [4]. In many cultures, this may be because it is commonly believed that girls should not play sports or play outside but rather should be engaged in household chores [1, 11]. Even in cultures with more gender equality, researchers have found that complex gender norms may cause girls to struggle between wanting to appear strong and competitive versus wanting to appear feminine; furthermore, adolescent girl participation in physical activity may be more influenced by body image and appearance concerns, including discomfort with having to wear uniforms and being self-conscious about how one appears while exercising [27].

Body Satisfaction

Among different cultures, there may be significant differences in what body types, weights, and shapes are considered attractive or desirable. For example, a higher weight body size is considered more desirable in oneself and in the opposite sex among many Black and Latino cultural groups, and may be associated with greater wealth and/or happiness [10, 19, 26]. However, many studies demonstrate that compared to African-Americans, white and Asian-Americans are more

likely to endorse a thinner body ideal, worry more about their weight, have a stronger desire for thinness, and feel more pressure to have a thin partner [2, 5, 8, 21, 23]. Cultural variations in preferred body size and shape may greatly impact body image, risk of disordered eating, nutritional behavior, and how weight disorders are perceived.

Interactions with the Health Care System

It has unfortunately been demonstrated that with ethnic minority patients, providers are less likely than with white patients to give empathic responses, establish rapport, provide sufficient information, or encourage the patient to participate in decision-making [7, 25]. Furthermore, ethnic minority patients are less likely than white patients to be assertive or verbally expressive with their providers [25].

There are several potential contributors to this. As discussed earlier, culture has significant impact on the explanatory models that shape our perceptions of health and disease. When these explanatory models differ from those that are intrinsic to Western health care, patients and families may feel disconnected from their health care system and providers. Individuals from ethnic minorities may experience additional cultural barriers to accessing quality health care, including feeling like their values differ from their providers, cultural differences in preferred dynamics of the provider-patient relationship, linguistic barriers, and outright racial/cultural bias [25]. If these cultural barriers are not addressed, then adolescents and their families may face inequitable access to effective nutritional health care.

Acculturation

Adolescents may challenge the cultural contexts in which they spent their childhoods, and conflict with their caregivers can arise as adolescents evolve in their cultural identities. This is clearly demonstrated in their nutritional patterns.

There is evidence that adolescent nutritional health may worsen with acculturation. Individuals who immigrate to the Western world frequently experience a rapid deterioration in overall health status after their arrival, primarily related to changes in diet and physical activity; this effect appears to be most pronounced among adolescents and young adults [9]. Adolescent children of immigrants may also engage in worse nutritional habits the more acculturated they are. For example, a study of Chinese-American adolescents found that those who identified more as ‘American’ than ‘Asian’ were also more likely to indicate a preference for ‘American’ foods, which they identified as pizza, burgers, fries, cereal, spaghetti, chicken nuggets, chips and salty snacks, and soda [3].

Outside of the Western world, Westernization may similarly contribute to poor eating habits among adolescents. For example, Jamaican adolescents reporting a more ‘American’ identity and preferences were more likely to engage in unhealthy eating; furthermore, increased exposure to American cable television was specifically associated with worse food choices [6]. In Mexico, which has one of the fastest-rising adolescent obesity rates in the world, one study described that adolescents in the last decade have undergone a ‘nutritional transition’ in which there has been a decline in traditional and homemade foods and physical activity among adolescents, with an increase in consumption of processed and pre-prepared foods, sweetened beverages, and indoor screen time [1]. Perhaps most fascinatingly, in Cilento, Italy, where the original studies demonstrating the health benefits of the Mediterranean Diet were first conducted, the majority of high school students surveyed in the area adhered very poorly to the Mediterranean Diet with a far greater intake of processed and convenience foods and a much lower intake of plant-based foods [24]. The authors describe their dismay that in the land where the healthful Mediterranean Diet has its origins, “there has been a complete break in eating habits from one generation to another.”

What Providers Can Do

Awareness of how cultural elements influence adolescent nutritional health is a critical first step. There are a number of ways that this awareness can be translated into clinical practice.

Taking a History

Initial evaluations of nutritional disorders in adolescents need to include a lens into the family's cultural context. Providers should inquire about all members of the household and develop an understanding of the family structure and support system. Providers should determine the following:

- What types of foods are regularly eaten by the family, and whether the adolescent eats similar foods as the rest of the family or chooses to eat different foods
- The family's eating routine, including who eats together, where they eat, and the timing of meals and snacks
- Which members of the household take primary responsibility for procuring and preparing food
- Which members of the household participate in physical activity, and what types of physical activity are considered most acceptable for the adolescent
- Typical media and screen use by the adolescent and the family
- What body type is considered desirable by the adolescent and the family
- Gender roles within the household, and how these influence the division of 'nutritional responsibilities' at home (e.g., shopping, food preparation, and decision-making related to physical activity and nutritional health), food allocation, and the acceptability of physical activity

It is helpful to ask open-ended questions about how the adolescent and family would describe the way their culture influences their nutrition and exercise habits, whether there

are differences in cultural perspective between the adolescent and the rest of the family, previous experiences with the health care system, and who participates in decision-making related to the adolescent's health.

Optimizing Communication

For patients who are most comfortable with a language other than the provider's primary language, it is helpful to try learning at least a few words of the patient's native language, to have written materials available in multiple languages, and to have access to trained interpreters. It is important to consider that patients and/or caregivers may not be literate in any language; routinely using a variety of modalities to communicate, including pictures and diagrams, can facilitate more effective communication without causing embarrassment. Providers should remember that many elements of good communication go beyond speaking the same language: listening, attempting to paraphrase the patient's own thoughts and expressions, and checking for patient understanding [22].

Providers should consider how non-verbal communication may be interpreted differently across cultural groups. For example, physical contact and eye contact between a provider and a patient may be reassuring for some patients and uncomfortable for others; providers should consider whether a patient avoiding physical or eye contact is expressing modesty or discomfort [20].

Incorporating Cultural Humility Into Effective Nutritional Counseling

Changes to an adolescent's nutritional pattern should never be suggested before gaining a thorough understanding of the adolescent's cultural context. When proposing changes, providers should ask (and never assume) whether these changes would be culturally acceptable to adolescents and their care-

givers. Ideally the provider should engage the patient and family in developing their own solutions, acknowledging that the family is best positioned to know what would be acceptable and feasible.

The provider should acknowledge differing degrees of acculturation and/or Westernization among household members. At the same time, the provider's nutritional education should include unifying principles that can be applied to any preferred cuisine or style of eating. The value of each food group, the importance of combining food groups in appropriate proportions, the notion that there are no 'bad' foods, the benefits of eating at regular and consistent times, and the positive effects of physical activity all create 'common nutritional ground' where family members can come together. Whether an adolescent prefers to eat dosas or doughnuts, sopas or spaghetti, stir fries or French fries, these principles still apply. Furthermore, adolescents and their families should be encouraged to challenge the idea that 'Western' or 'American' diets need to be primarily comprised of calorically dense but nutritionally poor convenience foods.

It serves the provider well to learn about the strengths of a culture through adolescents and their families. These strengths may include close family relationships, respect for elders, strong social support networks, a sense of community, and spiritual satisfaction. Many of these qualities have critical influence over nutritional patterns. Family members and friends may demonstrate their love and affection by preparing food for each other; specific foods may be traditionally enjoyed during holidays and celebrations; joyful community gatherings often center around food. The provider should encourage adolescents and their families to capitalize on these strengths to optimize their nutritional health. Above all, providers should discourage the belief that enjoying food-related culture and tradition is somehow incompatible with overall nutritional health. An individual who is afraid to enjoy birthday cake at a birthday party because of concerns about 'carbs' or 'sugar' is probably detracting from their global nutritional health, which encompasses not only consideration of the nutrients consumed, but also positive and pro-

social nutritional behaviors. Caring for one's body, enjoying a variety of foods, and mindful eating are all concepts that easily bridge with cultural strengths.

It is important for providers not to be afraid to discuss attitudes, values, and practices that might be negatively impacting an adolescent's nutritional health out of fear that the provider might appear culturally insensitive. Providers should trust that they can reach a shared understanding with their patients that both acknowledges their cultural beliefs and provides helpful information that can assist their decision-making [16]. Providers should always assume that their patients are fundamentally rational and that there is logic underlying all of their behaviors. If a patient engages in a nutritional behavior that seems unhealthy, the provider needs to consider why it might be a logical behavior for that particular patient. For example, if a family believes that eating raw fruits and vegetables may cause sickness, which may certainly be the case in many places in the world, it would make sense that they avoid eating them. As such, providers should pro-actively ask their patients about the explanatory models that are the foundation of their understanding of nutrition and how their bodies work. Then, rather than trying to prove these explanatory models 'wrong,' providers should act as reassuring sources of additional information that families can use to modify or expand their explanatory models – such as discussing local water safety and how to prepare fresh fruits and vegetables so they are safe to eat.

One of the pitfalls of attempting to increase one's cultural awareness is to unwittingly begin to stereotype. It is essential for the health care provider to regularly self-reflect, to assess oneself for unconscious bias and check unfounded assumptions.

Conclusion

Establishing rapport and a comfortable clinical space with adolescents and their families is a necessary prerequisite to effective nutritional counseling and care. This is very difficult

without understanding the unique cultural backdrop of an adolescent's world. Nutritional disorders are already often sensitive issues to discuss, and lack of cultural humility only widens the divide between the patient and provider. Information about the adolescent and family's cultural influences on nutritional health must be actively sought out, not passively and incompletely learned over time. Taking time early on to do this will earn trust, dramatically improve the impact of motivational interviewing, and make it far more likely that the adolescent and family will attempt to change their nutritional behavior. Being willing to learn from the strengths of other cultures while acting as a trustworthy source of information will lead to rewarding and impactful nutritional health care for adolescents and families.

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Chapter 11

International Considerations



Preeti M. Galagali

Adequate nutrition in adolescence is a key determinant of health. Nutrition influences current, future and intergenerational health of the population. An overview of international perspectives on adolescent nutrition is discussed in this chapter.

Global Statistics

Currently, the largest-ever population of 1.2 billion adolescents inhabits the earth [1]. Maximum numbers of adolescents live in LMIC (Low Middle Income Countries). A large number of adolescents in HIC (High Income Countries) and LMIC suffer from nutritional disorders. World Health Organisation has included improvement in adolescent nutrition as a important goal in Global Strategy for Women's, Children and Adolescents' Health (2016–2030). This global strategy is a part of the newly adopted agenda for attaining Sustainable Development Goals by 2030 [2, 3].

The world is facing the double burden of adolescent malnutrition - both undernutrition and overnutrition exist concurrently. In HIC, 1 in 5 adolescents is overweight and in

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LMIC 1 in 10 is overweight. The prevalence of adolescent overnutrition is increasing rapidly in LMIC, which are currently undergoing nutrition transition from healthy traditional high fibre diet to unhealthy highly processed diet. Iron deficiency anaemia is the leading global cause of loss of disability adjusted life years in adolescents. 20.8% adolescents in LMIC and 18% adolescents in HIC have anaemia [4]. Due to food insecurity, poverty, illiteracy, chronic nutritional disorders in early and middle childhood, poor sanitation, increased prevalence of infections and helminthiasis, many adolescents are stunted and underweight in LMIC [5]. Calcium and micronutrient deficiencies like folic acid, Vitamin D, Vitamin B12, iodine and zinc are commonly detected in adolescents.

Adolescent mothers contribute to 10% of global births. 90% of these births occur in LMIC. Poor nutritional status of pregnant adolescents contributes to increased maternal and infant mortality [6]. Most of these mothers give birth to intra-uterine growth-restricted babies with poor health and increased susceptibility to both communicable and non-communicable diseases in childhood and adulthood [7]. Hence there is an intergenerational effect of maternal under-nutrition as shown in Fig. 11.1.

In the past few decades, there has been an increase in international migration including those seeking asylum and refugee status. An international migrant is a person who is living in a country other than the country of origin or birth. According to a United Nations Report, there are currently 258 million international migrants. There has been an increase of 49% compared to 2000. High income countries host almost two-thirds of all international migrants [8]. In 2017, the largest number of international migrants resided in U.S., Saudi Arabia, Germany, Russia, U.K. and North Ireland. These migrants were mainly from India, Russia, Mexico, China, Bangladesh, Syria, Pakistan and Ukraine. 7.6% of the migrants were adolescents and 14% were less than 20 years. In 2016, the total number of refugees and asylum seekers in the world were estimated at 25.9 million. Countries hosting

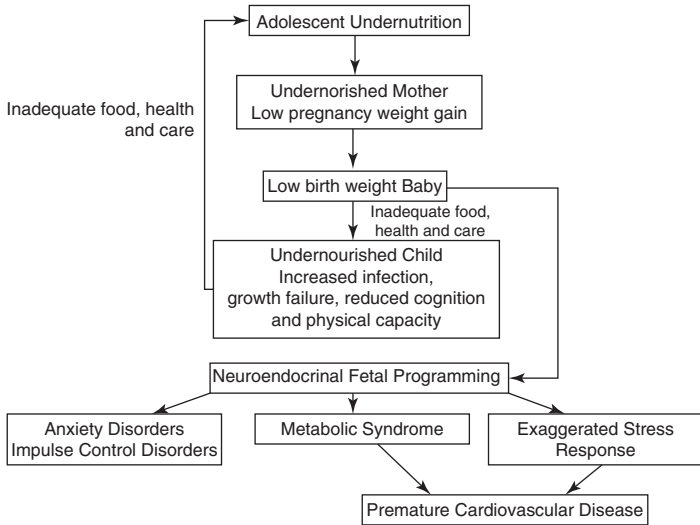


FIGURE 11.1 Effect of adolescent undernutrition over life cycle. (Source: This figure was originally published in Galagali et al. [7])

the maximum refugees include Turkey, Jordan, the State of Palestine (as designated by the United Nations), Lebanon, Pakistan and Uganda. Large numbers of refugees and asylum seekers were found in the continent of Africa. Almost half of the refugees were below the age of 18 years. People migrated to HIC to seek better employment opportunities and quality of life while refugees sought shelter in LIC to escape from violence and traumatic environments in their countries.

Migration can be stressful for families as they face the challenge of acculturation in addition to those related to economic, educational and employment issues, all of which have implications on nutrition. Unemployed migrant youth are especially susceptible to nutritional problems. United Nations 2030 agenda for sustainable development urges countries to cooperate internationally for safe, orderly and regular migration, ensure health and basic human rights and protect the migrant and refugee population against discrimination [7].

Immigration and Adolescent Nutrition

Family functioning is known to be affected by the process of immigration. The migrant families have to cope with adjustment and acculturation stressors and later adapt to the socio-cultural environment of the host country. These have implications, both positive and negative, on the health of all family members. Adolescents who are undergoing rapid biopsychosocial changes and identity crisis are particularly vulnerable to these stressors.

Immigration is an important socio-ecological determinant of health and nutrition. Nutritional status of migrants is fluid and dynamic and depends upon the social economic and political condition prior to and after immigration. Though initially, the migrant population has a healthier nutritional status, with time the health risks overtake those of the native population [9]. Studies in Europe point towards an adverse effect on physical and mental health of immigrant population while those in the U.S. report an increase in life expectancy, albeit with poor access to preventive health care and insurance services [10, 11].

It was noted that although the prevalence of obesity in children and adolescents in the initial post immigration period of one year was lower than that of native children, it later increased with the time of residence [12, 13]. The adolescents belonging to second and third generations of migrant families had a high prevalence of obesity, even more than the native population. This is known as immigration paradox [14]. This was because the countries to which migration was sought were usually of higher socio-economic status with increased dietary intake of high fat, high sugar and processed food. According to Global Burden of Disease study, prevalence of overweight and obesity in children has increased by 47.1% from 1980 to 2013 [15]. Genetics and exposure to obesogenic environments are said to influence the development of obesity.

Case Vignette

15-year old boy, an American citizen and a third generation immigrant from India presents to the adolescent health specialist with exogenous obesity and essential hypertension. His Body Mass Index (BMI) was 30 and blood pressure 140/90 mmHg. His father, the main family wage earner was obese and diabetic, died a few years ago due to myocardial infarction at 50 years. His mother, who works as a waitress in a restaurant and his 20 year old college student brother are also obese and have diabetes. His grandfather, who is 85 years old, a first generation migrant, lives with the family and has no medical problems.

This is a case of immigration paradox. The 15-year old migrant has a high risk of developing metabolic syndrome and has to undergo detailed investigations, including oral glucose tolerance, lipid profile, renal function test, serum electrolytes and serum insulin. The family history and South Asian parentage aggravates the risk of cardiovascular morbidity. The management would include history taking, including HEEADSSS psychosocial screening offering privacy and confidentiality within limits, examination and investigations. Extensive individual and family counselling would be required regarding balanced diet, regular physical activity, limited media usage and managing psychosocial stressors. Culturally appropriate counselling would motivate the adolescent and the family towards adopting a therapeutic lifestyle change. A decision to start medical therapy in the form of Metformin and/or antihypertensives would depend on the report of investigations and response to therapeutic lifestyle changes. It is important for the health professionals such as doctors and nutritionists to overcome the language barrier while counselling. Use of an interpreter would also be important to enable effective communication for empowering the adolescent and family with scientific knowledge and skills to adopt a balanced eating pattern and daily exercise regimen. The counsellor would need to be sensitive regarding culturally specific dietary preferences, economic constraints and psychosocial challenges in the form of racial discrimination that

the joint family, with a single wage-earning member may be facing in the migrant country. Teaching life skills, coping skills and adopting a problem-solving approach would enable the family to make an informed decision regarding behavioural change.

Factors Affecting Nutritional Status of Migrant Adolescents

Health care professionals attending to the medical needs of migrant adolescents must be familiar with the different factors influencing the nutritional status [7] These factors are multidimensional and complex as shown in Fig. 11.2. They include the following:

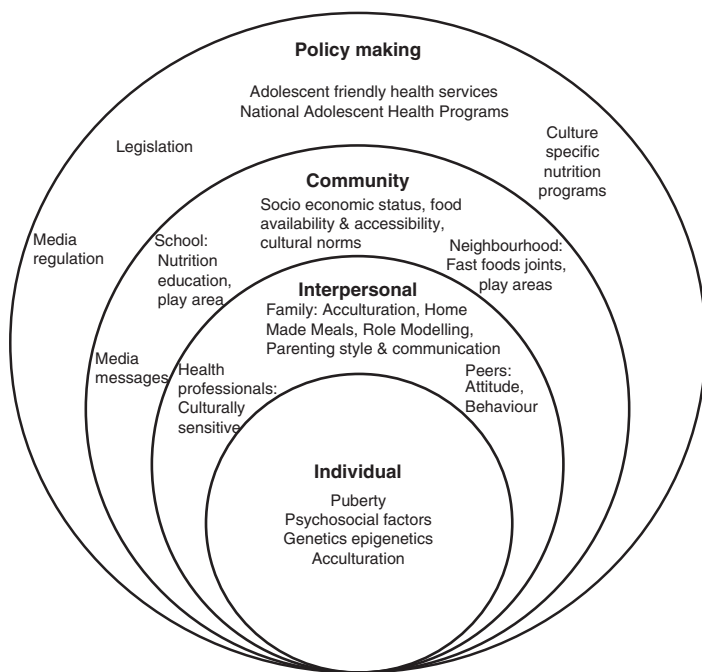


FIGURE 11.2 Factors Affecting Nutritional Status of Immigrant Adolescents. (Source: Adapted from a figure published in Galagali et al. [7])

1. Genetics and Epigenetics

Some ethnic populations may be more prone to develop obesity, such as South Asians [16]. Exposure to obesogenic environments in migrant countries may promote the development of obesity in these adolescents. Although causes of obesity are multifactorial, 127 sites on human genome are said to be linked to obesity that affect the levels of hormones like leptin, ghrelin and adiponectin [17]. According to Barker's hypothesis, small for gestation age premature babies are prone to develop metabolic syndrome later in life if they put on weight rapidly in childhood and adolescence. There is a high prevalence of premature live births in LMICs to the extent of 27% [18]. Such a migrant population is prone to develop obesity in HICs [19].

In 2004, WHO proposed that Asians should have lower thresholds for defining overweight and obesity [20]. This would have clinical implications in defining overnutrition for migrant population. Recently a few research studies have stated that such homogenisation of population in defining obesity may be inappropriate, as the risks appear to vary in different ethnic populations at the same BMI [21].

2. Socio Cultural Factors

Socio cultural factors influence both dietary habits and physical activity levels. It has been found that dietary habits of migrant populations are in general healthier than the native population. The country of origin would continue to influence dietary and physical activity levels of parents and children through media and social networks and physical visits [22]. The easy availability and affordability of high calorie, high fat and processed food in HICs influences the use and intake of 'home-made' traditional food in these populations depending on the degree of acculturation [23]. The unbalanced nutrient-poor food is consumed more by adolescents and young adults than older adults [24].

According to WHO, the highest rate of physical inactivity is seen in HICs [25]. Immigrant adolescents from LMIC may adopt the lifestyle of the migrant country and have lower rates of physical activity compared to their country of origin

[3, 26]. This could also be related to religious and cultural barriers to participation, especially for girls in outdoor physical activities, fear of racism and name-calling in outdoor facilities like parks, sports complexes and gardens [27]. Increased involvement in sedentary activities like excessive digital media use and video games due to peer influence and easy accessibility in the host country predisposes to development of obesity in adolescents [13].

3. Body Image Issues

High levels of acculturation are associated with greater degrees of dissatisfaction with body shape and weight especially in girls and women of migrant population [28]. This may result in eating disorders and poor nutritional intake. In some ethnic communities, girls are fed more calorie-dense food with onset of menarche and 'large size' is associated with better health status and marriage prospects. Such cultural practices may promote excessive weight gain resulting in obesity.

4. Socio economic Status

In the initial years of immigration, few population groups may have a lower socio-economic status compared to natives. Systematic reviews have shown that in HIC, adolescents living in families with low socio-economic status have higher prevalence of obesity [29]. This is because of easy availability and accessibility of cheap calorie-dense nutrient poor food in comparison to more expensive and healthy fruits and vegetables. Proliferation of fast food outlets in the community neighbourhood and lack of grocery stores and outdoor play facilities in the form of parks and playgrounds also promote obesity in adolescents.

5. Acculturation

Acculturation is defined as the process of moving from one culture to another. This process would include forming a new culture identity, developing social connections and adopting the language, food, norms and lifestyle preferences of the host country. Migrant populations increase acculturation with longer years of residence in the new country.

Acculturation leads to increased obesity in adults due to adoption of unhealthy lifestyle. Acculturation in adolescents may be assessed to some extent by using adaptations of adult standardised acculturation scales. A recently published systematic review of international studies on the effect of acculturation on body weight status of children and adolescents suggested variable results including positive, negative or insignificant [12]. If the adolescents were born in the migrant country with a limited exposure to the culture of country of origin, they would easily adopt the prevailing unhealthy eating habits of the host country. Physical visits and maintaining social networks through media interactions with the native country, nurtured a healthy lifestyle in migrant adolescents. Adolescents of all nationalities except Asians, migrating to the U.S. (which has a very high prevalence of obesity) had either positive or mixed effect on weight gain. There was no relationship between acculturation and weight for Asian adolescents. Adolescents migrating to Australia and Canada had a negative correlation between acculturation and weight. Hence, unlike adults, the effect of acculturation on weight is heterogeneous in adolescents and may vary with the country of origin.

6. Stress

Stress has been linked to obesity in adolescence [30]. Immigration can lead to stress in adolescents. Adolescents have to make major lifestyle adjustments to adjust to a new living environment. They also have to cope with the risks of social isolation, racism and marginalisation. These are called acculturation stressors. Adolescents are known to have physiologically poor stress management abilities. Stress overload can lead to mental health problems and disorders, which would have an adverse effect on adolescent nutrition.

7. Obesity prevention programs and accessibility to health care services

Immigrants require special effective obesity prevention programs, as those designed for native population may not be culturally appropriate. A 2014 systematic review showed

a positive effect of such programs [31]. A randomised control trial done for promoting healthy eating and physical activity in immigrant families in U.S. showed a positive effect on adults but no effect on adolescent population [32]. This was attributed to the unavailability of adolescents for counselling and intervention sessions post school hours. Hence it is important to design personalised counselling sessions for adolescents that should be delivered to them at their convenience. A U.S.-based focus group study on healthy eating habits, knowledge and barriers of migrant adolescents from Somalia, Mexico, Sudan and Cambodia revealed that adolescents preferred unhealthy calorie-dense nutrient poor food due to taste preferences, had knowledge about fruits and vegetables being healthy, and that their dietary intake was influenced by communication abilities and eating habits of the parents. Hence, it is vital to involve families in programs designed for prevention of adolescent obesity in migrants [33].

Immigrant families may have poor access to health care facilities due to lack of insurance coverage and hesitation in seeking help from culturally-different health care professionals. It is important that the health professionals provide non-discriminatory care to immigrant populations. They should be sensitive to the effect of cultural and social practices on health and should provide therapy accordingly [34]. This would form a therapeutic alliance with adolescents and their families and ensure adherence to treatment.

Nutritional Status of Adolescent Refugees and Asylum Seekers

According to the 1951 United Nations Convention Relating to the Status of Refugees, a refugee is a person who 'owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his/her nationality and is unable or, owing to such fear, is unwilling to avail

himself/herself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it'. An asylum seeker is a person seeking international protection whose claim has not been determined by United Nations High Commissioner for Refugees (UNHCR) or authorities of the host country.

Adolescent refugees and asylum seekers are vulnerable to many physical and mental health disorders, including nutritional problems [35]. The refugees are known to flee from their country of origin due to violent or traumatic conditions [36]. The poor living conditions in the native country and host country and many life stressors add to the already existing challenge of puberty and psychosocial changes of adolescence. The stress increases for unaccompanied adolescents who are separated from, or bereaving family members. This leads to increased prevalence of nutritional disorders and poor health in this subgroup of asylum seekers [37].

Case Vignette

A 16-year old girl, asylum seeker from Syria, presents to the American health refugee camp with abdominal pain, short stature, undernutrition and prolonged fever and cough. Her height is 140 cm, weight 30 kg and BMI 15. After a detailed history taking, clinical examination and investigations, she is detected to have HIV, and cavitatory tuberculosis with severe depression. Her parents are also detected with HIV and tuberculosis. She has received her last immunisation shot at 5 years of age.

This 16-year old was referred to child protection agencies as her parents were too sick to take care of her. She received therapy for depression, HIV and tuberculosis. Later she underwent cognitive behaviour therapy, nutritional counselling and received age appropriate immunization.

The reasons for the poor nutritional status of adolescent refugees include the following:

1. Food insecurity, unavailability of balanced nutrition and unfamiliarity with the food available in the host country
2. Poor socio-economic and educational status
3. Infections like malaria, tuberculosis, helminthiasis, strongyloides, gastroenteritis and sexually-transmitted infections
4. Mental health issues like acculturation stressors, discrimination due to refugee status, post-traumatic stress disorder, substance use, depression, anxiety and sexual abuse
5. Separation or loss of family members
6. Poor access to curative and preventive health services

Malnutrition, anemia, micronutrient and Vitamin D deficiencies are the common nutritional disorders seen in refugees. These have an impact on puberty, growth and development in adolescence, including short stature, cognitive function and poor fertility in adulthood. Easy availability and accessibility of calorie-dense nutrient-poor food in the host nation may predispose to overnutrition in some refugee groups.

Health professionals caring for adolescent refugees and asylum seekers have the dual role of ensuring health and seeking legal care and protection through child protection agencies. Adolescent refugees and asylum seekers need extensive evaluation of both physical and mental status. In addition, the immunisation status has to be scrutinised carefully. The management would include sensitive and empathetic history taking, including HEEADSSS psychosocial screen, detailed examination and relevant investigations to rule out infectious diseases. Treatment for physical and mental health disorders and counselling has to be individualised for each case. Vaccinations should be given according to the immunisation schedule of the host country.

Conclusion

Adolescence is a nutritionally vulnerable period of life. With large scale migration of populations on the rise and internet connectivity, the world has become a global village with the mixing of various cultures having variable impacts on nutritional status of adolescents. Health care professionals should keep themselves abreast of advances occurring in the field of adolescent nutrition due to these widespread complex changes in socio-ecological determinants of health. International and national governmental and non-governmental agencies, health care professionals, lawyers, child protection and educational agencies, religious and community leaders, parents, teachers and youth groups, should cooperate and coordinate to advocate for adolescent health and nutrition at multiple levels and forums. Adequate and appropriate nutrition in adolescence will ensure optimal health over the entire life span and for the future generations.

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Chapter 12

Health at Every Size®



Lauren Rice and Lauren Collins

Brief Introduction to Health at Every Size

The Health at Every Size (HAES) approach is one that challenges the traditional weight-centered approach to treating patients and clients. It is founded on the belief that measures of body weight and size alone are not appropriate indicators of an individual's health status. Rather, the HAES approach focuses on helping patients and clients of all sizes in developing health-promoting behaviors. It aims to promote size-acceptance, to end weight discrimination, to lessen the cultural obsession with weight loss and thinness, and to promote respect for the diversity of all people regardless of their shape, size, health condition, or ability level [2].

The HAES approach is guided by five principles developed and trademarked by the steering committee of the Association for Size Diversity and Health (ASDAH). The

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principles initially appeared on the ASDAH website in 2003 and were redeveloped in 2013 to incorporate a social justice perspective and consideration of access concerns.

The Health At Every Size® Principles are:

1. **Weight Inclusivity:** Accept and respect the inherent diversity of body shapes and sizes and reject the idealizing or pathologizing of specific weights.
2. **Health Enhancement:** Support health policies that improve and equalize access to information and services, and personal practices that improve human well-being, including attention to individual physical, economic, social, spiritual, emotional, and other needs.
3. **Respectful Care:** Acknowledge our biases, and work to end weight discrimination, weight stigma, and weight bias. Provide information and services from an understanding that socioeconomic status, race, gender, sexual orientation, age, and other identities impact weight stigma, and support environments that address these inequities.
4. **Eating for Well-being:** Promote flexible, individualized eating based on hunger, satiety, nutritional needs, and pleasure, rather than any externally regulated eating plan focused on weight control.
5. **Life-Enhancing Movement:** Support physical activities that allow people of all sizes, abilities, and interests to engage in enjoyable movement, to the degree that they choose.

What HAES Is Not

This HAES paradigm shift represents a new approach to nutrition counseling and interventions that has been met with both support and skepticism in the healthcare community. It is unlikely that providers have received robust training to thoroughly understand the HAES paradigm, which highlights the importance of understanding what HAES *is not*, as outlined by these common myths.

Myth #1: An individual is healthy at every size

A HAES-informed approach is not one in which individuals are deemed healthy at every size. Rather, it promotes that individuals can be healthy across a broad spectrum of weights. There are individuals in smaller and larger bodies who received a diagnosis that would benefit from some changes to their health behaviors. The HAES-approach focuses on helping an individual change their behaviors - while considering their individual circumstances, unique abilities, motivation, and available resources - rather than pathologizing their weight or size.

Myth #2: The HAES approach disregards eating habits and choices

A HAES-informed approach appreciates the importance of nutrition education and interventions, but does not promote restrictive diets for weight loss. There are certainly specific situations in which a more prescriptive diet is necessary, but the overall goal of nutrition interventions using a HAES-informed approach is to teach a patient or client how to honor their body's internal regulators of hunger and fullness. A patient or client will not feel energized and satisfied if they only subsist on kale, nor will they feel energized and satisfied on a diet consisting of only chocolate. That goal of a HAES-approach to nutrition counseling is to guide a patient or client in learning to fuel their body in such a way that makes them feel good.

Myth #3 HAES is just a new diet/approach to weight loss

The language of body positivity and HAES is often co-opted by companies promoting a variety of products. Diet companies utilize terms like “wellness” or “lifestyle change” in an attempt to separate themselves from the deprivation inherent in intentional weight loss, while still promoting dieting as the overall goal. A HAES approach recognizes that people don't have full control over our weight, and that intentional weight loss/attempts at controlling weight in the past may have led to increased weight and poorer health over time [3]. The HAES focus on health-promoting behaviors, such as

moving our bodies in ways that are enjoyable and fueling our bodies in response to hunger and fullness cues, acknowledges that we have some control over our bodies. However when health-related behaviors are prioritized, sometimes people gain or lose weight as a side-effect of these changes; sometimes weight remains the same. Not promising weight changes allows HAES providers to remain weight neutral and support the patient in improving their overall wellbeing, including developing a positive relationship to food, discovering joyful movement, acknowledging and working to end weight bias and discrimination, and focusing on emotional and social needs, to name a few.

Myth #4 HAES is anti-weight loss

While focusing on positive behavior changes using a HAES-informed approach, a patient/client's weight may stay the same, decrease, or increase. Weight loss as an outcome of participating in joyful movement, honoring hunger and fullness, eating for physical and emotional wellbeing, and caring for themselves, is simply an outcome and should not be labeled as "good" or "bad." A patient should be praised for their efforts to change their behaviors to better care for their bodies, not praised for their weight loss.

Myth #5 HAES is just "giving up"

The idea that by not engaging in intentional weight loss one is "giving up" on their health is predicated on the belief that the only way to show care for health is through constant attempts to manipulate weight. Often patients may think that if they aren't maintaining or losing weight they have no indicators for their health status. HAES encourages letting go of short-term weight loss, diet cycling and body dissatisfaction and fosters respect and acceptance of one's own body in the present moment. People with a strong sense of self-respect are more likely to take care of themselves and change their health behaviors in positive, sustaining ways. People do not tend to take care of things they hate, and shame and self-loathing do not foster lasting positive changes in caring for one's body and health.

Myth #6 HAES is only applicable to people in larger bodies

While the HAES principles were formulated within the context of the fat acceptance movement, people of all sizes attempt to manipulate their weight in the pursuit of health. It is impossible to determine an individual's health status based on their size alone as people of all sizes range in terms of measures of metabolic health. Although there are no current standard criteria for defining "metabolically healthy," some criteria used in research include absence of metabolic syndrome, insulin resistance, hypertension, diabetes, or dyslipidemia [21]. Data indicates that 29.2% of men and 35.4% of women classified as obese according to BMI are metabolically healthy. In contrast, 30.1% of normal-weight men according to BMI and 21.1% of normal-weight women according to BMI exhibit cardio-metabolic abnormalities [41]. HAES offers a path towards body acceptance and health promotion for anyone looking to improve overall health outcomes.

A HAES approach may need to be modified for people recovering from anorexia. Due to the unreliability of internal hunger and fullness cues, these patients are not initially able to incorporate an intuitive approach to eating and movement. While weight gain is not a specified goal of treatment utilizing the HAES framework, increased nutrition and improved mental health outcomes do fall within HAES principles. Ultimately the HAES model is appropriate for people of all sizes due to its focus on personal health choices within the context of one's physical, social, spiritual and emotional needs, rather than the singular goal of controlling weight.

The Normalization of Body Diversity

In the traditional weight-centered approach, providers may assume that patients living in larger bodies lack self-control and willpower, over-eat, and do not participate in physical activity. This approach fails to acknowledge the large and natural diversity of body shapes and sizes and dangerously perpetuates the assumption that thin is healthy. Providers

have an opportunity to normalize dramatic changes to the body during adolescent growth and development. During adolescence, 50% of adult body mass is gained as bone and muscle mass increase, blood volume expands, and the heart, brain, liver, kidney, and lungs increase in size [8].

Limitations of BMI as an Indicator of Health

Body Mass Index (BMI) is the most widely-accepted metric for categorizing body fat mass among individuals and assessing disease risk. While BMI is frequently referenced by providers and in health literature for ease of classification, BMI is limited as an indicator of health. The measurement of BMI fails to take into consideration an individual's bone mass, fat mass versus muscle mass, or overall build (broad or narrow) [25]. For example, two individuals of the same BMI could have drastically different body compositions. Regardless, an elevated BMI is likely to prompt a conversation between patient and provider regarding the individual's weight and a recommendation to reduce weight.

Without proper nutrition education, adolescents may turn to unhealthy means of attempting to lose weight. In a cross-national study conducted in conjunction with the World Health Organization, 76–98% of adolescent girls (ages 13–15) classified as overweight were either trying, or felt that they should, lose weight. In contrast, 19–64% of adolescent boys classified as overweight considered their weight to be fine or wanted to gain weight. More commonly used weight loss practices included increased exercise and reduced intake of sweets. Less commonly reported tactics included fasting, vomiting, diet pill, laxative use, and an increase in smoking [26].

Although weight loss attempts in adolescent populations may contribute to positive health outcomes, it may lead to restrictive eating, disordered eating, or a diagnosable eating disorder. Traditional nutrition counseling for adolescent patients classified as obese according to BMI standards focuses on achieving negative energy balance and weight loss

over time through energy restriction. Ample available evidence shows that restrictive dieting is ineffective in the long term and may lead to additional weight gain that exceeds a person's weight prior to restriction, increased body dissatisfaction, increased food and body weight preoccupation, increased disordered eating behaviors, development of eating disorders, low self-esteem, and feelings of shame and guilt [10, 20].

Accessibility of a HAES Approach

While a review of clinical trials comparing a HAES approach to a weight-centered approach shows an improvement in physiological health markers such as blood pressure and serum lipids, improved health behaviors such as increased physical activity and normalized eating, and improved psychosocial factors such as mood, self-esteem, and body acceptance [4], its clinical implementation should not be a “one size fits all” approach. Just like any intervention, its mileage and rate of success may vary based on multiple patient factors. One of the biggest challenges in implementing a HAES approach is patient access to a variety of foods and physical activities they may enjoy. Many provider suggestions may be based on a middle class, white, able-bodied point of view that does not translate to a patient and their family's lived reality. In its discussion of HAES principles, ASDAH makes mention of this fact in the Q&A, noting that economic access and environmental safety directly impact an individual's ability to be “eating for wellbeing” and engaging in “life-enhancing movement” (principles 4 and 5) [2]. Living in poverty often results in food insecurity, abiding by food purchasing restrictions, limitations, and conditions required by programs such as the Supplemental Nutrition Assistance Program (SNAP), living in neighborhoods lacking grocery stores, recreational activities, paved sidewalks or safe parks and outdoor spaces for play, environments that may not be safe due to violence and disproportionately high police presence, and parents working multiple jobs, often at low wages and with few benefits. When

consumed with the challenges of daily survival, asking patients and families to explore what foods are nourishing for them, and if there is a gym in their area they can afford and attend, is not only ineffectual but may also harm the patient-provider relationship.

Family views of what constitutes healthy eating and activity behaviors vary and are heavily influenced by not only access, but also caregiver views and historical family eating patterns. Younger children learn appropriate food groups and amounts from family norms, and can internalize shame if they do not adhere to standards set by parents and other family members. Denial of food as a child will impact how adolescents view eating and food variety as they age, including restriction of certain food groups labeled as negative (i.e. carbohydrates, sugar, etc.) The prioritization of physical activity, types of activities, who in the family engages in these activities, and whether they are discussed in a punitive way can affect adolescent willingness to engage in movement joyfully and consistently. Division of labor in the home in regards to childcare, food preparation, and communication impacts if caregivers are present and willing to consistently promote HAES to children. If a particular parent or caregiver primarily meal plans, shops for food, and prepares meals, their views of what constitutes an acceptable amount of food to prepare/eat can hold sway in both overt (i.e., verbal comments noting when a child has “eaten enough” of a meal or food type) and covert (i.e., only making a certain amount of food that caregiver deems adequate) ways. Providers may primarily work with the caregiver frequently available for appointments, but this may not be the person primarily in charge of feeding the family. As with other health interventions, viewing and working with the entire family as a unit of change ensures the best possible outcomes.

Cultural factors impact willingness to engage with HAES principles as well. While still a burgeoning field, research on implementation of HAES interventions in a variety of populations is still lacking. What research has been done indicates a need for tailored approaches. For example, in a study of

Latina/Latino immigrant communities resettled in the United States [12], parent participants showed interest in HAES principles but noted many cultural factors that pose challenges. Eating all food presented on the plate as a sign of respect limited the ability to stop at satiety, and a cultural tradition of mothers “putting their family first” made it difficult for them to prioritize their own health needs. Participants also noted that available foods and diet were more healthful in their home countries, and that in the United States their income went further purchasing cheaper foods with less variety. In this sample, job schedules did not allow parents time at home to prepare food or time at work to eat, and the long working hours, commute time, and heavy physical labor left parents unable to realistically promote many HAES approaches in the time they spend with children at home. Other cultural and identity considerations in promoting HAES include a patient’s location (rural or urban settings and resulting environmental differences), racial and ethnic identity, the importance of certain cultural foods and eating practices (including those with spiritual or religious connotations), their ability status (including physical, developmental, and mental health), gender identity and comfort in one’s current body and gender expression, and prior or current experiences of stigma based on any individual or family identity. Exploration of socioeconomic, familial, and cultural factors ensures a more tailored approach that meets adolescents and families where they are in the moment, and allows families to incorporate HAES principles into their lives in meaningful and sustainable ways.

Weight Stigma

Stigmatizing behavior based on someone’s weight is considered acceptable in many personal, familial, community, and social spheres. Adolescents experience weight stigma in a variety of settings, impacting their self-esteem, social ties, and physical and emotional health. Weight-based harassment by

peers is the most prevalent form of harassment reported by adolescent girls, and the second-most common by adolescent boys [6]. In a 2012 study by Puhl & Luedicke, 29% of adolescents reported weight victimization, of which a substantial proportion (65%) had a BMI in the normal-weight range. With the developmental importance of acceptance by a peer group during adolescence, weight-based bullying from peers plays a strong role in a teen's understanding of the acceptability of their weight. Weight stigmatizing behavior from peers is seen consistently across all weight categories [9], highlighting the message to teens that almost no body size or weight is acceptable to one's peer group.

School is another site of stigmatizing views of weight. While it may be considered an appropriate location for weight-based interventions there is little proven efficacy. In a study of junior and high school teachers and health care workers, those interviewed believed obesity was primarily under individual control; larger-size people are untidy (20%), more emotional (19%), less likely to succeed at work (17.5%), more likely to have family problems (27%); larger sized persons are undesirable marriage partners (46%); and that becoming fat is one of the worst things that could happen to a person (28%) [24]. Assigning these attributes to larger-sized children can result in differential treatment and attributing certain student outcomes to weight instead of the entirety of a student's psychosocial situation. Schools in about a dozen states are increasingly utilizing weight-based tactics such as sending "BMI report cards" home to parents of children in higher weight categories as a way to single out these children as unhealthy and in need of family intervention, regardless of family views of their children's health behaviors or the child's current health measures.

Research on the effects of weight stigma on teen health and well-being indicate a wide variety of negative health outcomes. The Fig. 12.1 illustrates the effects of weight stigma on adolescent health that have been studied so far.

Internalized weight stigma is a particularly challenging effect for adolescents, as it describes a variety of behaviors

Chronic stress response [23]	Psychological distress [29]
Poor social and emotional adjustment/loneliness [25]	Fewer friends [35]
Disordered eating [26]	Somatic symptoms (in girls) [19]
Increased depression, anxiety, substance use, self harm (after accounting for age, sex, BMI, and age of onset) [5; 8; 16; 18; 35]	School avoidance/worse grades [35]
	Internalization [29]

FIGURE 12.1 Effects of weight stigma on adolescent health (*Citations included in Figure*)

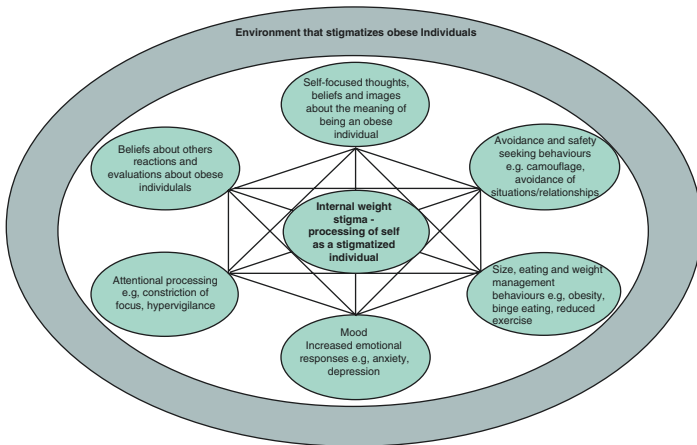


FIGURE 12.2 Process of internalized weight stigma (Ref. [35])

that reinforce a teen’s view that their weight (and, by extension, themselves) is inherently problematic and in need of correction. Ratcliffe & Ellison [35] note the various co-occurring behaviors that define internalized weight stigma in Fig. 12.2.

In health care environments, weight stigmatizing behaviors often result in maladaptive approaches to health by patients.

The following effects have been shown to result from experience with stigmatizing health care environments:

- Decreased preventative health care services; delay in breast and gynecological exams [11]
- Appointment cancellations [27]
- Ineffective or harmful weight management strategies; exercise avoidance, disordered eating patterns, increased calorie consumption [33, 36, 38]
- Inappropriately calibrated drug doses [23]
- In adolescents, a preference for sedentary, isolative-type activities [16]

Parents are also impacted. In a 2011 study, when parents were asked how they would react if a doctor referred to their children's weight in a stigmatizing way, 34% surveyed would switch doctors, and 24% would avoid future medical appointments for their children [3]. As health care clinicians, incorporating non-stigmatizing approaches such as HAES is critical to ensuring that patients trust and utilize health care services, and feel affirmed in the health choices they make.

Provider Bias

A barrier to incorporating a HAES approach is the prevalence of anti-fat attitudes found across the health care spectrum. Providers live and work in the same society that stigmatizes people of a larger size and are not immune to the effects of weight bias. Recent literature indicates that many medical doctors view large patients as unattractive, difficult to work with, non-compliant, sloppy, lazy, dishonest, unintelligent, inactive, weak-willed, showing poor hygiene, and unpleasant to touch [18, 31]. Physicians spend less time and engage in less discussion in office visits with patients with a higher BMI and are more reluctant to perform preventative health screenings [13]. These attitudes are found in medical students as well, with adjectives used to describe larger patients, including unattractive, ugly, noncompliant, lazy,

sloppy, out of control, and more personally responsible for presenting complaints [1, 29, 40]. Dietetic students and registered dietitians report negative attitudes towards obesity, with a study by the American Dietetic Association finding beliefs that larger-sized people are seen as indulgent, lacking willpower, and having a higher incidence of family problems [22]. A quote from a study of dietitians [37] expresses the frustration that many in this field feel in working with larger-sized clients: “and this situation repeats itself, this frustration of people coming and not losing any weight. This frustration of knowing that I did my best, and I kept my end of the deal, and now it’s your turn [the patient’s]” (p. 771). Larger-sized people also experience provider bias when seeking mental health treatment. In clinical judgments among mental health workers, larger-sized clients are most frequently assigned negative symptoms compared with “average weight” clients including on a variety of dimensions of psychological functioning [39]. Therapists are more likely to diagnose an eating disorder and to set goals like “improve body image” and “increase sexual satisfaction” for higher-weight clients, even when clients did not express concerns about either [15].

Patients bear the brunt of weight-based microaggressions from clinicians and the clinical environment. The term microaggressions was initially coined by psychiatrist Chester M. Pierce, MD, in the 1970s in the context of experiences of racism by people of color. In regards to weight, microaggressions are brief and commonplace daily verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative slights and insults toward people of a larger size (definition modified from Columbia professor Derald Sue). Examples of microaggressions from providers include: using sizeist, alarmist language such as “obesity epidemic” and “unhealthy weight;” equating weight with physical and/or mental health; engaging in patient stereotyping (i.e., automatically seeing larger patients as non-compliant, undisciplined, etc.); praising larger-sized patients for doing things that would be labeled unsafe or disordered in slimmer patients; complimenting

weight loss without knowing the cause; assuming larger patients are engaging in self-care practices; assuming weight loss as a patient goal without consulting the patient; supporting partners or family members who shame higher-weight patients; and failing to educate oneself about how activities of daily living, family life, parenting, sex, etc., might need to be adapted for patients with larger bodies [15]. Clinical environments are often designed to be inaccessible and hostile spaces for larger-sized patients. Scales, scanners, M.R.I. machines, blood pressure cuffs, and needles may not accommodate larger-sized patients, or patients may be forced to wait while the appropriate medical supplies are found. Images used in pamphlets, posters, and other clinic materials often only feature thin and able-bodied people and send the message that they are who is healthy. Patients may not be able to fit in standard waiting room or clinic rooms chairs. The message sent to larger-sized patients is that they do not belong in the clinic space and cannot expect to be treated with the same respect and consideration as thin patients.

The provider's size and weight also impact patient experience of clinical care. In a study looking at the effect of physician weight on patients' provider selection, trust in that provider, and willingness to follow medical advice, study participants were more likely to follow medical advice and not change providers if the provider was perceived as normal weight, regardless of the participant's own body weight [24]. However in a survey of overweight patients, participants more strongly trusted diet advice from primary care providers they perceived to be overweight when compared to providers with a BMI in the normal weight range [5, 32]. It may be easier for larger-sized patients to trust advice from providers in bodies that appear similar to their own. Conversely, clinicians with thin bodies may be perceived as lacking understanding or awareness of the challenges of living in a stigmatized larger body, even as patients may also equate thin bodies with health and view slimmer providers in a more favorable light due to internalized weight stigma.

Limitations of a HAES Approach

As a health promotion approach, the literature suggests HAES can be effective at the individual level. However, it is important to not overstate HAES research as these studies do have limitations in regard to intervention study size, design, and generalizability to other populations. As noted in Penney & Kirk [28], existing HAES studies tend to comprise of small sample sizes, limited evaluation of physiological outcomes, inclusion of individuals with BMI within the overweight and class I (low-risk) obesity range rather than medium- or high-risk classes, a tendency to focus on individual characteristics to the exclusion of environmental influences, and samples mostly comprised of white female participants with a history of binge eating or chronic dieting in Western cultures. There is little data speaking to the scalability of the intervention to the general population as a public health intervention, and focusing on individual health behaviors can overly simplify what is in fact a complicated interplay of environmental, community, family, and individual factors that impact one's access to health promotion behaviors and overall health outcomes. HAES approaches do show promise, but we should remain cautious about generalizing these results beyond their intended target populations. It should also be noted that at the time of publication, there was no available HAES research on adolescent patient populations.

Suggestions for Implementation of HAES in Nutrition Visits (Fig. 12.3)

In addition, language usage with patients of a larger size is another avenue where providers can make small changes that result in a higher level of patient engagement in treatment. Many of the terms used to describe patients with a higher weight are perceived as stigmatizing, and also attempt to medicalize what some would argue is a natural diversity of

HAES Principle	Suggestions for implementation in nutrition visits
Weight Inclusivity /Respectful Care	<ol style="list-style-type: none"> 1. Pay attention to your own weight bias and work to challenge those thoughts. 2. Do not assume that a patient in a larger body would like to lose weight 3. Do not assume that a patient in a larger body does not have an eating disorder 4. The focus of visits should be on helping the patient change their behaviors, not on changes to the scale 5. Discuss rationale, evidence, and concept a paradigm shift to a non-diet approach 6. Do not comment on a patient's body in any capacity
Health Enhancement	<ol style="list-style-type: none"> 1. Focus of visits should not only relate to diet. Consider asking questions about: factors affecting access to food, appetite patterns, stress levels, home environment, history of dieting/weight loss efforts, perceptions of body image, cultural practices and beliefs around food, etc.

FIGURE 12.3 Suggestions for implementation of HAES in nutrition visits

Eating for Well-being	<ol style="list-style-type: none"> 1. Normalizing hunger and cravings 2. Emphasize that “normal eating” includes eating for hunger, satiety, nutritional needs, and pleasure 3. Promoting messaging that all foods can fit in a healthy diet and food variety can promote overall health 4. Guide patients in helping them learn to listen to and recognize their own hunger and fullness cues 5. Acknowledge that learning to become an intuitive eater is a privilege
Life-Enhancing Movement	<ol style="list-style-type: none"> 1. Encourage patients to engage in physical activity that is enjoyable and accessible to them

FIGURE 12.3 (continued)

sizes and body types. Using “person first” descriptors is often the most supportive way to refer to patients with certain body types and puts their individuality ahead of their body size. A list of stigmatizing terms and preferred terms (delineated by those who have experienced stigma based on their weight) is included in Fig. 12.4.

Usage of preferred terms in the clinical encounter also models and normalizes these preferred terms with adolescents and families, potentially mitigating the use of stigmatizing language in the home and amongst teen peers.

One challenge in the adoption of preferred language is the use of stigmatizing terms in standard charting as well as for

Stigmatizing Terms	Preferred Terms
Obese	“Overweight/obese according to current BMI standards”
Overweight	Healthy Weight
Skinny	People of larger size
Unhealthy Weight	Larger-bodied
Healthy Weight	Slender-bodied

FIGURE 12.4 Terms used in the clinical encounter

insurance billing purposes. While overhauling entire documentation systems may be out of the scope of one’s individual practice (but can be a source of continued advocacy), focusing on the aspects that are patient-facing can help patients to avoid feelings of shame and disengagement. For example, listing a patient’s BMI category and/or delineating “obesity” as a diagnosis on their post-visit summary takes the focus away from measurable health outcomes and defines their quality of health solely within their weight. Many documents provided to the patient may list their height and weight by default, which can be triggering for those with eating disorders or chronic dieting/weight cycling. If the provider has clearly and compassionately engaged with the patient regarding their health goals and behaviors, utilizing stigmatizing language in patient-facing documentation could undo much of that positive rapport and overshadow any health behavior gains the patient has made.

In 2017, the American Academy of Pediatrics released recommendations for pediatricians in response to the high rates of stigma experienced by children and adolescents with obesity [30]. They highlight several areas for potential improvement in clinical practice, including role modeling, clinical documentation, the clinical environment, behavioral health screenings, language and word choice, and the implementation

of a HAES approach with patients. Behavioral health screening is an important component of adolescent care, and especially pressing with patients of a larger size who experience emotional comorbidities associated with higher weight, including bullying, low self-esteem, poor school performance, depression, and anxiety [7, 14, 17]. For patients who seek wellness or weight management services, the precipitating event in seeking care may in fact be bullying from family, peers, or others in the community, not acute medical concerns or their own dissatisfaction with their weight. Addressing stated patient concerns, and setting related goals, allows the patient to feel heard and acknowledged instead of shepherded into dieting or exercise as a panacea to social and emotional challenges.

One additional approach recommended by the American Academy of Pediatrics that bears a closer look is utilization of behavior change counseling such as motivational interviewing. Motivational interviewing is a directive, person-centered counseling style for increasing intrinsic motivation by helping patients explore and resolve ambivalence [23]. This evidence-based approach to health behavior change is collaborative in nature, and acknowledges that the provider does not ultimately have the power to make patient change happen, but is able to explore with the patient what changes feel appropriate and attainable in the moment. The use of motivational interviewing is especially critical during adolescence when developmentally, they are seeking autonomy and independence. When patients are ambivalent, or have opposing feelings about a particular behavior change, they are more likely do the *opposite* of what is recommended if they are directed down a particular path. A major component of motivational interviewing is reflecting back what the patient has said in order to acknowledge that they are the experts of their own experience and the answers are found within themselves, not from an outside provider. True reflection of what the patient says, and not the meaning that a provider may place on the patient's words, requires some initial practice but ultimately strengthens rapport and a patient's exploration of their own motivations for behavior change.

Finally, creating a clinic environment that is non-stigmatizing to patients of different sizes requires a close look at the overall staff culture as it pertains to bodies, food, exercise, and notions of health. It is challenging to utilize a HAES approach with patients and then step into staff spaces that feature food moralizing, diet talk, and body dissatisfaction. Providers live in the same thin-centric weight-focused culture as patients, and addressing our own views of food, exercise, and weight is an integral part of the work of supporting patients of all sizes. One way to initiate this culture change is to create communal staff standards around food and weight talk in staff spaces, and revisit them consistently. Leadership can signal the importance of this work by prioritizing time, space, and resources. Staff might consider avoiding moralization of foods in the professional environment (i.e., staff not referring to their or other's food as healthy/unhealthy, good/bad, etc.), not discussing diet or exercise regimens in an unsolicited way with peers, and utilizing the above-referenced preferred terms when consulting with colleagues about patients. Many organizations implement "wellness challenges" such as walking groups or physically active teambuilding activities; while these are not inherently negative, employees with seen or unseen disabilities or a history of eating disorder may feel subtle or overt pressure to participate lest they miss out on tangible benefits such as prizes, or intangible benefits such as being viewed as a team player by management or peer relationship building. Selecting internal champions of staff culture that work at different levels of the organization can allow them to provide ongoing gentle reminders regarding language as well as training and reflection space. The work of culture change is long and often difficult, as providers brush up against their own health training as well as internalized healthism and sizeism. Consistent support and follow-through can foster a weight-neutral professional environment that actively seeks to avoid stigmatizing staff and the patients they serve.

Case Study

A 13-year old patient was referred by her Primary Care Provider to an Adolescent Medicine Clinic for concerns of obesity. Results of her recent (within the past three months) comprehensive metabolic panel were unremarkable. Review of her growth records notes that prior to six years of age, her weight consistently trended around the 50th percentile-for-age. Between ages 6 to 12, weight gain accelerated to above the 75th percentile for age. In the last year, weight has continued to trend upwards to above the 90 percentile for age. Upon meeting with family and patient, Mom does the majority of the talking while the patient sits with her gaze towards the floor. Mom is asking for advice on how to help her daughter lose weight because “they’ve tried everything and nothing is working.” How might one proceed?

Before the Visit

What assumptions might have already been made about this patient and her family based on reviewing her chart and growth records? Would the same assumptions be made about a patient in a different BMI classification? Please see Table 12.1 and Table 12.2 below for information to consider in planning for the visit.

In the first hour of the visit, provider meets with the patient and her mother together, and then the patient alone, to gather additional information included in Table 12.3 below. Mom is very concerned about the potential health risks associated with her daughter’s accelerated weight gain in the past year, and also expresses concerns about the mixed messaging that her daughter is receiving at Dad’s house. Mom feels that Dad is “not healthy” and is setting a bad example for the patient.

TABLE 12.1 Assessment questions

Here are sample assessment questions to consider asking the patient at the start of a nutrition visit to better understand her medical, nutrition, and social history:

Ask the patient what her goals are for the visit and why they are important to her

Assess current family composition (who is living in the home, custody arrangements, etc.)

Assess for family history of nutrition-related diseases and eating behaviors of other members of the family living in the household

Verbal description of growth and eating behaviors throughout childhood and the start of adolescent

Family history of dieting/eating behavior changes and rationale for making changes

Forbidden foods in the home

Meal and snack patterns and frequency of eating

Meal and snack composition

Assess for eating disorder behaviors and body image concerns

Assess daily screen time usage

Assess for food insecurity using the USDA Self-Administered Food Security Survey Module

Access to safe outdoor parks and spaces

Relevant cultural or spiritual practices that pertain to eating

Participation in physical activity/joyful movement

History of mental health diagnoses in patient or immediate family. If yes in patient, a screening tool may be administered (i.e., PHQ-9 for depression, GAD-7 for anxiety, etc.)

History of size-based bullying from family, peers, or others patient is in contact with on a regular basis

Any recent social stressors, losses, or trauma experienced by patient/family

TABLE 12.2 Explaining a HAES-based approach to patients and families

It is important during the initial visit with a patient and or family member to understand the rationale for a goal of weight loss. The reasoning will guide the provider on how to introduce the concept of a weight-neutral approach. Potential topics to discuss with a patient and/or family member include:

The goal nor the focus of nutrition counseling is on weight loss. Natural outcomes of changing eating behaviors may include weight gain or weight loss.

Provide a brief summary of the research of short-term and long-term negative outcomes of intentional weight loss attempts (i.e., weight cycling, additional weight gain above starting weight, development of disordered eating/eating disorders, feelings of guilt and shame when dieting “fails”).

Provide education on expected weight gain during adolescence and normalize body shape and size diversity.

Provide education that a multitude of factors contribute to a person’s weight and that correlation does not equal causation.

Introduce the concept and rationale for focusing on positive health behaviors rather than weight loss.

With the patient alone, the provider learns that she has placed a lot of pressure on herself to lose weight to be healthy. She shares that she purposefully skips meals earlier in the day in an attempt to eat less, but is finding that she is waking up in the middle of the night and eating due to hunger. The patient also has less energy in the mornings at school, which makes it hard for her to concentrate in class and participate in her PE class. The patient has also started to eat alone in the bathroom at lunch because she is embarrassed that people will judge her for what she is eating. She has heard negative comments from peers regarding her weight gain. The patient shares that despite the efforts she is making, she feels guilty that she continues to gain weight.

TABLE 12.3 Case Study Patient Information

Age	13
Sex	Female
Household	Splits time between two households. Mom, Grandmother, patient, sister (8 years) (4 days per week). Mom works nights (6 pm-2 am) Dad, step-Mom, step-brother (3 years) and step- sister (2 months) (3 days per week)
Food insecurity	Present. Dad qualifies for food assistance, Mom does not qualify.
School	7th grade. Positive history of bullying by peers.
Family history	Hx of type II diabetes melitus on Dad's side. Mom has hx of diet cycling Grandmother has rule of eating 100% of what is served at meals
Eating behaviors	Restriction: present. Patient skips breakfast and is trying to limit intake at lunch Forbidden foods: chips, candy, soda, processed foods at Mom's in the last year. No forbidden foods at Dad's Grazing behaviors: present, especially after school between lunch and dinner Eating out: 3 times per week at dinner with Mom Binge-eating: denies Hunger cues: disrupted Eating past fullness: present Eating at night: present Activity: limited, but Mom tries to take patient to the gym with her

Recommendations to Consider During the First Visit

Using motivational interviewing, engage the patient and mother in a conversation about the recommended meal pattern for a growing adolescent (3 meals and 2–3 snacks per day). Explain the potential consequences of restricting intake,

such as overeating later in the day, obsessive thoughts about food and increased cravings, reduced energy, declined mood, increased frequency of eating alone or in secret, and increased feelings of shame and/or guilt around food. Ask if the patient can identify with any of these consequences. Use her response to guide your recommendation and provide counseling on how a consistent meal pattern can support health and help to reduce some of these consequences. You may want to start by only focusing on increasing the frequency of breakfast during this first visit. Initially, provide the suggestion to Mom that she focus on the positive behavior changes that the patient is engaged in and encourage Mom to redirect conversations about weight and size.

Resources

- American Academy of Pediatrics Recommendations, Stigma Experienced by Children and Adolescents With Obesity
 - <http://pediatrics.aappublications.org/content/140/6/e20173034>

Organizations

- *Association for Size Diversity and Health*
 - sizediversityandhealth.org/
- *Council on Size and Weight Discrimination*
 - cswd.org
- *Health at Every Size*
 - haescurriculum.com
 - haescommunity.org
 - lindabacon.org

- *Be Nourished* (Portland, OR)
 - benourished.org/
- *Rudd Center for Food Policy & Obesity*
 - <http://uconnruddcenter.org/weight-bias-stigma>
- *The Body Positive*
 - <https://www.thebodypositive.org/>
- *National Association to Advance Fat Acceptance*
 - <https://www.naafaonline.com/dev2/index.html>
- *The Fat Nutritionist*
 - <http://www.fatnutritionist.com/index.php/articles-evidence/>

Patient Resources

- Find a Health At Every Size Expert Near You
 - <https://haescommunity.com/search/>
 - <https://www.joseesovinskynutrition.com/find-a-haes-expert/>
- NOLOSE
 - <http://nolose.org/>
- T-FFED: Trans Folx Fighting Eating Disorders
 - <http://www.transfolxfightingeds.org/>
 - <https://www.facebook.com/groups/1472759929621399/>
- Dances With Fat
 - <https://danceswithfat.wordpress.com/blog/>
- Adios, Barbie: The One Stop Body Image Shop
 - www.adiosbarbie.com

- Travel Tips for People of Size
 - https://www.naafaonline.com/dev2/about/Brochures/NAAFA_Travel_tips_for_people_of_size_v3-15.pdf
- *Things No One Will Tell Fat Girls: A Handbook for Unapologetic Living*
 - <https://www.amazon.com/Things-One-Will-Tell-Girls/dp/1580055826>
- Jes Baker
 - <http://www.themilitantbaker.com/>

Body-Positive Instagram Accounts

- @chr1styharrison
- @with_this_body
- @tessholliday
- @thereallife_rd
- @foodpiecedietitian
- @marcird
- @bravespacenutrition
- @jennifer_rollin
- @hgoodrichrd

Motivational Interviewing

- Molly Kellogg, RD, LCSW
 - <http://www.mollykellogg.com>
 - <https://go.kognito.com/changetalk>

Videos/Podcasts

- Poodle Science: <https://www.youtube.com/watch?v=H89QQfXtc-k>

- Food Psych Podcast - <https://christyharrison.com/foodpsych/>
- The Mindful Dietitian Podcast - <https://themindfuldietitian.podbean.com/>
- Unpacking Weight Science Podcast - <https://www.unpackingweightscience.com/>

Books

- *Intuitive Eating: A Revolutionary Program that Works* by Evelyn Tribole and Elyse Resch
- *Health at Every Size: The Surprising Truth About Your Weight* by Linda Bacon, PhD
- *Body Respect: What Conventional Health Books Leave Out, Get Wrong, or Just Plain Fail to Understand about Weight* by Linda Bacon, PhD and Lucy Aphramor, RD, PhD
- *The Intuitive Eating Workbook: Ten Principles for Nourishing a Healthy Relationship with Food* by Evelyn Tribole and Elyse Resch
- *Body of Truth: How Science, History, and Culture Drive Our Obsession with Weight--and What We Can Do about It* by Harriet Brown
- *Beyond a Shadow of a Diet: The Comprehensive Guide to Treating Binge Eating Disorder, Compulsive Eating, and Emotional Overeating* by Judith Matz
- *The Non-Diet Approach Guidebook for Dietitians* by Fiona Willer
- *If Not Dieting, Then What?*, by Rick Kausman, MD

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Chapter 13

Juvenile Justice



Lauren Mozer and Jamie Weber

Introduction

Youth who interface with the juvenile detention system have their own health and mental health needs, both prior to interaction with the juvenile justice system and as a result of being a part of it. This chapter will provide a brief description of Juvenile Detention in the United States, an overview of the youth who end up in the system, how that system both fails and supports the optimal nutritional needs of its youth, and how nutrition services are designed and implemented with recommendations for further research and improvements. This chapter will examine the unique challenges of the juvenile detention population and some of the challenges that are present when treating incarcerated youth.

According to the U.S. Department of Justice's Office of Juvenile Justice and Delinquency Prevention (OJJDP), while

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the U.S. has experienced a substantial decrease in juvenile arrests in the last 10 years, nearly 1 million youth are still being arrested every year [1]. Approximately 48,000 adolescents are held in Juvenile detention across the U.S [2]. The Census of Juveniles in Residential Placement lists crimes for which adolescents are adjudicated and sentenced to detention; including, but not limited to, assault, violent sexual assault, murder, robbery, property damage and or theft, public order disturbances, and status offenses, which refers to truancy, running away, incorrigibility, curfew violation, and underage drinking [3]. There are over 2,500 residential detention centers nationwide [4]. The majority of youth are detained for non-violent crimes [5].

Healthcare provision at these residential facilities varies widely and is paid for by states, counties or the private sector [4]. Healthcare providers in pediatric healthcare settings will have the opportunity to either care for youth in detention or patients who have a history of involvement with juvenile detention. Therefore, pediatric providers have a responsibility to educate themselves and appreciate the unique nutritional needs of this population.

A literature review returned limited results in terms of evidenced-based approaches for providing adequate, medically informed nutrition programs in juvenile justice facilities. The USDA provides oversight and regulatory guidance for the nutrition programs within juvenile justice facilities with similar expectations and provisions to the guidelines provided to school systems. Details regarding how USDA guidelines are implemented and evaluated will be reviewed. Prior to outlining the details of how the dietary needs of incarcerated juvenile defenders are addressed and how these decisions affect health outcomes, a broad overview of the juvenile detention system and who is served by this system will be offered.

What Is Juvenile Detention in the U.S.?

Juvenile detention are facilities and programs used by the criminal justice system to incarcerate a minor either prior to or after being adjudicated for a crime. Within the United

States, the system was separated and developed for juvenile offenders over 100 years ago, with the goal of promoting rehabilitation over punishment [6]. In the 1980s there was a shift away from rehabilitation toward a tougher, more punitive approach to juvenile crime, particularly violent crime. This was deemed a threat to public safety due to growing concerns raised by criminologists at the time that there was not enough concern for juvenile crime and that their crimes were not being dealt with harshly enough [6].

A Juvenile Detention Center (JDC) is exclusively for the imprisonment of minors. A minor, or youth, is defined by age and varies by state. According to OJJDP, “[t]he upper age of jurisdiction is the oldest age at which a juvenile court has original jurisdiction over an individual for law violating behavior.” [7] For example, “an upper age of 15 means that the juvenile court loses jurisdiction over a child when they turn 16” and the adolescent then falls under the jurisdiction of the adult criminal justice system [7]. In 45 states, the maximum age of juvenile court jurisdiction is age 17. Five states (Georgia, Michigan, Missouri, Texas and Wisconsin) now draw the juvenile/adult line at age 16 [8]. Depending on what crime a youth offender is being adjudicated for, some jurisdictions may opt to try the minor as an adult before they have reached the upper age of jurisdiction.

The OJJDP is clear to define detaining a juvenile in a correctional facility as the most “severe sanction” a court can impose as it results in the youth’s complete loss of freedom. The OJJDP formalizes its understanding of the consequences that result from this action by a State with the following statement,

Out-of-home placement results in a great burden both on the youth who receive this sanction and on the juvenile justice system itself. The youth experience a disruption in their normal routines, schooling, and family/social relationships. The juvenile justice system must bear the responsibility for mental health care, substance abuse treatment, and education, among other requirements [9].

Juvenile detention facilities act as organizations with specific purposes and missions that typically reflect the desire of the local juvenile criminal justice system, which is formed by the desires of local political constituents at the state and

county levels. In other words, local governments, elected by the people they serve, heavily influence juvenile detention spending and policies. For example, the City of Seattle is located in King County where they state, “Juvenile Division is responsible for the care and custody of youth in detention” [10]. Washington State law requires King County to provide a juvenile detention facility. King County formalizes its role in terms of following its obligation to adhere to State Law and provide juvenile detention by stating,

King County uses detention sparingly and only for the most serious or violent crimes and high-risk offenders. While in detention, youth attend school and have access to a wide range of programs and services. The focus is on rehabilitation, not punishment, and ensuring community safety. King County is committed to helping youth involved in Juvenile Court develop into healthy, productive adults [10].

Local jurisdictions can both adhere to the Federal law requiring juvenile detention and minimize its potential harmful outcomes by providing juveniles within the system with positive supports, evidenced-based care and prioritizing rehabilitation over incarceration. Nationwide statistics continue to indicate that incarcerating minors does not reduce crime. Local communities can use their constituent influence to construct and design programs that are designed to rehabilitate offending minors in the effort to both build the health of their youth and reduce crime.

There has been a movement in recent years referred to as alternatives to detention and confinement, which the office of OJJDP refers to as, “approaches taken to prevent juveniles from being placed in either secure detention or confinement facilities when other treatment options, community-based sanctions, or residential placements are more appropriate” [11]. This shift has reduced detention admissions by 38% since 1992. Further, the reduction in directing juvenile offenders to detention and towards alternative community options has increased public safety. The OJJDP estimates that of all the juvenile offenders who are detained as much as 70% are

rearrested within two years due to reoffending [12]. Youth who are detained instead of offered alternative community treatment and rehabilitation are more likely to commit crime, decreasing lasting public safety [12].

Demographics

Racial Disparities

Youth of color are overrepresented in the juvenile detention system in the United States. Of the current population of detained adolescents, anywhere from 55% to 65% are considered to be minorities. They are more likely to be arrested, found guilty and subsequently sentenced to detention for non-violent offenses [13]. In response, in 2002 the U.S. Congress reauthorized the Juvenile Justice and Delinquency Prevention Act originally passed in 1974. With reauthorization came a further mandate to further monitor the over-representation of minority youth in the juvenile justice system. More people across the lifespan are incarcerated in the U.S. than any other country, with black populations being disproportionately represented [14]. The reasons for youth of color being over represented are multifactorial, largely related to historical disparities caused by slavery, colonization and overt economic discrimination throughout U.S. history.

Income Disparities

Additionally, over representation of youth who are incarcerated come from socioeconomic disadvantaged communities. For example, research has been conducted specifically on the correlation between environmental inadequate access to food and juvenile misconduct. This research has shown that the behavioral development of male children is particularly

sensitive to food insecurity [15]. In other words, physical and mental development is adversely impacted when children's basic needs, like adequate nutritional intake, go unmet.

Child Abuse and Neglect

The correlation between child abuse, neglect and an increased risk for criminal activity in adolescence is well-established. In 2017 The National Institute of Justice summarized research by Dr. Herrenkohl and colleagues that examines the connection between childhood maltreatment and later criminal behavior. Researchers found that children exposed to abuse and neglect between the ages of 18 months and 6 years-of-age self-reported criminal behavior as much as three decades later. A 2013 study found that as many as 60% of juvenile offenders have experienced childhood physical and or emotional abuse [16].

School-to-Prison-Pipeline

According to the Center of Juvenile Justice reform, overall, juvenile crime rates have decreased and far fewer minors are being incarcerated. However, those who are incarcerated tend to be from the highest risk populations, like youth with diagnosable mental health conditions and behavioral disorders. For example, studies consistently find that 65–70% of youth in such placements have at least one diagnosable mental health issue [17]. Many scholars attribute this trend to the school as the “prison pipeline”, which refers to the criminalization of behavior disorders in the school system, particularly for children of color whose behavioral needs are often treated as delinquent and punishable behavior. Miguel and Gargano write, “The school-to-prison pipeline is the pattern of (either subtly or forcibly) removing students from educational institutions, primarily through zero-tolerance policies, and putting them directly and/or indirectly on the track to the juvenile and adult criminal justice systems” [18].

What Does It Cost?

Both public and privately run juvenile detention facilities are funded by taxpayers at the Federal, State and County level. These funding decisions vary state by state, with some states opting to contract with private companies to run detention programs for the state. In some cases, private-run companies can make a profit off running juvenile detention facilities. The documentary work of the Juvenile Law Center, “Kids for Cash”, reveals financial kickbacks that were given to a Pennsylvania juvenile court judge from private detention centers to sentence minors to incarceration, often without being represented by counsel [19].

The decision to incarcerate a youth as retribution for crime is an expensive choice. In 2014 the Justice Policy Institute reported that incarceration costs states on average \$148,767 per youth per year, with 46 out of 50 States reporting yearly expenses. How this money is spent on the incarcerated adolescent depends on the state they are detained in and the type of facility they are sentenced to. The Federal government allows states to allocate and design how funding is allocated for juvenile detention. In essence, there are 51 different financial models for juvenile detention, which contributes to a high amount of irregularity in terms of how health care is implemented [20].

Many juveniles who are adjudicated and sentenced to detention enter this system already burdened by adversity that has had an impact on either their physical and or mental and behavioral health. Many states and local communities are opting for alternatives to detention to not further put these adolescents at risk, but thousands continue to be incarcerated every year. The Justice Policy Institute’s 2014 report “Sticker Shock: Calculating the Full Price Tag For Youth In Incarceration,” thoughtfully makes the fiscal argument for spending taxpayer money on investing in rehabilitation, rather than on punishment. The report indicates that a focus on punishment through incarceration costs taxpayers billions of dollars a year due to increased risk of reoffending and

recidivism, lost wages due to the impacts that incarceration has on education and employment, and higher Medicaid and Medicare costs [12]. Not only would investing in rehabilitation rather than detention reduce costs it would also decrease the opportunity for private, for-profit detention centers to benefit from juvenile crime.

Social Determinants

The work of pediatrician Nadine Burke, MD examines how exposure to early childhood adverse experiences is correlated with higher rates of poor health outcomes throughout a lifetime. Dr. Burke's work examines how exposure to Adverse Childhood Experiences (ACEs) increases stress that is toxic both physically and mentally for children and has lifetime impacts. Her research found that the higher amount of exposure to ACEs the higher the risk for chronic disease as an adult [21]. Exposure to four or more ACEs is correlated with significantly increased risk of developing 6 out of the 10 leading causes of death, and people with six or more ACEs die nearly 20 years earlier than those with zero ACEs [22]. The Center for Disease Control and Prevention now refers to early childhood experiences as a public health issue and provides research and direction for how ACEs can be prevented [23].

In order to adequately appreciate the health needs of both youth in detention and with a history of exposure to detention, using the ACEs framework to inform assessment and interventions will likely greater increase the impact of care. Clinical decisions that take into consideration how ACEs and toxic stress impact clinical presentations can more comprehensively address nutritional counseling needs. Some research has indicated that over 90% of adolescents entering a juvenile detention center have at least one ACE [24].

Placing an adolescent in juvenile detention removes them from their opportunity for typical, prosocial, community-based development and connection to therapeutic services

designed to rehabilitate health and behavior. If an adolescent enters detention with ACEs, incarceration has the potential to potentiate the toll of toxic stress by removing the youth from support and community-based resources familiar to them.

For example, a child who grows up with income, food, and housing insecurity, family violence and or a parent with a mental health or substance use disorder has a developing brain with significant exposure to ACEs, which acts as toxic stress on their entire system. This toxic stress then increases the adolescent's risk for emotional and behavioral dysregulation, which can lead to truancy from school or other behavior deemed illegal and or criminal, increasing their risk for adjudication and possible detention. If the detention center is not prepared to address the impacts of early adversity that youth face, optimal outcomes for rehabilitation may be at risk.

Potential Benefits of Improving Access to Nutrition Education

More research is needed to examine the potential cost savings of reduced recidivism by investing in treatment of the underlying physiological and psychological needs of adolescents in the criminal justice system [25]. Whether or not improving access to evidenced-based nutritional counseling would improve health outcomes for these youth also needs further study. In the general adolescent population, providing access to nutrition counseling has shown to improve health outcomes [26]. Youth in detention are more likely to have preexisting health problems [25], therefore establishing and investing in a standard of health care that reduces recidivism and improves long-term health outcomes for criminally involved youth would both improve the quality of their lives and chances of success at functioning in society. Society would subsequently benefit from a lower tax burden if the juvenile justice system was reformed to better prepare individuals and the families who support them, and are con-

nected to their well-being, to functionally participate in their communities.

Food

Federal Guidelines

Food in prison systems has evolved over the years and now have guidelines on quantity and quality of food served, staff and kitchen facility, dining room space, and sanitation of food offered [27]. Meals served at Juvenile Detention Centers fall under the Residential Child Care Institutions (RCCI) through USDA Food and Nutrition Service [28, 29]. Institutions that fall under RCCI are intended for the care of children confined for 30 days or more. Juvenile detention centers follow the national school breakfast and lunch program guidelines. These meals are prepared and served in a manner that meets established government health and safety codes, remain within the allocated budget and have been deemed nutritionally adequate. Unless otherwise indicated, all juvenile offenders receive the same meals offered in a dining room setting [30]. For adolescents who are housed in adult detention facilities, meals served will be recognized as having special needs to meet the juvenile's different nutritional requirements. Meal patterns served in these facilities will be changed so that they will be served with milk, fruit and one or two snacks per day [31]. Each facility institutes security measures, such as having rules about knife points, locking yeast in a secured supply area to reduce the risk of use for manufacturing illegal products, and number of keys allowed to access these items [30], to ensure the safety of their population.

Menu adequacy is reviewed annually at the national level, and assesses nutritional content, product pricing, operational impact, as well as preferences of juvenile offenders based on survey responses. This is initiated by USDA's National Institute of Food and Agriculture (NIFA), who requests feedback from juvenile detention facilities in October to deter-

mine if changes to the certified National Menu need to be made. No changes are made at the local or regional level to meal guidelines. Any changes made to the national menu will be noted on the Food Service Branch Sallyport, a secure online database specifically for prisons. Information will include new or updated recipes and product specifications broken into the following categories: meat and eggs; fats; starches, potatoes and dried peas, beans and nuts; milk and cheese; fruit and citrus; miscellaneous food or adjuncts; and non-edible supplies. This helps to track costs within categories of products. Local or regional facilities can use an alternative menu when authorized by policy. Facilities must use the approved software for food service management. This software helps the federal government track food costs and is designed to determine cost per inmate per meal.

While personal food preferences are not honored on an individual basis [31], general food waste has to be considered within the choices made for meals served. As the menu is under the discretion of each facility, as long as it meets government guidelines, thinking how food waste affects the facility's overall budget affects the inmate food choices. A study that looked at the nutrition quality of inmate eating habits discussed how a government official recognized the inmates rarely eat a protein and more than one vegetable at meals outside of custody [32]. This pattern resembles one commonly seen on fast food restaurant menus in the U.S. Therefore, when the recommended meals are served in detention, they may be rejected and food waste increases. In order to decrease food waste, facilities may opt for foods that resemble "fast food." [32]

Meal Pattern

Three predetermined meals are served each day, two of which are hot, and no more than 14 hours can be between the end of the evening meal and the beginning of breakfast. Meals and snacks cannot be withheld as part of a disciplinary sanc-

tion. A sandwich meal can be served on the same day as a continental breakfast if a hot soup is paired with the sandwich [30]. Menus will be available to juvenile offenders at least a week prior to serving. Foods that are heart healthy, made or seasoned with pork, or a vegan alternative will be identified on the menu.

Beverages

Milk (plain and chocolate) and water are provided daily to juvenile offenders. While soda is not offered or available for purchase at juvenile detention facilities, other sugar-sweetened beverages are, in particular juice. Juice is offered at breakfast and some snacks each day.

Other beverages, such as decaffeinated coffee and tea, are typically offered within each cottage for residents to drink ad lib, while sports/energy drinks, milkshakes, smoothies or specialty coffees can be used as part of an incentive program within the facility. As caffeinated beverages can be an appetite suppressant, knowing how often your patient is being offered these drinks can be helpful while counseling.

One difference with this population is the consideration of safety and access within the facility. Bottles can be weaponized, which should be considered when making recommendations about fluid intake. Reusable water bottles are also not universally available, as these may be a for purchase item within the facility. Discussing other options to help support fluid intake (e.g., cups and water fountains) with the adolescent and staff will be helpful during counseling session.

Food for Purchase/Commodity Foods

Juvenile offenders are given the opportunity to make food choices through facility commissaries or food stores. These foods do not follow the same Federal guidelines as meals and snacks, and are often convenience foods, such as chips, candies,

pastries and instant soups. In adult facilities, these foods can be ordered twice a week with orders placed 1–2 weeks ahead of time [33]. At a Federally run facility in Washington State, juvenile offenders can obtain non-USDA approved foods through an incentive program that is set up per cottage based on the behavior of the juvenile offenders. Number of times residents can order from an outside vender (e.g., Costco) and types of foods purchased is determined at the cottage level. Common snacks ordered are Gatorade, chips and candy. Juveniles will order food through their staff members, and residents are not monetarily charged for their selections since it is a merit-based purchase. Other facilities have commissaries on site, and require an order form to be filled out ahead of time indicating what the inmate wants [34]. These foods are purchased using available funds in the juvenile's account, managed through the Fund Accounting Commissary Trading System (FACTS), a real-time accounting and inventory management system owned and maintained by the Department of Corrections [35]. These funds can be replenished through money deposited by family members, wages obtained through detention facility jobs or through tokens received for good behavior or progress in treatment. Prices of these foods are often at a premium and correctional facilities can profit off the sales of items sold [36]. Local vendors often rely on the Department of Corrections facilities' commissary business as a substantial portion of their sales [37], however the companies (e.g., Aramark, TIGG's Canteen Services, Summit and Tiger Correctional Services) that supply meals and snacks may also be contracted to supply commissary items [36]. Yet, not all juvenile detention centers have a commissary, or allow foods from the outside (given to offender via mail or during visitation) [38].

Medical and Religious Diets

Foods served at juvenile detention facilities can accommodate medical and religious needs, such as chronic kidney disease,

diabetes, celiac disease and increased calorie requirements, as well as to accommodate an altered meal schedule due to fasting for religious holidays [39]. Medical diet needs are documented in the detention facility's patient medical records and include type of diet, duration it should be provided and any special instructions [40]. A copy of the medical diet menu and certification letter/request are also maintained in the Sallyport or Food Service Administrator's office. Diet needs documented as a medical diet order in the electronic medical records system are available to the kitchen staff. The staff will print out a special diet roster prior to food service which will list any allergies, intolerances or specific diet needs (i.e., allergic to pineapples). Medical diets are provided by mainline self-selection options, unless unable to meet necessary medical requirements due to the nature of disease state or through determination by a Registered Dietitian (RD). In this case, these medically necessary foods are provided by pre-plating or controlled plating [30]. Medical diets are reviewed every six months to determine nutritional adequacy [40].

For juvenile offenders who adhere to a specific diet for religious purposes, such as halal or kosher, detention centers will offer foods that are certified to meet these criteria upon approval of the religious leader. Pork is also not served as the only entree during a holiday meal. Detention facilities will also accommodate for religious fasts and make bag meals available during this time. If an inmate receives a bag lunch for >5 days in a row, then the FSA will provide a Bag Lunch Alternative until they are returned to a regular menu service. For Ramadan, the mainline lunch and dinners will be made available after sundown [30]. For Passover, residents will be offered foods that specifically meet the requirements of the holiday (ex., unleavened bread).

Food-Borne Illness

Incarcerated individuals have little to no choice in where and what they are served. During their incarceration, they are

completely reliant on the facility for their food and the safety of that food. Due to this, food safety is addressed in 5 of the 12 chapters in the Department of Justice's Food Service Manual [41]. Additionally, each member of the juvenile detention kitchen staff is required to have yearly trainings on food safety, as well as a valid Food Worker Card. The facilities Food Service Manager oversees kitchen staff training and ensures compliance with the food safety regulations and guidelines. Despite the attention on prevention measures, incarcerated individuals are 6.4 times more likely to suffer from a food-related illness than the general population [42, 43], and 6% of all confirmed outbreak-related cases of food-borne illness in the United States were in detention facilities [43]. One such case, in 2012, was due to the mislabeling of meat, resulting in incarcerated individuals being served meat that was intended for pet food [44]. Based on a meta-analysis of food-borne diseases from 1974 to 1991 and 1998 to 2014 [42], these outbreaks are mostly caused by *Clostridium perfringens*, *Salmonella* and norovirus due to foods remaining at room temperature or in warm outdoor temperature too long, food being handled by an infected person and improper sanitization and cleaning of cooking/food preparation equipment or utensils. It should be noted that incarcerated individuals are a convenience sample of infected individuals, whereas the general population may not disclose their food-borne illness or be able to easily identify the exact food-borne source due to the complexity of diet and increased food choices. Therefore, the percentage of infected individuals who are incarcerated may be unfairly skewed.

Dietitian's Role

Registered Dietitians in correctional facilities serve various roles. They are a mandatory part of the annual review of menus for nutrition adequacy and federal guideline adherence, are liaisons between juvenile detention centers and government agencies, provide Medical Nutrition Therapy

(MNT) and nutrition counseling to juvenile detention residents, and coordinate care with kitchen and other medical staff to create medical diet plans for juvenile offenders with special diet needs. Nutrition counseling is completed one-on-one with the youth, using both verbal and visual aids to help increase understanding, as well as the facility menu for help with diet recall and goal setting. All written materials provided during counseling must not exceed a fourth-grade reading level to ensure all inmates can understand the text [45].

In most facilities, the RD does not perform nutrition education or counseling due to access issues. Therefore, other members of the medical team will offer these services. Despite the low access of RD services, nutrition counseling from a credentialed dietitian is important, as clinical practice has shown that many juvenile offenders have either not had any nutrition education in the past, or received minimal education in school. Although juvenile offenders do not have a wide variety of foods available each day, they can still make independent choices, such as skipping meals, being selective in their food consumption, saving snacks offered to eat instead of the scheduled meal, or opting for convenience foods purchased from the commissary. Foods can also be traded for preferred items from other residents. It is known that food refusal of fruits and vegetables is common in this population [46]. All of these behaviors and choices limit the variety of nutrients and food groups consumed.

These juvenile detention residents are also removed from parental oversight, which may or may not have offered a supportive food environment prior to incarceration. While monitored in small groups, youth in detention are not given individualized supervision to help them with food choices. This allows them to be independent with daily intake while within the facility. Counseling can help them make appropriate individualized healthy eating decisions within the confines of the juvenile detention menu.

Lack of individualized support can be a barrier for implementing general nutrition counseling goals, such as increasing vegetable intake or drinking more water. It is imperative that

set nutrition goals are communicated with the facility staff assigned to the juvenile, as well as documented in the individual's electronic medical record, to help support goals set in a nutrition visit. Aligning messaging and offering available support where possible will help increase the success of achieving their goals.

Other less intensive nutritional support, such as culinary classes, can be implemented by facility staff or volunteers. These classes (e.g., barista program, bread baking, cake decorating, cooking basics), are not intended for improvement of personal nutritional decisions or knowledge, but can help set them up with usable vocational skills after release [47]. Unfortunately, official nutrition programming is not currently part of a standard curriculum within most facilities; therefore, there is a lack of consistency with these interventions. There is also not a standard practice for addressing and reducing food access/security issues once the adolescent has been released from detention.

As will be detailed later in this chapter, current health outcomes for incarcerated adolescents are poor. Increasing utilization of and access to RDs may help to improve the health status of the adolescent not only while incarcerated, but also after release.

Juvenile Detention Training for Registered Dietitians

Due to the vulnerability of this population, all employees working within the detention facility, including RDs, receive detention facility-specific training, as well as the Prison Rape Elimination Act (PREA) training when entering their role. For medical professionals, specific training on the facility's electronic medical record system is an important piece, as they are set up differently than systems used in a hospital setting and often more rudimentary. The patient's chart will contain any current and past medical exposure within the facility, as well as information on the juvenile's arrest record.

The facility electronic medical record system is not accessible off campus due to privacy-protected laws for the juveniles.

Registered Dietitians should also work with the facility's security staff to gain an understanding of the different security levels that can be applied to residents, and reasons for the application. Typically, these include procedures for juvenile offenders who are at an increased harm risk to either themselves or others. Some classifications are determined prior to arrival at the facility, others are determined during intake using screening tools, and others are applied during incarceration when the juvenile offender has exhibited concerning behavior or vocalized concerning thoughts. Security levels can be increased or decreased based on additional assessments completed by cottage staff and/or designated medical professionals. The minimum time for reducing a security level may differ by facility and severity of risk. To easily identify security status, some juvenile residents wear colored uniforms:

- (a) Orange Uniform: maximum-security juvenile offenders, juveniles who are a flight risk, and for Fight Prevention Level (FPL) individuals who display behavior that threatens the safety of facility staff and other juvenile offenders [48]. There may be multiple risk levels within each classification, with Level 1 being the most severe cases with the highest level of restrictions. Wearing an orange uniform may limit the amount of personal items allowed, out of cottage activities, contact with other residents, as well as communication with individuals outside the facility. These patients may or may not present in shackles, depending on their tier within the security levels.
- (b) Yellow Uniform: juvenile offenders who have indicated increased risk on the Suicide/Self-harm Screen (SSS) tool during intake, or have exhibited concerning behavior or thoughts during incarceration, and need to have a protective course of action taken to ensure their safety. There are three Suicide Precaution Levels (SPL) which can be reduced or increased based on subsequent assessments [48, 49]. Again, Level 1 is given to the most severe cases, and requires constant direct monitoring (every 2–5 minutes),

limitations to out of cottage activities, and special clothing to reduce self-harm risk, such as tear away smocks. Other levels require consistent, but less frequent checks by staff. These residents may also require an escort at all times to allow for consistent monitoring [50]. These juvenile offenders may or may not present in shackles, depending on their tier within the security levels.

Counseling a Juvenile Offender

Rapport building is crucial when counseling all adolescents, and motivational interviewing is an evidenced-based style of engaging someone to explore their own internal readiness for change and goal setting around nutrition choices. It is important not to make assumptions about the youth in counseling sessions and give the juvenile an active role in their nutrition plan, while still trying to hold them accountable by engaging the support of their detention staff.

When planning to counsel at a juvenile detention facility, it can be helpful to discuss meal procedures and menu specifics with the facility's Food Service Manager. They are the front-line person who oversees the meal program, and who you will be working closely with when modifications need to be made for a juvenile offender.

Ten helpful things to know or do prior to nutrition counseling at a juvenile detention facility are:

1. Obtain a facility menu.
2. Obtain a meal schedule, and know if meal times differ for each cottage.
3. Ask where the adolescents are served their meals (cottages, central dining room or in their rooms).
4. Ask if each cottage has non-standardized foods that residents can choose to eat between the offered meals and snacks, such as peanut butter and bread, fruit, popcorn or other pre-packaged foods.
5. Know whether the facility has a commissary. If yes, understand what is available for purchase, how many days it is

- open, procedure for purchasing items and how often items are restocked.
6. Ask if residents are allowed to have food given to them by family members or friends.
 7. Ask if there are any incentive programs run by the facility that use food rewards for good behavior or other goal progress.
 8. Obtain information on any nutrition programs run by the facility, such as cooking classes.
 9. Ask what the hours are for the physical recreational center, frequency of use allowed, equipment available and procedure for use.
 10. Understand what the different security classification levels are in your facility, how that level is determined and how the security classification may impact the juvenile offenders day-to-day activities rehabilitation timeline.

Initial Nutrition Assessment

Before starting your assessment, use motivational interviewing to allow them to give some insight about what they want from the nutrition visit, “what is something you wanted to discuss today?” or “what are some goals you have for our meeting today?” As they have most likely not worked with a RD in the past, it is also helpful to explain your role within their care team to them.

Next, complete a thorough nutrition focused H.E.A.D.S.S. assessment (Table 13.1). Some of the information listed in italics will not be asked in your visit, but should be reviewed ahead of time, if available, to help complete your background knowledge of the juvenile.

Next, a dietary recall of current intake should be completed, as well as identifying any preferred foods and reasons for meals missed. Depending on the adolescent’s level of nutrition knowledge, reason for their visit (e.g., celiac disease vs. obesity) and whether there was a goal set with you at the beginning of the session, it is helpful to start by establishing

TABLE 13.1 H.E.A.D.S.S. assessment

Home	<p><u>Outside Facility:</u></p> <p>What was the housing status like prior to incarceration?</p> <p>Who did they live with prior to incarceration? (e.g., with nuclear family, with extended family, with friends, on the street?)</p> <p>How was their relationship with their caregivers? Do they have contact with them now?</p> <p><i>Gang Involvement: self and/or family member?</i></p> <p>Food environment at home: who purchased and prepared foods; family meals; commonly eaten foods; foods omitted for religious reasons; history of dieting in the household; level of food security:</p> <ul style="list-style-type: none"> free school breakfast/lunch family run out of food (if yes, how often), how was food obtained (i.e., grocery store, food banks) <p><u>Within Facility:</u></p> <p>Who are they reporting to in the detention center?</p> <p>What are the rules of their detention facility cottage?</p> <p>How is it going with the other cottage residents?</p>
Education/ Employment	<p><u>Outside Facility:</u></p> <p>Any suspensions or terminations prior to incarceration?</p> <p>Previous nutrition education received? From where? What do they remember about the nutrition information discussed?</p> <p>Plans for school and work after they are released?</p> <p><u>Within Facility:</u></p> <p>How is school going now?</p> <p>Favorite and least favorite subjects?</p> <p>Working anywhere in the facility?</p>

TABLE 13.1 (continued)

Activities	<p><u>Outside Facility:</u> Anything they have done in the past and are looking forward to doing again?</p> <p><u>Within Facility:</u> Current physical activity level? Hobbies they enjoy? Involvement in any programs within the facility?</p>
Drugs	<p><u>Outside Facility:</u> <i>*Physicians will complete this inquiry during the Receiving Health Screening</i> <i>Previous use: what, frequency of use, when did use begin, patterns of use/abuse, operating a vehicle while intoxicated? How did they obtain drugs/alcohol? Family members involvement with drugs or alcohol? Friends or other peers level and frequency of use?</i></p> <p><u>Within Facility:</u> Current symptoms of withdrawal? Current prescription medications taken? Vitamin D Supplement?</p>
Sexuality	<p><u>Outside Facility:</u> <i>*Physicians will complete this inquiry during the Receiving Health Screening</i> <i>Orientation?</i> <i>Experience and level of experience?</i> <i>Number of partners?</i> <i>History of pregnancy/abortion? Currently pregnant?</i> <i>Use of birth control? What kind was used?</i> <i>Frequency of use?</i> <i>History of sexual abuse?</i> <i>Has anyone approached them for sex trafficking purposes?</i></p>

TABLE 13.1 (continued)

Suicide/ Depression	<p>Within Facility:</p> <p>Appetite/eating behavior changes? Sleep Disturbances?^a Current affect of the adolescent? <i>*Physicians will complete this inquiry during the Receiving Health Screening</i> History of withdrawal or isolation? Feelings of hopelessness or helplessness? How long have they experienced this? Emotional outbursts and/or highly impulsive behavior? Juvenile's history of previous suicide attempts, depression, or psychological counseling? Family history of suicide, depression or psychological counseling? Peer history of suicide?</p>
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^aNote that sleep disturbances are more common for residents in a juvenile detention facility. A study [51] that compared incarcerated and community adolescents found that a greater number of incarcerated juveniles reported trouble sleeping (42%) than community adolescents (39%)

a basic level of nutrition knowledge. This can help them understand how their bodies metabolize food, identify which foods are in the different food groups, describing the difference between whole and refined grains, or discussing the health effects of excessive intake of sugar-sweetened beverages.

Make small goals, and assess barriers to completing the goal (“What concerns do you have about making this change?”). Complete the chart note, and then contact the adolescent’s detention staff to keep them updated on ways they can support the nutrition goals set. Coordinate care with other medical providers who are following that adolescent to also enforce goals set, especially as availability for RD return visits may be poor.

Health/Nutrition Status

Each juvenile detention facility offers health services to its inmates [52], however the scope and quality of health services provided varies greatly from jurisdiction to jurisdiction. State facilities usually have more services available, such as on-site dental clinics, medical providers, psychologists, substance use counselors and registered dietitians. County facilities services and access are more limited, as they may have an on-site clinic, or might just have a county nurse for a few hours each week, or send juvenile offenders to another facility for medical care. Larger, state facilities have more health-related visits per month with various medical needs than do county jails. One study showed that inmates were seen for nutrition-related visits 2.1 times during their incarceration, compared to 14.2 times in state facilities [53]. This is a notable disparity, since the average length of time incarcerated does not differ by institution (jail: <1 year; juvenile detention facility: <1 year) [54, 55].

There is little research on the health/nutritional status of juvenile offenders, and female juvenile offenders are under-represented within the study populations. Within the studies available, and including clinical practice experience of the author, the following is the current understanding of the nutritional status of this population.

Nutritional Status Prior to Incarceration

Juvenile offenders get a Receiving Health Screening as soon as possible and no later than seven calendar days after arriving at the detention facility. In a situation where newly arrived juveniles cannot be screened immediately, reception personnel will perform a medical clearance assessment to determine health-screening priority [56]. These screenings focus on mental health, physical health and medical history. A nutrition assessment is not currently part of the standard screening process. Screenings are completed by juvenile

detention center medical staff directly or contracted with partnering agencies, such as academic medical centers or private correctional health care providers [57].

A year 2000 position paper by the Society for Adolescent Health and Medicine (SAHM) emphasized that the time frame of this process was important as many juvenile offenders entering a detention facility have long-term neglected health care needs [58] and incomplete medical histories [57]. The recommendation was to break the initial health screening into two parts to allow all newly incarcerated juveniles to receive a screening within 24 hours of arrival. First screening would be to rule out emergent medical needs, contagious diseases, and evaluate current medication needs. The second screening would be completed within the first week of arrival and “include a medical and social history, physical examination, and assessment of immunization status [58].” The adolescent would then be scheduled for any follow-up care and referred to other specialties for health maintenance and continued care as needed [58], based on the clinical judgment of the medical provider.

A study found that 46% of newly detained juveniles have urgent medical needs requiring immediate attention [59]. Additionally, only one-third of the juvenile inmates reported having an identifiable, regular source of medical care before admission [60]. Two studies showed that prior to incarceration 38% (40% of males and 27% of females) [61] and >50% [60] of adolescents had not seen a doctor within the last 12 months, though some experienced a medical issue within that period. A small, but notable group reported never visiting a doctor (3% male, 0% female) [61]. Incarcerated juveniles also have a history of poor dental hygiene and lack of dental care. A study found that about one-half of incarcerated youth had untreated tooth decay and 6% had urgent oral health conditions including abscess, jaw fracture, or severe gum disease with bleeding [57]. This may also affect nutrition status, as these individuals may have avoided foods that were painful or difficult to chew. Compounding this, diet habits that include consuming high quantities of sugar may

also contribute to the deterioration of teeth. A study found that juvenile offenders who reported low levels of family connectedness were less likely to consume adequate servings of fruits and vegetables, and that it was common for diets to consist of foods high in fat and sugar [46].

Obesity is a data point that is often studied among this population. Body composition measurements, such as height, weight and age taken during medical intake assessments are used to identify an individual's body mass index (BMI) and assume health status. While BMI is not a perfect measure of health, it is often used to give a snapshot of an individual and help understand the health status of the population at a specific period in their incarceration. A single center study that looked at both male and female juvenile offenders found that 22% of males and 18% of females were classified as obese when they entered the juvenile justice system [62]. Another study looked at only female juvenile offenders and found that 57.4% were overweight or obese at their initial medical assessment [63]. These studies also found that African-American adolescents had the highest percentage of being overweight but those that identified as Hispanic had the highest rates of obesity [62], and that >50% had a family history of diabetes and 35% had a family history of heart disease [63].

As incarceration may be the only significant contact juvenile offenders will have with a healthcare provider outside an emergency setting [60] to impact health outcomes/trajectory. Initiating medical care as soon as possible allows for increased touch points for juvenile offenders during incarceration. Initiating proactive medical care may also help to identify nutritional inadequacies and nutrition knowledge deficits that can be addressed while the juvenile is incarcerated and receiving an adequate meal pattern. Again, barriers to this are often access to RDs within the facility, either by not employing a RD or low RD availability for initial and follow-up care. Additionally, refusal of care or reluctance to cooperate with healthcare staff during a clinic visit increases the challenges to appropriate follow-up care [57].

Nutrition Status During Incarceration

As noted previously, incarcerated juveniles often have chronic health issues that have inadequate medical attention prior to arrival at the detention facility. Studies have focused mainly on obesity, diabetes, liver disease, and pregnancy during incarceration, though this population is treated for a wider range of diseases. Although pregnancy is not a “chronic disease,” studies looked at birth outcomes of infants born to incarcerated mothers and the chronic disease that may result from maternal incarceration.

Due to the limited scope of research available, some information will include health status from the adult population. In the adult inmate population, there was a higher prevalence of hypertension, asthma, arthritis, cervical cancer and hepatitis compared to the general population when adjusted for race, education, marital status, birth location, employment and alcohol consumption for all incarcerated individuals surveyed [64].

Obesity

Juvenile offenders are at a greater risk for developing obesity than their non-incarcerated peers, and incarceration may be contributing to the increased risk. This might be caused by emotional eating while adjusting to life in the detention facility [65, 66], generally eating for comfort, overeating due to an increase in available foods, overeating with the intention of gaining weight to appear bigger to other inmates [65], dissatisfaction with detention food, foods for purchase and low physical activity levels [66].

A study that looked at male juvenile offenders over a period of 12 months found that those that were classified as overweight/obese increased from 33% to 52.5% during that time [65]. Another found that a higher percentage of incarcerated females (35.9%) were overweight/obese than were males (33.7%), but of those, a higher percentage of males

were obese (13.7%) than were females (12.9%) [46]. A 2017 systematic review and meta-analysis [66] of weight gained during incarceration found that there was an average reported weight gain of 0.37 lb/week for males incarcerated for an average of 179 days, and 1.1 lb/week for females incarcerated for 23 days. The time frame of incarceration may have been a major factor in weight differences seen, as previous studies have showed a quicker rate of weight gain when incarcerated youth entered the facility. Eating habits were not statistically significant except that overweight/obese female adolescents consumed fewer potato chips per day than their normal-weighted peers [46], and another study found no significant eating differences between racial and ethnic groups [65]. Metabolic factors and medications that may affect weight should also be considered for these adolescents, as a normal BMI does not immediately indicate health or a balanced diet. In one study, more overweight/obese males reported to consume breakfast, fruit, green salad and vegetables, and normal weighed females reported consuming more dessert foods, and meats associated with higher saturated fat (ex., hotdog, sausage, meat pie, and hamburgers) [46]. Additionally, psychiatric medications are among the most commonly prescribed to juvenile offenders. These can affect weight status, as mood stabilizers and antipsychotics can increase weight and stimulants can decrease weight by suppressing hunger signals.

Inversely, some of these studies also showed that many (40–66%) adolescents remained in a normal BMI range during their entire incarceration [22, 46, 65] while others showed that some adolescents who arrive at the facility with a BMI indicating overweight/obesity ended up losing weight due to food refusal or loss of hunger signals. For example, an adolescent was referred to nutrition for counseling on weight management, and, due to access issues, was unable to be seen by the dietitian until two months later. During that time it was noted that the adolescent had a significant decrease in weight, with an even greater weight decrease seen since admission. The adolescent met with the dietitian, and during the counseling session the juvenile offender stated that they were

previously eating chocolate pudding-filled hotdog buns for most meals, and having Kool-Aid as their main drink prior to incarceration, with little parental involvement during meal times or with meal preparation. Since incarceration they refused most foods offered due to unfamiliarity/limited exposure and presumed dislike, which lead to the rapid weight loss seen in their medical chart. The individual also self-reported not having any previous nutrition education. Counseling was provided and nutrition goals were set around eating something at meal and snack times. The juvenile offender's counselors and staff were contacted and involved in goal setting to encourage intake during meal times.

Pregnancy

Seventy-five percent of incarcerated female adolescents have had sexual intercourse before 13 years old. One study showed that 33.3% reported having been pregnant, and 20% of these individuals had sex with the intent of getting pregnant [63]. A national survey of juvenile detention facilities found that there were between 1 and 5 pregnant adolescents on any given day [67], and in Washington State there are at least 14 pregnant adolescents incarcerated on any given month [53].

As is detailed further in Chap. 24 on pregnant adolescents, pregnant mothers have special nutritional needs, with even greater consideration of nutritional needs for a still developing adolescent female. If a juvenile offender is pregnant, she will receive prenatal care that includes advice on appropriate levels of activity, diet and nutrition, as well as a prenatal vitamin [68]. A physician, if a RD is not available, will complete a medical diet order for these individuals to offer additional dairy products in their meal pattern.

According to research, birth weight outcomes are adversely affected by incarceration and that the effect on birth weight depends on when during the pregnancy the mother was incarcerated [69]. Women (ages 20–35) who were incarcerated early during their first trimester had higher infant birth

weights and lower preterm rates than when mothers were incarcerated during their 2nd or 3rd trimester. However, mothers who were incarcerated after their 34th week of pregnancy had no preterm deliveries and no low birth weight babies. Maternal age was similar among all groups. Therefore, pregnant mothers who spend the majority of their pregnancy outside of prison have the best birth weight outcomes.

Diabetes

It is estimated that 4.8% of those incarcerated, or nearly 80,000 inmates (adult and juvenile) have diabetes [70]. Yet, in a study of incarcerated adolescents, no males (total = 209) and only 2 females (total = 18) had self-reported diabetes [61]. Since these numbers were by self-report, there is the potential that these individuals did not know that they had diabetes, and were therefore not receiving appropriate education and follow-up care. Please see Chaps. 22 and 23 on Adolescent Diabetes for more information on the importance of nutrition within this population.

Liver Disease

Incarcerated youth have liver function issues, such as non-alcoholic fatty liver (NAFLD). NAFLD is a complication of obesity, type II diabetes, and metabolic syndrome. A study that looked at male juvenile offenders found that being overweight or obese was significantly associated with having elevated liver enzymes, as were having higher levels of triglycerides and total cholesterol [71].

Lifestyle interventions that promote improvements in diet and physical activity are recommended as first-line treatment. Although there is no specific diet for NAFLD, counseling an adolescent to reduce sugar-sweetened beverages and make health promoting food choices, such as consuming foods lower in saturated fats (e.g., lean proteins, fruits and vegetables) may be helpful to improve liver functions tests. Also working with

the youth on general meal pattern habits that may be contributing to unintentional weight gain could also be helpful [72].

Eating Disorders/Poor Body Image

Eating disorders and poor body image issues are prevalent in juvenile detention facilities. Research showed that almost 5% of those studied were classified as having a binge-eating disorder [73].

In incarcerated adolescent males, a study found that 20% who committed a sexual offense had body disapproval and 5.9% of these individuals scored high enough on the MACI body disapproval subscale to meet criteria for clinically concerning levels of body disapproval or body dysmorphia. Approximately 2.7% also showed clinically concerning levels of eating dysfunction. White males scored higher than their non-white peers for body disapproval. Previous sexual assault on the study participants was a significant predictor of eating dysfunction and body disapproval scales [74].

In incarcerated females, despite actual weight gained, women had a higher perceived weight gain than males [66]. Length of time may also be a factor for body dissatisfaction within the juvenile detention population, as adolescents who are incarcerated for >12 months have a higher level of perceived weight gain. However, if the adolescent perceived themselves to be overweight at baseline, then their perceived weight gain was lower than actual weight gained [66]. Another study showed that more adolescent females (16%) than males (0%) were diagnosed with an eating disorder [75].

Nutrition Interventions Already Researched

Correcting Nutrient Deficiencies and Food Offered

In research studies, supplements are sometimes used instead of food to allow control over the study environment and

blind themselves to the case participants. In the incarcerated population, results have shown that violent juvenile and young adult offenders who receive active supplements have a greater decline in infractions and commit fewer violent offenses than those that receive a placebo [76, 77]. The adolescent-focused study included nutrition education through weekly self-directed learning modules to all participants. Results showed that both case and control groups had improvements in nutrient deficiencies. Researchers hypothesized that the nutritional counseling was the main factor for improvement seen in nutrient deficiencies. Another nutrition intervention offered self-completed eating habit aids (e.g., food guide and food log) [78], but was shown to be not as effective.

A study showed that both incarcerated and non-incarcerated adolescent males had nutrient deficiencies higher than the national average, but non-incarcerated adolescent males actually had a higher level of severe deficiency [79]. For Vitamin D, a fat soluble vitamin that is needed to help the body absorb calcium, three studies [32, 33, 80] looking at incarcerated adults found that study participants had deficient levels or were served meals that had inadequate levels of Vitamin D. Supplementation was not noted in these studies. Ninety percent of those incarcerated >1 year were deficient compared to 37.9% of those who were recently processed. Additionally, only 3.3% of long-term inmates were found to have adequate levels of Vitamin D, compared to 31% of new prisoners [80]. Length of sun exposure available to prisoners may also play a role in deficient lab results [32].

When the nutritional adequacy of food offered was researched at the macro- and micronutrient levels and compared to the recommended intake at that time, it was found that grains were close to the recommendation [32] in one study but were exceeded in another [33]. Protein also exceeded recommended servings in two studies [27, 32], but met recommendations in another [33]. Fat met or was close to the recommendation in all studies [32, 33]. Vegetables, fruit, fiber,

and milk [33], as well as selenium [32], iron, ascorbic acid, [27] Vitamin E, Potassium, and Magnesium [33] were below recommended levels; and sodium [32, 33, 81], sugar and calcium [33] exceeded recommended levels depending on the study. A systematic review found that energy intake for female inmates exceeded the RDA, and were met for males in higher-income countries, however were not met for males in low to middle-income countries [81].

Studies often use menus to assess nutrient content of foods, but did not assess actual consumption to determine whether intake equated to adequacy [81]. However, considering what is actually consumed gives a greater understanding of why certain nutrition lab values may read as deficient in this population. Research showed that when dietary intake of adolescent males who were both incarcerated and living in the community were compared, no significant differences in macronutrients (protein, carbohydrate and fat) were found between study groups. At the micronutrient level, incarcerated adolescents had significantly lower intakes of iron, sodium and copper. Thiamin and Vitamin C for both study groups exceeded the RDA. Food provided to incarcerated individuals offered 3200–4000 kcal/d and met 80% of the RDA for all major nutrients. Calories provided to adolescents in the communities was not noted, most likely due to the variation in foods consumed. It should be considered that although the study participants were instructed not to change the way they ate, the simple knowledge of being studied could have caused them to change their eating habits. It should also be noted that data was recorded differently for incarcerated and non-incarcerated individuals. Incarcerated adolescents were instructed to keep a food log and were also prompted during an interview using the institutional menu to remember items they consumed but did not write down. Those in the community had their dietary recalls done by recall only as there was not a standardized menu to work off of to prompt them on additional foods eaten that were not remembered [82].

Exercise/Nutrition Programs

Exercise has also been studied in this population, as interventions are easily monitored to track progress and compliance, though most will rely on self-report. These studies have been small, convenience samples of participants in a single center, and the results showed an improvement in participant self-esteem [83], body image and emotional wellbeing (reduced anger, reduced stress) [84] for both male and female participants. Exercise interventions ranged from 6–8 weeks, and involved an in-person demonstration of gym equipment, fitness classes [83] and one-on-one fitness coaching [84]. While studies noted differences in athletic ability and body composition, one study discussed that due to the similarity in food and exercise for some paired participants, metabolism and biochemical conditions could be a large influence in results. This study compared adolescents who were in the community and incarcerated, with seven of them being paired siblings. Therefore, to optimize health, adolescents should be treated for their individualized needs [85], especially when considering that with individualized nutrition counseling, nutrient deficiencies were reduced [86].

A systematic review of 31 studies from a range of low-income to high-income countries looked at diet and physical activity of inmates, the majority male (86%). This systematic review, unfortunately, eliminated juvenile offenders from its analysis, though some studies had participants in their teens (>15 years old). The review found that for high-income countries, obesity rates increased greater than rates in low and middle-income countries; however, obesity rates increased for all countries. Male prisoners in the United States were less likely to be overweight/obese compared to the general population of the same age, however female prisoners had similar or higher rates of overweight/obesity. Rates of physical activity differed by country for both male and females, and all physical activity measures were self-reported [81].

Long Term Nutrition Status

Literature on the effect of incarceration on longitudinal health after incarceration during adolescence or young adulthood is associated with worse general health, severe functional limitations, stress-related illnesses, such as hypertension [87, 88], left ventricular hypertrophy [88] and higher rates of overweight/obesity during adulthood [87]. It has also been associated with increased substance use, early mortality, and worse social function [57]. In a study that surveyed adolescent offenders 7 years after release from incarceration found that 33% met the diagnosis criteria for depression, more than three times the rate within the same state [89]. Additionally, juveniles who have been incarcerated have a mortality rate that is four times higher than the general population, with homicide accounting for 90% of deaths [57].

There may be a dose-response relationship for the health outcomes of these individuals, as recidivism of the incarcerated juvenile has also shown to worsen health-risk behaviors and impaired health in adulthood [60]. A study that looked at the length of time incarcerated during youth (<25 years old) found that being imprisoned for >1 month was associated with the worst general health outcomes as an adult and being imprisoned for >1 year is associated with worse mental health and functional limitations as an adult [87]. Seven years after release, one-fifth of surveyed juvenile offenders, both male and female, were not criminally active or in jail, 36% indicated they had a full time job, were in school or in the military [89]. When comparing young adults (age 24–32, 75% male) who had been incarcerated to those that had been convicted of a crime but not incarcerated, those that were incarcerated had poorer health habits (smoking, increased fast food consumption), and were less likely to complete high school [90].

Incarceration likely compounds existing socioeconomic and psychosocial health risks in vulnerable populations. Youth who end up incarcerated may also have worse health initially, such as drug use and mental illness [87]. Incarceration also

displaces youth from their natural supports. For individuals who have poor coping skills, this may lead to increased stress-related poor health behaviors and an increase in depression.

Ninety percent of individuals released from jail are uninsured and lack financial resources to pay for medical care in the community, and mainly use emergency departments for medical needs that will not address chronic health issues [88]. Therefore, to support medical needs once the juvenile is outside of the facility, the American Academy of Pediatrics issued a policy statement in 2001 that children and adolescents in juvenile detention facilities should have a medical home established prior to release [60] to help improve access to medical care and support continued health interventions when living in the community.

Conclusion

There are considerations to make when counseling an individual who is either currently or previously incarcerated. Understanding their unique background and nutritional challenges will be helpful when setting goals either within the facility or in the community.

Based on research available, the current juvenile detention system is lacking in adequate nutrition support for these individuals, which may be impacting their long-term health effects. More research is needed to understand this population from a long-term health perspective. Additional research on the benefit of individualized nutrition counseling from a RD, while adolescents are still incarcerated, would help quantify the need for standardizing this part of the medical care team for this population.

Questions to ask yourself before working with a current or previous juvenile offender

- Do you know the environment they are currently living in?
- Are they still involved in the juvenile system, and does that influence any of the goals or recommendations you are making with them?

- What is their support system currently if they are incarcerated?
- Are they at risk for re-offense, and how will that impact their health?
- What are their risk exposures, and how can those be addressed while also providing evidence-based recommendations?
- How can I better prepare them for taking care of their nutrition health when they are released?

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Part III
Disordered Eating

Chapter 14

Anorexia Nervosa



Robyn Evans Duran and Rebecca Levens

Background

Adolescence is a time of profound physical growth and transformation as the human being transforms from a child to a young adult. It is also a time during which rates of onset of psychiatric illnesses increase. This is thought to be related to the growth and development of the brain during this period. Many times brain development during adolescence is overlooked as attention focuses on the more obvious external markers of pubertal physical development. The brain is also undergoing a rate of growth and development during puberty. After a time of relative quiescence during middle childhood, it has not experienced similar growth and development since the adolescent was a toddler.

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This physical growth combined with genetic factors are thought to support the presentation of various psychiatric disorders during adolescence, including eating disorders and specifically anorexia nervosa [1]. Current research suggests anorexia nervosa evolves under significant genetic influence [2] Emerging research is helping to dispel long-held myths that parenting styles are responsible for eating disorders including anorexia nervosa. Although eating disorders are often conceptualized as a continuum of conditions ranging from morbid obesity on one end and restrictive anorexia nervosa on the other end, current research suggests the underlying genetic markers and subsequent neurohormonal control of the behavior of eating (cognition about food, appetite, satiation and reward processing pathways) are far more complex than a simple linear continuum suggests.

Early descriptions of anorexia nervosa are from religious writings from the eighth century. Frequent examples of restrictive eating disorders are found in the writings of early Catholic saints, including Catherine of Siena. The first medical writing on the illness was by English physician Richard Morton in 1689. The diagnostic term anorexia nervosa was created in 1873. Fast forward nearly a century, it was not until 1980 that the Diagnostic and Statistical Manual of Mental Disorders III (DSM) added a category entitled “Special Symptoms - Feeding Disturbances”. In DSM 5 published in 2013 two diagnostic categories are listed for anorexia nervosa: restricting type and binge eating / purging type.

Diagnostic Criteria

Current diagnostic criteria are as follows:

- Anorexia Restricting Type:
 - A. Restriction of nutritional intake resulting in weight loss
 - B. Intense fear of gaining weight
 - C. Disturbance in the way one’s body weight is experienced (also referred to as dysmorphia).

- Anorexia Binge Eating / Purging Type:
 - The criteria A - C above with either binge eating and/or purging. Purging can be defined as self-induced vomiting, over-exercise, misuse of laxatives, diuretics or enemas.
 - It is important to note that with DSM 5 the earlier criteria of amenorrhea (absence of at least three menstrual cycles) was removed. Additional DSM 5 changes include the addition of Binge Eating Disorder, changes to criteria for Bulimia Nervosa, and a new diagnostic category, Avoidant Restrictive Food Intake Disorder (ARFID), replaced Selective Eating Disorder. These changes allow for the inclusion of more patients for diagnostic consideration, including natal males and patients of higher weight.

Under Diagnosis

The incidence rate of anorexia nervosa is at least 1.7% of the population [3]. It is often cited as the most lethal of psychiatric diagnoses when associated suicides are taken into account [4]. This tragic reality points to the importance of enhanced screening and improved comprehensive care for this difficult to treat illness. It is widely believed that eating disorders in general are under-diagnosed and that the majority of patients do not receive care for their illness. Lack of appropriate screening and accurate diagnosis are likely due to a variety of factors. It is common for medical and nursing students to receive limited instruction on eating disorders during their academic coursework. This lack of academic preparation exists in a broader cultural context of myths and misconceptions about what constitutes healthy eating and western standards of beauty, including cultural preferences for thinness. Stereotypes about eating disorders are pervasive in the culture including beliefs that white females and gay males are more likely to suffer from eating disorders than their non-white or heterosexual counterparts. Other stereotypes sug-

gest a correlation between higher socio-economic groups and higher incidence of eating disorders, when in fact the higher incidence could be explained by increased access to health care. Emerging scholarly work is beginning to uncover the role of weight bias in accurately diagnosing restrictive eating disorders. Some studies suggested higher psychological distress from atypical anorexia nervosa in the previously obese patient with precipitous weight loss as compared to the previously normal weight patients [5]. Studies with representative samples of non-white patients are lacking. Recently published research suggests higher than expected rates of eating disorders in transgender patients [6]. More work is needed to further explore the incidence and experience of eating disorders in LGBTQ youth.

The lack of professional training combined with strong cultural factors often collides with the insidious onset and denial of eating disorder behaviors to create a synergy which eludes timely diagnosis by a qualified professional.

Clinical History and Exam

As with nearly all other illnesses, especially psychiatric conditions, a thorough clinical interview is the cornerstone of accurate diagnostic evaluation. Commonly, and especially with adolescents, it is someone other than the patient who is concerned about mounting symptoms and resulting worrisome physical manifestations. The adolescent patient's motivation to participate in her/his clinical assessment ranges widely from overt refusal to active participation.

In our multidisciplinary clinic in a tertiary pediatric teaching hospital, comprehensive evaluations with a medical provider (physician, nurse practitioner or physician's assistant) typically take between 90 and 180 minutes. Patients are separated from parent(s) for individual history [taking. Spending time individually with the adolescent is recommended by the American Academy of Pediatrics and the The Society for Adolescent Health and Medicine [7]. Parents meet separately

with a registered nurse during this time. Key pieces of information to ask the parents include the adolescent's past medical history and family medical history (specifically about anxiety, obsessive compulsive disorder, depression, substance use, prior attempted and completed suicides and eating disorders).

Initially rapport-building with the adolescent is done utilizing the HEADDSSS assessment (see Table 14.1) [8] in which questions about less sensitive information builds in a stepwise

TABLE 14.1 HEADDSSS assessment

H - Home: With whom do you live?
E - Education: Where to you go to school? What grade are you in? How many times a month are you absent from school? What is your easiest/most difficult class? Are you failing any classes?
A - Activities: What do you like to do for fun? With whom do you enjoy these activities?
D - Drugs: In the past 2 weeks have you taken anything to get high or drunk? Are you worried about a friend or family members drug or alcohol use? Have you ever received a ride in a car from a driver that was drunk or high?
D - Depression: In the past 2 weeks have you felt down, depressed, bored or sad most of the time?
S - Sex: How do you define your gender? What pronouns do you use? Are you attracted to males, females or both? How many sexual partners have you had? When you have sex, what body parts are involved? Do you use condoms and/or dental dams? Are you or your partner using birth control?
S - Safety: Do you feel safe at home and at school? Have you been bullied before (including online)? Have you ever been in a relationship in which you felt unsafe? Have you experienced unwanted touching or sexual contact? Is there a gun at home? Have you ever self-harmed?
S - Suicide: How often do you think of suicide? Do you have a plan to end your life or someone else's life?

fashion to build rapport for gathering information that might be more uncomfortable for the adolescent to disclose. Interviews are prefaced with face-to-face discussions on confidentiality rules specific to the state where care is being provided. Motivational interviewing techniques, specifically permission-asking, is utilized especially when resistance is experienced between the medical provider and the patient. Reassuring patients of a standardized interview process can also help to ease fears and decrease obstacles to communication.

A review of behaviors from the last 24 hours is often a well-received framework for eliciting eating disorder symptoms. This is an opportunity for the clinician to better understand the division of nutritional responsibility at home [9] and exercise patterns, as these are also important to evaluate when diagnosing an eating disorder.

The teen can be asked to describe a typical day using the following prompts:

- What time do you wake up on a school day?
- How long after you wake up do you eat? Who prepares it and what do you eat?
- When do you eat next?
- Do you or a parent pack a lunch for school? Do you buy or receive lunch? Do you ever skip lunch?
- How do you get to and from school?
- Do you have a PE (Physical Education) class?
- What time do you get home from school?
- Do you have an after school snack?
- What time is dinner? Who makes it? Do you eat with a family member or alone? Where do you eat at home (i.e., in a common area or alone in your room)?
- Do you eat after dinner or before you go to bed?
- What time do you go to bed? How long does it take to fall asleep?

Once this is completed, specific questions are asked about restrictive patterns (i.e., certain foods versus complete food groups, “good” versus “bad” food beliefs), purging (over

exercise, clandestine exercise, volitional vomiting, use of laxatives or diet pills). The patient is asked to describe their thoughts and feelings about their body shape and size to determine the presence or lack of dysmorphic thoughts. It is also important to inquire about a number of obsessions, such as counting calories or frequent weighing of self at home, whether or not they have a goal weight in mind and if they fear weight gain.

At this juncture, the clinician may embark on a standard format Review of Systems (ROS). Areas to focus on include the patient's level of fatigue, hair loss or new hair growth, chest pain, swelling of extremities or shortness of breath, abdominal pain and bloating, regularity of bowel movements, as well as presence of headaches and dizziness.

In natal female patients a complete menstrual history should be obtained, including age at menarche, interval, duration and intensity of menstrual bleeding, and an inquiry about any recent changes in the menstrual pattern during the time of weight loss or changed eating and activity patterns. Amenorrhea is a common side-effect of weight loss seen in restrictive eating disorders due to changes in the hypothalamic-pituitary-gonadal system functioning. Bone loss is a common side-effect of chronic amenorrhea (defined as greater than six consecutive months) which requires monitoring using widely available DEXA scans.

Screening should be done to rule out other co-occurring psychiatric conditions, including anxiety, OCD, depression and non-suicidal self-injury. Incorporating validated screening tools can expedite history-taking. Teens are sometimes more comfortable with written measurement tools as compared with the conversational clinical interview.

With this information the medical provider will likely have much of the information needed to begin making an accurate diagnosis prior to completing the physical exam. The physical exam serves to confirm the physical manifestations of the reported behaviors and weight loss and to look for clues which would suggest a diagnosis *other* than an eating disorder from the differential diagnosis. The physical exam should be

performed in the standard fashion with attention paid for common manifestations of eating disorders, which are explained below. In the likely event that the clinician is working with a medical assistant, he/she should be trained to obtain blind weights with the patient turning away from the balance or digital scale. Blind weights should be obtained with the patient dressed in a gown. Clinicians should be attuned to the possibility of weight fabrication. Common methods include water loading prior to appointments, padding bras and underwear and inserting vaginal or anal weights.

It is not uncommon for the patient to present with a cachectic appearance, often with large appearing eyes and sunken cheeks due to loss of facial fat stores. Hair loss and lanugo is also common. For patients routinely engaging in purging the parotid glands will sometimes appear swollen and can be tender. Calluses are sometimes seen on the first or second metacarpophalangeal joints of the dominant hand and result from volitional vomiting. Acrocyanosis is sometimes present on the hands and feet indicating cardiovascular compromise due to weight loss. The skin should also be examined for signs of recent or past self-harm. Common areas include the forearms, abdomen and inner upper legs.

The cardiovascular portion of the exam should be detailed and thorough beginning with a set of orthostatic vital signs. The patient should rest in each position for 3–5 minutes for accurate measurements. Heart rate changes from supine to standing of more than 30 beats per minute indicate orthostasis. Orthostasis is a hallmark symptom of mild and moderate starvation. When the body experiences a change in position from lying or sitting to standing, the heart is too weak to compensate for the additional cardiac output need to supply the upper body with sufficient blood flow. The heart responds by beating faster to make up for its lost strength.

While the patient is lying down the abdominal exam can be performed noting any scaphoid appearance from malnourishment. Special attention should be paid to any distention present as the patient may have water-loaded prior to

her/his appointment to falsify his/her weight. Abdominal percussion can aid the examiner in determining the presence of gas, evaluating a distended bladder and assessing for possible presence of stool indicating constipation. Constipation is common due to delayed gastric motility as a result of inadequate nutrition. With the patient remaining in the supine position, capillary reflex and distal pulses can also be examined. The lower extremities should be checked for swelling and edema.

Laboratory, Radiologic and Diagnostic Testing

The following standard laboratory tests are recommended by current practice guidelines [10] to evaluate the degree of severity of the eating disorder and to look for other causes of weight loss:

- Complete Blood Count
- Comprehensive Metabolic Panel - Electrolytes, Liver Enzymes, BUN/Creatinine, Magnesium and Phosphorus, Calcium, Protein and Albumin
- Thyroid Stimulating Hormone and T4
- Please note that because cholesterol levels often increase during states of malnourishment, measurement of lipids is *not* recommended.
- A urinalysis is sometimes helpful to rule out water-loading by measuring specific gravity.

Results commonly seen in starvation include decreased White Blood Cells, increased ALT liver enzyme, Low TSH with normal T4 and elevations in Protein and CO₂.

A 12 lead EKG is recommended to evaluate for bradycardia, low voltage QTc and pre-existing arrhythmias [11].

Lastly, in female patients who have not had a period for six or more months it is recommended to obtain a DEXA to evaluate for decreased bone density.

Patients, parents and sometimes clinicians are surprised at the lack of significantly abnormal laboratory findings in patients with moderate and severe anorexia nervosa. Unfortunately this can have an adverse effect of further sup-

porting patient and sometimes parents denial about the illness. However, the body has a surprising adaptive response in this regard as it gradually accommodates itself to increasingly less nutrition. What should be noted by the clinician is that often the most critical time period for laboratory monitoring for the hospitalized eating disorder patients is the initial weeks of refeeding during which time patients with severe anorexia nervosa (<75% TGW at admission) face the risk of the potentially fatal condition of refeeding syndrome due to changes in the intracellular metabolic pathways which, with increased glucose utilization, result in decreased potassium, magnesium, phosphorus and thiamine. This results in ominous tissue hypoxia and possible myocardial myopathy.

Less ominous and equally concerning effects of starvation as a result of anorexia nervosa affect nearly every body system as outlined below:

- Hair loss is common and signifies a change in estrogen levels. Lanugo signifies a loss of body fat and the body's attempt to warm itself. Skin breakdown is common especially among patients who compulsively exercise in ways that cause repeated skin contact (i.e., the skin over the spine breaks down after repeated contact with the floor from sit ups).
- Bradycardia and hypotension are common as are changes in circulation that result in poor regulation of body temperature, especially in the extremities, sometimes resulting in stasis and discoloration of the fingers and toes. Dizziness especially with position change is also frequently observed and can in some cases lead to loss of consciousness and increased risk of head injury.
- The gastrointestinal system undergoes a myriad of changes as a result of infrequent and inadequate nutrition. Gastroparesis and constipation are common as the rate of digestion slows in response to decreased food intake. When nutrition is increased in early treatment it is not uncommon for patients to experience temporary gastroesophageal reflux as the gastrointestinal system has a difficult time recalibrating itself for the increased digestive needs. When purging or volitional vomiting is present,

esophagitis is common as are dental caries and erosion from exposure to gastric acid.

- Menstrual irregularities and amenorrhea are hallmark symptoms of anorexia nervosa as the estrogen levels fall below the levels required for regular monthly menses. This level of inadequate estrogen to sustain regular periods also signifies likely bone thinning or interruption of laying down of bone mass during a key time of accrual, usually measurable by six months time.
- In extreme cases of malnutrition a rare complication Superior Mesenteric Artery Syndrome may develop. This occurs when the fat pad between the aorta and superior mesenteric artery decreases in size to the point that the duodenum of the small intestine can become trapped in the now abnormally narrow space between the two arteries. This condition is evaluated using CT Scan.

Only recently are we beginning to more fully understand the neuro-cognitive effects of anorexia nervosa. Published MRI studies show reduction in white matter [12, 13] during the early stages of severe anorexia nervosa. Aside from altered perceptions of one's body and the food it needs, signals for hunger and satiety are dysregulated. Cognitive slowing is also observed in these patients. Patients often complain of difficulty completing school work, struggles with word finding and diminished memory capacity. Decreased cognition often impacts patients' ability to retain information and recommendations from one visit until the next.

Treatment

Despite the widespread systemic effects of malnutrition associated with anorexia nervosa, the most reassuring aspect of treatment is that the cure is easily accessible and affordable for most patients in the western hemisphere, namely consuming food. The challenge of the condition of course is most patient's resolute refusal to consume the cure for their illness.

For clinicians with even a basic understanding of the spectrum of eating disorders, anorexia remains one of the easiest to uncover with a straight forward differential diagnosis. The challenge often lies not in the diagnosis itself but in putting the treatment plan (again simple at first glance) into action. For these reasons, it is helpful to have a clear understanding of one's own comfort in treating these often complex patients and an equally clear view of when it most benefits to refer the patient to a higher level of care.

Patients and parents describe the burden of treatment to be immense and that it is something that often takes over every dimension of their lives. This is understandable when we consider we are asking patients (usually after a long period of food restriction) to eat six times a day by consuming a meal or snack.. For older patients this burden is amplified if they are responsible for purchasing, preparing and serving themselves their nutrition. Food plays an important role in how days are structured and how holidays are celebrated. Eating disorders invade the patient's life in multiple environments. Given the amount of work required and the typical length of recovery, caregiver fatigue is common.

Once emergency hospitalization is ruled out and the patient is advised to receive outpatient care, close follow up is necessary to support recommended nutritional rehabilitation and restore weight. Patients benefit most from having a registered dietitian treating them at regular and frequent intervals. Patients and caregivers often appreciate learning that the typical duration of treatment for most patients with anorexia nervosa is two years.

Higher Levels of Care

For patients needing higher levels of care, consideration should be made to locate treatment at the Intensive Outpatient (<10 hours per week), Partial Hospitalization (20–40 hours a week) and Residential levels. Currently in the

United States lack of insurance coverage poses the most significant barrier to access this level of care. Mental health parity laws helped narrow the gap beginning in the early 2000's. However, lack of acceptance of state-sponsored insurance by higher level of care providers presents a challenge for a great number of patients. Finding competent, evidence based treatment providers and programs can be challenging. The National Eating Disorder Association (NEDA) is often a good place to start to familiarize oneself with local programs.

Consideration for referral to an emergency department should be made for any patient with a heart rate of equal to or less than 50 beats per minute. This cut off does not vary even for the self-identified athlete but may prove to be a point of contention between the treatment team, subspecialty providers, parents and other caregivers. Orthostatic changes of more than 30 beats per minute from supine to the standing position also warrants emergency evaluation. Additional reasons to refer to a hospital include electrolyte disturbances and abnormal EKG. Patients should also be assessed for suicidal risk and self harm at regular intervals.

Patients often fall prey to the disordered thoughts of anorexia nervosa and attempt to convince their healthcare provider they are not sick enough to need a higher level of care. Clinicians should remain confident, steadfast, and unwavering in their recommendations and rely on their team members for support to uphold the same. For patients refusing more comprehensive care, risks of untreated anorexia nervosa, including sudden death, should be reviewed and colleagues in ethics consulted as needed.

Nutrition History and Assessment

This nutrition history and assessment is a critical component of determining the treatment plan for anorexia nervosa, the severity of the illness and the degree of malnutrition. Clinical nutrition evaluation includes the following: anthropometrics,

eating history, current intake, behavioral history, physical activity, physical symptoms and body image [14, 15].

Anthropometric Measures and Treatment Goal Weight

Key anthropometric markers to obtain include current weight, height, BMI, BMI z-scores, median BMI and percent median BMI. In addition to current anthropometrics, learning about historical trends for weight, growth velocity, BMI and body composition are imperative to get a better understanding of growth patterns. Questions should be asked about previous high weight, lowest weight and the dates in which the changes in weight occurred [14, 15]. Age of menarche, last menstrual period and mother's age of menarche can aid in growth assessment for females [16]. If possible, obtaining previous growth records can be instrumental in creating a more complete and objective picture of the growth history [15–17].

With anorexia nervosa, weight restoration is commonly one of the goals for treatment. The amount of weight restoration needed is determined by comparing an individual's current weight to their treatment goal weight (TGW). The dietitian in conjunction with medical provider determine the TGW [15]. Historical anthropometric data helps to inform the treatment goal weight through considering pre-morbid trajectories for height, weight and BMI. The treatment goal weight should also take into account age of pubertal onset and current pubertal stage [15, 17]. Please note that the TGW is not necessarily the same as the weight associated median BMI or BMI at the 50th percentile for age. While this may be an appropriate estimation for some individuals, the comparison to normative population is not always appropriate due to the need to assess weight goals based on individual needs [15]. Median BMI can help to inform a TGW if there is limited growth and weight history available [17]. Of note, further research is needed in order to determine accurate methods of

estimating TGW for individuals who were overweight or obese prior to the onset of the eating disorder. For these individuals, it is still important to review historic trends, often TGW is estimated around the 75th percentile for age [18].

Over the course of treatment, nutrition recommendations will be altered in order to account for normal adolescent growth and development, in addition to weight trends in comparison to the treatment goal weight [14]. During a period of growth it is recommended that an individual's TGW be reassessed every 3–6 months [15]. It is also important to note that once TGW is reached, weight maintenance is often not appropriate in the pediatric and adolescent population due to ongoing growth and development. Even if peak linear height has been reached, there will continue to be changes in body composition and activity, which will result in changes in weight. This is important to discuss with patients and parents during the recovery process [19].

Diet History

The assessment of current eating versus historical eating is another integral part of the assessment. This also includes historical information from childhood. For example, comparisons of changes in eating patterns aid in getting a better understanding of how eating habits have changed over time. It is also important to assess for food allergies, food intolerance, preferences, dislikes and restrictions/avoidances [20]. In the adolescent population, it is helpful to complete the assessment with both teen and parents, in order to obtain an accurate diet recall, as it can be difficult for the patient to separate out behaviors that are tied to the eating disorder [21]. Reported intake through a 24-hour recall and reported general intake patterns allow for a critical assessment of how current intake compares to estimated energy needs. This also provides detail regarding accepted foods in comparison to foods that are being omitted such as energy dense foods like fats or sweets or animal protein. Dieting history in patient

and family members, family eating habits, cultural food practices and infant/childhood feeding as well as eating behaviors should be discussed in order to obtain a complete picture of the eating habits [14, 20]. It is also helpful to assess for food insecurity, using the following validated questions: (1) Within the past 12 months, we worried whether our food would run out before we got money to buy more (Yes or No) (2) Within the past 12 months, the food we bought just didn't last and we did not have money to get more (Yes or No). Screening results may be shared with social work and the team, allowing for connection to resources as needed [22]. All of the information in the assessment also helps to assess parents' food beliefs and food practices, which can impact the ability for families to implement nutrition recommendations [14, 20].

Eating Behaviors

The assessment of behavior history includes gathering information about specific eating disorder behaviors. For example, frequency of restriction, bingeing, use of caffeine laxatives, diuretics or appetite suppressants, calorie counting and diets. When assessing for binge-eating behaviors, assessing the frequency this is occurring in addition to the patient's description of what qualifies as a binge. Sometimes patient's perception of a binge can be distorted due to the degree of restriction and presence of early satiety. It can also be helpful to discuss the timing of life transitions such as changes in family systems and school changes, as these can relate to changes in eating behaviors [20].

Physical activity patterns, currently and historically, are additional aspects of the nutrition assessment. With this it is vital to review the frequency, intensity, duration and type. Information about the motivation, with whom the activity takes place and where can help to illuminate the degree to which these behaviors are tied to the eating disorder. For example, activities that are geared at changing a specific part of one's body, especially when done alone, are behaviors that

are likely tied to the eating disorder. This is different from someone who enjoys movement or the social aspects of activity, such as participating on a sports team. These differences help providers understand the compulsive or compensatory nature of physical activity [20]. Additionally, it is common for providers to work with individuals who are also athletes. If a patient is involved in a team sport with intensive practices and insists on additional strength training and/or cardiovascular activity, it is imperative to work with the team on adjustments to moderate activity. Practices alone typically provide an adequate amount of physical activity. The Safe Exercise at Every Stage (SEES) guideline is a helpful tool that medical providers can use to determine physical activity recommendations for patients [23].

Physical and physiological characteristics are another component of the nutrition assessment. As part of this there is the assessment of the frequency and consistency of bowel movements due to this population often having constipation from inadequate energy intake [20]. The presence of hunger and fullness cues gives additional information regarding what is occurring internally. Often, this population experiences early satiety due to restriction and inadequate energy intake. The early satiety can make it hard for individuals to increase their intake, as this can also be accompanied with nausea. Due to inadequate intake, the digestive tract has slowed and requires re-introduction of adequate nutrition in order to function optimally [19–21]. Age of menarche, last menstrual period and sleep changes are additional hormonally-based changes that should be assessed for, as both can be disrupted as a consequence of inadequate intake [15, 16, 20]. Visual, and if trained, physical assessment can offer additional information. Nutrition-focused physical exams (NFPE) have been identified as a valuable tool in determining the degree of malnutrition [24, 25]. Depending on the degree of malnutrition, adolescents with anorexia nervosa may have depleted total body fat and protein. In addition to the assessment of body weight and BMI, the use of triceps skinfold measurements can be used to help to assess body composition and

nutritional status. Triceps skinfold in combination with the mid-upper arm circumference, allows us to calculate the upper arm fat area and the upper arm muscle area [26]. Results are compared to reference tables and are considered to be an estimate for total body fat and protein [26, 27]. In our clinic, during the weight restoration process, triceps skinfold measurements are taken every 3–6 months to calculate arm muscle area, and moreover to educate the teen, about the repletion of fat and muscle. Physical assessments can also be helpful to identify micronutrients deficiencies and to note any changes in hair, skin, nails and eyes [20, 25].

Body image is a complex and critical component in the diagnosis of anorexia nervosa. To get a general sense of the degree of body image concerns, this can be assessed through asking questions about self-perception and how one feels about their body. A more detailed assessment includes questions about body checking, which is the practice of frequently looking at one's own body or pinching folds of skin. Body checking may be focused on a specific body part such as the stomach. Additional questions, which can be helpful to assess body image concerns include the frequency of self-weighing, stated desired weight, and the willingness to restore/gain weight or increase intake [20]. Work to improve body image is primarily done in therapy sessions, although other team members can work to uncover meaning and assess the impact of the body image concerns on the eating disorder behaviors [20, 28].

A new demographic of particular concern is adolescents with a history of being overweight or obese. Research indicates that identification and treatment of eating disorders in this population is often delayed because of their weight history. While these individuals may appear healthy or be within the healthy range of BMI percentiles, they are often considered equally, if not more, malnourished when compared to underweight individuals [14]. Additionally, with rapid rate of weight loss, this population is at high risk for medical complications from the eating disorder [15]. It is critical to be attuned to the presence of eating disorder behaviors in this population.

Treatment Options and Goals

Treatment Team

An integral part of eating disorder treatment is the multidisciplinary care team. This team consists of an adolescent medical provider, dietitian and a mental health provider [29]. In our clinic, we also utilize social workers and nurses as part of the interdisciplinary team. In an ideal state, all providers have experience and expertise with adolescents and with treating eating disorders, although this is not always possible. The role of the medical provider is to assess for normal growth and development, monitor for medical complications and signs of malnutrition, and provide medical clearance for physical activity [15]. The dietitian's role is to provide recommendations to ensure adequate nutrition intake for weight restoration, reversal of signs of malnutrition and to support normal adolescent growth and development. In addition to this, the focus is on normalization of eating behaviors and increased flexibility with eating [14, 15, 30]. As noted previously with medical providers, there are different levels for the nutrition provider. It is important for this team member to be a Registered Dietitian (RD). Registered Dietitians are credentialed through the Academy of Nutrition and Dietetics, which is recognized internationally. RDs have at minimum obtained a bachelor's in nutrition, have completed supervised practice and have passed a registration examination. Additionally, there are minimum continuing education hours to complete every five years. The distinction between a RD and other nutrition professionals such as Certified Nutritionists (CN) is important to note [31]. Mental health providers operate under several different job titles, including psychologists, licensed therapists or counselors and Licensed Counselor of Social Work (LSCW). The role of the mental health provider, is to provide individual, group and/or family therapy, which are considered to be cornerstones of eating disorder treatment. The goal of the therapist is to address eating disorder cognitions, assist patients in understanding situations which

may increase eating disorder thoughts and to develop coping skills to manage these cognitions, and help to develop positive self-esteem and body image [32]. In our interdisciplinary team, social workers complete a psychosocial assessment. This is a valuable tool that provides additional family history and aids in identifying where the patient and family are in regards to treatment. Social workers also connect families to additional community resources that may be needed. Both our social workers and nurses help to provide families education about eating disorders and strategies for behavior management during the treatment process.

FBT/Maudsley Approach

Most adolescents can be managed as outpatients, and family-based therapy (FBT)/Maudsley approach is the first-line, evidence-based approach for treatment, which has multiple clinical trials [15, 19]. Timely intervention is critical since improved outcomes are associated with shorter duration of illness [15]. FBT is based on the principle that parents involvement is an integral part of treatment and is vital to therapeutic success. FBT works to build on parental strengths and this treatment model has parents at the center of changing the eating disorder behaviors of the adolescent, by empowering them to provide their child with adequate nutrition to restore health [15, 19]. It is important to note that parents are not to blame for their child's eating disorder [33].

There are three phases to this treatment approach, each with specific goals. The ultimate goals of treatment are physical, behavioral and psychological recovery [19]. The focus of the first phase is on weight restoration [15]. During this phase parents are recommended to be in control of the food choices. Making decisions about food is often difficult for an adolescent who is recovering from an eating disorder. Depending on the degree of malnutrition present, an individual's cognition may be distorted, so it can be very challenging to self-feed the quantity and types of foods necessary for recovery.

Therefore, especially early on in treatment, it is recommended for parents to be involved in food selection and portions. Removing choice from the patient, allows the individual to focus on providing their body with the nutrition that it needs to recover. When prompted with choice, the adolescent is continually being asked to choose whether he or she gives into the eating disorder thoughts or not. During this phase there are often food exposures, which are used to target anxieties and aversions to specific foods or food groups [19, 33]. Parents/caregivers may need education in creating balanced meal/snack composition in order to meet the adolescent's high energy needs. In our clinic, the standard is for energy needs to be met without the reliance on nutrition supplements or by sneaking high calorie foods into meal/snacks.

Once energy needs are consistently being met, weight restoration has occurred (typically 90–95% TGW) and the adolescent has discovered effective tools in therapy, the adolescent may become more involved in food selection [31]. The second phase of treatment gradually returns developmentally appropriate control of eating over to the adolescent. These changes can include food selection and food preparation [15, 19]. Examples of interventions include selecting part of the meal, portioning with parental oversight and choosing between two equivalent snacks [33]. Of note, parents or caregivers may need guidance on the division of responsibility for feeding and reasonable expectations around food behaviors based on developmental stages [34].

The final phase is based on reaching and sustaining a healthy weight, in addition to behavioral progress in regard to independence with eating. This phase addresses relapse prevention plans, adequate nutrition to support normal adolescent developmental changes and addressing other developmental challenges, such as school work and peer relationships [33]. FBT usually occurs over a 6–12 month time period [19].

In FBT, in addition to the previously mentioned metrics, the absence of eating disorder thoughts is also an important goal, although it is not uncommon for these thoughts to be

present beyond the phase of weight restoration. These cognitions usually normalize around one year later [31]. Research has demonstrated that 50–60% of patients engaged in FBT achieve full remission within one year, and 25–35% with improvement in eating disorder symptoms but not full recovery [19]. Early weight gain of 4–5 pounds within the first month of treatment is considered a strong indicator of prognosis for full recovery [33].

Alternative Approaches to FBT

While FBT is considered the evidence-based approach to treatment of anorexia nervosa, it is important to note that when FBT is not considered to be an acceptable or sustainable option, there are other therapy options available [21]. These include Individual or Adolescent Focused Therapy (AFT) and Cognitive Behavioral Therapy (CBT). These approaches are patient- and family-centered and also work with an interdisciplinary team. AFT is individual therapy which is focused on autonomy and self-efficacy within the context of adolescent development. As part of the focus on individuation, adolescents learn skills to manage their own eating and progress with weight gain. Additionally, there is a focus on increased awareness and ability to tolerate emotions. CBT is another type of individual therapy, which has been shown to be effective in adolescents with bulimia nervosa, and is being adapted for those with anorexia nervosa. In CBT the focus is on the management of behaviors and distorted cognitions associated with the eating disorder [21]. Please note that evidence and efficacy for these treatment options is limited, although ongoing studies continue to be conducted [19].

Nutrition Recommendations

Nutrition interventions consist of an oral diet which encompasses nutritional adequacy, balance, variety and flexibility

[28]. Regular meals and snacks are recommended to be consumed approximately every 2–4 hours. This results in 3 meals and 2–3 snacks depending on physiological needs. This meal pattern helps to allow the body time to digest the food and then have a break from eating before the next meal or snack. It also helps with the return of normal hunger and satiety signals. Sometimes time limits for meal and snack times need to be enforced in order for meals/snacks to not be stretched out, which can result in eating times blending into one another. It is recommended that meals take no longer than 30 minutes and snacks no longer than 15–20 minutes. When reviewing meal pattern recommendations, this can also be used as an opportunity to provide education to patients and caregivers about how food works in our bodies and the physiologic needs for energy. Additional information can be found in Chap. 4.

It is common to see patients with vegetarian or vegan diets. If this diet is inconsistent with family food practices or has emerged as part of the eating disorder, it is recommended that these diets are not honored. This is especially true for vegan diets since it can be difficult to meet macronutrient and micronutrient needs during the refeeding process on a vegan diet due to the volume of food that needs to be consumed [28]. It is typically recommended that the individual eat the same foods at the rest of the family in order for family members to facilitate modeling of normal eating [32]. Additionally, individuals with anorexia are often restrictive with the types of foods that they will eat. Part of the treatment process is reintroducing foods that the individual ate prior to the onset of the eating disorder. It is important for moderation and variety to be emphasized, and to moving away from the dichotomy of “healthy” or “good” vs “unhealthy” or “bad” foods [20].

The amount of food to be included at each meal and snack time depends on individual physiological needs. For patients with anorexia, typically a high calorie, moderate protein and moderate fat diet is recommended [28]. Equations for caloric needs and macronutrients can be used as a starting point for

providers, and should be adjusted based on individual patient needs. During repletion and weight restoration, it is recommended to use the resting energy expenditure (REE) multiplied by a stress factor. A starting point for stress factors is 1.5–1.8 and increasing as needed in order to promote appropriate weight gain [28]. Patients with eating disorders often have high caloric needs, especially if there have been significant muscle loss and malnutrition. As refeeding begins, these individuals are considered to be in a hypermetabolic state, which means that these patients are very efficient at using the energy from food. In order for weight restoration to occur, a very high calorie diet is needed [19]. It is possible that an individual may need a stress factor as high as 3.5–4.5 [28]. It is important to note that this hypermetabolic state can remain up to two years from the start of the refeeding process. Often caloric needs are 3000–6000 kcal/day, depending on the degree of malnutrition and activity level [19]. Individualized treatment with regular assessment assists in ensuring knowledge of current needs.

Macronutrient recommendations are typically as follows:

- Carbohydrates: normal dietary recommendations (45–65% of total calories), unless higher fat intake is needed in order to meet estimated needs for weight gain
- Fat: normal to high fat intake (25–35% + of total calories) as needed for weight gain without excessive food volume
- Protein: normal dietary recommendations (10–30% of total calories), which is generally achieved with eating regular, balanced meals and snacks at estimated goal caloric level [28]

Typically, maintenance fluid needs are appropriate for this population. Through regular consumption of beverages at meals/snacks and water throughout the day, fluid needs for the day are met. Typically specific fluid recommendations are not needed, although they can be helpful when fluids are restricted and complications from this are present. Fluid needs are calculated from the actual weight [28].

Equations are as follows [14]:

- 10–20 kg: 1000 mL + 50 mL/kg for every kg above 10 kg
- 20–40 kg: 1500 mL + 20 mL/kg for every kg above 20 kg
- >40 kg: 1500 mL per body surface area [$m^2 = \text{square root}(\text{height in cm} \times \text{weight in kg}) / 60$]

Levels of Care

Levels of care for treatment, in order of increasing level of intensity, are as follows: outpatient, intensive outpatient (IOP), partial hospitalization (PHP), residential and hospitalization. Research suggests that outpatient is the ideal level of care for adolescents, although there may be times when an individual needs to be hospitalized due to medical complications of the eating disorder prior to the initiation of outpatient care [15]. Outpatient treatment consists of regular visits with all treatment team members. IOP, PHP and residential are treatment options offered by treatment facilities across the country. PHP and IOP offer high levels of support systems than is offered outpatient [20]. The level of care needed should be determined on an individual basis taking into consideration medical complications, severity and duration of eating disorder behaviors, safety considerations, an individual's support system and family preference [19, 20].

Goal of Care

Outcome goals for treatment of anorexia nervosa include weight restoration at a goal of 0.5–1 pound per week (if underweight), resumption of menses (which typically occurs at 95% estimated treatment goal weight), metabolic recovery, reversal of medical complications, improved psychological functioning, improved body image, improved and normalized eating behaviors, optimization of growth and bone development, age-appropriate independence around eating and par-

ent/patient education on relapse [15, 16, 19]. It is important for these treatment goals to be shared with patient and caregivers, although the pace at which it is communicated should be individualized based on the particular adolescent and family.

Case Studies

Case One

Jared is a 12-year old boy brought to clinic by his mother. He is described as a life-long selective eater. His mother brings in a list of foods categorized by his willingness or lack of willingness to eat them (i.e., red = never, yellow = sometimes, green = always). His pediatrician became concerned during the last 18 months when his weight did not increase. Jared has not had a significant past medical history. He was born at term and weighed 7 pounds 4 ounces. There were no feeding issues earlier in life other than the mentioned selective eating. Jared's parents often wonder if he may exhibit behaviors consistent with mild autism, however he has not been formally assessed. Jared expresses a desire to gain weight. He is fearful he will be forced to eat food he doesn't like as part of his treatment.

1. Does Jared have anorexia nervosa? If not, what diagnosis more accurately fits his constellation of symptoms.
2. How might Jared and his parents benefit from working with a registered dietitian during his treatment?
3. At what point would it be appropriate to refer Jared back to his pediatrician?

Case Two

Emma is a 16-year old female brought to clinic by her parents due to conflict in the home about eating. Emma developed rigid beliefs concerning food over the last year as she experimented with removing specific food groups from her diet for extended periods of time. Emma denies this was motivated

by a desire to lose weight. Her weight, while it has fluctuated 3–5% up and down over the last year, has essentially been stable. Her menses are monthly. Emma reports that her motivation to remove food groups from her diet was often due to suggestions made by friends or based on what she read online. In her words she wants “to be healthy”. She also admits she often feels lost and confused about what it means to be a healthy 16-year old. Emma’s only exercise is physical education at school. Emma’s scores for anxiety are moderately elevated while her depression scores are low.

1. Does Emma have anorexia nervosa? If not, which diagnostic category best fits her presenting symptoms?
2. How might Emma benefit from working with a registered dietitian?
3. What would need to change with Emma’s symptoms to raise concern that she was developing anorexia nervosa?

Case Three

Isaac is a 17-year old male seen for 20 pound weight loss in the last 4 months while he participated in a highly competitive rowing team. He is referred due to bradycardia ranging from 52–58 beats per minute. Isaac comments to his parents and siblings that he is “fat”. He will often stare at the mirror in his bathroom for 40 minutes at a time and grab and pinch parts of his body that he feels are “obese”. Isaac would like to lose another 10 pounds and says he would like to have better muscle definition in his abdomen and upper arms. Isaac often complains of dizziness when standing up and was started on an over-the-counter stool softener for constipation. He is often cold and typically wears more layers of clothing than his family members and friends. Isaac is a straight A student although recently he is having an increasingly difficult time completing homework on time and is worried he may get a B in his most difficult subject, physics. To enhance his athletic performance he is eating only meat and vegetables. He often adds in additional work outs in addition to what he does with his rowing team. At the recommendation of his pediatrician,

his parents have attempted serving him increased portions of foods at meals and snacks. He responded to this by throwing his plate at the dining room wall and yelling at his parents that “they are trying to fatten him up”

1. Which eating disorder diagnosis most closely matches Isaac’s symptoms?
2. Which approach to treatment would according to published evidence likely lead to resolution of his symptoms in the shortest amount of time with a better long term prognosis.
3. In your opinion should Isaac continue to participate in rowing?

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Chapter 15

Bulimia Nervosa



Michaela Voss and Amber Brust

Introduction

Adolescence is a critical time period in life where many changes are occurring physically, emotionally and socially. It is this time period that experimentation occurs, and self-image evolves. Unfortunately, these traits also place adolescents at risk for negative health behaviors. Concerns about peer conformity, reputation and sexual interactions are all common psychosocial factors that can trigger body image disturbances. These, combined with genetic, environmental, cultural and psychological traits, can set up an adolescent for developing an eating disorder. Unfortunately, only 20% of adolescents with eating disorders seek treatment, so it is important that those who routinely interact with adolescents be aware of the common traits, concerns and risk factors associated with eating disorders [1]. The eating disorder bulimia

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nervosa is no exception, with onset most commonly occurring between 16 and 17 years old [2]. This chapter focuses on the diagnosis and multidisciplinary management of bulimia nervosa in adolescents, expanding on the nutritional components specific to this population.

Case

Olivia is a 16-year-old Latina female who had to drop out of cheerleading due to an ankle injury. To account for the decreased activity, she changed her eating habits by eliminating carbohydrate-containing foods such as rice, tortillas, and high sugar items such as cookies and ice cream. However, she became increasingly discouraged because her weight was continuing to climb, and she was hungry all the time. For the past 3 months, she has episodes almost nightly where she “gives up” and eats large quantities of food at night, often eating an entire box of cookies or bag of cereal. Afterwards, she feels guilty for eating so much and is disappointed in herself. In response to these feelings, combined with her fear of gaining more weight, she vomits to “eliminate” the food from her body.

Criteria

In the most recent version of the Diagnostic and Statistical Manual of Mental Disorders, DSM-V, Bulimia Nervosa is defined by five criteria (See Table 15.1). There must be reoccurring episodes of binge eating followed by reoccurring inappropriate compensatory behaviors. These behaviors must occur, on average, at least weekly for 3 months. In addition, self-evaluation must be “unduly influenced by body shape and weight.” [3] Despite the fact that these episodes must occur outside a diagnosis of anorexia nervosa, 25% of those who meet criteria for bulimia nervosa have a previous history of anorexia nervosa [4], indicating these disorders often overlap.

TABLE 15.1 DSM-V diagnostic criteria for bulimia nervosa

Criteria	Current severity	Remission
A. Recurrent episodes of binge eating	This based on the number of inappropriate compensatory behaviors per week, on average A. Mild – 1 to 3 B. Moderate – 3 to 7 C. Severe – 8 to 13 D. Extreme – 14 or more	The following remission markers can be used if (1) all criteria for bulimia nervosa was previously met and (2) it is indicative of the past 3 months A. Partial – Some, but not all, criteria are no longer met B. Full – All criteria are no longer met
B. Recurrent inappropriate compensatory behaviors in order to prevent weight gain		
C. Frequency of binge eating and inappropriate compensatory behaviors occur, on average, at least weekly for at least 3 months		
D. Self-evaluation is influenced by body shape or weight		
E. Symptoms are not occurring exclusively during episodes of anorexia nervosa		

A binge episode is defined as eating a larger amount of food than most people would within a discrete amount of time – usually less than 2 hours – while feeling a lack of control over what or how much is eaten. Binge eating is often used as a coping mechanism in response to a particular event, behavior or emotion. The most common precipitating emotion is an internal negative response to an emotional challenge, often described as a negative affect. Other common causes that prompt a binge include: negative feelings related to weight, body shape, body size, or food; current stressors;

restrictive intake or fasting; and boredom. Because people who binge often feel ashamed, they will attempt to hide their binges by eating in private, at unusual times of the day or night, or in multiple locations.

Although not necessary for a diagnosis, individuals will often describe strong emotions associated with a binge. Commonly, people state that a binge provides relief, calm, or distraction. Occasionally, individuals will describe a dissociative quality, meaning they feel outside of their body or as if they are watching themselves from afar. Following the binge, however, are negative thoughts that are often described as shame, guilt, or disgust. It is usually these thoughts that lead to a compensatory behavior.

A compensatory behavior, or purge, is defined as the use of one or more inappropriate method(s) to prevent weight gain. These behaviors may include vomiting, use of laxatives, diet pills, diuretics or other medications, excessive exercise, or fasting. Although vomiting is the most common method, most individuals employ a variety of methods. Vomiting, itself, can also produce a strong sensation of relief, and sometimes becomes the reason for a binge.

In order to further classify bulimia nervosa for communication or billing purposes, the DSM-V delineates severity and remission. Severity is described as mild, moderate, severe or extreme and is dependent upon the frequency of inappropriate compensatory behaviors (See Table 15.1). Remission can be described as partial if some, but not all, of the criteria remain after a period of time; or complete, when all criteria are no longer met after a period of time.

Epidemiology

Bulimia Nervosa affects all ages, races and genders. The peak incidence is 16–20 years old, but the average age of onset is decreasing. Although predominately diagnosed in females, male rates are thought to be under-representative. The incidence of bulimia nervosa varies based on age and region but

is thought to be between 40 and 500 person-years. This means, for any given year, there is thought to be between 40 to 500 cases of bulimia nervosa for every 100,000 people. Lifetime prevalence represents the percent of people diagnosed with bulimia nervosa at any point in their life and is thought to be around 0.9–2.9%. In adolescents, the lifetime prevalence rate was found to be 1.3–1.6% in females and 0.1–0.5% in males. Bulimia nervosa is more prevalent in Hispanics/Latinos than non-Latino whites, with a lifetime prevalence of 2% and 0.51%, respectively. Those with bulimia nervosa are almost twice as likely to die than the general population, with almost a quarter of deaths accounted for by suicide [5].

Etiology and Risk Factors

The etiology of eating disorders is not fully understood but is known to be multifactorial. Genetics, environment, and psychosocial factors are all determinants. A relative of someone with an eating disorder is ten times more likely to develop an eating disorder than a relative of someone without an eating disorder [6]. In addition, adolescents with caregivers (defined as any family member or guardian who is largely responsible for a child's health and well-being) who have a mental illness or express rigid or negative views on weight are at greater risk of developing bulimia nervosa [7]. Individual traits posing a risk for development of bulimia nervosa include low self-esteem, depressive symptoms, social anxiety, and a history of childhood sexual or physical abuse [8].

Co-morbidities

Comorbid psychiatric disorders are common in those with bulimia nervosa. Up to 90% of these patients will have at least one episode of a mood disorder, most frequently depression. Other psychiatric comorbidities include Attention

Deficit/Hyperactivity Disorder (AD/HD) (30%), Oppositional Defiant Disorder (ODD) (11%) and Obsessive Compulsive Disorder (OCD) (7%) [7]. Borderline personality disorder is the most common personality disorder seen. Thirty percent of those with bulimia nervosa will abuse alcohol or stimulants, usually in attempt to control weight. Bulimia nervosa patients also have an increased risk for self-harming behaviors, such as non-suicidal cutting or burning, and suicide [3].

Prognosis

Bulimia nervosa identified in adolescence has a better recovery rate than if identified later in life [9]. One review reported that, overall, 45% of patients had a full recovery, 27% had improvement in symptoms, and 23% had a chronic course. Negative and protective factors are listed in Table 15.2.

Screening

Using a screening tool can help identify those with potential eating disorders. There are a variety of screening tools that can be used. One should take into consideration the environ-

TABLE 15.2 Prognostic factors in bulimia nervosa

Negative prognostic factors	Positive prognostic factors
Continuous overemphasis on body shape and weight	Younger age at presentation
A history of physical maltreatment	Shorter duration of illness
Disturbed family relationships	Less frequency of symptoms
Poor motivation	Absence of laxative use
Self-injurious behaviors	Close social relationships
Presence of a personality disorder	A good therapeutic response within the first month of treatment

ment, time, interpretation, and cost that best suits the needs of the provider and patient. Additionally, allowing for development of a plan for intervention for when there are positive results should be considered.

The most common screening tools used in a primary care setting are those that screen for general eating concerns. These include the SCOFF and the Eating Disorder Screen for Primary Care (EDS-PC). Both are brief questionnaires that have been validated for low to normal weight subjects. For more in-depth screening, there are validated eating disorder tools that discern various eating disorder behaviors. The Eating Pathology Symptoms Inventory (EPSI) is a 45 item self-report measure utilizing Likert scale sums to identify a variety of eating disorder pathologies, including binge eating and purging. It is currently validated for ages 14 years old and greater [10]. Other scales include the EDI-3, EDE-Q, and EAT. A screening tool is not necessary, however. A structured clinical interview, as outlined below, may be just as effective in diagnosing most eating disorders, including bulimia nervosa [11].

Confidentiality

An important first step in establishing care and fostering rapport with an adolescent is to define terms of confidentiality and its limits. Confidentiality should be discussed with both the adolescent and his or her caregivers present, so that each party understands the confidentiality laws and limits. Typically, this means that private concerns discussed with the clinician will not be shared unless something is expressed that appears life-threatening or dangerous to oneself or others. Studies have shown that after defining confidentiality and its limits, adolescents are more likely to share private information [12]. In situations where dangerous or life-threatening information is shared, we recommend openly discussing your concern about the adolescent's safety (or the safety of others) and the need to divulge this information to their caregiver.

In addition to asking sensitive questions about eating behaviors and body image, it is imperative that the clinician ask about the adolescent's life and their unique world. This helps build rapport as discussed in the 'Communication with Teens' chapter and helps provide the clinician with a picture of the adolescent's daily life, which influences his/her eating cognitions and behaviors. It is not uncommon to experience dishonesty or a lack of full disclosure in the early stages of treatment due to the secretive nature of eating disorders and the shame experienced by many individuals with eating disorders, including bulimia nervosa. When the clinician asks questions and listens without judgement or interjection, the adolescent begins to gain trust. With a foundation of trust, the adolescent will be more likely to share honestly and adhere to treatment recommendations [13].

Case Continued

Olivia's caregivers find hidden candy wrappers under her bed and notice she uses the bathroom after dinner every night. They become more concerned after receiving a phone call from Olivia's coach. Olivia confided in the coach that she is worried she has an eating disorder and that this might preclude her from returning to the team. Caregivers schedule an appointment with their primary care provider for the following day.

Medical Assessment

Often patients with eating disorders will present for reasons other than the eating disorder and may try to hide their disorder from the clinician. This is especially true for those with normal body weight, such as in bulimia nervosa. However, the astute clinician can identify bulimia nervosa through careful questioning and evaluation.

An initial medical appointment requires taking a detailed history of the present medical condition as well as any past

medical conditions, pertinent family history and social history. Extra time should be allotted for initial visits to ensure accurate assessments, treatment, and so education can be provided. If time is a consideration, it is often helpful to have trained nursing staff take a detailed history, so they can assist with interviewing the caretakers while the provider interviews the patient. Alternately, if working with a team, it can be helpful for the entire team to be present during the initial history taking. Typically, this includes a medical provider, a registered dietitian (RD) and a social worker or therapist. This format prevents the patient from having to repeat information that can often be difficult to discuss and allows for clinicians to clarify needed information. Important questions to ask at an initial visit are highlighted in Table 15.3. It is best if the adolescent can provide as much information as possible, with the caregivers assisting as needed.

TABLE 15.3 Eating disorder specific questions to ask during an initial medical interview

General	When did the behaviors start? Can you identify anything that may have contributed to the start of these behaviors? Do you feel guilty when you eat? Do you feel fat? Do others think you are too thin? Is anyone worried about your eating habits? Do you find yourself constantly looking in the mirror? Focusing on your body shape or size? Pinching parts of your body? Wanting to hide your body? Making comments about your body? What kind of exercise do you do? When and how often do you exercise?
Weight	Do you know your highest weight? Do you know your lowest weight? Do you have a goal weight or a number you don't want to exceed? Where did you get this number? Do you weigh yourself? How often? How does this effect your behaviors for the day? Is there a scale at home? School? The gym?

(continued)

TABLE 15.3 (continued)

Nutrition	<p>What meals did you eat before you changed your eating habits? (i.e., did you eat breakfast every day?)</p> <p>What does the dinner routine look like at home?</p> <p>Do you mostly eat at home, out, both?</p> <p>Who does the cooking? Shopping? Has this changed over time?</p> <p>Do you request special foods?</p> <p>Where do you sit when you eat (in your room, at the table, in front of the TV, etc.)?</p> <p>How much fluid do you drink in a day?</p>
Restriction	<p>Do you count calories?</p> <p>What is your calorie goal for the day?</p> <p>Do you read labels? What are you looking for?</p> <p>Do you keep track of your intake with an app or by writing it down?</p> <p>Do you have any foods that you used to eat, but no longer do (i.e., fear foods)?</p> <p>Do you use caffeine, diet pills or excessive water to help you feel full?</p>
Binge	<p>Do you ever eat beyond fullness?</p> <p>Do you feel you can't stop eating or lost control over eating?</p> <p>Do you get a sensation of being disconnected or outside of your body while eating?</p> <p>How often do you binge?</p> <p>Is there a particular time of day you tend to binge?</p> <p>How do you feel before, during, after the binge?</p> <p>What types of foods do you crave during a binge?</p> <p>Do you purge afterwards?</p>
Purge	<p>Do you ever do anything to rid of the calories you ate?</p> <p>Have you ever used laxatives or diuretics to help you lose weight?</p> <p>Do you exercise immediately after eating?</p> <p>Have you vomited on purpose? If so, what do you use to make yourself vomit? How often? Where (home, school, room, bathroom, etc.)? Any blood or bile in the vomit? What oral care do you do afterwards?</p> <p>How do you feel before, during, after purging?</p>

During the assessment, any past medical diagnoses should be noted. For females, it is important to gather a menstrual history. Irregular, infrequent, or prolonged menstrual bleeding is not typical after the first 2-3 years post-menarche (date of first period). Family history should be targeted towards those conditions that could explain recurrent vomiting or weight changes (such as endocrine or GI conditions) or would put the patient at high risk for complications (such as prolonged QTc syndrome). A family mental health history should include disorders around weight (eating disorders, obesity, orthorexic behaviors) and assess for the most common co-morbidities (see above). Ideally, a social history is obtained in private and includes safety, history of abuse, bullying, drug/alcohol/tobacco use (noting if these substances are used for weight management), gender and sexual identity, self-harm, and any suicidal ideation or attempts. A review of systems should target common symptoms of malnutrition as well as those associated with overeating and/or vomiting. Once an eating disorder is established, the goal for a medical provider is to determine associated health risks and if medical stabilization in an inpatient setting is needed.

In addition to the medical admission criteria for those with severe malnutrition (see Chap. 14), bulimia nervosa patients may need to be admitted for instability directly related to purging behaviors. This includes loss of consciousness/passing out (usually due to dehydration), intractable vomiting, esophageal tears, hematemesis (coughing up blood), cardiac arrhythmias, hypokalemia (low potassium levels), hypochloremia (low chloride levels), suicidal ideation, or outpatient treatment failure [14]. Ideally, these patients should be admitted to a hospital that has access to clinicians that specialize in the management of eating disorders in adolescent and young adult patients. Changes in labs and physical exam findings are often subtle but, if found, can prevent further serious complications such as refeeding syndrome. Patients also need to be monitored closely for surreptitious exercise and vomiting, as this will likely delay their discharge. The inability to limit these traits also provides insight that the patient may need a

higher level of care prior to outpatient treatment (see Section “[Treatment](#)” for the definition of higher levels of care).

If immediate medical admission is not warranted, then the visit should shift focus to assessment of current risk factors for decline in physical health and education on protective and preventative measures. In private, the clinician should ask about the methods used for purging (i.e., vomiting, laxatives, exercise, etc.), the frequency of binge/purge cycles, the typical location binge/purge cycles occur, and any associated feelings of euphoria or guilt. If the patient is purging via forceful vomiting, the clinician should ask what objects or methods are used to initiate vomiting, if there has been blood or bile in the vomit, and if any oral care measures are used after purging. It is important to not judge or try to “fix” the purging behaviors, as there is often a great deal of shame associated with them. This type of response can lead to omission of future event reporting, ultimately increasing the potential for a major medical complication.

Physical Exam Work-up and Treatment

Physical exam findings in adolescents with bulimia nervosa are often subtle and require careful examination, because many of the more prominent signs only occur after years of disordered behaviors. Identifying the physical exam abnormalities is important to help determine severity of the current condition and provide objective data supporting the diagnosis. Often, it is hard for family members to accept the diagnosis of an eating disorder and providing objective data towards such a diagnosis is helpful.

We recommend developing a systematic way for assessing a patient with bulimia nervosa. This helps ensure evaluations specific to bulimia nervosa are consistently completed. One way to do this is a head-to-toe approach, focusing on the following exams. Vital signs should include temperature, orthostatic heart rate and blood pressures, a blind weight and, for those individuals with a uterus, last menstrual period. In purg-

ing disorders, weights are not always an accurate measure of recovery, as fluid shifts are common, so utilizing all available information is essential to make an accurate assessment.

Exam	Finding	Potential Cause
HEENT	Subconjunctival hemorrhages (blood shot eyes)	Recent forceful vomiting
	Parotitis (“puffy cheeks” or “chipmunk cheeks”)	Increased salivary production in response to chronic bingeing or purging or sudden cessation of such
	Erythematous, edematous pharynx (red swollen throat)	Recent or reoccurring vomiting
	Enamel erosion (most common along dorsal side of upper incisors)	Re-occurring vomiting
Cardiovascular	Bradycardia ^a (low heart rate)	Malnutrition
	Tachycardia (high heart rate)	Dehydration
	Arrythmia ^a (abnormal heart beat)	Electrolyte imbalance
Pulmonary	Pulmonary edema ^a (fluid in the lungs)	Fluid retention from chronic purging or sudden cessation of such
Abdomen	Distention, retained stool	Gastroparesis or constipation as a result of malnutrition
	Epigastric or LUQ tenderness	GERD, PUD (heart burn or ulcers)

(continued)

Exam	Finding	Potential Cause
Extremities	Russell's sign (callouses over knuckles)	Chronic use of fingers to induce vomiting
	Edema (swelling) ^a	Fluid retention from chronic purging or sudden cessation of such
Skin	Cyanosis (blue skin), mottling or cool to touch	Malnutrition
	Bruising or pressure ulcers (particularly on spine, feet, palms)	Chronic exercising
	Multiple linear abrasions at different stages of healing (often on wrists, arms, thighs, belly)	Self-harm ^a

^aIndicates a potential need for admission

Patients have a hard time admitting to vomiting because it feels shameful and, therefore, they often deny such occurrences. In addition, caregivers feel embarrassed or ashamed for not recognizing this behavior and will often support their child's denial of such claims. Because of this barrier, obtaining and interpreting objective data such as labs and physical exam findings is essential when determining medical stability and severity of disease in bulimia nervosa.

Initial labs should include those that assess for malnutrition and other disorders on the differential diagnosis. Typical labs include complete blood count (CBC), complete metabolic panel (CMP), magnesium, phosphate, iron studies and urinalysis. In addition, thyroid studies and a pregnancy test may be useful depending on the presenting symptoms. For those who are purging via vomiting, the most common lab abnormality will be a hypokalemic hypochloremic metabolic

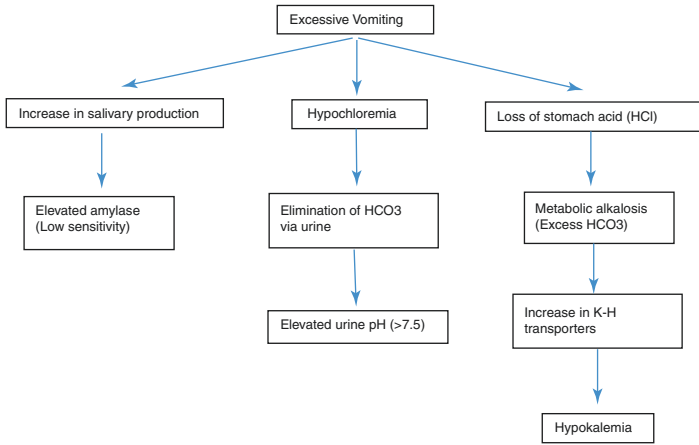


FIGURE 15.1 Mechanism of Metabolic Alkalosis

TABLE 15.4 EKG findings in Bulimia Nervosa

Finding	Potential Indications
Bradycardia	Malnutrition
Arrhythmia	Electrolyte imbalance from purging via vomiting, laxatives, or diuretics
Flattened T waves	Hypokalemia
Prolonged QTc	Malnutrition, purging, medications

alkalosis (See Fig. 15.1). In adolescents, these values may fall within the end range of normal. Therefore, it is important to look at trends over time. In addition, urine pH and amylase may be helpful in correlating normal appearing labs when index of suspicion is high. An electrocardiogram (EKG) should also be performed and read by a pediatric cardiologist. Common EKG findings in bulimia nervosa are listed in Table 15.4.

Medical treatment should focus on individual symptoms, utilizing medications when necessary. It is important to

emphasize the “food is your medicine” approach and make clear that any medications prescribed are not a substitute for eating. Common medications used are H2 blockers (i.e., famotidine) or proton pump inhibitors (PPIs) (i.e., omeprazole) for gastric reflux, polyethylene glycol or docusate for constipation, and metoclopramide for gastroparesis.

Although there is emerging evidence regarding the use of a variety of selective serotonin reuptake inhibitors (SSRIs) to treat bulimia nervosa [15], currently fluoxetine is the only SSRI that is FDA-approved to treat bulimia nervosa, and must be used at higher doses (60 mg) to see effects [3]. However, the data to support its use in adolescents with bulimia nervosa is limited, and there are increased risks to utilizing this higher dose. Therefore, fluoxetine is not routinely used to treat bulimia nervosa in adolescents at most institutions unless there are other indications (such as comorbid depression or anxiety).

Case Continued

Olivia’s physical exam was normal except for redness over her knuckles and a red, swollen throat. Her labs showed a mild metabolic alkalosis, elevated amylase, and alkaline urine; all consistent with recent vomiting. EKG was normal. She denied other forms of purging but admits to self-harming with a razor blade. She is not suicidal and wants to seek treatment. Olivia was diagnosed with bulimia nervosa and found to be appropriate for outpatient treatment. Oral care and wound care were reviewed, monitoring of meals and bathroom visits were recommended. Olivia was referred to a therapist and dietitian who specialize in eating disorders and told to return for medical follow-up in 1 week.

Follow-up Visits

Patients should initially be seen by a medical provider weekly, slowly spacing appointments out as behaviors decrease and medical complications diminish. Assessment should focus on

physical risks and the need for medical admission. Medications should be reviewed and patient should be weaned from these as needed and able. If ongoing purging is suspected, serial labs including basic metabolic panel (BMP), amylase, and urine pH should be performed. Prevention strategies should be reviewed with the family. Whole body skin checks should occur at each visit to look for signs of self-harm. In addition, the clinician should assess for co-morbid psychological disorders such as depression and anxiety. A suicide screen should be performed at each visit. The Columbia-Suicide Severity Rating Scale (C-SSRS) or Ask Suicide-Screening Questions (ASQ) are brief, free validated tools for adolescents and are offered in multiple languages [16–18].

Re-introduction to exercise or sports should occur in consultation with treatment team members and only after medical stability has been sustained for a reasonable amount of time. It is important to collaborate with the patient's therapist prior to allowing further activity to ensure the adolescent has the proper mental capacity to move forward. It is essential for recovery that the exercise is not a precipitant for the eating disorder. Once cleared by both the medical and mental health provider, exercise should be slowly introduced to prevent injuries and assess for any relapses or triggers. At the same time, it is also important to collaborate with the patient's dietitian to ensure the adolescent understands how increasing their physical activity will impact their nutritional needs. The teen will likely need concrete guidance around ensuring nutritional adequacy of food intake to support the increase in allowed activity.

Nutrition Assessment

The goal of the nutrition assessment is to assess the adolescent's nutrition status, changes in eating behaviors, beliefs about food, baseline nutrition knowledge, and level of motivation. To assess nutrition status, the dietitian conducts a nutrition-focused physical exam, reviews current anthropometrics and growth history, and assesses current food and fluid intake. The Nutrition-Focused Physical Exam includes a

head-to-toe assessment, noting changes or abnormalities in hair, skin, nail, eyes, muscle mass and adipose tissue. (See Chap. 1 for more information on Nutrition-Focused Physical Exam and the above medical assessment section for common clinical signs associated with bulimia nervosa).

Anthropometrics and Growth History

Height and weight (blinded, gowned) should be obtained and BMI calculated. Anthropometric measurements should be plotted on a growth chart for comparison to the reference population. In the United States, the Centers for Disease Control and Prevention (CDC) recommends using the 2000 CDC growth charts [19]. Other countries may recommend their own nationally derived growth charts, or use the World Health Organization growth charts [20]. Percent median BMI can be calculated to compare the adolescent's current BMI to that of the reference population (current BMI/50th percentile BMI for age and sex $\times 100$). Additionally, determining the BMI z-score provides the ability to assess the degree of deviation from the median. While terminology and methodology for assessing severity of malnutrition has not been standardized, BMI z-score is one of the proposed criteria for classification of degree of malnutrition for adolescent and young adults with eating disorders by the American Academy of Pediatrics, American Society for Parental and Enteral Nutrition, and the Academy of Nutrition and Dietetics [19].

Whenever possible, one should obtain previous growth charts to assess pre-morbid growth patterns and diversions from expected channels of growth. If weight loss has occurred, amount and rate of weight loss should be calculated and assessed for degree of malnutrition. If previous growth records are not available, asking the adolescent and caregiver to each describe the adolescent's growth history in qualitative terms can be informative. Asking for a description of physical traits (height and shape/build) during early elementary, middle school, and high school can provide insight into growth patterns as well as provide information upon how the indi-

vidual has perceived themselves and their body's changes. Asking caregivers the same questions can provide further information and reveal any discrepancies between perceptions. Additionally, asking about highest previous weight (when/at what age and height) as well as lowest weight since then (when/at what age and height) can provide information needed to determine percent of weight loss.

It is important to note that an adolescent with bulimia nervosa may appear underweight, within an average weight range, overweight, or obese. Most individuals with bulimia nervosa have a BMI within the normal range or are overweight [2, 3]. The proposed classification of degree of malnutrition for adolescent and young adults with eating disorders aims to identify and assess individuals who are malnourished, despite being within a "normal" weight range [19]. We also want to emphasize that even if an individual does not meet the proposed criteria for malnutrition, there can be serious nutritional deficits and underlying disordered eating behaviors warranting professional treatment. Lastly, it is important for clinicians to monitor for large weight fluctuations as these are common signs of ongoing struggles with bingeing and purging behaviors, or abuse of laxatives or diuretics.

Establishment of a Treatment Goal Weight

An important part of the assessment is establishing a treatment goal weight for the individual and comparing current weight to treatment goal weight (% treatment goal weight or %TGW). This is the term recommended by the Society for Adolescent Health and Medicine, replacing previous terms such as ideal body weight (IBW), expected body weight (EBW) and median body weight (MBW) [19]. For all adolescents, including those with eating disorders, it is important to recognize that treatment goal weight for an individual is not necessarily the median BMI, and therefore should not be simply extracted from the growth chart. There are a wide range of healthy weights within the population. When making recommendations for treatment goal weight, the following

should be considered: family history, the adolescent's unique growth and development pattern starting at the youngest age available, body composition or frame size, the adolescent's weight history, timing of onset of symptoms or changes in eating behaviors, and actual physiological and psychological functioning. A healthy weight supports physical growth and development, puberty and physical activity, as well as physiological processes, including normal hormone function, reproductive function, vital signs and laboratory values. A healthy weight should also help maintain mood stability and cognitive functioning to allow the adolescent to engage in psychotherapy, school, work, physical activity, and interpersonal relationships. Thus, treatment goal weight may need to be reevaluated if physical signs of health have improved, yet the individual continues to struggle in various realms of their life. A female adolescent's weight, at which regular menstruation occurred prior to the eating disorder or onset of disordered eating behaviors, may not be indicative of a current healthy weight. Menstruation may not resume until a higher weight is achieved, in part due to the ongoing growth & development that should have occurred during the duration of the eating disorder. The treatment goal weight represents an informed target range and should be reassessed every 3–6 months during adolescence due to expected ongoing growth and development [21].

Menstruation and Nutrition

Disruption to regular menses in females is common in eating disorders, including bulimia nervosa [22–24]. Dysmenorrhea may be attributable to inconsistent eating patterns, compensatory behaviors, or inadequate intake of dietary fat, cholesterol, and calories, all of which are necessary for production of the sex hormones (estrogen, testosterone, and progesterone), as well as other hormones required for normal reproductive function via influence upon the hypothalamic-pituitary-ovarian axis (ghrelin, insulin, leptin, Peptide YY, and cortisol) [24].

Assessing age at menarche, frequency and duration of menses, and any changes to the individual's typical menstrual cycles are important as inadequate and/or inconsistent nutritional intake negatively impacts hormone production, which in turn, disrupts bone mineralization (see Chapter on 'Female Athlete Triad', for further information on adolescent bone mineralization). Compensatory behaviors can also disrupt menstrual cycles, including volitional vomiting, laxative abuse, and excessive exercise that is not supported with adequate nutritional intake.

For the adolescent using oral contraception, exogenous hormones mask menstrual dysfunction, one important sign of metabolic dysfunction. Therefore, regular menstruation (or return to regular menstruation) is not a viable indicator of health for an individual using oral contraception or intrauterine devices known to impact natural menses. In addition, hormonal contraception should not be used as treatment for secondary amenorrhea related to eating disorder behaviors. Rather, eating disorder treatment should focus upon consistent and adequate food intake to meet metabolic, growth, and physical activity needs; as well as cessation of compensatory behaviors. Cumulatively, this achieves energy balance between energy intake and output, and thus supports optimal hormone production and bone mineralization.

Family-History of Nutrition-Related Diseases and Conditions

We recommend obtaining a family history of nutrition-related diseases, including heart disease, hypertension, hypercholesterolemia, diabetes, osteoporosis, cancer, disordered eating, and obesity. The presence of these conditions in biological family members provides insight into possible genetic risk factors for these conditions as well as alerts the clinician to assess for adolescent worries or anxiety about developing these diseases or conditions, which may have triggered or be reinforcing the adolescents' eating behaviors. Additionally,

obtaining a family history of mental health concerns & substance abuse informs the risk assessment of the adolescent and appraises the clinician of potential barriers that may affect the caregiver's ability to implement treatment recommendations.

Family Eating Habits and the Home Meal Environment

As a part of the individual's nutrition assessment it is important to assess the family's eating habits and the home food environment, including screening for food insecurities and economic hardship. Inquiring about cultural & religious food practices, as well as dieting history and food avoidances by caregivers, siblings and anyone else living in the home is essential to providing individualized care. This information can also reveal significant influences upon the adolescent. Inquiring about caregiver exercise habits is appropriate as well when completing an assessment for bulimia nervosa. Information regarding family members' roles around food preparation, the family meal environment, and screening for food insecurity should also be obtained and information incorporated appropriately into the treatment recommendations and overall support being offered to the family. See Table 15.5 for a list of helpful questions. A licensed social worker is a tremendous asset to a multidisciplinary team to help address barriers related to food insecurity, housing, and cost of care. Yet, in the absence of one, the medical provider, dietitian, and/or therapist can assist in this assessment.

Assessing Eating History and Current Dietary Intake

Assessing for differences in the adolescent's current intake versus historical eating habits and patterns can help the provider, adolescent, and family members recognize how eating

TABLE 15.5 Helpful questions to better understand family roles around food preparation & the meal environment

Who helps with the grocery shopping in your house?

Who does most of the cooking in your house?

Who else helps with the cooking?

Does anyone in the home/in your family, have special dietary needs? If so, what are these? Were these prescribed by a physician, other medical provider or RD?

Are there any foods or beverages that are forbidden or not allowed in your house?

What rules does your family have about eating? (i.e., finish everything on your plate, no seconds, must eat your vegetables before X, Y, or Z etc.)

How often is a meal prepared for the whole household/family? Do members of your family sit down together to eat, or do they eat separately?

Where are meals consumed? Is there the presence of TV, cell phones, lap tops, or other screens where you or others are eating?

How about during snacks? Where do you usually eat snacks?

Do you sometimes stand while eating a meal or snack?

Going back to meal times, can you please describe the atmosphere or mood of mealtimes in your home? If the teen comments that it is stressful, ask them to rate this on a scale of 0–10, and follow-up with asking why they chose that number and not a number higher or lower.

Ask caregivers how they describe meal times as well

In the last month, how many times have you worried about having enough money for food, or were unable to purchase the food you wanted for your family?

behaviors have changed. Food allergies, intolerances, preferences, dislikes, restrictions and avoidances should be assessed for historical and current state. By establishing a timeline of

changes to the adolescent's food preferences and food avoidances, the clinician is better able to discern between long-standing preferences and avoidances rooted in eating disorder beliefs or fears.

The most common method for assessing current intake is obtaining a 24-hour dietary recall. Obtaining a dietary history with the caregiver and adolescent together can often provide more information compared to asking either party separately, however using clinical judgement is strongly advised, especially when working with older adolescents. It is important to also assess general intake patterns over the past week since cyclical patterns as well as random variations are common in adolescents with bulimia nervosa. With all adolescents, especially those with an eating disorder such as bulimia nervosa, it is helpful to remind the adolescent that there are no right or wrong answers, no right or wrong ways to eat, and no right or wrong foods. The dietary recall should include both a weekday and weekend day, as there can be great variation. If the adolescent spends significant time outside of the home with peers or other family members, or it is a dual household, dietary intake information should be gathered for all settings.

As with all diagnoses, it is important to ask non-leading questions when obtaining the 24-hour dietary recall. An example of how to start is by asking what time the adolescent wakes up in the morning on school days. This can be followed by, "*When is the first time you have something to eat or drink?*" Many adolescents with bulimia nervosa may skip certain meals or snacks. By avoiding making assumptions and comments that may be perceived as approving or disapproving, a skilled dietitian will obtain a more accurate description of intake. In addition to obtaining the types and quantities of foods consumed, key components of the 24-hour dietary recall for an adolescent with bulimia nervosa should include the following:

- Timing of meals and snacks, including any grazing or night-time eating (meal pattern)
- Location/environment where meals/snacks are consumed (specific room or setting as well as whether the adolescent is standing or sitting when eating)

- With whom the adolescent is eating or whether eating alone
- Presence of any screens during meals/snacks
- Duration of meal and snacks
- Hunger and satiety levels before and after meals /snacks

Asking about sleep patterns during the dietary recall is an efficient way to assess for adequacy of sleep and disturbances in sleep patterns. Individuals with bulimia nervosa often have dysregulated eating patterns and dysregulated sleeping patterns.

Once a detailed dietary intake has been obtained, the dietitian can assess the overall pattern of eating, looking for cyclic patterns of restricting, bingeing and purging. Common intake patterns for individuals with bulimia nervosa are listed in Table 15.6. Despite these common examples, it is important to note that bingeing and purging can occur at any time of the day. Inquiring about circumstances around the time of day the adolescent engages in bingeing and purging behaviors can help identify possible triggers besides food restriction, such as

TABLE 15.6 Common patterns of eating in adolescents with bulimia nervosa

Minimal or no breakfast

Minimal or no intake during school hours

Very large intake/bingeing after school, especially if coming home to an empty house or there is no structure to afternoons and evenings

Grazing/bingeing in the afternoon or evening

Eating after family members have gone to bed. This is most common if the adolescent experiences shame with eating, or if caregivers are attempting to restrict the adolescent's intake or there is an overemphasis upon "healthy" eating in the home.

Night eating just before bed or waking in the night to eat

Irregular eating patterns when there is a lack of structure in one's schedule, such as weekends or school breaks. This may include frequent snacking or going long periods without eating, followed by bingeing.

school or familial stress, lack of structure or boredom, or other emotional triggers.

The dietitian assesses for adequacy of total energy, macronutrients, micronutrients, fluid and fiber intake. There are multiple equations available for assessing total energy needs, which are suitable for an adolescent with bulimia nervosa as well. Table 15.7 outlines equations for estimated energy needs using the World Health Organization's BMR (basal metabolic rate) tables. As with all individuals, tracking growth trends overtime allows the dietitian to assess whether the individual's dietary intake is supporting optimal growth and development.

It is common for adolescents with eating disorders, including bulimia nervosa to avoid entire foods groups, which may lead to an imbalance in macronutrients as well as micronutrient deficiencies. The recommended balance of macronutrients for adolescents with bulimia nervosa is outlined in Table 15.8.

Normalization of eating patterns, increasing variety, and ceasing of purging behaviors, will usually resolve micronutrient deficiencies and minor electrolyte imbalances. If a patient requires hospitalization due to electrolyte imbalance, therapeutic supplementation and intravenous fluids may be neces-

TABLE 15.7 Estimating energy needs for the adolescent with bulimia nervosa

Low weight for height: (Weight < 90% of Treatment Goal Weight)	Treatment Goal Weight BMR × 1.7–2.0
Proportional weight/height: (90–110% of Treatment Goal Weight)	Actual body weight BMR × 1.5–1.7 (Depending upon needs for weight maintenance vs. Weight gain)
Overweight: (BMI > 85th % for age or >110% Treatment Goal Weight)	Treatment Goal Weight BMR × 1.1–1.3

TABLE 15.8 Macronutrient recommendations for adolescents with bulimia nervosa

Carbohydrates	50–55% of total calories, unless higher fat intake is necessary to meet needs for weight gain.
Fats/Oils	30–40% of total calories (normal to high fat intake, as needed to meet needs for weight gain without excessive food volume).
Protein	15–20% of total calories, which is generally achieved with eating regular, balanced meals and snacks at the goal total energy intake.

sary (see more above in Section “[Medical Assessment](#)”). In the outpatient setting, the most common micronutrient requiring therapeutic levels of supplementation is vitamin D. In cases of medically documented lactose intolerance, adequate intake of calcium and vitamin D is often still attainable using soymilk or other cow’s milk alternatives. In the event of a long-standing dislike of drinkable milk products, efforts to meet calcium and vitamin D needs via other sources should be pursued prior to pharmaceutical supplementation.

Assessing fluid and fiber intake is essential as well. The adequacy and balance of macronutrients, fiber, and fluid all play important roles in the physiology of digestion, elimination, and production of hormones that help regulate hunger and satiety cues. Until purging compensatory behaviors have ceased, individuals with bulimia nervosa may have heightened fluid needs due to excessive fluid losses.

Additional components of the nutrition assessment include: use of alternative sweeteners, diet- or low-calorie, low-fat, low-carb foods, caffeine intake, dietary supplements (vitamins and minerals), as well as protein-supplements and energy drinks. While the medical provider and therapist will also be inquiring about substance use, it is important for the dietitian to inquire about use of cigarettes, alcohol, and recreational drugs, as these can affect appetite and eating behaviors.

To gain an accurate assessment of bingeing and purging behaviors the dietitian should definitely meet separately with

the adolescent and caregivers due to the shame often associated with these behaviors. The dietitian may wish to describe how a binge is defined, but should also ask the adolescent to describe their personal experience and what they consider a “binge.” It is noteworthy that sometimes individuals with eating disorders including bulimia nervosa may assign a very normal amount of food intake as a binge. In addition to assessing for eating patterns that may contribute to bingeing, the dietitian also assesses the composition of meals and snacks to see if intake is overly limited in protein or fats, two key components for satisfaction and satiety. It is important for the dietitian to obtain information regarding timing and frequency of purging, as these behaviors disrupt hunger and satiety cues leading to further dysregulated eating behaviors.

A detailed assessment of physical activity is important to both the dietitian and the medical provider. Whether this part of the interview is conducted separately or jointly varies by clinical settings and institution. Frequency, duration, intensity, type, setting, motivation, and with whom are key elements for helping to assess the adolescent’s mentality around physical activity and the activity’s contribution towards total energy needs. It is also important to inquire about motivation and whether physical activity is compulsive or compensatory in nature. We also recommend asking about days of rest, including frequency, and asking if the individual experiences guilt for taking days of rest.

Other components of the nutrition assessment include assessing body image and level of motivation. The dietitian should inquire about self-perception, body checking (frequently looking at one’s body, over-focus upon a specific body part or pressing skinfolds together), frequency of self-weighing, stated desired weight, and willingness to gain weight or increase intake if recommended.

Case Continued

Through Olivia’s visits with the dietitian and therapist, Olivia is able to recognize her pattern of daily restriction, bingeing, and purging that has evolved. Although she understands the

health risks of continuing her disordered eating and compensatory behaviors, she is hesitant to trust the dietitian's recommendation to eat more during the day. However, after two follow-up visits and further discussions about the importance of fueling herself with balanced meals during the day, and how this will help prevent bingeing and purging behaviors in the evening, Olivia is open to experimenting with eating breakfast and lunch again. Her caregivers have followed through on recommendations to prepare balanced meals and snacks for Olivia, and they are eating together as a family as often as possible. One week later, Olivia expresses that having someone prepare her breakfast and eat with her has been extremely helpful. She reports that she still has some restrictive thoughts but having someone else prepare and serve her meal helps prevent her anxiety from building. She also reports only one episode of bingeing and purging in the past week, for which she is proud of her progress.

Treatment

Typically, patients start with an outpatient treatment team, increasing the intensity of treatment only if unable to make expected progress in the outpatient setting or an intense relapse occurs. Outpatient treatment often begins with weekly appointments with each member of the team (medical provider, dietitian, and therapist), and gradually decreases in frequency of visits as the individual's eating behaviors stabilize, compensatory behaviors decrease and/or cease, and the individual progresses through treatment. For the individual who requires a higher intensity of care, an intensive outpatient program (IOP) can be a step-up from standard outpatient care, typically offering 9–15 hours of treatment per week. This time is often distributed into 3–4 hour segments 3–5 days per week with the goal of the individual being able to continue to participate in school or work. Intensive Outpatient Programs (IOP) offer individual appointments with the dietitian, therapist and medical provider, as well as group classes (such as development of effective coping skills, dialectical behavioral therapy, psychoeducation, and nutri-

tion education). Typically, at least one meal is supervised by supportive staff during each IOP visit.

Beyond outpatient and intensive outpatient treatment, partial hospitalization and full residential programs offer 6–12 hour or 24 hour per day care, respectively. Partial hospitalization programs (PHP) is appropriate for the individual who is medically stable yet has a need for daily physiological and psychological assessment and support. For bulimia nervosa, this usually means the individual continues to struggle with daily fasting, bingeing, and purging despite adequate outpatient treatment, thus requiring a higher intensity of care. Residential programs offer 24/7 supervision and monitoring with all meals and snacks supervised by trained staff to provide meal support. Residential programs typically require the patient to be medically stable, although most have access to inpatient medical management when needed. Residential care is reserved for patients who have been unable to respond to the other levels of care or are in need of significant weight gain (often patients are <75% of treatment goal weight). The different acuities of care can be utilized in a step-down or step-up fashion. For the individual who becomes medically unstable, acute medical hospitalization is necessary to allow for 24/7 medical monitoring and stabilization, upon which transfer to a treatment facility can be arranged if needed.

For the purposes of this chapter, we focus primarily upon treatment in the outpatient care setting. For adolescents, there are two main treatment approaches to outpatient eating disorder care, both of which require a multidisciplinary team. The first is the traditional approach, also called the individual treatment approach or adult model. This includes a medical provider, a registered dietitian and an individual therapist. Typically, the dietitian provides physiology, food and nutrition education and guidance directly to the patient, establishing incremental goals at each visit. Most often, family members are brought in at the end of the visit and educational concepts and goals are shared and discussed. Family meals are encouraged in this model, and additional guidance is often provided to the caregivers as well. Weights and measurements are kept

confidential. Mental health therapy should be provided by a licensed professional who has specific training in or extensive expertise with eating disorders. Therapy is focused on the patient's concerns and co-morbidities, most often using cognitive behavioral therapy (CBT), dialectical behavior therapy (DBT), and exposure work.

The second approach is called the Family Based Treatment model (FBT), also known as the Maudsley Approach. This approach is led by a therapist specially trained in FBT, who acts as a coach in supporting and empowering the caregivers. In a traditional FBT model, treatment is divided into three phases, starting with phase one where caregivers are empowered to take full control over feeding their adolescent. This includes meal choice, preparation, quantity, time and location. Phase two promotes a gradual return of choice to the adolescent, and phase three establishes healthy independence. Caregivers implement predetermined consequences and rewards to behaviors and meal completion. Once medically cleared, caregivers also guide activity level and frequency. There is not a dietitian involved in this type of treatment as a way of further empowering and entrusting the parents. In a modified FBT model, the dietitian provides guidance to the caregivers regarding meal times, quantities, and balance at meals and snacks from the beginning of treatment, helps assess for risk of refeeding syndrome by promoting an optimal pace of increased intake, and considers any physiological and psychological needs. In either a traditional FBT or modified FBT approach, weights and measurements are openly discussed during sessions to help support the recovering individual with any anxiety these numbers pose.

Regardless of treatment type, additional members of the support team often include a psychiatrist to treat co-morbid mental health disorders, a family therapist to help with caregiver alignment and communication, and medical social workers to assist in any barriers to treatment such as transportation, insurance needs, and time away from school or work. Support groups or processing groups for patients and caregivers are another augmentation to treatment that is

often helpful. A quality group will be specifically designed for adolescents with eating disorders and their families, as adult or mixed groups may provide inadequate structure or introduction to risky behaviors seen in adults. It is important that all team members are regularly communicating with each other as well as the adolescent's family support system so accurate, consistent education and treatment is provided. Caregiver involvement should be reassessed to ensure it is leading towards recovery rather than maturation of the eating disorder through newly learned behaviors and "tricks" which can be well hidden and sometimes difficult to detect.

The primary focus of the nutrition treatment for bulimia nervosa begins with stabilization of eating patterns. Often individuals with bulimia nervosa are engaging in restrictive eating behaviors or have rigid rules around food that are not achievable or sustainable. Binging behaviors may result from the physiological and/or psychological effects of dieting or restrained eating that is common in the U.S. and other countries. The individual may then experience guilt and perhaps physical discomfort after binging, which triggers compensatory behaviors as a means to manage those emotions, purging both calories and associated guilt. Once the adolescent has fallen into a pattern of restriction, binging, and purging it can be difficult to break out of this vicious cycle without professional and familial support. It is most helpful if the adolescent's family can provide structure and predictability of meal and snack times. Whether using a family-based or individual approach, the dietitian can support the adolescent and/or caregivers during this time by providing guidance for optimal timing of the meals and snacks, taking into account school, work, afterschool activities, and other scheduling commitments. Restriction may include skipping meals or snacks completely or eating unbalanced meals and snacks due to avoidances or restrictions of specific foods or food groups. Thus, the dietitian provides developmentally appropriate guidance to help ensure adequate, balanced meals and snacks, individualizing recommendations based on specific needs and behaviors.

Family meals, in which all family members are eating the same meal at the same time, is important. This is an opportunity to model normal, healthy eating behaviors for the adolescent and provide emotional support during meals, often referred to as meal support. Sometimes discussing the importance of this with families and providing coaching is enough, but if caregivers are struggling with their own eating or body image concerns, they may be unable to effectively participate in family meals themselves (meal planning, preparing, or eating normally), in which case additional support is needed. Caregivers who are dieting to lose weight need to understand the implications of their actions upon the child's eating and relationship with food. Furthermore, if a caregiver is struggling with an eating disorder, he or she should be referred for eating disorder treatment themselves.

Quantities of food should be gradually adjusted to a level and pattern of intake that meets the adolescent's needs for growth and development, physical activity, and to promote a healthy weight for the individual in the long run. For some this may be a matter of weeks, and others this may take 1–3 months once the full treatment team is in place. With bulimia nervosa, there may not be much of an overall change in caloric intake, but rather the goal may be for energy intake to be distributed more evenly throughout the day. If an individual with bulimia nervosa requires inpatient hospitalization for medical stabilization, it is recommended to provide meals and snacks beginning typically between 1200 and 2000 kcals/day and advancing by approximately 200 calories per day to the individualized goal [21, 25]. The starting energy level should be matched to the estimated current intake of the individual (if below estimated needs). Although most individuals with bulimia nervosa are often not at as high of a risk for refeeding syndrome compared to individuals with anorexia nervosa, a maximum increase of ~200–300 calories per day is still recommended as this promotes psychological adjustment to eating adequate volumes at meals and snack and helps prevent an increase in compensatory behaviors. Furthermore,

if hospitalization is required due to medical instability, patients with bulimia nervosa should be closely monitored for signs of refeeding syndrome, similar to those with anorexia nervosa. If weight restoration is needed, weight gain at a rate of 1–2 pounds per week is generally recommended for hospitalized patients [21]. In the outpatient setting, an average rate of weight gain of 0.5–1.0 pounds per week is considered acceptable and desirable [26].

Increasing the variety of foods and beverages consumed is another component of the nutrition intervention. It is important to advance the variety of foods offered in a timely manner to help ensure a balance of macronutrients are present in the meals and snacks which will also help promote satisfaction and satiety. If the adolescent continues to restrict the variety of foods he or she is consuming, satisfaction can be difficult to achieve, and thus bingeing behaviors may continue. If the adolescent fears eating specific foods, it is important to develop goals for reintroduction and ongoing inclusion of these foods in the individual's diet. It is optimal to increase the variety of intake early in treatment so that avoidances are not reinforced. If there is a high level of fear and resistance to certain foods, the dietitian and therapist can collaborate to develop a plan for reintroduction of these foods, while also providing simultaneous support via exposure therapy and nutrition education to debunk any false or harmful beliefs about food. Caregivers will likely require additional support if there is significant resistance on the part of the adolescent to increasing variety of the meals and snacks.

Throughout treatment in the outpatient setting, nutrition education should be tailored to meet the individual's learning needs with consideration for developmental appropriateness, age, cultural and religious practices, cognitive functioning, activity level and treatment approach (individual vs. family based treatment approach). Common nutrition education topics are listed in Table 15.9.

TABLE 15.9 Common nutrition education topics in bulimia nervosa treatment

Concept of metabolism
Eating patterns, related to supporting one's metabolism
Recognizing patterns of restriction, bingeing, and purging and how to break this cycle
Pitfalls of restrictive eating and dieting
Hunger and satiety signals, awareness and response
Importance of meal composition for optimizing hunger and satiety
Understanding one's energy and nutrient needs for growth, development and activities
Meal and snack guidance - We recommend starting general and becoming more specific with guidance, only as needed.
Measuring foods and providing specific numbers or exchanges can lead to increased rigidity around eating.
Challenging fears & harmful beliefs around specific foods or types of foods
Discerning nutrition messages (public health, dieting industry, social media)
Emotional eating & discernment of different types of hunger
Negative effects of chronic dieting
Bone development and bone health
Disruptions to hormone production/menses & effects upon bone mineralization
Health risks associated with disordered eating and compensatory behaviors
Healthy growth and development; components of expected growth and weight gain during adolescence
Body weight vs. body composition; impact of eating pattern, adequacy of intake and compensatory behaviors
Family beliefs about diet, weight and health
Education regarding family medical history and risks, if applicable and appropriate
Recognizing differences in individuals' needs (family members, peers, etc.)
Body image (partnering with mental health)
Personal goals

Caregiver Education and Support

Caregiver support and education is extremely important, whether using a family-based treatment approach, or an individual treatment approach. Both approaches value family meals and supporting the adolescent with his/her treatment goals. We recommend that caregivers receive education about the diagnosis, symptoms, and treatment options. All family members should be given the opportunity to discuss the emotional response they are experiencing to the diagnosis of their family member and the treatment of an eating disorder. It is extremely common for caregivers to feel guilty and blame themselves for their son or daughter's illness. However, we encourage caregivers to shift their focus towards supporting their adolescent during treatment and recovery.

One of the most important elements of caregiver education and ongoing support is to help caregivers learn to discern between typical adolescent behaviors vs. disordered eating behaviors. Setting limits and clear expectations are essential, as there will almost certainly be resistance on the part of the adolescent due to the ambivalence that individuals with eating disorders often experience during treatment. Cognitive functioning, as well as emotion regulation, may be quite impaired in an individual with an eating disorder, preventing the individual from being able to reason or respond with logic. Caregivers and other support persons should be educated upon the importance of not engaging in negotiations around food or physical activity, as this only allows the eating disorders thoughts to perpetuate and anxieties to increase. Furthermore, the ability to regulate one's emotions becomes even more difficult due to the anxiety inherent in eating disorders. Outbursts, especially during meals, can be common. Validation and recognition of how difficult the situation is for the individual is appropriate and can be helpful. Again, setting and upholding limits and being consistent with expectations are crucial to providing the best support for the individual. Because emotions can be so strong and behaviors so unlike their child, some caregivers find it helpful to separate and

label certain behaviors as coming from the eating disorder, rather than their child. By externalizing the eating disorder, the patient and caregiver can better separate out disordered thoughts and actions from more typical behaviors for age.

All family members should be consistent with setting expectations and following through with the treatment plan. It is important that caregivers are providing similar meals and snacks regarding timing, portions, and types of foods offered, as well as consistent monitoring and support after meals. If the family is split between two households, dedicated communication between caregivers is essential. Team members should expect to provide extra support for caregivers in this situation. A family therapist that focuses on aligning parental guidance and treatment can be another useful resource for the team and parents.

We recommend the patient be monitored for all meals and snacks initially, often including those at school, and especially so if the individual continues to struggle despite the family implementing recommendations in the home environment (see next paragraph). This may require moving the adolescent out of the cafeteria to the health room, nurse's office, a trusted teacher's classroom, or the counselor's office during meal-times. The individual should be excused from classrooms as necessary for required snacks during the day. After eating, the individual should be escorted back to the classroom to ensure bathroom use does not occur immediately following intake.

When at home, the individual should eat with a family member. Avoiding discussion of food, dieting, body size or shape is helpful in preventing anxiety. After meals and snacks, the family support team can provide distractions, as the urge to purge is usually the highest at this time. Common distractions include non-body focused conversation, watching television, helping with homework, or doing a family activity such as a game or crafts. Bathroom use should be prohibited for 1 hour after all meals and snacks. If the individual purges via vomiting, oral care should be reviewed. We recommend the patient rinse thoroughly to remove as much acid from the mouth as possible. Mints can be used to improve breath.

Immediate brushing of teeth is not recommended due to concerns of enamel erosion, but if performed, it should be done with light pressure and soft bristles. Regular dental check-ups are important to assess for enamel breakdown from stomach acid in vomit and cavities from excessive intake. Lemon drops are known to help with parotitis and excessive saliva production the following weeks after cessation of vomiting.

For those patients involved in exercise or sports, it is important to evaluate the current intentions of the activity along with the physical risks of performing such activity. If the activity is used for weight control or a response to eating-disordered habits and thoughts, it should cease immediately. If the patient is displaying any physical instability on exam or by report, activity should also be restricted. When in doubt, exercise (including any physical education classes) and sports should be fully restricted. It is often necessary to write medical necessity letters to the school for excused participation.

If self-harm is evident, the areas should be evaluated for infection and proper healing. Wound care should be reviewed. Occasionally, deep cleaning and stitches are needed. We recommend caregivers do thorough "room checks" to look for and remove any object that could be used for self-harm, including razors, scissors, thumb tacks and nail clippers.

Additional steps to establishing a supportive home environment include removal of any scales, diet-foods (low-fat, low-carb, low-calorie, etc.), diet books and avoidance of dieting & weight talk by all family members. It is recommended that talk about appearance be avoided as talk of this nature most often heightens anxiety, even when well-intended, as an individual with an eating disorder often has a distorted sense of body image and may be experiencing ambivalence toward recovery. Pre-occupation with appearance, weight or body shape is inherent in bulimia nervosa, and talk focused upon these topics only reinforces valuing such things. We recommend that caregivers focus upon the individual's hard work, improvements in concentration, functioning at school, increased engagement in activities, etc.

Finally, if caregivers are struggling with their own eating or weight concerns, we recommend the treatment team encourage those caregivers to seek support for themselves. This should be provided by clinicians outside of the adolescent support team so that there is no question or doubts around confidentiality.

Goals of Treatment

The goals of treatment for an adolescent with bulimia nervosa include restoration of physical health, optimization of growth and development, and promotion of psychological well-being. For an individual with an eating disorder, psychological well-being includes building a positive relationship of trust with one's body and food, feeling comfortable eating a wide variety of foods, as well as developing effective coping strategies for various emotions and stressors, and thus ceasing compensatory behaviors. Often there is a threshold of physical health, achieved through stabilization of eating and sleeping patterns, and cessation of compensatory behaviors that is necessary before psychological well-being improves.

Achieving a Healthy Balance of Independence

Independence is a key developmental task of adolescence. When an adolescent has an eating disorder, independence may be reduced during early treatment with more responsibilities around food preparation directed to their caregivers. This is to decrease anxiety by eliminating or reducing the number of decisions that adolescent needs to make regarding one's food intake. Decreasing independence with meals and snacks should continue until the adolescent is able to demonstrate and maintain consistent and adequate eating behaviors, as well as cessation of compensatory behaviors. Generally, the treatment team works together to develop a plan of gradually increasing or restoring independence to a developmentally

appropriate level. From the nutrition perspective, this may include starting with the caregiver offering a couple of choices for a snack, then progressing to the adolescent preparing their own snack with caregiver supervision, and eventually the teen preparing and eating some snacks and meals independently, or with peers, rather than caregivers. This is all based upon what is developmentally appropriate for the adolescent, and their success with each of these steps. For example, it is developmentally appropriate for an adolescent in middle or high school to prepare their own breakfast, lunch, and snacks, while dinner may remain a meal predominantly prepared by caregivers, until the adolescent is ready for more advanced cooking skills and more responsibility. Of course, there is cultural variability in terms of child and adolescent involvement in meal preparation, which should be explored with each family and within the context of other activities.

Ultimately, the adolescent needs to gain the necessary skills for meal planning and preparation prior to leaving the family home. However, it is important not to rush into the adolescent being involved in meal preparation if hyperinvolvement in the food preparation and control over specific ingredients has been a part of the individual's eating disorder. If behaviors of control and restriction are present and persistent despite coaching from caregivers and the treatment team, it is best to delay the adolescent's involvement in grocery shopping and/or food preparation until the adolescent is further along in treatment and able to participate in these tasks without demonstrating disordered eating behaviors/thoughts (i.e., negotiating about ingredients, altering recipes to decrease certain macronutrient content, etc.)

Another key component of independence with eating is the adolescent returning to intuitive eating in regard to how much to eat at a given meal or snack. In this regard, intuitive eating is the ability to listen and respond appropriately to one's hunger and satiety cues, rather than having quantity of intake guided by the caregiver or dietitian. Working towards independence with this skill is also usually a stepped progression starting with one meal or snack, where the adolescent

practices listening and responding to their satisfaction and satiety cues, and overtime progresses to full self-regulation of quantities consumed at all meals and snacks. During this transition, the dietitian can provide support, guidance and education to the adolescent and family.

Summary

The case described throughout this chapter illustrated an adolescent who attempted to revise her eating due to changes in her physical activity level. However, like many weight-conscious teens she applied dieting tactics that set her up for “failure” and experiencing ravenous hunger in the afternoons and evenings, which evolved into bingeing and purging. As she continued to struggle with body image concerns and weight gain, the cycle of restriction, bingeing and purging only worsened, until she sought help.

Bulimia nervosa is often less recognizable by caregivers, teachers, coaches and friends compared to anorexia nervosa. However, once identified, diagnosis and treatment should not be delayed as early intervention is associated with better prognosis. A multidisciplinary team offering treatment specific to bulimia nervosa as discussed in this chapter can support the adolescent in ceasing bingeing and purging behaviors, eating adequately to support their physiological needs, developing trust of one’s body, and restoring psychological well-being.

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Chapter 16

Avoidant/Restrictive Food Intake Disorder (ARFID)



Lisa Holman and Emily Ruedinger

Introduction

Avoidant/restrictive food intake disorder (ARFID) is a newly described restrictive eating disorder that was first introduced in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) in 2013, replacing the pediatric feeding disorder diagnosis. Included are one or more of the following diagnostic criteria: weight loss or failure to achieve appropriate weight gain, nutritional deficiency, dependence on enteral feeding or nutritional supplements, and/or significant interference with psychosocial functioning. Notably absent from this definition are body distortion (weight, shape, size) and fear of weight gain, distinguishing its clinical presentation from that of other eating disorders such as anorexia nervosa (AN) or bulimia nervosa (BN) [1]. Also excluded are patients

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whose presentation is explained by food availability, skill deficit, another medical or mental disorder, and cultural eating practices. There are no parameters surrounding age, although notably ARFID patients have been found to be younger at time of diagnosis compared to AN and BN patients [2]. This population has also been found to present with a longer duration of illness; are more likely to be male compared to patients diagnosed with AN or BN; are more likely to have a comorbid medical condition or anxiety disorder; and are less likely to have a mood disorder [2, 3].

The etiology for ARFID patients is heterogeneous in terms of nutritional, medical, and psychological factors. The recurrent theme is food avoidance. Two ARFID subtypes have been identified: short-term (or acute) ARFID, and long-term (or chronic) ARFID. Short-term ARFID presentations have been described as relating to a precipitating event or fear of such event, such as choking or vomiting. Chronic ARFID has been described as longstanding picky eating with or without medical issues, extended Generalized Anxiety Disorder (GAD) or related to (but not caused directly by) an extended gastrointestinal (GI) disorder. Predisposing factors such as cognitive impairment, learning disorders and Autism Spectrum Disorder (ASD) have also been correlated with ARFID [3, 4]. It has been hypothesized that those that are highly sensitive to taste (“super tasters”) may be also predisposed to ARFID [5]. Perpetuating factors may include: parental anxiety, ASD, Attention-Deficit/Hyperactivity Disorder (ADHD), and/or challenges with the parent-child feeding relationship and feeding dynamics [6].

In the adolescent, a healthy weight is important to ensure proper physiologic, cognitive and psychosocial functioning. It is estimated that 15–20% of final adult linear height is obtained during adolescence and approximately 50% of adult ideal body weight [7]. It is then not surprising that in the setting of associated energy requirements, ARFID patients are often diagnosed around the time of anticipated growth spurt when they are no longer able to maintain growth trajectory in the setting of selective eating practices and their desire

to gain weight. Behaviors associated with ARFID can result in an increased risk for malnutrition, over nutrition, micronutrient deficiency or dehydration.

A note on picky eating: Although there are notable similarities, ARFID is distinct from picky or selective eating. While picky eating may be transient, ARFID is more persistent [8, 9]. Further, picky eating practices do not create such an impact that meeting energy needs for growth and development are impeded. The restricted volume and variety of foods eaten affect the ARFID patient's ability to meet nutritional or energy needs. It has been suggested that there is a common etiology to picky eating and ARFID and that they operate on the same continuum [10].

ARFID is underdiagnosed and under recognized. It is not uncommon for patients who meet diagnostic criteria for ARFID to be referred to feeding disorder programs or GI clinics given its presentation, which exhibits features of both disorders [6, 11]. Retrospective data has placed incidence of ARFID between 5–13% in children and adolescents [2, 12]. Gold standard treatment interventions remain emergent, including best nutrition practices. As a result, this chapter will place emphasis on case studies and evidence informed by clinical experience from our practice in a pediatric tertiary care eating disorder program.

Evaluation

There is no empirical evidence surrounding best evaluative practices in ARFID patients. This, combined with the variation in presentation, leads the clinician to rely on research informed practice. Recommendations should be made in consideration of adolescent growth and development, known literature associated with other restrictive eating disorders, known literature associated with picky or selective eating and clinical expertise based in clinical practice. Stage of cognitive and psychosocial development can help to inform caregiver and teen involvement during the encounter.

During an initial evaluation, the division of responsibility for information gathering will vary based on to whom the patient first presents; resource/provider availability within a particular clinical setting or community; and group practice patterns. A number of aspects of the initial evaluation may be conducted by any type of provider. In addition to medical specialists and nutrition professionals, this could include primary care providers, mental health professionals and occupational therapists. We present below basic information that may be gathered by any team members, as well as discipline-specific information that will more likely fall within the scope of the medical provider or the dietitian. While some overlap in history-taking can be helpful and is usually unavoidable, close coordination among team members will minimize unnecessary redundancy.

We have found it is almost always worth the effort to track down historical growth records to obtain at least a few years' worth of data from prior to the onset of the eating disorder. Historical growth charts can reveal deviations in weight or linear growth velocity based on individual trajectory. This, along with Tanner Staging (aka Sexual Maturity Rating), menstrual history, evaluation for other medical complications of malnutrition, and Nutrition Physical Assessment, can also be useful in determining estimated treatment goal weight (eTGW). Depending on age and stage of linear growth, eTGW should be reassessed every 3–6 months. Notably, in patients presenting with chronic subtype ARFID, historical growth may reveal a pattern indicating long-term underweight status.

The provider should inquire about historical eating patterns, starting from early childhood. We typically ask parents if the teen had any feeding or growth difficulties as an infant, and if they were a “picky eater” in early childhood. Patients with extensive taste and/or texture preferences may also experience other sensory hypersensitivities, such as to certain auditory (for example, the sound of the vacuum or of other people chewing) or tactile (for example, tags or seams on their clothing) stimuli. Proprioception and vestibular func-

tion are also often impacted in children with extreme sensory sensitivities, so the patient may be described as clumsy, having difficulty with balance, or lacking in awareness of where their body is in space. A brief developmental history, including social milestones and educational progress may be useful, even among patients who do not have a prior diagnosis of autism spectrum disorder or ADHD. While none of the information derived by asking for the above information is diagnostic in and of itself, it can bolster confidence in the ARFID diagnosis. Further, uncovering a co-morbid psychiatric or developmental disorder can be useful when determining the best treatment approach and which team members to involve.

Likewise, it can be helpful to understand if there was a clear precipitant to the food avoidance in a patient for whom these behaviors are new-- such as a gastrointestinal illness, an anaphylactic episode, an emotional trauma, or some other similar event. Explore for current or past anxious symptoms, including any history of obsessive thoughts or compulsive behaviors. Inquire about willingness to eat with others, to eat food that has been prepared by others, any food- or eating-related rituals, or any magical beliefs around food and eating. As noted in the chapter on Anorexia Nervosa, standardized screening tools such as the GAD-7 and PHQ-9 can be helpful in elucidating current symptoms. Keep in mind that these do not provide a historical perspective and do not capture all psychiatric disorders (such as obsessive-compulsive disorder and ADHD) that are more prevalent among patients with ARFID than they are among patients with other restrictive eating disorders [2].

The clinician should inquire as to the impact of symptoms on the patient's social and emotional functioning. Even when growth and physical health remain appropriate, adolescents and their families can experience increasing distress around their eating behaviors as they progress through adolescence. Youth and their families may have been able to accommodate picky or unusual eating behaviors earlier in childhood. This becomes more difficult as adolescents spend more and more time away from their family unit, and begin eating in

social settings apart from the family unit. Developmentally, most adolescents go through a phase of wanting to fit in closely with their peers; it can be more difficult to retain picky eating behaviors and not 'stick out' when eating in settings such as restaurants, at extracurricular events, on dates, or in friends' homes. Older teens and their families may worry about maintaining adequate intake once they transition out of their family home, where availability of their preferred items may not be as reliable. This can be a particular concern for patients who plan to enter college, the military, or other similar settings. The use of Motivational Interviewing can be helpful in eliciting this information and can then be used to inform patient-centered goals.

Medical Evaluation

When seeing a patient with weight loss and/or concern for any eating disorder, the initial medical evaluation should broadly screen for alternative or co-morbid etiologies; include questions to distinguish diagnostically among the restrictive eating disorders; and evaluate for medical consequences of malnutrition. It is also necessary to gather basic psychosocial information in order to guide therapeutic recommendations.

For a full overview of the initial evaluation of restrictive eating, please see other chapters on the topic of eating disorders, including Anorexia Nervosa, Bulimia Nervosa, and Otherwise Specified and Unspecified Feeding or Eating Disorders. The initial history and examination for a patient exhibiting restrictive eating or malnourished state is generally similar, as the provider will not know what disease process is occurring until they have conducted the evaluation. However, some areas deserve particular attention when evaluating a patient with suspected ARFID.

Because many patients presenting with a chronic ARFID-type picture have often exhibited poor growth throughout the lifespan, a more thorough work-up for co-morbid or alternative medical conditions is often necessary. Whether acute

or chronic, a basic laboratory evaluation should include all items outlined in previous chapters on restrictive eating disorders. A thorough history, physical examination and review of symptoms can be used to guide additional work-up. It is important to keep in mind that eating disorders and other illnesses can be co-morbid and/or present similarly, e.g., with food refusal, loss of appetite, and weight loss. In our practice, we have had numerous experiences of seeing patients with clear eating disordered behaviors, and in some cases a true eating disorder diagnosis, who have ultimately revealed themselves to have an additional or alternative diagnosis. The existence of a co-morbid diagnosis is more common in patients with ARFID than with AN or BN; ARFID can be more difficult to ‘pin down’ given lack of body image concerns [2].

With regard to additional diagnostic assessment, providers must strike a balance between being thorough, and providing timely diagnosis and treatment that is mindful of the costs of prolonged or extensive evaluation (financial, time, emotional). Providers should have a low threshold for celiac testing in all patients, as celiac disease has been shown to have a bidirectional relationship with eating disorders [13]. Patients with prominent gastrointestinal symptoms may warrant additional evaluation, such as hemoccult, fecal calprotectin, upper or lower endoscopy, or upper GI with small bowel follow-through (if fullness is a prominent complaint, particularly when this complaint pre-dates the weight loss). Often this additional testing is done under the guidance of a gastroenterologist. We recommend an EKG for patients with bradycardia, an abnormal cardiac examination, cardiovascular symptoms (such as dizziness, reduced exercise tolerance, palpitations etc.) or a history of chronic poor growth who have not had prior cardiac evaluation. Rarely, careful evaluation may indicate the need for pulmonary or cardiac work up beyond the physical exam, basic labs, and EKG (for example, sweat testing, CXR, or echocardiography), but this would be exceptional. If the patient is experiencing oligo- or amenorrhoea as a relatively new phenomenon, and this does not well

match their weight trajectory; or is not exhibiting expected pubertal progression, additional hormonal testing (such as FSH, prolactin, and/or androgen testing) and/or a bone age may be indicated. At a minimum, an external GU examination should be performed in patients with primary amenorrhea; further work-up, such as laboratory screening and/or US imaging, may be indicated. We usually pursue these studies more readily in patients with a chronic ARFID picture and without obvious weight loss. Our experience indicates many patients with chronic low weight will still exhibit appropriate pubertal progression. A significant decline in linear growth, particularly if this pre-dates a decline in their weight trajectory, warrants evaluation by a pediatric endocrinologist. Patients with focal neurological symptoms; positional, persistent and/or significantly worsening headache; or morning nausea, vomiting or headache, should undergo a thorough neurological examination and may require cranial imaging.

Of note, a number of autoimmune illnesses, including celiac disease and inflammatory bowel disease, type 1 diabetes, and thyroid illness are also associated with eating disorders [14]. The root of these associations is not yet clear. Hypotheses include a potential autoimmune component to eating disorders, including contributions of the gut microbiome and cytokines (Avila 2019). Children with chronic illnesses that require nutritional modifications (for example: diabetes, cystic fibrosis, ulcerative colitis, etc.) are also at higher risk for development of an eating disorder post-diagnosis [15].

Patients presenting in early adolescence or pre-adolescence warrant special attention to their pubertal progression. Initial evaluation should include asking about thelarche and menarche (for natal females) or changes to testicular size, voice deepening, or hair growth (for natal males); adrenarche; Tanner staging; assessment of parental pubertal timing and growth; and potentially a radiographic bone age assessment. Tanner staging can be repeated every 3–6 months to ensure appropriate progression, until the patient has resumed normal growth patterns. Cessation or slowing of pubertal pro-

gression can occur with nutritional deficiency, and may prompt the patient, family, and care team to approach weight restoration more aggressively than for a patient who is progressing normally through puberty.

Patients with ARFID can experience medical complications identical to those of anorexia nervosa. Complications such as bradycardia and significant orthostasis are often more prominent in patients with acute ARFID than those with chronic ARFID; in our experience, the severity of these symptoms often correlates not only with percent estimated treatment goal weight, but also with the rapidity of the weight loss. Additionally, we have observed that many (though not all) patients with chronic ARFID may still experience normal pubertal development and female patients may continue to menstruate despite low body weight.

Nutrition Evaluation

Diet Recall

The diet recall can bolster the clinician's understanding of how ARFID is affecting growth and development as well as psychosocial function. It can more directly illuminate the degree of nutritional risk. Although parent, caregiver and youth report is valuable, it is important to remember that this information may not be completely accurate [16]. Therefore, the diet recall should be used in the context of other features of the youth's presentation. It will assist the clinician in gaining a general sense of meal and snack frequency, number of meals/snacks per day, quantity of food portioned, percent of food completed, fluid intake (calorie containing liquids and water) as well as the youth's dependence on nutrition support. It is ideal to capture both a weekday and weekend recall, as they often look quite different. Home recorded food logs could also be considered, though we use this tool infrequently. Generation of home food logs can cause anxiety in some patients and/or families, such as those with extreme

rigidity who also strongly desire to please the provider, or if there is excessive parent/child conflict around food. In these instances, the clinician must weigh this potential harm against the benefit. We generally avoid use of this tool if the diagnosis is unclear and an alternative restrictive eating disorder such as anorexia nervosa remains under consideration. Lack of food variety is common, and it is not atypical for patients to report complete or near complete avoidance of entire food groups. The diet recall can highlight such gaps. In our clinical practice, we have, at times, worked with patients whose intake is limited to fewer than 20 foods.

Accepted and avoided food presentation in ARFID patients is distinct from other restrictive eating disorders. The youth does not avoid energy dense foods for fear associated with weight gain or health impact. Commonly seen in our practice are food avoidances based on sensory characteristics such as smell, taste, texture, temperature or appearance. Often, these foods are specific to brand or other limiting characteristic (e.g., smell of a certain of food). If in the acute ARFID presentation there is a positive history of choking or vomiting, avoidances may be directed towards foods associated with this experience(s). Understanding the youth's food likes and acceptances as well as frequency hierarchy ("daily"; "sometimes"; "never") will help the clinician better understand macronutrient, micronutrient, fluid and fiber intake. This should be regularly assessed as the youth may fatigue of a particular food, especially if they are eating it often. This will help paint the picture of overall energy intake.

Youth presenting with ARFID may be at particularly high risk of several micronutrient deficiencies. Picky eating has been shown to lead to the following deficiencies: E, C, folate, fiber, Zn, Fe, D [17]. In the broader adolescent population, common vitamin and mineral deficiencies include calcium, zinc, Vitamin D and iron [18]. Half of adult bone mass is accumulated during adolescence. Bone accrual is related to intake of calcium, phosphorus, boron and iodine; therefore these micronutrients should be given special attention during assessment.

Given the probable complexity of the ARFID patient's food preferences, and the risk of energy- and micronutrient-deficient

intake, a thorough understanding of the youth's eating practices is essential to evaluation and treatment. One could consider organizing the assessment of food acceptances as follows:

- Accepted foods including specific preparation or brand: protein/combination foods, starch, fruits, vegetables, fats/spreads and dairy or dairy alternative
- Accepted liquids: sugar sweetened beverages, milk including fat percentage, caffeine containing drinks, water
- Intake frequency: always, sometimes, never.

Nutrition support; Compared with Anorexia Nervosa, ARFID patients have been shown to more often be reliant on nutrition supplementation, either oral or enteral [19]. In this case, type, frequency and volume of nutrition support should be assessed. In addition to standard commercial formulas, the use of smoothies, milkshakes or other energy-containing liquids should be considered. The use of nutrition support or a high liquid diet can impact hunger and satiety signal regulation, which can displace food interest.

Beyond the Diet Recall

By obtaining a better understanding of psychosocial and physiologic symptoms related to food, the clinician will be better able to contextualize the youth's feeding and eating practices as related to broader presentation. Although not diagnostic, the assessment can be used to support the diagnosis and best inform treatment recommendations within the interdisciplinary team (Tables 16.1 and 16.2).

Management

Communication between all team members is ideal to provide comprehensive care. Most patients will require care by a medical provider, a dietitian, and one or more therapists. While the bulk of this section will focus on specific management intervention guided by the dietitian and the medical

TABLE 16.1 Psychosocial factors related to food to include in nutritional assessment

Psychosocial factor	Examples
Meal and snack environment	Eating in the same space as other family members Eating in a bedroom Distracted or mindless eating
Feeding relationship	Parental catering to food preferences Parent and youth conflict, tension or pressure Readily available meal and snacks Over- or under-engaged caregiver Caregiver role-modeling behaviors
Meal pattern and eating frequency	Grazing Excessive time between meals and snacks Overeating Missed meals Night eating
Duration of meal	Rapid eating Slow or prolonged eating
Food security ^a	Enough to eat and types of food wanted
Cultural or family practices ^a	Elimination or inclusion of food types for reasons associated with belief system, health concerns, ethical practices Meals eaten away from home (fast food, restaurants)
Parent and caregiver eating practices	Historical or current picky eating Dieting practices
Peer interactions	Impact on meals and snacks eaten away from home including school, social, and extracurricular activities

^aNot specific to DSM-5 diagnostic criteria for ARFID but can assist in better understanding home environment as related to feeding and eating

TABLE 16.2 Physiologic factors related to food to include in nutritional assessment

Physiologic factor	Examples
Hunger signals	Hunger signals recognition Appropriate response to hunger signals Early satiety (feeling of fullness before age-appropriate portion has been completed) as related to gastroparesis Changes in comparison to normal eating pattern
Constipation, nausea or vomiting	Commonly observed and can impact hunger
Medications	Can impact meal pattern, hunger and satiety
Activity level	Low energy, suboptimal performance throughout activities of daily living or extracurricular activities

provider, the dietitian and/or medical provider is often in a position to recommend referral to other disciplines.

Given the high degree of co-morbidities, clinicians will need to determine the goals of care when determining referrals. For some patients, addressing ARFID as their primary or most pressing issue may not be appropriate. For example, if a patient is medically stable and, in addition to their ARFID symptoms, is also exhibiting depression and suicidal ideation, it may be prudent to table the ARFID care until their depressive symptoms have stabilized. It is important to use clinical judgement, collaborate with the family, and explore the adolescents priorities and goals when determining how aggressively to address the ARFID diagnosis.

Assuming that you are targeting ARFID as the most pressing and primary issue, ideally all team members will have expertise in ARFID care. However, this is not feasible in many areas of the country. In absence of finding a mental health therapist with ARFID expertise, the clinician should consider the patient's other mental health co-morbidities. If anxiety or ADHD, for example, is a prominent feature of the patient's presentation, it would be appropriate to refer to a

provider with that expertise. If there is not a prominent mental health co-morbidity, there is some research indicating Cognitive Behavioral Therapy (CBT) or Family Based Therapy (FBT) may be effective treatment modalities for patients with ARFID, so it is appropriate to consider referral to a therapist who has this expertise. Patients with a co-morbid developmental difference will likely benefit from having a therapist with training specific to the diagnosis. In our experience, this is especially critical for patients with Autism Spectrum Disorder (ASD), for whom we would favor a provider with a background in ASD over a provider with CBT, FBT or other eating disorder expertise.

Some patients may also benefit from involvement of an occupational therapist, particularly if they have rigid taste and texture preferences. In our experience, this tends to be most effective if the occupational therapist has expertise in food exposure with older children or adolescents. We have had the most success with providers who have advanced training in working with patients on the autism spectrum or with significant sensory integration challenges.

Of note, the availability of these other disciplinary team members may guide treatment approach. Certain treatment goals may not be appropriate to address without the support and input of individuals with requisite expertise. For example, we would not recommend a dietitian or medical provider working either alone or only with each other to target increased food acceptance as an outcome goal; caution should be taken in expanding food acceptance without appropriate support and collaboration with a therapist. In our experience, it is often frustrating and damaging to rapport when families are referred to a team member for whom this is outside the scope of their usual care. If this is the case, it is likely better to tailor the goals of care to fit within the scope of the available team members. Given the novelty of this diagnosis, we have worked with many providers who are “learning along” with the family; this can be well-received as long as the team members are all open to learning and are transparent with the family about their level of expertise.

Ideally, one or more members of the team will have expertise and be available for very frequent collaboration.

Nutrition Management

ARFID patients have been found to present as similarly malnourished compared to anorexia nervosa patients; therefore catch-up growth in the form of weight gain is often a goal of care [2]. This intervention should be assessed individually and in consideration of historical growth as earlier discussed. In our clinical practice targets for rate of gain can range between 0.5 and 2 lbs per week, with higher weight gain goals correlating with higher degree of malnutrition and lower starting treatment goal weight. Please refer to the chapter on anorexia nervosa for additional Goal of Care considerations in regard to physiologic function. When within range of treatment goal weight and determined to be adequately nourished, it is important to monitor and ensure ongoing weight and height progress to maintain optimal trajectory for age. It is also important to communicate the goal of ongoing age-appropriate growth to the patient and family. We have encountered many families who feel they are “done” when they reach the initial treatment goal weight, and are surprised to learn that the treatment goal weight is a moving target because growth continues into early adulthood. As previously discussed, these professional Goals of Care should take into consideration family and youth’s goals as well.

It is not uncommon for ARFID patients to experience blunted hunger signals. Often this is observed in association with malnutrition, medication or other co-occurring diagnosis. While there is limited research on the effectiveness of hunger and satiety promotion in ARFID patients, we have found it to be foundational to treatment as physiological motivation to eat can significantly aid in treatment progress. It is therefore important to assess “early and often”. It is also useful as a point of education, helping the youth to better understand the relationship between improved energy

intake, physiologic function, and subjective changes they may begin to notice. For example: increased ability to focus at school or improved energy levels while playing a sport. Education can also be directed towards mindfulness and eating intuitively. For example: exploring with the youth different ways the feeling of hunger presents in the body (e.g., feeling of emptiness in stomach, stomach growling, wandering concentration, lower energy, crankiness, headache, lightheadedness), and identifying which of these are early vs. late signals. Comparing this to other body functions (“How do you know you are thirsty? How do you know you are tired?") can sometimes be helpful for teens who are unaccustomed to interpreting hunger cues.

Appropriate spacing of meals and snacks will promote hunger cues. When youth eat too frequently or time between eating is prolonged, healthy appetite can be blunted. Emphasis is therefore placed on meal consistency in the form of set meal and snack times without “grazing” in between. We have found that in most patients, 3 meals and 2–3 snacks is appropriate. This translates into a meal and snack frequency of every 2–4 hours. In addition to hunger and satiety, this frequency, in combination with adequate quantity, will aid in supporting indicated weight gain.

A balanced composition of meals and snacks will also promote hunger and satisfaction. Determining accepted foods from categories including fruit/vegetable, starch, protein, dairy/dairy alternative and fats/spreads can aid families in laying out a roadmap to creating balanced, heart healthy meals. Ensure intake that is high-calorie, moderate protein and moderate fat when weight restoration is indicated. It is often advisable to encourage a multivitamin with iron to prevent iron or other micronutrient deficiencies. Adequate fiber, based on Daily Recommended Intakes (DRIs), and maintenance fluid, are recommended to restore GI function, measured as the absence of diarrhea, constipation and bloating as well as to promote normal voiding and stooling patterns. On the other hand, dependence on liquid nutrition has been shown to suppress hunger drive. In our

practice we have observed that when energy containing beverages constitute greater than 40–50% of daily calories, it becomes difficult to meet estimated energy needs with solid foods. The clinician should consider recommendations that promote food intake which will, again, support hunger and satiety regulation. Expansion of food variety should be considered with caution and may not be appropriate in all cases. Often adequate energy intake, including macronutrient and micronutrient balance, can be met using currently accepted foods. Guiding youth and families to understand this, is an important part of nutrition education.

Long term, the work of the interdisciplinary team is to support the patient to engage in developmentally appropriate eating patterns that will continue to support growth and development as well as overall health. This process takes time. As much as possible, the parent role is to provide food predictably. The youth's role is to decide what and how much of these foods they elect to eat. As the teen progresses to later adolescence, it is appropriate to increase their involvement in meal and snack preparation as a means of developmentally appropriate autonomy [20]. For many youth, this means ensuring there is adequate food when eating meals and snacks away from home, whether prepared in advance or purchased. The clinician can aid parents and youth to partner in strategizing these variances in daily schedule. Prioritization of family meals that are free from distraction can further aid in promoting consistent meal times. This may be the time in treatment that it is reasonable to consider discontinuation of care.

Case Study 1

Chris presented at 11-years 10-months of age due to concerns associated with weight loss and restrictive eating. Mom describes Chris as a longstanding adventurous eater who has always enjoyed a wide variety of foods. Notable in Chris's history are both a choking and a vomiting incident associated

with eating. When he was 5 years old, he choked on a chicken nugget while the family was eating away from home. Dad had to perform several abdominal thrusts to dislodge the food. This prompted parents to schedule a visit with the pediatrician who recommended a Swallowing Study. Results from the evaluation were unremarkable. At age 7 years, he quickly ate a slice of cake at a birthday party then vomited shortly after. The second incident prompted parents to schedule a visit with the pediatrician that resulted in an occupational therapist (OT) referral. The OT noted that Chris is quite wiggly and easily distracted when eating. Chris and his parents received education at the OT's office focused on eating behavior (small bites, calm body while eating) with no follow up recommended.

Since that time, Chris occasionally complained of having a "choky" sensation in his throat. Mom reports occasional anxiety with playdates or social outings because he is worried about the possibility of choking or vomiting. This anxiety is worse when parents are not present. One month ago, Chris was eating fish and chips for lunch with mom at the local mall food court. Shortly after finishing his meal, completing 100%, he vomited the entire contents of his stomach. After this, his anxiety worsened significantly surrounding food due to fear of a repeat vomiting incident. This has resulted in decreased food intake. He has also been unable to return to the local mall, or even drive by it, due to anxiety associated with the vomiting incident. He struggles to eat lunch at school. For the past several weeks mom has come to eat with him at school in a quiet space. They report that this has helped improve his intake from "nothing" to "a few bites". Eating is less difficult at home, although it remains challenging. This has resulted in some conflict between Chris and his parents as they push him to finish an appropriate portion of food at breakfast and dinner. Since the vomiting incident, the family has not eaten away from home at any restaurant, a deviation from typical practice. Chris has been invited to and missed one peer's birthday party due to anxiety.

Currently avoided foods include fish and chips because it reminds him of the vomiting incident and the mall. When anxiety is low, he is able to complete an appropriate amount of food, consistent with long-standing history and family practice. When feeling more anxious, as has been the case almost daily at the time of presentation, it's difficult for him to eat more than a few small bites. There have been a few instances where Chris experiences extreme hunger and loss of control associated with eating after a spell of restriction. At the recommendation of a friend, mom has been offering a meal replacement shake several times per day, which Chris is willing to drink.

Chris denies bullying, past or present. He has a good group of friends at school. His hobbies include soccer and playing the drums. The family, including mom, dad and younger sister, is not food insecure. He denies a desire to lose weight. When asked, he reports feeling that his weight is too low but is unsure what a healthy weight would be because he hasn't thought about it much. He identifies his largest barrier to eating is low appetite. Mom feels it is anxiety.

Family has identified a mental health therapist who they have met with once. The plan is to engage in CBT including exposure. There is a medication consult pending with a community psychiatrist.

Family medical history is significant for dad with anxiety; younger sister with anxiety and school avoidance; and mom with history of being underweight associated with collegiate sport participation.

Early growth records indicate that Chris has trended between the 50th and 75th percentiles for weight from ages 2 until 11-years 9-months. The day after the choking incident mom took Chris to his pediatrician where weight was 38 kg. His current weight for age is 36 kg (25–50th percentile for age). Height for age has consistently remained between 75th and 90th percentiles along the same timeline. Current height is 158 cm. BMI is 15.6 kg/m² (~10th percentile for age). Tanner stage is 1–2. Pulse, blood pressure, orthostatic changes, and full examination were unremarkable.

Key Questions

1. Is this ARFID? Which features of Chris's presentation would support this diagnosis?
2. Is this Chronic or Acute ARFID?
3. How would you determine Chris's treatment goal weight?
4. What coexisting conditions are you concerned about?
5. What goals of care should be considered? How should goals of care be prioritized?

Expert Commentary

1. Chris meets diagnostic criteria for ARFID based on the following:
 - (a) failure to achieve appropriate weight gain
 - (b) interference with psychosocial functioning
2. Based on Chris's choking incident and report of eating habits prior to this, we would consider this acute subtype ARIFD. Although he has a longer history of choking and vomiting issues, they did not previously rise to the point where weight and psychosocial functioning were impacted.
3. Review of growth records including weight for age, height for age and BMI for age with data points capturing growth prior to Chris's choking incident should be reviewed and will assist the provider in determining an appropriate treatment goal weight. Chris has lost 2 kg (4.4 lb) in the past month, equivalent to a 5% loss in usual body weight. This is concerning as he is losing a little over a pound per week, considered to be acute moderate malnutrition. Of note, Chris is not yet to Tanner Stage 3, where we would expect his "pubertal growth spurt" in stature to occur. This tells the clinician that treatment goal weight will likely need to be adjusted less frequently, approximately every 5–6 months, with ongoing assessment as he progresses towards this stage of growth. Also of note, parent report of

recent high weight can be a starting point if historical growth records are not immediately available.

4. Chris and mom report a long history of anxiety. A formal Anxiety Disorder diagnosis should be considered. Loss of control associated with eating is puts him at risk of binge eating.
5. This case study highlights the important role of the mental health team in ARFID treatment. We would coordinate closely with both therapist and psychiatrist as anxiety is addressed through therapeutic treatment modalities (CBT) and possibly medication. Weight loss and associated moderate malnutrition due to inadequate intake is also a priority. To accomplish this, the nutrition goal of care is for Chris to resume eating a variety of foods at regular intervals in age-appropriate portions. This will help ensure his ongoing needs are met for growth and development. We would expect Chris to make faster progress towards nutrition goals if his anxiety is being concurrently addressed.

Case Conclusion

- Chris was started on a low dose of Fluoxetine by his psychiatrist, who he sees monthly.
- Chris's mental health team diagnosed him with Generalized Anxiety disorder
- Chris continued to meet with his mental health therapist weekly. Exposure therapy was initially directed towards the vomiting incident at the mall. The future plan is to continue focusing on his anxiety
- Along the same timeline, Chris continued to meet regularly with a dietitian and medical provider at our clinic. Weight restoration of 100% eTGW was achieved over the course of 3 months. Working towards this goal required close coordination between the mental health therapist and our team. Fortunately, in addition to training in CBT, the mental health provider holds expertise in eating disorders

- After the initial evaluation, additional assessment revealed that during each choking and vomiting incident, Chris was eating a highly preferred food very quickly due to hunger and excitement. Family-directed nutrition education was focused on eating frequency (every 2–4 hours) as well as meal and snack balance to promote hunger and satiety regulation. Parents were coached to provide meals in a distraction free environment, eaten at the table when at home.
- Once eTGW was reached, Chris was seen by our team once more. He was successful at demonstrating weight maintenance and age-appropriate gain therefore care was transferred back to his pediatrician. This was five months from the time he was first seen.

Case Study 2

Samantha presented at the age of 14 years, due to concerns about her eating patterns and habits. Samantha has always been a picky eater. As a very young child, her parents would offer a wide variety of foods but when asked to taste something she did not want, she would throw a tantrum or gag on the bite. Ultimately, they started accommodating most of her preferences.

Recently, the foods she will accept have become even more limited, and she has not tried a new food in over four years. At the time of presentation, she was accepting 35 different foods in total, which were specific not only in type but also by brand (for example, she would only eat chicken nuggets from a certain restaurant, or a particular brand of macaroni and cheese).

For a long time, the family was told that she would likely “grow out of it.” However, her parents are now worried because her restriction seems to be worsening, rather than improving, with time. They are also concerned that as Samantha transitions into adolescence, her eating habits will have a greater impact on her social life. Samantha often has

to bring food with her to social engagements, and she is very selective about what she will order at a restaurant.

Samantha reports that she sometimes worries about things such as traveling and being able to eat, and will sometimes avoid social functions that are highly food-related. She feels uncomfortable when other people comment on her eating. Overall, however, she does not feel her pickiness is having a big impact on her life. She cannot identify any particular reason why she has recently become more restricted in her food choices. She and parents both note that she tends to be hypersensitive to many tastes, smells, and textures. She also tends to have other sensory sensitivities, such as to certain fabrics, tags on her clothing, and loud noises.

Samantha feels she is underweight but does not spend a lot of time thinking about this. She denies any body image concerns, other than occasionally wishing she weighed a little bit more or had more strength. She denies having a goal weight. She has neither lost nor gained weight over the past couple of months. She denies ever engaging in any efforts to purposefully lose weight. She regularly eats three meals and one snack per day, though parents reported relatively small portion sizes.

Symptomatically, Samantha endorses having some difficulty with sleep, overall low energy level, longstanding constipation, and difficulty gaining weight. Samantha experienced menarche at the age of 12, and continues to menstruate monthly, with normal duration and flow, and without significant cramping. She describes herself as an anxious person.

The family medical history is unremarkable. She lives with both of her parents and a younger sibling in a supportive household. There are no concerns around substance use or sexual health. She and her parents both acknowledge that the transition to high school has been somewhat challenging, with increasing academic demands and more complex peer relationships. She reports a small but tight-knit friend group. She denies bullying, depressed mood, suicidal ideation, or self-harm. The family has never experienced food or housing insecurity.

A review of the patient's chart revealed that she saw a gastroenterologist several years prior for abdominal pain, weight loss, nausea and heartburn. At that time, she had upper and lower endoscopies, which were both normal, and celiac testing, which was negative. Growth charts reveal height that has consistently been near the 90th percentile, a weight that has been in the range of the 50th percentile, and BMI that has bounced around between the 25th and 50th percentiles.

On examination, Samantha is 169 cm tall, with a weight of 49.6 kg and a BMI of 17.2 kg/m² (between the 10th and 25th percentiles). Her pulse and blood pressure were both within the normal range, without orthostatic changes. A full examination was unremarkable. Her breast and pubic Tanner staging were both Tanner Stage 4.

Key Questions

Try to use what you learned in this chapter to answer the following questions before you continue reading:

1. Is this ARFID? Which features of Samantha's presentation would support this diagnosis?
2. Is this Chronic or Acute ARFID?
3. How would you determine Samantha's treatment goal weight?
4. What coexisting conditions are you concerned about?
5. What goals of care should be considered? How should goals of care be prioritized?

Expert Commentary

1. We would call this ARFID. Samantha is medically stable but has a slightly downtrending BMI percentile and her escalating food restriction is starting to interfere with psychosocial functioning. Samantha denies any body image concerns or other clear etiology of her poor weight gain and eating behaviors.

2. Samantha has a longstanding history of pickiness consistent with a chronic subtype. Of note, other features of her presentation, including additional sensory sensitivities and anxious temperament, are often seen along with ARFID.
3. Samantha has had somewhat poor intake her whole life, so use of historical growth records can be challenging; there is no clear “drop off” from her normal growth. Possibly her weight has been blunted for many years. However, she is still menstruating and has normal vital signs, and progressed through puberty normally, so is likely not significantly underweight. The treatment team may consider subjective measures, such as improved energy levels and strength, as well as objective measures such as body composition testing, in helping determine a treatment goal weight. Long term, with adequate energy intake, we would expect her weight to stabilize at a place appropriate for her body habitus, expectedly higher than previous growth trajectory.
4. The treatment team should ensure to rule out possible comorbid organic contributors to chronic or acute-on-chronic difficulty gaining weight. This will include careful history taking, including ROS and family history, and a complete physical examination. For Samantha, given her longstanding difficulty with weight gain, consider diagnoses such as cystic fibrosis, inflammatory bowel disease, renal disease, rheumatologic illness, etc., as you go through your history taking and examination. You likely will not need to do significant laboratory work-up given her clear history of a strong behavioral component with other sensory sensitivities, unremarkable ROS and FH, and benign examination. However, given the high co-morbidity of eating disorders and gastrointestinal illnesses, we would include celiac testing in addition to the standard screening labs outlined in the chapters on restrictive eating disorders. Both Samantha and her parents note numerous anxiety symptoms throughout the history, and this likely requires further attention and evaluation.
5. Given Samantha’s overall well appearance, we would target goals of care to psychosocial functioning and the issues

that are bothering Samantha and/or her parents. This may include poor strength and energy noted by Samantha, improving her ability to participate in food-related events/outings, and minimizing stress she experiences around situations where she may be required to try new foods. It is important to keep an eye on weight trajectory and physiologic functioning during adolescence, as energy demands can change rapidly. Given her current level of stability, this may end up being a secondary focus of care. Ideally, Samantha and the team will at least work towards getting her back on her former growth trajectory; the changes she will need to make to accomplish this will likely be congruent with changes that will need to occur to improve her energy and strength, and minimize the psychosocial impact ARFID is having on her. Of note, Samantha's level of concern does not quite match that of her parents, and therefore getting everyone on the same page may require some attention.

Case Conclusion

1. Samantha was referred to a therapist, primarily to target her anxious symptoms.
2. *She* engaged with a dietitian who focused first on meal patterning (increasing amounts/frequency) to get growth back on track, and then started to introduce the idea of adding in new foods.
3. *We kept conversations targeted at* elucidating and capitalizing on her motivators/goals (feel more energy, be comfortable in social situations), rather than focusing on a weight number
4. Ongoing medical checks showing continued stability of BMI just below the 25th percentile, no other signs of medical instability (still menstruating, etc.)
5. She stopped cutting out more foods, and introduced a couple more but not making much progress there
6. *She worked on building skills* to navigate food-related social situations, with increasing confidence over time

7. *As Samantha built skills in navigating food-related social situations and demonstrated that this was no longer impeding her social development, Samantha's parents* also expressed less concern regarding her picky eating. Her parents continued to wish she would eat more variety, but Samantha was not motivated to work on this. The parents opted not to allow this to become a source of conflict, given her appropriate physiological and social function. The decision to “let this go” was supported by her team members.
8. *Samantha and her family* transitioned out of care, and were invited to return if Samantha felt the desire to expand her palate further in the future, or if any new medical or social concerns related to ARFID returned.
9. *Samantha* returned one year later, at her behest, after she noted weight loss in the context of decreasing parental involvement in reminding/prompting her to eat. Her parents expressed that they were finding it challenging to support Samantha's overall increasing autonomy as an older adolescent with her need for parental intervention around food and eating. The team (including Samantha and her parents) worked together to create a more gradual plan for parents to reduce their involvement in food-related tasks, while supporting Samantha in skill-building around this area and promoting greater autonomy in other realms.

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Chapter 17

Binge Eating Disorder in Adolescents and Emerging Adults



Jessica Barth Nesbitt and Elizabeth Wassenaar

Binge eating disorder (BED) is the most common eating disorder in the United States and impacts individuals of all ages, genders and socioeconomic status. BED has a prevalence rate of 1.9–2.8% in adults and 1–5% in adolescents and 10.8% meeting criteria for subthreshold/unspecified BED [1–3]. In adults, BED is the second most commonly diagnosed psychiatric disorder [4]. BED is defined in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) as recurrent episodes of binge eating at least once a week during a period of three months [2, 5]. Binge episodes are described in the DSM-V as consuming a larger quantity of food than individuals would consume in a similar time period under normal conditions, in addition to experiencing a lack of control throughout the bingeing episode [5]. BED was identified in 2013 as an official diagnosis in DSM-V and prior to this was listed under Eating Disorder Not Otherwise Specified (EDNOS) [5].

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Bingeing episodes occur in absence of engagement in compensatory behaviors including self-induced vomiting, laxative use and exercise, and include three or more of the following characteristics: (1) Eating more rapidly than normal, (2) Eating until feeling uncomfortably full, (3) Eating large quantities of food in the absence of hunger, (4) Eating alone related to shame or embarrassment related to the quantity of food consumed, (5) Feeling guilt or depressed following episodes of binge eating [5].

Pubertal onset increases the risk for the onset of eating disorders due to biologic factors as well as an increase in social consciences and social awareness [2, 6]. Following puberty, adolescents have a higher incidence of BED [2].

Diagnosing BED in adolescents has been identified as challenging related to adolescent development and changes in eating and growth patterns. Self-reporting of bingeing episodes can be a limiting factor related to the accuracy of the report, especially if engagement on the behavior is misunderstood [7]. Loss of control (LOC) eating has been more commonly reported when compared to binge eating episodes in adolescents as a result of the above limitations. Subclinical Binge Eating Disorder (SBED) has a higher prevalence compared to a BED diagnoses in adolescents at a rate of 2.5% for SBED and 1.6% for BED in both males and females [2]. In adults, BED has been identified as having a similar diagnosis ratio between males and females as compared to Anorexia Nervosa (AN) and Bulimia Nervosa (BN), with a higher incidence in females than males (28.6%: 13.2%) [8]. Likewise, female adolescents have higher rate of BED and SBED and a higher persistence of BED into adulthood [2].

The elucidation of binge eating disorder can be intimidating in the primary care setting due to difficulty of knowing how to ask the right questions, and the nature of the disease, including shame and hiding of binge eating behaviors. In addition, as stated above, adolescents may struggle to determine what behaviors are associated with binge eating. The

use of various screening tools including Adolescent binge eating scale (ADO-EDO), Child EDE (Ch EDE) and Questionnaire on eating and weight patterns (QEW) can support pediatricians and primary care physicians with identifying potential LOC eating, SBED and BED. Further evaluation and interviewing should also be conducted prior to providers making a diagnosis related to the variability of self-reporting in children and adolescents [2, 3].

Risk Factors

Biological, psychological and environmental risk factors play a role in the development of eating disorders, including BED. These factors can include, and are not limited to, genetics, family dynamics, restrictive eating patterns, family eating styles and an individual's temperament [6].

Environmental Risk Factors

Dieting is defined as limiting food and/or drink in order to lose weight [9] and is a \$60 billion dollar industry per year and a Western culture norm [9]. Up to 66% of teenaged girls and 31% of teenaged boys admit to having tried a diet for weight loss [10].

Dieting and dietary restriction ignores the body's natural physical hunger and satiety cues. Development of food rules related to labeling and categorizing of foods as healthy vs. unhealthy, and severely limiting an individual's energy intake make an individual more susceptible to the physical and psychological effects of under-nutrition. This can lead to loss of control eating, with especially high risk of precipitating binge eating from these pre-existing binge eating disorder behaviors [11].

Dieting practices and dietary restriction can be common practices in BED related to the desire to lose weight. The

participation in dietary restriction and dieting practices has been shown to increase an individual's risk for engaging in binge eating and BED and is associated with the onset of binge eating symptoms in both adolescents and adults [12]. Dieting was observed to be the most important predictor of developing an eating disorder in adolescents age 14–15 during a 3-year study. In a 2-year study of 9–14 years old an increase in weight gain and binge eating was seen with dieting [13]. In a study of 8–13-year-old boys' and girls' engagement in dietary restriction was a predictor of binge eating after one year [14].

Further highlighting the impacts of dieting and food restriction on the development of an eating disorder, adolescents who engaged in moderate restriction were five times more likely to develop an eating disorder. Adolescents who engaged in extreme restriction were 18× more likely to develop an eating disorder when compared to non-dieters [13]. Weight loss achieved through dieting has been shown to have limitations regarding success of maintaining long-term weight loss [15]. Weight cycling seen in dieting practices can increase an individual's shame, guilt, depressive symptoms and further decrease an individual's self-esteem and body image dissatisfaction [16].

Weight related to teasing among overweight adolescents increased their engagement in dieting practices compared to those adolescents who experienced no teasing [14]. Weight teasing predicts weight gain, binge eating, and extreme weight control measures; close to 40% of overweight boys and girls report experiencing teasing related to weight by peers and family members [13, 15]. Weight teasing from parents and peer groups, in addition to conversations related to weight, have been associated with an increased engagement in emotional eating in overweight adolescents [13, 14].

Emotional feeding by parents or family members related to emotional regulation has been shown to increase the frequency of emotional eating in adolescents. Emotional feeding

can impact an individuals' emotional flexibility when food is not present, leading to an increased incident of binge eating and loss of control eating [17]. Emotional eating is also associated with binge eating and binge eating may be utilized as a coping mechanism to manage stressful situations. The use of binge eating to cope with stress can be seen in individuals of all weights. It is estimated that 40% of individuals consume more food when stressed [18, 19].

Socioeconomic status also is considered a risk factor for BED among overweight and obese adolescents in both low and high socioeconomic status. A higher incidence of BED has been observed in adolescents in higher socioeconomic status related to body image distress, dieting practices and family pressure and teasing [12]. Overweight or obese adolescents in lower socioeconomic status are at increased risk to develop BED as result of food insecurity and dieting practices [12].

Psychological Risk Factors

Personality traits associated with BED include neuroticism and urgency, impulsivity, and a tendency toward experiencing negative emotionality [20, 21]. Altered activation of the brain's regions in BED have been shown related to impulsivity, compulsivity and decreased reward sensitivity with greater influence towards food [14, 22]. An increase in impulsivity seen in BED may explain the reported loss of control during bingeing episodes. Increased depressive symptoms and decreased self-esteem are associated with greater punishment and impulsivity in individuals with BED [21–23]. Individuals with BED also displayed self-criticism and overvaluation of weight and shape [24]. Limitations in attention and mental flexibility, executive functioning and inhibitory control have been seen in individuals with BED [22–27].

Family Dynamics

In the analysis of families of persons with BED, families were found to have low cohesion, low emotional expressiveness, high conflict and control, and low independence. Higher family functioning, including parent connectedness and maternal knowledge of one's child's whereabouts, were associated with lower binge eating behaviors in both adolescent girls and boys [28].

Biological Risk Factors

Obesity does not cause BED but has been shown to increase an individual's risk of developing BED [5, 6]. Binge eating, or LOC eating have been reported in 25% of children and adolescents who are overweight or obese [4]. Weight status classification in children and adolescents is based on Center of Disease Control (CDC) growth chart [5]. Individuals who are obese and overweight have a higher incidence of engaging in binge eating episodes and being diagnosed with BED when compared to normal weight peers [12].

Genetics and eating disorders have been increasing studied with a significant correlation being made between familial history and AN [5]. A twin study showed the heritability estimate for BED range from 41% to 57% based on the BED criteria [3]. Genetic studies have been limited for BN and BED, requiring further research as it relates to the role of genetics and BED.

Medical Complications and Comorbidities

Obesity and overweight status are considered risk factors for BED but are not necessarily related to one another. Obesity is associated with numerous physical and psychological health problems. Medical complications seen in persons with BED are often weight-related complications.

However, not all individuals who are diagnosed with BED will have overweight or obesity and obesity-related medical complications have been observed separate from weight status in some persons diagnosed with BED [29, 30]. Individuals with BED are 3–6× more likely to have obesity compared to individuals without BED [31]. An increase in pediatric obesity has been observed with an estimate of 17% of adolescents meeting criteria for pediatric obesity [32]. 30% of adults with BED reported childhood obesity and BED is associated with early onset of being overweight [31]. Health problems associated with obesity in adolescents can include hypertension, polycystic ovarian syndrome, obstructive sleep apnea, type II diabetes, dyslipidemia, asthma, acid reflux, mobility limitations, depression and anxiety [13, 33]. It was also found that loss of control eating in children can predict the future development of metabolic syndrome, weight gain, increased visceral adipose tissue and elevated triglycerides.

Gastrointestinal

Gastrointestinal complications associated with BED can include acid reflux, dysphagia, bloating, diarrhea, constipation, abdominal pain [4], gastric dilation, pancreatitis and in rare cases gastric rupture [33] as result of bingeing episodes. Dysmotility has also recently been identified in individuals who experienced rapid weight gain of >3 kg in 3 months. These individuals were also identified to be at increased risk for deliberate purging following bingeing episodes [4, 12]. Individual's with BED may have an increased incidence of autoimmune gastroenterologic disorders including Crohn's disease [4]. Gut microbiome is an area of interest related to the influence on weight regulation, energy uptake, appetite, inflammation and psychiatric illnesses. There is no data available evaluating microbiota changes related to BED, highlighting the need for further research and evaluation in this emerging field [4].

Reproductive Health

Polycystic ovarian syndrome (PCOS), amenorrhea, oligomenorrhea and premenstrual dysphoric disorder have all been linked to BED. PCOS is the most common endocrine disorder in females [34]. 17–23% of women diagnosed with PCOS also meet criteria for BED [4, 12, 35–37]. Early menarche is not directly correlated with BED. Early menarche in adolescents is associated with obesity and trauma which are also associated with BED [4].

Sleep

Sleep impairments are more commonly seen in individuals with BED compared to obese individuals when sleep activity is measured [12]. Obstructive sleep apnea (OSAS) is a sleep disorder with an increased incidence in obesity. An estimated 60% of children who are obese are diagnosed with OSAS [38]. A study of individual's presenting for bariatric surgery found that 52% had obstructive sleep apnea and BED was found to be more common among these individuals [12].

Night eating syndrome (NES) is classified under the DSM-V diagnosis of Otherwise Specified Feeding and Eating Disorders [5] It is defined as consuming most calories following the evening meal and is often associated with insomnia and morning anorexia [2]. Individuals with NES consume more than 25% or more of their daily calories after their evening meal [5, 39]. An increased presentation of NES in young adults and late adolescents can be traced back to behaviors of snacking and grazing in place of mealtimes, sleeping challenges, and to parental eating patterns [39]. Studies related to NES in adults has shown that 15–20% of adults with BED also have NES [31]. Adolescents have a higher incidence of nighttime eating and NES when compared to both older adults and children [39].

Psychiatric Comorbidities

Increased incidences of depression, anxiety, alcohol and drug use have been associated with adolescents diagnosed with BED and SBED [2]. A higher incidence of anxiety was observed in adolescents diagnosed with BED and adolescents with SBED had a higher incidence of alcohol and drug use [2, 40]. BED and depressive symptoms have a strong link, with BED being the only identified eating disorder predictive of depressive symptoms [41]. Besides major depressive disorder, BED is the mostly commonly diagnosed psychiatric disorder in adults seeking bariatric surgery [12]. Studies have shown an increase in both functional and mental health impairments and emotional distress in adolescents diagnosed with BED and SBED [2]. Impairments and impacts on adolescents with BED and SBED have been observed related to social life, work and school functioning. One study reported 9% of adolescents with BED had severe impairments in social life and 2.8% of adolescents with SBED had impairments with work and school [2].

Adolescents with BED reported suicidal ideation following onset of BED [2, 42]. Associations between suicidal ideation in both males and females with BED and SBED were seen, with a higher incidence in BED [2, 19, 43]. Increased incidence of self-harm was observed in SBED and not BED in adolescents [2, 44].

Malnutrition

Malnutrition and refeeding syndrome are medical risk factors that are commonly associated with individuals who are underweight or are diagnosed with anorexia nervosa. Refeeding syndrome is defined as fluid and electrolyte shifts that occur related to the reintroduction of nutrition following a period of food restriction or significant weight loss [45]. Malnutrition is the result of changes in body composition

related to overnutrition and undernutrition. Severity of disease and nutritional intake are factors used to diagnosis malnutrition [46]. Malnutrition and refeeding syndrome can occur in individuals of all weights and sizes including individuals diagnosed with BED and Atypical Anorexia Nervosa (AAN). AAN is classified under the diagnosis of Otherwise Specified Feeding and Eating disorders and is defined in the DSM-V as having met all the criteria for Anorexia Nervosa, but despite significant weight loss the individual's weight is not classified as underweight [5]. Individuals with AAN have a history of previously being overweight or obese and AAN is more commonly diagnosed in males and youth of lower socioeconomic status [47]. AAN has been associated with increased odds of cardiac complications related to percentage of weight loss [48] and medical instability that matches or exceeds AN [47]. Weight loss of 5% has shown to have clinical significance when occurring with engagement in food restriction [49], and an individual's percentage of weight loss was also shown to predict an individual's risk of refeeding [47].

Malnutrition can be overlooked in BED and AAN as a result of the individual's weight status and not being classified as underweight. Encouragement to participate in dieting or extreme weight loss practices for weight loss can unintentionally come from receiving praise for weight loss by family members or healthcare providers. This can further increase an individual's risk for malnutrition and medical complications related to the continual engagement in extreme dieting and weight loss practices. The importance of evaluating an individual's risk for malnutrition is crucial, and evaluating the percentage of weight loss versus BMI [47] can help improve the identification of individuals who are malnourished or at increased risk for refeeding in higher weight bodies. Classification of the degree of malnutrition in adolescents with eating disorders has been proposed to help identify malnutrition by healthcare providers. The proposed classification uses percent median BMI and

percentage of weight loss as risk factors to determine level of malnutrition as mild, moderate or high risk [13].

Nutrient Deficiencies

Overnutrition is a form of malnutrition that occurs as result of overfeeding or excessive nutrient intake and can lead to nutrient deficiencies and obesity [50]. Nutrient deficiencies can be observed in BED despite the perception of overconsumption of calories related to weight status. Binges often consist of calorically dense foods higher in carbohydrate and fat content. Limited protein intake is also found related to the higher carbohydrate and fat content of binges [4]. Diets that contain a higher fat content often limit an individual's intake of foods rich vitamin C, vitamin A and folate [4, 51].

Vitamin D deficiency can be seen in individuals who are considered obese related to reduced bioavailability caused by vitamin D being sequestered in adipose tissue [51]. A higher incidence of vitamin D deficiency has been reported with children and adolescents who are overweight [51]. Decreased consumption of milk can lead to calcium and vitamin D deficiencies, which can impact bone health in adolescents and young adults [52]. Vitamin D deficiency may also have a relationship with obesity and depression [4]. Iron deficiency can be seen in obesity, and is related to hepcidin being made in liver impacting absorption [53].

B vitamin deficiency has been observed with obesity and could place individuals with BED at increased risk. Zinc deficiency is commonly seen in AN. A recent study showed up to 28% of individuals had a zinc deficiency who were obese and presenting for bariatric surgery [4]. Zinc deficiency is the result of excessive urinary zinc excretion due to hyperinsulinemia [54]. Zinc supports taste and appetite regulation. Research is ongoing related to the role of zinc in insulin resistance in obesity and BED [4].

Neurobiology of BED

BED impacts on the brain are similar to the impacts seen with substance abuse. A reduction in activity in the prefrontal and orbitofrontal cortex of the brain related to self-control has been observed with BED [21, 55]. Varying forms of the dopamine and opioid receptor genes can lead to an increase in reward sensitivity to high in carbohydrates, sugar and fats considered highly palatable [21]. Palatable food intake has been associated with an increased release in dopamine and endogenous opioid peptides [56]. Tryptophan is an amino acid required for serotonin synthesis; low levels of serotonin and tryptophan are associated with an increased desire or engagement in binge eating of highly palatable foods [21, 57, 58].

Psychotropic Medications

There are currently no medications approved for the treatment of BED in children and adolescents. Several psychiatric and weight loss medications have been tested to assess their potential to reduce the frequency of binge eating episodes and support weight loss. Cognitive behavioral therapy (CBT) and Interpersonal psychotherapy (IPT) and Dialectical behavioral therapy (DBT) have shown promise in treating BED [59]. Numerous medications have been studied in combination with CBT to assess the effectiveness in symptom interruption. Lisdexamfetamine dimesylate (Vyvanse) is the first FDA approved medication for the treatment of BED in adults with moderate to severe illnesses. Vyvanse originally entered the market for the treatment of attention deficit hyperactivity disorder in both adults and children. Vyvanse in studies have shown a reduction in binge episodes, weight and obsessive thoughts [7].

In adults, antidepressants including selective serotonin reuptake inhibitors (SSRI), serotonin norepinephrine reuptake inhibitors (SNRI), tricyclic antidepressants and others have been assessed for their effectiveness in reducing fre-

quency of binge eating episodes and weight loss. While a reduction in binge episodes and weight loss have been seen, none of these medications alone have led to remission from BED [60].

Certain antiepileptic medications used in the treatment of seizure disorders have demonstrated efficacy in the treatment of obesity and have been assessed for their effectiveness in the reduction of bingeing [61]. Topiramate (Topamax) and zonisamide (Zonegran) both showed a reduction in weight in addition to a reduction in the severity and frequency of bingeing episodes [60]. Topiramate has also been studied for its potential benefit in the treatment of BN and supported a reduction in frequency of bingeing and purging episodes [61, 62].

A medication for attention deficit-hyperactivity disorder (ADHD), atomoxetine (Strattera), has been studied in the treatment of BED. In studies atomoxetine was shown to be superior to placebo to decrease binge eating and weight [63].

Opioid Antagonists: Naltrexone supported improvements in the reduction of bingeing frequency when combined with fluoxetine and when provided alone at supratherapeutic doses [64]. Opioid antagonists may be the most helpful in individuals with BED and severe comorbid neuropsychiatric and medication disorders [64].

As previously stated, overweight and obesity are not diagnostic criteria for BED despite being commonly observed in individuals diagnosed with BED. For this reason, several weight loss medications have been or are being tested to assess their ability to reduce binge eating episodes while supporting weight loss in individuals with BED.

Orlistat reported mixed results in the reduction of binge eating episodes. When combined with CBT a reduction in binge eating episodes was observed when compared to placebo [60]. Bupropion-naltrexone (Contrave) and phenetermine-torpiramte (Qsymia) have shown to support a reduction in bingeing episodes during initial studies. Liraglutide (Saxenda) is currently in clinical trials to test effectiveness in BED treatment [44].

Due to the medications impact on weight loss, several medications have the potential to be misused by patients to support large percentages of weight loss. This has been observed with Orlistat, Topiramate and Vyvanse. A patient's oral intake, bingeing frequency and weight trend should be evaluated during use of all the above medications to prevent misuse and to ensure efficacy [60, 61, 64].

Notably, there is a large placebo response to pharmacologic treatment. Placebo treatment has been associated with decreased eating disorder pathology and stabilized BMI [35].

Nutrition/Behavioral Interventions

Dietary restriction is a significant environmental risk factor associated BED. Individuals seeking treatment for BED often have attempted numerous weight loss programs or diets in an attempt to lose weight and interrupt bingeing episodes. In addition to caloric restriction, limiting food choices and inconsistency with meal planning and meal timing can impact binge eating behaviors by prompting the consumption of highly palatable foods higher in carbohydrates, sugars and fats. Binge eating itself may be a risk factor for dieting. Avoidance of social situations or engaging in dietary restriction in public due to fears of judgements, shame and guilt associated with food choices may reinforce the bingeing behavior. Several cases highlight that concerns related to weight and engagement in binge eating preceded engagement in dieting and weight control behaviors [14]. Implementation of a meal plan that meets one's nutritional needs, self-monitoring, nutrition education and mindful eating are interventions that have shown to support a reduction in bingeing episodes [65]. Meal plans are effective tools to support consistent regular caloric intake to ensure an individual's nutrition needs are being met while supporting satiety [65]. Incorporating proteins and fat at meals can interrupt binge episodes and support appetite regulation [65]. Meal plans should be reviewed by a registered dietitian and

adjusted as needed to ensure an individual's nutritional needs are being met.

Foods associated with bingeing may be avoided as a binge control strategy. Incorporation of variety, including binge foods, supports a decrease in cravings, feelings of deprivation and challenges food rules related to foods being healthy or unhealthy [65]. However, inconsistent incorporation of highly palatable past binge foods can result in bingeing or overeating episodes. In cases where the binge foods are too feared to allow for consistent incorporation, exposure response prevention therapy (ERP) can be effective to support normalization of binge foods by systematic introduction of the feared foods, thereby reducing the avoidance of these binge foods [65].

Individuals with binge eating disorder may struggle with buy-in regarding a meal plan because of fears of gaining weight due to establishing a consistent eating pattern. To support a consistent eating pattern, caloric items should only be consumed during meal and snack times. Following an episode of bingeing, individuals should return to the meal plan by completing the next scheduled meal or snack. In some cases, weight gain can be observed during the initial stages of treatment and often stabilizes or decreases as episodes of bingeing are interrupted. Providing nutrition education regarding the impacts of binge eating and dietary restriction on weight status, in addition to the function and benefit of macro and micronutrients, portion sizes, food's impact on mood, meal planning, grocery shopping and challenging dieting myths can support maintenance of the recommended meal plan.

The use of electronic or handwritten food logs support self-monitoring of meal plan to help individuals and treatment providers observe patterns related to bingeing episodes. Self-monitoring can bring awareness to the relationship between bingeing and restriction in addition to identifying triggers that can influence bingeing urges and episodes [65]. Additional interventions to support interruption of bingeing behaviors include practicing mindful

eating, discarding leftovers, limiting the quantity or completely eliminating binge foods from the home, using pre-packaged food items, carrying limited money and brushing teeth following eating [65]. Planned bingeing episodes can also support a reduction in bingeing episodes when full symptom interruption has been unsuccessful. Locking food in cabinets or containers to interrupt bingeing behaviors may indicate the need for a higher level of treatment to provide consistent support and containment to achieve symptom interruption [65]. Mindful eating is defined as making conscious food choices, awareness of hunger and satiety cues and eating in response to these cues [66]. Mindful eating is derived from the mindfulness practice associated with Dialectical Behavioral Therapy (DBT) and Acceptance and Commitment Therapy (ACT). Intuitive eating is different but complementary of mindful eating and is described as honoring hunger cues, avoiding categorization or labeling of food as healthy vs. unhealthy, rejection of diets and the dieting mentality, and finding satisfaction in food choices [66]. The role of mindful eating is to bring awareness to every bite of food and encouraging an individual's full presence during the eating experience with minimal focus on calories and percentages of macronutrients [67]. Mindful eating interventions have been shown to help interrupt bingeing episodes, reduce emotional eating and eating in response to external cues. Mindful eating is positively associated with behavior change as it relates to eating behaviors [66]. Mindful eating practices support a reduction in food consumption by reducing eating pace and improving awareness related to satiety cues, leading to a decrease in energy intake and potentially weight loss [66, 68, 69]. Studies looking at mindful eating and weight loss have provided mixed results; more favorable results were seen related to mindful eating practices and weight stabilization in addition to the prevention of additional weight gain [66]. Trusting of their body's satiety cues, which resulted in ending a meal or snack in adolescent females, showed a decreased likelihood of engaging in dieting and bingeing

behaviors [70]. The use of the intuitive eating scale and mindful eating questionnaire can help assess an individual's use of intuitive and mindful eating practices [66]. Behavioral weight loss practices commonly focus on exercise, monitoring of food intake and goal setting [71] also associated with BED interventions and can diminish the frequency of binge eating episodes and may support weight loss [59]. Behavioral weight loss often doesn't meet an individual's expectation related to weight loss, and desire for weight loss is often a significant motivator in individual's with BED who are also obese or overweight related to the medical, physical limitations experienced as result of weight status. Weight loss of 5–10% is the amount of weight loss commonly associated with behavioral weight loss, which can include engagement in exercise, calorie reduction and improved nutrition [36, 59]. BED and obesity are linked with increase in weight gain following successful weight loss and may not benefit from conventional obesity management strategies [59, 72].

Psychotherapeutic Interventions

Psychotherapeutic interventions when combined with pharmacologic interventions have produced the most positive results related to interruption of bingeing episodes [59]. Psychotherapies shown to be the most effective related to the treatment of BED included Cognitive Behavioral Therapy (CBT), Interpersonal Therapy (IPT), and Dialectical behavior therapy (DBT) [59]. Acceptance-based therapies are also a therapeutic modality with evidence to support treatment of BED.

Cognitive Behavioral Therapy (CBT)

CBT has been extensively researched and is considered a first-line treatment option for BED based on the effectiveness of interrupting binge eating episodes [37, 59]. CBT when

used in BED treatment targets thinking patterns related to weight and weight loss that can influence an individual's engagement in bingeing and calorie restriction frequently referred to as the binge restrict cycle [37,73]. CBT attempts to replace the faulty thinking patterns related to weight loss and the use of maladaptive eating disorder behaviors with healthy eating habits [37]. The binge-restrict cycle can be described as a pattern of weight shaming and desire for weight loss through the participation in dietary restriction followed by an episode of bingeing as a result of an emotional vulnerability. CBT supports a decrease in binge eating by supporting a normalized eating pattern and improvement in body image [73]. Adult BED remission rates of 60–70% have been achieved with the use of manualized CBT with most individuals seeing ongoing success in maintaining at the one-year mark [36, 37]. Increased abstinence of binge eating episodes were observed in adolescent females at the 3 and 6 months follow-up following CBT treatment [2]. CBT is also associated with a decrease in depressive symptoms and body image concerns in adolescents [2].

Self-guided CBT provides an increase in access to care for individuals with BED. A self-guided CBT workbook, used in conjunction with routine therapeutic appointments, supports the development of regular eating patterns. Self-monitoring and problem-solving are the focus in the self-guided CBT to support the interruption of binge eating [73]. An abstinence rate of 65–67% in binge eating episodes is associated with self-guided CBT and produces similar results to Interpersonal Therapy (IPT) [73]. Internet-based self-guided CBT in conjunction with behavior weight loss support, showed a reduction in BMI, binge eating episodes and body image concerns in adolescents when compared to adolescents in a 9-month weight loss control [2]. Self-guided CBT can be an effective initial treatment when compared to no engagement in any form of treatment and has been shown to be less effective in individuals with more severe BED presentations when compared to IPT [73].

Interpersonal Psychotherapy (IPT)

IPT focuses on improving interpersonal functioning which supports the improvement of psychiatric symptoms [74]. IPT is considered a brief therapy, often occurring over a period of 4–5 months that consists of three phases, initial, intermediate and termination phase and requires quick identification of the interpersonal problem and linking it to the eating disorder behavior [74]. IPT supports identification and expression of painful emotions to decrease the use of food as a coping mechanism while developing healthy interpersonal skills to decreasing the frequency of binge eating episodes and promote a healthier self-image [36, 73].

IPT is associated with a decrease in bingeing episodes and weight stabilization in adults with BED and demonstrated similar long-term absence results when compared to CBT at 1- and 5-year follow up [73, 74]. IPT in adolescents produced a reduction in LOC eating at 6-month follow-up and BMI at 1-year follow up compared to adolescents in health education class [73]. A reduction in binge eating episodes in adolescent females was observed with IPT in a 12-month follow-up when compared to females attending health education class [2, 74].

Dialectical Behavioral Therapy (DBT)

DBT is a mindfulness-based, third-wave cognitive behavioral psychotherapy originally developed for the treatment of borderline personality disorder (BPD) [75]. DBT utilizes the teaching of skills including emotion regulation, distress tolerance, core mindfulness, and interpersonal effectiveness to target emotion dysregulation to interrupt target behaviors [75]. Bingeing episodes in BED can be viewed as a way to navigate emotional negativity related to self and interpersonal situations, in addition to managing emotions related to food and body image [75, 76]. Anxiety and sad-

ness have been identified as the emotions that most commonly trigger episodes of binge eating, followed by emotions of loneliness and anger [75, 77].

A limited number of randomized controlled trials have been conducted to assess the effectiveness of DBT for adolescents with BED [2, 78, 79]. In one trial, participants in the DBT group condition showed a decrease in binge eating episodes and lower dropout rate compared to adolescents in the control condition, but improvement was not maintained at one-year follow-up [78]. When compared to behavioral weight loss intervention, DBT showed similar and significant reductions in a sample of female adolescents on measures of eating- and shape-related concerns, disordered eating attitudes and negative affect [2, 80].

Acceptance Based Therapies

Acceptance based therapies use emotional regulation and connecting an individual to their values to promote behavioral change. Acceptance based therapies include Acceptance and Commitment Therapy (ACT) and Acceptance Based Behavioral Therapy (ABBT). ACT supports improved psychological flexibility and function by connecting an individual to their values to support behavior change [81]. A reduction in emotional eating has been associated with the use of ACT based therapies to reduce the need to control negative emotions through supporting more flexible thinking, improving tolerance to emotional distress and incorporating value-oriented activities [82]. ABBT combines both the behavioral components from CBT with the emotional regulation components from ACT and DBT [83]. In an open pilot study using ABBT, a decrease in binge eating was observed at the start, midpoint and follow up stages of treatment. Improvements in emotional regulation and experiential acceptance were associated with a reduction in eating pathology [83].

Family Based Treatment (FBT)

FBT is a first-line treatment AN in adolescents and has shown promising results with BN. In FBT, parents are in control of restoring their adolescent to health [84]. Family involvement has been shown to be more effective in both adolescent obesity and eating disorder treatment [13, 85]. The use of FBT for BN resulted in similar clinical results when compared to self-guide CBT related to reduction of bingeing and purging behaviors. FBT has been studied for the effectiveness in pediatric obesity (FBT PO) related to the support of parental involvement in weight loss [85]. FBT PO uses a similar structure as FBT AN where the parent is responsible for meal and snack monitoring and all mealtimes decision based on the adolescents age [84, 85]. FBT-PO differs from other forms of FBT related to the incorporation of physical activity [84]. Focus on healthy lifestyle modifications, use of family meals to help demonstrate normative eating and reducing distractions, and discussions regarding weight and diets can be interventions that support adolescents [13]. To date there have been no studies reviewing the effectiveness of FBT and BED.

Alternative Therapeutic Interventions

Neuromodulation is designed to activate or deactivate neural circuitry through use of a controlled electrical current [86]. Neuromodulation includes Deep Brain Stimulation (DBS), Transcranial Magnetic Stimulation (TMS) and repetitive TMS (rTMS), Electroconvulsive Therapy (ECT) and Transcranial Direct Current Stimulation. (tDCS). Neuromodulation therapies may help interrupt food cravings, decreasing overeating episodes in individuals with BN and BED [86]. None of these interventions have been specifically investigated in adolescents with BED, however many modalities have been safely used in adolescents with other psychopathology, with the exception of DBS.

Repetitive TMS (rTMS) acts via magnetic pulses to targeted areas of the brain and has been shown to potentially cause cortical change and increased neuroplasticity [87]. Case reports in patients with a diagnosis of bulimia nervosa have demonstrated remission in symptoms, but larger studies have not demonstrated impact on purging behaviors [88, 89]. In patients with obesity but not BED, rTMS was shown to decrease calorie intake and impact weight loss in only four sessions over two weeks [90]. Trials for efficacy of TMS in patients with binge eating disorder (BED) are in process [69].

Transcranial direct current stimulation (tDCS) delivers a weak electrical current to specific brain regions through electrodes placed on the scalp [91]. Limited studies have looked at tDCS binge eating and bulimia nervosa with mixed results [92, 93].

Deep Brain Stimulation

Deep brain stimulation (DBS) is an invasive neurosurgery that results in electrical pulses via implanted electrodes in targeted brain structures and is evidenced for use in refractory movement disorders and OCD [94]. Targeting the nucleus accumbens has been demonstrated to impact appetite signaling in hyperphagia [95, 96]. Furthermore, there is limited evidence for the use of DBS in severe binge eating, with reduction in severe bingeing and weight loss following placement in the lateral hypothalamus [97].

Electroconvulsive Therapy

Electroconvulsive therapy (ECT) involves inducing a seizure in an anesthetized patient. It is a valuable treatment neuro-modulatory intervention for severe depression, bipolar disorder, psychosis, and catatonia [98]. There is a single case report of a male patient with severe obesity and binge eating disorder who was successfully treated with ECT [99].

Neurofeedback

Neurofeedback is the volitional control of neuro reactions to real-time EEG or functional MRI information about brain activity. Neurofeedback has been used to decrease overeating and disinhibited eating in patients subclinical BED which resulted in decrease in overeating episodes and decreased over-valuation of food [100, 101].

Virtual Reality Therapy

Virtual reality (VR) is “...a three-dimensional, computer generated environment [in which a] person becomes part of this virtual world or is immersed within this environment...” [102]. Using computer technology, VR therapy can be used to replicate virtual exposures to foods, food environments like kitchens or grocery stores, and address body image distortions. Following treatment, patients treated with VR interventions demonstrated improvements in body attitudes, eating behaviors, and weight loss [103, 104].

Bariatric Surgery

Bariatric surgery is a surgical intervention for adults and adolescents with obesity or overweight and medical comorbidities. Weight loss is achieved by significantly restricting one’s ability to intake food (restrictive) or absorb calories from food (malabsorptive) [105]. The three most common bariatric surgery procedures in the United States are the sleeve gastrectomy (SG), Laparoscopic Adjustable Gastric Band (LAGB) and Roux-en-Y gastric bypass (RYGB) [106], however LAGB is not approved for adolescents under the age of 18 years old. Bariatric surgery can be a treatment option for obesity in adolescents who have achieved pubertal maturity with significant comorbidities not responsive to behavioral weight loss strategies [107].

Weight loss results after bariatric surgery are varied and impacted by BED. BED is associated with poorer surgical outcomes, less weight loss, more weight regain, and surgical revision [108–110]. Prior to bariatric surgery, the prevalence of BED in adults is reported as 4–49%, with LOC eating rates of 13.3–61%; and in adolescents binge eating or LOC eating is reported as 20–48% [108, 109]. LOC and subjective bingeing after bariatric surgery can result from limitations in ability to consume large quantities due to anatomical changes [109]. Following bariatric surgery in adults, LOC eating was observed at a rate of 16.9–39% [109]. Individuals diagnosed with post-operative BED usually had BED prior to weight loss surgery, indicating the importance of identifying BED prior to weight loss surgeries.

After bariatric surgery, individuals can experience nutrition deficiencies related to surgical interventions or compensatory behaviors to support weight loss. Protein malabsorption, as evidence by below normal albumin levels, is the highest nutritional complication in RYGB [111]. Vitamin and mineral deficiencies are seen in both adults and adolescents post operatively, including Calcium, vitamin D, Thiamine, Iron and Folate and these deficiencies can result from rapid weight loss, malabsorption, poor diet and supplementation compliance [111, 112]. The impacts of vitamin and mineral deficiency can be seen related to bone health with a decrease in bone mineral by 7.4% in post-operative adolescents after 24 months, however, Z scores remained unchanged [112].

Post-operative involuntary vomiting can be related to consuming intolerable foods, eating too rapidly, not completely chewing one's food, or plugging, which refers to eating foods that cannot pass successfully from the surgical pouch [109] and dumping syndrome, which is an osmotic overload from calorie-dense intake resulting in fluid sequestration in the small intestine resulting in nausea, diarrhea and fatigue. This can occur with increase intake of sugary foods or higher volumes of food [111]. Vomiting was reported in 30–60% of post bariatric surgery patients and dumping

syndrome reported in 40–76% post bariatric patients which has shown to resolve in 18–24 months post-surgery [101]. Induced vomiting and self-induced dumping can be used in individuals post operatively to support weight loss and should be viewed as eating disordered behaviors [109]. Monitoring individuals post operatively for development of eating disorder and improved screening preoperatively to support identification of eating disorders is necessary for all bariatric surgery clients [109].

Athletes and BED

There is believed to be an increased incidence of eating disorders in athletes [113]. Studies have shown that 13.5% of athletes will meet the criteria for a subclinical or clinical eating disorder [114]. A higher incidence of eating disorders are associated with aesthetic sports and weight focused sports with a higher prevalence of eating disorders seen in female athletes [114]. However, BED appears to occur at equal or higher rates in male verses female athletes [115]. A study of division I NCAA student athletes showed 10% of female athletes and 13.02% of male athletes reported binge eating 1× a week, and a higher incidence of binge eating was also reported in male bodybuilders at 46% and male rowers at 12% [113]. Reasons for the high occurrence of eating disorders in athletes include personality traits commonly seen in athletes, including perfectionism, self-discipline, goal-oriented, persistent and strong-willed. (Coelho) [116]. Increased focus on weight goals, performance and winning can also support eating disorder behaviors in athletes. Athletes with specific body weight goals and participation in caloric restriction to reach weight goals are at increased risk for BED due to risks detailed above related to the restriction-disinhibition cycle of binge eating [114]. A multidisciplinary team that includes psychologists, registered dietitians, athletic trainers, coaching staff, psychiatrists and family therapists experienced in working with athletes and eating disorders

will have the expertise needed to effectively treat athletes with eating disorders in addition to provide support to the athletes' families [113].

Sexual Minorities and BED

Body image-related concerns and engagement in weight control behaviors are increased in sexual and gender minorities and, developmentally, adolescence is a time of exploration of gender and sexual identity [117]. Nearly 5–7% of adolescents identify as lesbian, gay, bisexual or transgender in the United States [118] and almost 3% identify as transgender or gender nonconforming [119]. A study of adolescent boys and girls showed a higher incidence of binge eating and being influenced by the media related to their appearance [118]. There was a decrease in dieting and media's influence on body image in lesbian and bisexual girls [118]. Screening for eating disorders in sexual minorities by medical providers, in addition to education prevention efforts on college campuses, are needed related to the higher risk for developing an eating disorder [120, 121].

Males and BED

Males account for 36% of individuals with BED and is the most common eating disorder diagnosed in adolescent males [121, 122]. The rate increases in males with subclinical eating disorders with 42–45% reported binge eating [122]. Concerns regarding factors that influence an individual's perception of what it takes to be a man can lead to binge eating [122]. Body image concerns regarding weight and muscularity are also common in males with eating disorders. The broadening of diagnosis criteria related to eating disorders in the DSM-5 has increased the inclusion of males who previously didn't fit within the diagnosis criteria [122]. Stigma related to males and eating disorders, in addition to males viewing binge eat-

ing as a normative eating behavior, [123] can impact access to eating disorder treatment. Additional research, education and screening tools are needed regarding eating disorder, including BED in males of all ages, to help improve diagnosis and treatment access [122].

Level of Care Guidelines for BED

Eating disorder treatment opportunities for patients with BED are limited by poor recognition of the disorder by both individuals and health care professionals. Patients with BED may spend years receiving medical care for co-morbidities without recognition of the need for specialized eating disorder treatment that can address the disorder at multiple levels. Guidelines for higher levels of care in eating disorder treatment traditionally have been inclined towards patients who are underweight due to restricting behaviors or experiencing medical consequences of purging, medication misuse, or over-exercise. Higher levels of care for patients with BED can address psychiatric, medical, and/or nutritional instability and containment may be necessary to interrupt “automatic,” impulsive, and/or compulsive binge eating behaviors.

The following are considerations for higher levels of care for BED:

1. Eating disordered behaviors that cannot be interrupted at a lower level of care evidenced by either treatment attempts or severity of symptoms.
2. Medical co-morbidities that create clinical instability that would need medical support, especially those that may be destabilized by interruption of the eating disorder
3. Psychiatric co-morbidities that are amenable to higher levels of care, including unstable mood, poor responsiveness to psychiatric medications, and safety concerns, especially those that become more active when the eating disorder is interrupted
4. Substance abuse concerns or withdrawal concerns. Co-occurring substance use disorders are common in BED

(>23% lifetime co-occurrence) and can complicate treatment by either active use or withdrawal. This is especially pertinent in the post-bariatric surgery population, with up to 40% of post- RYGB patients developing a new alcohol use disorder [123].

5. Family or psychosocial concerns that make treatment participation in a lower level of care difficult. This could include issues such as distance from professionals with experience in treating BED, family conflict, especially surrounding the eating disorder, living alone, or family's inability to make changes needed for treatment success without more intensive intervention.

Thoughtful functional impairments include missing a lot of school or work, difficulty leaving the house, difficulty taking care of activities of daily living, or difficulty with social connectedness. BED is associated with functional impairments that can be exacerbated by physical limitations and/or the impact of undertreated mood or anxiety concerns [124].

Case Study

J.N. is an 18-year-old female with a history of binge eating at the age of 15 years old related to an increase in depression, anxiety and challenges with school transition. At time of admission to PHP she reported a history of engaging in daily episodes of binge eating on donuts, chips and cookies after school in room. Patient reports purchasing binge foods on the way home from school and reported a recent history of stealing food from a local store to engage in bingeing behaviors after her parents began monitoring debit card purchases prior to PHP admission. Patient reported engaging in food restriction following episodes of binge eating, typically restricting breakfast and lunch during school. Patient also consumed all her meals separately from her family related to their schedule and feeling restricted by the family's food choices.

At time of PHP admission patient had reached her highest weight of 205 lbs, reported gaining nearly 100 lbs since onset of binge eating episodes. J.N. reported a powerful desire to lose weight and was checking her weight multiple times a day prior to PHP admission. J.N. identified her goal weight 120vlbs. J.N's medical history included major depressive disorder and general anxiety disorder. Current medications included Wellbutrin and Remeron.

J.N. was admitted to PHP level of care to support normalize eating behaviors, develop skills to support interruption of binge eating episodes, mood regulation and to identify triggers related to bingeing episodes. J.N worked with a multidisciplinary team, including psychiatrist, dietitian and therapist during her PHP admission. She attended therapeutic groups 8–10 hours a day, 7 days a week during PHP that including DBT, ACT and CBT skills group in addition to nutrition education and ERP. J.N. was placed on a meal plan included three meals and two snacks and utilized electronic food logs to record intake, hunger and satiety, and her feelings and emotions following all meals and snacks. Patient participated in food exposures with cookies during exposure response group and was successfully able to incorporate cookies into her meal plan without bingeing. J.N. overall was able to maintain consistency with meal plan completion during PHP. She engaged in occasional episodes of food restriction in PHP related to body image concerns and a desire to lose weight.

Routine lab and EKG monitoring were completed during PHP. J.N. was started on Topamax after Remeron was discontinued due to potential impact on appetite and bingeing episodes. Vitamin D deficiency was observed on admission labs (22 ng/ml) and patient was started on 1000 units of Cholecalciferol 1× a day and MVI 1× a day.

J.N. was admitted to PHP for a four-week period and successfully interrupted binge eating episodes during PHP admission and was binge free for a period of seven days prior to stepdown to IOP. J.N. was admitted to IOP for a total of eight weeks and following discharged returned to her outpatient community providers. J.N. maintained a meal plan that

included three meals and two snacks and began eating meals with parents at the kitchen table. J.N. continued to work on incorporating fear foods, including completing exposures with donuts and chips, and regained access to her debit card and her driving privileges. J.N. began participating in exercise during IOP admission and initially struggled with occasional food restriction due to a desire to lose weight, which led to two episodes of binge eating. J.N.'s weight did trend down during admission to PHP and IOP and reached a discharged weight of 198lbs. J.N. returned to her meal plan following each bingeing episode and was able to successful maintain her meal plan and participate in exercise. J.N. also began volunteering at a local animal shelter and applying for college supporting her connection back to valued activities.

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Chapter 18

Otherwise Specified and Unspecified Feeding or Eating Disorders



Tracy Kenela

Introduction

When I started my private counseling practice nearly 10 years ago, my professional experience as a counselor had been primarily in the field of vocational rehabilitation, where I helped adults with work-related injuries and illnesses return to gainful employment. I enjoyed the work and did it well. Yet, something was missing.

My decision to begin working with those who struggle with food, eating and body image developed as a result of my own challenges in adolescence and young adulthood. Western culture is saturated with media, advertisements, and expectations for bodies that do not necessarily equate with health. In times of stress, many turn to (or away from) food as a way of coping. The period of adolescence was one that intrigued me. I had navigated through the period with help of family, professionals, and friends. I felt I could help others manage their struggles during this period of development.

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Although I had my doubts about whether people (and especially adolescents) would trust me with their innermost thoughts, feelings and behaviors concerning food, eating and body image, I decided to give it a try. I let the public know that I was comfortable working with issues surrounding food, eating and body image, and was also transparent about my own past struggles in these areas. I worked with colleagues who were (and are currently) passionate about treating this population. I gave hours of my time to the community as a facilitator of a free eating disorders support group, and as an educator by presenting educational talks on eating disorders at some local colleges and universities. I spent the extra time and effort to obtain an international certification as an eating disorders specialist. I also served as president of a local eating disorders chapter that presented educational events about eating disorders to a wide variety of treatment professionals in our community.

In my office, adolescent clients and their family members have experienced pain, anger, comfort and relief. They have held back secrets and made confessions. They have laughed, cried, and expressed anger. They've hugged their parents and have stormed out of my office. Yet each client has bravely talked about their emotional pain, and sometimes intense trauma. They have shared with me their victories and successes, and I have been honored to help every one of them.

Most of my adolescent clients hope to find freedom from disordered eating so that the quality of their lives will improve. And so it is my hope that in this chapter, I can provide some insights to parents, educators, professionals and others about what I have learned from working with adoles-

cents who struggle with disordered eating, as well as to offer some insights about how these conditions can be understood and effectively treated.

What Are “Otherwise Specified Feeding or Eating Disorders?”

Other Specified Feeding or Eating Disorder (OSFED) are recognized in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as conditions where there are feeding and/or eating challenges that cause clinically significant distress or impairment in a variety of major domains, and yet do not meet the full criteria for a diagnosis of an Eating Disorder [1].

Mental health counselors, therapists, psychologists, psychiatrists and social workers use the criteria outlined in the DSM-5 make official diagnoses, or to determine “what the specific problem is.” Each mental disorder in the DSM-5 has certain criteria that need to be met in order to fulfill a diagnosis. Once the criteria is met and a diagnosis or “problem” is defined, a treatment plan can be developed that is based on research on treatment outcomes for that diagnosis.

OSFED is a diagnosis in the DSM-5 that includes five (5) *specific* conditions that can occur with food, eating and body image that do not meet the full criteria for the more commonly known eating disorders such as anorexia nervosa, bulimia nervosa, or binge eating disorder. Fig. 18.1 lists the DSM-5 Criteria for OSFED [1].

- **Atypical Anorexia Nervosa:** All of the criteria for Anorexia Nervosa are met, except that despite significant weight loss, the individual's weight is within or above the normal range.
- **Bulimia Nervosa (of low frequency and / or limited duration):** All of the criteria for Bulimia Nervosa are met, except that the binge eating and inappropriate compensatory behaviors occur, on average, less than once a week and / or for less than 3 months.
- **Binge-Eating Disorder (of low frequency and / or limited duration):** All of the criteria for Binge-Eating Disorder are met, except that binge eating occurs, on average, less than once a week and / or for less than 3 months
- **Purging Disorder:** Recurrent purging behavior to influence weight or shape (i.e., self-induced vomiting, misuse of laxatives, diuretics, or other medications) in the absence of binge eating.
- **Night Eating Syndrome:** Recurrent episodes of night eating, as manifested by eating after awakening from sleep or by excessive food consumption after the evening meal. There is awareness and recall of the eating. The night eating is not better explained by external influences such as changes in the individual's sleep-wake cycle or by local social norms. The night eating causes significant distress and / or impairment in functioning. The disordered eating is not better explained by Binge-Eating disorder or another mental disorder, including substance use, and is not attributable to another medical disorder or to an effect of medication.

FIGURE 18.1 Otherwise Specified Feeding or Eating Disorders (OSFED)

Below are case examples of how OSFED can present in adolescents and emerging adults:

- An adolescent female goes to her pediatrician for a physical so that she can play sports at school. During the examination, her doctor notes that she is considered overweight according to the Body Mass Index (BMI). She immediately feels shame. She becomes fearful of being labeled as “fat” and rejected by her peers. She then takes extreme measures to restrict food to lose weight. Because of the extreme food restriction, she begins to lose weight. Within a short period of time, she loses a significant amount of weight. However, because her current weight is considered within or above the normal range for her age and height, her pediatrician does not consider it a problem.
- An adolescent male is upset because his parents are getting divorced. He notices that food makes him feel better when he is upset. Once every couple of weeks, he engages

in binge eating (or eating, within a discrete period of time, an amount of food that is definitely larger than what most people would eat within a similar timeframe), and then engages in exercising, vomiting, fasting and using laxatives to compensate (compensatory behaviors).

- An adolescent female is obsessed with doing well in school. Every couple of months, during the week when final exams and projects are due at school, she becomes extremely anxious. During this time, she engages in binge eating. She doesn't compensate for the food eaten by exercising, vomiting, fasting or using medications. When that week is finished and her anxiety calms down, she stops binge eating until months later, the next time final exams and projects are due at school.
- An adolescent male watches a lot of reality television, and admires the trim, muscular bodies of the males he sees on the shows. He dislikes his own body, and decides to change it. He becomes very careful about what he eats because he wants to be a film star one day. He is concerned about his body weight, and how his body will appear on film. He does not binge eat, but he does use exercise in an effort to control how his body looks and how much it weighs.
- An adolescent female is dissatisfied with the way her body looks. She thinks she is overweight, so she restricts her food intake all day. She eats an evening meal with her family so that they will not suspect she is dieting. She goes to bed at 10 pm, but wakes up hours later ravenously hungry. When she is sure that all her family members have gone to bed, she gets out of bed, goes to the kitchen, and eats an excessive amount of food. She goes right back to bed. In the morning, she remembers what happens, and throughout the day is preoccupied by feelings of guilt and shame about eating.

Each of the adolescents in these examples meet *specific* criteria for an OSFED diagnosis. Because OSFED is a rela-

tively new diagnostic category in the DSM-5, adolescents with OSFED are less likely to be recognized, detected or treated for their eating disorders until years after it starts. This is also true for the diagnosis of EDNOS, where there are *unspecified* struggles with food, eating and body image.

What Are “Unspecified Feeding or Eating Disorders?”

Unspecified Feeding or Eating Disorders (UFED) are recognized in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as conditions where there are feeding and/or eating challenges that cause clinically significant distress or impairment in a variety of major domains, and yet are *not specific*...they do *not* meet the full criteria for a diagnosis of an Eating Disorder.

Like OSFED, those struggling with UFED (also known as eating disorder not otherwise specified or EDNOS) do not meet criteria for the more commonly known eating disorders such as anorexia nervosa, bulimia nervosa, or binge eating disorder. In this chapter, ED NOS or UFED may be used interchangeably. Those who struggle with OSFED exhibit what are known as “disordered eating behaviors.” Disordered eating behaviors include any method of restricting food, binging on food or using compensatory behaviors to “undo” the effects of what is eaten. And so, individuals who struggle with EDNOS are those who report having problematic behaviors with food and eating that are disordered but unspecified, and thus do not meet DSM-5 criteria for a specific Eating Disorder. Figure 18.2 lists the DSM-5 Criteria for EDNOS [1].

Presentations in which symptoms characteristic of a feeding and eating disorder cause clinically significant distress or impairment in social, occupational, or other important areas of functioning, yet do not meet the full criteria for any of the disorders in the feeding and eating disorders diagnostic class. This category is used in situations in which the clinician chooses not to specify the reason that the criteria are not met for a specific feeding and eating disorder and includes presentations in which there is insufficient information to make a more specific diagnosis (i.e., an emergency room).

FIGURE 18.2 Unspecified Feeding or Eating Disorder (EDNOS)

Below is a case example of how EDNOS can present in an adolescent:

At the age of fifteen, Avery struggled with acne. It was embarrassing, and she wanted it gone. She'd heard that certain types of food could cause acne, and so began restricting certain foods (mainly processed sugar and oils) from her diet in hopes of getting rid of the acne. At the time, Avery's weight was normal for her size, and her main objective was not to lose weight. However, because of the extent of the foods restricted, Avery did lose a significant amount of weight. People noticed, admired her, and commented on how great she looked. For some reason, she liked that her clothes fit more loosely than they had before, and that peers admired her. The more weight Avery lost, the more confident she felt about being accepted by peers. The more confident she became, the more acceptance she gained.

To those who weren't close to Avery, her life must have looked great. Yet she was miserable. She was constantly tired and cold. Avery lived in California, and was freezing even during the summers. She was also struggling in school because she just couldn't focus. Homework took longer to complete, and it was more difficult to do. Avery was also constantly anxious, depressed, or angry about something. She also had problems with anger. She regularly lashed out at family and friends by throwing temper tantrums, and by giving them the silent treatment. Her behaviors toward friends and family members caused her to become angry and ashamed of herself, which caused increased isolation.

Avery continued to restrict food through high school and into college, without anyone becoming very concerned. She successfully minimized the negative effects of the disordered eating. This was easy to do because she didn't really experience any major physical or reactions as a result of engaging in disordered eating behaviors. Avery hadn't been hospitalized, and still had her menstrual period, which (in her mind) meant that she was doing all right. Other than one incident where she requested that her mother take her to the doctor's office because she felt weak and light-headed, there were no medical

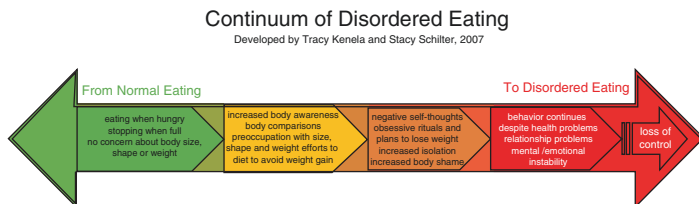


FIGURE 18.3 A progression from Normal Eating to Disordered Eating

visits. And because we did not have awareness and information about eating disorders in the mid-1980's, there were no visits to a counselor for help coping with Avery's emotions.

Figure 18.3 represents how normal eating patterns can progress into disordered eating behaviors:

I find it helpful to view specific or unspecified eating disorders on a continuum. The value of this is because a continuum does not look at things as all or nothing. Rather, a continuum views struggles as a fluid progression, wherein each individual can identify his or her own unique point between “Normal Eating” and “Disordered Eating.” This is also a very helpful visual image to help adolescents see where they are in their own, unique progression toward disordered eating.

The Continuum of Disordered Eating (Figure 18.3) is a simple tool for parents, educators, and professionals to use to determine whether an adolescent is struggling with disordered eating. It can also be a good indicator of how intense any struggle might be. The continuum identifies four factors that are used to assess the presence and severity of disordered eating: (1) negative thought patterns, (2) negative beliefs about self, (3) painful emotions, and (4) disordered eating behaviors. Each of these are described below:

- Negative thought patterns in adolescents can start as fleeting thoughts, such as “She looks great,” or “He’s really popular,” and progress to more negative thoughts, such as, “I look awful because I don’t look like her,” or “I’m not as

popular as he is.” The presence of overly harsh and judgmental thoughts can indicate an underlying core belief about the self that can cause problems emotionally. ***If the adolescent says any of these things out loud, a careful exploration should be made about how often these thoughts are present, how harsh the thoughts get, and whether any of the thoughts indicate any underlying core beliefs about self.***

- Negative beliefs about self in adolescents include long-standing and inflexible beliefs that are negative, often not true, and always unhelpful. For example, the thought “She looks great” and “I look awful because I don’t look like her,” can indicate the presence of a negative belief about self that “I am awful” or “I am ugly.” Similarly, the thought, “He’s really popular” and “I’m not as popular as he is,” can indicate the presence of a negative belief about self that “I am a loser,” or “I am a failure.” ***If an adolescent appears to believe any of these negative things about the self, painful emotions are likely to result. It is recommended that therapy be explored at this point, to help reverse the beliefs about self, and to cope with any painful emotions that can happen as a result of these beliefs.***
- Painful emotions in adolescents can occur regularly, and at random, during the teen years. In the presence of painful emotions, it is important to determine what is causing the emotions to occur. Painful emotions can arise because of physiological or hormonal changes, negative life situations (such as a relationship conflict or breakup), or because of negative thought patterns and negative beliefs about self. For example, if an adolescent thinks, “She looks great and I look awful because I don’t look like her,” and believes “I’m ugly,” painful emotions of sadness, fear, anger and/or shame can result. ***If an adolescent appears to have painful emotions, it is likely that there will be urges to “do” something to make the emotions go away. This is where the behaviors come in.***
- Disordered eating behaviors in adolescents are what they choose to “do” to cope with the painful emotions they feel

because of their own negative thinking and negative beliefs about themselves. Disordered eating behaviors can include dieting, weight loss rituals (such as over-exercising, laxative use or purging food), isolation, increased body awareness and body comparisons. The behaviors are considered “disordered” because they arise out of, and cause, significant disorder in their lives. *If disordered eating behaviors are observed in an adolescent, a thoughtful and non-judgmental inquiry should be made about the presence of negative thought patterns, negative beliefs about self, and painful emotions.*

Understanding the Struggle

Parents, teachers, friends and family members will often recognize struggles with food by simply observing changes in the adolescent’s behaviors around food and eating. Noticing what the adolescent is “doing” differently with food and eating involves seeing what is going on externally, on the surface. These external behaviors are what typically cause parents and others to schedule adolescents for a medical appointment, or for a psychotherapy session.

Noticing *external* behaviors with food and eating in adolescents is an important first step to getting them an accurate diagnosis and treatment plan. However, if there are truly disordered eating behaviors happening, it is important to find out what is going on in the adolescent’s world, and how it affects the *internal* processes, which include beliefs about themselves, their thoughts and their feelings. This can be done by seeing a psychologist, psychotherapist or mental health provider trained in working with eating disorders (e.g. licensed social worker).

1. Here is a simple way to understand how adolescents can struggle with disordered eating: Changes in eating behaviors are often utilized to cope with painful emotions;
2. Painful emotions happen because of situations that occur in daily life, or because of physical feelings we feel in our bodies, or because of how we feel about how we look;

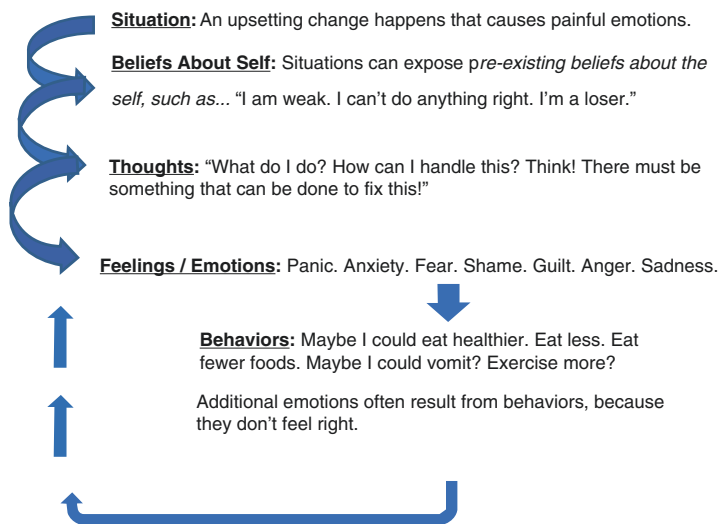


FIGURE 18.4 The process of Think, Feel, Do

3. Painful emotions result because of how we think about what is happening to us, and because of the beliefs we have about ourselves.

Figure 18.4 is a "Think, Feel, Do" model of how struggles can happen with food and eating.

This flow chart can help parents, family, friends, educators and professionals begin to understand what is happening in the mind of a person who struggles with disordered eating, and why disordered eating behaviors happen.

Here is a way to analyze and understand the case example of EDNOS given earlier in the chapter, using Fig. 18.4:

Situation Her struggles with food and eating began as a result of a specific situation that upset her: the presence of acne. This was not only an unexpected life event that produced unwanted change, but it was also something that happened to her body. It also seemed beyond her control.

Beliefs about Self There were pre-existing negative beliefs she had previously established about herself, including, “I am worthless. I am flawed. I don’t do well at things. I’m no good. Nobody will ever be interested in me. I am gross, disgusting, and nobody will ever want me the way I am.” These extreme, negative, judgmental and unhelpful beliefs were triggered by the presence of acne.

Thoughts When extreme, negative, judgmental and unhelpful beliefs exist in an adolescent, their moment-to-moment thoughts about themselves can be unhelpful, and quite harsh. For example, she could think, “Acne is totally unacceptable,” and “Something needs to be done about these stupid zits,” and “How could you have let yourself break out again?” Although these thoughts could appear to be about acne, they are also likely about how she perceives herself as being unacceptable.

Feelings/Emotions As a result of the unhelpful beliefs and harsh thinking patterns about herself, she is more likely to feel a variety of painful feelings and emotions. For example, she could feel shame or embarrassment when thinking about herself as being unacceptable. She could also be fearful of peer rejection, and of the possibility that she may not be able to do anything to control her acne. She may also feel depressed or sad at the thought that it because of her flaws (acne and otherwise), nobody would ever like her or want to spend time with her.

Behaviors When unhelpful thoughts and painful emotions occur, she is more likely to notice increased urges to “do something” to cope with the pain she feels. “Doing something” might mean fixing her (external) acne or fixing any (internal)

personal failures she perceives are within herself. When adolescents believe that fixing external problems will also fix internal problems, it can be easy for them to change their behaviors with food and eating. In this way, they believe they are “doing something” to help them feel better about both external and internal problems.

Adolescents can change their behaviors around food and eating by increasing or decreasing the amount, type or quantity of food eaten. They may also try to increase physical activity to burn more calories, or increase weighing the body to monitor weight loss, or to control weight gain.

Below are some examples of adolescents who change their behaviors around food and eating:

- Adolescent used to appear delighted at the prospect of eating cake or ice cream, but now appears uninterested or even afraid of eating cake or ice cream.
- Adolescent used to want to go out to eat with friends, but now prefers to be at the gym.
- Adolescent previously didn't make any comments about bodies, but is now making harsh and critical body comments about herself and others to those in her social world.

When looking at my own struggles (as presented in the Case Study of EDNOS), parents, teachers, friends and family members could have recognized the following changes in behavior that could alert them to the possible presence of disordered eating:

- She doesn't eat as many sugary foods as she used to. She also avoids French fries, and she used to love French fries.
- She is wearing a sweater, and it is 80 degrees outside
- She got a “C” grade in English, it is her best subject, and she always gets “A” grades.
- She has become contentious. Why does she always seem to want to pick a fight with us?

Had my parents, teachers, friends and family members recognized that changes in my eating behaviors and my body could progress to disordered eating, I am sure they would have taken action to prevent me from struggling as much as I did. However, since I was growing up during the late 1970's and early 1980's, when very little information about Eating Disorders existed, my friends and family praised my behaviors around food and encouraged me to improve my body! Because of this, I struggled with disordered eating into my mid-twenties.

Fortunately, today we know so much more about Eating Disorders and disordered eating behaviors in adolescents, and about how detrimental they can be to adolescents and their families. We know that the beliefs, thoughts and feelings of adolescents play strong roles in their internal experiences, and that disordered eating behaviors are merely external signals that there are deeper internal emotional struggles going on as they live day to day in their environments.

The next section will describe the environment, and how the environment can contribute to and reinforce and disordered eating behaviors.

The Environment

Disordered eating behaviors are specific behaviors (such as restricting food, hiding food, or binging on food) that are used to cope with painful emotions that occur after upsetting situations happen in the adolescent's day to day environment. Most of the adolescent clients I see in my private counseling practice struggle with disordered eating behaviors that occur because of upsetting situations that occur in their environments.

Upsetting situations can happen in an adolescent's *external environment* from *external sources of distress* (such as social media, or interactions and comments from friends or family members about food, eating or bodies). These situations can trigger external disordered eating behaviors. Similarly, upsetting situations can also happen in an adoles-

cent's *internal environment* from *internal sources of distress* (such as negative self-thoughts and negative self-beliefs). These situations can trigger unhelpful thoughts and painful feelings. Upsetting situations can also happen in the adolescent's external and internal environments, from *both* external and internal sources of distress.

Below are examples of what can be included in an adolescent's environment:

Who The people who are present in the lives of adolescents

What The things adolescents encounter each day, and the expectations that are put upon them (or expectations they have of themselves).

Where The place adolescents live in, whether they are safe, supported and secure.

As a mental health professional, I like to get a good idea of what adolescents face in their daily environments. I ask them questions about who the people are in their lives, what situations they encounter, and where they go each day. Knowing this is key to finding out **how** adolescents interact with what is in their environment, and also how the environment may or may not be supporting (or "reinforcing") an adolescent's disordered eating behaviors.

After a few meetings with adolescents and their families, I talk with them about ways that the environment can intentionally or unintentionally be reinforcing disordered eating behaviors, and helping them continue. This can be a difficult subject to introduce, primarily because there is a tendency to want to put blame on something as the "cause" of the unwanted and disordered eating behaviors. As such, I find it helpful to steer away from placing blame on anything. I encourage my clients and parents to do this as well. Instead, I offer up the possibility that the internal or external environment can intentionally or unintentionally reinforce disordered eating behaviors, and that understanding (not blame) is the first step toward recovery.

Reinforcing Disordered Eating Behaviors

We'll use the first hypothetical case example of OSFED (presented earlier in the chapter) as an example of how to look at an adolescent's environment. Here is the case study:

An adolescent female goes to her pediatrician for a physical so that she can play sports at school. During the examination, her doctor notes that she is considered overweight according to the Body Mass Index (BMI). She immediately feels shame. She becomes fearful of being labeled as "fat" and rejected by her peers. She then takes extreme measures to restrict food to lose weight. Because of the extreme food restriction, she begins to lose weight. Within a short period of time, she loses a significant amount of weight. However, because her current weight is considered within or above the normal range for her age and height, her pediatrician does not consider it a problem.

Who A medical professional, parents, teachers, family and friends, the self.

In order to get a good view of her **external environment**, I would ask her about the feedback she's received from friends, family and others about her body. This could include the information from the medical professional, her parents, siblings, teachers, family and friends. In the course of this discovery, we may find out that the feedback she has received supports rejecting people they view as "fat."

In order to get a good view of her **internal environment**, I would ask her what she thinks and how she feels about the feedback she's received from friends, family and others about her body. I would also try to find out more about her beliefs and thoughts about her body. Wrapping this up, I would ask her how she believes using food and eating and other disordered eating behaviors could possibly help her cope.

What The sport she is trying to play, how school is going, and how life is at home.

In order to get a good view of the things she encounters each day, and the expectations that are put upon her, I would ask her how things are going at school and at home. She may be influenced by what she sees on the Internet or on social media about body size, shape or weight, or about conversations she hears amongst her peers about food, eating and body weight, shape and size. Again, she may be influenced by **external forces**, such as friends, family, school or social media, or she may be influenced by **internal forces**, such as her own feelings of self-worth, and “thinner is better,” that “to be thinner is to be worth much more.”

Engaging in disordered eating behaviors could give her relief from the painful emotions she feels because both forces are occurring, and because she is actually doing something to help her move away from her beliefs that she is worthless.

Where The place in which she lives, where she goes to school, which sports she plays and get together with friends.

In order to get a good view of the **external** places she goes to each day, I would ask her to describe the places in which she typically finds herself (like home, car, bus, room or school), and ask her how emotionally safe she feels in these places. For example, she may feel fear at school or at home because she doesn't feel accepted. She may also feel shame at home or in social situations because she views parts of herself as embarrassing. I also like to get a good view of the **internal** places she inhabits. These are mainly the thoughts, feelings she has, in addition to urges to engage in disordered eating behaviors that come from within her, and not from external forces.

As you can see, disordered eating behaviors can negatively affect an adolescent's quality of life. That is why when I meet with adolescents who struggle with disordered eating, I try and determine which areas of life (or “Major Life Domains”) have been negatively affected by behaviors surrounding food, eating and body image.

Major Life Domains

When we start to consider whether food and eating behaviors are normal, disordered, or somewhere else on the Disordered Eating Continuum, we need to look how disordered eating behaviors may be affecting an adolescent's quality of life. A tool for determining whether behaviors are affecting an adolescent's quality of life can be found in simply assessing their major life domains.

Figure 18.5 is a model I developed that shows six (6) Major Life Domains of adolescents that can become affected by disordered eating:

Physical Behaviors with food and eating are affecting physical wellbeing. Restriction in food intake, binging or purging food by

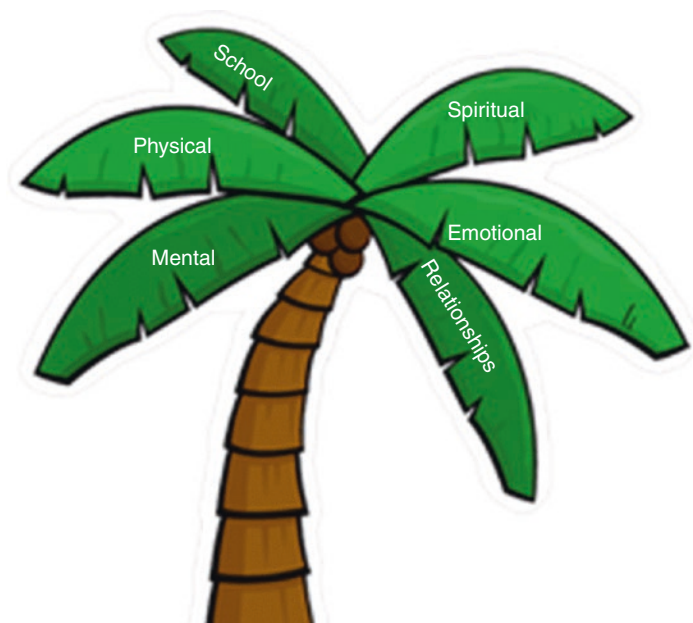


FIGURE 18.5 The Major Life Domains of Adolescents

vomiting can cause hypoglycemia, high cholesterol, high or low blood sugar levels, anemia, malnourishment or electrolyte imbalances.

Mental Behaviors with food and eating are affecting mental functioning. Restricting or overeating food can result in mental confusion, which occurs from malnourishment and electrolyte imbalances which can affect daily memory, work or school.

Emotional Behaviors with food and eating are affecting the frequency/intensity of emotions. If an adolescent notices uncomfortable feelings in the body, experiences unwelcome feedback, or feels guilt or shame about behavior, increased emotional distress can result despite using behaviors to cope which can affect family and social interactions.

School/Academic Behaviors with food and eating are affecting school or academic performance. Any of the above mentioned physical, mental or emotional effects, can affect the quality of thinking, which can in turn affect academic performance.

Spiritual Behaviors with food and eating are affecting spirituality. If emotional distress persists, adolescents can experience changes within the spiritual choices they have made thus far, which can leave them feeling like they are confused, alone, and without a spiritual presence who loves, protects and helps them through the tough times in their lives.

Relationships Behaviors with food and eating are interfering with important relationships. When adolescents are preoccupied with disordered eating behaviors, they often have limited time to spend with the people they love, and who care for them. They isolate and have limited social relationships.

When Behaviors Continue (Reinforcement from the Environment)

Now that you understand that painful situations can lead to negative thoughts and painful emotions, and that disordered eating behaviors can be enlisted to cope with emotional pain, here is an example of how the environment can reinforce disordered eating behaviors to continue:

1. When an adolescent receives positive feelings or attention as a direct result of their new behaviors with food and eating, painful emotions can be relieved, and can subside. As a result, the new behaviors around food and eating will likely become “reinforced”; which means that the behaviors are more likely to continue because they have produced positive relief from the painful emotions.
2. When negative feelings or attention occur as a direct result of their new behaviors with food and eating, painful emotions will likely remain, or get worse. As a result, the new behaviors around food and eating are likely to stop, and other coping methods (including giving up) will be tried.

In summary, new behaviors around food, eating and body image are most likely to continue if they elicit a positive emotional outcome. And, new behaviors around food, eating and body image are most likely to discontinue if they elicit a negative emotional outcome.

Figure 18.6 illustrates how positive feelings and attention around disordered eating behaviors can encourage future

Positive feelings: “The feeling of control I have over my body gives me a feeling of control over my life. I think I will continue this routine!” (Reinforces future behaviors)

Positive attention: “I enjoy the acceptance and admiration of peers. It is amazing! I also think it’s cool that my parents are concerned about my wellbeing. I appreciate that. I think I will continue this routine!” (Reinforces future behaviors)

Negative feelings: “I have low energy. I have physiological problems. I am tired all the time. I have more volatile emotions, and I have conflict with my family and friends. There’s got to be an easier way. Or, maybe I’ll just give up.” (Does not reinforce future behaviors)

Negative attention: “I hate it when someone talks about my behaviors around food, or comments on my physical appearance in a shaming or blaming way. There’s got to be an easier way. Or, maybe I’ll just give up.” (Does not reinforce future behaviors)

FIGURE 18.6 Environmental Reinforcements

disordered eating behaviors, and how negative feelings and attention around disordered eating behaviors can discourage future disordered eating behaviors.

Case Examples

Using the last four (4) hypothetical case examples of OSFED presented earlier in this chapter, we can now look at how the Major Life Domains can be affected by OSFED:

- **Situation:** *An adolescent male is upset because his parents are getting divorced. He notices that food makes him feel better when he is upset. Once every couple of weeks, he engages in binge eating (or eating, within a discrete period of time, an amount of food that is definitely larger than what most people would eat within a similar timeframe), and then engages in compensatory behaviors in an effort to control his body weight (such as exercising, vomiting, fasting or using laxatives).*

Which Life Domains are being Affected: His mental and emotional life domains are being affected because he is using food, exercising, vomiting, fasting, and laxatives to cope with the emotions he is feeling because his parents are getting a divorce. His relationships can also be affected because of the limitations he has on time, and types of food eaten.

How behaviors are being reinforced: When food helps him feel better, this reinforces his behavior of going to food to help cope with emotions. When being away from people helps him feel better, this reinforces his behavior of isolating from others in order to cope with emotions.

- **Situation:** *An adolescent female is obsessed with doing well in school. Every couple of months, during the week when final exams and projects are due at school, she becomes extremely anxious. During this time, she engages in binge eating (or eating, within a discrete period of time, an amount of food that is definitely larger than what most people would eat within a similar timeframe). She doesn't compensate for the food eaten by exercising, vomiting, fasting or using medications. When that week is finished and her anxi-*

ety calms down, she stops binge eating until months later, the next time final exams and projects are due at school.

Which Life Domains are being Affected: Her relationships with her family can be affected when she is preparing for final exams and projects because her parents are likely to notice and comment when food that was recently purchased is no longer available to the family. Parents can also notice and comment when the financial burden for food becomes too much to bear in order to replace the excessive food eaten. This can result in parental anger, which is often directed at the adolescent who has been eating the food. In turn, this can produce shame in the adolescent if she is identified as the cause of her parents' financial upset. Additionally, because there are no compensatory behaviors enlisted, the adolescent may experience weight gain, which could produce even more shame if family members or peers begin to comment on the weight gain in an insulting way.

How behaviors are being reinforced: When food helps her feel less anxious, this reinforces her behavior of eating to cope with the stress and anxiety of final exams and projects. And if her parents continue to buy extra food and have it available for her to eat during times of final exams and projects, and do not express a concern, it could reinforce her behaviors to continue. She could think that all is well, or that her parents don't notice, and so the behaviors would be more likely to continue. And, depending on how her family members or peers react to any weight gain, she may or may not choose to continue these eating behaviors.

- **Situation:** *An adolescent male watches a lot of reality television, and admires the trim, muscular bodies of the males he sees on the shows. He dislikes his own body and decides to change it. He becomes very careful about what he eats because he wants to be a film star one day. He is concerned about his body weight, and how his body will appear on*

film. He does not binge eat, but he does use exercise to control how his body looks and how much it weighs.

Which Life Domains are being Affected: His mental and emotional life domains are being affected because he is using food and excessive exercising to cope with the feelings he has about his own body when comparing it to the male bodies he sees on reality television. His relationships can also be affected because the amount he spends exercising may not allow him the time to spend with family or friends. He may also avoid social outings with friends and family that involve food or eating, as he may find it hard to deviate from his careful list of “safe” foods.

How behaviors are being reinforced: When food helps him feel better, this reinforces his behavior of going to food to help cope with emotions. When being away from people helps him feel better, this reinforces his behavior of isolating from others in order to cope with emotions.

- **Situation:** *An adolescent female is dissatisfied with the way her body looks. She thinks she is overweight, so she restricts her food intake all day. She eats an evening meal with her family so that they will not suspect she is dieting. She goes to bed at 10 pm but wakes up hours later ravenously hungry. When she is sure that all her family members have gone to bed, she gets out of bed, goes to the kitchen, and eats an excessive amount of food. She goes right back to bed without doing anything to compensate or “undo” her eating behavior. In the morning, she remembers what happens, and throughout the day is preoccupied by feelings of guilt and shame about eating.*

Which Life Domains are being Affected: Family conflict can arise if parents notice and comment when food disappears from the home, and when evidence of night eating is found on the morning after behaviors occur (For example, seeing dirty dishes, crumbs or food particles on the countertops, food disappearance, disruptions in food containers or other “evidence” of food being consumed after the evening meal). Parents may also become angry as they notice and comment on how much money is spent because

food needs to be frequently re-purchased and replaced. If she is specifically identified as the cause of the food disappearance and the source of parental anger, she may experience fear and/or shame. Additionally, because there are no compensatory behaviors enlisted, the adolescent may experience weight gain, which could produce even more shame if friends and/or family members begin to comment on the weight gain in an insulting way.

How behaviors are being reinforced: When daytime dieting behaviors result in excessive hunger that comes out in the late hours of the night, eating behaviors can continue if she is not caught eating the food, or if parents or other family members don't notice that the food is missing. She could also replace the food herself so that family members don't notice. Or, her parents could continue to buy food without asking any questions. Either way, if the food is replaced without question, it could reinforce her behaviors to continue. Also, if her family members or peers react to any weight gain, she may or may not choose to continue these eating behaviors.

Assessing Adolescents

As you can see from the case examples above, adolescents can respond to upsetting situations by *thinking* certain ways and *feeling* certain emotions. When such thoughts and feelings become overwhelming, adolescents can sometimes choose to *behave* in ways that help them cope, and to feel better. Using food, either by restricting it, binging on it and/or purging it, is one way of that adolescents can cope with their feelings. Behaviors with food can become maladaptive if they negatively affect any of an adolescent's major life domains.

In order to develop an appropriate treatment plan for adolescents who struggle with food, eating and body image, a thorough and accurate assessment of the adolescent's functioning is necessary. Preferably, a mental health professional who is certified in assessing and treating eating disorders can accurately assess adolescents and recommend an appropriate plan of treatment. This is something I do as a Licensed Mental Health Counselor and Certified Eating Disorders Specialist.

Throughout my years as mental health professional in private practice, I've been contacted by adolescents, as well as their friends, family members and caregivers asking me for help. Each person who calls is usually contacting me because they, or someone they care about, is struggling, and one or more of their major life domains are being affected. Sometimes, adolescents or others will contact me for help with issues that are unrelated to food, eating or body image, and yet during our first meeting I will discover that there are significant struggles in these areas. Regardless of the reason for contacting me, I commit to getting to know the client at his or her pace as I thoroughly assess emotions, behaviors and all the major life domains.

Since many of the people who contact me for help are scared or feel ashamed about reaching out for help, I believe it is crucial to maintain a kind, caring and non-judgmental approach when I do an initial assessment. When I first meet an adolescent, I am naturally interested in how they are experiencing their lives, and I convey this interest when I ask them questions. I am careful not to become so clinical in my questioning that I lose sight of the fact that there is a real, thinking and feeling human being sitting across from me in my office. I will also thank the adolescent for attending the appointment and being brave and willing to provide me with information so that I can come up with a treatment plan for them.

During the initial assessment, a lot of information is exchanged between the adolescent and I, and between his or

her family member or caregiver. However, the most important piece of information I convey to the adolescent is that he or she is an individual, with a unique way of coping with problems, and a unique method of recovery. I will say something like this:

“Nobody has ever developed problems with eating in quite the same way that you did. Nobody struggles with food and eating in quite the same way as you are struggling, and nobody will recover in quite the same way that you will.”

During the initial assessment, I provide adolescents and their families with information, resources, understanding, support, hope and encouragement so that everyone in my office can feel safe and comfortable while developing an appropriate treatment plan. One of the resources I offer adolescents and family members is the full version of the Continuum of Disordered Eating.

Earlier in the Chapter, I introduced The Continuum of Disordered Eating as a simple method of understanding disordered eating. The full version of the continuum (as seen in Fig. 18.7) continues to address the four factors used

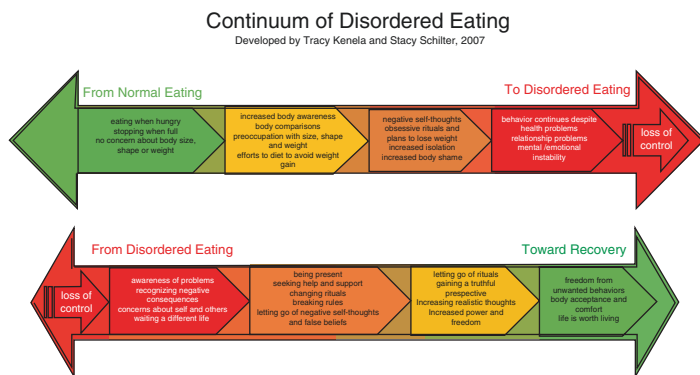


FIGURE 18.7 Progression to Disordered Eating and to Recovery Continuum

to assess the presence and severity of disordered eating: (1) Negative Thought Patterns, (2) Negative Beliefs About Self, (3) Painful Emotions, and (4) Disordered Eating Behaviors.

As you can see in Fig. 18.7, the Continuum of Disordered Eating below provides a step-by-step picture of how problems with food, eating and body image can develop and worsen (top line), while also displaying the steps, goals and milestones that can happen while moving toward recovery (bottom line).

Looking at the Continuum of Disordered Eating (bottom line), you can see that the path toward recovery involves increasing the level of flexibility an adolescent has regarding eating or food rules, eating rituals or behaviors. It also involves reversing any negative thought patterns and beliefs about the self that can block progress toward flexible thinking. Flexibility is an important skill for adolescents to learn because it helps them use their creativity to find ways to cope with their emotional distress without using food or disordered eating behaviors.

The Continuum of Disordered Eating clearly shows that each adolescent who engages in disordered eating behaviors can struggle at a specific and unique *intensity level*, and that each adolescent can struggle with specific and unique *areas of concern*. Both the intensity level and the area(s) of concern need to be assessed thoroughly in order to determine the best treatment plan for each adolescent.

As mentioned previously, it is best that thorough assessments of adolescents be performed by professionals who are certified, trained and experienced in assessing and treating eating disorders. Once a thorough assessment is completed, these professionals will typically provide adolescents with recommendations for treatment. The following section presents some treatment guidelines I've used as a Certified Eating Disorders Specialist to help adolescents who struggle with disordered eating.

Treatment Planning for Adolescents with Disordered Eating

When considering treatment planning for adolescents who are struggling with disordered eating, it is necessary for any treatment professional to ask the following questions:

1. What is the level of intensity that disordered eating is causing impairment and/or distress in the adolescent, and negatively affecting his or her major life domains?
2. What are the specific area(s) of concern where disordered eating is causing impairment and/or distress in the adolescent, and negatively affecting his or her major life domains?

It is necessary for treatment professionals of all specialty areas to know about the level of distress that the adolescent is experiencing, as well as what specific area(s) or type(s) of concerns that need to be addressed. And so, in the next section, I will describe what systems and levels of care are in place to help treat adolescents who are struggling with disordered eating.

Levels of Care for Treatment

There are five (5) levels of care that are available to help adolescents who are struggling with eating disorders and disordered eating behaviors. We will use the first case study to illustrate how to assess and treat this adolescent at all five (5) levels of care. Here is the case study once again:

Case Study:

- An adolescent female goes to her pediatrician for a physical so that she can play sports at school. During the examination, her doctor notes that she is considered overweight according to the Body Mass Index (BMI). She immediately feels shame. She becomes fearful of being labeled as “fat” and rejected by her peers. She then takes extreme measures to restrict food to lose weight. Because of the

extreme food restriction, she begins to lose weight. Within a short period of time, she loses a significant amount of weight. However, because her current weight is considered within or above the normal range for her age and height, her pediatrician does not consider it a problem.

Below are brief descriptions of all five (5) levels of care available, and an analysis of how this client could be assessed and treated at each level of care.

Level 5: Inpatient Treatment (Hospitalization)

An inpatient treatment (or full hospitalization) program is recommended for adolescents who are struggling with disordered eating behaviors if they experience such high levels of physical and/or emotional distress that they need constant medical attention. The hospital setting allows adolescents to receive medical testing, treatment and monitoring 24 hours a day. This includes, but is not limited to daily lab testing, monitoring electrolytes, blood pressure and heart rate, and administering IV fluids or nutrition. Inpatient treatment also provides a contained environment for those requiring medication, stabilization and monitoring for psychiatric symptoms if there is an attempted suicide or intent and specific plan to commit suicide.

Although recommendations for inpatient treatment are more commonly seen in those who are diagnosed with specific eating disorders such as anorexia nervosa, bulimia nervosa and binge eating disorder, there are some instances where adolescents with otherwise specified or unspecified eating disorders may require hospitalization for medical or psychological reasons. These instances are described below:

- Her heart rate and blood pressure are critically low, and risk cardiac arrest.
- She has extreme dehydration and malnutrition because she refuses to eat or drink anything because she believes that any food or fluids will result in weight gain.
- She has become so distressed at her inability to lose all of her body fat, that she has made a specific plan to end her life and intends to commit suicide at her soonest opportunity.

If one or all these conditions are present, inpatient treatment will be the best level of care to stabilize the adolescent and provide her with help for the medical and psychiatric effects of her disordered eating behaviors. However, it is important to note that once medical and/or psychiatric stabilization is attained, the adolescent will be released from the hospital, but may continue to struggle with disordered eating behaviors until the underlying emotional causes of the behaviors are identified and treated within a contained environment, such as a residential treatment facility.

Level 4: Residential Treatment

A residential treatment program is recommended for treating adolescents who are struggling with disordered eating and have attained enough medical stability to survive without hospitalization, and yet still need to have day to day help managing the physical, emotional and psychological effects of disordered eating.

In residential treatment, adolescents will literally leave their homes in order to take up residence at a residential treatment facility that specializes in treating eating disorders. During their time in residential treatment, they will live with other adolescents who are also struggling with disordered eating. Treatment includes, but is not limited to, eating daily meals with other adolescents with the support of professionals, daily monitoring of weight and vital signs, medication management (for medical and psychiatric reasons) and individual, family and group therapy to resolve the underlying emotional issues that have caused and reinforced disordered eating behaviors.

Again, although recommendations for residential treatment are more commonly seen in those who are diagnosed with specific eating disorders such as anorexia nervosa, bulimia nervosa and binge eating disorder, there are some instances where adolescents with otherwise specified or unspecified eating disorders may require residential treatment for behavioral or psychological reasons. These instances are described below:

- The adolescent is medically stable, but still isn't able to or can't seem to eat.

- The adolescent has such intense fears of being fat that there are constant distraction about food and the body. If such distraction results in rituals to keep body weight down, this can effect concentration at school, performance in sports or other activities, or can effect time spent with family or friends or participating in social events. These actions can severely interfere with one or more of her major life domains.
- The adolescent has suicidal thoughts, urges to self-harm or actively engaging in physical self-harm (such as cutting) to the extent that a contained environment is necessary to help modify problematic behaviors.

If one or all these conditions are present, residential treatment would be the best level of care to stabilize the adolescent. In a residential treatment center, the adolescent can take advantage of a contained and safe environment to address their disordered eating behaviors, resolve their underlying emotional and mental health conditions, and obtain support with social and dietary concerns each day.

In residential treatment, adolescents can learn how to live their lives with others and eat regularly and somewhat comfortably within a supportive environment. They will have also begun to work on resolving the medical, social, emotional and mental health conditions that create urges to engage in disordered eating behaviors. However, it is important to note that once an adolescent is released from residential treatment, he or she may continue to struggle with disordered eating behaviors. This is primarily because their medical, social, emotional and mental health conditions need additional exploration and treatment. This sort of treatment can happen in a partial hospitalization program.

Level 3: Partial Hospitalization Program Treatment (Full day outpatient care program with medical support)

A Partial Hospitalization Program (PHP) is recommended for treating adolescents who are struggling with disordered eating behaviors and are stable enough medically and behaviorally to live at home or in a supported community in evenings and early mornings, while they attend an eating

disorder treatment program each day that is focused on supporting medical, psychiatric, nutritional and mental health.

In partial hospitalization treatment, adolescents spend their days attending an intensive treatment program that helps adolescents practice eating supported meals with other adolescents while preparing them to return home, or to a supported community during the evenings and early mornings. Such a program involves monitoring weight and vital signs, medication management, daily meals and dietary support, and individual, family and group therapy sessions to help them resolve the underlying medical, nutritional, emotional and behavioral issues that reinforce disordered eating behaviors.

A recommendation for partial hospitalization treatment would be most commonly seen in those who are diagnosed with specific eating disorders such as anorexia nervosa, bulimia nervosa and binge eating disorder. However, there are cases where adolescents with otherwise specified or unspecified eating disorders may require partial hospitalization for disordered eating behaviors, as noted below:

- The adolescent can eat during the day in a supported environment, but cannot seem to eat when returning home at night, or before leaving home in the morning.
- The adolescent has such intense fears of being fat that seem to subside in a supported environment, but there is heightened anxiety and panic when interacting with family, friends or in social or school situations, and especially around food and eating.
- The adolescent has passing suicidal thoughts and some urges to self-harm, but no plan or intent to commit suicide. The adolescent engages in physical self-harm (such as cutting) once per week when out of the controlled environment. The adolescent continues to struggle with eating when around family, friends and/or in public.

If one or all these conditions are present, partial hospitalization treatment would be the best level of care to stabilize the adolescent. In a partial hospitalization treatment pro-

gram, the adolescent can take advantage of a contained and safe environment during the day to address their disordered eating behaviors, resolve their underlying emotional and mental health conditions, and obtain support with eating in the presence of others on a daily basis.

In partial hospitalization treatment, adolescents learn to live outside of a treatment facility during the evenings and early mornings, and still receive the support and structure of a residential treatment program during the day. During the program, medical and psychiatric treatment will occur on a weekly basis to ensure the adolescent maintains medical and psychiatric stability. Each day, adolescents participate in a program with other adolescents where they receive supported meals, attend individual, family and group therapy, and commit to resolving any medical, social, emotional and mental health conditions that can create urges to engage in disordered eating behaviors.

Once an adolescent completes partial hospitalization treatment, they may continue to struggle with disordered eating behaviors. If this is the case, it is likely because they have not fully resolved their medical, social, emotional and/or mental health conditions. In this case, treatment can happen in an intensive outpatient treatment program.

Level 2: Intensive Outpatient Treatment (full day outpatient care program)

An Intensive Outpatient Treatment Program is recommended to treat adolescents who are struggling with disordered eating behaviors and are stable enough medically and behaviorally to live at home or in a supported community in evenings and early mornings, while attending an eating disorder treatment program for a few days a week.

When in intensive outpatient treatment, adolescents spend each day attending an intensive program of treatment that is geared toward helping them practice eating supported meals with other adolescents, and receiving individual and group therapy aimed at helping them resolve their underlying emotional issues that have caused and reinforced disordered eating behaviors.

Although it is still true that a recommendation for intensive outpatient treatment would be most commonly seen in those who are diagnosed with specific eating disorders such as anorexia nervosa, bulimia nervosa and binge eating disorder, there are some instances where adolescents with otherwise specified or unspecified eating disorders may require intensive outpatient treatment for behavioral or psychological reasons. These instances are described below:

- In the home environment, the adolescent finds it difficult to eat during the day, and requires support and continued therapy to obtain additional skills to cope with eating in the home environment.
- The adolescent's intense fears of being fat are magnified when living at home. There is contact with family and friends but the adolescent is constantly afraid of comments that may arise about food (for example, comments about good foods and bad foods); about eating (for example, how much or what is eaten); or about how people look physically (for example, fat, thin, healthy, unhealthy, ugly, pretty, etc.). The adolescent needs support and care while learning how to manage any fears or emotions, and learning how to live life in a body that is comfortable and safe while eating.
- The adolescent has passing suicidal thoughts and urges to self-harm, but no plan or intent to commit suicide. The adolescent may have passing thoughts of engaging in physical self-harm (such as cutting) at least once per week when out of the controlled environment. The adolescent continues to struggle with eating with family, friends and/or in public.

If one or all these conditions are present, intensive outpatient treatment would be the best level of care to stabilize the adolescent. In an intensive outpatient treatment program, the adolescent can take advantage of a contained and safe environment during the day to address their disordered eating behaviors, resolve their underlying emotional and mental health conditions, while obtaining support with eating within a social context.

Once an adolescent completes intensive outpatient treatment, they may continue to struggle with disordered eating behaviors during the time they are at home. This is primarily because their medical, social, emotional and mental health conditions need continued exploration and treatment. This sort of treatment can happen with an individual therapist and others in an outpatient treatment setting.

Level 1: Outpatient Treatment. Outpatient treatment is the first line of treatment recommended by the American Association of Child and Adolescent Psychiatry as well as the Society for Adolescent Health and Medicine. While a patient may ultimately need a higher level of care, starting with outpatient treatment that includes a full multidisciplinary team is preferred.

It is common practice among those who specialize in treating eating disorders to use a multi-disciplinary “team” approach to treat adolescents at the outpatient level of care [2]. An outpatient treatment team typically consists of a group of professionals, each of whom specializes in different areas of eating disorder treatment, who agree to meet with adolescents once per week and exchange information about treatment planning.

Members of the outpatient treatment team may or may not practice under the same roof. Regardless, all outpatient treatment team members are committed to remain in contact with each other regularly to coordinate care (i.e., provide the team with updates on their findings, express areas of concern, and ask questions to other members of the treatment team at every area of specialty), as described below:

Medical care includes seeing a medical doctor, physician assistant or nurse practitioner who monitors the adolescent’s weight and vital signs, who orders necessary laboratory testing, and who prescribes medication as needed.

Nutritional care includes seeing a nutritionist or dietitian (with credentials of RD (Registered Dietitian) or RDN

(Registered Dietitian Nutritionist) who talks with the adolescent about what foods are eaten during each day, who helps develop meal plans, and who models how to use food as a positive form of nutrition and self-care.

Psychiatric care includes seeing a psychiatrist or psychiatric nurse practitioner on a regular basis who can prescribe medication for any psychiatric conditions that may be present, and who monitors the effects of medications prescribed.

Emotional and Behavioral care includes any combination of individual, family or group therapy with a psychotherapist, social worker or psychologist with the goal of addressing and treating any emotions that are felt when eating, as well as teaching coping skills that are free from restricting food.

Below some instances where adolescents with otherwise specified or unspecified eating disorders may require outpatient treatment:

- The adolescent is able to function at home, school and work, but needs ongoing care that is not within the strict structure of an intensive outpatient treatment program.
- The adolescent is aware that help with food and eating is needed, yet the idea of attending an outpatient treatment program is so scary that all efforts to recover are abandoned.

Now that you have a good idea about how adolescents can develop disordered eating, and receive assessment and treatment to recover from disordered eating, I will now present what it is like to work with other members of an outpatient treatment team, as well as some of the methods I commonly use as an outpatient psychotherapist to help adolescents resolve the mental, emotional and behavioral aspects of disordered eating, and move toward recovery.

Treating Adolescents with Disordered Eating: Working in an Outpatient Treatment Team

As a psychotherapist who works with adolescents in an outpatient treatment level of care, one of the first questions I ask adolescents who are struggling with disordered eating is whether they have recently seen a medical professional. I ask this question primarily because the most serious problems with food and eating tend to occur in the physical body and are best treated medically.

In a perfect world, the adolescent will already be seeing a medical professional (such as a Medical Doctor, Nurse Practitioner or a Physician Assistant) who is informed, experienced or educated about treating individuals who struggle with eating disorders and disordered eating behaviors. If not, then one of the things I do is refer adolescent clients to my list of Physicians, Physician Assistants and Nurse Practitioners who are eating disorder informed, experienced and educated so that they can have a solid medical professional as part of our outpatient treatment team.

If one of my adolescent clients has a medical professional they trust, but who is *not* eating disorder informed, experienced or educated, I will offer to consult with that medical professional so that the best possible treatment plan can be developed. As a Certified Eating Disorders Specialist, I have received the education, experience and training necessary to consult with medical professionals and offer them information and insights about food, eating, body image and disordered eating behaviors that can help all of us more effectively treat our mutual clients. Over the years, most of the consultations I've had with medical professionals have been mutually beneficial, and quite productive. They have also resulted in developing more thoughtful and effective treatment plans.

Below are some examples of when I could offer some consultation to medical professionals:

- If an adolescent client reports that they become upset at seeing their weight after they are weighed in a doctor's

office. I can share methods of blind weighing with medical professionals and offer them some insight on the adolescent's emotional experience when seeing their weight and share with them how to keep weight separate from the medical care they provide during office visits.

- If an adolescent client reports that their labs, weight and vitals are perfectly normal, and yet they still complain of physiological symptoms that could be caused by disordered eating, I can talk with medical professionals and suggest additional labs, or to check the orthostatic blood pressure.
- If an adolescent client reports that a medical professional has made comments or judgments about what they eat, their weight, or their body size and/or shape, I can explain how such remarks can trigger painful emotions, which then can trigger even further disordered eating behaviors. I can also suggest some non-judgmental and weight neutral language that medical professionals can use during office visits.

Consulting with a medical professional can make a profound difference in an adolescent's experience while undergoing medical treatment for disordered eating.

Optimally, consultation occurs between all members of an outpatient treatment team on a regular basis so that all the adolescent's needs are being met during the treatment process. For example, I may communicate with the team's dietician or nutritionist to learn more about how they are managing meal planning, food, eating and nutritional aspects of recovery, while also letting them know about how I am helping adolescent clients manage the cognitive, emotional and behavioral aspects of recovery. I may also communicate with the team's psychiatrist or psychiatric nurse practitioner to learn more about how they are medically managing any underlying mental health conditions, while sharing what I am doing to help adolescent clients manage the cognitive, emotional and behavioral aspects of recovery.

Since my role as a member of an outpatient treatment team as a psychotherapist is to help adolescents and their

families recover from the emotional and behavioral aspects of disordered eating, the following section will describe some of the methods of treatment I use when working with adolescents on an outpatient basis to help them overcome disordered eating behaviors.

Treating Adolescents with Disordered Eating: Working as an Outpatient Psychotherapist

Although psychotherapists use many different methods to treat adolescents who struggle with disordered eating, the following are three (3) methods I use most often in treating adolescents with OSFED and EDNOS. I've found these methods work best when working with adolescents and their families who wish to move beyond disordered eating, and toward a stable recovery.

Method I: Cognitive Behavioral Therapy

The Cognitive Behavioral Model specifically looks at identifying and errors in thinking, which happen when individuals adopt distorted or unrealistic beliefs about the world and themselves. They then feel painful emotions, and behave in ways that are unhelpful [3].

Adolescents can experience upsetting situations in life that can trigger them to think in certain ways (cognitive or thinking errors). Pre-existing distorted or unrealistic beliefs about the world and the self can combine with thinking errors to produce painful emotions or *feelings* of distress. When situations trigger thinking errors and feeling pain, there is often an urge to *do* or *behave* in certain ways to relieve the painful feelings that occur when upsetting situations happen [3].

Earlier in this chapter, I introduced Fig. 18.4, which is a flow chart that shows how struggles can happen with food, eating and body image can develop from upsetting situations, beliefs, thoughts and feelings:

Using the simple concept of “**think, feel, do,**” health care professionals, parents, educators and others can develop a basic understanding of how upsetting situations can cause

unrealistic beliefs to surface, which can produce negative thoughts (or thinking errors) and painful feelings. Unwanted eating behaviors can surface when adolescents choose to behave in certain ways in order to cope with the painful feelings that develop when situations cause unrealistic beliefs that produce negative thoughts and painful feelings.

Cognitive Behavioral Therapy (CBT) is a way of treating errors in thought that lead to painful feelings and maladaptive behaviors. Since its development, CBT has become one of the most prevalent and evidenced-based treatments psychotherapists use to treat eating disorders and disordered eating behaviors [4]. In fact, most of the evidenced-based research supports the use of cognitive behavioral approaches to treatment of disordered eating [4].

In his 2008 book “Cognitive Behavior Therapy and Eating Disorders,” Christopher Fairburn describes Enhanced Cognitive Behavior Therapy, which is a method wherein the factors that are reinforcing maladaptive eating behaviors are identified, and these factors are used to develop unique and personalized ways to address treatment goal and plans for recovery [4].

Like Fairburn, I also adopt a unique and individualized approach to treating each of my clients. In fact, as a psychotherapist who is also a Certified Eating Disorders Professional, I use CBT as a first line treatment for adolescents and adults who struggle with eating disorders and disordered eating behaviors. The method of treatment I use teaches adolescents that they are unique in their ways of thinking, feeling, and behaving, and that they can change their ways of thinking, feeling and behaving in their own unique ways during the process of recovery.

As a psychotherapist using CBT to treat adolescents who struggle with disordered eating, I help adolescents identify, challenge and restructure any unrealistic beliefs and thoughts (or “cognitive distortions”) that can lead to painful emotions. For example, an adolescent may view food or physical appearance in terms of extremes: either extremely good or attractive, or extremely bad or hideous. This is called

dichotomous thinking, where adolescents will fail to see reality, which tends to exist on a continuum. Once dichotomous thinking is recognized and challenged in sessions, adolescents can be taught to adapt more realistic, truthful and helpful thoughts about food their bodies and themselves, which makes it easier to move past disordered eating behaviors and toward recovery [4, 5].

I also use an environmental approach to using CBT to treat adolescent clients with disordered eating. With each adolescent client, I will consider whether the environment (home, school, friends, social media) is reinforcing unhelpful or disordered eating behaviors to continue or discontinue. For example, if an adolescent continuously restricts food and loses weight, and members of her family are dieting, praising thin bodies and encouraging continued weight loss, it is more likely that the adolescent's restricting behaviors will continue because they are being reinforced by the adolescent's environment. In this case, I would help the entire family realize how the environment can reinforce problematic eating behaviors, and encourage all of them to explore the ways that they might be contributing. Ultimately, I work toward having those who are regularly in the adolescent's environment develop ways to reinforce desired behaviors, such as regularly eating sufficient amounts of food, and adopting a neutral attitude about body size, shape and weight.

Because disordered eating behaviors often arise in response to intensely painful emotions, I've also included a highly researched and evidenced-based approach to teach adolescents and their family members how to use specific skills to help them tolerate distress and manage painful emotions. For this, I use a method known as Dialectical Behavioral Therapy (DBT).

Method II: Dialectical Behavioral Therapy

Dialectical Behavior Therapy (DBT) was developed by Dr. Marsha Linehan as a treatment method for individuals who experience extreme emotional suffering, erratic behaviors, suicidal ideation, self-harm urges and behaviors, suicide attempts, and disordered eating behaviors [6, 7]. Currently,

DBT appears to be the most comprehensive and empirically supported emotion regulation treatment for individuals who struggle with extreme emotions, suicidal urges and attempts, and Borderline Personality Disorder [8]. An adapted version of DBT treatment for eating disorders has been supported through randomized trials [7].

Dr. Linehan's DBT treatment model emphasizes teaching skills in mindfulness (being aware of painful emotions), distress tolerance (responding to emotional crisis), emotion regulation (using distress tolerance and cognitive skills to calm the mind and the body) and interpersonal effectiveness (using skills to manage relationships) [6]. Because there is a strong body of evidence that supports DBT as a treatment for eating disorders [7] and for adolescents [9], I find that teaching DBT skills to adolescents in counseling sessions is a concrete and effective way to help them learn specific skills that will help them become aware of emotions, and cope with them as they occur in their day to day lives.

DBT can be taught in groups, or in individual outpatient psychotherapy sessions. I teach DBT to adolescents in individual sessions using the *DBT Skills Manual for Adolescents* [9]. This manual is specifically geared toward adolescents, and has a variety of handouts and worksheets on all of the DBT skills. Using this manual, I help adolescents identify and process problem behaviors, to observe, describe and experience emotions as they come up in day to day life, and to use a variety of adaptive skills to cope with feelings and intense emotions as they show up in the physical body.

I use DBT with adolescents who struggle with disordered eating in a variety of different ways. For example, if an adolescent male has been overly restricting his eating and also reports having anxiety at the thought of giving up restricting food, I would ask him if he would be willing to learn a new skill that would teach him reduce his overall anxiety levels. Usually, adolescents are willing to learn something new if it has the potential of helping them cope with unwanted emotions like anxiety! However, adolescents tend to be less willing to give up food restriction, especially if food restriction is

actually helping them manage overall anxiety levels. And so in this case, I would start by teaching him how to recognize how anxiety feels in his body, and teach him to use some simple DBT skills to calm and soothe the anxiety he feels in his body.

One of the easiest and most effective DBT skills I teach is “Self-Soothe using the 5 senses” ([6, 9]. Most adolescents can name the 5 senses of sight, touch, taste, smell and hearing. And so with this client, I would go through each of the 5 senses and have him develop a plan of self-soothing that can help him cope with his anxiety at all levels of distress. Once his plan is developed, I will write his plan on a note card for him to keep and use in times of crisis. Once he uses and practices the “Self-Soothe” skill, he will hopefully see this as an adaptive way of coping with anxiety, and the skill will eventually become a habit. I can then challenge him to use the same skill to manage the fear he feels when eating or being around food. We can do this by having him bring a snack into a session and have him practice using the skill to reduce the anxiety he feels as we eat a snack together.

Since body dissatisfaction is prevalent among adolescents who struggle with eating disorders [5, 10], I believe it is important to incorporate a variety of mind-body approaches to help my adolescent clients find adaptive ways of coping with emotional distress and disordered eating behaviors. DBT is just one of the many methods that work in the mind and the body to help adolescents find adaptive ways of coping with emotional distress and disordered eating behaviors. The following are some additional mind-body methods that I use with adolescents who struggle with disordered eating.

Method III: Mind-Body Approaches to Treatment of Disordered Eating

Research has continued to support the idea that the thinking mind naturally connects with the feeling body in order to process emotional distress, and that disordered eating behaviors are just one way in which adolescents cope with emotional distress [5, 10]. For example, in a network analysis on adolescents with OSFED, Goldschmidt and her colleagues

found that disordered eating thoughts and behaviors in adolescents were most strongly associated with concerns in the body, such as body weight, “feeling fat,” fear of weight gain, empty stomach, guilt about eating, eating in secret and social eating [5]. Similarly, in a cross-temporal meta-analysis, Karazsia and his colleagues found that concerns with the body (including body dissatisfaction, or thoughts and feelings about the body that lead to dissatisfaction and painful emotions) strongly predict disordered eating behaviors and depression in adolescents [10].

One of the mind-body approaches I developed when treating those who struggle with eating disorders and disordered eating behaviors is called the “RADICAL” approach, as seen below:

- **Reflect** on the unique struggles you are having with food, eating and body image.
- **Acknowledge** any emotions that may emerge, and notice how they feel in your body.
- **Describe** the emotional experience you have in your mind (thoughts) and body (feelings).
- **Intuitively** sense your level of distress, and use adaptive skills to cope with painful feelings.
- **Communicate** to yourself what you need, and then communicate your needs to others.
- **Allow** yourself to accept and receive help and assistance from yourself and others.
- **Let** go of your emotional suffering.

I developed this method as a simple and gentle approach to help clients notice and face any mental and emotional turmoil that shows up in their minds and bodies so that they can behave in ways that are more helpful to them. In counseling sessions, I teach clients to notice how distress feels in their bodies, to clarify what they are struggling with, to name and describe their emotional experience, to assess their level of distress, to use skills to cope with whatever comes up (including asking for help from others), and to reach a point of

acceptance so that emotional suffering can be released. This method can be used with adolescents who restrict eating during the day, or who binge eat night, or who binges and purges, or who becomes upset in a social environment when eating with others.

To assist clients in coping with emotions outside of sessions, I developed a CD that teaches a variety of mind-body techniques and exercises that are simple to learn and take under ten minutes to practice [11]. Using short and simple practices such as these can help clients learn to notice feelings in their bodies, and to develop creative ways to cope with uncomfortable or painful feelings by turning the mind away from what is *not* helpful, and toward what *is* helpful.

Conclusion

Enlisting the care of a multi-disciplinary treatment team offers adolescents a variety of different treatment methods to support healing all their major life domains. For example, healing physical life domains can mean stabilizing weight and vital signs. Healing nutritional life domains can mean ensuring an adolescent eats a balanced diet on a regular basis. Healing mental, emotional and behavioral life domains can mean providing continuous help and support to adolescents using the treatment methods I've described in this chapter to help adolescents find effective ways of managing emotional distress, moving beyond disordered eating and finding recovery. I truly appreciate all efforts that went into writing this chapter. Take care!

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Chapter 19

Co-occurring Eating Disorders and Type 1 Diabetes Mellitus



Erin Phillips

Significance, Background, and Prevalence

A Brief Primer on Type 1 Diabetes

For an in-depth description of type 1 diabetes, including pathophysiology, current trends, and treatment approaches, see the chapter on type 1 diabetes in this text.

Type 1 diabetes (T1DM) is an autoimmune disorder which destroys the islet cells of the pancreas, leading to insulin deficiency. Without insulin, blood glucose (BG) levels rise, and the body attempts to regulate blood glucose by excreting glucose in the urine. The body is also unable to use glucose as fuel, which leaves the body in a starvation state, leading to rapid dehydration and weight loss as the body turns to using muscle and fat as fuel [1]. Treatment consists of insulin replacement either by multiple daily injections or by insulin pump. The current gold standard of care is calculating these multiple daily insulin doses based on carbohydrate intake, premeal glucose levels and anticipated physical activity [2].

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Background of ED-DMT1

T1DM requires constant daily management of food, insulin, and activity. Traditional management has also historically included a strong focus on weight [3]. As discussed in other chapters in this text, common traits of those at risk of developing eating disorders (EDs) include preoccupation with food and weight. Because of the strong correlation between what is involved in daily diabetes management (a heavy focus on food and eating, restriction of carbohydrate intake, drive for perfection with BGs, eating when not hungry to treat a low BG, etc.) and disordered eating behaviors, individuals with T1DM are at increased risk of developing an eating disorder when compared to those without T1DM [4]. Eating disorders in T1DM can include anorexia nervosa, bulimia nervosa, binge eating disorder, and other specified feeding and eating disorder (OSFED). A term used in the media and among patients with T1DM is “diabulimia,” which refers to insulin restriction or omission for the purpose of weight loss. Although extremely dangerous, insulin manipulation is a fast and effective tool for weight loss due to dehydration and cell starvation. It is important to note that although “diabulimia” is most commonly discussed in the media, an individual with T1DM can suffer from any type of eating disorder.

Goebel-Fabrizi and colleagues have developed a model for eating disorders in T1DM based on these risk factors unique to people with T1DM (see Fig. 19.1).

Prevalence of ED-DMT1

Prevalence rates of co-occurring T1DM and ED vary among the literature, possibly due to the difficulty in distinguishing between disordered eating behaviors and behaviors expected to manage diabetes. Cross-sectional research has shown that adolescent females with T1DM are 2.4 times more likely to develop an ED than those without diabetes [4], and are up to four times more likely than controls to report disordered eating behaviors (DEB) [6].

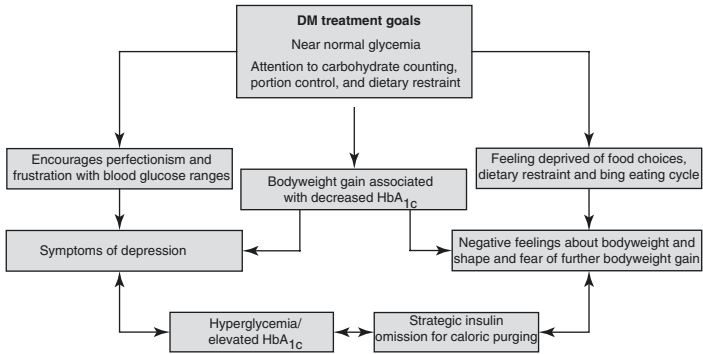


FIGURE 19.1 Model of eating disorders in T1DM with insulin restriction [5]

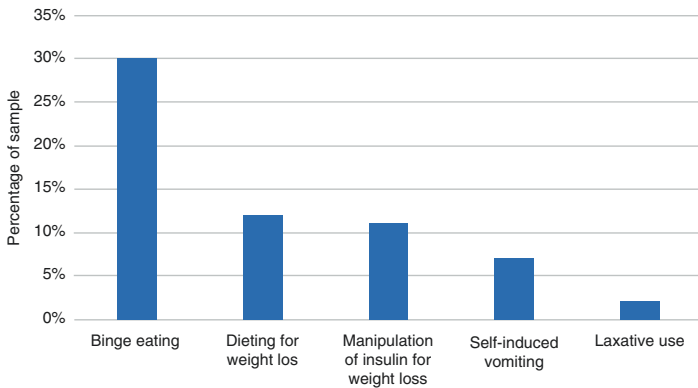


FIGURE 19.2 Prevalence of disordered eating behaviors [4]

A meta-analysis of eating disorders in patients with type 1 diabetes found significantly higher rates of bulimia nervosa in those with T1DM vs. those without diabetes (1.73% vs. 0.69%) and no increase in anorexia nervosa among those with T1DM [7]. Another meta-analysis found the overall prevalence of 7.0% of eating disorders in adolescents with T1DM, vs. 2.8% of those without T1DM [8]. See Fig. 19.2 for

an illustration of the high frequency of DEB among those with T1DM.

Prevalence of insulin misuse/restriction varies among studies of ED and T1DM, ranging from 48% [9] to 90% [10] in populations with co-occurring ED and T1DM, and 4.1% [11] to 58% [12] in T1DM populations without diagnosed ED. The literature agrees that prevalence of insulin misuse/restriction increases with age during adolescence, with ~ 15% of preteen and young adolescents reporting withholding insulin for weight loss [4], increasing to up to 30% of older teenagers and young adults [13–17].

Prevalence of disordered eating behaviors overall (which include clinical eating disorders and sub-threshold ED) is as high as 50% for older adolescent females [13].

Complications of ED-DMT1

The complications of co-occurring ED with T1DM include both short and long-term complications. Short-term complications include more frequent episodes of diabetic ketoacidosis associated with insulin omission, and higher rates of severe hypoglycemia with all types of ED [3]. Due to chronically elevated BGs as a result of insulin omission, individuals with T1DM and ED experience diabetes-related complications at higher rates than those without EDs. Diabetes-related microvascular complications are 2.4–3.5 times more likely in people with T1DM and insulin omission. Microvascular complications include retinopathy, nephropathy and peripheral neuropathy [17].

A diagnosis of ED-DMT1 also increases mortality rates. Goebel-Fabbri and colleagues found that the risk of death for those with a dual diagnosis of ED-DMT1 was 17-fold compared to T1D alone and seven-fold compared to anorexia nervosa alone [15].

Warning Signs and Risk Factors

Warning Signs of ED-DMT1

Many of the behaviors displayed by an individual with diabetes and an eating disorder can also be displayed by a “perfect” or “compliant” person with diabetes; therefore, ED-DMT1 can be especially difficult to detect. Many eating disorder screening tools such as SCOFF, EDE-Q, and EAT-26 have many questions that can be influenced by having T1DM. Examples include statements such as “I feel that food controls my life,” or “I particularly avoid food with high carbohydrate content.” In addition, many of the warning signs or symptoms of someone omitting/restricting insulin for the purpose of weight loss can also be confused for a “rebellious adolescent.” Looking out for signs and symptoms of disordered eating behaviors can help identify those at risk of developing or already displaying ED behavior. Some of these signs and symptoms include:

- Elevated A1c (>9%, but especially if >10%)
- Missing BG checks
- Numbers in BG log/meter do not match A1c
- Frequent hospitalizations or episodes of DKA
- Erratic clinic attendance
- Decline in social functioning, including relationships, school attendance
- Significant weight gain or loss
- Frequent dieting
- Poor body image
- Increased concern over weight or shape

In addition to the above, warning signs that might be seen by family members or other close friends outside of the clinical setting include:

- Being more secretive with insulin injections

- Less rapid-acting insulin being used; parent/caregiver might notice that refills for this insulin are needed less often
- Compliments on weight loss before the diagnosis of T1DM

Risk Factors

Due to the dangerous consequences of the dual diagnosis of ED-DMT1, it is essential to know the risk factors predisposing an adolescent to engage in disordered eating behavior in addition to the warning signs mentioned above. Risk factors include the following:

- Higher body weight – Adolescent girls with T1DM who reported ever being overweight engaged in more disordered eating behavior [18, 19].
- Age of diabetes onset – Puberty is a time of great changes, and is associated with significant weight gain. Adolescent development includes a rate of growth and weight gain that rivals only that during infancy. In fact, weight gain during adolescence accounts for approximately 50% of adult weight. And in females, the fastest rate of weight gain occurs before the height growth spurt [20]. Some research has shown a higher incidence of disordered eating behaviors and EDs among those who were diagnosed with diabetes during preadolescence and adolescence [22].
- Family dynamics – Adolescents with higher rates of eating disorders also had a higher incidence of family members making comments about weight [23], less support from and poorer communication with family members [24].
- Rigidity with diet – Perceived necessity to follow the “diabetic diet” without any flexibility can lead to either a tendency toward Anorexia Nervosa or lead to craving “forbidden foods,” followed by bingeing on these foods without taking the appropriate insulin dose [10].

Case Study

Diabetes history: Emily was diagnosed with T1DM at age 6 (7 years ago). Her family struggles with communication around diabetes, including Emily resorting to lying about BGs to get more snacks, or fear of telling her parents about high BGs because she worries her parents will get mad at her. Diabetes management began to drastically worsen around age 12.

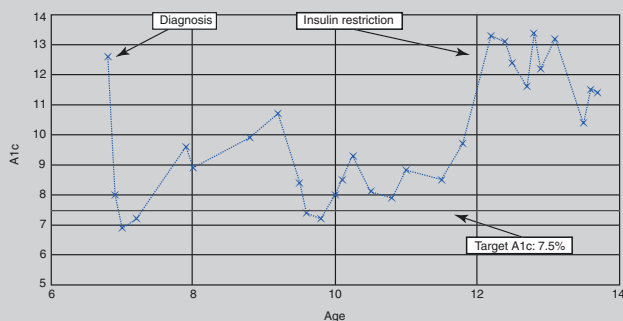
Social history: Emily describes being emotionally abused by her mother from an early age and that she was not provided adequate management of her diabetes from mother. Emily ended up in the care of father and step-mother, but will still be exposed to abusive statements from mother in their engagement on the phone or in person. Emily also experienced bullying during middle school which resulted in her being home-schooled her eighth-grade year.

Weight and growth trends: Weight loss first began at age 9, with her weight for age decreasing from 97th to the 80th percentile (a total of 5 kg lost). Unfortunately, no red flags were raised nor a full nutrition assessment completed at this time. On the contrary, family was praised for this weight loss by the diabetes team, since Emily's BMI was above the 95th percentile, even though her weight had been trending along the same percentile line for 2 years prior, indicating healthy appropriate weight gain. Emily began to gain weight again at age 10 (see growth charts), trending along the 90th percentile, until age 13 when she began losing. She lost a total of 5 kg, again decreasing to the 80th percentile. However, an eating disorder was not considered, as Emily was assumed to be a "non-compliant teenager."

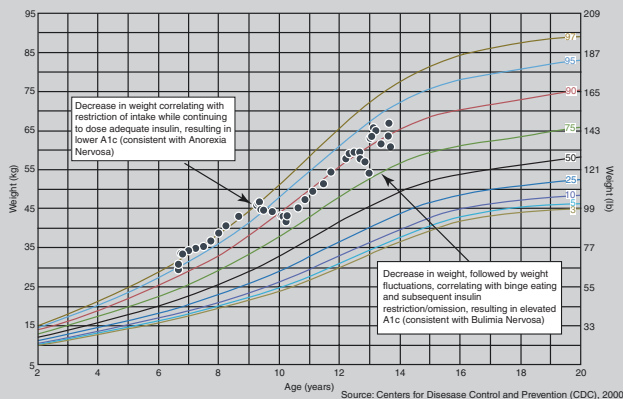
Nutrition: Emily first began struggling with out of control eating related to low blood sugar at age 9, and shortly after family began to restrict portions after her endocrinologist and dietitian told the family her weight

was considered in the obese range. At age 12, she began binge eating and decreasing insulin doses once she noticed she was losing weight despite eating more than usual. She endorses distorted body image, fear of gaining weight, lack of control over eating. She also engages in restriction, which is triggered by negative interactions with her mom or feeling fat.

A1c:



Growth chart:



Screening and Assessment

Early detection of ED-DMT1 and referral to treatment is critical as persistence of ED behaviors and recurrence is incredibly high. In a longitudinal study of 126 adolescent females, 92% of those who reported any disordered eating behaviors continued those behaviors 5 years later [25]. However, as mentioned earlier, disordered eating behaviors can be challenging to detect among the T1DM population due to the overlap between specific behaviors required to manage diabetes and disordered eating behaviors. (Including, but not limited to, constant close attention to food and exercise, preoccupation with carbohydrate content and food labels, common need to override hunger and fullness cues to manage blood glucose.) Many of the screening tools used to detect EDs in the general population are inappropriate and will generate many false positives. In addition, patients rarely openly state that they have an eating disorder, and this topic must be treated delicately.

A small but growing body of literature has examined, developed, and tested various screening tools, which are described in Table 19.1. It has been proposed that a simple screening question of “Have you ever been overweight?” or statement of “I take less insulin than I should” can screen for ED-DMT1 [15, 18]. In a study of 90 adolescent females aged 12–19 with T1DM, the question “Have you ever been overweight?” had 83% sensitivity and 94% negative predictive value in detecting disordered eating, so it may be an excellent screening question when time with the patient is limited [18]. Both of these simple questions can be followed up by one of the screening tools in Table 19.1 and a more in-depth conversation and assessment of the adolescent’s behaviors, attitudes, and beliefs about body image, eating, nutrition, mental health, and diabetes.

Many providers worry about inadvertently “planting the seed” for insulin restriction or other unhealthy weight control behaviors when attempting to assess for disordered eating. This is a valid concern and should be taken into consideration

TABLE 19.1 Screening tools for disordered eating

Screening tool	Description	Considerations for use	References
DEPS-R	16-item diabetes-specific self-report screening	Asks about specific ED behaviors, concerns about “planting ideas,” some recommend it only be used if strong suspicion of behaviors already exist	Markowitz [26]
mSCOFF	5-item questionnaire modified for diabetes-specific use	Has not been validated against a gold standard. Demonstrated 80% sensitivity and 90% specificity when compared to mEDI	Zuijdwijk [27]
SEEDS	20-item diabetes-specific self-report screening	Screens for those at risk of developing an eating disorder. Does not ask about specific disordered eating behaviors	Powers [28]
ESP	5-item questionnaire for non-diabetes specific population	Not diabetes-specific, might result in false positives. May need additional questions that pertain to insulin restriction	Anstine [29]

when having these conversations. See Box 19.1 for a guide to a conversation that helps explore these behaviors without suggesting them.

Regardless of the specific screening used, when concerns arise about symptoms of an eating disorder, early referral to a mental health provider or practitioner who has expertise with the diagnosis and management of eating disorders is imperative.

Box 19.1 Example Conversation and Questions for Exploring the Possibility of Disordered Eating with an Adolescent with T1DM

HCP: *As a member of your health team, one of my jobs is to help your body be as healthy and strong as possible. One of the things that came up today is your A1c, which is on the high side. As you probably already know, it tells us that your body isn't getting enough insulin. That could happen for any number of reasons. What do you think is the barrier for you?*

Patient: *I don't know...*

HCP: *Well, some people have talked to me about fear of needles or low blood sugar, and other people have talked to me about not taking enough because they can't afford all their insulin, or because they want to make their parents mad... There's a lot of different reasons. What thoughts do you have?*

[As the conversation starts to narrow in the direction of food and body, then the HCP can ask the following questions:]

HCP: *Does it ever connect to concerns you have about your body? Like wanting to gain weight or wanting to lose weight?*

If yes, suggested questions for follow-up include:

- How do you feel about your weight/shape/body?
- How much of the day do you think about weight, body shape, or size?
 - If yes: What have you used to try to change how your body looks? Or to lose weight?
- Do you ever feel out of control when eating? (*Note that it is common for people with T1DM to feel out of control with eating during an episode of hypoglycemia*)

- Do you have a hard time figuring out how much insulin you need for your carbohydrates? / How do you go about figuring out how much insulin you need for meals or snacks?
- Is it hard to give your insulin sometimes? What things make it difficult?
- Do you give “partial” insulin doses because it is hard to give the full amount?
- Do you ever purposely skip insulin injections?
- How often do you miss insulin injections?
- Do you ever adjust your insulin to influence your weight?
- How often are your decisions about how much insulin to take influenced by wanting to change your weight, body shape or size?
- Do you ever feel guilty about what you have eaten?
- How often do you check your blood glucose? Do you ever skip the checks because you don’t want to see the numbers?
- Do you check for ketones? When?
- Are there certain foods or foods groups that you avoid? What are they?
 - What are your thoughts when you have eaten them?
 - What do you do after you have eaten them?

Treatment of ED-DMT1

Few studies have been published regarding best practice and treatment outcomes for ED-DMT1. Treatment guidelines have been created based on clinical experience by experts in the field, but only small-scale studies have examined treatment effectiveness.

A small body of research has investigated treatment outcomes of ED-DMT1 [10, 30–32]. All focused on Cognitive

Behavioral Therapy, which is a standard treatment for eating disorders, and included outpatient, residential and inpatient treatment. Overall, these studies found lower than expected recovery rates, increased risk of treatment dropout, and lower patient motivation than among those with ED and no T1DM, despite having no difference in pathology other than insulin mismanagement.

General Treatment Recommendations

For both diabetes and EDs, a multidisciplinary approach is recommended. For treating ED-DMT1, the multidisciplinary team should include an endocrinologist, a nurse Certified Diabetes Educator, a Registered Dietitian Nutritionist with diabetes and/or eating disorder expertise, and a mental health therapist with diabetes and/or eating disorder expertise. If any member of the treatment team does not have diabetes or eating disorder experience, it is imperative that they educate themselves about the pathophysiology and the current best practices in the treatment of ED-DMT1. Patients with T1DM who have sought treatment for ED have voiced frustration over feeling the need to educate their treatment team about their condition, which can be a barrier to recovery [33]. All members of the treatment team should establish regular communication between team members in order to ensure the patient receives consistent messages regarding treatment goals. Furthermore, each provider should prioritize establishing rapport and developing a strong therapeutic relationship with the adolescent as those with T1DM and with EDs report feeling judged and criticized for their behaviors, which, if present in the treatment relationship, can be a significant barrier to recovery [34, 35].

If inpatient or specialized treatment is required, there are a growing number of treatment centers that specialize in ED-DMT1. See Box 19.2 for a list of treatment centers.

Box 19.2 Treatment Centers with Specialization in ED-DMT1

Center for Change

- Orem, UT
- Phone: (888) 224-8250
- Website: www.centerforchange.com/diabulimia

Center for Hope of the Sierras

- Reno, NV
- Phone: (866) 690-7242
- Website: www.centerforhopeofthesierras.com/eating-disorders/diabulimia

Cumberland Hospital for Children and Adolescents

- New Kent, VA
- Phone: 804-966-2242
- Website: www.cumberlandhospital.org

Eating Recovery Center - Denver

- Denver, CO
- Phone: (877) 825-8584
- Website: www.eatingrecoverycenter.com/diabulimia

Melrose Center

- St. Louis Park, MN
- Phone: (952) 993-6200
- Website: <https://www.parknicollet.com/specialtycenters/melrose-center/type-1-diabetes>

Renfrew Center

- Philadelphia, PA
- Phone: 1-800-RENFREW
- Website: <http://renfrewcenter.com/node/886>

DKA Prevention

For DKA prevention, teaching the adolescent about the signs and symptoms of DKA and when to seek urgent medical attention is critical. If the adolescent is able to commit to at least taking their long-acting insulin for DKA prevention, outpatient management of the ED is warranted. If not, inpatient stabilization and management is necessary [36].

Insulin Edema

As regular insulin administration is reintroduced and blood glucose improves, patients will experience significant water retention, a symptom known as “insulin edema” [37]. It is critical to warn and educate patients about these symptoms, which can be felt in the face and abdomen in addition to the lower extremities. Insulin edema is often a reason for relapse, as the fear of weight gain is significant among those with EDs [33].

Refeeding Syndrome

Individuals who have been restricting insulin are at greater risk of refeeding syndrome [38]. In this case, refeeding should begin in an inpatient setting with medical management assumed by those with expertise in medical management of eating disorders. Close monitoring of electrolytes and glucose with repletion of all deficiencies is critical. Insulin needs will vary and also need to be closely monitored and adjusted to avoid significant and relative hypoglycemia [36]. See the chapter on Anorexia Nervosa in this text for further discussion of refeeding syndrome in eating disorders.

Treatment-Induced Complications

Adolescents with blood glucose that has been elevated for prolonged periods are at high risk for developing treatment-induced microvascular complications, including neuropathy and retinopathy. One study found that a 2–3% decrease in A1c over 3 months resulted in a 20% risk of developing treatment-induced neuropathy, while a 4% or higher decrease resulted in an absolute risk of greater than 80% [39]. Therefore, gradual improvements in BG should be encouraged, with a recommendation of no more than a 2% decrease in A1c every 3 months [33].

Language and Perfectionism in Diabetes Care

The traditional treatment approach for T1DM can lead to rigidity and concrete thinking. Part of this may stem from the language used around diabetes care, such as “diabetes control,” “blood sugar test,” and “good/bad blood sugar.” The term “diabetes control” is a misnomer, since one can never have complete control of diabetes [40]. The way diabetes education is carried out often encourages perfectionism, which as discussed earlier, is also a risk factor for eating disorders. Teaching and demonstrating non-judgmental and neutral language with the patient is an essential part of treatment and guiding the patient in getting away from rigidity in diabetes care. See Table 19.2 for examples of language to use and to avoid.

Furthermore, the treatment team should consider where the adolescent already is with diabetes care, and focus on improvements that the adolescent has already made. For example, if BG has been averaging 400–500, an improvement to 300–400 is clinically and personally very significant. If the focus instead was on getting blood glucose down to levels that are within range, this will more likely result in a relapse of ED behaviors than improvement in diabetes care.

TABLE 19.2 Language to use in support of a nonjudgmental and trusting treatment relationship

Language to support a nonjudgmental treatment relationship	Examples of preferred language	Rationale
“Diabetes management” (Instead of diabetes “control”)	<i>“She is struggling with diabetes management lately.”</i> <i>“He is working on taking insulin with food at lunch.”</i>	“Control” suggests that it is possible to be completely in control of all aspects of diabetes, whereas in fact there will always be factors out of our control [40] Focus on factors that the person is doing well and ask yourself how you can build on that
Blood glucose “check” (Instead of blood glucose “test”)	<i>“They are checking blood sugar three times per day”</i>	“Test” signifies that there is a pass/fail component, which can exacerbate perfectionist behaviors [33]. “Check” is a more neutral term that is less likely to bring up feelings of being “good/bad”
Avoid labeling patients as “non-compliant,” “non-adherent,” or “difficult” Use words such as: Engagement Involvement Focusing Medication taking	<i>“She has been having difficulty taking all of her insulin.”</i> <i>“He is much more engaged in his appointments when we ask about non-diabetes life first.”</i> <i>“I’m having a difficult time with this patient.”</i>	Focus on facts rather than judgments; state exactly what the patient is or isn’t doing [40] Use words that do not blame, shame or judge Focus on factors that the person is doing well and ask yourself how you can build on that Describe what is going on with the patient rather than labeling

(continued)

TABLE 19.2 (continued)

Language to support a nonjudgmental treatment relationship	Examples of preferred language	Rationale
Describe blood glucose values or trends without good/bad judgments Within range / out of range High/low blood glucose (Instead of “Your blood sugar has been really good this week!”)	<i>“Your blood sugar has been lower overall the last 3 months.”</i> <i>“It looks like their blood sugar is out of range more often in the evenings.”</i>	Using “good/bad” to describe blood sugar can often bring about shame and make patients feel criticized/judged for their blood glucose numbers [33] Patients and family members will often use these terms themselves, which can perpetuate eating disorder behavior. Teaching and demonstrating use of neutral terms to describe blood glucose can be therapeutic in treatment and prevention of EDs
Use person-first language “Person with diabetes” (Instead of “diabetic person” or “diabetic education”)	<i>“How long have you had diabetes?”</i> <i>“What has helped you remember to bring your diabetes supplies to school?”</i>	Avoid using a disease to describe a person “Diabetic education” is incorrect; education doesn’t have diabetes [40]
Declined (Instead of “refused”)	<i>“It sounds like you’ve declined to meet with a dietitian so far, can you tell me a little more about that?”</i>	“Refused” paints a picture of a stubborn, “difficult” patient Respect the autonomy of the individual and explore what their intentions are when declining a service, medication, change, etc.

Fear tactics do not work. It can be tempting to try to “scare” an adolescent into change by discussing the consequences of continuing these dangerous, disordered eating behaviors: microvascular complications and even death. However, patients report only feeling pushed away rather than motivated to change [33].

Hypoglycemia

Hypoglycemia can lead to feeling out of control, especially related to food, and can lead to binge eating. Therefore, for people with ED-DMT1, treatment of hypoglycemia with glucose tabs or gels is recommended [37]. Adolescents with chronically elevated BG may also report symptoms of hypoglycemia while BG levels are within range or even high. This relative hypoglycemia is another reason to decrease BG levels gradually, and it will resolve over time [36].

Nutrition Therapy

The current nutrition recommendations for people with T1DM include a flexible eating plan that matches insulin dosing with carbohydrate intake [41]. This requires close and constant knowledge of the carbohydrate content of foods consumed, including reading labels and referencing nutrition databases for carbohydrate content. However, eating disorder nutrition therapy includes avoidance of the focus on food labels or specific nutrient content, as it can worsen or encourage ED behaviors [37,42]. Therefore, nutrition therapy should be individualized in order to best support the patient’s recovery, considering individual triggers, insulin regimen, and symptoms.

Carbohydrate Counting

For those matching insulin dose with carbohydrate intake, estimation of serving sizes may be beneficial in order to avoid

triggering ED behaviors. For those with a simplified insulin regimen or those who are only checking BG 1–2 times per day, carbohydrate counting may not be necessary. In these situations, the goal of nutrition therapy can be to normalize eating patterns and establish consistent meal and snack patterns. An additional and vital part of the assessment by the Registered Dietitian includes assessment of diabetes-related complications such as gastroparesis and should be included and considered in the treatment plan.

Weight Goals

For adolescents requiring weight restoration, a recommendation of 1–2 pounds per week is usually recommended in the outpatient setting [37]. For those whose weight is at their genetic set point or have continued with steady weight gain following along their growth curve, continued weight gain along their same growth curve is recommended, even if that is at or above the 95th percentile for BMI. Weight loss is counterproductive and can worsen ED symptoms, which will also contribute to poor diabetes management [37].

Long-Term Goals of Nutrition Therapy

The eventual goal of nutrition therapy is intuitive eating, with an additional component of self-awareness of how exercise, food, and behaviors affect BG. An ability to make nutrition and exercise decisions based on knowledge of how individual BG is affected by these factors with flexibility rather than rigidity is a crucial component of intuitive eating with diabetes. Merging inner wisdom (“How does my own body and blood glucose respond to this food/behavior?”) with external knowledge and science (i.e., eating carbohydrate alone vs. with a protein-containing food) is an ongoing journey for people with T1DM, which can be assisted by the RD, CDE.

See Box 19.3 for an overview of short- and long-term goals of nutrition therapy.

Box 19.3 Short- and Long-Term Goals of Nutrition Therapy in ED-DMT1**Short-term goals of nutrition therapy**

- Nutrition rehabilitation, including weight restoration if needed
- Normalize eating patterns (may include a meal plan of 3 meals plus 3 snacks)
- Increase frequency of regular insulin doses, though insulin dose may be liberalized and/or simplified based on individual needs (i.e. take insulin with dinner every day)
- Increased frequency of blood glucose monitoring
- Gradual decreases in average blood glucose levels (i.e. decrease in A1c from 14% to 12% over 3 months)

Long-term goals of nutrition therapy

- Intuitive, flexible eating
- Self-awareness of how exercise, foods and behaviors affect one's own BG, and ability to adjust these to help manage BG without engaging in rigid dieting or exercise behaviors
- Consistently taking appropriate insulin doses
- A1c <7.5%

Prevention of ED-DMT1

Opportunities for prevention of ED-DMT1 are frequent in the medical setting, whether it is during initial diabetes education, in the primary care clinic or endocrinologist's office.

Initial Diabetes Education

Initial diabetes diagnosis and education is a critical time for prevention of ED-DMT1. Care must be taken around the

specific language and behaviors used and demonstrated. During initial (as well as ongoing) diabetes education, there is a strong, consistent focus on body and food. Insulin injections are given into the subcutaneous (fat) tissue, so the patient is frequently having their stomach, thighs, and buttocks examined, pinched and touched by their physician, diabetes educator and parent. In order to avoid creating or exacerbating preoccupation with body shape or size, health care providers can ask permission before using the patient's body to teach or examine injection sites. Furthermore, when teaching about daily diabetes care tasks at initial diabetes education as well as follow-up visits, the diabetes educator or medical provider needs to pay close attention to the language used when discussing diabetes tasks. See Table 19.2 for recommendations and examples of specific language to use and to avoid.

Nutrition Education

During and after teaching about carbohydrate counting, patients and families can often become overly worried that they are eating too much carbohydrate, and either begin to restrict carbohydrate, or eat the same amount and feel like they are “bad” or doing the “wrong diet.” Women with ED-DMT1 reported that having off-limits foods often led to intense feelings of deprivation, which then led to feelings of shame and secrecy when they inevitably ate them [33]. This cycle then leads to an increased risk of bingeing and purging. The current recommendation for people with T1DM is a flexible eating plan that matches insulin dosing with carbohydrate intake [42]. There is no recommendation to restrict certain foods or overall food intake; people with diabetes can eat the same foods as those without diabetes [41, 43].

When discussing food and carbohydrates, great care should be taken to avoid creating fear about carbohydrates or other foods. Much of the popular media and general

knowledge about diabetes focuses on deprivation of carbohydrates and sugar, so it is imperative that the medical team counteract this message [17]. Sharing typical carbohydrate amounts consumed at a meal and in a full day with adolescents and families can be helpful to dispel myths that a low carbohydrate diet is necessary, but care should be taken to emphasize that the average or typical amount is not a prescription. It is imperative for patients and families to understand that it is acceptable and expected to consume more carbohydrates than average at times. Flexible eating should be encouraged by all members of the diabetes team.

Weight

Since clinical practice usually includes weighing patients at each visit, health care providers should be sensitive to preoccupation and concern with weight, especially during adolescence. If possible, providers can adopt a policy to decrease the frequency of obtaining weight measurements to once annually. Obtaining weight measurements annually is adequate enough to analyze weight trends while meeting recommendations for best practice [44]. If this option is not available, another strategy is to give patients the option to step on the scale backward.

As previously discussed in this chapter, adolescence is a time of rapid weight gain, and since this weight gain occurs before the height growth spurt in adolescent girls, many parents and teens become concerned about weight [20]. Providers should provide anticipatory guidance to parents and teens about this increase in weight gain, which can be expected to occur around menarche and 6–9 months before the increase in height. Reassuring families that this weight gain is a normal, healthy part of development can be a helpful and powerful tool both for prevention of disordered eating and to open the door to more conversations about body image and self-compassion.

Perfectionism and Burnout

Perfectionism, a risk factor for the development of an eating disorder, is also a common symptom of living with diabetes [45]. Avoiding concrete and absolute such as ‘always’ or ‘never’ thinking and celebrating small improvements with adolescents can help prevent the type of thinking that can lead to disordered eating. Assessing diabetes burnout and helping patients discuss their concerns, fears, and barriers can be beneficial in preventing ED-DMT1 during the treatment of T1DM as well [16].

Summary

Adolescents with T1DM are at increased risk of developing disordered eating behaviors or full-blown EDs, and screening for these behaviors is critical for early referral to treatment. Establishing a caring, nonjudgmental treatment relationship and encouraging adolescents to have flexibility with eating are keys to preventing ED-DMT1 and treating both T1DM and ED-DMT1.

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Chapter 20

Co-Occurring Eating Disorders and Orthorexia Nervosa



Virginia Newman

Case Study

Kelly is a 16-year old white cis gendered female who came into the office for her first visit, quiet and anxious. She reported that she had lost 20 lbs. over the course of the past year—it had been a particularly stressful one for her, with the loss of her mother to brain cancer. Her weight continued to decline and her dad and two older siblings were eager for her to get support for the visible weight loss that she had told them she could turn around on her own. Kelly reported never having had an issue with her body. She was always happy and active and noticed the eating disorders in her peer group but was never influenced by counting calories and the culture of body hatred. She was concerned about the current weight loss but felt she had a healthy intake and couldn't imagine shifting anything; her focus was on health and she felt great. She admitted not wanting to gain weight, as when she was at her higher weight she was not happy with how she looked. In sessions she would have specific questions about nutrition content of foods, and how to protect her liver,

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kidneys, brain, and lung health through food choices. Her high anxiety was palpable at the suggestion of straying from her daily intake regimen by adding additional carbohydrate sources. She had a regimented workout routine and loved the way she felt in her body when she was working out vigorously and building strength. Her hands were discolored as a result of carotenemia, a clinical condition resulting in yellow pigmentation of the skin resulting from high consumption of carotene rich foods such as carrots, squash, and sweet potatoes. When I noted the discoloration, she beamed with pride and talked about her love for those foods. Her friends' parents applauded her restraint and dedication to healthy eating. She had seen a nutritionist once before, who also applauded her "clean" diet and dedication to health at her age. Though the nutritionist had suggested more overall caloric intake to address the weight loss, no mention was made about of the amount of time, effort, energy, and stress that Kelly was pouring into her meals and snacks. These external appraisals confirmed for Kelly that there was nothing really seriously wrong with her dietary regimen.

Daily Intake

- **5AM Breakfast:** smoothie with whey protein powder, ¼ cup blueberries, ¼ cup acai berries, 1 teaspoon chia seeds, 1 teaspoon ground flax seeds, 1 teaspoon turmeric, 1 cup kale and spinach leaves.
- **9AM Snack:** 2 large carrots
- **11:30AM Snack:** ¼ cup raw dry roasted almonds
- **1:15PM Lunch:** Salad with lots of vegetables, 3 ounces of turkey, apple cider vinegar and turmeric sprinkle
- **3:00PM Snack:** 1/2 cup lentils
- **6:00PM Dinner:** 3–4 ounces of lean protein (chicken, fish) and lots of roasted vegetables with a small amount of olive oil
- **8:30PM Snack:** ¼ cup cacao nibs and cup of herbal tea

Significance, Background, and Prevalence

Physician Steven Bratman coined the term “orthorexia” in 1997. “Ortho” meaning straight, correct, and true and “nervosa” from “anorexia nervosa.” Bratman wanted a term to define what he was seeing in his patients characterized by a fixation on eating healthy food [1]. Described as “a disease disguised as a virtue” orthorexia nervosa (ON) presents as an incessant preoccupation with proper nutrition characterized by a restrictive diet, ritualized eating patterns, and rigid avoidance of foods believed to be “unhealthy” or “impure” [2]. Though frequently observed by clinicians, there is minimal empirical evidence available and it is not formally recognized as a psychiatric disorder [3]. In contrast to patients with anorexia nervosa, patients with ON focus on quality rather than quantity of the foods they consume [4]. Patients will spend ample time considering the source of their foods to determine whether any pesticides, hormones, or additives were used in production; considering cooking methods to maximize nutrient availability, as well as packaging and any potential carcinogenic contamination [5]. These preoccupations with food quality are focused on a person’s physical health and well-being rather than motivated by concern for environmental sustainability, animal welfare, or for religious beliefs [1]. Preoccupations can become complex and involve specific food combinations at meals and snacks or at particular times during the day, or involve long periods of time in between certain foods related to perceptions of optimal digestion. Other areas of life are often impacted related to preoccupation outside of meal and snack times, allowing for research, weighing and measuring foods, and planning for future meals.

Although orthorexia nervosa is motivated by a desire for optimal health, the pathology can lead to nutritional deficiencies, medical complications, and poor quality of life [2]. There is a lack of long-term empirical evidence, however

anecdotal evidence exists to show that this type of dietary extremism leads to medical complication seen in severe anorexia: weight loss, osteopenia, anemia, hyponatremia, metabolic acidosis, pancytopenia, testosterone deficiency, and bradycardia [1, 6, 7]. ON compromises mental health as well. Suffering individuals experience intense frustration when their food practices are disrupted, disgust if purity is seemingly compromised, and guilt and self-loathing when “transgressions” are committed [8]. Transgressions can lead to self-punishment via even stricter dietary patterns [1]. Social isolation is common as sufferers find that it is too difficult to spend time with others who do not have similar obsessions to maintain their food rituals [8].

Because diagnostic criteria is limited, it is difficult to assess the prevalence of orthorexia nervosa in U.S. populations. There is preliminary research to indicate that high-risk populations for ON include adolescents, athletes, performance artists, physicians, medical students, and dietitians [9]. It is well documented that the onset of most eating disorders occur during adolescent and early adulthood [10]. Adolescents are high users of social media; Turner and Lefevre found that high Instagram use, with a focus on healthy eating communities, was associated with greater tendency towards orthorexia [9]. Some studies have found ON tendencies within the healthcare profession, both students and professionals, to be quite high [11–13]. This suggests a need for better education and resources within healthcare education about screening, risks, and treatment for ON so that patients with the diagnosis can get adequate care from providers who have a healthy relationship to food themselves.

It is important to note that in the absence of a diagnosed eating disorder, individuals who pursue healthy and clean eating do not maintain restrictive behaviors. Dropout rates for these types of restrictive eating patterns, whether in the interest of weight loss or for chronic illness is 35–55% [14–16].

Risk Factors and Treatment

Treatment for ON can be difficult for a number of reasons. Research on the pathology is limited and as discussed earlier, there is not yet established diagnostic criteria. Additionally, patients typically do not seek treatment. This is related to denial that there is an issue with their food habits, as well as society's focus on healthy habits allows for suffering individuals to be praised for their behavior [9]. Patients consider their food rituals and habits morally superior, and the ideologies underpinning their habits provide structure and order to their lives, serves as a means to reduce anxiety, and provides the illusion of control over one's environment [17].

Donini et al. expanded on Bratman's original 10-question self-quiz, published in his book *Health Food Junkies*, to develop the ORTO15 [18] test which has been the most widely used screening tool in research to date. Its validity is still under review and a handful of other screening tools have been developed. Below are the questions listed on the ORTO15.

1. When eating, do you pay attention to the calories in food?
2. When you go into a food shop do you feel confused?
3. In the last 3 months, did the thought of food worry you?
4. Are your eating choices conditioned by your worry about your health status?
5. Is the taste of food more important than the quality when you evaluate food?
6. Are you willing to spend more money to have healthier food?
7. Does the thought about food worry you for more than 3 hours a day?
8. Do you allow yourself any eating transgressions?
9. Do you think your mood affects your eating behavior?
10. Do you think that the conviction to eat only healthy food increases self-esteem?
11. Do you think that eating healthy food changes your lifestyle (frequency of eating out, friends, ...)?

12. Do you think that consuming healthy food may improve your appearance?
13. Do you feel guilty when transgressing?
14. Do you think that on the market there is also unhealthy food?
15. At present, are you alone when having meals? [18]

Risk factors for adolescents include parents who place an undue importance on healthy food in the home and at family meals, childhood illness involving diet and or digestive issues, medical issues that can't be addressed by medical science, traits of perfectionism, OCD, and extremism, fear of disease, or chronic illness [19]. Athletes are susceptible to orthorexia because of the focus on optimal sports performance [9].

There is no research to date on adequate treatment for orthorexia disordered eating patterns [20]. However ideal intervention should be similar to other eating disorders and include a multi-disciplinary team that includes a physician, psychotherapist, and dietitian all trained in eating disorder treatment and practice [9]. Interventions should be individualized to the patient and support the family with resources on how to best support their child's recovery, as well as how to navigate the strained relationships that arise when a family member is suffering from ON. Resources on how to help patients navigate the many cultural triggers, or stimuli that prompt eating disorder thoughts found within their environment will be helpful to the adolescent's recovery. This can include removing pages from social media accounts that focus on "healthy living" and "clean eating" that can be triggering for someone in recovery from orthorexia and other eating disorder pathologies.

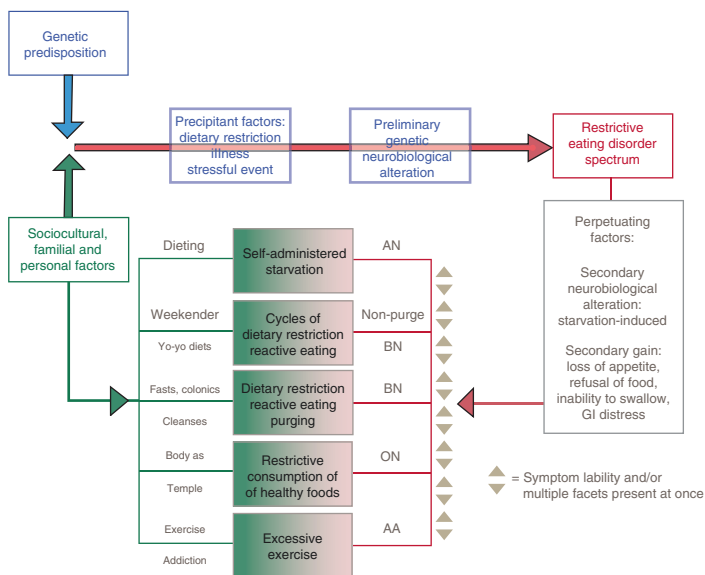
There is some evidence that medications have been useful for reducing symptoms of those suffering from ON. Mathieu found serotonin reuptake inhibitors helpful [8]. Other studies have found antipsychotic drugs, such as olanzapine to reduce obsessive tendencies around "magical" food-related thinking [6]. If medication treatment is initiated co-occurring psychotherapy is important to monitor symptoms and improvement.

Treatment should also include helping patients shop, prepare, and cook meals with ingredients outside of their current food philosophies.

Helping patients to develop a more flexible eating pattern, with a focus on adequacy, variety, and pleasure, should be goals of treatment, as well as addressing the individual symptoms presented by the patient. Moving patients from their disordered eating patterns to a more competent and intuitive eating style can be supported by Ellen Sattyr's eating competence model and a weight neutral approach, Intuitive Eating principles, and utilizing motivational interviewing techniques to support a patient's journey toward healing their relationship to food and their bodies [21, 22].

Intersection with Other Pathologies

Eating disorder pathology does not entirely fit into one diagnostic criteria. Patients will spend some time with restrictive behaviors and then develop binge/purge behaviors as well as many other combinations as a means to control food and weight, and to cope with the trauma, oppressions, or difficulties present in their lives. Figure 20.1 illustrates the connections between genetic predisposition, cultural and societal factors, and various expressions of eating disorders: anorexia nervosa (AN), non-purge BN (restrict/ reactive eating cycles), BN (bulimia nervosa), ON (orthorexia nervosa) and AA (anorexia athletica) [23]. The left and right side of Fig. 20.1 highlight dietary modifications and influences on these and possible progression and precipitating factors that influence the diagnosable pathologies shown on the left side. In the case of interest, note the difference between an interest and focus on healthy eating and the progression towards orthorexia nervosa. What separates the two is the underlying genetic predisposition. As it is difficult to ascertain this underlying predisposition, it is important for healthcare providers and health educators to



© Gwyneth Olwyn, 2012, Modified from C. Ramacciotti et al., P.J. Swain [ed.], *Trends in Eating Disorder Research*, Novo Science Publishers, 2005

FIGURE 20.1 Cycles of eating disorders and disordered eating [23]

assess how food recommendations are presented to adolescents in an effort to prevent eating disorders. The goal should be to support the path to competent eating as opposed to healthy eating [22].

Similarities and Distinctions Between ON, AN, and OCD

There are many similarities between characteristic traits of individuals suffering from orthorexia nervosa (ON) and anorexia nervosa (AN) including perfectionism, high trait anxiety, and a highly present need to exert control [24], as well as the intention of weight loss [5] to fit into societal standards of a beauty ideal. Individuals suffering from either disorder observe a deviation from their dietary patterns as a failure of self-control. As achievement-oriented individuals, this is a blow to their value of self-discipline and can cause

even more stringent restriction or modifications. Differences between ON and AN include the motivation for the dietary habits and patterns, as well as how willing the individual is to share or talk about their food choices [9]. In AN, there typically is a great deal of shame about the diagnosis, whereas those suffering with ON attach a morality to their food choices and often are willing to share their ideology with others.

Those with ON also exhibit certain obsessive-compulsive tendencies, including recurrent and consistent thoughts about food and health at inconvenient times, exaggerated concern over contamination and impurities, and a commanding desire and strong need to arrange food and eat in a particular manner [1, 25].

Kelly's Case

Kelly was interested in the sciences and hoped to go into the medical field one day. She was fascinated with how the body worked and so in therapy sessions we discussed the three different macronutrients, nutrients that give our body fuel and play important and specific roles in how our body functions. We also discussed the societal and cultural influences on our perception of healthy eating. Kelly was able to recognize that though popular diets were demonizing carbohydrates, they are an important component to our bodies' overall well-being. She was fascinated to learn about the dieting industry and how powerful it can be in influencing our perceptions of health and our relationship to our bodies.

It was difficult for Kelly to increase her intake. We did a lot of work around her relationship to her body, by chasing to their source negative thoughts about weight gain, or being in anything other than a thin body. She was also able to see that the ideas that she had about bodies were all "handed to her" from our culture. The idea of healing her body with adequate and varied food intake was a motivator for her as she was passionate about health. She reminisced about her mom in session, and could remember that though her mom rarely talked about her body or food, she was consistently on a diet

that would last a few months, then she would give in to enjoying meals with the family again and not constantly worrying about and monitoring her food intake.

I helped Kelly's father find a therapist who specialized in eating disorders / disordered eating, and grief counseling. Kelly was able to grieve and process her mom's sudden death, and her time in therapy helped her see that the loss was so shocking and earth shattering that she turned towards regimented food intake as a source of comfort and control.

As Kelly healed her relationship to food and her body, she began to enjoy the communal nature of the time she spent eating and enjoying foods with her family. She learned to cook some of her mom's favorite foods and the family always ate together on Sundays despite everyone's busy schedules.

Summary

Though there is a growing need for more research and diagnostic criteria for orthorexia nervosa, there is ample indication that this is a growing potential for adolescent populations. As such, ON should be screened for and monitored within healthcare settings so that patients can get adequate care from an eating disorder trained treatment team. Treatment models that heal any physiological damage and promote competent and flexible eating that focus on variety and adequacy, as well as address underlying psychological distress, will be important for adolescents recovering from ON.

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Part IV
Additional Health
Considerations

Chapter 21

Polycystic Ovarian Syndrome (PCOS)



Sarah A. Golub, Amy Cantor, and Katrina Schroeder Smith

Introduction

Polycystic ovarian syndrome (PCOS) is a common hormonal imbalance that typically presents during adolescence and affects both the reproductive and metabolic systems. It is characterized by a wide spectrum of clinical symptoms including hirsutism, acne, irregular menses, increased adiposity, insulin resistance, and related comorbidities. Nutrition has been shown to play a major role in both the development and management of PCOS, and adolescence is the prime time to cultivate habits that may influence health throughout the life course (see Chap. 12). Given the increased associated lifetime risk of type 2 diabetes (T2DM) and cardiovascular disease,

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early diagnosis and management may prevent sequelae later in life. In this chapter, we provide an overview of PCOS in adolescents, and then focus on strategies for nutritional assessment, diagnosis and management.

Medical Background

PCOS is the most common endocrine disorder in women of reproductive age, affecting upwards of 10% of females in the general population [1, 2]. Rates vary significantly by racial and ethnic background, with women from East Asia having lower prevalence (5%) compared to Caucasian women (11–21%) [3]. The etiology of PCOS remains unclear, but is likely multifactorial. Genetics and environmental exposures are thought to play a role; it is inherited in an autosomal dominant pattern though phenotypic expression is variable [4, 5]. Evidence suggests that endocrine disrupting chemicals (EDCs), such as foods and other consumer products that interfere with hormone biosynthesis and metabolism, may be implicated as well. Some studies have shown that prenatal exposure to androgen-like EDCs may contribute to metabolic dysfunction and PCOS during adulthood [6]. Certain medications, such as valproate, an antiepileptic drug, have also been shown to increase the likelihood of developing a PCOS phenotype [7].

Pathogenesis

Multiple hormonal factors contribute to the development of the PCOS phenotype. Increased production of luteinizing hormone (LH) and insufficient follicle-stimulating hormone (FSH) lead to elevated production of testosterone by the ovaries, resulting in menstrual dysfunction. Elevated levels of insulin also increase ovarian and adrenal production of free testosterone [8, 9]. In addition, increased adiposity may be associated with higher androgen concentrations, possibly making the phenotype of PCOS more severe [10]. One study

has shown that as BMI increases in adolescent girls, free testosterone concentration rises proportionally [11].

Diagnosis

The diagnosis of PCOS generally requires the presence of clinical hyperandrogenism (hirsutism, acne) or hyperandrogenemia (elevated serum androgen levels), as well as some form of menstrual dysfunction [12]. Historically, there have been three distinct diagnostic criteria used to define PCOS, sometimes making identification a challenge. Diagnosis in adolescents is even more complicated given that irregular menses and acne are often normal physiological findings at this age. The National Institutes of Health (NIH) PCOS criterion were the first to emerge in 1990 [13], followed by the Rotterdam consensus in 2003 [14], and finally the Androgen-Excess PCOS (AE-PCOS) Society in 2006 [15] (see Table 21.1). In 2012, an NIH evidence-based methodology PCOS workshop convened in attempt to merge these divergent criteria, resulting in reinforcement of the broader and more inclusive 2003 Rotterdam criteria, with the addition of a phenotypic classification system to help with diagnosis. This classification describes four distinct PCOS phenotypes, each with varying degrees of clinical severity [16].

TABLE 21.1 Diagnostic criteria for polycystic ovarian syndrome

Diagnostic criteria	Hyperandrogenism (clinical or biochemical)	Ovulatory dysfunction (oligo- or anovulation)	Polycystic ovaries on ultrasound
NIH (1990)	X	X	
Rotterdam (2003)	X	2 of 3 required	X
AE-PCOS Society (2006)	X	1 of 2 required	X

Clinical Presentation

About two-thirds of adolescents with PCOS will present with menstrual irregularities. However, it is difficult to distinguish what is normal physiology in young women from oligomenorrhea secondary to PCOS, given that anovulatory cycles can persist until 5 years after menarche [17]. As such, workup for PCOS would be warranted in the setting of: primary amenorrhea in adolescents who have otherwise completed pubertal development, secondary amenorrhea with cycles absent for greater than 3 months, or persistently irregular bleeding with cycles lasting fewer than 21 days, especially if there is evidence for hyperandrogenism [9, 17].

The hyperandrogenism that is seen with PCOS includes moderate to severe hirsutism or acne. Hirsutism in women is the presentation of excessive, coarse hair appearing in a male-type pattern which can be objectively quantified using the Ferriman-Gallwey scoring system [18]. This scoring system was validated in white female adults, so generalizing its use to adolescents of varying racial and ethnic backgrounds is not without its limitations. Given that many adolescents develop acne during puberty, only more extreme cases should be considered an indication of hyperandrogenism. A finding of moderate to severe inflammatory acne as defined by greater than 11 inflammatory lesions, unresponsive to topical medications, would be reason to pursue further laboratory workup [17]. Table 21.2 lists some of the common clinical and biochemical findings of PCOS in adolescents.

Medical Workup

The recommended initial step for assessment of laboratory abnormalities is measurement of serum free testosterone, which is the most sensitive indicator of elevated androgens. Total testosterone and sex hormone binding globulin (SHBG) can also be evaluated to determine the amount of circulating free testosterone. Elevated levels of dehydroepiandrosterone sulfate (DHEA-S), an adrenal steroid and precursor of

TABLE 21.2 Common clinical and laboratory findings of PCOS in adolescents

Physical exam

- Moderate to severe inflammatory acne
- Excessive “male-type pattern” hair growth (hirsutism)
- Alopecia
- Acanthosis nigricans

Measurements

- Hypertension
- Elevated Body Mass Index (BMI)

Laboratory evaluation

- Elevated free or total testosterone
- Elevated DHEAS
- Normal or elevated LH:FSH ratio
- Elevated AMH
- Elevated fasting glucose
- Elevated HbA1c
- Elevated fasting insulin level
- Hypercholesterolemia or hypertriglyceridemia
- Transaminitis

^aPCOS presents with a wide range of phenotypes. The table lists potential findings that may be present in some, but not all, patients. Please refer to Table 21.1 for diagnostic criteria

testosterone, is also an indicator of hyperandrogenism [19]. Though non-specific, an LH to FSH ratio greater than 2.5 is frequently observed in patients with PCOS; however, this is more commonly seen in lean patients with PCOS, as BMI is negatively correlated with LH levels [20, 21]. Recent studies have suggested that the measurement of a patient’s serum anti-müllerian hormone (AMH) may be an emerging clinical tool in the diagnosis of PCOS. AMH is involved in ovarian follicular development, and is significantly higher in women with PCOS, though a clear diagnostic cut-off value has not yet been defined [22]. Further laboratory workup is needed to monitor for development of metabolic and cardiovascular comorbidities (see below). Depending on the clinical presentation, it is also recommended that other etiologies of androgen excess, amenorrhea and/or oligomenorrhea be ruled out

before a diagnosis of PCOS is made; these include androgen-producing tumors, late onset congenital adrenal hyperplasia (CAH), Cushing's syndrome, premature ovarian insufficiency, hyperprolactinemia and thyroid disorders.

Pelvic ultrasound is an additional tool, which can be useful for diagnostic clarification in adolescents with suspected PCOS. Polycystic ovarian morphology (PCOM) is due to an excess number of small ovarian follicles that have arrested before pre-ovulatory development. PCOM diagnosis was previously based on the presence of a minimum of 12 follicles or an ovarian volume of greater than 10 cm³ in at least one ovary, though with improved transducer frequencies, this definition was recently updated to include at least 25 follicles in adult patients using transvaginal ultrasonography. In adolescents, however, follicle counts may be less reliable with transabdominal imaging, which is the preferred method in this age group. In addition, due to normal physiological changes associated with pubertal development, these findings can be present in up to half of asymptomatic adolescents, particularly within the first 2 years after menarche. Given these frequently misleading findings, the Endocrine Society guidelines caution against use of PCOM as diagnostic criteria for adolescents. As such, ultrasound use in adolescents is reserved only for patients with an unclear diagnosis [17, 23, 24].

Comorbidities

Additional factors to consider in the presentation and management of PCOS are comorbidities associated with insulin resistance, which can lead to multiple metabolic complications including pre-diabetes, T2DM, hyperinsulinemia, dyslipidemia, cardiovascular disease, hypertension (together often referred to as metabolic syndrome), and non-alcoholic fatty liver disease (NAFLD) [25]. An estimated 50–80% of adolescents with PCOS are overweight or obese [26], further increasing their risk of developing metabolic disturbances. The prevalence of hypertension in adolescents with PCOS

and a BMI in the obese range has been reported to be as high as 27% [27]. About 30–35% of women in the U.S. with classic PCOS have impaired glucose tolerance, and 8–10% develop diabetes [26]. A recent meta-analysis demonstrated that the odds of developing metabolic syndrome among adolescents with PCOS was 6.1-fold higher than among adolescent healthy controls [28]. While all girls with PCOS are at higher risk for developing these comorbidities, the risk increases with higher BMI [27]. Another study showed that obese adolescents with PCOS who had normal blood pressures and lipid profiles were found to have greater carotid artery thickness, greater arterial stiffening and more atherogenic lipid metabolisms, thus putting them at increased risk of poor cardiovascular outcomes, when compared to obese youth without PCOS [29].

Given the prevalence of significant comorbidities with PCOS, current guidelines recommend screening for T2DM and for cardiovascular risk. It is generally recommended to perform a fasting lipid profile and a 2-hour oral glucose tolerance test (OGTT); alternatively, a hemoglobin A1c (HbA1c), which is often easier to obtain in youth, can be performed in place of an OGTT [30]. Most guidelines recommend screening for these comorbidities at the time of diagnosis of PCOS, and repeating every 1–5 years depending on patient characteristics (interval weight gain, signs/symptoms of T2DM), though there is no clear consensus on frequency of repeat screening [23, 26]. Although there are no formal recommendations regarding the evaluation of hyperinsulinemia or liver function, it may be useful to obtain a fasting insulin level and alanine aminotransferase (ALT) to guide management, particularly in patients with increased adiposity or signs of insulin resistance.

A potential consequence of ovarian dysfunction in adult women with PCOS is infertility, though this is not an issue that is typically of immediate concern for adolescents. Reassurance should be provided that many women with PCOS conceive with or without fertility therapies. As such, sexually active adolescents should be counselled that they

can indeed become pregnant and should use contraception. Endometrial cancer is a possible late complication of prolonged anovulation as unopposed estrogen stimulation of the uterus can lead to endometrial hyperplasia. The lifetime risk of endometrial cancer among women with PCOS is estimated to be as high as 9% [26].

Other notable and all-too-often overlooked comorbidities associated with PCOS include depression and anxiety. The social and emotional aspects of the physical presentation of acne, unwanted facial hair, and increased adiposity can be quite distressing, leading to significant declines in health-related quality of life in these patients [31]. Providers evaluating for PCOS should be mindful of potential body image concerns, disordered eating, weight stigma and bullying, and thorough mental health screening should be performed. Several instruments have been created to specifically evaluate the quality of life in patients with PCOS; the PCOS Health-Related Quality of Life Questionnaire (PCOSQ) and the 36-item Short Form Health Survey (SF-36) are the two most commonly used [32]. Another option, the Patient Health Questionnaire 9 (PHQ-9), is a brief general screening tool for depression which has been validated in adolescents and is often readily available in primary care settings [33].

Medical Management of PCOS

Treatment of PCOS in the adolescent should generally focus on managing symptoms of hyperandrogenism and menstrual irregularities as well as preventing or treating any comorbidities such as dyslipidemia, insulin resistance, and increased adiposity. The main treatment modalities consist of lifestyle modifications and pharmacotherapy [34], however, given the variety of treatment options, we recommend a shared decision-making approach with the adolescent and, if applicable, their parent or guardian, to focus on the symptoms that are most bothersome to the individual patient. It should also

be emphasized that not all adolescents are bothered by their acne, hirsutism, or menstrual dysfunction, so working with patients based on their concerns is critical.

Current literature suggests that in patients with an elevated BMI, a decrease in body weight and increase in physical activity have been effective in improving the endocrine and metabolic complications of PCOS. Several studies have demonstrated that a 5–10% reduction of body weight can improve hyperandrogenism, insulin resistance, dyslipidemia, menstrual regulation, and emotional wellbeing [35–37]. It is unclear if similar reductions in body weight will improve the PCOS phenotype in women with BMIs in the normal range. The 2013 Endocrine Society guidelines for PCOS recommend lifestyle modifications, with a goal of weight loss, as the first line treatment for adolescents with PCOS in the overweight or obese categories [23]. Although data on bariatric surgery outcomes in adolescents with PCOS is not yet available, adult data has shown resolution of hirsutism and ovarian dysfunction in 96% of adult women with PCOS who underwent surgery [38]. That said, psychosocial outcomes of bariatric surgery in adolescents continue to be poorly understood [39, 40]. It is also important to note that evidence on the feasibility and long term sustainability of weight loss in adolescents is limited, and further research is needed to evaluate the unintended consequences of weight as a target for health interventions [41]. We recommend focusing less on weight loss, and more on a healthy and balanced approach to eating and exercise (see Chap. 12).

For pharmacologic therapies, combined hormonal contraceptives (CHCs) remain the mainstay of treatment in adolescents who do not have contraindications to estrogen use. CHCs serve to decrease ovarian androgen production and thus lower serum free testosterone levels. They also increase the liver's production of sex hormone binding globulin, which further reduces serum free testosterone. This results in a reduction of hirsutism and acne, as well as regulation of menses, thereby providing endometrial protection [42]. Spironolactone, an aldosterone antagonist and potassium-sparing diuretic, inhibits

the action of androgens as well as the biosynthesis of adrenal and ovarian androgens; it is often used as adjunct or even individual therapy for clinical signs of hyperandrogenism, but its teratogenicity must be considered. Topical or oral acne medications as well as hair removal techniques (waxing, laser, and electrolysis) can also be offered based on the severity of the patient's symptoms and their goals of treatment [21].

Insulin sensitizing medications, which are primarily used to treat T2DM, are often prescribed for adolescents with PCOS and insulin resistance. Metformin, a commonly used insulin sensitizer, improves glucose tolerance and has been shown to decrease triglycerides, reduce hyperinsulinemia, lower BMI, decrease cardiovascular risk, and lower serum testosterone levels in patients with PCOS [43]. Metformin use can result in menstrual regulation; thus it is often used in adult women with PCOS who are seeking fertility. Given the potential side effect of lactic acidosis, it is important to counsel patients to avoid alcohol use while on metformin, and to discontinue use if they develop vomiting or diarrhea. Metformin can also affect the absorption of Vitamin B12, thus patients should be encouraged to take a multivitamin [44]. Newer insulin sensitizers are becoming available, but have not yet been studied in adolescents.

In addition, there is some evidence to support the role of vitamin D supplementation in the management of PCOS as it has been found to decrease levels of free testosterone [45], though this association has not yet been well established.

Finally, as noted above, improving quality of life by supporting adolescents' mental health needs with counseling, if applicable, is critical in decreasing the psychological morbidity often present in PCOS [32].

Nutrition Assessment

A nutrition assessment has five distinct components including: food and nutrition history, anthropometric measurements, biochemical data, the nutrition focused physical exam, as well as health history [46]. These components should be

tailored to fit the medical and emotional needs of an adolescent with PCOS. The goal of this assessment is to conceptualize a nutrition intervention.

Food and Nutrition Related History

Given the preponderance of nutrition myths, it is important to begin by gauging an adolescent's understanding of nutritional recommendations as they pertain to PCOS. Thereafter, a clinician should gather information regarding the adolescent's current and past eating patterns, including a 24 hour dietary intake, and assess for eating disordered behaviors. For an individual with PCOS, it is important to be cognizant of current nutrition habits within the context of their unique health risks.

Dietary Intake

A 24-hour diet recall is the standard method to assess for typical dietary intake. The literature regarding dietary intake for adolescents with PCOS reveals a number of differences compared to adolescents without PCOS. These include the fact that adolescents with PCOS have higher caloric and dietary fat intakes than individuals without PCOS [47], as well as higher saturated fat intake and lower fiber intake [48] compared to their non-PCOS peers. From a micronutrient prospective, adolescents with PCOS are at a higher risk of a vitamin D deficiency [49]. A clinician should note dietary sources of vitamin D as well as inquire about supplement use.

Given the heightened risk of insulin resistance and a predisposition to T2DM, it is relevant to assess for intake of sugar-sweetened beverages as well as refined carbohydrates. Additionally, given the metabolic and cardiovascular risks associated with PCOS, dietary sources of items high in saturated fats, trans-fats, sugar and sodium should be noted. Finally, with the known benefits of small, frequent meals for blood glucose stability, meal frequency and portion size should be assessed during a dietary recall.

Assessing for Disordered Eating in Adolescents with PCOS

A part of any adolescent nutrition history should include a screening for eating disorders. There is an established link between PCOS and heightened risk of eating disorder behaviors as well as body dissatisfaction [50]. Research shows that adolescents with PCOS are at particular risk of engaging in a variety of eating disordered behaviors [51]. Specifically, there is an increased risk of binge eating behaviors in adolescents who have both PCOS and higher body weight. Additionally, adolescents with PCOS have been found to have higher food craving scores, which are often linked to increased rates of binge eating behaviors and elevated weight status [52]. It is important to note that dieting, or intentional caloric restriction, is also highly correlated with higher food cravings. Thus, a clinician must be careful not to make recommendations that could contribute to or perpetuate restrictive eating. There is also a growing body of literature which shows a connection between dieting and weight dissatisfaction with decreased health and health related-quality of life [53]. Thus, any discussion about weight, body size and eating patterns should be done in a sensitive matter. If an adolescent does endorse eating disorder behaviors, refer the patient to a treatment team specializing in this field.

Below are examples of screening questions for eating disorder behaviors in adolescents with PCOS:

- *How often, if ever, have you skipped meals to change your body weight?*
- *How often, if ever, do you eat in a way that feels out of control (as if you cannot stop if you wanted to)?*
- *How often, if ever, have you restricted carbohydrates to change your body size?*
- *How much time do you spend wishing to change your body? How does this compare to a friend or family member - less time, about the same or more time?*

Anthropometric, Biochemical and Growth Chart Data

Adolescents with PCOS are at an increased risk for type 2 diabetes (T2DM), coronary artery disease, and elevated weight [54]. Lab values, as noted above, and growth, should be reviewed in the context of dietary patterns and physical activity. A CDC growth chart should be used from the ages of 2–20 and weight status for a pediatric and adolescent population (up to age 18) is determined by BMI percentiles. A BMI between the 85th and 95th percentile is considered the overweight category and a BMI equal to or greater than the 95th percentile is the obese category. Upward deviations in BMI and lab value abnormalities will inform the nutrition diagnosis and subsequent recommended intervention.

Nutritional Interventions for PCOS

The first-line treatment for PCOS is lifestyle intervention that focuses on healthful eating patterns, physical activity, and, potentially, weight loss [55]. Nutrition plays a key role in these behavior changes. Despite proven symptom resolution with lifestyle change, such change can prove challenging. This is especially true for adolescents, as they may have an established eating routine, and may not want to eat differently from their peers. Many adolescents also dislike foods deemed “healthy,” and teens are often not responsible for purchasing or preparing the food that is available to them at home.

Weight Loss and Dietary Modification

Though weight loss of approximately 5% has been shown in the short term to reduce symptoms of PCOS (such as menstrual dysfunction, infertility, hyperandrogenemia, and cardiometabolic comorbidities), it is more difficult for adolescents with PCOS to lose weight when compared to their peers

[56, 57]. That is in part because women with PCOS have been found to have a lower basal metabolic rate than those without PCOS [58]. Additionally, one study found that levels of ghrelin and cholecystokinin, hormones that help regulate appetite, are impaired in women with PCOS [59]. This could lead to increased appetite and excess nutrient consumption, as well as compromised awareness of body hunger and fullness cues.

All young women with PCOS can benefit from dietary modification. Evidence suggests that this holds true even for normal weighted women, per CDC BMI classification, for whom weight loss is not the goal [55]. Studies have shown that in adolescents with PCOS and elevated BMI, the mechanism for weight loss is not as important as the actual weight loss itself [55]. There is no specific “PCOS diet,” per se, so dietary recommendations should be individualized [34]. Particularly in adolescent women, providers should be wary of excessive calorie restriction or elimination of food groups which can lead to or exacerbate disordered eating. This is especially true for young women with PCOS who have been shown to have an increased risk of disordered eating and body dissatisfaction [50, 51].

Adolescents are impressionable, and may attempt to make impulsive, drastic dietary changes, or to follow “fad diets” that may seem to be quick solutions. Fad diets are typically unsustainable, often resulting in higher body weight over time [60]. Such “yo-yo dieting” and weight cycling contribute to a gradual slowing of metabolism, making long-term weight loss increasingly more difficult [60]. Educating an adolescent on a healthful dietary approach and guiding them to elicit dietary change using motivational interviewing will be more effective and sustainable.

If appropriate, engaging parents or caregivers in supporting an adolescent in making dietary changes can be impactful, especially if caregivers are responsible for food shopping and meal preparation. While important to give the patient autonomy, ask if it would be helpful to include the caregiver in the discussion. Caregivers may benefit from education on the importance of dietary changes and their intended impact on

PCOS symptoms. Providers should encourage caregivers not to stigmatize their teen about their body size or eating patterns. Rather, a shift towards changing the entire family's health behaviors would likely support the adolescent in adherence to any lifestyle change.

Lifestyle Change and Motivational Interviewing

Motivational Interviewing (MI) is an evidence-based style of counseling for adolescents. Use of MI is recognized to be effective in helping to motivate individuals to change behaviors. MI, addressed in other sections of this book, is a patient-centered model of care which helps in assessing motivation and readiness for making change [61]. For example, if an adolescent wants to lose weight, a follow-up question might include, "How might you accomplish that?" The provider can then guide them to help set attainable goals, while providing nutrition education when appropriate. In some short-term studies, motivational interviewing in tandem with counseling on healthy behaviors has been shown to be effective for weight loss in adolescents [62]. A skilled clinician can help to elicit change while providing nutrition education on healthful balanced eating.

When using motivational interviewing, it is important to meet the adolescent where they are and to help them to make SMART (specific, measurable, achievable, realistic, time-based) goals. Ideally, the adolescent will follow-up with a healthcare provider to track progress with their specific goals in order to keep them accountable. The following are examples of SMART goals for an adolescent with PCOS:

- *Ask parent to purchase broccoli when grocery shopping for the week. Add broccoli to dinner Monday night and Thursday night. On follow-up try increasing vegetables to four nights per week.*
- *When eating at a restaurant on Friday night, order seltzer water to drink instead of soda. On follow-up try limiting soda to 1 cup per week.*

- *Bring one piece of fruit to eat with lunch at least 3 days in the next school week. On follow-up try increasing to fruit daily with lunch.*
- *Over the weekend, make trail mix using whole-grain cereal, nuts, pumpkin seeds, and dark chocolate chips. Snack on 1 cup after school each day. On follow-up discuss whether this helped to satisfy craving for sweet and salty treats.*

Nutrition Recommendations for Adolescents with PCOS

Regardless of weight status, young women with PCOS should attempt to have a balance of nutrients at each meal consisting of lean protein, whole-grain, high-fiber carbohydrates, heart healthy fats, fruit, and vegetables. The USDA MyPlate helps illustrate a ratio of these nutrients by dividing the plate into four equal sections: fruit, vegetable, carbohydrates, and protein, as well as a glass of milk [63]. Another tool is the Harvard Medical School Healthy Eating Plate (Fig. 21.1) which specifies the grains should be whole grains, the proteins should be lean and plant-based when possible, the fats should be heart-healthy, and the vegetables should be the largest portion on the plate.

Both of these plates are appropriate for adolescents with PCOS, especially within the context of what they leave out: processed foods, refined grains, sugar, and sugar-sweetened beverages. The intake of food and beverages high in sugar should be limited in adolescents with PCOS due to their negative effects on insulin and blood sugar [60]. Additionally, trans-fats and saturated fats should be minimized due to their effect on cardiovascular health and risk of metabolic syndrome. It is important to counsel *moderation* rather than *elimination* to prevent any foods or food groups seeming “off limits,” which can lead to higher desirability and/or overconsumption. Additionally, it is important to be sensitive to the fact that processed foods may be the most readily available

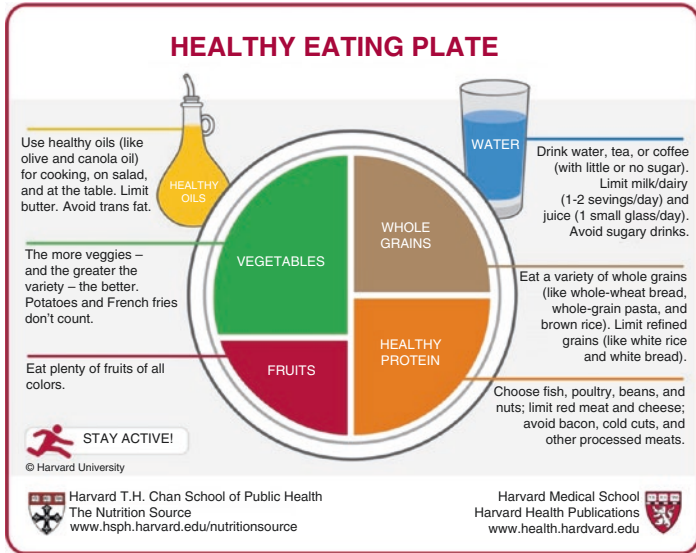


FIGURE 21.1 The Healthy Eating Plate. (Copyright © 2011 Harvard University. For more information about The Healthy Eating Plate, please see The Nutrition Source, Department of Nutrition, Harvard T.H. Chan School of Public Health, <http://www.thenutritionsource.org> and Harvard Health Publications, health.harvard.edu)

and affordable options to a family. Consider a discussion about which of these options are the least processed.

Other styles of eating that are appropriate for adolescents with PCOS are the DASH Diet (Dietary Approaches to Stop Hypertension) and Mediterranean Diet. Both of these eating patterns promote high-fiber intake through fruits and vegetables as well as unsaturated fat intake found in items such as nuts, oils, and fish [64–66]. Both diets promote limiting intake of red meat, sugar-sweetened foods and beverages, and processed foods.

Young women with PCOS should try to consume small, frequent meals eaten consistently throughout the day in order to help maintain even serum glucose levels. This is in contrast to a more typical intake of small or skipped breakfast,

medium-sized lunch, and large dinner with evening snacks. An example of small frequent meals might be whole grain toast with eggs and fruit for breakfast, yogurt with slivered almonds for morning snack, quinoa with beans, veggies, and avocado for lunch, carrot sticks with hummus for afternoon snack, salmon with baked sweet potato and sautéed spinach for dinner, and mixed berries with a dollop of whipped cream for dessert. The goal of eating approximately every 3 hours helps prevent spikes and dips in blood sugar that can occur with larger, less-frequent meals, particularly those that are carbohydrate-heavy [60]. Additionally, pairing carbohydrates with foods that contain fat and protein will result in slower absorption into the bloodstream. Fiber-rich foods such as fruits, vegetables, legumes, and whole grains also help to slow absorption, resulting in a more gradual increase in blood sugar. Ensuring that meals and snacks all have a source of protein and a source of fiber will lead to prolonged satiety [60].

Although limiting refined carbohydrates and sugars is recommended, a diet high in protein and low in carbohydrates has not been shown to lead to lasting symptom resolution or to any sustained weight loss in PCOS patients. In addition, restriction of carbohydrates can result in limiting the intake of healthy fruits, vegetables, and whole grains. Excessive protein intake can also be harmful to the kidneys [60]. Despite this, reducing carbohydrate intake may be an effective strategy for short-term weight loss in adolescents with excess carbohydrate consumption [67]. As stated above, moderation rather than elimination of any one specific type of nutrient is key. Counseling on the quality and type of carbohydrate rather than the amount or percentage of carbohydrate in the diet may be better and more flexible for adolescents [59]. It is important that adolescents understand that they should not eliminate all carbohydrates from their diet due to the important fuel this nutrient provides, especially to the brain [60].

A low-glycemic index diet is often recommended for women with PCOS. Glycemic index refers to the ability of a particular food to raise blood glucose levels, when compared

Impact of Nutrients on Blood Sugar

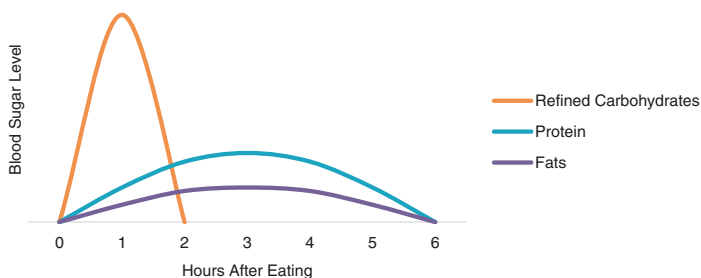


FIGURE 21.2 This graph approximates the increase in blood sugar level that occurs with ingestion of refined carbohydrates, protein, and fat

to a reference food. Because it is suggested that young women with PCOS eat foods and follow meal patterns that help maintain a low blood sugar level, a low-glycemic index diet is often suggested in the treatment setting of PCOS despite having been developed originally for patients with diabetes [59]. Glycemic load takes into account the glycemic index as well as the amount of fiber in a given food. Glycemic index and load only indicate how any one specific food might affect blood sugar [60]. However, a food is rarely eaten in isolation, and the effect on blood sugar changes when mixed with foods containing fat and/or protein (see Fig. 21.2). Therefore, counseling on this approach might not be as effective as general healthful eating with a focus on small, frequent meals, and foods high in fiber.

PCOS and Specific Nutrients

More research is needed to evaluate the impact that specific nutrients have on adolescents with PCOS. Currently, there is an abundance of misinformation available on the internet, which is

often confusing and misleading to patients. The following foods or food groups are often referenced in the media as categories to be avoided by women with PCOS:

- **Dairy:** There is a widely held belief that dairy should be avoided in PCOS as it can cause acne and alter hormones. There is also concern about the carbohydrate content due to the lactose. Few scientific studies have looked at the association between dairy intake and PCOS. One small study showed weight reduction following a low starch, low dairy, energy-restricted diet; however, it is unclear whether this was due to the decrease in carbohydrate content [68]. In fact, other studies have shown a link between dairy intake and weight loss, and posited that whole milk can lead to decreased intake of refined carbohydrates due to increased satiety [69].
- **Gluten:** Gluten is the protein found in certain grains such as wheat, barley, malt, and rye. Individuals with diagnosed celiac disease or non-celiac gluten sensitivity must avoid eating or drinking products containing gluten, as exposure can damage their digestive tract. To date, there are no scientific studies linking gluten to PCOS. In order to compensate for the lack of flavor that wheat provides, gluten-free products often contain more calories, sugar or other refined carbohydrates than gluten-containing foods. As such, in the absence of a confirmed celiac diagnosis, young women with PCOS should not restrict gluten.
- **Sugar:** Women with PCOS should indeed limit their intake of sugar, due to corresponding hyperinsulinemia [70]. However, it is important to remember that removing sugar altogether is likely not practical or sustainable; counseling instead on healthy alternatives (for example, mixing fruit into plain yogurt rather than eating fruit-flavored yogurt) is a preferable approach.
- **Soy:** Foods containing soy have phytoestrogen, which can alter estrogen levels in the body, leading some to believe that it is harmful for women with PCOS. However, the science

suggests that soy may be beneficial for women with PCOS given its potential to lower cholesterol levels and decrease body mass index [70].

Physical Activity

As stated above, the first-line treatment for PCOS is lifestyle modification, which includes physical activity [55]. An increase in physical activity can provide benefits such as the potential for weight loss and improved cardiovascular health with a subsequent decreased risk of metabolic syndrome. Providers can use motivational interviewing to help persuade an adolescent to increase their physical activity. Adolescents who engage in a form of physical activity they enjoy may be more likely to sustain this lifestyle change.

The Centers for Disease Control and Prevention (CDC) recommends 60 minutes or more of moderate to vigorous activity each day, as well as at least 3 days per week where the activity is vigorous. Terms such as moderate and vigorous can be too vague when making suggestions to an adolescent, thus it may be helpful to provide specific examples. Given the health benefits of increased physical activity such as decreased insulin sensitivity as well as the risks of long-term weight gain in women with PCOS, finding a way to incorporate physical activity into daily life is essential to symptom reduction [66].

Use of Interdisciplinary Teamwork (IDT)

When possible, a registered dietitian/nutritionist (RD or RDN) should be utilized for individualized nutrition counseling. Dietitians are in a unique position to devote an entire appointment to lifestyle change and can help to empower an adolescent in making these changes. Mental health providers are essential for discussing co-occurring depression, the stress

related to symptoms of PCOS, body image, and motivation for behavior change. A multidisciplinary approach including medical, nutrition, and mental health will benefit the adolescent [71]. Depending on the age and level of independence, including the parents or guardians in the treatment process can be helpful [34]. Some studies have shown that the degree of readiness to change on the part of the parent or guardian can have an impact on the outcome of treatment for the adolescent with PCOS [34, 55]. It may also be helpful to incorporate the expertise of other clinical specialists, such as physical therapists, personal trainers, and members of a bariatric surgical team, if deemed appropriate.

Monitoring and Evaluation

A comprehensive, interdisciplinary approach to follow up is recommended for adolescents with PCOS. This includes consideration of the patient's symptoms, dietary modifications, emotional well-being, physical exam and anthropomorphic measurements, as well as lab tests, if indicated.

Medical follow up visits should be tailored to the specific treatment approach taken. If hormonal contraceptives or insulin sensitizers were prescribed, a clinician should assess for adherence, any side effects the patient may be experiencing, as well as medication effect. It is important to review the adolescent's interim menstrual history, and ask about changes in acne and hirsutism. A physical exam should evaluate for any objective changes in signs of hyperandrogenism or insulin resistance, as patients on metformin may show improvements in acanthosis nigricans, if initially present. As discussed above, a clinician may choose to repeat lab work periodically to monitor the trajectory of metabolic risk, though there are no evidence-based guidelines regarding the frequency of biochemical follow-up in adolescents with PCOS [34].

From a nutrition perspective, an adolescent should be monitored for changes in dietary habits (such as meal and snack

content, portions, or frequency), body satisfaction and eating disorder behaviors. At a follow up visit, the provider can reference the SMART goals that the adolescent created to track progress and set new goals, if appropriate. Regarding weight changes for an adolescent, multiple examples in the literature do demonstrate improvement in PCOS symptoms with weight loss for adolescents with a BMI greater than or equal to the 95th percentile [35–37]. While intentional weight loss can improve symptoms, there are risks to consider. Harmful side effects of calorie or food group restriction include eating disorders, weight cycling, and reduced self-esteem if the weight is regained. In the setting of weight loss, monitoring for any unsafe practices such as compulsive exercise, excessive restriction, purging, or use of laxatives, diuretics, or weight loss medication should be done at each follow-up appointment. Sometimes, lifestyle change results in cessation of weight gain, which is a success in and of itself for some adolescents. A Health at Every Size (HAES) perspective would consider measuring lab values and behavior changes versus weight as markers of health improvement (see Chap. 12).

It is still important for the provider to give positive reinforcement to the adolescent for keeping follow-up visits, even if they have not made any behavioral changes. A discussion with the adolescent around barriers to making changes as well as potential motivators may help the clinician to problem solve and offer additional useful information.

Example Case

Nutrition Assessment

Patient history: Mia is a 17-year-old female with irregular menses, acne, and visible coarse hair on her upper lip and lower abdomen who presents to clinic for an initial visit. Lab work performed by her primary care provider reveals elevated free testosterone and DHEA-S, which in combination with her oligomenorrhea confirms the diagnosis of PCOS.

Food and Nutrition Related History

Mia reports she generally eats 2 meals and 2–3 snacks per day. She does not typically have time for breakfast. Mia denies any bingeing, purging, or diet pill or laxative use. She does endorse a desire for weight loss and notes she has tried different fad diets over the past 18 months, but has recently given up because “nothing seems to work.” She weighs herself “a few times” per week and her body weight now is ultimately higher than it was when she began the first of her dieting attempts. The dietitian asks Mia about her motivation for making any nutrition related change. Mia offers, “I’d like to lose weight but I’m not sure it’s possible. I also don’t really understand why my doctor sent me here since I already know all about dieting.”

24 Hour Dietary Recall

- 7 am – wake up
- 9 am – bagel and fat-free chocolate milk or juice at school, sometimes will skip breakfast
- 12 pm – 1 slice of pizza or snacks such as: gummy fruit snacks & chips, water to drink; sometimes school lunch
- 4 pm – snack at home: bowl of cereal or crackers with cheese, sweetened iced tea
- 7 pm – rice, beans, meat (1–2 plates), sugar-free diet juice
- 9 pm – hot chocolate, cookies

Anthropometric Measurements

- BMI is 32.4 kg/m² (5'3"; 183 lb; above the 95th percentile for BMI)
- HbA1c is 5.8% (elevated)
- Cholesterol is normal (HDL of 43, LDL of 90)

BMI growth chart indicates she has continuously grown along the 90th percentile until age 13, when her weight accelerated beyond what was expected per her growth pattern.

Assessment

Mia's intake reveals irregular eating patterns, a desire for weight loss and a nutrition-related knowledge deficit. The provider notes an elevated HbA1c in the context of Mia's intake of sugar-sweetened beverages (fat free chocolate milk, sweetened iced tea and hot chocolate). The provider also notes that on the days that Mia does not eat breakfast, she goes up to 5 hours without eating. Finally, the provider recognizes Mia's drive for weight loss is likely a result of her body dissatisfaction.

Nutrition Diagnoses

1. Nutrition-related knowledge deficit related to lack of prior nutrition counseling as evidenced by diet recall high in refined carbohydrates and inadequate in fiber intake.
2. Altered nutrition lab values (glucose) related to elevated insulin levels in the setting of PCOS as evidenced by elevated HbA1c of 5.8%.

Nutrition Intervention

Mia and the dietitian make a SMART goal. Because Mia is unsure of what she would like to start with, the dietitian offers different ideas such as eating breakfast containing a protein and whole grain daily, or minimizing intake of sugar-sweetened beverages (SSB). Mia suggests she would rather work on minimizing intake of SSBs. Mia decides she will aim to have only one SSB per day. They agree that Mia will return to clinic in 2–3 weeks for follow-up.

Summary

PCOS is a common hormonal imbalance presenting during adolescence, but typically persisting throughout the reproductive years. Many women struggle with acne, hirsutism, increased body weight, and menstrual dysfunction. Health care providers who work with adolescents should be aware of the symptoms, common laboratory findings, associated cardiometabolic comorbidities, as well as the risk of psychosocial concerns and disordered eating. While there is no individual evidence-based dietary intervention that has shown to be superior in the management of PCOS, lifestyle modifications to promote healthy eating and physical activity, along with hormonal contraceptives, continue to be the first-line treatment. In caring for young women with PCOS, it is important to allow the patient's concerns and preferences to guide management. Finally, a comprehensive, interdisciplinary approach to care utilizing the expertise of medical, nutrition, and mental health professionals is strongly recommended.

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Patient Resources The Center for Young Women's Health, Boston Children's Hospital Adolescent/Young Adult Medicine Clinic, PCOS patient booklet: <https://youngwomenshealth.org/wp-content/uploads/2014/10/PCOS-Resources-for-a-Healthier-You.pdf>

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Chapter 22

Type 1 Diabetes Mellitus



Paula Woo and Kendra B. Baldwin

Etiology, Diagnostic Criteria and Prevalence

Type 1 diabetes, once known as juvenile diabetes or insulin dependent diabetes, is a chronic condition in which the pancreas produces little or no insulin. It is characterized by the body's own autoimmune reaction of destroying insulin-producing pancreatic beta cells resulting in the loss of endogenous insulin production.

This autoimmune reaction can be determined by the presence of antibodies against proteins in the islets of the pancreas which may include islet cell autoantibodies, autoantibodies to insulin, autoantibodies to Glutamic Acid Decarboxylase (GAD65), autoantibodies to the tyrosine phosphatases IA-2 and IA-2 β ; and, autoantibodies to zinc transporter 8 (ZnT8). Type 1 diabetes is defined by the presence of one or more of these autoimmune markers.

Once insulin production falls, symptoms of hyperglycemia and ketosis appear. Rapid weight loss, hyperphagia (frequent eating/increased appetite), polyuria (frequent urination),

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nocturia (urination at night), polydipsia (excessive thirst); and, occasionally diabetic ketoacidosis (DKA) appear. At the point of medical care, blood glucose investigation in the following range confirms high blood glucose (hyperglycemia) and determines the need for insulin initiation:

- A1C >6.5%
- Fasting blood glucose >126 mg/dl
- Random plasma glucose \geq 200 mg/dl with hyperglycemia symptoms or crisis

Although Type 1 Diabetes (T1D) can develop at any age, it is typically diagnosed in children and adolescents. T1D accounts for roughly 5–10% of all diabetes diagnoses; and as of 2014, it is estimated that 21–42 million people have T1D worldwide [1]. The estimated prevalence of T1D in the United States for youth under 19 years of age is between 1.5 and 2 per 1000 [2]. Although much effort has been made to assess the incidence and prevalence of T1D, the exact etiology and pathophysiology of the condition is still unknown. As it stands, T1D remains primarily an autoimmune disorder with a strong genetic component. However, it is also postulated that environmental factors could have triggered the autoimmune response causing the destruction of pancreatic beta cells; and, leading to the absolute dependence on exogenous insulin treatment [1].

Standards of Care

Once a person is diagnosed with T1D, they must receive insulin to survive. While there is no cure for T1D, it can be managed with insulin, either via injections or continuous subcutaneous infusion therapy. Blood glucose can be measured using a glucose meter (glucometer) or a device called a Continuous Glucose Monitor. An understanding of blood glucose values throughout the day guide the person with T1D to administer insulin according to these values compared to

age-appropriate targets or, tailored to the amount of food or activity they planned. Table 22.1 details the blood glucose goals in children and adolescents. Food is one of the pillars of diabetes management as its relationship to hyperglycemia and low blood glucose (hypoglycemia) can be seen and felt through blood glucose tracking and in relationship to insulin doses.

American Diabetes Association Recommendations on maintaining optimal glycemic control

1. The majority of children and adolescents with type 1 diabetes should be treated with intensive insulin regimens either via multiple daily injections or continuous subcutaneous insulin infusion
 2. All children and adolescents with type 1 diabetes should self-monitor glucose levels multiple times daily (up to six to ten times per day), including pre-meal, pre-bedtime, and as needed for safety in specific situations such as exercise, driving, or the presence of symptoms of hypoglycemia.
 3. Continuous glucose monitoring should be considered in all children and adolescents with T1D, whether using injections or continuous subcutaneous insulin infusion, as an additional tool to help improve glucose control.
 4. An A1C target of <7.5% should be considered in children and adolescents with T1D but should be individualized based on needs and situation of the patient and family.
-

American Diabetes Association 2019 [3]

TABLE 22.1 Blood glucose goals for children and adolescents

Blood glucose goal			
Before meal	Bedtime/overnight	A1C	Rationale
90–130 mg/dl	90–150 mg/dl	<7.5%	A lower goal of <7% is reasonable if it can be achieved without excessive hypoglycemia

Hypoglycemia defined as <70 mg/dl

American Diabetes Association 2019 [3]

Being diagnosed with diabetes is life changing. In an adolescent who needs to manage T1D, the situation becomes even more delicate as the adolescent developmental period in itself is a time of dramatic change. It is also considered a nutritionally vulnerable period of life. Not only does the increased velocity of growth alter physical body shape quickly, it is also accompanied by hormonal, cognitive and emotional changes. In the context of T1D, this presents multiple challenges. At a physiological level, hormonal and growth changes require ongoing insulin adjustment as puberty increases insulin resistance. Adjusting insulin doses to better meet changing needs requires an individual's engagement with diabetes, including frequent blood glucose monitoring, accurate carbohydrate counting, appropriate administration of insulin and a variety of other self-care behaviors. During adolescence and emerging adulthood, diabetes care tasks transition from primarily the parent or caregivers to primarily the young adult. What this often results in is shifting parental and child roles and responsibilities in caring for diabetes while diabetes is becoming more challenging to manage due to changes in underlying physiology. Thorough understanding of developmental stages, physiological differences in puberty and family dynamics is crucial in developing and implementing an optimal diabetes treatment plan [3]. A multidisciplinary team trained in these areas of pediatric diabetes management is essential.

A pediatric multidisciplinary team often includes:

- Social workers
- Pediatric endocrinologists or advanced nurse practitioners
- Pediatric dietitians
- Psychologists
- Medical assistants
- Nurses
- Research assistants

Diabetes self-management education, medical nutrition therapy and psychosocial support are recommended at diag-

nosis and regularly thereafter. The International Society for Pediatric and Adolescent Diabetes (ISPAD) recommends that the youth with T1D and family should maintain follow-up visits with a multidisciplinary team every 3 months and at minimum, be evaluated once per year [4].

Nutrition Concerns Encountered in the Youth with T1D

Medical nutrition therapy needs to be individualized based on family and individual habits, preferences, religious and cultural needs, daily routines, physical activity, literacy (language and numerical); as well as prior health knowledge, degree of self-care efficacy and abilities. Monitoring carbohydrate intake by carbohydrate estimation is important in achieving optimal in-range blood glucose. Nutrition education and counseling is therefore, recommended at diagnosis and at follow-up assessments. A registered dietitian skilled in pediatric diabetes is recommended to assess caloric and nutritional intake in relation to growth, glycemic control and cardiovascular disease risk factors and to counsel and educate about macronutrient choices for best health.

Shared Management Around Food

A health program that acknowledges the fine balance between the ability and desire of independent self-care in the youth and adult supervision is essential. This acknowledgement is as important as individualized care that is built on the educational, nutritional, behavioral and emotional needs of the growing youth and family [4]. At diagnosis, it is optimal that all family members involved with food preparation and determining insulin doses receive complete education on carbohydrate counting or other method of determining insulin for food. Parents, often primarily involved in food prepa-

ration, are the focus of education to ensure that they can appropriately determine and administer medication for their child's intake. As adolescence progresses, young people are more independent, seeking out more time with peers. For the young person with T1D, this requires the ability to independently determine carbohydrates for food and insulin dosing, regardless of type of insulin therapy.

Eating Patterns, Macronutrient Distribution and Meal Planning

Since carbohydrates relate to immediate response in blood glucose and are part of insulin dosage calculation for the patient, it is the key macronutrient upon which many adolescents and their families require counseling and education. Recent marketing and popularity of “ketogenic” or “low-carb” diets also create confusion about the appropriateness of carbohydrate intake for optimal health. There is no consistent evidence of the ideal percentage of calories from carbohydrates, protein and fat for everyone with diabetes. Macronutrient distribution should be based on individual needs, metabolic goals, growth, and preferred eating patterns as well as food choices of culture, religion and health beliefs. Recommended carbohydrate intake can be inferred from a number of national and international guidelines. The Recommended Dietary Allowance (RDA) is set at a carbohydrate intake of no less than 130 grams per day for children and adults [5]. The 2010 Dietary Guidelines for Americans support a carbohydrate intake at 45–65% of total calories, while the ISPAD guidelines offers the most detailed description of macronutrient distribution [6, 7]. Table 22.2 summarizes carbohydrate recommendation from different diabetes guidelines around the world.

In research, a variety of eating patterns have shown positive data on improving glucose and lipid profiles for persons with diabetes. Examples include: The Mediterranean Diet [11, 12]; Dietary Approaches to Stop Hypertension (DASH)

TABLE 22.2 A summary of national and international diabetes guidelines

	Canada		
	ADA (2014)	ISPAD (2009)	Australia (2011)
Overview	Total amount of carbs has most impact on blood glucose	Optimal macro-nutrient distribution varies	Match insulin to carbs on meal by meal basis to improve glycemic control
Food quality	Vegetables, fruits, whole grains, legumes & dairy products over intake from other carbohydrate sources, especially those that contain added fats, sugars, or sodium	Consuming a variety of foods from the 4 food groups	Match insulin to carbs on meal by meal basis to improve glycemic control
			More vegetables, fruits, whole grains, pulses, seafood, nuts & less red meat, processed meat, sugar-sweetened drinks, sugar-sweetened foods, & refined grains

(continued)

TABLE 22.2 (continued)

	Canada			UK
	ADA (2014)	ISPAD (2009)	Canada (2013)	Australia (2011)
Carb amount/ percentage	Majority T1D and T2D eat ~45% total calories as carbs	Carbs at approximate 50–55% of energy, fat <35% of energy (saturated fat <10%), and protein 15–20% of energy (C)	No less than 45% to prevent high intakes of fat, as this is associated with reduced risk of chronic disease	45–65% of energy intake
				Carbs at approximate 50–55% of energy, fat <35% of energy (saturated fat <10%), and protein 15–20% of energy (C)

References: [3, 7–10]

[13]; and, vegetarian diets [14–16]. However, a personalized meal plan that aligns with the adolescent’s health status, growth needs, food preferences, and that also coordinates with his/her insulin treatment plan, school and physical activity schedule is most essential. For the youth on insulin, consistency in carbohydrate intake and structured spacing of food/beverages (at meals and snacks) may offer the best glucose and metabolic balance [7, 17].

Beverages

Beverages

Food is often the primary concern, so beverages or drinks may be neglected as part of a macronutrient assessment; and, in type 1 diabetes, effects of these beverages on glycemic balance may be missed. Carbohydrates, calories, alcohol and caffeine content in drinks can have immediate or delayed effects on blood glucose. According to NHANES data from 2011 to 2014, almost two-thirds of youth consume at least one sugar-sweetened beverage per day [18]. Sugar-sweetened beverages include 100% fruit juice; coffee and teas (with added sugars such as sugar, honey, condensed milk); alcohol; and, flavored milks. Sugar-sweetened beverages contain both extra calories and carbohydrates, often without quality nutrients for growth. One 12-ounce of soda contains about 150 calories and 40 g carbohydrates as sugar (equivalent to 9–10 teaspoons of sugar). In the short-term, ingestion of sucrose in a liquid beverage (high glycemic index and load) raises blood glucose much faster compared to a low glycemic index food. This leads to immediate post-prandial hyperglycemia. When the habit of sweetened beverage consumption becomes daily, extra calories may lead to overweight and obesity increasing risks for insulin resistance. Table 22.3 shows the recommended added sugars per day for various age groups. There are many popular beverages with added sugars and their carbohydrate contents are estimated in Table 22.4. For example: the sugar content in one 12-ounce soda already meets or

TABLE 22.3 Recommended amounts of concentrated sweets per day in various age groups

Age	Sedentary	Moderate	Active
3–8 year old	25–35 gm/ day	35–40 gm/ day	40–50 gm/day
0–13 year female	35–40 gm/ day	40–50 gm/ day	45–55 gm/day
0–13 year male	40–50 gm/ day	45–55 gm/ day	50–65 gm/day
14–18 year female	45 gm/day	50 gm/day	60 gm/day
14–18 year male	50–60 gm/ day	60–70 gm/ day	70–80 gm/day

Reference: ADA Guidelines [3], 2010 Dietary Guidelines [6], ISPAD Guidelines [7]

exceeds these limits/recommended intakes. It is no wonder that the 2015–2020 Dietary Guidelines for Americans recommend reducing added sugar consumption to less than 10% of calories per day and, specifically, to choose beverages with no added sugars [8].

Caffeine

Conventional plain coffee and tea can generally be thought of as offering few calories and carbohydrates. However, flavored coffees, sweet blended coffees, and tea drinks with added tapioca pearls have become the mainstream at beverage chains across the globe. In addition, the emergence of energy drinks containing added caffeine offer another way of consuming the stimulant. The counseling about these beverages with youth is similar to counseling around using sweetened beverages. Sweetened cream, sugar, flavored syrups, tapioca, jelly, agar added to coffees and teas add varying amounts of carbohydrates that can be difficult to quantify. Generally, these contribute excessive carbohydrates to an individual's diet and may raise blood glucose

TABLE 22.4 Beverages with added sugars (estimated amounts of carbohydrates from added sugars extrapolated after accounting for carbohydrates from milk/milk alternatives and starches)

Type of beverages 12oz.	Total carbohydrates	Estimated amount of carbohydrates from added sugars (corn or other syrups, sugar, cane sugar, honey, agave)	Estimated equivalent amount of granulated sugar (extrapolated from added sugars for visual comparison)
Black tea with milk, sweetened	45–52 g	28–35 g	5–7 teaspoons
Milk tea sweetened with tapioca pearls	60–90 g	30 g	6 teaspoons
Flavored tea lattes	33 g	17 g	3 teaspoons
Mocha	45 g	30 g	6 teaspoons
Frappaccinos TM	37–45 g	20–30 g	5–6 teaspoons
Flavored coffee lattes	27 g	12 g	2 teaspoons
Flavored milk: Chocolate milk Vanilla milk Strawberry milk	34–39 g	15–20	3–4 teaspoons
Sodas (Coke TM , Pepsi TM , Dr. Pepper TM)	37–42 g	37–42 g	7–8 teaspoons

(continued)

TABLE 22.4 (continued)

Type of beverages 12oz.	Total carbohydrates	Estimated amount of carbohydrates from added sugars (corn or other syrups, sugar, cane sugar, honey, agave)	Estimated equivalent amount of granulated sugar (extrapolated from added sugars for visual comparison)
Soda (Mountain Dew TM)	45 g	45 g	9 teaspoons
Iced teas, sweetened Lipton Brisk TM Arizona Teas TM	21–37 g	21–37 g	4–7 teaspoons
Lemonade, sweetened Minute Maid TM Simply Lemonade TM Tropicana TM	42–45 g	42–45 g	8–9 teaspoons
Slurpees TM	22–25 g	22–25 g	5 teaspoons
Energy drinks:			
Red bull	30 g	30 g	6–9 teaspoons
Monster	40 g	40 g	
Rockstar	46 g	46 g	
Full throttle	43 g	43 g	

Reference: Total Carbohydrates from www.calorieking.com

quickly and unnecessarily. Other research has also shown that coffee intake (plain with no carbohydrates) can increase blood glucose in the short term for someone with Type 1 diabetes [19].

As many of the above sweetened-beverages contain large amounts of added sugars, frequent consumption of these beverages by the adolescent could contribute to excessive concentrated sugar intake. Raising awareness that these drinks increase blood glucose and helping youth plan and modify their drinks or insulin doses help improve their blood glucose. At the same time, education about a variety of low carbohydrate alternatives may also reduce their distress during social events where these beverages are often consumed.

Drinks with less than 5 g carbohydrates per serving:

- Water
- Plain herbal tea
- Sparkling water
- Flavor-infused water made at home by adding slices of fruit to plain water or carbonated water: cucumber, mint, 1–2 sliced strawberries, lime or lemon wedge, orange slice
- Replacing sugar with non-nutritive sweetener
- Low calorie or no carbohydrate drink mixes or concentrates in moderation (diet lemonade, iced teas, fruit punch)
- Order coffee with ‘no whip’ and sugar-free syrups
- Order ‘plain tea with no pearls’ for bubble tea orders
- Order ‘less or no sugar’ for tea drinks when diet or sugar-free options are not available

Alcohol

The liver functions as emergency storage and production of glucose to raise blood glucose in the event of hypoglycemia. However, alcohol blocks the production of glucose in the liver. When the liver’s stores of glucose are depleted, alcohol suppresses the liver in making extra glucose in response to hypoglycemia. Under the influence of alcohol when the person is already least aware of the symptoms of low blood glucose, severe hypoglycemic events (unconsciousness, death) can occur. In short, alcohol increases risks for hypoglycemia for the youth taking insulin. Alcohol can cause hypoglycemia shortly after drinking and for up to 24 hours after drinking.

In a recent Youth Risk Behavior Survey, close to one-third of high school students identify consumption of an alcohol-containing beverage in the past 30 days [20]. Although drinking by persons under the age of 21 is illegal in many states in the United States, people aged 12–20 years consume large quantities of alcoholic drinks (typically 4–5 drinks) at one episode. This is double the amount reported by adults [21]. Alcohol use obviously presents risks to any youth and young adult using insulin and requires proactive anticipatory care. The alcohol guidelines for the young adult with diabetes at a legal drinking age is the same for the general population. It is recommended that women consume no more than one drink per day and for men, no more than two drinks per day [22, 23]. One drink is equal to a 12 oz beer, 5 oz glass of wine or 1 ½ oz distilled spirits (vodka, whiskey, gin, etc.).

The medical team can provide the following safe practical tips to the youth, family or close friends should the youth choose to drink:

- Hypoglycemia symptoms like slurred speech and delayed verbal response may be mistaken for being drunk. Wear a medical alert bracelet indicating that you have diabetes.
- Since the risk of hypoglycemia increases after drinking, do not drink on an empty stomach
- Always have food with carbohydrates before drinking
- Understand how the drinks can affect your blood glucose. When in doubt, reduce/decrease insulin matched to the alcohol drink with carbohydrates
- Choose a diet or calorie-free drink mixers like diet soda, club soda, diet tonic water or water for your mixed alcoholic drink and cocktails
- As with anyone with or without diabetes, do not drive or plan to drive for several hours after you drink alcohol. Arrange for a ride service or trusted friend or adult to get you home.
- Eat a small snack containing carbohydrates before bed if your blood glucose is lower (for example less than 100 mg/dl).
- Check blood glucose before drinking, while drinking, before bed and throughout the night. Designate a friend who can check your blood glucose at night if possible.

Weight Loss and Weight Gain

Significant weight loss is a classic symptom leading to the diagnosis of T1D. This is due to altered or poor nutrient utilization related to the lack of insulin. Following diagnosis and introduction of insulin, the body is better able to utilize food for energy and maintain fluid balance. As a result, weight restoration or weight gain beyond that was previously lost occurs. Depending on the youth's relationship with his or her body and whether weight loss at diagnosis was desired, regaining weight and the associated body shape changes can be emotionally challenging.

In the established patient with T1D, weight and relationship with the body often present challenges. People with diabetes are required to determine how much they are eating prior to actually eating, meaning they may in fact eat inappropriately based on their body's hunger cues but appropriately to match insulin. They also may be required to eat when they are not hungry if they are hypoglycemic in order to appropriately treat their lows. Additionally, in order to be active, many people rely on food as a primary method of maintaining blood glucose, essentially eating before and during most episodes of activity, whether warranted from a sports nutrition perspective or not. Although insulin adjustment may be more physiologically appropriate to maintain blood glucose, it often requires more deliberate planning and skill than eating. Physical activity can also increase insulin sensitivity for up to 48 hours after activity is completed. Therefore, the active person with diabetes may also need to adjust insulin for many hours after activity or have increased hypoglycemia, which would require increased intake to "feed" the insulin. The young T1D population is actually more overweight than their peers without diabetes and has significantly more barriers to achieving a healthy relationship with food, exercise and body [31].

Potential strategies to avoid needing to "feed" insulin as often include: an understanding of exercise physiology and strategies for insulin adjustment before, during and after;

appropriate treatment of hypoglycemia (not over-treating); addressing fears of hypoglycemia and modifying intake around activity to support satiety, needs of activity and blood glucose management.

Disordered Eating and Disturbed Eating Behavior

Management of diabetes was historically characterized by restriction of sugar-containing foods and sweet foods. The food-associated stigma that people with diabetes experience, both Type 1 and Type 2, is harmful and prevalent. With a better understanding of the impact of different foods on blood glucose, more rapid-acting insulins and the potential for adjusting insulin timing and delayed release to better match food, the need for restriction of most foods is lessened [7, 8]. However, this does not necessarily translate into decreased feelings of restriction or, an improved relationship with food [34]. In fact, screening for eating disorders within people with diabetes needs to be adjusted due to the constant focus on food in the life of someone with T1D, such as in mSCOFF. Many people with diabetes may feel restricted or have guilt associated with consumption of perceived high sugar or high carbohydrate foods. They may also have a level of insulin that they perceive to be “too much”; even if it appropriately matches a food.

There is a move, overall, in society to low-carb diets and carbohydrate restriction. Within the community with T1D, this takes on many forms. One is restriction of carbohydrates to maintain euglycemia and decrease needed insulin. Many parents have the perception that diet can be controlled in order to control blood glucose. As previously discussed, there are many factors that impact blood glucose, most of which are beyond the individual’s control. In children, this restriction of carbohydrates has been associated in case studies with impaired growth and negative relationship with food [34]. For families who are restricting carbohydrates, ensuring that adequate insulin administration for proteins and fats as well as ensuring a selection of high fiber and antioxidant-rich

lower carbohydrate choices is important. Euglycemia may be more difficult to achieve during puberty as hormonal growth during this period is associated with increased insulin resistance. In adolescence and young adulthood, where linear growth is completed, carbohydrate restriction may be helpful in maintaining euglycemia without the risk of stunting height [34, 35].

The relationship that a person with diabetes has with food in order to manage diabetes can look like disordered eating due to the tasks involved with diabetes management. Rigid rules around food and activity for the purpose of determining appropriate insulin doses, making sure that blood glucoses are not overcorrected or maintaining euglycemia during activity all are necessary for appropriate diabetes management. However, similar habits exhibited in a person without diabetes would be considered disordered eating behaviors. The use of exercise to make up for foods may even be a strategy some use to maintain blood glucose after larger meals. Even in treatment of hypoglycemia, where disinhibited eating and overeating occur regularly, some characterize as feeling a loss of control around eating [35]. Although many professional organizations outline the nutrition goals of T1D management as “restriction of food only when medically necessary,” it is challenging to distinguish disordered eating behaviors from appropriate diabetes management strategies.

Celiac Disease

T1D is often associated with other autoimmune diseases. The occurrence of Celiac Disease (CD), an immune-mediated disorder, increases in patients with type 1 diabetes. The prevalence of CD range from 1.6% to 16.4% in individuals with T1D compared with 0.3–1% in the general population. Due to this higher occurrence, there are guidelines from the American Diabetes Association on screening all individuals with T1D soon after diagnosis and repeatedly throughout the lifespan even in the absence of CD symptoms. [24]

Once diagnosed with CD, it is essential to follow a strict gluten-free diet to avoid small bowel damage and other health risks such as vitamin and mineral deficiencies, multiple food intolerances, early onset osteoporosis/osteopenia and gastrointestinal malignancies. Despite these serious health complications, the adherence to a gluten free diet by children with CD with T1D has been generally lower than other patients with CD. The most frequent problems with adherence to the gluten-free diet occur during adolescence [25].

Recommendations by the American Diabetes Association on T1D and celiac disease:

Screen individuals with type 1 diabetes for celiac disease soon after the diagnosis of diabetes by measuring IgA tissue transglutaminase antibodies, with documentation of normal total serum IgA levels or, if IgA deficient, IgG tissue transglutamine and deamidated gliadin antibodies.

Repeat screening within 2 years of diabetes diagnosis and then again after 5 years and consider more frequent screening in children who have symptoms or a first-degree relative with celiac disease.

Individuals with biopsy-confirmed celiac disease should be placed on a gluten-free diet and have a consultation with a dietitian experienced in managing both diabetes and celiac disease [12]

Reference: American Diabetes Association 2019 [3]

Poorly managed celiac disease in T1D may lead to hyper and hypoglycemia [26]. A clinician experienced in T1D and CD can share their observation of blood glucose and food choices while providing educational support to improve the acceptance of gluten-free choices at home and when eating out.

Skills the dietitian can work on with the adolescent and family are:

- Label reading ingredients
- Prepare them that gluten-free diet may change blood glucose patterns
- Help find high fiber and lower glycemic gluten-free grains

- Ensure adequacy of key growing nutrients such as iron, vitamin D, B12 and calcium even when intolerances of some food groups are encountered
- Plan gluten-free acceptable choices or food to bring to social events when gluten-free options are scarce or unavailable
- Plan gluten-free snacks that are easy to bring and eat on-the-go
- Educate about gluten-free choices to treat or prevent hypoglycemia

Dyslipidemia

It is well established that diabetes is associated with increased risk for premature cardiovascular disease. Dyslipidemia is common in children with T1D and it is often related to glyce-mic control [27]. Hyperglycemia can be related to: inadequate insulin dosing from underestimation of carbohydrates eaten; eating without insulin; delayed insulin adjustments; and over-treating hypoglycemia symptoms. These key concerns occurring during adolescence put individuals at an increased risk for developing dyslipidemia. A recent position statement from the ADA recommends lipid profile screening at the time of diagnosis at age 10 years and above; and, suggests lipid profiles be repeated every 1–5 years. LDL cholesterol values of less than 100 mg/dl (2.6 mmol/L) are considered acceptable. ADA and the American Heart Association recommend both lifestyle and pharmacological treatment for youth with T1D and elevated LDL cholesterol levels [28].

They recommend lifestyle measures as the first line of treatment for those with mildly elevated LDL cholesterol levels. If LDL continues to be greater than 160 mg/dl, the use of statins in such adolescents should be strongly considered.

Initial lifestyle therapy for dyslipidemia in children and adolescence [29]:

- Step 2 American Heart Association diet which restricts saturated fat to 7% of total calories and restricts dietary cholesterol to 200 mg/day

- Reduce food and beverages with added sugars
- Eat a variety of fish at least twice a week, especially fish containing omega-3 fatty acids (for example, salmon, trout and herring).
- Physical Activity: 150 minutes of moderate to intense activity per week
- Maintain at a reasonable weight for height. Prevent overweight and obesity.
- Adequate fiber for age from high fiber grains, vegetables and fruits
- Use predominantly mono and polyunsaturated fats while reducing partially hydrogenated fats and eliminate trans fats
- Use of low fat dairy products and lean meats to reduce saturate fats

Exercise

One of the more challenging aspects of diabetes management is maintaining in-range blood glucose during activity. During activity, the muscles are able to move glucose into the cell independently from insulin via GLUT4 movement to the cell surface. This allows muscles to get adequate fuel during activity. For the athlete with diabetes, this may cause some challenges. This GLUT4 movement is occurring regardless of whether the individual gave insulin for the food or not. This can have a compounding impact on blood glucose and often results in hypoglycemia during or after activity. In order to prevent hypoglycemia, many add in additional carbohydrate containing food sources. Another, often more challenging strategy, is to appropriately reduce insulin, preserving glucose for muscle use. This must be done carefully. Reducing insulin excessively will result in hyperglycemia, which can impact mental concentration and hydration as well as performance while inadequate reduction will result in hypoglycemia. Refueling guidelines should be contextualized in recommen-

dations for an athlete without diabetes and not rely too heavily on food to maintain blood glucose. Use of food alone to maintain blood glucose, although often more straightforward, can cause gastrointestinal upset, “feed the athlete’s insulin” and not necessarily their hunger cues. Some scenarios will benefit more from insulin dose adjustment and/or addition of food to maintain euglycemia, often depending on duration, intensity and frequency of activity. Many athletes have a preferred blood glucose at which they begin activity to prevent rapid blood glucose rises during activity. This may take time to develop, but for most, this is somewhere between 120 and 200 mg/dl. However, this range also depends on several factors: the type of activity; whether the activity occurs while the athlete is fasting or not; duration of activity; and options for refueling during the activity. Blood glucose levels above 200 mg/dl are associated with increased water loss via osmotic diuresis as well as changes in electrolyte concentration. Many athletes may choose to maintain lower blood glucose to avoid this [32]. Individuals may have elevations in blood glucose during high intensity activity, resistance training and during higher stress events, such as race or game day or performance sports. They may require a bolus of insulin prior to, during or immediately after to address gluconeogenesis that results in elevations of blood glucose [32].

Pharmacotherapy and Diabetes Technology

Many factors beyond food can contribute to hyperglycemia. These may include beverages, adrenaline (due to stress, physical activities, upset wake and sleep schedules), growth hormones, mental stress and inadequate insulin doses. Ironically, causes of hypoglycemia can be similar and may include stress, physical activities, disturbed wake and sleep patterns, mental stress and excessive insulin injections. The goal of pharmacotherapy in T1D is to match timing and action of exogenous insulin to mimic what would otherwise be secreted endoge-

nously by the pancreas to maintain euglycemia most of the time. The pancreas secretes insulin continuously, titrated to unexpected blood glucose rises as well as in biphasic patterns in response to macronutrient absorption.

Development of new technology strives to improve in these areas of treatment specifically in varied insulin types, continuous glucose monitoring and continuous insulin delivery methods. These advances will continue to evolve to provide the youth with options that will fit their lifestyles and unique circumstance. Ways to accurately and spontaneously measure blood glucose with the least interruptions to daily activities will also be needed for the next generation of insulin delivery and management.

Insulin Types

To date, there are four types of insulin: rapid-acting, short-acting, intermediate-acting and long-acting. They are mainly characterized by their activity times as outlined in Table 22.5.

TABLE 22.5 Insulin types and characteristics

Type	Insulin name	Onset	Peaking times	Activity duration
Rapid acting insulin	Insulin lispro, aspart, Apidra	5–15 minutes	1.5–2.5 hours	3–5 hours
Short acting insulin	Insulin R	~1 hour	2–3.5 hours	5–7 hours
Intermediate acting insulin	Insulin NPH	~1–2 hours	4–9 hours	14–20 hours
Long acting insulin	Insulin glargine, detemir, degludec	~1–4 hours	6–10 hours	18–26 hours

Reference: Donner and Sarkar [33]

Insulin Delivery Methods

Insulins which were originally designed to be given via syringes and needles can now be loaded as insulin cartridges into an insulin pen. An injection can be given by dialing to the desired dose on the insulin pen making on-demand injections more convenient and less intrusive to daily living. In the past 10 years, insulin pumps have also been developed and refined further. Insulin pumps are small mechanical devices containing insulin reservoirs that will infuse insulin via a filament tube, placed subcutaneously, every few minutes and as needed with the touch of a few buttons by the pump user. An overview of the various insulin delivery methods is shown in Table 22.6.

TABLE 22.6 Overview of insulin delivery methods

Delivery method	Examples
Multiple daily injections	Basal insulin (intermediate or long acting insulin) paired with bolus insulin (short or rapid acting insulin)
Insulin pump – conventional Or insulin pump – conventional tubeless	Insulin lispro or aspart delivered in small doses every hour as basal insulin, bolus meal insulin or insulin to correct high blood glucoses delivered on demand by the user as needed
Insulin pump paired with continuous glucose monitor (CGM) Suspend before low Predictive low glucose suspend Closed loop systems	Insulin lispro or aspart delivered in small doses to manage basal insulin administration-based on an algorithm that will adjust to actual blood glucose data from CGM. Meal insulin or insulin to correct high blood glucoses needs to be delivered by user. Pump can be set to suspend insulin infusion when blood glucoses per CGM are dropping to a set threshold. Closed loop system will adjust basal rate based on blood glucose patterns using an internal algorithm (also called smart pumps) but requires adherence to CGM

Continuous Glucose Monitoring and Sensor Augmented Pump Therapy

Real time continuous glucose monitoring (CGM) can be useful for improving A1C, reducing blood glucose variability and improving blood glucose time “in target.” It can also be used effectively for reducing the severity and shortening the duration of time spent in hypoglycemia for the youth with T1D. CGMs can now be paired with phones and apps to provide convenient real time reading and blood glucose tracking for the user. Meanwhile, phone and smart device applications that help form relational trends between blood glucose, insulin doses delivery patterns, diet and activity patterns continue to be developed.

Sensor augmented pump (SAP) therapy has shown to improve A1C in children and adolescents as compared to multiple daily injections with self-monitoring of blood glucose. The “suspend before low” and “predictive low glucose suspend” features of SAP has shown to reduce severity and duration of hypoglycemia without negatively impacting A1C control. This further provides security and safety for the adolescent in the setting of independent living. As of latest, automatic insulin delivery or closed loop systems offers yet another option. This system automate insulin decisions based on CGM data and adjust basal rates while it learns the user’s blood glucose patterns over weeks and months. The closed loop system has been shown to increase time in target, minimizing time spent in both hyperglycemia and hypoglycemia. It is particularly beneficial to attaining blood glucose goals during sleep. [30]

Transition from Pediatric to Adult Care

The act of moving from pediatric to adult care comes with many challenges. The changes in physiology during adolescence, as previously outlined, are now overlapping with a natural transition into emerging adulthood, where patients are assuming responsibility for their diabetes care as well as moving out of their parent homes, attending college or join-

ing the workforce. This period of time is also characterized by increases in A1c, increased occurrence of acute complications and emergence of complications that may go undetected or untreated. Changes or gaps in insurance may also impact access to care. Fundamental differences between pediatric and adult care, whether it be ability to order supplies, make appointments, the focus of the appointment being the individual and not the family, length of appointment and the competing attentions of emerging adult life all can result in loss to follow-up [36]. Teens and emerging adults require assistance with transition to prevent loss to follow up. This may occur through a transition program that can help to support young people as they enter into adult care. Such programs offers similar care team structure that is experienced by the youth in pediatric care (endocrine provider, dietitians, social workers, nurse) and is often situated close to previous pediatric clinic location. A transition coordinator will also assist the adolescent by helping them gain skills for independence (e.g., organizing appointment times; reminding them to bring blood glucose logs, glucometers and insulin pump data download documents to appointments, etc.) prior to initiating transition [36]. Some of the recommendations for transition include working collaboratively with patients and families to begin transition conversations prior to transitioning; reviewing diabetes self-management education concepts with the teen; and ensuring they can handle logistics of diabetes care. Additionally, it is essential to acknowledge the vulnerability of teen and as well as differences between pediatric and adult care settings, and ensure that the emerging adult is referred to a provider that matches their needs [36].

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Chapter 23

Type II Diabetes Mellitus



Grace Kim, Tran Hang, and Allison LaRoche

Epidemiology of Youth Onset Type 2 Diabetes

From the results of the SEARCH for Diabetes in Youth study, a multi-center epidemiologic study in the United States, the prevalence of youth with type 2 diabetes was estimated to be 0.24 per 1000 [1], and about 20,000 youth have a diagnosis of type 2 diabetes in the US [1]. Between 2001 and 2009, there was an estimated 30% increase in type 2 diabetes among youth in the US [2]. The incidence of youth-onset type 2 diabetes in the US has also been increasing significantly, particularly among ethnic and racial minorities [3]. According to a National Health and Nutrition Examination Survey

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(NHANES), type 2 diabetes accounts for almost one-half of adolescent diabetes. They estimate that one-third of adolescents with type 2 diabetes are undiagnosed [4].

Pathogenesis of Type 2 Diabetes

Obesity is the leading risk factor for the development of type 2 diabetes (T2D) [5–7]. Prediabetes can develop into T2D when the pancreatic β -cell is unable to compensate to the insulin resistance state [8–11]. β -cell insulin secretion can be influenced by genetic and environmental factors [12]. The distribution of fat partitioning is important in the development of insulin resistance [12]. Studies have shown that adolescents with prediabetes were more insulin resistant than obese adolescents with normal glucose tolerance but had the same degree of adiposity [12]. These adolescents with prediabetes were noted to have increased skeletal muscle insulin resistance, increased visceral fat, and decreased subcutaneous fat deposition [12]. The presence of fatty liver is also an important marker of insulin resistance and is a risk factor for T2D [13]. The progression from prediabetes to T2D in adults is a gradual process that occurs over 5–10 years [14]. T2D in youth has been associated with an accelerated course compared to adults [15].

Clinical Presentation

The clinical presentation of type 2 diabetes mellitus can be indolent, as about one-third of youth with type 2 diabetes present without symptoms [16]. Asymptomatic patients are generally identified from screening of random or fasting plasma glucose, glycosylated hemoglobin, or identification of glucosuria on urinalysis.

The remaining two-thirds of youth with type 2 diabetes mellitus present with hallmark symptoms of hyperglycemia,

including polyuria, polydipsia, polyphagia and weight loss [16]. Up to one-third of youth with type 2 diabetes have ketonuria at the time of diagnosis [17]. This emphasizes the importance of maintaining an index of suspicion for type 1 diabetes, even if the patient has a classic phenotype of type 2 diabetes. Female youth can present with infectious symptoms such as vulvovaginitis as the first sign of type 2 diabetes [18].

Between 10% and 25% of youth with a new diagnosis of type 2 diabetes present with diabetic ketoacidosis (DKA), defined by hyperglycemia (blood glucose > 200 mg/dL), ketosis or ketonuria, and acidosis (bicarbonate level < 15 mmol/L, blood pH < 7.3) [19]. Youth with type 2 diabetes can also present with hyperglycemic hyperosmolar syndrome (HHS) as characterized by profound hyperglycemia, hyperosmolality, severe dehydration, impaired neurological status, and minimal ketosis [20]. In both states of DKA and HHS, prompt identification and medical intervention is necessary to reduce morbidity and mortality. (See section “[Comorbidities](#)”)

Physical Examination

When examining youth, it is very important to look for signs of insulin resistance that may warrant further laboratory evaluation for evidence of type 2 diabetes. Acanthosis nigricans, is typically a benign finding, and is a hallmark feature of an insulin resistant state. It is seen in an estimated 85–95% of children with type 2 diabetes [20, 21]. Acanthosis nigricans is a leathery skin change that is characterized by hyperpigmentation and hyperkeratosis [22]. It occurs primarily on intertriginous areas of the body, including the nape of neck, axillary folds, inguinal region and flexor surfaces [21]. In a hyperinsulinemic state there activation of an insulin-like growth factor receptor, and subsequent dermal fibroblast and epidermal keratinocyte proliferation, which result in this physical exam finding [23].

Body mass index is a surrogate marker for adiposity, and obesity is closely linked to type 2 diabetes in children. More than 85% of affected children with type 2 diabetes are overweight or obese [24]. The distribution of body fat is also important, as visceral adiposity is correlated closely to insulin secretion and insulin resistance [25]. Measuring waist-to-hip and/or waist-to-height ratios helps to estimate visceral adiposity [26, 27]. Due to lack of reproducible measurements, the waist-to-height circumference ratio is not a widely implemented clinical measurement.

Non-modifiable Risk Factors

Age

According to the SEARCH for Diabetes in Youth study, type 2 diabetes is a rare phenomenon in children less than 10 years [28]. The median age of diagnosis of type 2 diabetes in youth is 13.5 years, which overlaps with the timing of puberty in adolescents [20, 29, 30]. During puberty, there is a decrease in insulin sensitivity by about one-third [16], which is potentiated when there are already metabolic changes from obesity [31]. The accelerator hypothesis helps explain why there is an increase in insulin resistance secondary to growth hormone and sex steroids development during puberty [32]. Since puberty starts later in males than in females, the median age of type 2 diabetes onset is estimated to be one year later in boys [28].

Gender

The Treatment Options for Type 2 Diabetes in Adolescents and Youth (TODAY) study [20] and the SEARCH for Diabetes in Youth study describe an observed higher prevalence of type 2 diabetes among adolescent females [2]. Females comprise upwards of two-thirds of youth with type 2 diabetes, but this female predominance is not observed in adults.

Race and Ethnicity

Type 2 diabetes is overrepresented among racial and ethnic minority groups in the United States, where the highest incidence of youth onset type 2 diabetes is among Native Americans, followed by Non-Hispanic blacks and Hispanics; Non-Hispanic whites have the lowest incidence of youth onset type 2 diabetes [3]. The prevalence of type 2 diabetes is also highest among racial and ethnic minority youth [2]. Youth-onset type 2 diabetes occurs in all ethnic groups, and an estimated 15% of all youth onset diabetes cases among non-Hispanic whites are classified as type 2 diabetes [28]. Please review the chapter on equity, which highlights systemic level disparities in society and how such disparities can impact health.

Family History

Approximately 75–85% of youth with type 2 diabetes have a first- or second-degree relative with type 2 diabetes [20]. In addition to family history of type 2 diabetes, it is important to assess if the youth is a product of a pregnancy complicated by gestational diabetes mellitus (GDM), as a hyperglycemic milieu during pregnancy can increase future risk of development of type 2 diabetes [33, 34].

Modifiable Risk Factors

The primary modifiable risk factor for the development of type 2 diabetes is obesity. Tipping the energy balance such that there is decreased energy expenditure, increased energy intake or both can increase the state of insulin resistance and potentiate type 2 diabetes. According to the SEARCH for Diabetes in Youth study, most youth (79.4%) with type 2 diabetes were obese [35]. Increasing insulin resistance during the inherently insulin resistant state of puberty in some individuals can portend derangements in glucose metabolism.

Thus, excessive caloric intake and low physical activity are lifestyle behaviors that place youth at risk for obesity and subsequently type 2 diabetes.

Other potential modifiable risk factors include emotional health, which can be intricately linked to physical health. Specifically, stress and depressed mood have been shown to be associated with risk for type 2 diabetes in obese youth [36]. Additionally, even though sleep disorders can be a comorbidity of obesity, it can also be a contributor, and is considered a risk factor [37, 38].

Comorbidities

Comorbidities associated with type 2 diabetes in children and adolescents include hypertension, dyslipidemia, NAFLD, and PCOS [39]. Often associated with obesity, these conditions may be present before or after diagnosis of T2D [39]. These comorbidities will be further discussed in full chapters.

Condition	Diagnosis	Treatment
Hypertension	BP \geq 95thile	1st line Modification of food intake that may result in weight loss or stabilization Limitation of dietary salt Physical activity Pharmacotherapy ACE inhibitor
Dyslipidemia	HDL < 35 LDL > 100 Triglycerides > 150	Dietary therapy Cholesterol <200 mg/dL Saturated fat <7% of total calories Pharmacotherapy Statins

Condition	Diagnosis	Treatment
NAFLD	Elevated transaminases Fatty liver findings on abdominal ultrasound	Modification of food intake that may result in weight loss or stabilization There are no FDA approved medications
PCOS	Amenorrhea or oligoamenorrhea in addition to hyperandrogenism (hirsutism, severe acne, voice deepening) or hyperandrogenemia (elevated testosterone/ androgen levels)	Metformin Oral contraceptives Spironolactone

Complications Associated with T2D

Diabetic ketoacidosis and hyperosmolar hyperglycemia can occur in patients with T2D and are associated with high morbidity and mortality if not treated adequately [42]. These conditions are different based on degree of dehydration and level of ketosis and acidosis [42]. Hyperosmolar hyperglycemia is associated with more severe dehydration than DKA [42]. Under close monitoring, both conditions need correction of dehydration, hyperglycemia, and electrolytes imbalances [42].

Microvascular Complications

Microvascular complications include retinopathy, nephropathy, and neuropathy (i.e., paresthesia, muscle weakness and autonomic dysfunction). Patients with T2D should regularly be monitored for these complications.

All children and adolescents with T2D require a yearly dilated eye examination by an ophthalmologist or optometrist [40, 43]. Screening can detect retinopathy in the non-proliferative stage. At this point, glycemic control improvement can reverse the non-proliferative changes and prevent progression [43]. Ophthalmologists need to see patients with macular edema, severe non-proliferative diabetic retinopathy, or proliferative retinopathy [40]. Laser photocoagulation therapy is a treatment modality used in patients with high-risk proliferative diabetic retinopathy and some cases of severe non-proliferative diabetic retinopathy [40].

Microalbuminuria is defined as urinary albumin excretion rate of 30–300 mg/g creatinine in a spot collection [40]. At the time of diagnosis, spot urine should be collected because many adolescents with T2D has albuminuria at time of diagnosis [40]. Higher A1c was related to risk of developing microalbuminuria [40]. If albumin is present, a repeat specimen should be collected in the morning [40]. If there is persistent albuminuria, an ACE inhibitor should be initiated [40].

Neuropathy is screened in T2D at puberty through a monofilament examination on the foot to detect loss of sensation [44]. If loss of sensation is found, a neurology referral is made. If the exam is normal, a yearly monofilament exam is performed [44]. In adults, the risk of diabetic neuropathy is increased with poor glycemic control and duration of diabetes [44]. Adult data has shown improved glycemic control can improve nerve function [44].

Macrovascular Complications

Macrovascular complications include coronary artery, peripheral and cerebral vascular disease [45–48]. Poor glycemic control increases risk for macrovascular disease [45–48]. In adults with T2D, clinical trials have shown that glycemic control and hypertension and dyslipidemia treatment can reduce risk of macrovascular disease [49]. Although data in pediatric patients is lacking, similar management principles are applied

to the pediatric population [40]. Adolescents with T2D are observed to have cardiovascular risk factors such as increased left ventricular wall thickness [50], increased arterial stiffness, and premature aging of cardiovascular system [51].

Treatment

The goals of T2D include: to achieve and maintain glycemic control based on hemoglobin A1c (A1c) less than 7% or 6.5% in some cases [40, 43, 52]; to identify and treat comorbidities, and to prevent microvascular and macrovascular complications of T2D [29].

Pharmacologic Agents

Metformin is one of two medications approved by the Food and Drug Administration for treatment of type 2 diabetes in children and adolescents [29]. Metformin is the first-line therapy for a majority of pediatric patients with T2D [29]. It is a biguanide and improves insulin resistance by increasing insulin-mediated glucose uptake in the peripheral tissues and by decreasing hepatic glucose production through decreased gluconeogenesis [20, 29]. Metformin may also promote modest weight loss [20, 29].

Metformin alone is used for patients with A1c <9% and no symptoms. Metformin dosing starts with 500 mg once a day, and then increases by 500 mg at 1-week intervals to a maximal dose of 1000 mg twice a day [29]. The most common side-effects of metformin is gastrointestinal (i.e., abdominal pain, diarrhea and nausea) [29]. Metformin is contraindicated in patients with hepatitis, impaired renal function, cirrhosis, alcoholism or cardiopulmonary insufficiency [29]. It can cause lactic acidosis [29]. Before initiating metformin, baseline ALT, AST, and creatinine should be checked [29].

Insulin therapy is the other medication approved for T2D in children and adolescents with severe hyperglycemia

(A1c > 9%), ketosis, and diabetic ketoacidosis [29]. Insulin is associated with weight gain. Typical total daily insulin doses ranges from 0.75 to 1.25 units/kg/day and as high as 2 units/kg/day. Basal insulin can be dosed between 0.25 and 0.5 units/kg.

Blood glucose self-monitoring (finger sticks) should be done regularly and frequency should be individualized [29]. Typically it is recommended at least four times a day on insulin and twice daily on metformin [29]. Pre-meal blood glucose should range between 90 and 130 mg/dL. Post prandial blood glucose should be <180 mg/dL [53].

Intensification

Data about the need for prompt treatment intensification came from the TODAY study which examined medical treatment in youth with T2D [8]. There were three groups: metformin alone, metformin and intensive lifestyle intervention, and metformin and rosiglitazone (adult medication for diabetes that increases insulin responsiveness and improves insulin secretion by preserving pancreatic beta cell function) [8]. TODAY study showed that most patients had an initial response to metformin, but only about 50 percent had a sustained response [8].

For patients who are initially on metformin monotherapy for four months, insulin therapy is needed for patients who have persistently elevated A1c >7% [41]. The starting dose of long acting insulin (i.e., glargine) at bedtime is 0.25–0.5 units/kg/day [41]. Prandial insulin is added for patients on metformin and basal insulin who fail to obtain A1c <7% [41].

Other Anti-diabetogenic Agents Approved in Adults

There are other classes of anti-diabetic drugs approved for adults and some currently are being investigated for safety and efficacy in adolescents [41]. Thiazolidinediones are PPAR

agonists and increases insulin sensitivity [41]. Incretin mimetic acts to stimulate insulin secretion with consumption of a meal [41]. Dipeptidyl peptidase 4 inhibitors increase insulin production and reduce amount of glucose made by liver [41]. Amylin analogs used to slow gastric emptying and inhibits glucagon secretion [41]. Alpha glucosidase inhibitors slow absorption of carbohydrates [41]. SGLT2 inhibitors block the action of SGLT2 in the kidney and block reabsorption of glucose into the body from urine [41].

Surgery

Weight loss surgery may be an option for adolescents. Working with a multidisciplinary team with experience and expertise in the area is of critical importance to allow safe outcomes. Adolescents and families pursuing weight loss surgery should be aware of short- and long-term benefits as well as risks associated with surgical procedures. Teen-LABS consortium reported three-year outcomes from a multi-center prospective study [54]. Inge et al. reported mean weight had decreased by 27%, remission of diabetes in 76%, remission of hypertension in 74%, and remission of abnormal lipid profile in 66% [54]. However, risks associated with surgery included micronutrient deficiencies and the need for additional intraabdominal procedures [54].

Nutrition Management in Adolescents with Type 2 Diabetes

Type 2 diabetes in adolescents often occurs at the mean age of ~13.5 years old and coincides with the peak of physiologic pubertal insulin resistance [55]. Nutrition management for adolescents with type 2 diabetes is different from that of young children and older adults. There is no such thing as a one-size fits all “diabetic diet” due to hormonal changes, behavioral changes, and changes in nutritional needs that

occur throughout the lifecycle. Medical nutrition therapy (MNT) is the most effective early treatment for children and adolescents with type 2 diabetes. Clinical studies on MNT have reported an improvement in HbA1c of ~1% in type 1 diabetes and 1–2% in type 2 diabetes [56, 57]. Lifestyle interventions should be individualized and focus on normalization of glycemic control, weight maintenance or gradual weight loss, increase in physical activity, and decreasing comorbidities for hypertension, dyslipidemia, nephropathy, and hepatic steatosis [55]. Medical nutrition therapy is often combined with diabetes medication to achieve glucose goals. Medical nutrition therapy is paramount in treatment of diabetes given we know that metformin and insulin are the only medications approved for use in children and adolescents in the United States.

The Feeding Mindset and Feeding Potential of Adolescents

When working with adolescents and their families it is important to gain understanding of the goals and motivations for the youth and adults in the home. Incorporating guidance on meal planning, hunger and satiety cues, as well as the importance of the timing of meals and snacks, should be offered to all involved in feeding the patient. Please review chapter on developmental nutritional needs of adolescents.

Energy Needs for Adolescents

The Recommended dietary allowance (RDA) for the pediatric population is a minimum of 100 grams of carbohydrate per day. The amount of carbohydrate recommended should be based on the individual's energy needs, blood glucose levels, lipid goals, and eating pattern. The recommended percentage of carbohydrate varies from 45% to

65% of total energy. Dietary studies of children with diabetes indicate that children who have a lower carbohydrate intake tend to have a diet higher in saturated fat [58]. Carbohydrate source should come from a variety of food groups such as fruits, vegetables, whole grains, legumes, and low-fat milk to provide adequate source of fiber, vitamins, and minerals. The use of glycemic index and glycemic load has shown to provide a modest benefit when carbohydrate is considered alone. In addition, many variables can influence the effect of carbohydrate containing foods. These variables include type of food consumed, type of starch, how the food is prepared (cooking method and cooking time), ripeness, degree of processing, and the macronutrient distribution of the meal [59].

Medical Nutrition Therapy for Hypertension

The American Diabetes Association defines hypertension in childhood as an average blood pressure of greater than 130/80 mm Hg on at least three separate days. Children with type 2 diabetes have insulin resistance, which in turn results in compensatory hyperinsulinemia. Hyperinsulinemia can cause sodium reabsorption in the kidney, which initiates retention of water along with the salt and increases the volume of blood circulating through the vessels, thus increasing blood pressure. Medical nutrition therapy management focuses on dietary intervention with low-sodium diet guidelines, weight management, and increased physical activity. Adolescents nine years and older should limit their salt intake to 1500 mg/day (3.8 gm of salt per day) [58]. Nutrition counseling should be focused on normalizing eating patterns, decreasing processed foods, learning how to read nutrition labels to look for lower sodium foods that have <140 mg/dL of sodium, and encouraging the entire family to consume more whole foods and use less added salt or use salt substitutes when cooking.

Medical Nutrition Therapy for Dyslipidemia: Pediatric Nutrition Care Manual (PNCM)

Children with diabetes are at high risk for early cardiovascular disease according to the American Heart Association. A fasting lipid profile should be performed soon after diagnosis. If lipids are abnormal, then a lipid profile should be monitored annually. If the low density lipoprotein (LDL) cholesterol value is within normal range, then a lipid profile should be obtained every five years according to the American Diabetes Association.

Lipid goals for children and adolescents with diabetes [44]:

- Fasting total cholesterol: <170 mg/dL
- Fasting LDL cholesterol: <100 mg/dL
- Fasting triglyceride for ages 10–19 years: <130 mg/dL
- Fasting high density lipoprotein (HDL): >45 mg/dL
- Non-HDL cholesterol: <120 mg/dL

When LDL cholesterol is greater than 100 mg/dL, nutrition intervention to decrease total fat, saturated fat, and trans fatty acids should be initiated. Lifestyle modifications that can improve lipid profile include:

- Physical activity: goal of at least 60 minutes per day of movement such as walking, running, dancing, active forms of play, or organized sports
- Meal planning (balanced meal pattern and portion size): minimum of three meals per day and 1–2 snacks per day depending on activity level
- Low sodium: decrease sodium intake by reducing salt intake and limiting high sodium processed foods (480 mg sodium per serving) to no more than once a day
- Vegetables and fruits at every meal: serving fruits and vegetables with every meal with an emphasis on fresh, frozen, or low-sodium canned types
- Whole grains: increased intake of whole grains such as whole wheat, oats, barley, brown rice, and quinoa

- Limit sugar intake: limited sugar-sweetened beverages and foods
- Low fat: decreased intake of saturated fat and trans fats to no more than 7% of energy needs; saturated fats are found in full fat dairy products, fatty meats, and high fat snacks, such as butter, lard, or shortening, and substitute with more monounsaturated fats (10–20% of energy needs) and polyunsaturated fats (10% of energy needs) such as vegetable oils or olive oil; modifying cooking technique to more baking or broiling and removing the skin from poultry or trimming fat from meats or choosing leaner cuts of meats; limit dietary cholesterol to <200 mg/day; minimize intake of trans fat; and encouraging two servings or more of fish per week to increase omega-3 fatty acids.

Sample meal plan:

- Breakfast: 1 cup of oatmeal served with 1–2 slices of turkey bacon and a side of fresh fruit salad and a cup of skim milk.
- Lunch: deli sandwich (2–3 slices of lean deli turkey on whole wheat bread) served with a side of carrots and cucumbers, an apple, and 6 oz low-fat Greek yogurt.
- Dinner: 3 oz skinless chicken breast served with a side of green beans and ~3/4 cup brown rice and a cup of skim milk.

Goal Setting

It is more motivating to make small steps to achieve goals steadily than to make drastic changes that are more difficult to achieve and decrease motivation. S.M.A.R.T. goals (**S**pecific, **M**easureable, **A**ttainable, **R**elevant, and **T**ime-bound) are used in clinical practice and used to set a goal and map what one needs to do. Goals for healthy eating and exercise should be specific, measureable, realistic and achievable. Examples of specific and measureable goals would be to choose three different food groups from the

above list/table at each meal daily or include a serving of vegetables twice a day or take 60-minute walks three times per week. In addition, modifying goals from week to week is helpful for flexibility in the schedule and helpful in advancing goals as the body gets used to healthier lifestyle changes. It is also helpful to focus on healthy lifestyle behavior goals to achieve long-lasting weight management instead of focusing on weight loss as the primary goal. This approach helps adolescents focus on the lifestyle tasks or goals at hand without being bogged down or distressed by daily or weekly fluctuations in weight. Weight management success comes in different forms, such as decreased rate of weight gain, weight stabilization, improved lab values (such as HgA1C) and slow and steady weight loss over a longer period.

Case 1

Jeffrey is 14-year old boy diagnosed with type 2 diabetes six months ago. Jeffrey's medical diagnosis includes obesity, abnormal liver enzymes consistent with non-alcoholic fatty liver disease, and type 2 diabetes mellitus. He lives with his parents and 10-year old sister. He is a freshman in high school. Jeffrey's mother reports that she has tried to help Jeffrey lose weight with various dieting strategies but has been unsuccessful over the years. His mother is overweight and has type 2 diabetes. Jeffrey has physical activity class at school twice a week. He expressed interest in joining the basketball team in the spring. He shares that he is tired after school and takes a long nap a couple of times per week. He spends greater than two hours a day watching television or playing video games. Jeffrey usually skips breakfast on the weekdays because he is not hungry in the morning and is always rushing to get out the door to get to school on time. He eats a school lunch. He is usually hungry after school. A couple of times per week, he

will take a long nap after school and wakes up just in time for dinner at 7 pm. Jeffrey expressed that he likes fruits, but fruits are not readily available at home. He reports that he will eat certain vegetables, such as corn, potatoes, peas, salad, and raw carrots. Jeffrey's mother cooks dinner for the family and he plates his own dinner. Jeffrey also occasionally likes to cook simple meals. His mother reports that he typically has second helpings at dinner and eats quickly.

Jeffrey is prescribed 1000 mg of metformin twice a day and 35 units of Lantus every evening. He reports that he forgets to take his metformin 2–3 times per week and forgets his Lantus dose once a week. He reports that the metformin causes him to be bloated and have loose stools. He checks his blood sugar 1–2 times per day. His hemoglobin A1c level in the past three months is 9.2%.

Jeffrey is motivated to make lifestyle changes to be healthy and have the energy and stamina to play on the basketball team in the spring.

Anthropometrics

- Weight: 85 kg (>95th percentile)
- Height 175 cm (90–95th percentile)
- BMI: 28.3 kg/m² (>95th percentile)

Diet Recall

- Breakfast-skips; not hungry and does not have time in the morning
- Lunch-pizza/cheese burger, fries, apple juice, chocolate milk
- Snack-leftovers/granola bar/string cheese/crackers/chips
- Dinner-chicken, rice/pasta, water/2% milk
- Snack-ice cream/cookie three times per weeks

Case Study Questions

1. Does Jeffrey need to remain on metformin and Lantus?

Since Jeffrey's hemoglobin A1c is still above 8.5% after >4 months of diagnosis with type 2 DM, it is recommended by the 2018 International Society for Pediatric and Adolescent Diabetes that he continue on metformin and be on Lantus, a long-acting insulin, due to insulin resistance and hyperglycemia. Once his glycemic control improves with HbA1c <7%, then his diabetes provider can consider slowly weaning him from the long-acting insulin and managing his diabetes with lifestyle modifications and metformin as a monotherapy. However, if his HbA1c increases >9%, it may be necessary to introduce fast-acting insulin in the form of the insulin correction factor and carbohydrate coverage.

Educating Jeffrey that the gastrointestinal side effects of feeling bloated and having loose stools is commonly associated with metformin. Prescribing Jeffrey with metformin extended release (metformin ER), and slowly titrating his medication dose and avoid taking metformin on an empty stomach can help with avoiding or reducing the severity of the GI side effects.

2. What lifestyle modifications would be beneficial for Jeffrey and what behavioral technique would the practitioner use to help prioritize behavioral changes for Jeffrey?

Factors that are contributors to Jeffrey's excess weight are:

1. Irregular meal pattern:

Irregular meal pattern such as skipping breakfast daily can affect his metabolism, causing his body to be more prone to conserve energy. This pattern of eating also affects his energy level, causing him to be tired and sleepy after school. It can also promote overeating at meals and snacking later in the day.

2. Large portion size:

His energy deficit during the daytime results in the likelihood of overeating after school, and in the eve-

ning making it difficult to maintain balanced portion size at dinner and snack times. In addition, he often eats quickly and is unable to give his brain enough time to sense how much he ate and his level of satiety.

3. Limited intake of fruits and vegetables and regular intake of processed foods that are high in sugar or fructose and low in fiber.

Studies suggest that soluble fiber can improve metabolic health by improving insulin sensitivity and reduce blood cholesterol and triglycerides. Rich sources of soluble fiber include fruits, vegetables, oat bran, flaxseeds, oatmeal, wheat bran, beans, and lentils.

4. Limit physical activity

His energy intake is greater than his energy expenditure, with limited physical activity and low energy level.

Often times in a wellness visit, a practitioner will identify multiple factors that are contributors to the client's excess weight. It is important to remember that a healthy weight management plan takes time, especially in the pediatric population. Assessing the client's readiness and motivation factor should be the starting point in strategizing a lifestyle modification plan. It is helpful to acknowledge to the client what lifestyle habits he or she is doing well. Some families do need basic nutrition education and are unaware of the family's unhealthy eating behaviors. Other families are aware of their child's unhealthy eating behaviors. The problem lies in how to make the behavioral change. Explaining to the adolescent that his portion size is large or that skipping main meals is unhealthy only gives him the knowledge, but it does not provide the tools or plan to make the change. This is where motivational interviewing plays a key role in finding where to start, and the steps to make the change, and the family support that is needed to make the change. Motivational interviewing is not about the clinician motivating the patient. It is about assessing what motivates the patient to engage in behavior change, develop-

ing rapport and trust, and bringing the patient's family back for additional supportive counseling.

Tools for motivational interviewing can be applied in practice using an O.A.R.S. format. O.A.R.S. stands for Open-ended questions, Affirmations, Reflections, and Summary. In this case study, after asking open-ended questions and listening to Jeffrey the practitioner would then clarify and reflect back the information shared by Jeffrey. His motivation to getting healthy is to be able to have the energy and stamina to be on the basketball team in the spring. The next step is to ask permission to provide education. After educating Jeffrey on how a regular meal pattern improves metabolism, improves energy level throughout the day, and helps with identifying hunger and satiety cues, in order to prevent overeating, it is important to invite Jeffrey to consider the new information and draw on the new information. Finally, the practitioner would then summarize and discuss the next steps to making the behavior change.

Here is an example of using open-ended questions, listening and providing affirmation, clarifying using reflections, addressing the issue with permission, inviting Jeffrey to consider the new information, and summarizing and discussing next steps.

1. Listen and use open-ended questions

Client: I know I'm overweight and need to lose weight. I've tried dieting by avoiding grains and junk foods but have been unsuccessful.

HCP: Why do you want to lose weight?

Client: I want to have more energy and have the stamina to be on the basketball team in the spring.

2. Affirmations

Affirmations are statements that focus on patient's strengths, and consider efforts, intentions, partial successes.

HCP: I'm hearing you say that you have made efforts in modifying your diet in the past. Thank you for being opened and honest about your struggles. You are here talking about the issue. Making healthy lifestyle changes is difficult for many people.

3. Clarify using reflections and identify incorrect or needed information and reflect back your understanding

HCP: You are reluctant to eat breakfast. Why do you skip breakfast?

Patient: I'm not hungry in the morning and I don't have time.

HCP: Sounds like if you have more time in the morning and if you feel hungry, you would be more inclined to eat breakfast.

Patient: I often hit the snooze button on my alarm and end up rushing in the morning to get to school on time.

4. Address the issue (with permission)

HCP: Would you mind if I shared some thought with you and you tell me what you think? I do understand that ultimately, this is your decision.

Patient: I suppose.

HCP: When a person skips breakfast on a regular basis, the body does not get the energy it needs and compensates by decreasing the body's metabolism, which then affects hunger cues. Following a regular meal pattern will help to improve hunger cues and motivate you to eat breakfast and regulate your appetite and energy level throughout the day.

5. Invite the patient to reconsider and summarize

HCP: Now that you have a better understanding of how your meal pattern affects your metabolism and affects your hunger and satiety cues, and improves your energy level, where does that leave you in regards to working on waking up on time to ensure you don't skip breakfast? Do you want to brainstorm ideas for quick and healthy breakfast choices?

Case 2

A 17-year-old obese female has a 7-month history of polyuria and polydipsia, coinciding with a 20-pound weight loss. She has darkening of skin beneath her neck, knuckles, groin and

axilla. Her weight is 290 pounds. Her BG is 280 mg/dL and her A1c is 9.2%. She has glucosuria and ketones on urinalysis.

What is the treatment plan for her diabetes?

- (A) repeat A1c in 3 months and do not start medications
- (B) Lantus 25 units and metformin 500 mg at night
- (C) dietary therapy only

Correct Answer: (B) In patients who are ketotic or in diabetic ketoacidosis, have venous BG >250 mg/dL, A1c >9%, patients should start insulin therapy. Patient will also meet with a multidisciplinary team including a diabetes educator and a dietician for lifestyle changes, including nutrition and physical activity.

Case 3

A 13-year old female is recently diagnosed with type 2 diabetes based on a hemoglobin A1C 7.5%. He has signs of insulin resistance, including acanthosis nigricans and obesity with a body mass index >95th percentile for sex and age. He is currently on metformin alone. Which of the following screening tests are NOT indicated to occur at the time or near the time of diagnosis?

- (A) AST/ALT
- (B) Lipid profile
- (C) Diabetic retinal exam
- (D) Blood pressure
- (E) Urine microalbumin/creatinine ratio
- (F) B & C
- (G) None of the above as all are indicated

Answer: (G) Based on the results from the SEARCH for Diabetes in Youth, about 75% of youth with type 2 diabetes will have evidence of a diabetes-related complication even at the time of diagnosis. Screening for retinopathy, hypertension, nephropathy, and neuropathy are indicated at the time

of diagnosis and yearly thereafter. Screening for comorbidities such as NAFLD, dyslipidemia, obstructive sleep apnea, and PCOS for females should also occur at the time of diagnosis and with follow-up.

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Chapter 24

Nutrition in Adolescent Pregnancy



Katherine E. Debiec and Judy Simon

Introduction

The terms “teenage pregnancy” and “adolescent pregnancy” are variably defined. “Teenage pregnancy” may refer to any pregnant girl between the ages of 13 and 19 years; however, data are more commonly reported and adolescent pregnancy programs generally directed at teen girls between the ages of 15 and 19. Fewer data are available for the youngest girls of reproductive capacity—those under age 15, some of whom may not yet be teenagers. For the purposes of this chapter, the term “adolescent pregnancy” will be used to refer to girls under the age of 19.

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With the exception of occasional increases, the teen birth rate for adolescents aged 15–19 years has gradually declined since its peak in 1957 of 96.3 per 1000 to 22.3 per 1000 women in 2015 [1, 2]. This represents the lowest rate since national data collection began in 1940 [2]. While rates of teen pregnancy and birth have fallen, there were still a total of 229,715 births to teenagers age 15–19 in 2015 [1]. Teen pregnancy rates in the United States remain substantially higher than those in other developed countries [3].

Evidence has shown that adolescent mothers have an increased risk of adverse birth outcomes, including anemia, infections, depression, and preterm birth [4–7]. In addition, studies demonstrate greater neonatal and infant mortality and major neonatal morbidities with higher rates of low birthweight, as well as neonatal and infant death [6, 8]. The cause of the adverse pregnancy outcomes for adolescents is uncertain, but has been attributed to several factors, including socio-economic status, adequacy of prenatal care, tobacco and substance use, anemia and other maternal nutritional concerns [9]. Biological factors that have been associated consistently with negative pregnancy outcomes are poor nutritional status, low pre-pregnancy weight and height, parity, poor nutritional intake and poor pregnancy weight gain [10].

One theory for the association of low birth weight and young maternal age is the competition for nutrients hypothesis—meaning that the mother, who is still growing herself, might have increased demands for her own growth, which may mean fewer nutrients for a developing fetus [9]. Some young adolescents are still growing during pregnancy; growing adolescents give birth to smaller infants than non-growing adolescents [9].

Many studies have shown the efficacy of prenatal care in mitigating the adverse birth outcomes associated with adolescent pregnancies [11–13]. While some pregnant adolescents receive prenatal care in dedicated teen pregnancy centers accustomed to addressing their unique needs, others may receive care from providers who have less adolescent experi-

ence. For those wishing for detailed care recommendations, the American Congress on Obstetricians and Gynecologists (ACOG) and the American Academy of Pediatrics (AAP) offer comprehensive recommendations for the structure and scope of prenatal care. See the chapter “Preconception and Antepartum Care” in their publication “Guidelines for Perinatal Care” [14]. ACOG and the AAP recognize adolescents as a special population with unique antepartum concerns, including reproductive choices, confidentiality, increased adverse pregnancy outcomes, sexually transmitted infections (STIs) and contraception [14]. The specific concerns regarding adolescent nutrition in pregnancy are addressed here, from antenatal nutrition to postpartum needs, like breastfeeding.

Typical Adolescent Diet, Periconception and Early Pregnancy Nutrition

Adolescents’ needs are increased to meet their needs for rapid growth and changes in body composition for puberty. There are many impacts on their nutrition status, including more time away from home, time spent with peers, increased concerns about appearance and body image, and unpredictable eating behaviors [15]. The teenage years are a time when adolescents are taking over more control of their food choices. Research has found teens frequently fail to meet nutrition recommendations. Many teens in the United States consume diets higher in fat or added sugar and consume inadequate intake of iron, calcium, vitamin D, vitamin A, folic acid, fiber and zinc than recommended [16].

Poor eating habits in adolescence can compromise intake of nutrients and energy needed for growth even more for a pregnant adolescent. Increased rates of dieting or disordered eating in teens also can impact their nutrition status.

More than 90% of adolescent pregnancies may be unintended, which impacts several aspects of the pregnancy, including nutrition [10]. An *unintended* pregnancy is one that

is either *mistimed*, meaning that a woman did not want to become pregnant at the time the pregnancy occurred, but did want to become pregnant at some point in the future, or *unwanted*, when a woman did not want to become pregnant then or at any time in the future [17]. When including only sexually active teenagers for calculations, women aged 15–19 have the highest unintended pregnancy rate of any age-group [17]. Pregnancies resulting from unintended or closely spaced pregnancies are associated with adverse maternal and child health outcomes, such as delayed prenatal care, premature birth, and negative physical and mental health effects for children [17].

In addition, adolescents may have less than adequate prenatal care, which can contribute to fewer opportunities for education and interventions regarding nutrition. Late entry into prenatal care (prenatal care accessed at greater than or equal to 25 weeks gestational age) has been found to be associated with higher risk of maternal anemia, iron and zinc deficiencies [9]. Only 69% of pregnant adolescents aged 15–19 years old received care beginning in the first trimester of pregnancy, and 64% received what was considered early and adequate prenatal care [18]. In a survey of nearly 700 adolescents aged 14–15 years, 70% thought that the ideal time to modify what a woman eats and drinks to ensure a healthy pregnancy was when pregnancy had been confirmed [19].

As noted later in this chapter, there are many important micronutrients for pregnancy and because of their typical diet, adolescents may have nutritional deficiencies in their diet before becoming pregnant or in early pregnancy. The most commonly noted deficiencies include calcium, iron, folate, zinc, riboflavin, and vitamins A and D [9]. Folic acid is important for the developing fetus, particularly in the first trimester, prior to when an adolescent might be aware of their pregnancy. A diet rich in folate is encouraged prior to conception, which is challenging to encourage in unplanned pregnancies.

Weight Gain in Pregnancy

In 2010, the Institute of Medicine (IOM) released revised guidelines for recommendations for weight gain in pregnancy [20]. The IOM guidelines for weight gain in pregnancy are based on prepregnancy weight category, as determined by body mass index (BMI). The recommendations suggest a range of total weight gain for the entire pregnancy. The guidelines recommend underweight individuals (BMI less than 18.5) gain 28–40 pounds total during pregnancy; those with normal weight (BMI 18.5–24.9) gain 25–35 pounds; overweight (BMI 25–29.9) gain 15–25 pounds and obese individuals (BMI greater than 30), regardless of class of obesity gain 11–20 pounds during pregnancy. The table is readily available from the IOM website. We recommend readers download it for reference. There were several reasons for updating the guidelines, which had previously been established in 1990, including the changing demographic population of the U.S., including a higher proportion of women from racial and ethnic subgroups and the growing numbers of women entering pregnancy overweight or obese [20]. The guidelines are intended for the United States and other developed countries, but may not be applicable to other regions of the world, where women may be shorter, thinner, or have fewer resources than in the United States [20]. The recommendations for weight gain are the same for both teens and adults.

Pregnancy Related Nausea and Vomiting

Appropriate weight gain and adequate nutrition, particularly in the first trimester, can be influenced by a woman's degree of nausea and vomiting. Nausea and vomiting are very common and affect 50–80% of pregnant women [21]. The duration of nausea and vomiting each day can vary for different women; the impact on quality of life can also vary. The

pregnancy-unique quantification of emesis and nausea (PUQE) index is a validated index that can assess the severity of nausea and vomiting in the first trimester [21]. Several factors, including severity of symptoms and a woman's desire for treatment, will impact decisions about treatment mechanism.

Nausea and vomiting generally begin prior to the ninth week of gestation and improve towards the end of the first trimester, but can persist for the duration of pregnancy for some women.

There are several theories for the causes of nausea and vomiting of pregnancy. Human chorionic gonadotropic (hcg) has been theorized to contribute as the peak of nausea and vomiting symptoms often correlates with the peak of hcg levels (which typically rise in the first weeks of pregnancy and then plateau in the late first trimester) [21]. Estradiol has also been implicated as nausea and vomiting of pregnancy are more common with elevated estradiol levels and less common with lower levels [21]. Some hypothesize that nausea and vomiting of pregnancy may be an evolutionary protective factor to prevent exposures to potentially dangerous foods [21]. While it has been theorized that certain personality types or psychological conditions are predisposed to nausea and vomiting, this assumption can lead to dismissal of the pregnant woman's concerns and potentially undertreatment.

Risk factors for nausea and vomiting include increased placental mass (twins or higher order multiple gestations, molar pregnancy), history of motion sickness, migraine headaches, family or personal history of hyperemesis gravidarum [21].

Hyperemesis gravidarum is the extreme end of the nausea and vomiting of pregnancy continuum. It is a diagnosis of exclusion without a single accepted definition, but is generally persistent vomiting not related to other causes, with a measure of acute starvation (usually large ketonuria) and some measure of weight loss, often at least 5% of prepreg-

nancy weight [21]. Electrolyte, thyroid and liver abnormalities can also be present in hyperemesis gravidarum.

Additional maternal and fetal consequences of severe nausea and vomiting in pregnancy include Wernicke encephalopathy due to vitamin B1 deficiency, splenic avulsion, esophageal rupture, pneumothorax, acute tubular necrosis and low birth weight for the babies of women with severe nausea and vomiting [21]. Mild to moderate vomiting has little effect on the embryo, fetus or newborn.

Prevention strategies for nausea and vomiting of pregnancy include taking a multivitamin prior to conception, eating frequent, small meals, avoiding spicy or fatty foods, eliminating iron-containing prenatal vitamins, and avoiding other sensory stimuli that may provoke nausea or vomiting (strong odors, heat, etc.). Ginger has been shown to be beneficial in reducing nausea; acupressure, acupuncture or acustimulation have conflicting reports regarding benefit [21].

The American College of Obstetricians and Gynecologists have a published algorithm for therapeutic treatment of nausea and vomiting of pregnancy [21]. First line therapies include nonpharmacologic options such as modifying prenatal vitamins intake, ginger, acupressure and eating small, frequent meals. Initial pharmacologic options include vitamin B6 and doxylamine. Secondary options include prescription medications. If these interventions fail to work, some women will require intravenous hydration and/or antiemetics for patients unable to tolerate oral hydration or with clinical signs of dehydration. Rarely, parenteral nutrition and or hospitalization will be necessary for women with hyperemesis gravidarum unresponsive to medical therapy and unable to maintain weight.

Nutritional Needs for Pregnant Adolescents

Pregnancy nutrient needs for adults are largely extrapolated to begin with, and then when you add in the additional needs of adolescents who are pregnant, inferences about the

requirements are made. There are documented differences in need for a few nutrients for pregnant adolescents (increased compared to adults for Ca, Mg, P, Zn; slightly decreased needs compared to adults for vitamins A and C) [9].

There is some evidence that the physiology of pregnancy in teens may be a bit different in that they mobilize fat and other nutrient stores somewhat differently. It's important to think about the physiology and use that as a guide. The first 20–22 weeks of pregnancy are largely anabolic for the mom and the fetus isn't growing very rapidly, so the energy and nutrient needs will be minimally elevated in most cases. A few exceptions include the nutrients needed for neural development like folic acid, some of the fatty acids, etc. The second half of pregnancy is when fetal growth accelerates, so macronutrients and most micronutrients will increase in relationship to the rate of fetal growth and energy needs. Iron is sequestered by the infant in the last trimester in anticipation of human milk, so needs are particularly high then. With teens, they already have elevated needs for nutrients related to their own growth (particularly to bone development and iron losses due to menstruation). Therefore, calcium and iron are nutrients of particular concern [9]. Of note, gummy vitamins (which many adolescents prefer) are not good sources of iron.

Dietary Reference Intakes

Pregnant and lactating adolescents have unique nutritional requirements compared with pregnant and lactating adults or non-pregnant peers. The Dietary Reference Intakes (DRIs) are nutrient reference values developed by the Institute of Medicine of The National Academies [22]. The DRI's are readily available for download by readers. In the mid-1990's, the DRIs replaced the Recommended Dietary Allowance (RDA) in the United States and the Recommended Nutrient Intake (RNI) in Canada [22]. These nutrient reference values are specified on the basis of age, gender and life stage, including during pregnancy and lactation. Pregnant and lactating

adolescents aged 14–18 years have higher requirements for water, carbohydrate, fiber, fat, protein, most vitamins and elements than non-pregnant teens of the same age. Compared with adult women, pregnant teenagers aged 14–18 require more calcium, magnesium, phosphorous, and zinc.

In a systematic review of dietary assessments of pregnant adolescents, Moran notes that in general, nutrient intakes of pregnant adolescents are low in several nutrients important to the developing pregnancy [9]. Compared with current United States' DRI's, the nutrient intakes that most frequently fell below recommendations were energy, iron, folate, calcium, vitamin E and magnesium [9]. All included studies reported iron intakes below the estimated average requirement (EAR) [9]. Folate and calcium intakes also fell below the EAR in the majority of studies [9]. The reasons for the discrepancy between recommended and reported intake are unclear, but may be related to study design, overestimates of actual needs, or underreporting of intake for studies relying on self-assessment.

There are special considerations regarding iron, calcium, and folate intake in pregnancy.

Iron

Iron deficient anemia is the most common nutrient deficiency in pregnancy. Iron deficient anemia has been associated with increased risks of low birth weight, preterm delivery and perinatal mortality [23]. The peak incidence for iron deficient anemia is between ages 15 and 19 in non-pregnant girls, which leads to the highest prevalence of iron deficiency anemia in pregnancy in teen mothers [9, 23]. Anemia in pregnancy is twice as prevalent in non-Hispanic black women compared with non-Hispanic white women [23]. Estimates for rates of iron deficient anemia are 1.8% in the first trimester, 8.2% in the second trimester and 27.4% in the third trimester among low income, mostly minority women [23].

Risk factors for iron deficiency include diet poor in iron-rich foods (such as red meat, enriched cereals, beans, lentil), a

diet low in iron absorption enhancers (Vitamin C, oranges), a diet high in foods that decrease iron absorption (such as dairy, coffee, tea), malabsorption conditions, heavy menses, and short interpregnancy interval [23].

The Centers for Disease Control and Prevention recommends universal screening for iron deficiency anemia and universal iron supplementation to meet iron requirements of pregnancy, except in cases of genetic disorders such as hemochromatosis [23].

The primary screening tests for identifying anemia are serum hemoglobin or hematocrit levels, but are not specific for determining the etiology of anemia or iron deficient anemia. Other findings include microcytosis, low plasma iron levels, high total iron-binding capacity, low serum ferritin and increase levels of free erythrocyte protophorphyrin [23]. Serum ferritin levels have the highest sensitivity and specificity for diagnosing iron deficiency in anemia, with levels of less than 10–15 micrograms/L confirmatory of iron-deficiency [23].

The recommended daily dietary allowance of ferrous iron during pregnancy is 27 mg; whereas the typical diet confers 15 mg of elemental iron per day [23]. Prenatal vitamins are recommended to meet this need. Iron supplementation decreases the prevalence of maternal anemia at delivery [23]. Iron supplementation may be difficult for some to tolerate. Giving in conjunction with stool softeners and gradually increasing dose (e.g., every other day to once or twice daily) may help improve tolerability.

Calcium

Pregnant adolescents aged 14–18 should consume 1300 mg of calcium/d throughout pregnancy and lactation [22]. Women aged 19 years and older should consume 1000 mg calcium/d [22]. Calcium helps to determine bone mineralization and bone density, both for the growing adolescent and growing fetus. Studies report pregnant adolescents' calcium consumption as less than recommended [9]. This may be related to a

decline in milk intake or an increase in consumption of low-calcium beverages like soft drinks [9]. Consumption of inadequate calcium may negatively affect fetal bone development [9].

According *Hypertension in Pregnancy*, which was developed by American College of Obstetricians and Gynecologists' Task Force on Hypertension in Pregnancy, calcium may be useful to reduce the severity of preeclampsia in populations with low calcium intake [24]. However, they suggest that this may not be relevant to a population with adequate calcium intake, such as in the United States [24]. This recommendation may fail to take into consideration a subpopulation, like adolescents, who may not actually have adequate calcium intake.

Folate

Supplementation with folic acid has been shown to help reduce the risk of neural tube defects. Women who could become pregnant are encouraged to take folic acid supplements (400 µg/d) in addition to consuming a diet rich in folate to help reduce the risk of neural tube defects [9]. Studies have shown that only 30% of pregnant women take folic acid around the time of conception and that less than 20% of 16–19 year olds are aware of the need to increase folate intake before conception [9]. Nutritional education for teens should include information about the importance of folate, particularly for teens at risk of or interested in becoming pregnant.

Vitamin C and E

The combination of anti-oxidants vitamin C and E for the purposes of preventing preeclampsia was not shown in large randomized, placebo-controlled trials to reduce the risk of pre-eclampsia or improve maternal and fetal outcomes [24]. Similarly, a Cochrane systematic review found

no benefit to vitamin C and E for the prevention of pre-eclampsia [24].

Dietary Salt Intake

A systematic review of trials that studied sodium restriction found no significant benefit for the prevention of pre-eclampsia, but trials may not have had adequate power to detect a benefit [24].

Breastfeeding

After delivery, the nutrition of the newborn is an additional concern for the new mother and her health care providers. Breastfeeding recommendations should be introduced in antenatal care [14]. For most mother-baby dyads, breastfeeding is generally recommended as the best source of nutrition [14]. There may be additional barriers to both breastfeeding initiation and continuation for teenagers, including stigma of breastfeeding in public, limited postnatal interactions with health professionals or lactation specialists [25].

Interventions for Healthier Pregnancies: Prenatal Care, WIC

There are several factors that influence eating behaviors and nutritional status of pregnant adolescents. Socioeconomic factors that affect adolescent nutrition include financial concerns that could prevent ability to afford a wide variety of foods, geographic lack of grocery stores, food providers or farmers' markets (food deserts), transportation difficulties, substances use or abuse. While some of these factors are not modifiable, there are several interventions that can help the pregnant adolescent to have the healthiest pregnancy possible, including prenatal care and nutritional support programs.

Prenatal care may be provided in traditional models of practice (one-on-one patient-provider interactions) or group-based prenatal care, such as the CenteringPregnancy program. There is evidence to support that such a model encourages health care compliance, satisfaction with care and low rates of preterm birth and low birth weight infants [26]. Ideally, prenatal care is established in the first trimester, and typically has visits monthly through 28 weeks gestation, every other week through 36 weeks and then weekly from 36 weeks through delivery [14]. In the course of routine prenatal care, pregnant women receive several assessments and resources. They are provided with options, including counseling about their available choices regarding pregnancy continuation or termination, parenting, co-parenting or adoption, either closed or open. They should be screened for depression, anxiety or other mental health concerns as well as substance use or abuse, in addition to assessment of housing, relationship and nutritional status. Interventions or referrals for any areas of concern (e.g., counseling or medication for depression, tobacco cessation counseling) may be provided. Dental care is recommended. Prenatal testing includes for maternal blood type, antibody status and several infections (e.g., HIV, syphilis, hepatitis B, gonorrhea, chlamydia, urinary tract infections, Group B strep assessment), assessment of Rubella and VZV immunity [27]. Screening for diabetes may occur earlier in pregnancy for those at high risk of diabetes or in the second trimester for those at routine risk. Vaccinations for influenza and Tdap are recommended. Prenatal screening for common birth defects, such as chromosomal abnormalities, neural tube defects and other anatomic anomalies is offered. Contraceptive counseling is discussed. Access to nutrition resources (dietician services, WIC) is provided.

The Special Supplemental Nutrition Program for Woman, Infants, and Children (WIC) was established in 1972 in order to enhance the nutritional status of these vulnerable groups [28]. There is ample evidence that shows that pregnant women who participate in WIC give birth to healthier infants, but also some concerns raised about whether the improve-

ment in outcomes is a reflection of selection bias for WIC participants, suggesting the more motivated, healthier or women with better access utilize WIC services [28]. Bitler and Currie (2005), showed that relative to Medicaid mothers, all of whom are WIC eligible, WIC participation are negatively selected in terms of education, age, marital status, father involvement, smoking, previous low birth weight or premature infant and other observable characteristics, and yet WIC participation is associated with improved birth outcomes, particularly amongst more disadvantaged women, including those who received public assistance, single high school drop-outs, and teen mothers [28].

A longitudinal approach to supporting first time and vulnerable mothers is the community based Nurse-Family Partnership®, which pairs young first-time mothers and specially trained nurses during pregnancy and for the child's first two years of life [29]. In addition to reductions in maternal hypertensive disease, reduced closely-spaced pregnancies, decreases in maternal smoking, reduction in maternal crime and protections offered to the children in the groups, nurse-visited women in the original trials had improved diets compared with the control counterparts, which suggests that for an at-risk population there are viable options for improving nutrition in adolescent pregnancies [29].

Cases

Case 1

AA is a 13-year old Gravida 1 Para 0 (first pregnancy) who has transferred care into your practice at 19 weeks gestational age by last menstrual period and an 8-week ultrasound. She was previously living in another state with her dad and step-mother and is now living in your state with her mother. Prior to her move, she received adequate and appropriate prenatal care starting at eight weeks, including dating ultrasound, prenatal labs, prenatal screening with the quad screen and treat-

ment for her nausea and vomiting of pregnancy. Prior to pregnancy, she was 5'1" and weighed 145 lbs. (BMI 27.4). When she comes to her first visit with you at 19 weeks, she has gained 22 pounds.

- How would you determine recommendations for her weight gain during this pregnancy?
 - Review and obtain from 2010 Institute of Medicine recommendations for weight gain in pregnancy. In this case, with her BMI of 27.4 (categorized as “overweight”), the recommendation would be 15–25 lb (7.0–11.5 kg).
- How would/should her nausea and vomiting of pregnancy be managed?
 - The American College of Obstetricians and Gynecologists have a published algorithm for therapeutic treatment of nausea and vomiting of pregnancy [21]. First-line therapies include non-pharmacologic options such as modifying prenatal vitamins intake, ginger, acupressure and eating small, frequent meals. Initial pharmacologic options include vitamin B6 and doxylamine. Secondary options include prescription medications. If these interventions fail to work, some women will require intravenous hydration and/or antiemetics for patients unable to tolerate oral hydration or with clinical signs of dehydration.
- What interventions do you recommend for her nutrition and diet at 19 weeks?
 - AA would benefit from medical nutrition therapy from a dietitian in a women’s health care setting. With the patient’s permission it might be helpful to involve patient’s mother in the session. Since she has had severe nausea, she may have been consuming a nutrient-deficient diet to help with her symptoms. If her nausea has improved or is effectively treated, helping plan sample meals with her can slow down her rate of gain and improve the quality of her diet.

- Assessment of her present diet, lifestyle, activity and nutrition supplements. Knowledge of relationship of diet and pregnancy and her motivation would be reviewed. If there is a family history of diabetes earlier screening for GDM could be warranted. The goal would be to optimize her diet, activity and slow her weight gain.
- Using motivational interviewing techniques with the patient could be helpful and follow-up visits between medical visits for ongoing assessments and weight checks would be advised.
- Coordination with a social worker or social services to provide additional resources if there is food insecurity would be helpful along with social support.

Case 2

BB is an 18-year old G2P0101 (pregnant with one prior pre-term birth) who delivered her first child via vaginal delivery at 35 and a one-half weeks gestation seven months ago. The last you saw her was at her six-week postpartum visit. At the time, she was breastfeed and supplementing with formula. She said that she had “okay” support from the father of the baby. They were each living with their respective parents and the baby was primarily living in her home, with her mother helping to care for the baby while she attended alternative school. Though the school has an in-school daycare, the family preferred that the baby stay at home with relatives. She had no postpartum depression. Despite encouraging the use of a long-acting reversible contraceptive like an intrauterine device or arm implant, she said that she preferred abstinence or maybe condoms as her form of contraception, because she “never wanted to push out a baby again” and she “[wasn’t] even thinking about sex. She reluctantly accepted prescriptions for both plan B and progestin only pill. She now presents to you for a “confirmation of pregnancy” visit. She reports that she never got her period after the delivery of her

baby, so her last menstrual period was actually prior to her first pregnancy. On exam, you palpate a fundal height 2 cm below the umbilicus. Fetal heart rate is auscultated at 140 beats per minute with the Doppler. An ultrasound confirms an estimated gestational age of 18 weeks.

At her previous visit, at six weeks postpartum, her height was 5'6" and she weighed 113 lbs. Her BMI was 18.2. She gained 25 lbs in her last pregnancy (she started that pregnancy at 108 lbs, BMI 17.4 and ended at 133 lbs), and has gained 15 pounds since you last saw her (she now weighs 128 lbs). She breastfed until about one month ago, but then stopped, because it did not seem like she was making much milk. She smokes about five cigarettes per day. She is disheartened and overwhelmed to learn that she is pregnant again, but thinks that it would be "good for her baby to have a little brother or sister" and declines resources for abortion services.

- How would you determine recommendations for her weight gain during this pregnancy?
 - Review and obtain from 2010 Institute of Medicine Guidelines. In this case, for a BMI of 18.2 (considered to be "underweight") the recommendation would be 28–40 lb. (12.5–18.0 kg).
- How might nutritional concerns affect pregnancy outcomes?
 - She has many risk factors for low birth weight and preterm delivery including prior preterm birth, short interpregnancy interval, smoking, low maternal weight. She likely is at high-risk for nutritional deficiencies given the demands on her body from recent pregnancy and breastfeeding.
- What interventions would you recommend?
 - Motivational interviewing could be used to address a number of concerns including: future life goals and

plans to achieve them, desire and optimal timing for future pregnancies, reliable contraception, safety, mood concerns, smoking cessation.

- Nutrition recommendations: Referral to a registered dietitian for assessment of her current dietary intake and a review of her labs. She is at high-risk for iron deficiency. It is important to determine if she is consuming adequate kcal, protein, Vitamin D for lactation, short inter-pregnancy interval, low maternal weight and age. The IOM guidelines for weight gain do not have a specific consideration adolescents. Teenagers gaining less than IOM recommendations are at higher risk for SGA, preterm delivery and infant death [30].
- Regular follow up for weight checks and review of her diet between prenatal visits would be beneficial. Suggestions for energy dense and nutrient dense foods that BB would accept should be provided. If BB is continuing to breast feed during this pregnancy additional calories would be needed. Support from her family for regular meals and snacks would need to be prioritized. Coordination with resources to support this teen mom could be very beneficial.

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Chapter 25

Adolescent Substance Use



Kristen Arquette, Andrew Gehl, and Erik Schlocker

Background

Many teens and parents lack knowledge of the heightened risks of adolescent substance use. Factors include key differences in brain development, increased potency in today's drugs, and a greater range of available substances than ever before. Youth use typically starts casually, occurs in a social setting, and is motivated by curiosity. Most teens have tried substances before completing high school [30]. Continued use is perpetuated by a variety of desired benefits, including to fit in and feel more confident, to manage difficult emotions, suppress or stimulate appetite, study harder, enhance athleticism, and to power through exhaustion. While some experimentation with substances is developmentally normal, many youth

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struggle to understand how their use can affect them as they age. Adolescent substance use occurs on a spectrum with differing degrees of dangerousness and impact. All substance use by adolescents is defined as risky due to the potential for negative impact on the developing brain and body, legal consequences, and because earlier use increases the odds of developing an addiction later in life. Nutritional deficiencies have been highlighted in particular as a highly influential factor related to addiction.

While reported rates of adolescent substance use are on the decline, the majority of youth have experimented with substances [32]. Mid-to-late adolescence is a critical period for initiation of alcohol and drug problems, with over 38% of subjects in a study by Wittchen et al. using for the first time before age 14 [69]. Rates of illicit drug use have decreased over the past several decades, with the exception of marijuana prevalence, which increased significantly starting in 2017 [30]. Johnston et al. [30] also note that prescription drug abuse remains of great concern due to misperceptions regarding safety. Although opioid overdose deaths are skyrocketing, many youth underestimate the dangers of use due to the associated legitimate medical purposes.

New substances are being developed and marketed, often to youth, every day. Researchers have only recently collected data regarding vaping, the inhalation of aerosols often including nicotine or marijuana. Studies indicated a dramatic increase in adolescent vaping that represented one of the largest substance use increases researchers have ever seen [30]. E-cigarette use increased by 900% between 2011 and 2015, and by 78% from 2017 to 2018 [55]. In 2019, the Center for Disease Control (CDC) initiated an investigation of e-cigarette and vaping products following an outbreak of lung injury associated with the use of the products. As of October 2019, there has been confirmation of 34 associated deaths [48]. These rates indicate a looming public health crisis.

Many adolescents who would have been unlikely to take up smoking traditional cigarettes initiate use through new high tech devices, such as the JUUL, that have become status symbols through the use of social media. As many as two-thirds of adolescent and young adult JUUL users do not realize that the flavored vapors they are using contain nicotine [55]. Vaping devices like the JUUL use nicotine salts, which allow higher levels of nicotine to be inhaled more smoothly and with less irritation, which results in more frequent use that is especially problematic for adolescents [55]. In addition to being highly addictive, nicotine use can impact the development of the prefrontal cortex, creating deficits in learning and memory.

Although the devices are often marketed as being less harmful than traditional cigarettes, known dangers of electronic cigarette and vaping devices include burns, pneumonia, cardiovascular disease, as well as unknown long-term risk of substances inhaled in the aerosols. These substances, which are inhaled deeply into the lungs, include heavy metals, volatile organic compounds, chemicals that cause cancer, ultrafine particles, and flavorings that have been associated with lung disease when inhaled [55]. E-cigarette use is also positively associated with higher rates of other illicit substance use. Adolescents who use e-cigarettes are 3.5 times more likely than their peers to use marijuana [12]. Up to 33% of adolescents use the electronic cigarette or vaping devices to smoke marijuana [59].

Additionally, the rates of all substance use are likely much higher than those reported. Many studies rely on adolescents to self-report their use, although stigma, fear of discovery and adverse consequences serve as significant motivations to minimize use or fail to report at all. Often, youth impact studies are conducted with students enrolled in public high schools. Thus, surveys do not capture the using profile of students at alternative high schools, dropouts or absentees. Accordingly, statistics on adolescent substance use reflect an under-representation of high-risk adolescents.

Review of Adolescent Substance Use

Short-term Effects of Substance Use on Adolescents

Adolescence is a critical time, full of important life experiences that guide teens to become healthy, responsible, and well-adjusted adults. Many increases in cognitive functioning occur during the teen years. These changes in the brain render adolescents particularly vulnerable to the detrimental effects of substance use. Youth use is correlated with negative consequences traversing multiple domains. Social and academic functioning, interrelated risky behaviors, a long-standing impact on brain development, and an increased likelihood of developing mental health and substance use disorders later in life are all potential outcomes of early use. Use at any amount has the potential to cause harmful effects. Even experimental use is enough to increase the likelihood of social difficulties, including damage to relationships, legal troubles, and problems in school.

Regular or problematic substance use vitally threatens an adolescent's ability to reach age-appropriate developmental milestones. Creating an identity separate from one's family system is the primary developmental task of adolescence. Substance use compromises a teen's ability to separate from the family and take on responsibilities that are commensurate with age. Failure begets more use. When teens start to fall behind their peers in reaching developmental milestones, such as graduating high school or living away from home, patterns of use often increase [47]. Adolescence is noted to be a time of heightened psychological distress for many youth, with a preponderance of research finding correlations with substance use [10]. Heavy drinkers, in particular, are more likely to have emotional and behavioral problems such as using illicit drugs, stealing, engaging in non-suicidal self-injury, attempting suicide, truancy, running away from home,

and persistent sad or depressed moods [28]. Resulting low self-esteem perpetuates further increases in substance use to mitigate negative emotions.

As intoxication changes the way teens perceive and navigate interactions and feelings, maturity is stunted. Inaba and Cohen [28] report that users suffer “developmental arrest,” as avoiding difficult emotions prohibits maturation at the typical rate. These users present developmentally at the age at which they begin using substances. Their abilities are out of sync with their chronological age, and they lack age-appropriate coping skills. Teens become increasingly isolated as time spent procuring, using, and recovering from substances interrupt healthy relationships and replaces more prosocial activities, or activities that are positive, helpful, and beneficial to both the developing individual and society at large. Teens who are dependent on substances are more likely to associate with antisocial peers [2]. Peer relationships that are based on substances and negative influence are superficial. Adolescents who use substances often distance themselves from their caregivers as well, to avoid detection. Loneliness and depression increase, creating greater reliance on the substance to create positive mood states. SAMHSA [61] notes that “adolescents may use substances to compensate for a lack of rewarding personal relationships.” Affiliation with a negative peer group also has implications for damaging attitudes towards the school community and academics.

While the effects of substance use on adolescent cognition is an area of emerging research, it is widely accepted that adults with chronic use of alcohol and marijuana experience cognitive impairments [56]. It is well established that youth who do poorly in school often initiate use of substances following poor academic performance [10]. Researchers are also exploring if substance use causes a decline in academic functioning. One theory is that substances result in cognitive declines that impact aptitude. Thoma et al. [56] noted deficits in attention and executive

functioning resulting from adolescent alcohol and marijuana use that mirrored that of adult users. The National Institute of Drug Abuse (NIDA) [45] found that marijuana use leads to problems with studying and learning. NIDA [45] cautions that those decreased learning abilities can persist throughout an individual's lifetime. Memory impairment was associated with higher marijuana use, and performance on tests of attention, executive function, and memory were decreased in those who drank more per day [56]. Zeigler et al. [71] found that binge drinking damages study habits and functional brain activity. Impairment of these key cognitive processes reduces the adolescent's cognitive capacity. Academic achievement is diminished at the very time that adolescents need their best grades and test scores to ensure opportunities in early adulthood.

Other studies question whether cognitive impairment associated with use at heavy levels would produce the same outcomes at lower levels of use, and whether such declines are permanent or could be remedied by periods of abstinence [34]. A second theory regarding how substance use affects academic functioning is related to motivational, behavioral and social components [34]. This theory states that poor academic functioning is attributable in part to an adolescent's motivation to do well, their level of school engagement, and ability to engage in behaviors that promote learning rather than disrupt it. Bryant et al. [10] found school misbehavior was coupled with substance use by age 14, whereas school bonding, school interest, school effort, academic achievement, and parental help with school was negatively associated. Adolescents who smoke cigarettes report making less academic effort, feeling less bonded to school, and were less likely to have college plans compared with non-smoking counterparts [10]. Unsurprisingly, adolescents who spend more time intoxicated and socializing with negative peer groups have less time and interest in studying. Further research is warranted to determine the extent of the impact of associated cognitive impairments and other related factors.

Colin is a 17-year-old male, diagnosed with ADHD, who lives with maternal grandmother. His mother has a history of substance use disorder and episodically lives with the grandmother and Colin. Colin is in high school and has a 504 plan for accommodations related to his ADHD diagnosis. He lost 10% of his body weight over the past year due to poor appetite and lack of motivation to prepare his meals and snacks. His grandmother works outside the home, and so he is on his own in the evening and they do not eat regular family meals. He is referred to care for depression and anxiety as well as ADHD medication management. He has low motivation to consistently attend school. He discloses routine marijuana use with no motivation to reduce use. He wants to engage in treatment for depression and anxiety but is unwilling to engage in mental health therapy. Colin later discloses that he has recently experimented with LSD and opiates. *How would you help Colin understand the implications of his use on his mental health symptoms and academic functioning?*

Correlated Risky Behaviors

Adolescent use varies from adult use in a number of ways. A youth's ability to accurately anticipate and project consequences of their behaviors into the future is less than that of an adult. The younger an adolescent is at the onset of use, the more likely they are to participate in other associated high-risk behaviors that pose risks for both themselves and others. Blackouts, hangovers, and alcohol poisoning are among the immediate consequences of alcohol use. All can coincide with first-time use for adolescents who are prone to taking risks and lack knowledge of the effects. Consequences range from mild to severe, and can be dangerous, or even fatal. Accidents, fights, and regrettable or unwanted sexual activity represent other possible outcomes of use.

Per Inaba and Cohen [28], a teen's lack of experience managing their use has increased safety and health risks. The number of adolescents who drive under the influence is estimated to be as high as 2.5 million, and up to 50% of motor vehicle accidents resulting in death are linked to the consumption of alcohol [61]. Adolescents who use substances engage in sexual activity at earlier ages and more frequently than their non-using peers, engage in sexual activities with higher risk profiles, and are less likely to use condoms [61]. Decreased inhibitions, poorer judgment, and increased levels of aggression contribute to regrettable sexual encounters and sexual violence. Seventy percent of teen suicides, one of the leading causes of death for adolescents, involve substances [28]. And substance use is highly associated with increased rates of adolescent crime. Many teens are under the influence at the time that their crime was committed, and over one-half of males test positive for illegal drugs while in detention [28]. Regardless of whether a teen is struggling with addiction, the aftermath of associated risky behaviors can have far reaching impacts on their future.

Substance Use and the Developing Brain

Brain development occurs rapidly throughout adolescence. Substance use is highly impactful on brain development during this formative time, as the brain requires over 20 years to fully mature [28]. The frontal lobe develops last, and is responsible for decision-making. A teen's abilities to think abstractly and rationally, plan for the future and set long-term goals, delay gratification, and employ deeper moral reasoning increase as the frontal lobe evolves. Mounting evidence indicates that substance use at an early age results in the development of cognitive deficits that compound over time. Zeigler et al. [71] found that underage drinkers are at higher risk than adult users of neurodegeneration, which impacts not only the way the brain functions, but the structure of the brain itself. Greater impact appears to occur in areas of the brain that

regulate learning and memory [71]. Additionally, according to Chooi et al. [15], the impact of substance use on brain development affects key cognitive processes that are integral to “decisions and behaviors related to drug use, drug discontinuation, treatment participation, and selection and attainment of recovery goals.” Those affected will face a considerably harder battle getting and staying sober.

The Impact of Adolescent Substance Use on Adult Behavioral Health

Adolescent substance users are at increased risk compared to adults to develop mental health and substance use disorders. The use of psychoactive drugs is considered a leading factor that increases a person’s likelihood of developing a mental illness, such as delirium, dementia, amnesic disorder, psychotic disorder, mood disorder, anxiety disorder, sexual dysfunction and sleep disorder [28]. Marijuana and stimulant use in adolescence is linked with increased rates of psychosis [7, 38]. Inhalants are associated with both psychiatric and neurological impairments [61]. While there is little evidence to confirm the theory that teens use to “self-medicate” symptoms of psychiatric disorders, there is increasing evidence that substance use makes mental health symptoms more severe [31]. Of additional concern are potential drug interactions between psychiatric medications and commonly abused substances. Drug interactions could be toxic, or may decrease the effectiveness of the psychiatric medication. Additionally, McCabe et al. [39] found that up to 13.8% of youth who have controlled pain, stimulant, anti-anxiety, or sleeping medications, have diverted that medication by selling it, giving it away, or trading for other substances. All forms of poor medication compliance can contribute to re-emerging or worsening mental health symptoms, the perception that medication isn’t working, and general feeling of hopelessness.

The earlier an adolescent is exposed to addictive substances, the higher risk they are of developing substance use

problems or addiction later in life. Once a teen has begun to struggle with substances, their ability to use safely as an adult may be compromised permanently. Cortical degeneration and associated increases in impulsivity caused by early use influence the development and severity of substance use disorders [17]. This trend is consistent across various classes of substances. For example, most users of nicotine began smoking before age 18, and nearly four out of ten people who use alcohol before the age of 15 eventually develop an addiction to alcohol [45]. Adolescents who experiment with alcohol, nicotine, and marijuana during ages 10–12 are more likely to abuse substances than those whose onset of use is 18 or older [28]. In contrast, individuals who wait until their mid-twenties to use drugs are less likely than those who use drugs in adolescence to become addicted [28]. Nora Volkow, the director of the National Institute on Drug Abuse (NIDA) explains how in addition to the detrimental effects of substances on the frontal lobe, the adolescent's brain's reward system is more sensitive than an adult's [63]. Consequently, youth experience a greater reward from substances. As individuals age, dopamine neurotransmission in brain reward regions change and sensitivity decreases, which explains why adult use isn't as reinforcing as adolescent use [63]. Genetics also play a role in the development of substance use disorders. Adolescents with a positive family history for addiction should be counseled regarding their increased risk.

An Epigenetic Lens on Adolescent Substance Use

The completion of the Human Genome Project in 2003 and subsequent advancements in genetic research such as Genome Wide Association Studies, has allowed researchers to begin understanding with increasing precision, the genetic factors associated with adolescent vulnerability to substance use. For example, research has found an association between genes and addictions to alcohol; mutations to the alcohol metabolizing enzyme ALDH2 gene can lead to severe nau-

sea, vomiting and facial flushing in approximately 40–50% of Asian individuals [20]. This mutation acts as a protective factor against alcoholism because drinking higher quantities of alcohol is aversive [60]. Research has also demonstrated that having a low level of response to alcohol is associated with increased risk for alcoholism because in part, individuals with lower levels of response require higher quantities of alcohol to achieve the desired effects from the alcohol [60]. Also supporting a genetic link to addiction are twin studies in which researchers compared monozygotic twins, who share 100% of their genes with dizygotic twins, who share 50% of genes, for alcohol use disorders. The finding was the proportion of risk for addiction due to genetic factors to be 50% [60]. The implication of this is that identical twins were more likely to have similar rates of substance use disorders compared to fraternal twins, suggesting a strong genetic contribution to addiction [72]. In addition, whereas environmental factors are thought to play a larger role in initiation of substance use, genetics seem to be a much greater factor in the development of substance use disorders [40]. Substance use has been implicated in shaping genetics. For example, when individuals use cocaine, it can mark the DNA by increasing the production of proteins commonly found in DNA of those with addictions. Increased levels of these altered proteins correspond with drug-seeking behavior in animals [46]. Research has also found correlations between dopamine availability and impulsivity, and susceptibility or risk to substance use disorders [21]. Other studies have shown links between behavioral addictions, impulsivity, and increased likelihood for drug use [16]. As advancements have been made in the science of genetic research, it is likely greater precision in identifying the specific genes that are implicated in substance use disorders will be achieved. This could lead to more effective interventions and prevention.

Adolescence is a time of tremendous growth and development. Teens begin to interact more with peers and romantic interest emerges. The onset of puberty has led to rapid growth in muscle mass and gender-specific physical characteristics

and the development of secondary sexual characteristics due to hormonal changes. There are opportunities for risk and there are opportunities for protection. Even typically developing adolescents experience more emotionality and drama and are more likely to engage in rule-breaking behaviors during this stage of development [36]. During adolescence, the brain is also going through rapid changes in the form of a process known as dendritic pruning, which increases the ratio of white matter to grey matter, resulting in greatly increased capability of abstract thought and reasoning over previous stages of development. For example, teens have increased self-regulation and inhibitory control capacity and can solve complex cognitive tasks beginning in the early-mid adolescent development phase [65]. While there is the capability of thinking more abstractly, adolescents are also in the transition from the concrete-operations stage of development and understanding of the world, to the formal-operations stage of development. Piaget's and Elkind's theories on adolescent cognitive development suggested that adolescents form a degree of egocentrism during this transition and before the formal operations stage of development is firmly established. They theorized that the adolescent sense of invincibility stems from this egocentrism and creates a sense of uniqueness [22, 23, 50]. For example, this sense of invincibility, or that bad things will not happen to the individual, may result in giving in to social pressure to experiment with alcohol. A typically rule-abiding teen who has a first romantic interest may suddenly be overcome with emotions; this could lead to behaviors such as sneaking out without permission or breaking curfew to be with a new romantic partner. The new romantic partners may engage in unprotected sex without thinking about STD or pregnancy. In this context, there can be poor linking of consequences. Other examples can include driving too fast or experimenting with drugs despite clear family rules against use. While the adolescent brain is developing increased abilities for complex reasoning and rational thought, it can be short-circuited when overcome by strong emotions.

Michael is a 16-year-old male diagnosed with bulimia nervosa. He has intentionally tried to lose weight through over-exercise and by purging. The medical provider requests social work involvement because the parents have recently found a nicotine vape pen in Michael's room along with a small bag of marijuana. They are insistent that they have no tolerance for his use and want to commence with formal drug testing. When Michael meets with the social worker independently, he states that yes, the items his parents found in his room were his. However, he states that he never uses drugs by himself. He only uses socially. When his mother expresses doubt and compares his use to a peer that was recently caught with drugs in his possession at school, Michael states that he would never use during school because he would not want to jeopardize his performance or get in trouble. *How do you assess Michael's level of risk? The parents are requesting that the provider engage in drug testing for Michael but are seeking your guidance and suggestions. How do you advise the parents to proceed?*

As genetics can shape one's behavior, family background and environmental factors can also influence one's genetics. This process is known as epigenetics, which is the study of outside or environmental influence on genetic expression. In each child's unique environment, there are opportunities for both protective and risk factors. Socioeconomic status (SES) plays a role across many domains in an individual's development. For example, SES can be a protective factor for building resilience against use of substances and or development of substance use disorders. Protective factors include prevention from exposure to violence, access to well-resourced schools, supermarkets with a variety of fresh, high-quality, nutritious foods and safe areas to play. Other protective factors include having parents, care-givers, extended family

members or invested members of the community playing an active role in a child's life and development. Each of these protective factors, or social determinants of health, contribute to reduced environmental stressors which positively affect child health [5], including brain development. When these protective factors are not present or are variably present and the environmental stressors are high, individuals engage in compensating behaviors that can affect brain development. This puts individuals at higher risk for experimenting with substances [24].

Protective and Risk Factors for Adolescent Substance Use

Over the past four decades, researchers in the fields of adolescent health and prevention science have identified a number of risk and protective factors for adolescent substance use. Risk factors predict an increased likelihood that adolescents will use substances, while protective factors predict the opposite. In their review of the evidence base for risk and protective factors, Harrop and Catalano [27] organize these factors into the social domains of community, school, family, and individual/peer. Table 25.1 provides a summary of known risk and protective factors.

Health professionals working with adolescents play a key role in preventing adolescent substance use before it occurs. Knowledge of risk and protective factors informs screening, assessment, and treatment recommendation practices. Even if an adolescent doesn't report substance use, the revelation of multiple risk factors during history-taking should increase concern from a clinician or practitioner that the teen is at heightened risk for substance use. Awareness of protective factors suggests intervention points for building patient and family resiliency against substance use.

TABLE 25.1 Risk and protective factors for adolescent substance use

Domain	Risk factors	Protective factors
Community	Availability of drugs Community laws and norms favorable to drug use Media portrayal of violence Low neighborhood attachment and community disorganization Extreme economic deprivation Transitions and mobility	Opportunities for prosocial involvement (after-school clubs, youth organizations, and community events)
School	Academic failure beginning in late elementary school	Opportunities for prosocial involvement (after-school clubs, youth organizations, and community events) Recognition for involvement in prosocial activities Perception of attachment to school
Family	Family management problems Family conflict Favorable parental attitudes and involvement in the substance use Family history of substance use	Prosocial family involvement (game nights, responsibilities for chores) Family recognition of prosocial involvement Perception of attachment or connection to family

(continued)

TABLE 25.1 (continued)

Domain	Risk factors	Protective factors
Individual/ peer	Early and persistent antisocial behavior Alienation and rebelliousness Favorable attitudes towards substance use Friends who engage in substance use Constitutional factors (sensation-seeking, risk-taking, low harm avoidance, impulsivity)	Religiosity Social skills Healthy beliefs Clear standards for self

Adapted from Harrop and Catalano [27]

Jason is a 16-year-old male who recently quit his public school in favor of an online program which he attends at home. He met his only friends through his older brother, and he doesn't participate in any extracurricular programs or hobbies. During a recent clinic appointment, he shared that these older friends often get drunk while camping on the weekend. Although Jason denies drinking with them, the risk factors present suggest that Jason would benefit from motivational support to increase his protective factors. *"It sounds like you're able to maintain friendships without having to drink. Do your friends support your decision not to drink? What values motivate you not to drink?"*

Adolescent Nutrition in the Context of Substance Use

Poor nutrition, substance use, and withdrawal have similar indicators, such as sudden weight changes, poor digestion, and persistent fatigue. Malnourishment can also result in altered

mental status mirroring substance use. Common symptoms are headaches, dizziness, confusion, and changes to mood. Increased rates of depression, anxiety, and irritability are frequently associated with substance use. Physical indicators of substance and nutrition problems often overlap, such as recurrent illness, increased vulnerability to infections and diseases, poor oral health, skin issues, and diarrhea or constipation. Research also suggests that calorie restriction and other types of restrictive diets used by adolescents to compensate for calories consumed from alcohol use may increase the likelihood of acquiring an eating disorder [29].

Similarly, substance intoxication and withdrawal symptoms overlap significantly with disordered eating. Chesney et al. [13] describe three case studies of youth presenting for eating disorders treatment with gastrointestinal symptoms, food avoidance, and associated weight loss. All ultimately met the DSM-5 criteria for cannabis withdrawal syndrome, but did not meet criteria for an eating disorder. The prevalence of substance use is significantly higher among those with concerns about weight status and poor body image, and those who engage in disordered eating than in the general population [62]. Practitioners working with eating disorder patients are likely to encounter individuals whose substance use is part of their disordered eating presentation. Substance use directly interferes with eating disorder treatment and negatively impact clinical outcomes if not recognized and addressed.

Likewise, it is common for substance use practitioners to find themselves called to address disordered eating behaviors. Such behaviors often escalate during the course of substance use treatment and during early recovery. Wiss [68] states, “for the most part, individuals don’t have much of a relationship to food while using, and while sober their hypothalamus wakes up, appetite and taste return, and oftentimes the eating can be ravenous.” Fears about weight gain in early recovery from substance use disorders can trigger relapse without psychoeducation and treatment planning. Substance use, disordered eating behaviors, and physical inactivity are often

related, and effects that begin in adolescence can continue far into adulthood [32]. Poor nutrition is an environmental factor thought to increase an individual's susceptibility to becoming addicted. Inaba and Cohen [28] suggest that brain chemistry is impacted by poor nutrition, as "there are insufficient vitamins and proteins in one's diet to synthesize neurotransmitters, which leads to substance use to try to balance the brain." While malnutrition signals a variety of problems, nutrition therapy offers promise as part of a more comprehensive intervention for both substance abuse and eating disorders.

Effects of Substances on Appetite

Stimulants, such as nicotine, cocaine, methamphetamine, or prescription medications for Attention-Deficit/Hyperactivity disorder (ADHD) are often the drug of choice for individuals who are seeking to suppress appetite, including those who struggle with disordered eating. In fact, they are marketed as a cure for obesity in the form of diet pills, appetite suppressant teas, and lollipops. Stimulants trick the body into believing basic needs, such as for food and water are met, leading to reduced appetite and subdued thirst. Adolescent females who are concerned with weight loss or maintenance are more likely to use nicotine at more frequent rates [57]. Stimulant medications for ADHD, such as Adderall and Ritalin, are sometimes diverted and used without a prescription or at higher than prescribed amounts for purposes of controlling appetite.

It is not unusual for individuals using stimulants to go without eating for several days, and more frequent users tend to forego meals altogether, instead relying on snacks [68]. Stimulant users tend to favor foods high in sugar that offer less nutritional value. Cocaine and methamphetamine use can cause nausea and facilitate purging [68]. And while stimulants are effective for weight loss, they're especially dangerous because tolerance develops quickly. Users require more

frequent dosing at higher levels, with many adverse side effects. Inaba and Cohen [28] suggest that using stronger stimulants and amphetamines at earlier ages may disrupt the body's own weight-control mechanisms. Malfunctioning weight-control mechanisms set the stage for a lifetime of difficulty with weight management. Voracious appetite and weight gain are common in individuals going off stimulants. Periods of rapid weight loss are followed by rapid weight gain in those who go on and off the drug. Many users follow periods of use with binge-eating behaviors prompted by nutritional deficiencies at the cellular level that cannot be observed by an individual's weight status. Weight gain is frequently a trigger to return to use even when other negative consequences are present.

Opiates also suppress appetite. Frequent use causes digestive issues that have a negative impact on eating and nutrition. Those who abuse opiates tends to prefer foods that are more calorically dense and easily digestible, with lower amounts of fiber (like that found in vegetables, fruits, and meats), and higher amounts of sugar, fat, and salt, typically found in processed or invented foods like candy, crackers, cookies, and bread [68]. Wiss [68] states that compromised gut health can persist for several months. Secondary malnutrition can occur relating to difficulties pertaining to absorption of amino acids, vitamins, and minerals [68]. Diarrhea, nausea, and vomiting are standard withdrawal symptoms and can cause an imbalance of electrolytes like sodium, potassium, and chloride.

Similarly to opiates, alcohol use is associated with nutritional deficiencies that may or may not affect weight status. However, rather than suppress appetite, alcohol use is known to stimulate it. Additionally, alcohol use may also change taste preferences. Individuals who abuse alcohol often gain weight as the alcohol itself is highly caloric, and use may also increase preferences for carbohydrates [35]. Alcohol and other drugs compete with food for corresponding reward mechanisms in the brain. Individuals with more severe alcohol use problems often replace food with alcohol, resulting in

nutritional deficiencies despite the increased calories. Notably, alcohol use is also associated with higher rates of bingeing and purging [68].

Researchers continue to study the mechanism of alcohol-induced weight gain in efforts to understand the relationship between alcohol use and obesity. Historically, researchers theorized that alcohol use reduced inhibition. This theory explained that the associated loss of restraint caused intoxicated individuals to eat more than they usually would. However, new research on rodents suggests that alcohol use produces a neural response, called Agouti-related protein (AGRP), that typically is only activated in instances of starvation [11]. When the researchers blocked the AGRP neurons, the mice ate less even when given the same amount of alcohol [11]. Researchers believe this pattern would be replicated in people, however further research on the physical impact of alcohol use, particularly on adolescent bodies, is needed.

Two of the immediate physical and mental effects of marijuana that impact nutrition are increased appetite accompanied by decreased inhibition. Food intake is controlled by the endocannabinoid system and CB1 receptors, and so appetite increases when receptors in the brain are flooded with tetrahydrocannabinol [28]. However, just as there are many different strains of marijuana, there can be drastic differences in how the body responds to use. In rare cases, marijuana use can cause cannabis hyperemesis syndrome, which causes abdominal pain, nausea, and vomiting. The effects of cannabis hyperemesis syndrome may lead to decreased calorie consumption, dehydration, and nutritional deficiencies.

Somewhat paradoxically, large epidemiological studies of adults and young adults reveal a correlation between marijuana use and lower BMI [53]. Why might people who use marijuana have, on average, lower weight than people who do not use marijuana? One theory suggests that short-term and chronic marijuana use have different impacts on weight gain. Another theory, based on the evidence that people who use marijuana are more likely than non-users to also use other

substances, suggests that the other substances are responsible for suppressing appetite and/or weight gain [18]. A third theory suggests that food and substances compete for the same reward sites in the brain, so an increase in substance use may lead to a decrease drive for food [64]. Certainly, further research is needed to fully understand what effect marijuana has on weight.

Substance Use and Disordered Eating

Substance use and disordered eating behaviors typically begin in adolescence. Both are associated with genetic and biological underpinnings. They symbolize efforts by adolescents to fit in with their peers, develop a sense of identity, individuate from their family of origin, and find initial relief from the many pressures facing young people today. Many similarities exist between substance use and disordered eating and the ways that individuals use them to cope. Substance use and disordered eating involve rigid thinking and extreme behaviors. These behaviors ultimately prove harmful, although intended as an attempt to manage challenging emotions or life stressors. Per Dr. Sarah Chipps [14], “disordered eating pose serious physical threats ... and physical dangers are increased and new dangers are added when substances are also being used.” Rates of comorbidity are staggering. Individuals who meet criteria for an eating disorder are five times more likely to abuse substances than those who do not struggle with disordered eating [66]. Up to a one-third of individuals with eating disorders will meet criteria for a substance use disorder within their lifetime, and 35% of those seeking substance abuse treatments endorse struggles with disordered eating [66]. For individuals with both disorders, the symptoms may occur at the same time or they may appear to switch off as the individual tries different forms of maladaptive coping [14]. Adolescents who rely on these behaviors tend to experience a substantial fear of abandoning the illusion of safety provided by their substance of choice or disordered eating behaviors.

Substance use and disordered eating behaviors are easily accessible, and are initially effective to neutralize emotional, mental, and physical pain. Yet, these efforts do not work well for long. Behaviors must be repeated with increasing frequency in order to avoid additional experiences of pain, and as an alternative to developing healthy social connections. Over time, these behaviors result in diminished health status. They often aid in the development of additional problems and consequences that exacerbate the issues they were intended to resolve. This pattern repeats until the behavior is out of control and attracts the attention of a supportive person in the teen's life, or results in an incident that increases awareness of the problematic aspects of the behavior [66]. Detection is usually accompanied by increased levels of guilt, shame, and remorse [66]. However, as associated stressors rise, there remains a greater need to continue to perform the behaviors. Repeating behaviors, in turn, advances the progression of either or both a substance use or eating disorders.

Substance use and the various styles of disordered eating exist on a continuum. Disordered eating behaviors produce a change in the affective state experienced similarly to a high induced by chemicals. Just as substances including stimulants and opioids produce a euphoric mood, so does the restricting of food intake and drastic self-denial associated with anorexia. Binge-purge behaviors, typically associated with bulimia, produce a feeling similar to a high by taking in copious amounts of calories and forcing them out of the body before they can be absorbed. Binge-eating parallels the process of tolerance, as the more an individual uses or eats, the less able the action is to produce formerly achieved levels of pleasure.

Screening and Responding to Adolescent Substance Use

Historically, substance use treatment for adolescents has been kept apart – both in funding and in delivery – from other health care concerns. This model of care – in which substance use was considered a special issue which could

not be addressed in general practice settings - may have prevented providers from developing the knowledge and skills necessary to address substance use and, in turn, deepened negative attitudes providers had towards people who use substances [51]. Additionally, this model of care was not suited to detecting the early warning signs of emerging abuse and dependence. As a result, instead of intervening early on in the course of a substance use disorder when change is more likely, practitioners responded to fully developed disorders, which are much more challenging and costly to treat. Given the impact substance use can have on adolescents, their families, and their communities, what can practitioners do with their patients to reduce risky levels of substance use and prevent the development of substance use disorders?

Integrating Care with Screening, Brief Intervention, and Referral to Treatment (SBIRT)

In more recent years, efforts and initiatives to integrate substance use and mental health treatment into the general health care setting have led to many clinics and practices adopting the evidence-based practice of Screening, Brief Intervention, and Referral to Treatment (SBIRT) for substance use. SAMHSA defines SBIRT as a “comprehensive, integrated, public health approach to the delivery of early intervention and treatment services for persons with substance use disorders, as well as those who are at risk of developing these disorders” [54]. The goals of SBIRT are to:

- Increase early identification of individuals at-risk for substance use problems
- Educate individuals on the risks of use
- Motivate those at-risk to reduce unhealthy, risky use and adopt health promoting behaviors
- Motivate individuals to seek help and link individuals at high risk to more intensive treatment services
- Foster a continuum of care by integrating prevention, intervention, and treatment services [47]

Since its development, variations of SBIRT have been used with many different populations across numerous settings, including outpatient clinics, primary care offices, emergency departments, schools, and other community locations.

Evidence Base for SBIRT

Researchers have conducted over 15 systematic reviews and meta-analyses of SBIRT in various settings – findings indicate that SBIRT is a cost-effective, flexible intervention which works across populations to reduce risky substance use [43]. More than a dozen professional health organizations, including the American Academy of Pediatrics and American Medical Association, recommend that health care providers of children and adolescents implement SBIRT for alcohol use [47].

However, less research supports SBIRT's effectiveness as an intervention for other drug use. In a systematic evidence review for the U.S. Preventive Services Task Force, Patnode et al. [49] found insufficient evidence on the benefits of primary care-relevant behavioral intervention in reducing self-reported illicit and pharmaceutical drug use in adolescents. Still, some pilot studies suggest that SBIRT may be able to promote marijuana abstinence or reduce consumption amongst adolescents and adults [6, 70]. Overall, SBIRT is a highly recommended practice for professionals who manage the health and well-being of children and adolescents (Fig. 25.1).

Screening

The first component of SBIRT is a quick screening delivered with a validated screening tool to all adolescents receiving health care. The purpose of screening is to quickly identify unhealthy or risky use; positive screens are followed by further assessment to determine the appropriate level of inter-

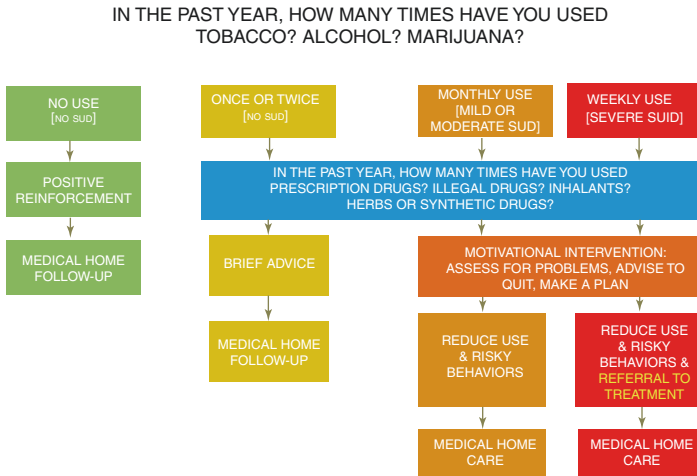


FIGURE 25.1 The S2BI-based approach to clinical SBIRT [37]. (Copyright 2014, Boston Children's Hospital. All Rights Reserved. Reprinted under Creative Commons Attribution-Noncommercial 4.0 International License)

vention. Popular screening tools are the CRAFFT (or its variants), S2BI, BSTAD, and the ASSIST modified for use with adolescents. Clinicians may want to educate themselves on local and state initiatives when choosing which tool to use. Ultimately, clinicians should feel empowered to choose the screener which fits best with their practice area. Additional resources for deciding on a screening tool can be found at <https://sbirt.webs.com/adolescent-screening>.

Brief Intervention

Different models of SBIRT for adolescents have their own algorithms to determine use risk levels and recommended interventions. In general, adolescents with *no use* should receive positive reinforcement, adolescents with *low use* should receive brief advice, adolescents with *moderate or severe use* should receive a brief intervention to increase

motivation to reduce use and risky behaviors, and adolescents with *severe use* should receive motivational brief interventions along with referrals to substance use treatment.

The goal of a brief intervention is to use principles of Motivational Interviewing to elicit a patient's or client's own reasons for change rather than telling them what they should do. Brief interventions are collaborative and nonjudgmental conversations in which the patient or client is treated as the expert of their own life. While a clinician may advise a patient to abstain from any and all substance use, brief interventions are fundamentally a harm reduction tool. This means that a number of strategies may be used to reduce the negative social and physical impacts of substance use. Everything from going to detox to choosing to eat food before playing beer pong can be appropriate topics for a brief intervention.

Practitioners will adapt their approach to brief interventions depending on the patient's "stage of change." The concept of "stages of change" comes from the Transtheoretical Model (TTM) of change, a framework for understanding and intervening with behavior change largely developed and studied in relation to the initiation and cessation of addictive behaviors [19]. Table 25.2 describes each stage of change and their corresponding motivational strategies.

Hailey is a 17-year-old female with a history of disordered eating recently discharged from the hospital after a brief admission for acute abdominal pain and vomiting. She smokes marijuana twice a day, usually to help her relax after work and fall asleep at night. When asked, she says that she doesn't like feeling "dependent" on marijuana to de-stress but she doesn't know what else she can do. She is also saving up for her own car, and she wishes less of her paycheck went towards marijuana. *What motivational questioning could help her decide to reduce her use?*

TABLE 25.2 Stages of change

Description of patients	Stage of change	Motivational strategies
<p>Not planning to make change within the next 6 months</p> <p>Unaware of the consequences of behavior, or</p> <p>Lack confidence in ability to change</p>	Pre-contemplation	<p>Establish rapport</p> <p>Elicit patients' perceptions of the problem behaviors</p> <p>Explore the pros and cons of behavior</p> <p>Develop discrepancy between patients' and others' perceptions of behavior</p>
<p>Intending to make change within the next 6 months</p> <p>Pros and cons of change are roughly balanced</p> <p>High levels of ambivalence may lead to prolonged stay in this stage</p>	Contemplation	<p>Normalize the experience of ambivalence</p> <p>Explore the pros and cons of behavior</p> <p>Examine the patients' personal values in relation to change</p> <p>Elicit statements of intent and commitment to change</p>
<p>Intending to make changes within the next month</p> <p>May have already attempted some changes recently</p> <p>Still considering which actions to take in the future</p>	Preparation	<p>Guide patients to clarify goals</p> <p>Explore options for treatment or support</p> <p>Negotiate a plan</p> <p>Explore barriers to change</p> <p>Develop a list of supports (family, friends, etc.)</p>

(continued)

TABLE 25.2 (continued)

Description of patients	Stage of change	Motivational strategies
Actively making changes but have yet to stabilize May benefit from additional, more extensive changes	Action	Reinforce positive changes and encourage continuation in treatment Identify potential triggers for relapse and create a plan to manage those triggers Provide information and advice as permitted
Achieved initial goal Working to maintain changes	Maintenance	Affirm patients' abilities to change and acknowledge positive changes Assist patients in practicing preventive strategies to reduce risk of relapse Guide patients in processing relapses when they occur

Adapted from Pro-Change Behavior Systems, Inc. [52] and Tomlin et al. [58]

While delivering a brief intervention, a clinician or practitioner moves teens through the stages of change by eliciting and exploring “change talk.” In Motivational Interviewing, “change talk” refers to statements indicating that a client has the desire or ability to change or recognizes the benefits or necessity of changing [42]. Research on Motivational Interviewing suggests a correlation between client statements in favor of change and client-reported levels of outcome success [4]. Therefore, clinicians use Motivational Interviewing skills to increase the amount of change talk which occurs dur-

TABLE 25.3 Finding change talk with DARN-CAT, Miller, W. R. & Rollnick, S. [42]

D esire (I want to change)
A bility (I can change)
R eason (It's important to change)
N eed (I should change)
C ommitment (I will make changes)
A ctivation (I am ready, prepared, willing to make change)
T aking steps (I am taking specific actions to change)

ing brief interventions. Table 25.3 describes a helpful mnemonic for identifying change talk.

One popular brief intervention model designed to elicit change talk is the Brief Negotiated Interview (BNI), which was made in collaboration with Stephen Rollnick, Ph.D., co-developer of Motivational Interviewing. The BNI was originally created to target alcohol use with adults in the emergency department, but it has since been found effective at facilitating a variety of positive health behavior changes in different settings. The script in Fig. 25.2 is a good starting point for practitioners interested in delivering interventions to their adolescent patients.

When possible, clinicians help their patients or clients translate their reasons for change into actionable plans. During the BNI, adolescents will often reveal areas in their lives for which resource referrals could be helpful. A youth drinking after school might say she'd be less likely to do so if she were in an after-school dance program. Someone who uses un-prescribed Adderall for all-night homework sessions might reduce his use if he had better organization skills. A teen smoking marijuana every night to fall asleep could reduce their use if they had other skills for managing their racing thoughts. All these scenarios provide opportunities for

BNI STEPS	DIALOGUE/PROCEDURES
Introduction/Ask Permission 1. Engagement	"Before we start, I'd like to know a little more about you. Would you mind telling me a little bit about yourself?" "What is a typical day like for you?" "How does alcohol/drugs fit in?" "What are the most important things in your life right now?"
2. Pros & Cons <ul style="list-style-type: none"> • Explore pros and cons • Use reflective listening • Reinforce positives • Summarize 	"I'd like to understand more about your use of (X). What do you enjoy about (X)? What else?" "What do you enjoy less about (X) or regret about your use?" <i>If NQ con's: Explore problems mentioned on the screening tool or elsewhere in clinical interview:</i> "You mentioned that... Can you tell me more about that situation?" "So, on one hand you say you enjoy (X) because... And on the other hand you say..."
3. Feedback <ul style="list-style-type: none"> • Ask permission • Provide information • Elicit response 	"I have some information about the guidelines for low-risk drinking, would you mind if I shared them with you?" "We know that for adults drinking more than or equal to 4F/5M drinks in one sitting or more than 7F/14M in a week, and/or use of illicit drugs can put you at risk for illness or injury, especially in combination with other drugs or medication. <i>[insert medical information.]</i> It can also lead to problems with the law or with relationships in your life." "What are your thoughts on that?"
4. Readiness Ruler <ul style="list-style-type: none"> • Readiness scale • Reinforce positives • Envisioning change 	"To help me better understand how you feel about making a change in your use of (X). <i>[Show readiness ruler]...</i> On a scale from 1-10, how <u>ready</u> are you to change <u>any</u> aspect related to your use of (X)?" "That's great! It mean's your ____% ready to make a change." "Why did you choose that number and not a lower one like a 1 or a 2?" "It sounds like you have reasons to change."
5. Negotiate Action Plan <ul style="list-style-type: none"> • Write down Action Plan • Envisioning the future • Exploring challenges • Drawing on past successes • Benefits of change 	"What are you willing to do for now to be healthy and safe? ...What else?" "What do you want your life to look like down the road?" <i>[Probe for goals.]</i> "How does this change fit with where you see yourself in the future?" "What are some challenges to reaching your goal?" "What have you planned/done in the past that you felt proud of? Who/what has helped you succeed? How can you use that (person/method) again to help you with the challenges of changing now?" "If you make these changes. how would things be better?"
6. Summarize & Thank <ul style="list-style-type: none"> • Reinforce resilience & resources • Provide handouts • Give Action Plan • Thank the patient 	"Let me summarize what we've been discussing, and you let me know if there's anything you want to add or change..." <i>[Review Action Plan.]</i> <i>[Present list of resources]:</i> "Which of these services, if any, are you interested in?" "Here's the action plan that we discussed, along with your goals. This is really an agreement between you and yourself." "Thanks so much for sharing with me today!"

FIGURE 25.2 Brief negotiated Interview algorithm, Boston University School of Public Health BNI ART Institute [9]

potential resource referrals: a dance program, tutoring, and brief therapy, respectively. Practitioners should consider a wide spectrum of possible interventions while talking with young people about their substance use.

Referral to Treatment

For a small number of adolescents, referral to further substance use assessment and treatment is warranted. When talking about treatment referrals, practitioners should maintain a nonjudgmental tone, refer back to the screening results and content from the brief intervention, and clearly state their concern and professional reasoning for discussing the treatment referral. When substance use poses a significant safety risk, practitioners may consider breaking confidentiality to discuss treatment options with a guardian or caregiver.

A multidimensional patient assessment delivered by a substance use/chemical dependency professional should evaluate the youth across the six dimensions recommended by the American Society of Addiction Medicine (ASAM). These dimensions are:

1. Acute Intoxication and/or Withdrawal Potential
2. Biomedical Conditions and Complications
3. Emotional, Behavioral, or Cognitive Conditions and Complications
4. Readiness to Change
5. Relapse, Continued Use, or Continued Problem Potential
6. Recovery/Living Environment

The results of an assessment will indicate a recommended treatment setting. For less severe use and fewer needs, treatment in an outpatient or intensive outpatient setting may be recommended. As severity and needs increase, adolescents may be better served by partial hospitalization, residential, or inpatient treatment [3].

Practitioners should familiarize themselves with reputable treatment referral resources local to their state, county, and city. Across the United States, one of the most comprehensive and user-friendly directories is the SAMHSA Treatment Locator (www.findtreatment.samhsa.gov or 1-800-662-HELP). Additionally, a patient's insurance coverage will

impact the treatment locations available to them, and practitioners can play a helpful role in helping patients and families navigate the often complex and confusing world of private and public insurance.

Several other considerations for referring to treatment are worth a brief mention. First, “warm hand-offs” in which the practitioner directly contacts the substance use treatment professional, preferably while the adolescent is in the office, are helpful when possible. Second, timing is critical, as young people become less likely to attend treatment the longer it takes to have a first appointment following the initial referral to treatment [47]. Finally, when teens express low motivation to go to treatment, practitioners shouldn’t abandon their nonjudgmental approach out of a sense of urgency or frustration. Instead, they should explore the ambivalence and screen for barriers to seeking care. This conversation may plant the first seeds of change, and if the practitioner nurtures a supportive conversational environment, then the young person is more likely to come back to discuss treatment options in the future.

Challenges and Barriers to Detecting and Intervening for Adolescent Substance Use

Caregivers and medical providers often miss indicators of adolescent substance use, especially in the early stages. Many adolescents are good at hiding their use. Adults are often hesitant to believe youth who are high achieving, doing well academically, get along well with others, are involved in athletics or extracurricular activities, and appear healthy, can be experimenting with substances too. And yet, the data is clear. While adolescent substance use rates are declining overall, abuse rates of specific substances, like marijuana, vaping, and e-cigarettes have increased as the perceived risk of harm associated with them drops [30].

Despite encouraging declines, too many teens use substances. The longer use goes unnoticed, the greater the associated consequences and side effects suffered by the teen, their family, and community.

Detection is challenging in part because use depicts itself in behavioral indications that mirror the effects of puberty. Adolescence is a time of rapid physical and emotional change. It can be difficult to determine whether behavioral, emotional, cognitive, or physical changes are hormonal or puberty-related, or due to the effects of a substance. It is important to know the behaviors and signs to look for to detect adolescent use in the early stages (Fig. 25.3). Early detection is critical as the gap between experimental use and routine or problematic substance use is relatively short, as is the gap between problematic use and addiction. Following detection, use should not be ignored, allowed or taken lightly. Those who get help at earlier stages of use typically have better outcomes [41].

While many erroneously believe that it is impossible to get help for an individual struggling with substance use until they hit “rock bottom,” the opposite is true for adolescents. The process of behavior change to reduce or eliminate substance use is easier when the adolescent is still engaged with their support network and has structure and purpose from their affiliations with productive, prosocial activities like school, work, and hobbies. Interventions should also address associated risk factors and consequences such as reducing the likelihood of being sexually assaulted, getting into legal trouble, or being unable to procure financial aid for college due to drug possession charges. Without early intervention, those who are genetically predisposed to addiction or have higher vulnerability stemming from risk factors will suffer disproportionately. Of the 9% of substance-using adolescents who need treatment, over 90% are unaware that they need help without intervention from a loved one or treatment provider [67].

Substance	Indicators of Intoxication	Indicators of Withdrawal
Alcohol	<ul style="list-style-type: none"> • Odor of alcohol • Watery, glassy, red or bloodshot eyes • A red or flushed face • Slurred Speech • Poor coordination and balance • Risk-taking behaviors 	<ul style="list-style-type: none"> • Nausea • Headache • Sweating • Shakiness
Marijuana	<ul style="list-style-type: none"> • Potent and distinct odor • Dilated pupils • Bloodshot eyes • Slowed mental processing time • Slowed reaction times 	<ul style="list-style-type: none"> • Irritability • Insomnia • Decreased appetite • Heightened Anxiety
Stimulants	<ul style="list-style-type: none"> • Dilated pupils • Nosebleeds • Restlessness • Stroke • Seizure • Methamphetamine and crack: odor of cleaning products, chemicals, burned plastic. The sweat of a person who is under the influence may smell like ammonia. 	<ul style="list-style-type: none"> • Exhaustion • Increased appetite • Restlessness • Slowed movement • Insomnia
Opioids	<ul style="list-style-type: none"> • Euphoria • Slowed breathing • Constricted pupils • Injection sites • Dry mouth • Itching • Constipation • Heroin: vinegary, acidic odor 	<ul style="list-style-type: none"> • Restlessness • Vomiting • Muscle and bone pain • Involuntary leg movements • Diarrhea • Goosebumps and/or chills • Insomnia
Hallucinogens	<ul style="list-style-type: none"> • Dilated pupils • Tremors • PCP: Smells like a permanent marker 	<ul style="list-style-type: none"> • Tremors • Headaches • Sleepiness • Depression
Inhalants	<ul style="list-style-type: none"> • Slurred speech • Confusion • Euphoria • Dizziness • Poor coordination • Drowsiness • Disinhibition • Nausea • Distorted speech: Helium can restrict vocal cords causing changes in the sound of a person's voice directly after use 	<ul style="list-style-type: none"> • Sweating • Nausea • Abrupt mood changes • Irritability • Insomnia

FIGURE 25.3 Signs an adolescent is under the influence. (Adapted from the National Institute of Drug Abuse [44])

Working with Caregivers, Respecting Confidentiality

When it comes to adolescent health concerns, providers walk a tight line. Substance use complicates the treatment of other medical needs and can have implications on discharge planning. To ensure the health, safety, or treatment adherence of the patient, providers may need to share sensitive healthcare information with caregivers. Practitioners must offer as many opportunities as possible for the adolescent to exert their independence and autonomy, and yet are also typically encouraged to involve and provide support for caregivers. Families of teen substance users tend to receive less assistance from their support networks than families of children with other medical issues do, likely due to stigma. The experience of helplessness can be overwhelming. Being the caregiver of an adolescent with substance use problems is frequently a source of guilt, shame and fear.

When feasible, caregivers should play an active role in helping their child avoid or resolve substance use problems. Data shows adolescent entry into treatment is correlated with parental pressure [33]. Involving caregivers in care offers numerous benefits. The caregiver has the ability to influence the adolescent and make supportive changes to the environment. Caregivers and adolescents both benefit from gaining insight regarding the impact of family circumstances on use. An effective response to adolescent substance use often involves the entire family, especially with substance-using teens who are the most difficult to treat [61].

Yet, assurances of confidentiality for adolescents seeking health care is equally important in regard to information exchange. Most medical societies recommend restricting parents' access to healthcare records during adolescence. Adolescents who are worried about privacy communicate less openly about risky behaviors, including substance use, with healthcare providers. Providers are encouraged to meet individually with adolescents on a routine basis to encourage communication about sensitive topics. Two large national

studies showed that one-quarter of the adolescents polled reported that they did not seek necessary health care due to concerns about privacy [26]. Care-seeking for sensitive health services, such as substance use, is likely impacted even more by privacy concerns [26].

Studies affirm that adolescents are more likely to seek help when they believe providers will keep information confidential, have expertise regarding substance use, and will be compassionate and nonjudgmental [8]. Laws on the federal and state level provide legal protections for confidential care in order to encourage adolescents and others to seek help for substance use problems. Additionally, it has been theorized that response to treatment may be enhanced when adolescents are responsible for some medical decision-making [33]. Many states allow adolescents to consent for their own substance use treatment and do not require parental consent. The implications remain unclear as data demonstrates many adolescents who need treatment for substance abuse problems do not self-initiate care [33]. Privacy rules that apply on a national level include HIPAA, the Health Insurance Portability and Accountability Act of 1996, and the Federal confidentiality requirements, or 42 CFR Part 2. Both impact the delivery of health services to adolescents and their caregivers.

HIPAA is a national law that governs how healthcare providers, healthcare plans, and healthcare clearinghouses protect patients' privacy [73]. Per HIPAA, providers can share information with family members if they have informed the patient of their intent to do so, and the patient agrees or does not object [1]. Likewise, if a patient is incoherent and incapable of providing information, practitioners can ask accompanying loved ones if they know which substances were consumed to inform treatment if the healthcare provider finds it in the patient's best interests [1].

42 CFR Part 2 pertains specifically to those seeking or providing care for substance use disorders, and limits the

accessibility of substance use disorder patient records. It ensures confidentiality to those who seek substance abuse treatment services by protecting identifying information. 42 CFR Part 2 was written in the 1970's when stigma about addiction and fear of prosecution for violating drug laws limited willingness to access treatment. It prevents disclosure or use of any information about an individual unless they have consented in writing to the disclosure. Disclosure is limited to the minimum information necessary. 42 CFR Part 2 was not created with the intent to restrict communication with caregivers, however that can occur especially in states which require the minor's consent for care. 42 CFR Part 2 also requires that any shared information bears a notice of prohibition on re-disclosure, which restricts providers who receive information from making further disclosures. However, 42 CFR Part 2 applies only in very specific situations, whereas HIPAA applies more broadly.

Paul is a 16-year-old male with a history of ADHD who lives with his mother and step-father in a rural area. He smokes marijuana daily and binge-drinks alcohol on the weekend, and does not perceive his use as problematic as he has many friends who use at similar or increased rates. Consequences to use include school failure, significant parental conflict, association with substance abusing peers and alienation with previous non-drug using peer group, and theft of family vehicle. Paul also reports incurring minor damage to the family vehicle while under the influence of alcohol, and states parents are unaware. Paul refuses to sign a release of information to allow providers to share information about his use with his parents. *Does the provider's mandated duty to warn regarding driving under the influence of alcohol supersede 42 CFR Part 2? What information, if any, can be disclosed without Paul's consent?*

Intoxication in the Clinic

How to Address Acute Intoxication in the Clinic

Discussion about confidentiality and mandated reporter laws in the state of residence must precede any interaction between a clinician and adolescent because of the possibility of disclosure of information during an appointment. If an adolescent were to present in clinic and there was reason to believe he or she was intoxicated, it would be reasonable for the clinician, nurse, medical assistant or patient coordinator interacting with the patient to consult with the clinic social worker or medical provider, if available, to engage the person in a mini-mental state exam [25]. The purpose of the mini-mental state exam is to determine if the individual is oriented to time, place, person, and situation. While this is not an infallible way to determine the degree of intoxication, it is a good proxy for determining current level of functioning.

Mini-Mental State Exam

Orientation to Time:

- What year is this? (1 Point)
- What season of the year is it? (1 Point)
- What is the month and date? (1 Point for each)
- What day of the week is it? (1 Point)

Orientation to Place

- What is the name of this place? (1 Point)
- What floor are we on? (1 Point)
- What city and state are we in? (1 Point)
- What county is this? (1 Point)

Immediate Recall

- I am going to say 3 objects After I say them, I want you to repeat them. They are: “Apple” “Table”

- “Penny.” Now you say them. Remember what they are because I’m going to ask you to name them again in a few minutes. (1 Point for each)
- (Interviewer: Repeat until all 3 are learned)

Attention (either item)

- (a) Subtract 7 from 100, then subtract 7 from the answer you get and keep subtracting 7 until I tell you to stop. (1 Point for each correct answer, maximum 5 Points)
- (b) Spell the word “world” backwards. (1 Point for each correct letter, maximum 5 Points)

Delayed Recall

- What are the 3 words I asked you to remember? (1 Point for each)

Naming

- Show patient wrist watch and pen and ask to name them. (1 Point for each)

Repetition

- Repeat the following sentence exactly as I say it. “No ifs, ands, or buts.” (1 Point)

3 Stage Command

- Now I want to see how well you can follow instructions. I’m going to give you a piece of paper.
- Take it in your right hand, use both hands to fold it in half, and then put it on the floor. (1 Point for each command, maximum 3 Points)

Reading

- Show patient attached Fig. 25.4 and ask patient to read what it says at the top of the page silently to him/herself, and then do what it says. (1 Point)

Copying

- Give patient clean sheet of paper and ask him/her to copy the design printed on the figure. (1 Point)

Writing

- On same sheet of paper, ask patient to write a complete sentence. (1 Point)

Total (Maximum score = 30)

If an adolescent is assessed to be intoxicated in clinic, it is important to determine if the teen came to clinic with a parent or guardian. A social worker, clinic nurse or medical provider can meet with the parent/guardian to learn about their knowledge of the teen's intoxication. In this situation, depending on the teen's condition and ability to wait while the provider meets with the parent/guardian, it would be important to learn about the teen's history of substance use, access to substances and frequency of use as well as the parent/guardian's level of concern with the current intoxication and the parent/guardian's plan for managing the teen in the near term. It would also be important to discuss strategies to intervene in the longer term. Depending on the age of the adolescent, it is also important to understand how the adolescent became intoxicated. There is an opportunity to engage in discussion with the parent/caregiver about the level of supervision in the home. There is also an opportunity to engage in education about home safety with regard to keeping alcohol

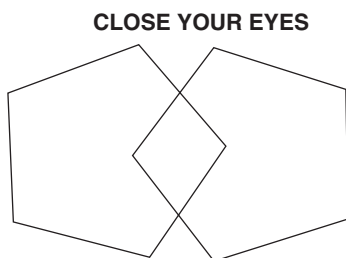


FIGURE 25.4 Mini-Mental State Exam - Reading

and other hazardous substances less accessible to the adolescent.

If the adolescent is clearly intoxicated but oriented and a parent/guardian is present, it is probably best for the parent/guardian to take the adolescent home to allow time for the substances to wear off. However, if the adolescent is demonstrating signs of acute intoxication, is not alert and oriented, for example, is not able to stay awake, is having trouble walking independently, it is important to call emergency medical services to transport the adolescent to an emergency department for a thorough medical evaluation. While such a decision may result in parental distress, it is important for the clinic to have standardized protocols for managing acute medical situations.

If an adolescent is unaccompanied and presents with signs of intoxication, it is important to evaluate the adolescent to determine if they are oriented. If they are oriented, it may be reasonable to contact a parent/guardian to come and pick them up from the appointment. However, if the adolescent is presenting as acutely intoxicated, it would be best to call emergency medical services for transport to a local emergency department for urgent medical evaluation.

If a parent presents in clinic with symptoms of intoxication, the clinician meeting with the adolescent needs to assess several factors. The primary factors relate to immediate safety concerns. The social worker or another available clinician should meet privately with the parent, if safe, to ascertain if the parent is intoxicated and if they are alert and oriented. The clinician meeting with the parent can determine if the parent drove the adolescent to the appointment and if it is their intention to drive home from the appointment. If the parent did drive the adolescent and has been assessed to be intoxicated or not alert and oriented, the clinician and a management representative or person in clinical leadership can jointly meet with the parent to express that it is not possible to allow the adolescent to be transported by the parent due to signs that indicate intoxication and the inherent risks of allowing this to occur. If the clinic has access to security per-

sonnel, it is important to call security staff to be in close proximity, in the possible event that the parent becomes escalated. The clinician and/or the clinic manager must have a conversation with the parent in which they inform the parent that it is not possible to drive the adolescent home due to suspicion that the parent is presenting with signs of intoxication. Conversations must also include discussion about alternative transportation options for the adolescent and parent to safely return home. This could include calling a co-parent, relative, neighbor, taxi, etc. It might include the clinic opting to use discretionary funds to pay for a safe ride home for the adolescent and parent.

Separately, the clinician or a social worker should meet with the adolescent and engage in a discussion and ask the following questions. Has the adolescent ever been transported in a vehicle by the parent when the parent is in a state of intoxication? If so, how often has this occurred? When did this occur? Has the adolescent or another adult ever made an attempt to stop the parent from engaging in this behavior? Additionally, the clinician or clinic social worker can ask the adolescent if the parent has ever offered substances to the adolescent. Based on the discussion, if there is evidence that the adolescent has been transported in a vehicle by the parent under the influence of a substance, there are grounds to make a report to Child Protective Services (CPS). The social worker and/or the clinician can offer to make the report together with the adolescent so that they can hear the report. The adolescent can make the report so that his/her own words are captured by the CPS intake worker. The clinician and/or social worker should meet privately to discuss whether in the moment it is reasonable to inform the parent that a report to CPS will be made.

The clinician should create clinical documentation to describe objective factors that led to concern that the parent was presenting with signs of intoxication. The documentation should also describe the efforts made to assess whether the parent was alert and oriented. Further, documentation should describe efforts to include clinic leadership with

decision-making about efforts to keep the adolescent safe, particularly when it comes to decisions about telling a parent that s/he cannot take his/her child home. There needs to be clear documentation about the decision process that led to the determination that the parent was intoxicated and that it was therefore unsafe for the adolescent to leave and ride in a car with the parent. Documentation should include reporting to authorities about risk to the safety of the adolescent.

If a clinician becomes concerned that a parent is providing substances for the adolescent, it is reasonable for the clinician to consult with or request an appointment with a clinic social worker, if available, to meet with the adolescent to conduct a psychosocial evaluation. Depending on the age of consent for mental health, substance abuse information, sexual and reproductive health information in the state, the clinician should initiate any discussion with an adolescent about confidentiality and the laws limiting confidentiality in the state before embarking on further discussion. Additionally, it is important to discuss mandated reporter laws with the adolescent prior to engaging in the psychosocial evaluation.

Psychosocial Evaluation

With a psychosocial evaluation, the social worker can learn about the adolescent in the context of his/her family of origin. In conducting the psychosocial assessment, the social worker engages in a conversation with the adolescent about their life experiences in the context of their family. The social worker simultaneously forms rapport with the adolescent and learns about their lives across home, school and social domains. Some of the routine questions of a psychosocial assessment include curiosity about substances, experience with trying substances, availability of substances in school and home. The conversation can also include whether the adolescent has any concerns about other's use of substances in the family and if other family members use to excess or to the point of intoxication. Questions at this point can include, do parents or

caregivers ever offer or provide substances to you? And if so, how often?

Safety

Within the context of the psychosocial assessment, it is important for the clinician to assess the patient's physical and emotional safety. It is important to describe what is meant by physical and emotional safety. The clinician should engage in a discussion about how safe the adolescent feels in the home environment. Inquire about history of domestic violence, physical and/or sexual abuse or neglect. It is important to ask the adolescent if anybody has ever touched their body in a way that has made them feel unsafe or has touched their body without permission. Alternatively, one can ask the adolescent if they have ever felt pressured to engage in touch (on their body or somebody else's body, that has made them uncomfortable). Ask the adolescent about the general feeling of safety of their home. The safety assessment should also include questions about the safety of the neighborhood. Ask whether unknown people come to the family home without warning.

The clinician should also ask about feelings related to financial security. Does the adolescent have concerns about the family having enough money to pay for rent or mortgage? Does the adolescent ever worry about the family having sufficient money to pay for food? Does the adolescent hear their parents/care-givers arguing about money or finances?

The clinician can then move on to ask about the presence of weapons, including whether there is a gun in the home. If there is a gun in the home, is it kept in a locked gun safe? Is there ammunition in the home and is it kept locked up and separately from the gun? Does the adolescent have access to the gun? Has there ever been Child Protective Services Involvement with the family?

After conducting a thorough psychosocial evaluation, the clinician can then engage in a discussion with the adolescent about specific concerns about their parent/care-giver supply-

ing them with substances. The clinician can expand the conversation to discuss the history of this practice, the frequency with which it occurs, the substances that are used and the venue in which the substances are consumed. Information should also include whether the adolescent feels the use of substances is coerced or volitional. This can include discussion about the adolescent's motivation to continue using the substance versus thoughts about reducing or stopping use.

The clinician can move on to ask if the adolescent ever rides in a vehicle with the parent who is under the influence of a substance. It is important to form sufficient rapport with the adolescent so that they are aware that the information gathering is out of concern for his/her health and safety. This is understandably a delicate process. The clinician is learning about a parent who is potentially unlawfully supplying a minor with illicit substances. It is possible that there are laws pertaining to mandated reporting about such information. If the adolescent raises an issue about why a clinician would be concerned about a parent supplying substances, the clinician can share information about the consequences of substance abuse on adolescent brain development and about laws pertaining to mandated reporting statute in the state.

The clinician must begin a conversation with the adolescent about mandated reporting requirements and the necessity of making a report to Child Protective Services or similar protective authority. When an adolescent discloses that a parent or care-giver is providing them with substances, the clinician must disclose that such information has to be reported to Child Protective Services. In such instances, it is likely that an adolescent will have strong feelings about such a disclosure and the clinician should have a plan for how to effectively manage such a response. The clinician should take time to inform the clinic manager to discuss possible escalation of behavior and create a plan for safety, before talking with the adolescent about the need to contact protective services. In such circumstances, the adolescent often feels empowered to witness the clinician making the call to protective services and to have the opportunity to participate in the

call. It is important to note that the clinician cannot predict whether Child Protective Services will commence with an investigation or what the outcome of any investigation will be. It is important for the clinician to be present and available for the adolescent to process emotions yet also understanding that the adolescent may have very strong negative feelings about the clinician and about making a report.

Conclusion

Substance use can negatively affect a youth's ability to get appropriate nutrition. In tandem with use, poor nourishment can result in reduced health outcomes, increased risks to emotional and physical wellbeing, and even increased mortality. Adolescents who use substances are more likely to eat a nutritionally inadequate diet that is either low in energy or provides excessive energy. They may miss meals entirely, or routinely choose foods that do not provide the nutrients, vitamins, minerals, or proteins they need. Adolescents may restrict calories, compulsively exercise, purge, or engage in other compensatory behaviors in addition to being less motivated to eat as a result of use. Calorie restriction maximizes intoxication levels. Restriction also functions as an attempt to counterbalance the calories consumed from alcohol, or atone for intoxicated overeating. Clinicians who are working with adolescents with eating or nutritional concerns are highly likely to encounter substance-using adolescents throughout the course of their work.

Adolescents often do not initiate conversations about their substance use. Caregivers and medical providers are often taken by surprise when they catch or encounter teens under the influence, or discover paraphernalia or other tell-tale signs of substance use. However, the first time a teen is found to be using substances is rarely the first time the teen has been using, despite any denials or attempts to minimize

use. Caregivers are concerned about teen substance use, even though most believe *their* teen does not use. As many caregivers are unaware of their teen's use, practitioners must frequently assess for substance use and related nutritional deficiencies directly and privately with adolescents. Such assessment should be conducted privately, away from parents. All discussions related to substance abuse should be preceded by an explanation of privacy guidelines, including HIPAA and 42 CFR Part 2.

Any indications of use must result in monitoring by both healthcare professionals and caregivers. Talk to the teen about the observed changes and related concerns. Whenever possible, share concerns with the parents, when in accordance with the privacy regulations. Teens will likely need help to access resources or supports. Link families with services, including drug and alcohol assessment, mental health counseling, or help to find opportunities to increase involvement in positive, prosocial activities with adult supervision. Addiction often runs in families, and some families may have prior knowledge about addiction and substances. However, many families rely on their child's medical providers to be keen observers of the signs and symptoms of use, and to provide education and referral to assessment and treatment. Other caregivers may be aware of their teen's use, but challenged by their child's refusal to accept help. Education and discussion with providers helps caregivers to develop empathy and understanding for their teen, learn their teen's triggers, and gain strategies for how to help decrease or eliminate their teen's use, particularly in situations where the adolescent is unmotivated to change. Providers are encouraged to work together across disciplines to offer a multidisciplinary approach to address substance use. The inclusion of differing perspectives of harm-reduction, treatment, and recovery are essential to prevent burnout among providers and to address the full range of needs of the teen and family.

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Chapter 26

Nurturing Healthy Transitions: Nutrition, Exercise, and Body Image for Transgender and Gender Diverse Youth

Lara Hayden

I am writing from the perspective of a cisgender queer white fat woman. I have the privilege of working with transgender youth and their families every day as they navigate issues of body image, eating disorders, nutrition, and exercise. I am grateful to have the opportunity to learn from these young adults, and to have the opportunity to share resources with other cisgender adults in how we can improve our support to trans youth. I have also learned from trans and non-binary colleagues who have been generous in sharing their lived experiences and professional expertise (some of whom you will see cited in this chapter). I look forward to continuing to learn from the experts, those with lived experience on these topics, and am committed to centering their voices in future conversations as I continue to work to expand my capacity to support trans youth.

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Why Talk About Transgender Youth and Nutrition?

Providers are often surprised to hear that gender diverse youth have unique needs and consideration when it comes to nutrition. Many assume that discussion of gender identity in health care is relegated to mental health providers helping youth explore gender identity, or even to the doctors who help youth navigate gender-affirming medical care, like puberty blockers and cross-sex hormones. The providers at Seattle Children's Gender Clinic were of a similar mind, until we launched a multidisciplinary Gender Clinic, serving patients up to age 21. We quickly realized that not only were we making many referrals out to the dietitians in our larger Adolescent Medicine department, but that many of our referrals into the Gender Clinic were coming from the dietitians and eating disorder providers we worked with. This trend led us to explore the intersection of gender identity with nutrition, body image, eating, and movement; the more we screened for these overlapping concerns, the more clearly we began to see risk and protective factors for gender diverse youth in having healthy relationships with nutrition and body image. My goal is to arm the adults who support these youth with the knowledge and resources to help every gender diverse youth foster a healthy relationship with nutrition and their bodies.

Eating Disorders in Gender Diverse Youth

One of the risk factors that has received the most attention recently is that of eating disorders in gender diverse youth. In 2018, the Trevor Project, a national nonprofit providing suicide prevention services to LGBTQ+ youth, and the National Eating Disorders Association, a national nonprofit supporting individuals affected by eating disorders, collaborated to produce a report about this unique population. Their report states that within their sample, 40% of gender non-conforming

youth and 39% of transgender male youth reported being diagnosed with an eating disorder [16]. Although research exploring the causes of disordered eating in gender diverse youth is sorely needed, what we know suggests that the stigma of transgender identity, including harassment, discrimination, and lack of social support, is linked to disordered eating behaviors such as binge-eating, fasting, and vomiting to lose weight [18].

Another unique risk for gender diverse youth is managing the distress of a body that does not fit with their internal sense of gender. For youth who are speeding towards a puberty which promises permanent and distressing gendered changes, disordered eating can be a dangerous way to slow the progress of puberty. For example, for a child assigned female at birth who has started to develop breasts and is told to expect their first menstrual period in the next few years, panic can set in for a child who dreams of growing up into a masculine body. Our clinic has seen previously healthy patients hospitalized after the sudden onset of restrictive eating, only to find out during their admission that their goal is to fend off puberty through starvation, because they cannot see any future where they can be healthy and comfortable in their body. Timely access to gender-affirming medical care is crucial for these youth. Treatments like puberty blockers (a reversible medication that essentially puts puberty “on pause” to allow more time for exploration and support) can help prevent emotional distress [10] and buy time for youth and families to explore gender without interruption to nutrition and mental health. Gender-affirming care, combined with support from family and community, can help maintain a healthy foundation for a child’s lifelong nutritional and emotional health.

For youth who have already made a social transition, which might include changing name, pronouns, and appearance to match their internal gender identity, they also face unique challenges. Most adolescents will experience insecurity about their appearance, pressure to fit in with peers, and being measured against unrealistic ideals of body image and

style. In addition to these average adolescent challenges, gender diverse youth often feel the pressure of “passing” as their affirmed gender. “Passing,” or presenting an appearance that convinces people you were born as your affirmed gender, can go beyond the pressure to fit into a beauty ideal, becoming a safety issue for many youth. Transgender and gender diverse youth, particularly transgender women and people of color, are at an increased risk of violence. “Passing” as their affirmed gender can be survival behavior to prevent being targeted for violence [5]. The combination of these obstacles put gender diverse youth at risk for disordered eating. For example, a transgender female teen may strive to appear thin while maintaining traditionally feminine curves, leading her to restrict her food intake while exercising excessively. While these social pressures must be acknowledged, they must also be mediated by supportive and healthy messaging from the adults supporting teens. An environment that celebrates the diversity of bodies for both cisgender and gender diverse people, while emphasizing nutrition and movement for the purposes of self-care and enjoyment, can be a safer space for teens to explore their gender expression and health.

One risk factor that is commonly discussed for eating disorders in people of all genders is the idea of disordered eating as a way to manifest control in their life. This theme takes a unique twist for trans and gender diverse youth. For youth experiencing gender dysphoria, they are often forced to reckon with intense symptoms and difficult choices about medical interventions, but with little to no control over the outcomes. In Washington State and many other states, youth cannot access gender-affirming medical care (including puberty blockers and cross-sex hormones) before age 18 without parental consent. They also cannot legally change names or gender markers on their identification before age 18 without parental support. Even in areas where youth are technically entitled to privacy and confidentiality, this may not play out in reality. For example, if a 14-year-old transgender male patient has parents who do not support his gender transition, there are two layers of limitations. Legally, he can-

not start testosterone therapy to feel more comfortable in his body, and he cannot change his name or gender on his identification, as parents will not consent. Even though the law in Washington State does allow for confidential access to mental health and reproductive health services for patients over ages 13 and 14 respectively, other practical barriers exist. For example, if the patient is covered under his parents' insurance plan and dependent on them for financial support and transportation, it can be impossible for him to see a gender-affirming mental health therapist or make an appointment with a doctor who will prescribe oral contraceptives to suppress his menstrual period. Even the laws that require Washington State's public schools to use chosen name and pronouns and allow access to bathrooms of the child's affirmed gender might not be enforced without strong advocacy from parents. Between these systemic barriers and the distressing permanent changes of puberty, youth often feel like they face insurmountable challenges with no way to make positive change. For youth in these situations, control over food and exercise can be the only area that they feel they can control. Particularly in scenarios where parents and providers have used health and mental health as a "carrot," asking youth to improve these areas before gender care will be provided, disordered eating can feel like a way for youth to take a stand in the power struggle over their body. Youth who already have other risk factors for eating disorder, including a history of restrictive dieting, are most at risk. However, providers at the Gender Clinic at Seattle Children's have also seen patients with no history of body image issues develop an eating disorder in situations like this.

Barriers to Healthy Movement and Exercise for Gender Diverse Youth

Whenever nutrition is discussed with adolescents, healthy movement and exercise are usually mentioned in the same breath. Like any other child, trans and gender diverse youth

need to develop a healthy relationship with both nutrition and exercise for optimal lifelong health. Unfortunately, their access to safe and accessible exercise is limited. School physical education and organized sports, two of the traditional avenues for adolescent exercise, are fraught with danger and discomfort for trans youth. While other aspects of school and after-school recreation are embracing gender diversity, binary gender continues to be a defining focus for these activities. Gender will define what locker room a child will use, what sports will be available with them, what team they can play on, and what uniforms they must wear.

Even in states that are generally supportive of transgender and gender non-binary students, physical activity spaces continue to draw different lines. Washington State is one example of these disparities. In Washington State public schools, once a child has shared their chosen name, pronouns, and how they identify, these schools are required to use only their chosen name and pronouns and allow students access to the bathroom that is most comfortable for the student [15]. However, students are not guaranteed access to the locker room that is most comfortable for the student, and in gym class, they will often be segregated by gender and held to activity standards of their sex assigned at birth. Organized sports are split into male and female teams, and even sometimes male and female sports (ex: baseball vs. softball). Students can choose to play on the team that matches their gender identity, but can only play “boys’ sports” or “girls’ sports.” One transgender male patient at the Gender Clinic had spent his childhood playing softball and despite being very uncomfortable on a girls’ softball team as a transgender male taking testosterone, was advised not to switch to boys’ baseball during his junior year for fear of losing his chance at a college scholarship. Even when playing on the team that matches their gender identity, students face considerable challenges. Young transgender male swimmers are often asked to continue wearing women’s swimsuits, rather than a more gender-neutral option, unless they have had top surgery to remove their breast tissue. Transgender female athletes have been asked to submit proof

of their testosterone levels to prove that they do not carry an unfair advantage in women's sports. While it is illegal to single out one student to ask them for medical information, the policies and laws in place to protect students do not always protect youth from being put in these uncomfortable positions.

Research shows that despite well-intentioned policies and laws, discrimination and harassment continue to pose significant barriers to movement and exercise for trans and gender diverse youth [4]. For medical providers, it is common to see youth drop out of organized sports as gender dysphoria and distress increases. In addition to losing the physical activity and mental health benefits of exercise, children may lose the routine, structure and sense of community of a team, at the time they need it most. Families may request a waiver from gym class for transgender and gender non-binary students when access to supportive locker rooms and activities are not available.

However, these waivers then put the onus for access to exercise on youth and families. This poses a two-fold risk for youth: no physical exercise or unsafe exercise with no adult oversight. Some youth will not have access to any healthy movement options outside of a school or organized sports setting. When a doctor recommends joining a gym or even taking a walk around the neighborhood, they may not be aware of the lack of resources for families to follow that directive. For families of relative privilege, who have the money to join a gym or live in a safe neighborhood, some youth still find that their local gym may not have a safe locker room, or that they don't yet feel comfortable walking around their community in the clothes that match their gender. For families of a lower socioeconomic status, the idea of paying to join the local YMCA or sending their children out in the neighborhood alone after dark are far out of reach.

For youth who are left on their own for exercise, the risks of injury and over-exercise are present. Youth who are working out in a gym on their own may see experienced adult athletes lifting very heavy weights or doing intense workouts

like CrossFit. Without an adult working out with them, youth may not realize that, yes, they really do need a spotter for weights, or that, pain is not “weakness leaving the body”, but instead can sometimes be the sign of an injury that needs attention. Over-exercise, lying about how much exercise, and exercising secretly can also be early warning signs of disordered eating behavior. When disordered eating is discovered during a doctor’s visit, parents are often shocked to learn about their child’s eating and exercise habits. Since gender diverse youth are particularly vulnerable to eating disorders, support from adults in establishing a healthy relationship with food and movement is key. Just like children need supervision and support when learning about brushing teeth, doing homework, and managing money, they need healthy messaging from the adults around them about nutrition and exercise so they are not left to fill in the blanks with advertising and misinformation.

Nutrition as a Support for Gender Affirmation

As with other adolescents, nutrition is an important building block of wellness for trans and gender diverse youth. Nutrition takes on particular importance for youth who are taking gender-affirming medications such as puberty blockers and cross sex hormones. The providers prescribing these medications will discuss nutrition with patients when medications are prescribed, but it is even more important for parents and other adults to support youth in understanding and implementing these recommendations.

For youth taking puberty blockers, the focus will be on using nutrition and exercise to support healthy bone density. Puberty blockers are a reversible medication that can be given to youth in early to mid-puberty. They work to press “pause” on puberty, preventing further development of sex characteristics such as breast growth and menstrual periods for children assigned female at birth, and preventing deepen-

ing voices and development of facial hair for children assigned male at birth. While there is no evidence that puberty blockers will affect adult height, bone density development must be carefully monitored for the time that children are on puberty blockers [3]. The building of healthy bone density is strongly influenced by the presence of sex hormones in the body, so when those hormones are blocked, patients are not building bone density at the same rapid pace as their peers who are not on puberty blockers. Anecdotal reports of young adult patients have suggested that patients, especially those assigned female at birth who later transition to male, may catch up to their peers once the puberty blocker is stopped and sex hormones are added. Many will have an average adult bone density, but research continues to provide more definitive guidance.

For those reasons, the goal is to support healthy bone density during the time that youth are taking puberty blockers without cross-sex hormones, which can range from six months to four years. The Endocrine Society recommends several approaches to optimize bone density: eating a calcium-rich diet, regular weight-bearing exercise, and regular testing and supplementation of Vitamin D [3]. Since all of these behaviors are great foundations for lifelong health, this a great time for adults to help kids get into the habit. Keeping in mind the larger goal of establishing a healthy relationship with food and exercise, it may take some time and creativity to help youth find ways to achieve these goals that feel like perks, not punishment. Experimenting with a full range of calcium-rich foods to find what works for each child is worthwhile, especially for those who may have food aversions, like youth on the autism spectrum and others with sensory sensitivities. Milk, yogurt, and cheese are great natural sources of calcium. Vegetables including broccoli, kale, Chinese cabbage, and spinach can also be good sources. If needed, foods fortified with calcium like tofu, cereal, and juice can help boost intake [9]. As mentioned earlier, youth may need help overcoming internal and external barriers to physical activity; adult help with identifying weight-bearing exercise can be key. Weight-

bearing exercise forces the body to work against gravity, which helps build and maintain bone density. Exercises that qualify include walking, jogging, dancing, hiking, tennis, and weight training. [8]. As mentioned earlier in this chapter, youth may need support locating trans friendly exercise spaces and activities. There are an increasing number of inclusive, supportive spaces for youth and families looking for exercise. Urban areas may have more resources available (for example, Seattle is home to events like city-wide All Gender Swims, groups like Fat Girls Hiking and Mountain-Queers, and gyms like Rocket Fitness and Rainier Health and Fitness), but contacting local LGBTQ+ using youth groups and adult LGBTQ+ business associations can be a great place to start the search.

For older adolescents who are on cross-sex hormone therapy (testosterone or estrogen), nutrition and exercise are equally important to highlight. Cross-sex hormones, also known as hormone replacement therapy or HRT, help teens to achieve physical changes that help them feel more comfortable in their bodies and affirm their gender identity. Just like any change in growing bodies, these changes can trigger new and challenging feelings about body image, nutrition, and exercise. The role of supportive adults is to help bring awareness of these changes before they happen, and support teens in developing healthy attitudes and behavior around body changes. Hopefully, this will be part of a lifelong conversation about positive relationship with food and body.

While every body reacts differently to any medical treatment, there are some common changes to be aware of for both testosterone and estrogen. As testosterone levels increase in teens who want to become more masculine, results can include changes in body fat, muscle mass, and appetite. Body fat redistribution becomes similar to people assigned male at birth, which means less fat around breasts, hips, and thighs, and more fat around the stomach and torso. People with higher testosterone can build muscle mass more easily with exercise. Patients taking testosterone often men-

tion a sudden increase in appetite; similar to anecdotes from parents with teenage boys who are constantly hungry and eating, people going through a “second puberty” by taking testosterone might expect the same [13].

As estrogen levels increase, teens who want to become more feminine will see their own changes. Body fat redistribution becomes similar to people assigned female at birth: more fat around breasts, hips, and thighs, and less around the stomach and torso. Loss of muscle mass is also possible for teens who are not actively working to maintain it; many patients report loss of muscle mass in arms and shoulders, which can be a welcome change for people hoping to call less attention to broad shoulders, but a challenge for some athletes. Some patients who take estrogen report a small weight gain, although the reasons behind this are unclear; depending on the teen, this weight gain can be a positive change or a source of distress [12].

The specific changes each teen experiences on hormone replacement therapy (HRT) may be less important than the messaging they internalize around those changes. Medical providers need to emphasize in the informed consent discussion for HRT that patients cannot pick and choose the changes they will experience. A trans male patient who is starting testosterone may be very excited about facial hair and low voice but very anxious to avoid increased appetite and fat redistribution; unfortunately, he cannot predict which changes he will experience and needs to be prepared for any combination of them. A trans female patient who is starting estrogen may be very excited about breast development and fat redistribution to her hips but very anxious about possible weight gain and losing muscle mass in her arms; she, too, needs to be prepared for any and all of those changes. While it is important to acknowledge a teen’s own wishes and goals for their transition and their body, adults can also message that all bodies change during puberty (either first or second puberty!) and changes are neither good nor bad, just a natural part of body physiology. Adults can shift the focus of the conversation from good and bad bodies to focus instead on how teens feel

about their changing bodies, and how those feelings can impact teens' actions when caring for their bodies.

While each adolescent is different, there are some experiences and identities that can inform what support teens will need around body changes from HRT. Athletes should be engaged in conversation not only about body changes, but also about how their medical treatment may affect their sports participation. Teens will need support from parents, coaches, and medical providers to advocate for their right to participate in the gendered divisions that feel most comfortable for them. Young trans athletes may need help adjusting their nutrition or training regimens to support changes in appetite and muscle mass. Teens with a history of disordered eating or body image concerns will need support to avoid relapsing into previous unhealthy behaviors and forming a positive relationship to their changing body. This is a great time to engage a mental health therapist with experience in both gender and eating disorder, a dietitian who is trans competent, and make sure that a teen's primary care doctor is keeping a close eye on changes in health behaviors and other health indicators like blood pressure, blood sugar, electrolytes, etc.

Reassurance is a key role that supportive adults can play for trans and gender diverse teens. In addition to the typical adolescent concerns about body image and fitting in, gender exploration and transition can add new dimensions of concern for teens. One common concern is about maintaining access to gender-affirming medical care. As a supportive adult, it is important not to dismiss this concern, but rather to understand it in the context of transgender health history. Medical providers have an unfortunate history of limiting and denying access to gender-affirming health care based on arbitrary criteria, like whether a patient presents as masculine or feminine "enough," or whether they were following all of a doctor's recommendations in another area. Trans youth may fear that parents and doctors will take away their hormone therapy if the teen is not meeting the expectations of adults

in their lives. This can result in a teen lying to their parents or their doctor about potential problems, out of fear, which prevents adults from offering help and support. For this reason, it is important to treat access to hormones as medically-necessary care, rather than a privilege to be taken away. For example, a common instinct for parents is to tell a teen with a history of anorexia that he will have to stop taking testosterone if his weight drops. Instead, parents can let the teen know that they are aware of the challenges of body changes for eating disorder recovery, and will check in with him regularly on how he is feeling about appetite and appearance, so they can help him schedule sessions with a therapist and dietitian for additional support. This reassurance from parents helps make it safe for adolescents to be honest about their behavior and concerns, knowing they will receive help rather than punishment.

What Can We Do to Help?

Medical providers, mental health therapists, and other health professionals have a unique and valuable role in helping trans and gender diverse youth maintain or achieve healthy bodies. These providers are the experts that parents will look to for advice, and the safe space where teens can ask questions and talk freely about their health and bodies. Providers have many opportunities to paint the picture for youth and families of overall health, as something that includes a healthy approach to gender diversity and body diversity, as well as a positive relationship with food and exercise. There are a number of simple changes providers can make to improve their practice and become needed allies for trans and gender diverse youth.

Before providers dive into the more scientific work of screening, assessment, and intervention, it is important to take a step back and examine personal attitudes and approaches to gender, food, exercise, and body. Most providers looking for resources on supporting nutrition for trans

youth have already grasped the basics: trans youth are deserving of health care; positive body image is important for teens; relationships to food, exercise, and body image are complex. However, it is crucial to go deeper and examine what internal biases every person picks up from living in a society that has strict (and often unhealthy) ideas of gender, bodies, and health. Parents and teens have internalized these same ideas, whether they are healthy or not, and they rely on providers to help debunk and reframe these concepts for their family.

Popular culture emphasizes that there is one type of “normal” body (white, cisgender, able-bodied, neurotypical, thin). The further a body is from this “normal,” the more likely the person is to be punished by social systems, including medical care, government services, social interactions, and law enforcement. For youth exploring gender and navigating body image, they get the message that their identities and bodies are the problems, and if they can change themselves to fit in the “normal” box, their problems will be solved. Evidence shows that trying to change gender identity [17] or manipulate body size is dangerous to youth health and mental health. This means that youth need supportive adults to combat that messaging. Youth need to hear that there is a wide variety of ways to be healthy and happy, and that their identities and bodies deserve to be recognized and celebrated. To put it another way, if a person or a body does not fit in the “normal” box, the problem is with the box, not the person!

Fortunately, there are concrete ways for providers and parents to bring these ideas to life for adolescents. It can be as simple as teaching children the names of anatomical body parts that any person can have (i.e., vagina and vulva vs. “girl parts”). Puberty is an important opportunity to talk about both gender and body image. Adults can teach kids that feelings about gender and sexuality are normal as they approach puberty, and that gender and sexuality continue to change for many people throughout their lives. Providers can educate

parents and youth that changes in height, weight, and body shape are normal throughout puberty, and that bodies will continue to change through adult life.

Increasingly, providers are employing a weight-neutral approach in working with patients. The Health at Every Size movement (see Chapter on this topic) encourages a focus on health habits such as nutrition and exercise and deemphasizes weight as a measurement of health. Ideally, kids and teens can develop a positive body image over time with adult support. However, it is important to acknowledge the reality that body positivity is more difficult for some than others. Specifically, evidence suggests that even with gender affirming medical care, trans and gender diverse teens often continue to struggle with other dimensions of body image [1]. This is when looking to LGBTQ+ health's history of harm reduction is helpful. Body neutrality is a realistic and helpful goal for many adolescents. Body neutrality does not demand that a person loves their body, but rather that they just acknowledge what their body can do for them and make an effort to keep their body safe and functional. For a teen who is struggling with body image issues, this might shift the focus from feeling good about the way their body looks to acknowledging that in order to go to school and go to a concert with friends, they need to fuel their body with food, water, and sleep.

For adults who are new to these themes and ideas, it can be a challenge to learn how to talk about gender and body image with youth. Here are some phrases and reframes that can help:

- There is no wrong way to have a gender. You can identify and look any way that feels comfortable for you.
- Gender, and how you express your gender, are fluid for most people over time, so it's ok to grow and change.
- Everyone's transition is different. Whether you medically or socially transition or not, your gender is valid and I respect it.
- All bodies are good bodies.

- People of all shapes and sizes can be healthy.
- There is nothing wrong with you or your body; you are not a problem to be solved.
- Your body is deserving of kindness and care, no matter what it looks like.
- It's ok to have hard days with body image. If you can't love your body right now, it's ok to try to be body neutral. You can just appreciate what your body can do and do your best to keep it safe.
- I would like to focus on how your body feels rather than how it looks.
- I would like to focus on health indicators that tell me about your body's function (ex: blood sugar, thyroid, cardiac health), rather than your weight, which just tells me about how gravity affects your body.
- I want you to be happy and healthy; what are your goals?
- My job is to help give you the information you need to make choices for yourself and your body.
- It makes sense that you have struggled with body issues. Our culture is not very kind to people with different bodies and genders, and you've probably heard a lot of negative things about your body. It's ok to seek out new messages about your body now.
- Having a healthy relationship with your body and your gender is a lifelong process, and it's not always straightforward. It's ok to feel like you're taking two steps forward and one step back. You can celebrate small victories and also be kind to yourself when things are hard again.

For providers looking for support around these themes, there are some great resources and providers to learn from:

Health at Every Size: <https://haescommunity.com/>

Body Trust Provider Certification: <https://benourished.org/body-trust-provider-certification-training/>

Three Birds Counseling and Supervision: <https://www.threebirdscounseling.com>

Have Heart Wellness: <http://www.haveheartwellness.com>

There are also some great resources for youth who are exploring gender and body image:

T-FFED (Trans Folx Fighting Eating Disorders): <https://www.transfolxfightingeds.org/>

Let's Queer Things Up: <https://letsqueerthingsup.com/>

The Body Is Not An Apology: <https://thebodyisnotanapology.com/>

NO LOSE: <http://nolose.org/>

Both medical providers and mental health providers often have a set of standard screenings they do with every adolescent, helping to detect needs around mental health, home safety, sexual activity, and more. Most providers are trained to ask questions about food and activity, although it is notable that these questions can sometime focus narrowly on weight, BMI, and other factors that do not actually provide insight as to a teen's overall relationship with food and body. Some providers have begun to think about gender identity more globally, asking every patient how they identify and what pronoun they use; this is progress to be applauded! Ideally, providers should reframe this conversation for themselves as an opportunity to learn how patients are relating to and caring for their body, in all ways.

For teens who are feeling comfortable and confident in their bodies, this is a great time for providers to offer reassurance and reinforce positive messaging about gender and body diversity. For youth who might be exploring gender beyond their sex assigned at birth or those struggling with relationship with food and body, this conversation is even more important. With what is known about the co-occurrence of gender dysphoria and disordered eating behavior, both groups of youth are exponentially vulnerable. Research suggests that providers and patients can benefit from mutual screening between these groups. Specifically, a provider can make it a practice to automatically ask every patient exploring gender about their relationship with food, exercise and body image; every patient struggling with dis-

ordered eating and exercise behavior can be given space to talk about gender identity [2].

When providers do identify a patient who is struggling with both gender dysphoria and disordered eating, it can be difficult to know where to start, and how to approach treatment. Parents and providers can both feel overwhelmed, and might suggest to focus on one problem at a time. Often, this looks like putting off gender-affirming care to focus on eating disorder care. While this temptation makes sense in some ways, the logic behind it is flawed. Both gender dysphoria and eating disorder are life-threatening diagnoses, when left untreated. Research also suggests that patients recover more effectively when treated concurrently [14]. It can be helpful to acknowledge the very personal emotions and biases that can play into these conversations. Despite being loving and supporting their child on an intellectual level, supportive adults may still harbor the hope that something else might be “causing” their child to be transgender/gender non-binary. Parents may hope that once their child’s eating disorder (or mental health or other co-occurring physical health condition) is treated, their child will go back to identifying with their sex assigned at birth. That belief, whether conscious or unconscious, is not supported by research, and can hinder timely and appropriate treatment of the adolescent as a whole person. Providers can help parents come to an agreement about how to support their child in both affirming their gender and developing a healthier relationship with food and body.

Once the adults in a child’s life are ready to support them in finding gender-affirming eating disorder care, it can be challenging to find the right care. Most traditional eating disorder care has been designed for white, middle to upper class, cisgender heterosexual women. In addition to the social discomfort of discussing personal and challenging issues with people who do not share the patient’s identity, there are more concrete challenges to accessing traditional eating disorder

care. The current standard of care for eating disorder treatment in adolescents is Family Based Therapy (FBT). In addition to being inaccessible to many due to cost, location, and its time intensive nature, FBT requires the full participation of supportive parents. Because transgender and gender diverse youth are less likely to have supportive parents [6], this can bar them from the benefits of FBT. While there are no current treatments recommended specifically for eating disorder treatment for gender diverse youth, there are alternatives to FBT that may be more accessible for this group. Enhanced Cognitive Behavioral Therapy (CBT-E) is an alternative to FBT that has shown promise in effective behavior change for eating disorders [11]. CBT-E consists of individual therapy, so teens can participate on their own if parents are not present or supportive.

For transgender and gender diverse youth whose symptoms require a higher level of eating disorder care, new barriers emerge. Many eating disorder treatment programs are designed for women, implicitly or explicitly. These explicitly women-only programs exclude transgender boys and non-binary youth, and even when programs are willing to accept transgender girls, trans girls may fear the confrontation or discrimination that is a common experience for trans women in “women-only” spaces. In programs that allow patients of all genders, youth may find themselves matched with clinicians who repeatedly use the wrong name and pronouns for the patient, and who are not aware of how gender dysphoria and eating disorders can interact. In the Gender Clinic at Seattle Children’s, providers have had difficulty finding residential treatment programs that will allow patients to continue access to their gender-affirming medications (puberty blockers, testosterone, estrogen) during their treatment. Eating disorder treatment can be challenging for patients in the best situation, so these challenges for transgender and gender diverse patients can deter any participation in needed treatment.

Case Studies and Trans Voices

Brianna

Brianna is a 17-year-old transgender female who first sought out gender-affirming medical care at age 15. When Brianna came to clinic, she had been thinking about gender for about six months. Her family was supportive of her gender transition, but concerned about her overall well-being. Brianna reported that in the past, she had been feeling numb but could not figure out why. She had recently started seeing a therapist who specialized in gender, and in addition to concerns about depression and anxiety, she was working with the therapist to address feeling socially isolated and passing thoughts of suicide. Parents also expressed concern that Brianna wasn't getting enough nutrition. Doctors in the past had warned family of her low weight, and Brianna herself stated that she missed meals frequently, but not with the intent of losing weight.

Gender clinic providers told Brianna that it was likely that she was experiencing not just the effects of gender dysphoria, but of several challenges at once that could make it hard to be healthy and happy if treated individually. Her providers worked to connect Brianna with a multidisciplinary team who could start working with her to unravel her wellness concerns and begin a holistic treatment plan. Through the course of her treatment, Brianna has since engaged with a primary care provider, an adolescent medicine specialist, a dietician, two psychologists, and a psychiatrist.

Through meetings and care conferences with different providers, Brianna's diagnostic picture became clearer. In addition to gender dysphoria, she learned how her symptoms fit the criteria for depression, anxiety, autism spectrum disorder, and ARFID (Avoidant/Restrictive Food Intake Disorder). Brianna's adolescent medicine provider worked with her family on a plan to start a testosterone blocker and estrogen, along with pursuing the other supports she needed. Her adolescent medicine provider and primary care doctor worked together to reach the ARFID diagnosis, and connected her

with a dietitian. With the goal of expanding the range of foods Brianna could eat and helping her develop coping skills and knowledge to ensure she gets adequate nutrition, she met with her adolescent medicine doctor monthly and her dietitian every two weeks. Her psychologist recognized some characteristics of autism spectrum disorder and worked with the adolescent medicine provider to connect Brianna to a psychologist who specializes in both autism and gender. This specialty psychologist confirmed the autism diagnosis and provided the ongoing psychologist, who focused on gender, with some autism-specific resources. Both psychologists helped to identify a psychiatrist who could prescribe a medication to help Brianna manage symptoms of depression and anxiety. The provider team helped Brianna and her family recognize that all of these diagnoses can present together and affect each other, and to ensure everyone had common goals about Brianna's health and happiness.

After 18 months in care, Brianna is in a much happier and healthier place. She has socially transitioned and is recognized as female in all areas of her life. She is eating three meals per day and is approaching an average weight for the first time; she continues to see her dietitian for support. Her mood has improved; she has started making friends and dating, and has fewer thoughts of suicide. She continues to take an antidepressant and see her psychologist. She is making plans to pursue gender-affirming surgery after her 18th birthday and to go to college in a few years. Her adolescent medicine doctor, who manages both her gender care and her eating disorder care, will continue to work with her until age 21 to ensure that Brianna has the support she needs for her gender transition and eating disorder recovery.

Atticus

Atticus is an 18-year old non-binary person who was assigned female at birth. When Atticus came to clinic, they (they, their and them are patient's chosen pronouns) were 16 and had come out

as non-binary at age 15. At that time, they were a thin person with a weight and body mass index in the average range. They had a history of depression, anxiety, and ADHD, and had recently been discharged after an inpatient mental health stay. Atticus and their parents disagreed about gender-affirming medical care for Atticus. Atticus was eager to begin testosterone therapy, believing it would help them feel more comfortable in their body. Atticus' parents felt strongly that their mental health should be treated and "resolved" before any gender-affirming medical care could be initiated. Atticus felt that mental health care was being used as a "carrot" or a barrier to gender care, and refused to see the therapist and psychiatrist that had been recommended after their inpatient mental health stay.

Over the next two years in care, Atticus' struggles intensified. They began restricting their food intake and rapidly lost weight, and they were diagnosed with anorexia nervosa. They participated in several eating disorder programs, including a lengthy inpatient medical stay, a residential program, and an intensive outpatient program. While participating in treatment, they did gain back some weight, but as they restricted food less, they began to compensate by purging after meals and over exercising. Atticus and parents continued to disagree about gender-affirming care; their parents saw their new struggles with eating disorder as another condition that should be "resolved" before testosterone. While Atticus had struggled with suicidality in the past, their symptoms became more severe, with them continuing to refuse therapy and medication management, stating that they did not know if they wanted to get better or continue living. Atticus stated that once they turned 18, they would transition on their own and felt that being independent would help them cope with the eating disorder and mental health as well.

Upon turning 18, Atticus did assert some independence in their medical care; they continued attending appointments for eating disorder management in our clinic. They shared that while they had gained motivation to consider recovery so that they could focus on college classes and gender transition, they were frustrated that patterns of disordered eating were

hard to break after so long. They requested referrals to a therapist and a psychiatrist who had experience with both eating disorders and gender, and eventually found a team who they felt was supportive. While they did not become fully weight-restored, they did notice a decrease in self-harm and some eating disorder behaviors such as purging. They continued to struggle with their relationship with their parents, who were supporting Atticus by allowing them to live at home for their first semester of college classes but still not supportive around gender transition.

Eventually, Atticus requested a referral to an adult primary care provider who could help them start testosterone and oversee their eating disorder recovery. Atticus says it is reassuring to have a provider with whom their parents have never been involved, so they feel their care is truly private; they also agreed to use a primary care provider who works in the same clinic as their psychiatrist, so that the two can coordinate to support Atticus' care. At our last appointment, Atticus expressed disappointment that they continued to experience suicidal ideations and eating disorder behavior despite all their hard work. The team reminded Atticus that it is important to celebrate their victories as well as acknowledging the challenges ahead. Providers congratulated Atticus on reducing harm to their body, connecting with new supports, identifying a hope for recovery, and completing their first semester of college, and wished them well on their continued journey to adult care.

*Riley, in His Own Words: Excerpted
with Permission from Athlete Riley McCormack's
"Becoming Me: Transitioning, Training
and Surgery" [7]*

"Even when I had socially transitioned, sometimes in the heat of the moment during a softball game, the other players on the field would call me by my birth name. It became harder and harder to focus on just playing. I felt uneasy, not right. I've

learned to call this sense of unease ‘dysphoria’- I struggled to play sport as a transgender athlete - whenever “she” or “birth name” were ever accidentally used, I understood, but little by little sport, often a happy space for me, became a frustrating, angry space...While riding home in a Lyft (a taxi summoned by a mobile phone app), the driver and I got on the topic of sports. We talked about what professional sports teams we loved (Chicago Cubs!), then he asked what sports did/do I play? I hesitated for a moment... deciding whether to bend the truth or come out as trans. I was scared and worried that the driver would be unfriendly, even aggressive towards me or ignorant of the trans community, and I’d have to explain. I told him I played volleyball, basketball, and baseball in high school. In reality, I played softball. I lied. In our society, boys play baseball, girls play softball. The Lyft driver mentioned he didn’t know high schools had men’s volleyball teams. I simply mumbled ‘yeah’ and let it go for fear of continuing that line of conversation. We went right back to professional sports. I took a breath, relieved. I felt sad in the moment. I didn’t like having to go against my values and be dishonest, but I was afraid. Today, I ran jamming to my music, running with the beat, thinking how I used to run around the track in high school before volleyball or softball practice. I miss running to train for something. I can’t play on the girls’ team anymore because I started T (testosterone) over a year ago. I can’t play on the guys’ team because I still have a chest that bounces up and down. So where do I go? I pick up my pace a little and run harder. Today my friend told me she found a gay softball league to play in. I’m happy for her, but I can’t help feeling sad also. I don’t belong to the lesbian/dyke community anymore. I’m passing more and more each day as I progress in my transition. I can’t help but feel loss about a community that once made me feel accepted. I think back to my experiences of playing sports in high school, playing intramurals in college, and how much fun they were. I wish I could join a lesbian softball league because I would feel most comfortable playing there. I can’t join now because I’m seen as ‘not female’ due to the T. I worry that people will think I’m “cheating” because I

have some sort of physical advantage due to the T. I listened to my friend talk about softball and kept silent. I can't play a team sport in the middle of transitioning unless I were to find an all queer/trans team, but I want to play with all different types of people, not just queer people. Running frees my mind and body from the trapped feelings of dysphoria. It provides the space where I don't have time to tear myself down or wonder how everyone else reads me. At times I can feel the T pumping through my veins. I feel powerful and more connected to my body. With each run I can feel my muscles becoming more defined. I can feel my muscles work harder. I feel my body becoming me with each run."

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