Susan G. Forman · Jeffrey D. Shahidullah
Editors

Handbook of Pediatric Behavioral Healthcare

An Interdisciplinary Collaborative Approach

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SGF
To Karen L. Westphal and Krista J. Stewart. First students, now lifelong friends.
JDS
In memory of my grandfather, Donald R. Clapp (1937–2013), for his love and encouragement.

Preface

The need for an interdisciplinary, collaborative approach to the provision of behavioral healthcare for children and adolescents has become apparent as a result of the comorbidity of physical and behavioral health problems; the prevalence of a range of mental health issues; the lack of access to behavioral health services for substantial numbers of youth and families in need of treatment, evidence-based treatments that in some cases are both pharmacologically and behaviorally based; and the need for evaluating treatment outcomes in multiple settings to which varying professionals have access. This book addresses the delivery of high-quality pediatric behavioral healthcare services that are multi-tiered, evidence-based, and integrated, involving interprofessional collaboration across child serving systems, such as the pediatrician's office and the school. The book sets forth an approach that reflects the relationship between biological and psychosocial development and between pediatric physical health and behavioral health problems. Behavioral aspects of commonly occurring chronic physical health conditions as well as physical health aspects of high-incidence mental health and educational problems are addressed. Service delivery approaches that emphasize prevention as well as treatment and recognize the role of systems in youth functioning are described.

This volume provides direction for facilitating interprofessional and inter-organizational collaboration around screening, assessment, and diagnosis, prevention and treatment planning and provision, and treatment monitoring and evaluation. It will be a resource for the wide range of professionals involved in behavioral health and physical health service delivery for pediatric populations. These professionals include practitioners in pediatric medicine, clinical and school psychology, nursing, counseling, social work, marriage and family therapy, physical therapy, pharmacy, and public health, as well as university trainers, researchers, and policy-makers in these areas. The book is organized in four parts which address the following topics: foundations of interdisciplinary, collaborative practice; behavioral health aspects of chronic physical health conditions; physical health implications of behavioral health and educational problems; and crosscutting issues relevant to common pediatric conditions.

The first part of the book, Foundations of Collaborative Pediatric Healthcare: Theory and Frameworks, addresses foundational issues in collaborative pediatric behavioral healthcare service delivery. Theoretical bases for this approach to healthcare are included, as well as the essential elements and processes of this approach. This part includes chapters on Systems of

Pediatric Healthcare Delivery and the Social-Ecological Framework; Multi-tiered, Evidence-Based Systems of Support; and Interprofessional Collaboration.

The second part of the book, Chronic Physical Health Conditions: Behavioral Health Aspects, addresses behavioral health issues associated with common chronic pediatric physical health conditions. Chapters include Obesity, Diabetes, Asthma, Epilepsy, Traumatic Brain Injury/Concussion, Cancer, and Chronic and Recurrent Pain. Each chapter addresses (a) background—definition, etiology, diagnosis, prevalence, physical health outcomes; (b) psychosocial concomitants and consequences; (c) psychosocial screening and assessment/evaluation; (d) prevention and intervention; (e) implications for interprofessional care; (f) a case study; and (g) conclusions and future directions.

The third part, Behavioral Health and Education Problems: Physical Health Implications, addresses common pediatric behavioral health and educational issues that have significant physical health concomitants and implications and/or are likely to present in pediatric medical practices. Chapters include Externalizing Disorders, Internalizing Disorders, Attention-Deficit/Hyperactivity Disorder, Autism Spectrum Disorder, Learning Disabilities, Substance Abuse, Eating Disorders, and Sleep Disorders. Each chapter addresses (a) background—definition, etiology, diagnosis, prevalence, outcomes; (b) physical health implications; (c) screening and assessment/evaluation; (d) prevention and intervention; (e) implications for interprofessional care; (f) a case study; and (g) conclusions and future directions.

The last part, Cross-Cutting Issues, addresses issues that cut across behavioral health service provision for common pediatric conditions. Chapters include Coping with Chronic Illness and Medical Stress, Treatment Adherence, and School Reintegration After Illness. Each of these addresses: (a) definition and prevalence of the issue; (b) assessment, prevention/intervention, monitoring, and evaluation approaches; (c) implications for interprofessional care; (d) a case study; and (e) conclusions and future directions. The final chapter in this part, Future Directions for Integrated Pediatric Behavioral Healthcare, synthesizes major issues presented in this volume and presents a set of conclusions and areas for future work that will lead to progress in high-quality behavioral health service delivery.

It is our hope that this volume will provide a knowledge base for healthcare practitioners who wish to move forward in provision of integrated services and for the university-based educators who provide training for future and current professionals. In addition, we hope that this book sheds light on the organizational and systems issues that are barriers to integrated service delivery and the actions that administrators and managers in healthcare organizations can take to address these barriers and facilitate integrated professional functioning. Finally, we also hope that in presenting the current knowledge base, we have illuminated areas for further research, the results of which can make the potential of integrated pediatric behavioral healthcare a reality.

New Brunswick, NJ, USA Susan G. Forman
New Brunswick, NJ, USA Jeffrey D. Shahidullah

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Her research and scholarship focus on factors that influence intervention implementation, the implementation of interprofessional collaborative approaches to pediatric behavioral healthcare, and the effectiveness of behavioral and cognitive-behavioral interventions in educational settings. She has authored approximately 100 publications, including *Implementation of Mental Health Programs in Schools: A Change Agent's Guide*, published by the American Psychological Association. She has served on the editorial boards of many psychology and education journals, including *School Psychology Review* and the *Journal of School Psychology*. Her work has been supported by grants from the US Department of Education, the National Institute on Drug Abuse, the National Institute of Mental Health, the National Science Foundation, and the American Psychological Association, as well as a number of corporate and family foundations.

She has also served on the executive boards of the School Psychology Division of the American Psychological Association and the National Association of School Psychologists and has served as chair of the Council of Directors of School Psychology Programs. She is a fellow of the American Psychological Association and has been elected to membership in the Society for the Study of School Psychology based on her scientific contributions to the field.

Jeffrey D. Shahidullah, PhD, is a licensed psychologist, a National Register Health Service Psychologist (HSP), and a Nationally Certified School Psychologist (NCSP). He is currently an assistant professor of school psychology within the Graduate School of Applied and Professional Psychology at Rutgers University. He also holds an appointment as an adjunct assistant professor of pediatrics at Rutgers Robert Wood Johnson Medical School. Dr. Shahidullah earned a BA in psychology and EdS in school psychology from Baylor University. He then earned a PhD in school psychology at Michigan State University. He completed his APA-accredited predoctoral internship at the Children’s Hospital of Philadelphia (CHOP) and postdoctoral fellowship at Geisinger Medical Center, both in pediatric psychology. While at CHOP, he was a Leadership Education in Neurodevelopmental Disabilities (LEND) fellow. Dr. Shahidullah’s clinical, research, and training interests pertain to the development and delivery of models of integrated behavioral healthcare that are evidence-based and coordinated among the numerous systems in which children and adolescents interact—the family, school, community, and healthcare system. He is also interested in models of interdisciplinary training and collaboration among healthcare providers.

Part I

Foundations of Collaborative Pediatric Behavioral Healthcare: Theory and Frameworks

1

Systems of Pediatric Healthcare Delivery and the Social-Ecological Framework

Jeffrey D. Shahidullah, Erica Lee, Rachel Shafrir,
and Liza Pincus

Abstract

Research continues to elucidate the finding that children's functioning is composed of numerous interdependent influences such as physical and psychological health, and ecological contexts which are inextricably linked. However, our nation's healthcare delivery system has not traditionally followed this framework in adequately addressing whole-person needs within a holistic framework. This care has often been fragmented (i.e., physical health providers functioning separately from behavioral health providers) and not coordinated among the numerous systems (e.g., family, school, healthcare) in which children interact. This chapter aims to highlight the importance of using a broader systems orientation and social-ecological framework in pediatric healthcare delivery.

Current Status of Physical and Behavioral Health Problems

Chronic health conditions among children and adolescents in the United States cause significant impairment in individuals and families, as well as financial burden to school and medical systems, employers, and federal spending. Defined as a prolonged health issue that prevents children or adolescents from attending school regularly, or doing usual schoolwork or activities, the estimated prevalence of chronic health conditions in US children is 15–18 million (25%) according to the *National Survey of Youth-Child Cohort* (Van Cleave, Gortmaker, & Perrin, 2010).

One implication of this high prevalence of chronic health conditions among children is the likelihood that these conditions will persist into adulthood. For example, childhood obesity is the strongest predictor of adult obesity (Whitaker, Wright, Pepe, Seidel, & Dietz, 1997). Therefore, children risk cardiovascular disease, hypertension, orthopedic problems, and social stigmatization in

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adulthood. Obese children are more likely to need disability services when they become adults, leading to higher welfare costs, lower employment, and lower educational status than non-obese individuals. As another example, asthma persists in adulthood in at least 25% of individuals. Roughly 1.4% of children experience disability due to their asthma, and asthma-related expenditures continue to increase into adulthood (Perrin, Bloom, & Gortmaker, 2007).

According to mental health surveillance among children from 2005 to 2011 (Perou et al., 2013), 13–20% of US children experienced a mental disorder in a given year. Most commonly, children were diagnosed with ADHD (6.8%), followed by behavioral or conduct problems (3.5%), anxiety (3.0%), depression (2.1%), autism spectrum disorder (1.1%), and Tourette syndrome (0.2%). Approximately 4.7% of adolescents aged 12–17 reported illicit drug use in the past year, 4.2% reported an alcohol abuse disorder in the past year, and 2.8% reported cigarette dependence in the past month. The suicide rate for adolescents aged 10–19 was 4.5 suicides per 100,000 persons in 2010 (Perou et al., 2013). An estimated 40% of children with one psychiatric disorder meet criteria for at least one other (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003). Children with mental disorders are at greater risk for chronic physical health conditions such as diabetes, asthma, and epilepsy than children without mental disorders (Perou et al., 2013).

Mental disorders among individuals under the age of 24 cost $247 billion annually in the USA, including spending on healthcare, special education, and juvenile justice services, as well as from decreased productivity (Perou et al., 2013). Costs to children and adolescents include difficulties at home, with peers, and at school (Kessler, Foster, Saunders, & Stang, 1995), as well as associated risks for substance use, criminal behavior, and other risk-taking behaviors (Copeland, Miller-Johnson, Keeler, Angold, & Costello, 2007). Because youth with mental health problems are also at risk for mental disorders in adulthood, this in turn contributes to decreased productivity, increased risk of substance use and injury, and further healthcare spending.

Healthcare Delivery in the United States for Children and Adolescents

Pediatric healthcare in America is a study in contrast. On the one hand, the USA spends more money on healthcare than any country in the world; on the other hand, patients and their families often struggle with inadequate insurance coverage for common behavioral health concerns due to "carve-outs" (insurance company relegates behavioral care to separate company in which they contract with) and limited provider panels (The Commonwealth Fund, 2015). Many children have access to specialist providers, renowned hospitals, and specialty care centers across the nation that provide leading edge care; yet, many children lack access to timely and appropriate care and "fall through the cracks" in terms of healthcare access, especially during pivotal times in which an illness is developing or its effects could be remediated more effectively by prevention and early intervention efforts. Research continues to elucidate the finding that children's functioning is composed of numerous interdependent influences such as physical and psychological health, and ecological contexts which are inextricably linked. However, our nation's healthcare delivery system has not traditionally followed this framework in terms of adequately addressing whole-person needs within a holistic framework. This care has often been fragmented (i.e., physical health providers functioning separately from behavioral health providers) and not coordinated among the numerous systems (e.g., family, school, healthcare) in which children interact.

These realities of service delivery are particularly concerning given the increasing number of youth in America who experience physical health (Perrin et al., 2007) and behavioral health concerns (Perou et al., 2013). In response to dissatisfaction with the state of the healthcare delivery system, a number of innovations have regained traction (e.g., integrated care and patient-centered medical home models), or have been initiated (e.g., "Triple Aim" goals and the Affordable Care Act [ACA]) over the past decade to improve delivery and patient outcomes (Tanenbaum, 2017). Guiding principles of these initiatives include team-based care, consisting of a unified approach from providers across multiple child-serving systems to promote health and prevent disease.

Integrated Care

The concept of integrated care (i.e., the systematic coordination of physical and behavioral healthcare) is not new. For over half a century, Kaiser Permanente has been experimenting with integrated care models in their clinics (The Commonwealth Fund, 2009). Since then, the integrated care movement has progressed in fits and starts. The ACA and patient-centered medical home concepts have recently progressed the movement and have created ways for disciplines that have previously been underrepresented and/or relegated to "specialty care" (e.g., psychology, social work, addiction counseling) to take prominent roles in primary healthcare.

In our nation's healthcare system, physical health and behavioral health services have traditionally been rendered by different providers and in separate settings. Communication and collaboration between physical health and behavioral health providers has generally been suboptimal (Cummings & O'Donohue, 2011). This fragmentation is thought to be the cause of much of our health system's inefficiencies because of duplication of services and/or failure to address critical aspects of care that are assumed to be the responsibility of another (e.g., failure to address contributory mental health issues). This fragmentation has been eased somewhat by the use of electronic health records within healthcare systems and the patient-centered medical home model in the context of integrated care. However, we still have a ways to go in terms of integrating behavioral health systems with physical health systems.

Patient-Centered Medical Home Model

The term "patient-centered medical home" was originally developed in the field of pediatrics in 1967 (American Academy of Pediatrics [AAP] Specialty Council on Pediatric Practice) when the AAP released its Standards of Child Care Report, stating: "For children with chronic diseases or disabling conditions, the lack of a complete record and a 'medical home' is a major deterrent to adequate health supervision. Wherever the child is cared for, the question should be asked, 'Where is the child's medical home?' and any pertinent information should be transmitted to that place" (Sia, Tonniges, Osterhus, & Taba, 2004, pp. 77–79). The patient-centered medical home model in its current state is intended to facilitate interdisciplinary collaboration around both physical and behavioral health concerns in an accessible primary care setting. The model also positions behavioral health providers to operate as part of the healthcare team, rather than be relegated to specialty care, where they are often inaccessible for families. This inaccessibility is due to several factors, notably transportation, location, costs/reimbursement, and stigma in accessing mental health support (Cummings & O'Donohue, 2011). A set of joint guidelines put forth by the American Academy of Family Physicians, American Academy of Pediatrics, American Academy of Physicians, and the American Osteopathic Association (2007) emphasized the patient-centered medical home's role in promoting comprehensive, team-based, coordinated, and compassionate care via a whole-person orientation that encourages shared decision-making. These goals of the patient-centered medical home are facilitated through integrated care.

Triple Aim Goals

The Triple Aim of healthcare reform was proposed by Don Berwick, Nolan, and Whittingham (2008) at the Institute for Health Improvement as a framework for optimizing health system performance by simultaneously: (1) *Improving the individual experience of care*, (2) *Improving the health of populations*, and (3) *Reducing* per capita *healthcare costs*. Berwick points out that each of these indicators reciprocally influences the other two. For example, coordinating behavioral health intervention into medical care may improve underlying behavioral lifestyle causes/contributors of many chronic health conditions (e.g., tobacco use, diet and activity patterns, alcohol abuse/illicit drug use, sexual behavior; McGinnis & Foege, 1993) and/or adherence to treatment regimens. This in turn may reciprocally reduce subsequent hospital/emergency room admissions or unnecessary medical procedures (e.g., diagnostics, imaging). Berwick et al. (2008) suggested that our nation's low performance in each of the aims mirrors the fragmented and uncoordinated health delivery system where providers largely operate within professional silos, and that achieving the Triple Aim must come through making healthcare more integrated by encouraging providers to rely on interprofessional teams.

Bodenheimer and Sinsky (2014) added an additional aim (i.e., "Quadruple Aim") of improving the work life of healthcare providers and their experience in providing care. This fourth aim was added after recognizing that low provider satisfaction, which often leads to provider burnout, impacts our ability to achieve the first three aims. Bodenheimer and Sinsky recognized that part of the antidote to low provider satisfaction was better coordination of care in the context of team-based care. Ultimately, Berwick and Bodenheimer's recommendations signal a paradigm shift that strives for the unification of our long divorced physical health and behavioral health systems and repackaging them in a way that is accessible, beneficial, and sustainable from a patient-, provider-, and population-based perspective.

The Affordable Care Act

The Triple Aim concepts have continued to be driving forces behind governmental healthcare policy—most notably the Patient Protection and Affordable Care Act (ACA, 2010). The ACA was highly aligned with Triple Aim concepts. ACA elements included the provision of incentives via "value-based payment" for patient satisfaction goals and consumer assessment of services provided (*Aim 1: Improve the experience of care*); offering patient-centered medical homes, creating and delivering Accountable Care Organizations and clinically integrated networks (*Aim 2: Improve health of populations*); and by making adequate health insurance coverage more affordable and available to the public by offering incentives to expand coverage, including offering first dollar coverage for preventative care and structuring payment based on quality (*Aim 3: Reduce the* per capita *cost of healthcare*).

The passing of the ACA also provided several provisions which explicitly encouraged integration of behavioral healthcare into primary medical settings in the context of integrated care. Notable changes included new parity regulations (e.g., Mental Health Parity and Addiction Equity Act) which dictated that payments for psychologists, for example, would be the same as medical specialists (Mechanic, 2012). Also, reimbursement for any DSM-5 diagnosis would receive the same coverage as any medical disorder. Additionally, health coverage offered through Medicaid expansion and the "Health Insurance Marketplace" incorporated the "10 essential health benefits" including mental health and substance use disorder benefits. The legislation also required many insurance plans to cover preventative services like behavioral assessments for children in pediatric well-child visits, which align with the screening recommendations of the AAP (Hagan, Shaw, & Duncan, 2017).

However, even after the passing of the ACA, which was intended to address the fragmented and uncoordinated system through team-based care including behavioral health providers, patients still experience significant issues with access to timely and appropriate behavioral healthcare. Even with more people covered, behavioral health services largely remained "carved-out" of many insurance plan carriers. Because providers must rely on separate funding streams for these services, many do not offer behavioral healthcare services. Many may elect to not treat children and adolescents, or may not be accessible from a geographical perspective given location or transportation barriers. This contributes to low treatment initiation rates for patients who are referred by their PCPs to specialty mental healthcare (Kessler, 2012).

Despite the signing of the ACA into law in 2010, which allowed millions of previously uninsured Americans to access healthcare, the future of this healthcare law remains uncertain (Obama, 2017). Despite what occurs with the ACA in the current political climate, the robust and irrefutable research findings which helped to initially spur the passing of the ACA will likely remain salient with providers, researchers, trainers, and administrators in healthcare. The most salient of these findings is the importance of social determinants in health. These social determinants (e.g., effect of exposure to child poverty on brain development, lack of access to healthcare and quality preschool in families of low socioeconomic status), particularly those that occur within the first 5 years of a life, are increasingly recognized as the most significant predictors in health outcomes (Adler, Glymour, & Fielding, 2016).

Mobilizing Diverse Models and Converging Knowledge

The following sections highlight the progression in how social determinants of health have been conceptualized in healthcare delivery. This progression begins with a description of the framework to which many healthcare providers subscribe, and which we now understand to be inherently outdated—the biomedical model. Then, more contemporary social-ecological models for understanding wellness and disease are presented in juxtaposition with the biomedical model.

Biomedical Model

The dominant model of disease in our nation has been biomedical, with biological and physiological mechanisms viewed as the necessary factors to understand, prevent, and treat illness. This model has contributed much to our understanding of health and disease processes and has led to many medical breakthroughs (e.g., the development of vaccines to prevent infectious diseases such as polio and measles). However, it is largely reductionistic in its focus on only those health conditions which have biological or physiological etiologies (e.g., infections, injuries, biochemical imbalances) and in which phenomena can be reduced to smaller parts and understood as molecular interactions. Criticisms of this model include its tendency to minimize the effect of psychological well-being and social context in health outcomes.

While the biomedical model has its roots in René Descartes' mind–body dualism of the seventeenth century, its influence has persisted well into the twenty-first century with an ongoing reluctance of many medical providers to treat conditions that are "above the neck." In fact, the biomedical model remains the dominant conceptualizing framework for many medical professions, including psychiatry (Suls & Rothman, 2004). Despite increasingly robust research pointing to the role that behavioral health factors and the patient's subjective experience play in physical health outcomes (Moussavi et al., 2007), the training of healthcare providers continues to be entrenched in "siloed" training programs. Physicians have little exposure to interdisciplinary collaboration with behavioral health colleagues in formal medical school and residency training (McMillan, Land, & Leslie, 2017).

Biopsychosocial Model

In a significant step forward in how we conceptualize health and illness, George Engel proposed the *biopsychosocial model* (1977, 1980), which maintains the importance of biological factors while also considering psychological and social factors. In the biopsychosocial model, *biological* factors include genetics, physical trauma, nutrition, hormones, and pathogens like germs and toxins. *Psychological* factors include a person's explanatory processes, emotional turmoil, negative thinking, and self-control. *Social* factors include socioeconomic status, culture, education, poverty, spirituality, and religion. This model offers a framework for considering how "nature" and "nurture" interact to shape child development, thus making the model more contextual and cross-disciplinary.

This recognition of the interactive relationship between genes and environment contrasted prior conceptualizations viewing biological and psychological development as mutually exclusive (e.g., Gessell (1925, 1929) understood skill development to be driven primarily by genes; Watson (1928) concluded that all behaviors are determined by the environment). Sameroff and Chandler (1975) described this concept as the "transactional" nature of development, in which interactions between genetic, historical, and environmental milieu over time are crucial to understanding a child's functioning. In the transactional model, nature and nurture are constantly being altered by their dynamic interaction with one another.

Soon after this time, Urie Brofenbrenner developed a model for understanding human ecology (Ecological Systems Theory; 1979). Brofenbrenner's model illustrates that children who are referred for problems within their clinics, schools, and communities arrive with interconnected layers of social and ecological influences. Any biologically oriented or even psychologically oriented intervention will not be sufficient unless perpetuating factors in multiple "systems" are addressed concurrently. The model conceptualizes three predominant systems in which children are influenced:

1. *Microsystems*—those proximal and immediate influences, including reciprocal relationships with families, teachers, coaches, clergy members, and doctors among others; two or more microsystems interact to form *mesosystems* (e.g., child–parent microsystem interacting with child–teacher microsystem).
2. *Exosystems*—include settings and events that indirectly influence processes which occur in the immediate setting of the child (e.g., neighborhoods, health systems, religious systems, schools, extended families).
3. *Macrosystems*—include cultural norms, customs, values, and expectations related to child development; these distal influences both shape and are shaped by broader issues such as health, social, and educational policy stemming from the state and national level.

Sameroff and Brofenbrenner both view the child as existing within an intricate system of variables which influence their development. The *transactional model* and the *social ecological model* emphasize both "proximal" and "distal" influences. Together, this Transactional-Ecological model of development provides a framework for moving past the nature–nurture dialectic, and into one in which biology, psychology, and cultural ecology are interactively related.

Ecobiodevelopmental Model

The *ecobiodevelopmental model* furthers the evolution from the biomedical to the biopsychosocial model. This model signifies a paradigm shift in the understanding of wellness and disease across the lifespan. Like the biopsychosocial model, the ecobiodevelopmental model reaffirms the significance of biological factors, such as genetic predisposition, on psychosocial functioning. However, it does so at the molecular and cellular levels. Further, it elucidates the effect that ecology has on altering molecular biological mechanisms that affect gene expression.

The significance of early developmental exposure to adversity and stress being able to "get under the skin" and alter neurochemistry was demonstrated in the Adverse Childhood Experiences (ACE) study (Felitti et al., 1998). This study demonstrated how early prenatal and postnatal adverse experiences affect future reactivity to stress by altering the brain's developing neural circuitry controlling neuroendocrine responses (Roth, Lubin, Funk, & Sweatt, 2009). Driven by advances in developmental neuroscience, biology, and epigenetics, the model highlights the dynamic continuum between wellness and disease while emphasizing the lasting effect that early experiences have on learning, behavior, and health.

An AAP report (Shonkoff et al., 2012) on early childhood adversity and toxic stress affirmed the use of the ecobiodevelopmental model by healthcare providers in promoting healthier ecologies. This model encourages providers to "think developmentally" while considering salient features of a child's ecology (e.g., nutritional, physical, psychosocial) and how those features become biologically embedded to influence developmental trajectories. Further, it shifts the emphasis toward providers asking, “What has happened to this patient?” rather than, “What is wrong with this patient?”. “Thinking developmentally” encourages providers to “go upstream” in remediating more distal etiologies such as the environmental ecology of a child. This type of remediation requires capitalizing on the collaborative strengths of numerous child-serving systems, including the family/community, educational home, and medical home for the purpose of prevention and intervention within the first 5 years of life.

Neal Halfon in his Lifecourse Health Development Model (Halfon, Larson, Lu, Tullis, & Russ, 2014) cites key factors within the first 5 years of life which influence healthy lifecourse trajectories across the lifespan. These early lifecourse factors include poverty, lack of health services, and exposure to toxic stress. Early lifecourse prevention programs can protect from and remediate the effects of these factors through parent education and educational health literacy programs, exposure to quality language/reading, positive parenting practices/appropriate discipline, access to health services and quality preschool. James Heckman, the Nobel Prize winning economist at the University of Chicago, has made a compelling financial argument for delivering high-quality early childhood (birth to age five) programming to all children (particularly those from poor families) from a societal return-on-investment perspective (Heckman & Masterov, 2007).

Approaching Pediatric Healthcare from a Systems Orientation

To change the focus of our current service delivery system from one that diagnoses and treats chronic health conditions to one that is focused on optimizing population health, we must do a better job at delivering preventative programs which are targeted at the early lifespan of an individual. Such a system requires connecting pediatric offices to a wider range of community services and supports. This is necessary, as child and adolescent developmental considerations include psychological, biological, socio-cultural, and educational factors or systems, which are each interdependent on the other. The following sections describe existing programs and approaches that aim to promote optimal child development through intervening in the context of the numerous systems in which children function, namely the healthcare system (i.e., primary care), educational system (i.e., schools), and family/community system.

Primary Care

Recent healthcare reform efforts have largely centered around increasing the capacity of primary care to address social and behavioral determinants of health using an integrated and collaborative approach. Children typically visit their primary care clinic several times in the first 3 years of life and then continue a regular appointment schedule throughout childhood. This setting offers an accessible venue for prevention and intervention services for physical and behavioral health concerns. Increasingly, behavioral health providers, such as psychologists, social workers, and mental health trained nurses, are integrating their services into primary care. These services can vary considerably in terms of level of integration and collaboration (Heath, Wise Romero, & Reynolds, 2013).

The accessibility of the primary care setting makes it an ideal venue to deliver prevention services like routine screening and anticipatory guidance, as well as clinical interventions. Screening in an interdisciplinary context can address issues such as adverse childhood experiences/toxic stress, developmental delays/disabilities, ADHD, anxiety, depression, and substance use. When behavioral health issues are identified, families often find the option of receiving services from an on-site behavioral health provider as less stigmatizing compared to an external provider. Because child behavioral and developmental problems are so prevalent, there are numerous opportunities for behavioral health providers to improve the standard of care, beginning with well-child visits. These services may include education and strategies around sleep, feeding and toileting concerns, positive parenting, and learning/academic performance, among many other issues.

From a population-based perspective, this setting may be equipped to deliver care within a tiered prevention model: *Tier 1*—universal screening, anticipatory guidance/psychoeducation, health communication promotion, community advocacy; *Tier 2*—on-site coordination of care, brief visits, parenting groups; *Tier 3*—on-site psychotherapy/treatment, multimodal therapies potentially involving psychotropic medications that can be prescribed by the primary care physician in collaboration with a behavioral health provider. If concerns require a higher level of care, patients can be referred to the appropriate setting such as a community-based mental health clinic, child and adolescent psychiatry provider, medical subspecialty clinic, or hospital.

Several studies have demonstrated that integrating behavioral health within primary care yields improved clinical outcomes in patients (Asarnow, Rozenman, Wiblin, & Zeltzer, 2015; Blount, 2003; Butler et al., 2008). Additionally, given that typically only 20% of patients access needed psychological treatment (Kataoka, Zhang, & Wells, 2002) (due to lack of local resources, inability to afford care, difficulty in getting an appointment, travel time, PCP training/time limitations), the integrated primary care model has shown to improve access to and family engagement in treatment as well as satisfaction in care (Asarnow et al., 2015; Burt, Garbacz, Kupzyk, Frerichs, & Gathje, 2014; Pomerantz, Cole, Watts, & Weeks, 2008; Power et al., 2014). Specifically, these integrated medical-behavioral models show that patients have higher rates of treatment initiation and completion, and less treatment dropout compared to non-integrated models (Kolko et al., 2014; Kolko, Campo, Kilbourne, & Kelleher, 2012). Evaluations have begun to assess cost of care reductions due to behavioral health integration in the medical home (Collins, Piper, & Owens, 2013; Yu, Kolko, & Torres, 2017). These models demonstrate financial cost savings as a result of improved management of behavioral health conditions such as depression, which is a major risk factor for several of our nation's most debilitating (and expensive) health conditions (e.g., diabetes, heart disease) (Katon et al., 2003; Unutzer et al., 2008). The cost savings also result from a reduced utilization of medical care and hospital/emergency department visits (Krupski et al., 2016).

School Systems

Schools play a pivotal role in child behavioral and physical healthcare. There are various school-wide multi-faceted approaches to preventing mental illness and physical health issues, as well as promoting health. Schools are an accessible and feasible setting to address behavioral and physical health issues as children spend roughly 40 h per week in schools and may not have access to resources needed at home or other service systems.

Early intervention Children's experiences prior to entering kindergarten are correlated with level of cognitive development, school readiness, and academic outcomes (Ramey & Ramey, 2004). The importance of early intervention delivery within school systems has been highlighted for a number of problems including neurodevelopmental (Myers & Johnson, 2007; Wong et al., 2015) and academic issues including reading and literacy (Lovett et al., 2017). Seminal research by Hart and Risley (1995) found that children living in poverty hear approximately 30 million fewer words by the time they are 4 years old than children from higher-income families. This "word-gap" exposure at an early age predicted academic and occupational attainment for decades to follow. Preschool programs such as Early Head Start focus specifically on addressing positive development of children from impoverished backgrounds (Olsen & Deboise, 2007).

Health prevention and promotion Interventions targeting multiple settings including schools have shown to effectively address common childhood health concerns such as obesity (Nigg et al., 2016). For example, effective obesity prevention programs educate and train children on healthy eating and physical activity through behavior change interventions within early school settings. Additionally, programs may involve teachers, school staff, and parents facilitating their child/students healthy lifestyle through dietary choices or involve increasing accessibility of environments for physical activity and play (McIsaac, Hernandez, Kirk, & Curran, 2016). The *Fun n healthy in Moreland!* intervention is a multi-level, long-term child obesity school-based program that resulted in policy implementation around obesity prevention; increased parent engagement and resources; improved child self-rated health; and increased fruit, vegetable, and water consumption; and reduction in sugary drinks (Waters et al., 2017). Other examples of school-based prevention initiatives include bullying and suicide prevention programming. The Olweus Bullying Prevention Program is a comprehensive, school-wide program aimed to reduce bullying and improve peer relations among students and has been shown to have a positive impact on bullying and antisocial behavior (Olweus & Limber, 2010). The National Association for School Psychologists (NASP) school crisis prevention and intervention training curriculum, PREPaRE, delivers training for educational professionals to serve on comprehensive school crisis teams (Brock et al., 2016).

School-based health clinics The US educational system offers students access to resources that address an array of academic, emotional, or behavioral needs. A review by Stephan, Weist, Kataoka, Adelsheim, and Mills (2007) found that schools are the most common setting in which children and adolescents receive needed mental health services. In recent years, School Based Health Clinics (SBHC) have evolved into comprehensive facilities offering physical and mental health, community, social, and other services for students and their families from professionals in various disciplines working collaboratively (Kubiszyn, 1999). Moore, Barr, Wilson, and Griner (2016) found that offering sexual health services such as STI/HIV testing and treatment, and condom distribution through SBHCs have the potential for positive impact on the sexual health of youth. Evidence suggests that many of the problems associated with adolescent pregnancy and parenting may be addressed by SBHCs that offer healthcare, counseling, and education (Strunk, 2008).

Family and Community Systems

Parenting programs Parenting plays a pivotal role in child development. *The Triple P* (Positive Parenting Program) is a community-wide approach to support parents and families in managing child emotional and behavioral issues. Triple P can be delivered in various settings by a range of providers from different disciplines. It involves five programming levels of increasing intensity to meet various parental needs, with a focus on destigmatizing the need for support by parents (Sanders, 2008). There is a robust evidence-base for Triple P in its effectiveness in reducing behavior problems, improving parenting practices, and enhancing parental self-efficacy (Fawley-King, Trask, Calderón, Aarons, & Garland, 2014). Other behaviorally based parent training programs have also been found to be effective in reducing problem behaviors in young children, which in turn has been linked to fewer issues like school failure and substance abuse in adolescence. The *Incredible Years* (Webster-Stratton & McCoy, 2015) and *Helping the Non-Compliant Child* (McMahon & Forehand, 2003) are evidence-based parenting programs which can be adapted for delivery in a wide range of service delivery systems including schools and primary care for intervention involving the family system.

Home visiting programs Home visitation programs offer a prevention and intervention mechanism to ensure that parents have the knowledge, social support, and resources to provide for the physical, emotional, and developmental needs of their children (Schonberg et al., 1998). These programs can also serve as links for families to public and private community resources. A recent systematic review (Abbott & Elliott, 2017) of home visiting programs in the USA found these programs to help disadvantaged families circumvent obstacles and possibly eliminate health disparities related to disease and accidents. A successful home visiting program is *Healthy Families America* (Whipple & Whyte, 2010), a program that targets overburdened families at risk for child abuse, neglect, and other adverse childhood experiences. Services commence during pregnancy and continue until the child is 5 years old. Its rationale is based on the idea that children need nurturing care from their families in order to lead healthy and productive lives. Healthy Families America is structured on 12 critical elements, but is flexible and allows service providers in the community to design services to meet unique local needs.

The *Nurse-Family Partnership* (NFP) program is a research-based program that aims to improve the health and development of mothers and infants, as well as their future life prospects, through home visits carried out by nurses. The target recipients of the NFP program are low-income mothers who are giving birth for the first time. The visiting nurses aim to improve: (1) pregnancy outcomes by teaching women to improve their prenatal health, (2) child health and development by providing parents with education about competent and sensitive childcare, and (3) the parental lifecourse by helping parents plan future pregnancies, complete education programs, and find jobs (Olds, 2012). A long-term study (Eckenrode et al., 2017) of 357 families enrolled in an NFP program reinforced the long-term success of the program in reducing child maltreatment due to its positive effect on pregnancy planning and economic self-sufficiency.

Community coalitions Grassroots initiatives such as community coalitions can facilitate changes by developing and implementing action plans to address community-wide issues regarding child development and health. These coalitions, which can involve citizens, schools, community agencies, government, religious groups, and media, can serve as powerful tools for stakeholders to facilitate systemic change (Janosky et al., 2013). Examples of successful community coalition models include the *Communities That Care* movement, which involves the development of a local coalition to match empirically based prevention/promotion methods with specific community needs. It has been used community wide to prevent drug abuse, foster positive youth development, and promote psychosocial competence. Another example is the *Healthy Communities Movement*, which emerged due to community recognition that environmental factors influence individual health, and both prevention and treatment are needed. For instance, after recognizing that engine exhaust can trigger asthmatic symptoms in children, a local asthma coalition in a Connecticut town advocated to implement a policy that school buses must turn off their engines as passengers board and unboard (Wargo, 2002).

Conclusions

To meet pediatric behavioral healthcare delivery goals, we must use biopsychosocial and ecobiodevelopmental models, which direct prevention and intervention efforts within these multiple systems. The use of a broader systems orientation and social-ecological framework in pediatric behavioral healthcare highlights the importance of:

- Re-focusing healthcare efforts around a priority of addressing social and behavioral determinants of child and family health, emphasizing prevention and early intervention within the medical home
- Emphasizing proactive approaches of prevention and early intervention, rather than the reactive approach of rendering services when individuals are older and their problems become more severe (which overwhelms the healthcare system, particularly mental health system, with cases that are difficult to treat, time-consuming, and expensive)
- The medical home establishing an active and engaged relationship between the family, school,

and community agencies (e.g., local early intervention programs, social services)

- Team-based approaches that require the blended expertise of multiple health professionals (e.g., physicians, physician assistants, nurse practitioners, psychologists, social workers, counselors, care managers)
- Care that is community-based, coordinated, multidisciplinary, developmentally appropriate, and family-centered
- Efforts to forge a multi-level and multi-systems approach to behavioral health promotion and prevention efforts that can appreciate the various processes that connect the biological, psychological, and social systems overtime

References

Abbott, L. S., & Elliott, L. T. (2017). Eliminating health disparities through action on the social determinants of health: A systematic review of home visiting in the United States, 2005–2015. *Public Health Nursing, 34*, 2–30.

Adler, N. E., Glymour, M. M., & Fielding, J. (2016). Addressing social determinants of health and health inequalities. *JAMA, 316*, 1641–1642.

American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, & American Osteopathic Association. (2007). *Joint principles of the patient-centered medical home*. Retrieved from http://www.aafp.org/dam/AAFP/documents/practice_management/pcmh/initiatives/PCMHJoint.pdf

American Academy of Pediatrics Council on Pediatric Practice. (1967). Patient records and a “medical home”. In *American Academy of Pediatrics, standards of child care* (pp. 77–79). Evanston, IL: Author.

Asarnow, J., Rozenman, M., Wiblin, J., & Zeltzer, L. (2015). Integrated medical-behavioral care compared with usual primary care for child and adolescent behavioral health: A meta-analysis. *Pediatrics, 169*, 929–937.

Berwick, D. M., Nolan, T. W., & Whittingham, J. (2008). The Triple Aim: Care, health, and cost. *Health Affairs, 27*, 759–769.

Blount, A. (2003). Integrated primary care: Organizing the evidence. *Families, Systems & Health, 21*, 121–133.

Bodenheimer, T., & Sinsky, C. (2014). From triple to quadruple aim: Care of the patient requires care of the provider. *Annals of Family Medicine, 12*, 573–576.

Brock, S., Nickerson, M., Louvar Reeves, M., Conolly, C., Jimerson, R., Pesce, R., & Lazzaro, B. (2016). *School crisis prevention and intervention: The PREPaRE Model* (2nd ed.). Bethesda, MD: National Association of School Psychologists.

Burt, J. D., Garbacz, A. S., Kupzyk, K. A., Frerichs, L., & Gathje, R. (2014). Examining the utility of behavioral health integration in well-child visits: Implications for rural settings. *Families, Systems, & Health, 32*, 20–30.

Butler, M., Kane, R. L., McAlpine, D., Kathol, R. G., Fu, S. S., Hagedorn, H., & Wilt, T. J. (2008). *Integration of mental health/substance abuse and primary care (Prepared by the Minnesota Evidence-based Practice Center)*. Rockville, MD: Agency for Healthcare Research and Quality. Retrieved from https://www.ahrq.gov/downloads/pub/evidence/pdf/mhsapc/mhsapc.pdf

Collins, W., Piper, K. B., & Owens, G. (2013). The opportunity for health plans to improve quality and reduce costs by embracing primary care medical homes. *American Health and Drug Benefits, 6*, 30–38.

Copeland, W. E., Miller-Johnson, S., Keeler, G., Angold, A., & Costello, E. J. (2007). Childhood psychiatric disorders and young adult crime: A prospective, population-based study. *American Journal of Psychiatry, 164*, 668–675.

Costello, E. J., Mustillo, S., Erkanli, A., Keeler, G., & Angold, A. (2003). Prevalence and development of psychiatric disorders in childhood and adolescence. *Archives of General Psychiatry, 60*, 837–844.

Cummings, N. A., & O’Donohue, W. (2011). *Understanding the behavioral healthcare crisis: The promise of integrated care and diagnostic reform*. New York: Routledge.

Eckenrode, J., Campa, M. I., Morris, P. A., Henderson, C. R., Jr., Bolger, K. E., Kitzman, H., & Olds, D. L. (2017). The prevention of child maltreatment through the Nurse Family Partnership Program: Mediating effects in a long-term follow-up study. *Child Maltreatment, 22*, 92–99.

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*, 129–136.

Engel, G. L. (1980). The clinical application of the biopsychosocial model. *American Journal of Psychiatry, 137*, 535–544.

Fawley-King, K., Trask, E., Calderón, N. E., Aarons, G. A., & Garland, A. F. (2014). Implementation of an evidence-based parenting programme with a Latina population: Feasibility and preliminary outcomes. *Journal of Children’s Services, 9*, 295–306.

Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., … Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. *American Journal of Preventive Medicine, 14*, 245–258.

Gessell, A. L. (1925). *The mental growth of the pre-school child*. New York, NY: The Macmillan Company.

Gessell, A. L. (1929). *Infancy and human growth*. New York, NY: The Macmillan Company.

Hagan, J. F., Shaw, J. S., & Duncan, P. M. (Eds.). (2017). *Bright Futures: Guidelines for health supervision of* *infants, children, and adolescents: Pocket guide* (4th ed.). Elk Grove Village, IL: American Academy of Pediatrics.

Halfon, N., Larson, K., Lu, M., Tullis, E., & Russ, S. (2014). Lifecourse health development: Past, present and future. *Maternal and Child Health Journal, 18*, 344–365.

Hart, B., & Risley, T. R. (1995). The early catastrophe: The 30 million word gap by age 3. *American Educator, 27*, 4–9.

Heath, B., Wise Romero, P., & Reynolds, K. (2013). *A review and proposed standard framework for levels of integrated healthcare*. Washington, DC: SAMHSA-HRSA Center for Integrated Health Solutions. Retrieved from https://www.integration.samhsa.gov/integrated-care-models/A_Standard_Framework_for_Levels_of_Integrated_Healthcare.pdf

Heckman, J. J., & Masterov, D. V. (2007). The productivity argument for investing in young children. *Review of Agricultural Economics, 29*, 446–493.

Janosky, J. E., Armoutliev, E. M., Benipal, A., Kingsbury, D., Teller, J. L., Snyder, K. L., & Riley, P. (2013). Coalitions for impacting the health of a community: The Summit County, Ohio, experience. *Population Health Management, 16*, 246–254.

Kataoka, S., Zhang, L., & Wells, K. (2002). Unmet need for mental health care among U.S. children: Variation by ethnicity and insurance status. *American Journal of Psychiatry, 159*, 1548–1555.

Katon, W., Von Korff, M., Lin, E., Simon, G., Ludman, E., Bush, T., … Rutter, C. (2003). Improving primary care treatment of depression among patients with diabetes mellitus: The design of the pathways study. *General Hospital Psychiatry, 25*, 158–168.

Kessler, R. (2012). Mental health care treatment initiation when mental health services are incorporated into primary care practice. *Journal of the American Board of Family Medicine, 25*, 255–259.

Kessler, R. C., Foster, C. L., Saunders, W. B., & Stang, P. E. (1995). Social-consequences of psychiatric-disorders. *American Journal of Psychiatry, 152*, 1026–1032.

Kolko, D. J., Campo, J., Kilbourne, A. M., Hart, J., Sakolsky, D., & Wisniewski, S. (2014). Collaborative care outcomes for pediatric behavioral health problems: A cluster randomized trial. *Pediatrics, 133*, 981–992. Retrieved from http://pediatrics.aappublications.org/content/early/2014/03/19/peds.2013-2516

Kolko, D. J., Campo, J. V., Kilbourne, A. M., & Kelleher, K. (2012). Doctor-office collaborative care for pediatric behavioral problems: A preliminary clinical trial. *Archives of Pediatrics & Adolescent Medicine, 166*, 224–231.

Krupski, A., West, I., Scharf, D. M., Hopfenbeck, J., Andrus, G., Joesch, J. M., & Snowden, M. (2016). Integrating primary care into community mental health centers: Impact on utilization and costs of health care. *Psychiatric Services, 67*, 1233–1239.

Kubiszyn, T. (1999). Integrating health and mental health services in schools. *Clinical Psychology Review, 19*, 179–198.

Lovett, M. W., Frigters, J. C., Wolf, M., Steinbach, K. A., Rose, S. A., & Morris, R. D. (2017). Early intervention for children at risk for reading disabilities: The impact of grade at intervention and individual differences on intervention outcomes. *Journal of Educational Psychology, 109*, 889–914.

McGinnis, J. M., & Foege, W. H. (1993). Actual causes of death in the United States. *Journal of the American Medical Association, 270*, 2207–2212.

McIsaac, J. L., Hernandez, K. J., Kirk, S. F., & Curran, J. A. (2016). Interventions to support system-level implementation of health promoting schools: A scoping review. *International Journal of Environmental Research and Public Health, 13*, 200.

McMahon, R. J., & Forehand, R. (2003). *Helping the noncompliant child: Family-based treatment for oppositional behavior* (2nd ed.). New York: Guilford Press.

McMillan, J. A., Land, M., & Leslie, L. K. (2017). Pediatric residency education and the behavioral and mental health crisis: A call to action. *Pediatrics, 139*, 21–41.

Mechanic, D. (2012). Seizing opportunities under the affordable care act for transforming the mental and behavioral health system. *Health Affairs, 31*, 376–382.

Moore, M. J., Barr, E., Wilson, K., & Griner, S. (2016). Support for offering sexual health services through school-based health clinics. *Journal of School Health, 86*, 660–668.

Moussavi, S., Chatterji, S., Verdes, E., Tandon, A., Patel, V., & Ustun, B. (2007). Depression, chronic diseases, and decrements in health: Results from the World Health Surveys. *The Lancet, 370*, 851–858.

Myers, S. M., & Johnson, C. P. (2007). Management of children with autism spectrum disorders. *Pediatrics, 120*, 1162–1182.

Nigg, C., Anwar, M., Braun, K., Mercado, J., Fialkowski, M., Areta, A., … Novotny, R. (2016). A review of promising multicomponent environmental child obesity prevention intervention strategies by the Children's Healthy Living Program. *Journal of Environmental Health, 79*, 18–26.

Obama, B. H. (2017). Repealing the ACA without a replacement—The risks to American health care. *New England Journal of Medicine, 376*, 297–299.

Olds, D. L. (2012). Improving the life chances of vulnerable children and families with prenatal and infancy support of parents: The nurse-family partnership. *Psychosocial Intervention, 21*, 129–143.

Olsen, L., & DeBoise, T. (2007). Enhancing school readiness: The Early Head Start Model. *Children & Schools, 29*, 47–50.

Olweus, D., & Limber, S. P. (2010). Bullying in school: Evaluation and dissemination of the Olweus Bullying Prevention Program. *American Journal of Orthopsychiatry, 80*, 124–134.

Patient Protection and Affordable Care Act (ACA) of 2010, 42 U.S. C. § 18001. (2010). Retrieved from http://www.gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf

Perou, R., Bitsko, S. J., Blumberg, P., Pastor, R. M., Ghandour, J., Gfroerer, S. L., … Huang, L. N. (2013).

Mental health surveillance among children—United States, 2005-2011. *Morbidity and Mortality Weekly Report, 62*(Suppl), 1–35.

Perrin, J. M., Bloom, S. R., & Gortmaker, S. L. (2007). The increase of childhood chronic conditions in the United States. *Journal of the American Medical Association, 297*, 2755–2759.

Pomerantz, A., Cole, B. H., Watts, B. V., & Weeks, W. B. (2008). Improving efficiency and access to mental health care: Combining integrated care and advanced access. *General Hospital Psychiatry, 30*, 546–551.

Power, T. J., Mautone, J. A., Marshall, S. A., Jones, H. A., Cacia, J., Tresco, K. E., … Blum, N. J. (2014). Feasibility and potential effectiveness of integrated services for children with ADHD in urban primary care practices. *Clinical Practice in Pediatric Psychology, 2*, 412–426.

Ramey, C. T., & Ramey, S. L. (2004). Early learning and school readiness: Can early intervention make a difference? *Merrill-Palmer Quarterly, 50*, 471–491.

Roth, T. L., Lubin, F. D., Funk, A. J., & Sweatt, J. D. (2009). Lasting epigenetic influence of early-life adversity on the BDNF gene. *Biological Psychiatry, 65*, 760–769.

Sameroff, A. J., & Chandler, M. J. (1975). Reproductive risk and the continuum of caretaking casualty. In F. Horowitz, J. Hetherington, S. Scarr-Salapatek, & G. Siegel (Eds.), *Review of child development research* (pp. 187–243). Chicago: University of Chicago Press.

Sanders, M. R. (2008). Triple P-Positive Parenting Program as a public health approach to strengthening parenting. *Journal of Family Psychology, 22*, 506.

Schonberg, S. K., Anderson, S. J., Bays, J. A., Duncan, P., Felice, M. E., Frader, J. E., … Ziring, P. R. (1998). The role of home-visitation programs in improving health outcomes for children and families. *Pediatrics, 101*, 486–489.

Shonkoff, J. P., Garner, A. A., & The American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health. (2012). Technical Report: The lifelong effects of early childhood adversity and toxic stress. *Pediatrics, 129*, 232–246.

Sia, C., Tonniges, T. F., Osterhus, E., & Taba, S. (2004). History of the medical home concept. *Pediatrics, 113*, 1473–1478.

Stephan, S. H., Weist, M., Kataoka, S., Adelsheim, S., & Mills, C. (2007). Transformation of children's mental health services: The role of school mental health. *Psychiatric Services, 58*, 1330–1338.

Strunk, J. A. (2008). The effect of school-based health clinics on teenage pregnancy and parenting outcomes: An integrated literature review. *Journal of School Nursing, 24*, 13–20.

Suls, J., & Rothman, A. (2004). Evolution of the biopsychosocial model: Prospects and challenges for health psychology. *Health Psychology, 23*, 119–125.

Tanenbaum, S. J. (2017). Can payment reform be social reform? The lure and liabilities of the "Triple Aim". *Journal of Health Politics, Policy and Law, 42*, 53–71.

The Commonwealth Fund. (2009). *Kaiser Permanente: Bridging the quality divide with integrated practice, group accountability, and health information technology*. Retrieved from http://www.commonwealthfund.org/~/media/Files/Publications/Case%20Study/2009/Jun/1278_McCarthy_Kaiser_case_study_624_update.pdf

The Commonwealth Fund. (2015). *U.S. Healthcare from a global perspective: Spending, use of services, prices, and health in 13 countries*. Retrieved from http://www.commonwealthfund.org/~/media/files/publications/issue-brief/2015/oct/1819_squires_us_hlt_care_global_perspective_oecd_intl_brief_v3.pdf

Unutzer, J., Katon, W. J., Fan, M. Y., Schoenbaum, M. C., Lin, H. B., & Della Penna, R. D. (2008). Long-term cost effects of collaborative care for late-life depression. *The American Journal of Managed Care, 14*, 95–100.

Van Cleave, J., Gortmaker, S. L., & Perrin, J. M. (2010). Dynamics of obesity and chronic health conditions among children and youth. *JAMA, 303*, 623–630.

Wargo, J. (2002). *Policy report: Children's exposure to diesel exhaust on school buses*. North Haven, CT: Environment and Human Health, Inc. Retrieved from http://www.ehhi.org/reports/diesel/dieselintro.pdf

Waters, E., Gibbs, L., Tadic, M., Ukoumunne, O. C., Magarey, A., Okely, A. D., … Gold, L. (2017). Cluster randomised trial of a school-community child health promotion and obesity prevention intervention: Findings from the evaluation of Fun 'n Healthy in Moreland! *BMC Public Health, 18*, 181–116.

Watson, J. B. (1928). *Psychological care for infant and child*. New York, NY: W. W. Norton.

Webster-Stratton, C., & McCoy, K. P. (2015). Bringing The Incredible Years® programs to scale. *New Directions for Child and Adolescent Development, 149*, 81–95.

Whipple, E. E., & Whyte, J. D. (2010). Evaluation of Healthy Families America (HFA) programme: A deeper understanding. *British Journal of Social Work, 40*, 407–425.

Whitaker, R. C., Wright, J. A., Pepe, M. S., Seidel, K. D., & Dietz, W. H. (1997). Predicting obesity in young adulthood from childhood and parental obesity. *New England Journal of Medicine, 337*, 869–837.

Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Brock, M. E., Plavnick, J. B., … Schultz, T. R. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of Autism and Developmental Disorders, 45*, 1951–1966.

Yu, H., Kolko, D. J., & Torres, E. (2017). Collaborative mental health care for pediatric behavior disorders in primary care: Does it reduce mental health care costs? *Families, Systems, & Health, 35*, 46–57.

2

Multi-tiered, Evidence-Based Systems of Support

Thomas J. Power and Seth D. Laracy

Abstract

The most commonly used service delivery systems for pediatric behavioral health care are primary care practices and schools. Increasingly, pediatric behavioral health care is being integrated with medical care to provide more comprehensive and coordinated services for children. Unfortunately, behavioral health services offered in primary care and school are disconnected, resulting in parents being in the position of attempting to coordinate care, which may not be feasible for many families, especially those experiencing heightened levels of stress and limited resources. In this chapter, we propose a cross-system service delivery framework that links integrated services based in primary care with services based in schools. This framework is based on a multi-tier, public health model that provides a continuum of prevention and intervention services.

Multi-tiered, Evidence-Based Systems of Support

Prevailing approaches to providing services to children and their families are based on several models consistent with a developmental-ecological framework in their emphasis on connecting systems of caregiving to promote child development in family, school, and neighborhood contexts. The Systems of Care model was designed to link administrative structures and processes to optimize access to services for individuals with serious mental health problems (Stroul & Friedman, 1986). This model applied to children and adolescents emphasizes the need for services that are comprehensive, coordinated along a continuum of care, and responsive to the unique needs of the child and family (Duchnowski, Kutash, & Friedman, 2002). Although this model has been highly influential, it generally does not account for the critical role that the medical system, particularly primary care, serves in addressing the mental health needs of children (Mandell, Guevara, & Pati, 2007).

The Pediatric Medical Home model emphasizes the importance of coordinating services for children with special health care needs in the context of pediatric primary care (American Academy of Pediatrics [AAP], 2002). A medical home is characterized by an enduring, caring relationship between the primary care provider (PCP) and family, service delivery that is highly responsive to the

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unique needs of the child and family, identification and referral to specialized services when indicated, and effective coordination of all medical services provided for the child. This model has evolved to include children with a broad range of mental health problems, although research suggests that core components of the medical home may not be sufficient to address children's mental health needs (Toomey, Finkelstein, & Kuhlthau, 2008). Recently, experts have sounded a call for integrating medical and behavioral health service delivery in the same context, with a particular emphasis on integrated primary care service delivery (McDaniel et al., 2014). Further, the need to better integrate behavioral health services for children across primary care and school settings has been strongly affirmed (Power, Blum, Guevara, Jones, & Leslie, 2013).

Service delivery for children has also been highly influenced by public health models of care. The public health model emphasizes prevention as a foundation of care and incorporates a multi-tier framework tailored for individuals with multiple levels of need (Sugai & Horner, 2006). The universal tier includes health promotion and prevention approaches for all children. The selective tier is designed for those identified at risk by virtue of the emergence of known risk factors and includes heightened prevention efforts or early intervention. The targeted tier is designed for individuals with identified problems who need more intensive services. Although the public health model typically is applied to all individuals in the general population, it has been re-conceptualized as applying to all individuals with a specified health condition (e.g., all children who have experienced post-traumatic stress; Kazak et al., 2007).

Service delivery for children with health and behavioral health conditions has emphasized the use of evidence-based practices, or strategies that have a research foundation and can be implemented feasibly in real-world settings. The extent of research support for professional practice depends upon multiple factors, including replication of findings by independent research teams, magnitude of effect sizes, the methodological rigor of the studies conducted, and the potential generalizability of study findings. The degree to which research supports service delivery that integrates medical and behavioral health services is variable but research is rapidly developing in this area.

The purpose of this chapter is to describe an integrative, multi-tier framework for promoting children's health that links three vital systems for children's development, the family, health system, and school. Within each tier of service delivery in a public health framework, we outline strategies that can be used by health and mental health providers and school professionals. Further, we describe strategies for promoting cross-system collaboration at each tier of service delivery.

Multi-tier Framework of Cross-System Service Delivery

The most commonly used service delivery systems for pediatric behavioral health care are primary care practices and schools. Increasingly, pediatric behavioral health care is being integrated with medical care to provide more comprehensive and coordinated services for children. Unfortunately, behavioral health services offered in primary care and school are disconnected (Guevara et al., 2005), resulting in parents being in the position of attempting to coordinate care, which may not be feasible for many families, especially those experiencing heightened levels of stress and limited resources.

In this chapter, we propose a cross-system service delivery framework that links integrated services based in primary care with services based in schools. This framework is based on a multi-tier, public health model that provides a continuum of prevention and intervention services. The framework is depicted in Fig. 2.1.

Universal Strategies

Universal strategies that aim to prevent later pathology are central to the mission of primary care. Some prevention strategies, such as vaccines, protect

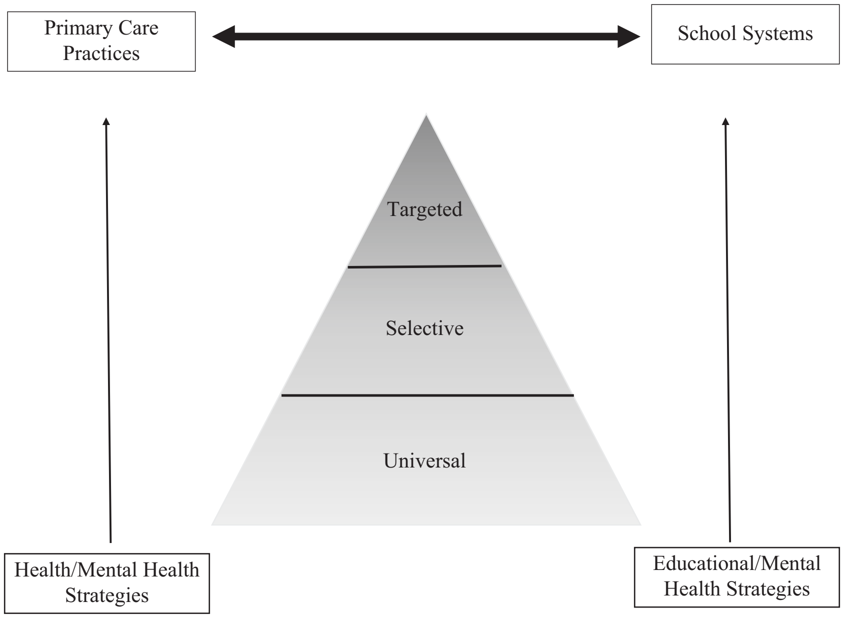

Fig. 2.1 A multi-tier public health framework for promoting children's health and development, including health and mental health strategies that can be applied in primary care practices, educational and mental health strategies that can be applied in schools, and strategies linking the primary care and school contexts

children from specific risks. Other strategies, such as promoting a healthy diet, good sleep, or proper hand washing, help to protect children from a wide range of negative outcomes. Universal strategies employed in pediatric behavioral health care are akin to this second type of strategies—by promoting several known factors related to resiliency, PCPs can contribute to children's mental health, physical health, and successful educational outcomes throughout the lifespan. The following are strategies that can be applied at the universal level.

Strengthening the Parent–Child Relationship

A secure parent–child relationship has been related to later competence in a range of functional domains, including self-reliance, social competence, cognitive and academic competence, mastery motivation, and behavior (Pallini, Baiocco, Schneider, Madigan, & Atkinson, 2014; Sroufe, 2005). Characteristics of secure parenting, including supportive parenting and behavioral control, also predict utilization of primary care (Serbin, Hubert, Hastings, Stack, & Schwartzman, 2014), which can help ensure healthy development. Secure attachment has also been associated with lower rates of psychopathology in early childhood and later in life (e.g., Sroufe, 2005).

Strengthening the Student–Teacher Relationship

A growing body of literature has documented the importance of strong, caring relationships within the school setting. Conflict with teachers is related to more externalizing problems and less prosocial behavior, whereas ratings of closeness are positively related to prosocial behavior (Roorda, Verschueren, Vancraeyveldt, Van Craeyvelt, & Copin, 2014). A positive, supportive relationship between a student and a teacher also has a significant effect on that student's popularity and academic reputation among peers, which in turn affects academic and social development and school engagement (Hughes, Im, & Wehrly, 2014).

In addition, teacher–student relationships in early childhood have a lasting effect on academic and behavioral outcomes (Hamre & Pianta, 2001).

Promoting Family Involvement in Education

A good relationship between a teacher and a student is often built upon the foundation of a strong partnership between a family and the school. Parental involvement in education can include engaging in educational activities at home or school or in collaborating with the school through conferences or written communication. Increased parental involvement in education has a positive effect on student motivation and attitudes toward school, attendance, social and behavioral functioning, and academic achievement (Mautone, Marcell, Tresco, & Power, 2015).

Primary care providers can begin setting the stage for family involvement in education by promoting educational activities early in development. This begins with guiding parents toward imaginative, child-centered play and away from unproven and highly structured products or interventions designed to produce "super-children" (Ginsburg, 2007). Such play contributes to cognitive, physical, social, and emotional development and helps to strengthen parent–child relationships. Pediatricians can also remind parents of the benefits of reading with children from a very young age (Ginsburg, 2007). For younger children, reading activities can center on having a conversation with children about any aspects of the story or illustrations that capture the child's interest. Drawing children's attention to rhymes and the different sounds and syllables that make up words can also help develop the phonological processing abilities that underlie reading development. Pediatricians can consult the website for Reach Out & Read (www.reachoutandread.org) for resources to help incorporate books and reading into well-child visits. Advocating for playing with blocks and engaging in building activities may also be beneficial, as developing skill in building with blocks has been associated with greater spatial reasoning skills and later math achievement (Casey et al., 2008).

Promoting Healthy Routines and Frequent Contact with Primary Care Providers

The promotion of healthy routines is a shared primary goal in both pediatrics and education. Schools pursue these goals through physical education, healthy eating initiatives, oral health activities, and drug prevention programs. In primary care, recommended screenings and guidance during pediatric well-child visits often focus on promoting healthy nutrition, physical activity, good sleeping habits, oral health, healthy sexual development, and safety and injury prevention. These essential prevention and health promotion activities can only happen with regular and supportive contact with a PCP. The first year of life offers an opportunity to forge this strong connection, as families make as many as five routine well-child visits occurring in the first year of life (Buchholz & Talmi, 2012).

Despite this focus on promoting healthy habits, PCPs often lack the time or resources to thoroughly address each of these vital topics. For example, healthy eating habits are discussed at as few as 6% of typical well-child visits and sleep is discussed at as few as 28% of visits (Buchholz & Talmi, 2012). Several initiatives have shown promising results in helping to increase the rate of health promotion activities in promoting healthy routines. The Healthy Steps for Young Children program, for example, pairs a developmental specialist with pediatricians during well-child visits. The program emphasizes the development of a strong relationship between the family, the pediatrician, and the developmental specialist. The Healthy Steps program has been associated with significant increases in the rates at which developmental topics are discussed at well-child visits, including such topics as home safety, temperament, promoting healthy eating, sleep, the importance of play, sleep, social skills, and language development (Buchholz & Talmi, 2012).

Screening for Developmental and Mental Health Problems

About one out of every six children will experience a developmental disability (Boyle et al., 2011). The AAP recommends surveillance for developmental concerns be a part of every well-child visit, with screening administered regularly at 9-, 18-, and 30-month visits (Council on Children with Disabilities [COCWD] et al., 2006). Screening typically includes eliciting and attending to parental concerns, maintaining a developmental history, observing the child, identifying risk and protective factors, and maintaining documentation of developmental surveillance. Screening includes administering a validated instrument, such as the Ages and Stages Questionnaire, the Battelle Developmental Inventory Screening Tool, 2nd Ed., Bayley Infant Neurodevelopmental Screen, Brigance Screens, or Child Development Inventory, or Social Communication Questionnaire (COCWD et al., 2006). Children should then be referred for further evaluation when results of screening are concerning.

Identifying emerging mental health problems is also a significant goal at the universal tier. About 20% of children and adolescents will experience a mental health condition (Merikangas et al., 2010). Very few receive timely treatment. For example, only about 7% of individuals with attention-deficit/hyperactivity disorder (ADHD), about 25% of individuals with anxiety disorders, and about 40% of individuals with mood disorders receive treatment within a year of symptom onset (Wang et al., 2005). Early detection and screening can help reduce the time to treatment. Several validated screening measures of overall mental health include the Brief Problem Checklist, the Pediatric Symptom Checklist/Youth and Parent Report, and the Strength and Difficulties Questionnaire (Beidas et al., 2015). Each of these instruments is available for free, allowing for wide-scale use in universal screening.

Strategies Based in Primary Care

A major goal for health care providers is helping to develop the relationships that will support optimal development, including strong relationships within the family and between the family and educational and health care systems. This can be accomplished by developing a supportive relationship with families, providing guidance on parenting techniques, and offering advice about school advocacy. Pediatricians can also advocate for free and imaginative play and early engagement with reading. Additionally, pediatricians can maintain up-to-date knowledge about resources in their communities to help families find additional educational opportunities or support when needed.

A second major goal for PCPs is detecting the early signs of developmental, educational, and mental health concerns. This can be accomplished through surveillance at every well-child visit and more formal screening at key ages. When risk is detected, children can be referred for further medical, developmental, or educational screening and intervention.

Strategies Based in Schools

Public education is itself a universal strategy for promoting the academic, social, and occupational well-being of each generation. Successful education begins with choosing evidence-based curricula and delivering instruction with effective teaching practices. In addition to this instruction, school professionals can take steps to promote the overall well-being of children by addressing the same main goals as PCPs. For example, schools should implement a program of universal screening to identify students at risk for academic and behavioral difficulties.

Schools can also take initiatives to help build positive relationships with families and students.

Building strong relationships between schools and families can begin by providing opportunities for families to become comfortable in the school setting, such as family events at the school and parent–teacher conferences. Professional development opportunities can be provided to help school professionals learn effective ways to build relationships with families and students. For example, *Banking Time*, a web-based training program that guides teachers through a series of one-on-one meetings with students, has led to greater teacher frustration tolerance and greater relational closeness between teachers and students in state-funded preschool programs (Driscoll, Wang, Mashburn, & Pianta, 2011). *My Teaching Partner,* another web-based professional development program for teachers, has led to gains in social competence among preschool students (Hamre, Pianta, Mashburn, & Downer, 2012).

Strategies Linking Health and School Systems

Successful collaboration between health and school systems starts with providers in each system developing knowledge of the goals, values, and methods used in the other system. For example, PCPs can make efforts to learn about school-based processes that support students with educational, developmental, and physical disabilities, including Section 504 of the Rehabilitation Act of 1973 and the Individual with Disabilities Education Act (IDEA). Educators can learn about medical conditions, procedures for referral, and procedures for communication within the medical community.

This shared knowledge can be helpful in providing accurate advice to families. This is crucially important as misunderstandings can diminish the critical trust that families have in one or both systems. For example, when medical professionals tell families that they should talk to the school and demand the Individualized Education Plan (IEP) to which their child is entitled, they condition parents to expect the schools to try to shirk their duties and to be mistrustful if schools determine that the student does not need an IEP. Conversely, school professionals who question diagnostic or treatment decisions while lacking medical expertise or important knowledge of a student's health status may cause families to mistrust evidence-based medical advice. Effective collaboration between systems should begin with each system respecting that the other has unique expertise and typically acts in the best interest of the child. Such understanding helps to foster relationships in which families respect and trust their physicians and educators.

Selective Strategies

Effective screening at the universal level will identify children at risk for negative health, behavioral, emotional, developmental outcomes. For these children, more targeted and intensive assessments and interventions can be used to help remediate weakness and prevent risk from progressing to pathology. The following is a description of strategies at the selective level.

Further Assessment for Children at Risk

If ongoing surveillance conducted at the universal level indicates an increased risk for developmental, educational, or mental health problems, further assessment is warranted. In the medical setting, this often takes the form of more targeted screening for particular conditions. For example, free validated screening measures are available for students showing signs of anxiety, depression, disruptive behavior, eating disorders, mania, and trauma (Beidas et al., 2015). When screening indicates potentially elevated symptoms of psychopathology, children can be referred to specialists for further evaluation and treatment. When available, integrated behavioral health providers or developmental specialists can help ensure that assessment, referral, and treatment follow evidence-based guidelines.

In the school setting, further assessment often takes the form of conducting a functional behavioral assessment. Functional behavioral assessment is a process by which problem behaviors are specified and the typical antecedents and consequences of the behavior are identified. This information is used to determine the function of the behavior (e.g., seek teacher or peer attention; avoid work demands), and the child is then taught or reinforced for exhibiting a more acceptable behavior that serves the same function. When qualified integrated behavioral health providers are available in primary care, behavioral assessment can be an effective strategy for helping families solve specific behavioral problems.

Ongoing Tracking of Behavior and Performance

Universal strategies often include surveillance and screening for all children. When risk factors or current symptoms are identified, more consistent tracking of behavior and performance may be warranted. This may include more frequent screening of selected symptoms and more frequent review of screening results.

Stronger Engagement of Family and School Professionals

As discussed above, strong relationships within the family and between the family and school support positive academic, health, social, and emotional outcomes. For children at risk for negative outcomes, selective strategies that promote strong family relationships can be helpful. Parenting programs such as Incredible Years or the Triple P-Positive Parenting Program can be used to teach parents to promote competence in language, emotional self-regulation, problem solving ability, and social skills (Sanders, 2012; Webster-Stratton, Reid, & Hammond, 2004). Additionally, supporting positive relationships in school is particularly important for children with early signs of emotional or behavioral disorders, as the teacher–student relationship in early elementary grades has been shown to mediate the relationship between temperament characteristics and later peer interactions (Rudasill, Niehaus, Buhs, & White, 2013).

Early Intervention

Young children with developmental delays or disabilities are eligible for early intervention services. The largest program providing such services is Part C of the Individuals with Disabilities Education Act. Children identified with developmental delays are eligible to receive services to help meet goals specified in an Individual Family Service Plan. State laws employ different eligibility guidelines, and recent estimates indicate that between 2 and 78% of children are eligible for services under different states' guidelines. Despite the wide availability of these services in many states, only 1.5–7% of children receive early intervention services across states (Rosenberg, Robinson, Shaw, & Ellison, 2013). Pediatricians can play a major role in reducing this discrepancy between eligibility and enrollment by maintaining an awareness of their state's criteria for eligibility, making prompt referrals for further evaluation when young children show early signs of developmental delay, and by providing family education about the importance of early intervention.

Strategies Based in Primary Care

Selective strategies employed in health care settings often are centered on providing selective family education related to targeted needs. This education often takes the form of providing recommendations for effective parenting practices and strategies to deal with specific behavioral or emotional concerns. When significant developmental or behavioral concerns are present, referral for more specialized evaluation and services, such as early intervention services, is warranted. More targeted assessment measures at the selective level can help determine the appropriate course of action.

The ongoing growth of integrated behavioral health provides an exciting opportunity to increase the use of effective, evidence-based strategies at the selective level. The integration of behavioral health practitioners into primary care allows for collaboration between medical and mental health professionals on a range of issues, including identifying and addressing developmental concerns, promoting healthy lifestyle choices, promoting positive parenting, and promoting behavioral and mental health. Integrated behavioral health can contribute to improved outcomes across both health and mental health domains (McDaniel et al., 2014).

Strategies Based in Schools

School professionals use selective strategies to begin providing additional support to children at risk for academic, developmental, behavioral, or emotional difficulty. This often begins with ongoing monitoring of concerning academic deficits or behavioral problems. A child study team or instructional support team is in place in many schools to provide this monitoring. Selective interventions are used when monitoring shows insufficient progress. Selective interventions in a school setting are often delivered through a process of consultation. A specialist, such as a school psychologist, school counselor, or educational interventionist, will provide teachers with strategies to address specific problems. Small-group interventions that target specific skills, such as phonemic blending or social skills, may also be used.

Selective interventions work best when parents collaborate with their child's school. Several strategies can help promote this. For example, a daily report card can be used to help facilitate communication between schools and families about a student's daily performance related to behavioral or academic goals. The use of daily report cards, which can allow for reinforcement to be delivered at home for meeting goals in the school, may be more effective than interventions implemented solely at school (Volpe & Fabiano, 2013). School-based professionals should also include parents in the consultative process. For example, strategies used in conjoint behavioral consultation (Sheridan & Kratochwill, 2008; discussed more fully with targeted strategies) can be helpful in involving parents in consultation at the selective level.

Strategies Linking School and Health Systems

Unfortunately, PCPs and mental health professionals working in primary care generally are limited in their efforts to assist students in school due to infrequent contact between providers in primary care and those in school (Power et al., 2013). Integrated care to promote student success in school can be enhanced by promoting collaboration between the primary care and school teams. In addition, co-locating school psychologists with training emphasizing integrated behavioral health in primary care practices may be an approach to bridge the health and school systems to promote school success (Adams, Hinojosa, Armstrong, Takagishi, & Dabrow, 2016).

In recent years, several internet-based systems have been developed to help support communication between schools and primary care practices. These systems have typically been developed by primary care practices to facilitate screening, assessment, and progress monitoring. Several systems are designed to support communication related to a range of medical, developmental, and mental health conditions, including the commercially available Comprehensive Health and Development Interactive System (CHADIS; http://www.childhealthcare.org/chadis) and Boston Children's Hospital's TriVox Health (Chan et al., 2016). Others have focused on facilitating collaboration for children with ADHD, including the Children's Hospital of Philadelphia's ADHD Care Assistant (Power et al., 2016) and Cincinnati Children's Hospital Medical Center's myADHDportal (Epstein et al., 2011). Web-based systems offer several advantages. First, teachers and clinicians can enter and view information whenever is most convenient, eliminating the need for highly scheduled professionals to coordinate availability. Second, systems can be designed to ensure compliance with both the Health Insurance Portability and Accountability Act (HIPAA) regulations that guide medical professionals and the Family Educational Rights and Privacy Act (FERPA) regulations that guide educators in protecting the privacy rights of patients and students. This reduces the need for individuals in each organization to keep track of paper permission forms that may not be easily shared throughout the organization. By facilitating direct communication between clinicians and teachers, the need to use parents to transmit information is reduced, thereby increasing the speed and reliability of communication. Third, many of these systems are linked directly to electronic health records, allowing for physicians to seamlessly access information during clinic visits.

In addition to communication about specific children, medical and school professionals should seek out opportunities to collaborate on issues that are prevalent within a community. For example, in communities with high rates of asthma, medical officials can collaborate with school officials in reducing environmental triggers. Similarly, school-based professionals can reach out to primary care practices that serve many children with ADHD and provide information about accommodations, school-based interventions, and special education procedures so that medical professionals can provide accurate advice to families.

Targeted Strategies

Targeted strategies are designed for children with identified emotional and behavioral problems. These strategies may include psychosocial interventions, pharmacological treatments, or combined approaches. Targeted interventions linking systems of care are typically based in health (primary care) or school settings, and they may vary with regard to their degree of focus on establishing and maintaining inter-system connections. These approaches incorporate evidence-based practices and generally include components to monitor progress during intervention and evaluate outcomes after a pre-determined amount of treatment is provided. When services cannot be provided in health and school settings, referrals are made to appropriate providers in the community (e.g., public and private mental health providers).

Strategies Based in Primary Care

Behavioral interventions are often provided in the context of primary care. Approaches have been adapted for implementation in primary care to treat a range of mental health conditions, including depression, anxiety, ADHD, and disruptive behavior problems (Asarnow, Rozenman, Wiblin, & Zeltzer, 2015). These approaches vary with regard to extent to which behavioral health services are provided in collaboration with PCPs. In some practices, behavioral health providers are co-located but the degree of collaboration with health providers is limited; in other practices, the extent and quality of collaboration may be pronounced. Psychosocial interventions provided in primary care are typically relatively brief (e.g., 6–12 sessions). Children with more complex needs are generally referred to mental health agencies for services.

An exemplar of this approach is the Doctor Office Collaborative Care (DOCC) model (Kolko et al., 2014). This approach involves clinicians (i.e., masters-level social workers) working in collaboration with PCPs to address the needs of children with behavior problems, ADHD, and anxiety. Interventions were modularized, matching evidence-based practices to the presenting problems of greatest concern to families (e.g., cognitive-behavioral treatment with exposures for the treatment of anxiety; behavioral and/or pharmacological treatment for ADHD). Treatment is provided in 6–12 sessions and progress is monitored using a goal attainment scaling approach (Kolko, Campo, Kilbourne, & Kelleher, 2012). The intervention includes ongoing collaboration with PCPs and office staff. Compared to a control group receiving psychoeducation and referral to the community for mental health services, DOCC resulted in higher rates of behavioral health initiation and completion, reduction in parenting stress and parent–child dysfunction, greater goal attainment, and modest reductions in mental health symptoms (Kolko et al., 2014). The DOCC model provided a high level of coordination between behavioral health and medical providers, but it did not emphasize collaboration with schools.

An example of an integrated approach that attempts to address the interface of family, school, and primary care practice is Partnering to Achieve School Success (PASS; Power et al., 2014). This intervention is provided by clinicians (post-doctoral fellows in psychology) working in urban primary care practice and targets children with ADHD between 5 and 11 years of age. The intervention is typically brief (i.e., less than 12 sessions) and is tailored to address the unique challenges faced by low-income families who often experience barriers in obtaining mental health care. A major emphasis is placed on engaging families in intervention through the use of motivational interviewing strategies during phone calls and treatment sessions, and problem solving to address barriers to care (Power et al., 2010). A modularized approach is used to map family priorities with intervention components, which include behavioral parent training, consultation to address school problems, collaborative care related to the use of medication, and crisis counseling, when indicated. Progress was monitored using a goal attainment scaling approach. The findings indicated that families who received PASS attended an average of 8 sessions. An evaluation of outcomes indicated that PASS appears to be promising in reducing barriers to care, improving parent perceptions of the acceptability of medication, reducing negative-ineffective parenting practices, and reducing functional impairments (Power et al., 2014). Although school concerns were the most common presenting problems, it was challenging to conduct school consultations and only 38% of PASS cases received this module. The major barrier to school consultation was obtaining principal and teacher permission, because most of participating students attended separate schools, including public, charter, and parochial schools in inner-city and nearby suburban settings.

Strategies Based in Schools

Several intervention programs linking systems of care have been developed and implemented in school settings. A common feature of most of these programs is that they focus on connecting families and schools. Unfortunately, most school-based applications typically do not emphasize linkages with the health system, although it is possible to adapt these strategies to promote family-school-health system collaboration (Sheridan & Kratochwill, 2008).

The Collaborative Life Skills (CLS) program is a multimodal intervention designed for students in grades 2–5 who have ADHD (Pfiffner et al., 2016). This program includes multiple components. The Classroom Component includes consultation with teachers as well as family-school collaborations. The intervention includes the design and implementation of daily report cards (Volpe & Fabiano, 2013) as well as classroom accommodations, and strategies to address homework challenges. The Parent Component is a 10-session behavioral parent training program that includes the traditional elements of parent training as well as training to support the child's acquisition or organization and social skills. The Child Skills Component consisted of a 9-session child group skills training program focused on training students in social skills and independent functioning (e.g., completing homework with minimal assistance). Compared to a treatment-as-usual control condition, students in CLS demonstrated reductions in ADHD and oppositional defiant symptoms, improvements in organizational skills and interpersonal skills, and improvements in academic performance (Pfiffner et al., 2016).

Conjoint Behavioral Consultation (CBC) is a model that involves parents and educators in a partnership to engage in problem solving to address mutually defined goals. This approach emphasizes the importance of establishing a strong relationship between family and school that promotes shared values, expectations, and contingencies for child behavior. In the context of a strong partnership, the consultant (typically a school mental health provider) guides parents and educators through the steps of behavioral consultation, including problem identification, problem analysis and intervention design, intervention implementation, and evaluation (Sheridan & Kratochwill, 2008). The consultant guides parents and educators in the development of evidence-based interventions that can be applied by each of them at home and school. The CBC model has been applied to address a wide range of behavioral and social concerns. Compared to a treatment-as-usual control condition, CBC has been shown to improve student adaptive behaviors and social skills, as well as teacher-reported relationships with parents. Further, improvements in parent–teacher relationships were shown to mediate the effects of CBC on improvements in child outcomes (Sheridan et al., 2012). The CBC model has been demonstrated to be promising in promoting cross-system collaboration when based in a developmental-behavioral pediatric practice (Sheridan et al., 2009), but research is needed to demonstrate its feasibility and effectiveness in promoting collaboration with health systems when the intervention is based primarily in schools.

Strategies Linking Health and School Systems

The care manager model is an approach that has an explicit focus on coordinating communications among systems of care. Originally developed to support intervention for adults with depression (Gilbody, Bower, Fletcher, Richards, & Sutton, 2006), this model has been used for the treatment of children with ADHD, internalizing, and externalizing conditions (Kolko et al., 2014; Power et al., 2013). Care managers are typically bachelors-level providers with degrees in nursing, social sciences, or education. Although their roles often include psychoeducation to families, progress monitoring during the course of intervention, and referral for mental health services, a major component of their roles is usually to facilitate communications among providers across systems. Interventions such as this have been shown to be more effective when providers are well trained and supervised (Katon, Von Korff, Lin, & Simon, 2001). A small-scale study of a care manager model among children diagnosed with ADHD between 5 and 12 years using a quasi-experimental design demonstrated high acceptability among parents' reductions in parent-reported ADHD symptoms and related impairments with small to medium effect sizes (Power et al., 2013).

Conclusions

Consistent with a developmental-ecological framework, service delivery models have been proposed that link systems of care to promote children's health and development. This chapter discusses the integration of a development-ecological framework with a multi-tier public health framework to promote children's success in school, at home, and in the community. Strategies at the universal, selective, and targeted levels are described, differentiating approaches that can be applied in primary care settings using an integrated approach to care, and those that can be implemented in school settings by educational professionals. In addition, the chapter highlights strategies that can be used to connect the primary care and school systems to promote children's health and development. The evidence base for the strategies discussed in this chapter varies markedly, and there is an enormous need for research to further develop and demonstrate the effectiveness of these approaches, especially strategies linking primary care and schools.

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References

Adams, C. D., Hinojosa, S., Armstrong, K., Takagishi, J., & Dabrow, S. (2016). An innovative model of integrated behavioral health: School psychologists in pediatric primary care settings. *Advances in School Mental Health Promotion, 9*, 188–200.

American Academy of Pediatrics. (2002). The medical home. *Pediatrics, 110*, 184–186.

Asarnow, J., Rozenman, M., Wiblin, J., & Zeltzer, L. (2015). Integrated medical-behavioral care compared with usual primary care for child and adolescent behavioral health: A meta-analysis. *JAMA Pediatrics, 169*, 929–937.

Beidas, R. S., Stewart, R. E., Walsh, L., Lucas, S., Downey, M. M., Jackson, K., … Mandell, D. S. (2015). Free, brief, and validated: Standardized instruments for low-resource mental health settings. *Cognitive and Behavioral Practice, 22*, 5–19.

Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M., … Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997-2008. *Pediatrics, 127*, 1034–1042.

Buchholz, M., & Talmi, A. (2012). What we talked about at the pediatrician's office: Exploring differences between Health Steps and traditional pediatric primary care visits. *Infant Mental Health Journal, 33*, 430–436.

Casey, B. M., Andrews, N., Schindler, H., Kersh, J. E., Samper, A., & Copley, J. (2008). The development of spatial skills through interventions involving block building activities. *Cognition and Instruction, 26*, 269–309.

Chan, E., Fleegler, E., Weas, S., Zhang, X., Rhodes, E., Kahn, J., … Loddenkemper, T. (2016). *Implementation of an internet-based patient monitoring system improves families' perception of quality of communication and experience of care.* Paper presented at the Pediatric Academic Societies Annual Meeting, Baltimore, MD.

Council on Children with Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, & Medical Home Initiatives for Children with Special Needs Project Advisory Committee. (2006). Identifying infants and young children with developmental surveillance and screening. *Pediatrics, 118*, 405–420.

Driscoll, K. C., Wang, L., Mashburn, A. J., & Pianta, R. C. (2011). Fostering supportive teacher-child relationships: Intervention implementation in a state-funded preschool program. *Early Education and Development, 22*, 593–619.

Duchnowski, A. J., Kutash, K., & Friedman, R. M. (2002). Community-based interventions in a systems of care and outcomes framework. In B. J. Burns & K. Hoagwood (Eds.), *Community treatment for youth: Evidence-based interventions for severe emotional and behavioral disorders* (pp. 16–37). New York: Oxford University Press.

Epstein, J., Langberg, J., Lichtenstein, P., Kolb, R., Altaye, M., & Simon, J. (2011). Use of an internet portal to improve community-based pediatric ADHD care: A cluster randomized trial. *Pediatrics, 128*, e1201–e1208.

Gilbody, S., Bower, P., Fletcher, J., Richards, D., & Sutton, A. J. (2006). Collaborative care for depression: A cumulative meta-analysis and review of longer-term outcomes. *Archives of Internal Medicine, 166*, 2314–2321.

Ginsburg, K. R. (2007). The importance of play in promoting healthy child development and maintaining strong parent-child bonds. *Pediatrics, 119*, 182–191.

Guevara, J., Fuedtner, C., Romer, D., Power, T., Eiraldi, R., Nihtianova, S., … Schwarz, D. (2005). Fragmented care for inner-city minority children with attention-deficit/hyperactivity disorder. *Pediatrics, 116*, e512–e517.

Hamre, B. K., & Pianta, R. C. (2001). Early teacher-child relationships and the trajectory of children's school outcomes through eighth grade. *Child Development, 72*, 625–638.

Hamre, B. K., Pianta, R. C., Mashburn, A. J., & Downer, J. T. (2012). Promoting young children's social competence through the preschool PATHS curriculum and MyTeachingPartner professional development resources. *Early Education and Development, 23*, 809–832.

Hughes, J. N., Im, M. H., & Wehrly, S. E. (2014). Effect of peer nominations of teacher-student support at individual and classroom levels on social and academic outcomes. *Journal of School Psychology, 52*, 309–322.

Katon, W., Von Korff, M., Lin, E., & Simon, G. (2001). Rethinking practitioner roles in chronic illness: The specialist, primary care physician, and the practice nurse. *General Hospital Psychiatry, 23*, 138–144.

Kazak, A. E., Rourke, M. T., Alderfer, M. A., Pai, A., Reilly, A. F., & Meadows, A. T. (2007). Evidence-based assessment, intervention and psychosocial care in pediatric oncology: A blueprint for comprehensive services across treatment. *Journal of Pediatric Psychology, 32*, 1099–1110.

Kolko, D. J., Campo, J., Kilbourne, A. M., Hart, J., Sakolsky, D., & Wisniewski, S. (2014). Collaborative care outcomes for pediatric behavioral health problems: A cluster randomized trial. *Pediatrics, 133*, e981–e992.

Kolko, D. J., Campo, J. V., Kilbourne, A. M., & Kelleher, K. (2012). Doctor-office collaborative care for pediatric behavioral problems: A preliminary clinical trial. *Archives of Pediatrics & Adolescent Medicine, 166*, 224–231.

Mandell, D. M., Guevara, J. P., & Pati, S. (2007). The search for coordinated, continuous community-based care: How the parallel efforts of the Medical Home and Systems of Care can inform each other. In W. J. Fisher (Ed.), *Research on community-based mental health* *services for children and adolescents* (pp. 77–94). Amsterdam: JAI Press.

Mautone, J. A., Marcell, E., Tresco, K. E., & Power, T. J. (2015). Assessing the quality of parent-teacher relationships for students with ADHD. *Psychology in the Schools, 52*, 196–207.

McDaniel, S. H., Grus, C. L., Cubic, B. A., Hunter, C. L., Kearney, L. K., Schuman, C. C., … Johnson, S. B. (2014). Competencies for psychology practice in primary care. *American Psychologist, 69*, 409–429.

Merikangas, K. R., He, J., Burstein, M., Swanson, S. A., Avenevoli, S., Cui, L., … Swendsen, J. (2010). Lifetime prevalence of mental disorders in U.S. adolescents: Results from the national comorbidity survey replication-adolescent supplement (NCS-A). *Journal of the American Academy of Child & Adolescent Psychiatry, 49*, 980–989.

Pallini, S., Baiocco, R., Schneider, B. H., Madigan, S., & Atkinson, L. (2014). Early child-parent attachment and peer relations: A meta-analysis of recent research. *Journal of Family Psychology, 28*, 118–123.

Pfiffner, L. J., Rooney, M., Haack, L., Villodas, M., Delucchi, K., & McBurnett, K. (2016). A randomized controlled trial of a school-implemented school-home intervention for Attention-Deficit/Hyperactivity Disorder symptoms and impairment. *Journal of the American Academy of Child & Adolescent Psychiatry, 55*, 762–770.

Power, T. J., Blum, N. J., Guevara, J. P., Jones, H. A., & Leslie, L. K. (2013). Coordinating mental health care across primary care and schools: ADHD as a case example. *Advances in School Mental Health Promotion, 6*, 68–80.

Power, T. J., Hughes, C. L., Helwig, J. R., Nissley-Tsiopinis, J., Mautone, J. A., & Lavin, H. J. (2010). Getting to first base: Promoting engagement in family–school intervention for children with ADHD in urban, primary care practice. *School Mental Health, 2*, 52–61.

Power, T. J., Mautone, J. A., Marshall, S. A., Jones, H. A., Cacia, J., Tresco, K., … Blum, N. J. (2014). Feasibility and potential effectiveness of integrated services for children with ADHD in urban primary care practices. *Clinical Practice in Pediatric Psychology, 2*, 412–426.

Power, T. J., Michel, J., Mayne, S., Miller, J., Blum, N. J., Grundmeier, R. W., … Fiks, A. G. (2016). Coordinating systems of care using health information technology: Development of the ADHD Care Assistant. *Advances in School Mental Health Promotion, 9*, 201–218.

Roorda, D. L., Verschueren, K., Vancraeyveldt, C., Van Craeyvelt, S., & Copin, H. (2014). Teacher-child relationships and behavioral adjustment: Transactional links for preschool boys at risk. *Journal of School Psychology, 52*, 495–510.

Rosenberg, S. A., Robinson, C. C., Shaw, E. F., & Ellison, M. C. (2013). Part C early intervention for infants and toddlers: Percentage eligible versus served. *Pediatrics, 131*, 38–46.

Rudasill, K. M., Niehaus, K., Buhs, E., & White, J. M. (2013). Temperament in early childhood and peer interactions in third grade: The role of teacher-child relationships in early elementary grades. *Journal of School Psychology, 51*, 701–716.

Sanders, M. R. (2012). Development, evaluation, and multinational dissemination of the Triple P-Positive Parenting Program. *Annual Review of Clinical Psychology, 8*, 345–379.

Serbin, L. A., Hubert, M., Hastings, P. D., Stack, D. M., & Schwartzman, A. E. (2014). The influence of parenting on early childhood health and health care utilization. *Journal of Pediatric Psychology, 39*, 1161–1174.

Sheridan, S. M., Bovaird, J. A., Glover, T. A., Garbacz, S. A., Witte, A., & Kwon, K. (2012). A randomized trial examining the effects of conjoint behavioral consultation and the mediating role of the parent-teacher relationship. *School Psychology Review, 41*, 23–46.

Sheridan, S. M., & Kratochwill, T. R. (2008). *Conjoint behavioral consultation: Promoting family-school connections and interventions* (2nd ed.). New York: Springer Science + Business Media.

Sheridan, S. M., Warnes, E. D., Woods, K. E., Blevins, C. A., Magee, K. L., & Ellis, C. (2009). An exploratory evaluation of conjoint behavioral consultation to promote collaboration among family, school, and pediatric systems: A role for pediatric school psychologists. *Journal of Educational and Psychological Consultation, 19*, 106–129.

Sroufe, L. A. (2005). Attachment and development: A prospective, longitudinal study from birth to adulthood. *Attachment & Human Development, 7*, 349–367.

Stroul, B. A., & Friedman, R. M. (1986). *A system of care for children and youth with severe emotional disturbances*. Washington, DC: Georgetown University Child Development Center.

Sugai, G., & Horner, R. R. (2006). A promising approach for expanding and sustaining school-wide positive behavior support. *School Psychology Review, 35*, 245–259.

Toomey, S. L., Finkelstein, J., & Kuhlthau, K. (2008). Does connection to primary care matter for children with attention-deficit/hyperactivity disorder? *Pediatrics, 122*, 368–374.

Volpe, R. J., & Fabiano, G. A. (2013). *Daily behavior report cards: An evidence-based system of assessment and intervention*. New York: Guilford.

Wang, P. S., Berglund, P., Olfson, M., Pincus, H. A., Wells, K. B., & Kessler, R. C. (2005). Failure and delay in initial treatment contact after first onset of mental disorders in the national comorbidity survey replication. *Archives of General Psychiatry, 62*, 603–613.

Webster-Stratton, C., Reid, M. J., & Hammond, M. (2004). Treating children with early-onset conduct problems: Intervention outcomes for parent, child, and teacher training. *Journal of Clinical Child and Adolescent Psychology, 33*, 105–124.

3

Interprofessional Collaboration

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Abstract

Collaboration is a process of collective action toward a common goal. Interprofessional collaboration in pediatric behavioral healthcare involves individuals in multiple professions and multiple settings working together to improve the quality of individual care, the health of populations, and to reduce the cost of care, using evidence-based practices, with providers sharing work and functioning as a team. This chapter explores definitions of interprofessional collaboration, the need and evidence-base for interprofessional collaboration in pediatric behavioral healthcare, and current barriers and facilitators. Interprofessional team functioning is addressed, as well as current literature on competencies for interprofessional care, and research on how to train future and current healthcare providers for interprofessional collaboration. Individual/relational factors and structural/organizational/systems factors impact the implementation of interprofessional collaboration. Additional research is needed that will document the professional and patient outcomes of interprofessional collaboration and that will identify evidence-based strategies for implementation.

Interprofessional Collaboration

Definition

Collaboration is typically defined as a process of collective action toward a common goal. Interprofessional collaboration in pediatric behavioral health involves individuals in multiple professions and multiple settings working together to improve the quality of individual care, the health of populations, and to reduce the cost of care, in accord with the Triple Aim of healthcare reform (Berwick, Nolan, & Whittington, 2008). Improving the quality of care to individuals and populations involves the use of evidence-based practices, with providers sharing work and functioning as a team (Ratzliff, Katon, & Unutzer, 2016).

Five principles are generally thought to provide a framework for provision of collaborative care. First, care is patient-centered, with providers using a shared care plan. The care is also population based, with all patients tracked and receiving care proactively and preventatively. The care is evidence-based and includes both psychosocial and biomedical treatments. The care is measurement-based, using outcome measures to track treatment effectiveness and

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inform treatment adjustments. Finally, the care is accountable, focusing on reaching specified treatment targets for patients and using quality improvement methods to improve healthcare team functioning (Ratzliff, Cerimele, Katon, & Unutzer, 2016).

Interprofessional collaboration is consistent with the concept of the Patient-Centered Medical Home (PCMH), and its applications to pediatric populations (Asarnow, Kolko, Miranda, & Kazak, 2017). The PCMH is a model of care that is comprehensive, patient-centered, coordinated, team-based, accessible, and focused on quality and safety. The goals of the PCHM are to integrate services and providers, deliver the best available evidence-based care, integrate the patient as an active participant in their care, and provide comfortable and convenient coordinated treatment for the patient. The American Academy of Pediatrics (1992) adopted this concept, focusing on care that includes prevention, access, continuity, communication among providers, involvement of the schools and community agencies, and use of a centralized health record.

Interprofessional collaboration has been defined and described in several ways. Doherty, McDaniel, and Baird (1996) identified five levels of collaboration between primary care and behavioral health providers. These include: minimal collaboration; basic collaboration from a distance (professionals communicate and see each other as resources, but do not share power or responsibility and do not understand each other's organizational culture); basic collaboration on site (services are co-located, but not integrated); close collaboration in a partly integrated system (services are co-located, treatment plans are coordinated, professionals participate in more frequent communication and consultation); and close collaboration in a fully integrated system (professionals co-locate, have integrated systems, meet routinely, understand each other's organizational culture, and share power and decision-making).

More recently, Asarnow et al. (2017) also set forth a continuum of collaboration in healthcare models, defining five levels of collaboration. Coordinated care involves professionals practicing separately, but exchanging information. When co-located care exists, behavioral health providers practice within the primary care setting, although a common treatment plan is not used. The term integrated care indicates that tightly integrated onsite teamwork occurs. Collaborative care is defined as a partnership between behavioral health and primary care clinicians, patients, and families using a shared treatment plan. Collaborative care based on the chronic care model incorporates a care manager and psychiatric consultant as part of the healthcare team. While co-location may make collaboration easier, it may not be possible in pediatric behavioral healthcare because of the range of organizations and systems through which care is accessed.

In studying collaboration, a distinction has also been made between communication and collaboration. Bradley-Klug, Sundman, Nadeau, Cunningham, and Ogg (2010) provide useful definitions of these two terms which highlight their differences. They define communication as a one-time, unidirectional sharing of information. They contrast this with collaboration, which is defined as two or more people working together, in an ongoing manner, to plan and problem solve to promote positive patient outcomes. In a review of literature on collaboration in healthcare, the most common concepts mentioned in defining collaboration were: sharing, partnership, interdependency, shared power, and a dynamic process (D'Amour, Ferrada-Videla, San Martin Rodriguez, & Beaulieu, 2005).

The Need for Interprofessional Collaboration

The rationale and need for interprofessional collaboration in pediatric behavioral healthcare stems from several sources. Healthcare and behavioral healthcare have become increasingly specialized, in large part as a result of the scope and complexity of current information about health and behavioral health, making it impossible for a single provider to have all the information needed to treat children and adolescents with a variety of physical and behavioral health conditions. In addition, many children and adolescents present with co-morbid conditions which increase the complexity of assessment, diagnosis, and treatment, and the information base needed to accomplish these tasks effectively. Also, the occurrence of chronic health conditions among children and adolescents has been increasing (Perrin, Anderson, & Van Cleave, 2014), leading to the need for complex, multi-faceted, long-term physical and behavioral health services. Additionally, as mentioned above, care access patterns for children and adolescents indicate that behavioral healthcare is accessed through a range of systems, including medical practices where a substantial percentage of presenting problems are related to behavioral health (Polaha, Dalton III, & Allen, 2011). At the same time, a majority of children and adolescents with behavioral health problems (75%) access services for these problems in the schools (Rones & Hoagwood, 2000). Therefore, many children and adolescents with behavioral health problems have involvement with multiple systems that may be providing assessment and treatment services (Kolko & Perrin, 2014). Finally, poor communication between behavioral and physical health professionals has been cited as an obstacle to receiving treatment (Kolko, 2009) and estimates indicate that only 20% of children and adolescents with behavioral health problems receive treatment (Merikangas, Nakamura, & Kessler, 2009). Thus, the need for collaboration across health professionals and across the organizations in which they work is imperative.

Current literature appears to indicate that collaboration in the provision of behavioral healthcare is not at optimal levels. In a review of studies of integrated primary care program characteristics, Martin, White, Hodgson, Lamson, and Irons (2014) identified several collaboration practices, defined as patterns of communication, collaboration, and recommendation between medical and behavioral health providers. Communication was viewed as any sharing of patient or treatment information between providers. Collaboration was viewed as any process of shared decision-making between providers (formal or informal). Recommendations were defined as specific suggestions for treatment from behavioral health providers. The authors found that few of the studies reviewed reported that collaboration as a shared decision-making process was used.

The Evidence Base for Collaboration

The value of care coordination, collaboration, and integration in pediatric behavioral healthcare is being established through a substantial number of studies. Documented benefits have included lower ratings of internalizing and externalizing problems, less functional impairment, and higher remission rates for some disorders, as well as improvements in observed child behavior, parent functioning and parenting practices, and client satisfaction (Kolko & Perrin, 2014).

For example, Asarnow et al. (2005) compared onsite collaborative care with the primary care physician versus treatment as usual for adolescent depression in a randomized trial (*n* = 418) in five healthcare settings. Collaborative care was found to be more effective in promoting service use, reducing depressive symptoms and disorders, promoting adjustment, and increasing satisfaction. Lower likelihood of severe depression for collaborative care was found at 6-month, but not 18-month follow-up (Asarnow, Jaycox, Tang, Duan, & LaBorde, 2009). Greater service use, improvement in individualized target behaviors, reductions in severity of oppositionality, inattention, hyperactivity, and functional impairment, and increased consumer satisfaction were found in a trial of a program called Doctor Office Collaborative Care (DOCC) used with children with behavior problems, including externalizing problems, internalizing problems, and ADHD (Kolko, Campo, Kilbourne, & Kelleher, 2012). DOCC involved a team approach to care delivery, with nurses and social workers serving as care managers and delivering and coordinating services with pediatricians. Treatment included brief modules of child cognitive-behavior therapy, parent management practices, family problem solving, and medication. The effectiveness of use of primary care pediatrician office practice staff (nurse or social worker) as co-therapists with mental health providers has also been shown in the delivery of The Incredible Years program to caregivers of 2- to 4-year-olds with disruptive behavior (Perrin, Sheldrick, McMenamy, Henson, & Carter, 2014). Compared to wait-list controls, those receiving this evidence-based parent training program showed greater reductions in reports of negative parenting behaviors and child behavior problems, which were supported by improvements in observed parent–child interactions after treatment and at 1-year follow-up.

In an examination of collaboration across child-serving systems, Power et al. (2014) evaluated the feasibility of use of the Partnering to Achieve School Success (PASS) program, a multimodal intervention for children with attention-deficit/hyperactivity disorder, based in primary care practices, and delivered in collaboration with the school and the family. Thus, PASS emphasizes collaboration across professionals and across systems. PASS components include family engagement strategies, family behavior therapy, family-school consultation, collaborative care with the primary care pediatrician, and trauma-informed care. PASS uses a shared decision-making approach among professionals and the family to determine which components to include in treatment. Teachers collaborate with parents in identifying target behaviors and developing intervention strategies. Findings indicated that parents viewed PASS as an acceptable treatment and that it is a promising approach to reducing barriers to care, improving parenting practices, and reducing problems of children. In a systematic review of studies on outcomes of interagency collaboration on mental health services for children and youth, Cooper, Evans, and Pybis (2016) found that interagency collaboration was perceived as helpful and important by service users and professionals. However, outcomes were mixed regarding amount of service use and quality.

Much of the literature in this area has several methodological limitations including uncontrolled designs, small samples, limited use of primary care physician measures, lack of client follow-up measures, and lack of client and staff diversity (Kolko & Perrin, 2014), indicating the need for further research with more rigorous designs. Although not focused on a pediatric population, a Cochrane Review based on 79 collaborative care trials found that collaborative care for depression and anxiety was more effective than usual care (Archer et al., 2012) and provides support for further examination and development of interprofessional collaboration in the provision of pediatric behavioral health services.

Factors That Impact Implementation of Interprofessional Collaborative Practice

The literature on developing and supporting collaboration among healthcare professionals focuses on both structural/organizational factors and relational factors that need to be considered. Structural/organizational factors include such things as memoranda of agreement, common policies and/or procedures related to patient care, and co-located facilities (Mattesich, Murray-Close, & Monsey, 2001). Relational factors include such things as trust, altruism, and understanding of different professional and organizational cultures. Attention to structural/organizational factors can provide the environmental supports necessary for collaboration. In addition, understanding of and trust between the various professionals involved is an essential prerequisite to collaboration among healthcare providers. In order to trust another provider, a provider must believe that the other has an adequate level of competency and is concerned about the best interests of the patient and the referring provider (i.e., benevolence) (Lee, Stajkovic, & Cho, 2011).

San Martin-Rodriguez, Beaulieu, D'Amour, and Ferrada-Videla (2005) used a systems lens in a review of literature on determinants of successful collaboration in healthcare, recognizing that multiple social systems have an impact on individual functioning. Interpersonal/interactional determinants, organizational determinants, and systemic determinants in the organization's environment, such as aspects of social, cultural, professional, and educational systems, were examined. The authors of this review cautioned, however, that empirical evidence on the determinants of collaboration is sparse.

Systemic factors identified that impeded collaboration included power differences based on gender stereotypes and the social status of professions, cultural values that support individualism and specialization, the process of professionalization that leads to differentiation of professionals and territorialism, and the educational system which does not address knowledge of other professionals. Organizational factors identified that could support collaboration included the organization's philosophy related to the value of collaboration, including a climate of openness, risk-taking, integrity, and trust; administrative support; team resources including time, space, and financial resources; and coordination and communication mechanisms, including standards, policies, protocols, standardized documentation, and formal meetings. Formalization, such as defined teams with specified goals, rules of operation, and meeting schedules, has been found to be an important structural/organizational factor for collaboration (Sicotte, D'Amour, & Moreault, 2002) because it is thought to provide a framework for professional work. Interactional/interpersonal factors that supported collaboration included willingness to collaborate, trust, respect, and communication skills.

This literature indicates the need for planning and action in a number of areas in order to develop and maintain effective collaboration among professionals in pediatric behavioral health. It is unlikely that effective collaboration will occur simply by bringing professionals together and labeling them "a team" (D'Amour et al., 2005). This is partially because the professionals involved in providing behavioral healthcare for children and adolescents such as pediatricians, psychologists, social workers, nurses, and teachers are trained in different professional cultures with different orientations, and also because of lack of structural supports for collaboration within and across the organizations and systems in which they practice. Collaboration around behavioral health may require addressing differences in attitudes about healthcare and differences in professional practice patterns, such as the scope, pace, and scheduling of care. In a review of studies focusing on methods for designing interventions to change healthcare professionals' behavior, Colquhoun, Squires, Kolehmainen, Fraser, and Grimshaw (2017) concluded that there are four steps that are common to intervention design: barrier identification, linking barriers to intervention component selection, use of theory, and engaging the user in assessing the feasibility or acceptability of the intervention.

Barriers and Facilitators

Several studies have focused on identifying barriers to collaboration in providing pediatric behavioral healthcare across professionals and across systems. These studies have examined barriers to collaboration across professionals as well as barriers to collaboration across child-serving systems. These studies yield information that can be used in the design of interventions to increase interprofessional collaboration. Such interventions can address structural issues in organizations that inhibit collaboration, and/or can develop the knowledge, skills, and attitudes needed by professionals in training and those in practice.

In a qualitative study of primary care providers' attitudes and perceptions of adolescent behavioral healthcare, Bitar, Springer, Gee, Graff, and Schydlower (2009) conducted focus groups at five primary care clinics with a variety of providers including physicians, physician assistants, nurses, allied healthcare providers, behavioral healthcare specialists, and clinic administrators. Thematic analysis of the data yielded information about obstacles to care integration. In identifying obstacles to adolescent behavioral healthcare integration, focus group participants included: provider issues—lack of time, lack of training to prepare providers to deal with behavioral health issues, lack of accessible and affordable behavioral health specialty care; parents—time, income; stigma; clinic management/organization—planning, communication, space, adolescent need for privacy; and cultural and language differences. Identified facilitators of integrated care included: technology—used for screening and assessment, used for parent and caregiver education; provider training—to increase provider confidence and competence; identifying and linking with behavioral health specialty care providers in the community; clinic management and organization—improving continuity in care, having adequate space; a strong patient–provider relationship; stigma—patients are less likely to feel stigma if they are treated by primary care physicians instead of specialists; and use of accessible, flexible, brief screening, and assessment tools.

In a study of pediatricians in a southeastern state, Grier, Bradley-Klug, Ax, Wuori, and Szadek (2005) found that greater than 50% of the sample indicated that they communicated or collaborated with school personnel a few times per year or less, and cited having little time to collaborate, limited access to school personnel, and a lack of knowledge about who to contact as major barriers. In a subsequent study on pediatrician collaboration with school personnel, using a national sample of members of the American Academy of Pediatrics, Bradley-Klug et al. (2010) also found that 53.9% reported that they communicated with the schools a few times per year or less. Respondents in this study also reported that their preferred method of communication was through phone calls, and that the individual they contacted most often was the school nurse or classroom teacher. Seventy-five percent of respondents thought that collaborating with school personnel was very beneficial. Frequently endorsed perceived benefits included improved patient outcomes (90.2%), cross disciplinary problem solving, assessment of patient progress across settings, and sharing resources. Similar to the Grier et al. (2005) study, perceived barriers were not having enough time (79.8%), finding school personnel inaccessible, not being able to obtain reimbursement for collaborating, and not knowing with whom to collaborate.

An additional small sample ($n = 13$) qualitative interview study explored pediatricians' perspectives on collaboration with the school and the family on treatment of children with disabilities (Sheppard & Vitalone-Raccaro, 2016). Barriers to collaboration with school personnel identified during the interviews included time, financial issues, and the school's willingness to collaborate. Participants cited the length of meetings related to patients' Individualized Education Plans, the fact that they would not be paid to attend these meetings, and the fact that some schools are not interested in collaboration and pediatrician treatment recommendations. This study also explored barriers to collaboration with families of children with disabilities. Pediatricians cited lack of parent compliance with recommendations, language barriers when English was a second language, cultural issues that impacted families' engagement and follow-through, families' lack of financial resources which impeded follow-through for additional recommended services, and lack of parent knowledge about available support services.

In a study of school psychologists' communication and collaboration practices with primary care pediatricians, Bradley-Klug et al. (2013) found that most school psychologists report communicating with pediatric professionals only a few times per year (60.6%) and 13.3% reported that they never communicated with pediatric professionals. Fewer indicated that they collaborated with pediatricians a few times per year (34%). Perceived barriers to collaboration were "pediatric professionals are not accessible," "there is not enough time in the day," and "different views on child development."

Factors identified as facilitators in a systematic review of studies of interagency collaboration on mental health services for children and youth included good interagency communication, joint trainings, good understanding across agencies, mutual valuing across agencies, senior management support, protocols on interagency collaboration, and a named linking person. Commonly identified barriers included inadequate resources, poor interagency communication, lack of valuing across agencies, differing perspectives, poor understanding across agencies, and confidentiality issues (Cooper et al., 2016). Although not focusing on pediatric populations, a systematic, qualitative review of studies addressing enablers and barriers to implementing collaborative care for adult patients with anxiety and depression (Overbeck, Davidsen, & Kousgaard, 2016) found that enablers included the presence of physician champions, reimbursement for extra work, face-to-face interaction between the professionals, and feedback on the effectiveness of collaborative care. Barriers included securing buy-in from the primary care provider, time pressure and competing priorities in primary care, information technology systems that hindered communication, and the professional and social skills of the care manager. The authors concluded that when planning collaborative care interventions, the following areas need to be addressed: effective training, especially for care managers; issues of reimbursement for the primary care provider; systems for communication and monitoring; and promoting face-to-face interaction between professionals.

Interprofessional Teams

Interprofessional teams are major vehicles for interprofessional collaboration. The team is an important context for collaborative care, and a team mindset is thought to be important to achieving successful patient outcomes (Tsou, Shih, & Ho, 2015). Teams related to provision of healthcare have been described and defined in multiple ways. The term *multidisciplinary team* has been used to describe situations in which several professionals work on a project in parallel, but independently. The term *interdisciplinary team* involves efforts at integration of knowledge and expertise among professionals in order to solve a problem. The term *transdisciplinary team* has been used to refer to the exchange of knowledge, skills, and expertise that transcend traditional disciplinary boundaries (Stepans, Thompson, & Buchanan, 2002).

Characteristics of effective teams have been found to include clear and stable membership; the authority to manage their work process; a compelling goal and direction; feedback on team effectiveness; an organizational context, including the reward system, the information system, and the education system, that is supportive of the team; and the availability of expert coaching (Hackman, 2002). The United Kingdom Centre for Advancement of Interprofessional Education has developed an interprofessional teamwork framework which identifies three areas that contribute to the quality of interprofessional teamwork: relational factors (e.g., power, hierarchy, roles), processual factors (e.g., routines, rituals, time), and organizational and contextual factors (e.g., organizational support, culture, political issues) (Stocker, Pilgrim, Burmester, Allen, & Gijselaers, 2016).

Effective collaboration and team functioning in healthcare have been found to involve the use of a number of strategies. These strategies include sharing behavioral health goals for the patient, clarifying roles and workflow, building trust among professionals, and strengthening communication methods. In effective interprofessional teams, members see their roles as important to the team, have open communication, exercise autonomy (i.e., independent critical thinking and active participation), and have equality of resources (Bridges, Davidson, Odegard, Maki, & Tomkowiak, 2011). The Institute of Medicine (2003) (renamed the National Academy of Science) has recommended that health professionals be trained to work in interdisciplinary teams and to cooperate, collaborate, communicate, and integrate care. Structural methods of supporting team functioning have been found to include the use of electronic systems to facilitate closed-loop communication, huddles, and regular team conferences (Osarogiagbon et al., 2016).

Competencies for Interprofessional Care

Several professional associations have developed statements related to the competencies needed to engage in effective interprofessional collaboration and to provide high quality interprofessional care. These lists of competencies provide a framework for understanding the specific types of knowledge and skills that are needed in order to engage in collaborative behavioral healthcare service delivery. They also provide a basis for development of training programs that will develop these competencies in behavioral healthcare providers.

The American Psychological Association has identified competencies needed for the practice of primary care psychology (McDaniel et al., 2014). Among those competency areas are: interdisciplinary systems and interprofessionalism. The essential component of the interdisciplinary systems competency is appreciation that primary care takes place in the larger healthcare neighborhood, within the community and social context. The essential components of the interprofessionalism competency include: values an interprofessional team approach to care; appreciates the unique contributions that different healthcare professionals bring to the primary care team; develops collaborative relationships to promote healthy interprofessional team functioning that is characterized by mutual respect and shared values; assesses team dynamics and coaches teams to improve functioning; demonstrates awareness, sensitivity, and skills in working professionally with diverse individuals.

In an additional effort to define interprofessional collaboration and to facilitate practice and training in this area, the Interprofessional Education Collaborative (2016) identified four broad competency domains for health professionals. These include:

1. Working with individuals of other professions to develop and maintain mutual respect and shared values.
2. Using knowledge of one's own role and the roles of other professions to assess and address the healthcare needs of patients and to promote and advance the health of populations.
3. Communicating with patients, families, communities, and professionals in health and other fields in a responsive and responsible manner that supports a team approach to the promotion and maintenance of health and the prevention and treatment of disease.
4. Applying relationship-building values and the principles of team dynamics to perform effectively to plan, deliver, and evaluate patient/population-centered care, population health programs, and policies that are safe, timely, efficient, effective, and equitable.

These competencies are designed to provide the basis for all health professionals to collaborate in order to attain positive outcomes in individual and population health.

Training for Interprofessional Collaboration

In order for those involved in provision of pediatric behavioral healthcare to collaborate effectively, they must develop knowledge and skills in communication, shared decision-making, and teamwork (Earnest & Brandt, 2014) and perceptions that the range of behavioral healthcare providers is competent and benevolent. Several authors have stated that the only way a provider can learn about the competence and benevolence of other providers is through personal exposure to them (Pollard Jr. et al., 2014). Opportunities to build perceptions of competence and benevolence among practicing professionals can occur in organizations in which providers are co-located, and through attendance at conferences and involvement in community programs. These contexts can provide opportunities for interaction with other professionals, and a basis for beginning to learn about their roles, skills, and approaches.

Training activities for knowledge and skill development can take place within the context of professional development programs for practitioners and within training programs that are preparing future professionals. The term "interprofessional education (IPE)" has been used to describe these training activities. IPE has been defined as occurring "when students from two or more professions learn about, from, and with each other to enable effective collaboration and improve health outcomes" (WHO, 2010, p. 13). There is emerging evidence that students who have engaged in IPE are more likely to become collaborative interprofessional team members (Bridges et al., 2011).

The American Psychological Association (2016) recently developed *A Curriculum for an Interprofessional Seminar on Integrated Primary Care*. The purpose of this document is to provide course materials that can be used to educate an interprofessional group of learners about the competencies needed to work together in an integrated primary healthcare team. The materials include modules that address eight areas: elements of interprofessional care, rationale for integrated primary care, population health, ethics, models of leadership, quality improvement, healthcare financing, and health policy and advocacy.

Team training curricula have been developed as a means of developing and improving the abilities of healthcare professionals to work effectively in teams. For example, the TeamSTEPPS program (Team Strategies and Tools to Enhance Performance and Patient Safety) developed by the U.S. Department of Defense and the Agency for Healthcare Research and Quality focuses on developing attitudes, knowledge, and skills that comprise teamwork (AHRQ, 2012). TeamSTEPPS addresses identifying the team structure—the components of the team that must work together to provide high quality patient care, as well as four major skills: communication, leadership, situation monitoring, and mutual support. Communication skills focus on exchanging information clearly and accurately among team members; leadership skills focus on ensuring that team activities and actions are understood, that any changes in information are shared, and that team members have necessary resources. Situation monitoring skills focus on scanning and assessing situational elements in patient care. Mutual support skills focus on anticipating and supporting team members' needs, in part through knowledge about their responsibilities and workload, and in part through being able to give constructive feedback to team members. Although developed as a means of training healthcare professionals in hospital settings to work effectively as a team, the competencies addressed in this training can also be useful for teams that span child-serving organizations.

Bridges et al. (2011) presented three models of IPE experiences in higher education professional preparation programs aimed at increasing interprofessional, collaborative, team-based skills. One model is didactic and course-based where students interact in interprofessional teams focusing on a collaborative approach to patient-centered care, emphasizing team interaction, communication, service learning, evidence-based practice, and quality improvement. An initial one-credit course has a didactic component, a service learning component focusing on development of a prevention program for a community partner, and a clinical component. A second one-credit course focuses on the impact of culture on healthcare, with students working in interprofessional teams to develop a culturally appropriate patient education tool, and completing a patient interview and reflection with emphasis on cultural sensitivity. Another model focuses on an interprofessional course consisting of community-based learning experiences in which interprofessional student teams provide home visits for local families. The final model consists of simulation activities in which interprofessional student teams collaborate to provide care for simulated patients.

Barriers and facilitators to provision of interprofessional education in higher education institutions have been examined (Lawlis, Anson, & Greenfield, 2014). A comprehensive review of the literature in this area found five key elements across stakeholder levels that inhibit or facilitate IPE: government funding, higher education institution funding, faculty development programs, higher education organizational structures that support embedding IPE into professional curricula, and faculty/staff ownership and commitment across disciplines. Faculty development programs that focus on educating faculty/staff in IPE principles and teaching/learning strategies were seen as key means of addressing barriers to IPE and facilitating change. In addition, champions in all stakeholder groups were considered to be critical. The authors noted, however, that it was not possible to determine whether all five fundamental elements were necessary for pedagogical change.

Conclusions

Interprofessional collaboration involves individuals in multiple professions and settings using evidence-based practices in planning, delivering, and evaluating patient care, with the goals of improving the quality of individual care and the behavioral health of populations, as well as reducing care cost. Both individual/relational factors and structural/organizational/systems factors impact the implementation of interprofessional collaboration. Training for interprofessional collaboration has evolved as a major vehicle for increasing the use of this approach to pediatric behavioral healthcare.

A number of training programs that focus on interprofessional collaboration at the graduate/professional school level and for use with professionals currently in practice have been developed, and use of these types of training programs and events is spreading. These programs can provide the basis for understanding the skills, roles, and perspectives of professionals that can contribute to pediatric behavioral healthcare, as well as for mutual trust among these professionals, and the communication skills that are needed for effective team and interprofessional functioning. As literature on adult learning of new practices indicates, didactic training alone is not sufficient to change existing practices and initiate new ways of delivering services (McHugh & Barlow, 2012). Efforts to spread the practice of interprofessional collaboration, with the aim of improving pediatric behavioral healthcare, can best be supported by strategies derived from the knowledge base in implementation science. That literature tells us that with regard to training efforts, coaching as well as didactic training is essential to supporting new learning. In addition, attention to context, within the implementing organization, as well as in the systems that surround that organization, is crucial in the planning of strategies that will support implementation of an innovative practice such as interprofessional collaboration.

In the development of interprofessional education programs, two questions should be answered: (1) What information do learners need to be provided with that will support the process of interprofessional collaboration? (2) Where will learners have opportunities for practice and coaching of interprofessional collaboration? In graduate/professional school coursework, and presentations and workshops for practitioners, opportunities for practice and coaching through role-play and simulations will be as essential to promoting learning and behavior change as didactic provision of information on the nature and skill components of effective interprofessional collaboration. Fieldwork, practica, rotations, internships, and residencies in graduate and professional training programs can also offer learning experiences focusing on practice and coaching of newly learned professional behaviors that include interprofessional collaboration. In his work on effective team functioning, Hackman (2002) has pointed to the need for expert coaching for teams, and this should be provided in efforts to develop interprofessional teams of practicing professionals. Provision of team coaching for practitioners is difficult as it is currently extremely rare, and thus will be an innovative practice itself. However, research in this area tells us that it is likely a prerequisite to effective team functioning, especially for those who have not learned about this during their graduate and professional school years.

In addition to attending to how professionals will learn about interprofessional collaboration, equal attention needs to be given to the organizational and systems context in which the collaboration is to take place. In the organizational context, administrative support will be essential in the form of both adaptive leadership, which focuses on inspiring and motivating stakeholders, encouraging interprofessional collaboration, and guiding potential and novice collaborators through uncertainty, resistance, and change; and technical leadership, which focuses on solving specific problems involved with using new practices (Forman, Ward, & Fixsen, 2017). Support from other stakeholders is also essential, and lack of support from professionals for investing time and resources in interprofessional collaboration has been identified as a barrier to this model of behavioral healthcare delivery. In this respect, additional evidence of the effectiveness of interprofessional collaboration in providing high quality behavioral health services and dissemination of this information to stakeholders will be essential.

Organizational supports for interprofessional collaboration include space, time, financial resources, information/data systems, and communication systems. Since interprofessional collaboration in pediatric behavioral healthcare is likely to involve collaboration among professionals across organizations such as pediatric primary and specialty care practices and schools, development of appropriate and feasible communication and information/data systems is likely to be a complex and difficult undertaking. However, development of feasible methods of accessing information about patient status across organizations will be necessary in order to develop shared goals and treatment plans, as well as to monitor patient progress. Ability across organizations to access electronic medical/educational records of children for whom treatment is shared would provide an ideal means of supporting interprofessional collaboration. However, in the absence of inter-organizational information/data systems which may take extensive time and financial resources to develop, development of policies and procedures for reporting on patient information at inter-organizational team meetings can provide a feasible communication bridge. Time and financial resources are also difficult but essential issues that need to be addressed. Although in education settings the tasks that professionals engage in can be managed by administrators in those settings, in medical settings, payment for physician services by health insurers typically dictates how much time healthcare providers spend on various tasks related to patients. The issue of payment for completion of tasks required for provision of collaborative behavioral healthcare, including time to meet, will need to be addressed by both the organizations in which healthcare providers work and insurers that provide payments to those organizations.

Interprofessional collaboration is a practice that has the potential to improve the quality of pediatric behavioral healthcare for individuals and populations. Widespread, successful use of this model of service delivery will require additional research to increase the knowledge base related to this practice. Existing theory and research in this area has provided a good foundation for understanding the positive impact of this model of professional functioning. However, additional research is needed that will document the professional and patient outcomes of interprofessional collaboration and that will identify evidence-based strategies for implementation. Given the complexity of working across disciplines and across organizations and systems, extensive effort with respect to implementation planning and action will be required to realize the promise of this model of pediatric behavioral healthcare service delivery.

References

Agency for Healthcare Research and Quality. (2012). *TeamSTEPPS 2.0*. Rockville, MD. Retrieved from https://www.ahrq.vob/teamstepps/index.html

American Academy of Pediatrics. (1992). The medical home. *Pediatrics, 90*, 774.

American Psychological Association, Interprofessional Seminar on Integrated Primary Care Work Group. (2016). *A curriculum for an interprofessional seminar on integrated primary care*. Retrieved from http://www.apa.org/education/grad/curriculum-seminar.aspx

Archer, J., Bower, P., Gilbody, S., Lovell, K., Richards, D., Gask, L., … Coventry, P. (2012). Collaborative care for depression and anxiety problems. *Cochrane Database of Systematic Reviews, 10*, CD006525.

Asarnow, J. R., Jaycox, L. H., Duan, N., LaBorde, A. P., Rea, M. M., Murray, P., … Wells, K. B. (2005). Effectiveness of a quality improvement intervention for adolescent depression in primary care clinics: A randomized controlled trial. *Journal of the American Medical Association, 293*, 311–319.

Asarnow, J. R., Jaycox, L. H., Tang, L., Duan, N., LaBorde, A. P., Zeledon, L. R., … Wells, K. B. (2009). Long-term benefits of short-term quality improvement interventions for depressed youths in primary care. *American Journal of Psychiatry, 166*, 1002–1010.

Asarnow, J. R., Kolko, D. J., Miranda, J., & Kazak, A. E. (2017). The pediatric patient-centered medical home: Innovative models for improving behavioral health. *American Psychologist, 72*, 13–27.

Berwick, D. M., Nolan, T. W., & Whittington, J. (2008). The triple aim: Care, health and cost. *Health Affairs, 27*, 759–769.

Bitar, G. W., Springer, P., Gee, R., Graff, C., & Schydlower, M. (2009). Barriers and facilitators of adolescent behavioral health in primary care: Perceptions of primary care providers. *Families, Systems, & Health, 27*, 346–361.

Bradley-Klug, K. L., Jeffries-DeLoatche, K. L., Walsh, A. S. J., Bateman, L. P., Nadeau, J., Powers, D. J., & Cunningham, J. (2013). School psychologists' perceptions of primary care partnerships: Implications for building the collaborative bridge. *Advances in School Mental Health Promotion, 6*, 51–67.

Bradley-Klug, K. L., Sundman, A. N., Nadeau, J., Cunningham, J., & Ogg, J. (2010). Communication and collaboration with schools: Pediatricians' perspectives. *Journal of Applied School Psychology, 26*, 263–281.

Bridges, D. R., Davidson, R. A., Odegard, P. S., Maki, I. V., & Tomkowiak, J. (2011). Interprofessional collaboration: Three best practice models of interprofessional education. *Medical Education Online, 16*, 6035.

Colquhoun, H. L., Squires, J. E., Kolehmainen, N., Fraser, C., & Grimshaw, J. M. (2017). Methods for designing interventions to change healthcare professionals' behaviour: A systematic review. *Implementation Science, 12*, 30.

Cooper, M., Evans, Y., & Pybis, J. (2016). Interagency collaboration in children and young people's mental health: A systematic review of outcomes, facilitating factors and inhibiting factors. *Child: Care, Health and Development, 42*, 325–342.

D'Amour, D., Ferrada-Videla, M., San Martin Rodriguez, L., & Beaulieu, M. D. (2005). The conceptual basis for interprofessional collaboration: Core concepts and theoretical frameworks. *Journal of Interprofessional Care, 19*, 116–131.

Doherty, W. J., McDaniel, S. H., & Baird, M. A. (1996). Five levels of primary care/behavioral healthcare collaboration. *Behavioral Healthcare Tomorrow, 5*, 25–27.

Earnest, M., & Brandt, B. (2014). Aligning practice redesign and interprofessional education to advance triple aim outcomes. *Journal of Interprofessional Care, 28*, 497–500.

Forman, S. G., Ward, C. S., & Fixsen, D. L. (2017). Comprehensive behavioral health and school psychology: An implementation agenda. *Journal of Applied School Psychology, 33*, 233–244.

Grier, E. C., Bradley-Klug, K. L., Ax, E. E., Wuori, D. F., & Szadek, L. (2005). *Chronic pediatric health issues in the school setting: Collaboration between primary care pediatricians and school psychologists*. Paper presented at the American Academy of Pediatrics 2005 National Conference and Exhibition, Washington, DC.

Hackman, J. R. (2002). *Leading teams: Setting the stage for great performances*. Boston, MA: Harvard Business Press.

Institute of Medicine. (2003). *Health professions education: A bridge to quality*. Washington, DC: National Academies Press.

Interprofessional Education Collaborative. (2016). *Core competencies for interprofessional collaborative practice: Report of an expert panel*. Washington, DC: Interprofessional Education Collaborative.

Kolko, D. J. (2009). Options for the delivery of mental health services. In T. K. McInerny, H. M. Adam, D. E. Campbell, D. M. Kamat, & K. J. Kelleher (Eds.), *American Academy of Pediatrics textbook of pediatric care* (pp. 1168–1176). Elk Grove Village, IL: American Academy of Pediatrics.

Kolko, D. J., Campo, J. V., Kilbourne, A. M., & Kelleher, K. (2012). Doctor-office collaborative care for pediatric behavioral problems: A preliminary clinical trial. *Archives of Pediatrics & Adolescent Medicine, 166*, 224–231.

Kolko, D. J., & Perrin, E. (2014). The integration of behavioral health interventions in children's health care: Services, science, and suggestions. *Journal of Clinical Child & Adolescent Psychology, 43*, 216–228.

Lawlis, T. R., Anson, J., & Greenfield, D. (2014). Barriers and enablers that influence sustainable interprofessional education: A literature review. *Journal of Interprofessional Care, 28*, 305–310.

Lee, D., Stajkovic, A. D., & Cho, B. (2011). Interpersonal trust and emotion as antecedents of cooperation: Evidence from Korea. *Journal of Applied Social Psychology, 41*, 1603–1631.

Martin, M. P., White, M. B., Hodgson, J. L., Lamson, A. L., & Irons, T. G. (2014). Integrated primary care: A systematic review of program characteristics. *Families, Systems & Health, 32*, 101–115.

Mattesich, P., Murray-Close, M., & Monsey, B. (2001). *Collaboration: What makes it work: A review of research literature on factors influencing successful collaboration*. Saint Paul, MN: Amherst H. Wilder Foundation.

McDaniel, S. H., Grus, C. L., Cubic, B. A., Hunter, C. L., Kearney, L. K., Schuman, C. C., … Miller, B. F. (2014). Competencies for psychology practice in primary care. *American Psychologist, 69*, 409.

McHugh, R. K., & Barlow, D. H. (2012). Training in evidence-based psychological interventions. In R. K. McHugh & D. H. Barlow (Eds.), *Dissemination and implementation of evidence-based psychological interventions* (pp. 43–58). New York, NY: Oxford University Press.

Merikangas, K. R., Nakamura, E. F., & Kessler, R. C. (2009). Epidemiology of mental disorders in children and adolescents. *Dialogues in Clinical Neuroscience, 11*, 7.

Osarogiagbon, R. U., Rodriguez, H. P., Hicks, D., Signore, R. S., Roark, K., Kedia, S. K., … Krasna, M. J. (2016). Deploying team science principles to optimize interdisciplinary lung cancer care delivery: Avoiding the long and winding road to optimal care. *Journal of Oncology Practice, 12*, 983–991.

Overbeck, G., Davidsen, A. S., & Kousgaard, M. B. (2016). Enablers and barriers to implementing collaborative care for anxiety and depression: A systematic qualitative review. *Implementation Science, 11*, 165.

Perrin, J. M., Anderson, L. E., & Van Cleave, J. (2014). The rise in chronic conditions among infants, children and youth can be met with continued health system innovations. *Health Affairs, 33*, 2099–2105.

Perrin, E. C., Sheldrick, R. C., McMenamy, J. M., Henson, B. S., & Carter, A. S. (2014). Improving parenting skills for families of young children in pediatric settings: A randomized clinical trial. *Journal of the American Medical Association Pediatrics, 168*, 16–24.

Polaha, J., Dalton, W. T., III, & Allen, S. (2011). The prevalence of emotional and behavior problems in pediatric primary care serving rural children. *Journal of Pediatric Psychology, 36*, 652–660.

Pollard, R. Q., Jr., Betts, W. R., Carroll, J. K., Waxmonsky, J. A., Barnett, S., DeGruy, F. V., III, … Kellar-Guenther, Y. (2014). Integrating primary care and behavioral health with four special populations: Children with special needs, people with serious mental illness, refugees, and deaf people. *American Psychologist, 69*, 377–387.

Power, T. J., Mautone, J. A., Marshall, S. A., Jones, H. A., Cacia, J., Tresco, K., … Blum, N. J. (2014). Feasibility and potential effectiveness of integrated services for children with ADHD in urban primary care practices. *Clinical Practice in Pediatric Psychology, 2*, 412.

Ratzliff, A., Cerimele, J., Katon, W., & Unutzer, J. (2016). Working as a team to provide collaborative care. In A. Ratzliff, J. Unutzer, W. Katon, & K. A. Stephens (Eds.), *Integrated care: Creating effective mental and primary health care teams* (pp. 1–24). Hoboken, NJ: Wiley.

Ratzliff, A., Katon, W., & Unutzer, J. (2016). Using collaborative care to create effective mental and primary health care teams. In A. Ratzliff, J. Unutzer, W. Katon, & K. A. Stephens (Eds.), *Integrated care: Creating effective mental and primary health care teams* (pp. ix–xiv). Hoboken, NJ: Wiley.

Rones, M., & Hoagwood, K. (2000). School-based mental health services: A research review. *Clinical Child and Family Psychology Review, 3*, 223–241.

San Martin-Rodriguez, L. S., Beaulieu, M., D'Amour, D., & Ferrada-Videla, M. (2005). The determinants of successful collaboration: A review of theoretical and empirical studies. *Journal of Interprofessional Care, 1*, 132–147.

Sheppard, M. E., & Vitalone-Raccaro, N. (2016). How physicians support children with disabilities and their families: Roles, responsibilities and collaborative partnerships. *Disability and Health Journal, 9*, 692–704.

Sicotte, C., D'Amour, D., & Moreault, M. (2002). Interdisciplinary collaboration within Quebec community health care centers. *Social Science & Medicine, 55*, 991–1003.

Stepans, M. B., Thompson, C. L., & Buchanan, M. L. (2002). The role of the nurse on a transdisciplinary early intervention assessment team. *Public Health Nursing, 19*, 238–245.

Stocker, M., Pilgrim, S. B., Burmester, M., Allen, M. L., & Gijselaers, W. H. (2016). Interprofessional team management in pediatric critical care: Some challenges and possible solutions. *Journal of Multidisciplinary Healthcare, 9*, 47–58.

Tsou, P., Shih, J., & Ho, M. J. (2015). A comparative study of professional and interprofessional values between health professional associations. *Journal of Interprofessional Care, 29*, 628–633.

World Health Organization. (2010). *Framework for action on interprofessional education and collaborative practice*. Geneva. Retrieved from http://www.who.int/hrh/resources/framework_action/en/

Part II

Chronic Physical Health Conditions: Behavioral Health Aspects

4 Obesity

Tarrah Mitchell and David Janicke

Abstract

Pediatric obesity is a complex, chronic disease that results from a multitude of genetic, biological, behavioral, environmental, and epigenetic factors, and it is associated with a range of physical and psychosocial health consequences both in childhood and into adulthood. The contributors and consequences of pediatric obesity can be viewed within the social-ecological perspective, which posits that bidirectional relationships exist between children's individual, environmental, social, and cultural factors. In accordance with this perspective, a multi-tiered and interdisciplinary approach is necessary for optimal screening, assessment, prevention, and intervention of pediatric obesity. This chapter begins with a background of the measurement, prevalence, and etiology of pediatric obesity, followed by a discussion of physical and psychosocial health outcomes. Next, evidenced-based prevention and intervention approaches are discussed, with a focus on interdisciplinary collaboration across child serving systems, including the home, school, community, and healthcare setting. A case study is also provided to help illustrate the interdisciplinary nature of pediatric obesity screening, assessment, prevention, and intervention. Finally, the literature is summarized and future directions are explored.

Pediatric obesity is defined as the excessive accumulation of fat or adiposity in youth (WHO, 2017). Pediatric obesity is a complex, chronic disease that results from a multitude of genetic, biological, behavioral, environmental, and epigenetic factors, and it is associated with a range of physical and psychosocial health consequences both in childhood and into adulthood. The contributors and consequences of pediatric obesity can be viewed within the social-ecological perspective, which posits that bidirectional relationships exist between children's individual, environmental, social, and cultural factors (Bronfrenbrenner, 1979). In accordance with this perspective, a multi-tiered and interdisciplinary approach is necessary for optimal screening, assessment, prevention, and intervention of pediatric obesity.

The current chapter begins with a background of the measurement, prevalence, and etiology of pediatric obesity, followed by a discussion of physical and psychosocial health outcomes. Next, evidenced-based prevention and intervention approaches are discussed, with a focus on interdisciplinary collaboration across child serving

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systems, including the home, school, community, and healthcare setting. A case study is also provided to help illustrate the interdisciplinary nature of pediatric obesity screening, assessment, prevention, and intervention. Finally, the literature is summarized and future directions are explored.

Measurement

Pediatric obesity is measured using a variety of direct and indirect measures (e.g., Freedman & Sherry, 2009; Hu, 2008). Direct measures of adiposity include dual-energy X-ray absorptiometry (DEXA), densitometry, hydrometry, computerized tomography, and magnetic resonance imaging. Although these direct measures are considered to be "gold standards" of adiposity measurement due to their accuracy, they are expensive, time-consuming, and often not feasible for clinical assessment and management of pediatric obesity. Therefore, indirect measures, such as waist circumference, bioelectrical impedance, skinfolds, and body mass index (BMI), are often used to approximate adiposity (Freedman & Sherry, 2009; Hu, 2008).

Perhaps one of the most commonly used indirect measures of pediatric obesity is BMI. BMI is calculated by dividing weight (in kg) by the square of height (in cm; CDC, 2016b). However, because the expected height and weight for youth varies between boys and girls and at different developmental stages, specific BMI cutoffs are not appropriate when determining overweight or obesity for youth ages 2–19. Using the U.S. Centers for Disease Control and Prevention growth charts, BMI is compared to other children of the same sex and age and is expressed as a BMI-for-age percentile. A classification of obesity is given if a child has a BMI-for-age percentile greater than or equal to the 95th percentile, and a classification of overweight is given if a child has a percentile between the 85th and 95th percentile (CDC, 2016b).

A primary limitation of using BMI as an indirect measure of adiposity is that it does not differentiate between body fat, lean muscle mass, and skeletal mass (Freedman & Sherry, 2009; Hu, 2008). However, BMI is easy to measure, reliable, and cost-effective, and it has been shown to be positively correlated with direct measures of adiposity (e.g., Freedman, Horlick, & Berenson, 2013; Wohlfahrt-Veje et al., 2014). Further, BMI has been shown to have moderately high sensitivity, specificity, and positive predictive value in youth (Freedman & Sherry, 2009; Harrington, Staiano, Broyles, Gupta, & Katzmarzyk, 2013). Given the benefits of BMI and the limitations of direct measures, BMI-for-age remains to be the most commonly used measure of pediatric obesity (e.g., Barlow, 2007; Harrington et al., 2013; USPSTF, 2010).

Prevalence

In the United States, approximately 18.5% of children have obesity, and rates are similar for boys and girls (Hales, Carroll, Fryar, & Ogden, 2017). However, the prevalence of obesity differs based on a number of child and family variables. First, the prevalence of obesity is higher among school-age children (ages 6–11; 18.4%) and adolescents (ages 12–19; 20.6%) compared to toddler and preschool-age children (ages 2–5; 13.9%; Hales et al., 2017). Trends indicate that for toddlers and preschool-age children, the prevalence increased from 1988 to 2004, but then decreased through 2014 (Ogden et al., 2016). For school-age children, the prevalence of obesity increased until 2008 and then stabilized through 2014, whereas the prevalence for adolescents continued to increase through 2014 (Ogden et al., 2016). Trends for the various age groups are not yet available through 2016, but the data suggest that, overall, the observed prevalence change from 2014 to 2016 was not significant (Hales et al., 2017). Second, the prevalence of obesity is higher among non-Hispanic black youth (22%) and Hispanic youth (25.8%) than among non-Hispanic white youth (14.1%) and non-Hispanic Asian youth (11.0%; Hales et al., 2017). Third, data from Ogden et al. (2016) suggested that the prevalence of obesity is higher when heads of households have less than a high school degree (21%) or a high school degree (22.2%) than when heads of households have a greater than high school degree (14.1%). The accumulation of evidence suggests that obesity disproportionally affects older youth, black and Hispanic youth, and youth whose guardians have less education.

Etiology

Considered most simply, obesity results from an imbalance between energy consumed and expended (CDC, 2016a; Gurnani, Birken, & Hamilton, 2015; Han, Lawlor, & Kimm, 2010; Karnik & Kanekar, 2012). More specifically, eating large amounts of high-calorie and low-nutrient foods/beverages, spending too much time sitting and on screens (e.g., television, phone, tablets, video games), and not engaging in adequate physical activity often result in excess body fat. However, caution must be taken when considering this simple energy balance explanation of obesity because it tends to stigmatize the condition as a consequence of poor personal decisions and does not fully elucidate the range of genetic, biological, environmental, and epigenetic factors that contribute to the excess accumulation of fat (CDC, 2016a; Gurnani et al., 2015; Han et al., 2010; Karnik & Kanekar, 2012). Instead, in accordance with the social ecological model of development (Bronfrenbrenner, 1979), all contexts in which children develop should be considered when understanding the etiology of obesity.

There are a number of genetic factors that contribute to pediatric obesity. Genetic contributors include rare single gene defects (particularly defects involving the leptin-melanocortin regulating pathway) and several genetic syndromes, such as Prader–Willi, Bardet–Biedl, WAGR, and Alstom (Han et al., 2010). It should be noted that only about 5% of children with obesity have a genetic causal determinant like those listed above (Anderson & Butcher, 2006; Atay & Bereket, 2016). For the remaining large portion of children, obesity most likely results from a complex interaction of individual and environmental factors.

Multiple prenatal and postnatal factors also contribute to pediatric obesity. For example, there is evidence to suggest that children whose mothers have higher BMIs or gestational diabetes mellitus are at increased risk for pediatric obesity (Han et al., 2010; Lau, Liu, Archer, McDonald, & Liu, 2014; Luca, Birken, Grewal, Dettmer, & Hamilton, 2012). Additionally, higher birth weight, “catch-up growth” after being small for gestational age, and early BMI rebound (i.e., rise in BMI that follows the natural BMI drop between 3 and 7 years of age) have been shown to be associated with pediatric obesity (Han et al., 2010). There is mixed evidence regarding whether breast feeding is a protective factor for pediatric obesity, but evidence from a large randomized control trial of an intervention targeting breast feeding suggested no causal link (Han et al., 2010; Kramer et al., 2007, 2009).

There are also a number of other individual characteristics that contribute to pediatric obesity. For example, a number of endocrine-related disorders influence risk for obesity, including hypothyroidism, growth hormone deficiency or resistance, Cushing syndrome, cortisol excess, polycystic ovarian syndrome (PCOS), and pseudohypoparathyroidism (Gurnani et al., 2015; Han et al., 2010). Further, hormones, such as leptin and ghrelin, and gut microbes, such as firmicutes and bacteroidetes, impact obesity (Gurnani et al., 2015; Han et al., 2010; Luca et al., 2012). Other individual factors that contribute to obesity are the use of psychotropic medications, chemotherapies, hormonal contraception, and surgery causing hypothalamic damage (e.g., Han et al., 2010; Luca et al., 2012). Lastly, it is important to note that children’s sleep has been shown to be linked to pediatric obesity, likely due to impacts of dietary intake, physical activity, and disruptions in the level of hunger and satiety hormones (Chen, Beydoun, & Wang, 2008; Hart, Cairns, & Jelalian, 2011). For example, Chen et al. (2008) found that children that slept less hours had a 58% higher risk of overweight/obesity and that the risk decreased by 9% for each hour increase in average total sleep time per night.

Because children primarily learn about food choices and activity practices from their parents, there are a number of family environment variables that contribute to pediatric obesity (Karnik & Kanekar, 2012; Patrick & Nicklas, 2005; Sahoo et al., 2015). First, parents serve as models for children regarding healthy lifestyle choices; children observe their parents and often mimic their behavior. Additionally, because youth often lack the capabilities to independently acquire their own food and access means of physical activity, parents' choices about what food to provide in the home and support for child activity have a large impact on children's choices. Variables associated with mealtime structure also impact pediatric obesity. For example, not eating meals as a family, eating away at fast-food or sit down restaurants more often, and watching television while eating are associated with higher risk for obesity (Karnik & Kanekar, 2012; Patrick & Nicklas, 2005; Sahoo et al., 2015). As children grow older, peers often serve as additional models and can also impact children's health behaviors (CDC, 2016a; Gurnani et al., 2015; Sahoo et al., 2015).

The community environments with which children interact also influence food choices and activity levels, which ultimately contribute to obesity. For example, children spend the majority of their waking time on weekdays at school and often eat two meals at school; thus, schools' availability and promotion of healthy food choices and physical activity impact children's health behaviors (CDC, 2016a; Karnik & Kanekar, 2012; Sahoo et al., 2015). Additionally, the built or physical environments surrounding children's homes and schools can contribute to obesity. For example, the lack of availability of affordable, healthy foods, safe sidewalks and bike paths, and safe parks impacts the ability to make healthy lifestyle choices (Anderson & Butcher, 2006; CDC, 2016a; Dunton, Kaplan, Wolch, Jerrett, & Reynolds, 2009; Karnik & Kanekar, 2012).

The societal and cultural environments with which children interact also contribute to pediatric obesity. For example, children from low- and middle-income countries are often born underweight; however, these children are prone to obesity when they experience over-nutrition after birth (Han et al., 2010). Additionally, in many cultures, food is used as a reward, as a way to show love, and as a center of socialization practices (Budd & Hayman, 2008), which can lead to unhealthy associations with food (Sahoo et al., 2015).

Other larger environmental influences impact pediatric obesity. Food preferences are very suggestible, and the food industry defines what is desirable through marketing (Harris, Pomeranz, Lobstein, & Brownell, 2009). Marketing campaigns targeted at children often portray positive consequences of eating high-calorie and low-nutrient foods/beverages, as well as unhealthy eating behaviors. As a result of increased exposure, children's desire for and consumption of these products and engagement in these behaviors increase (Andreyeva, Kelly, and Harris, 2011; Harris et al., 2009). Similarly, increased portion sizes over the last several decades, particularly at fast-food restaurants, has led to increased energy intake in youth, possibly due to visual cues and parental messages regarding the importance of eating all of the food on their plates (Fisher & Kral, 2008; Piernas & Popkin, 2011; Zlatevska, Dubelaar, & Holden, 2014).

As one can see, health behaviors such as diet, physical activity, and sedentary behavior clearly impact energy balance in children and contribute to obesity. However, viewing obesity as solely a consequence of energy imbalance is inadequate. Because pediatric obesity results from a complex interaction of individual and environmental factors, providers must consider these domains when screening and assessing the disease. As such, a multi-tiered, interdisciplinary approach to prevention and intervention is critical.

Physical Health Outcomes

Pediatric obesity is associated with a number of negative physical health outcomes in childhood and into adulthood, including type 2 diabetes mellitus, nonalcoholic fatty liver disease, cardiovascular disease, hypertension, high triglycerides, dyslipidemia, and hyperandrogenism in childhood (Abrams & Katz, 2011; CDC, 2016a; Sahoo et al., 2015; Skinner, Perrin, Moss, & Skelton, 2015). Additionally, pediatric obesity has been shown to be associated with asthma, sleep apnea, orthopedic complications, dermatologic conditions, gallstones, heartburn, and precocious puberty in childhood (Abrams & Katz, 2011;

CDC, 2016a; Sahoo et al., 2015; Skinner et al., 2015). Unfortunately, obesity and many of these negative physical health consequences track into adulthood and, in worst cases, can lead to cardiometabolic morbidity and premature mortality (CDC, 2016a; Reilly & Kelly, 2011). Therefore, prevention and early intervention for pediatric obesity is essential.

Psychosocial Health Outcomes

In addition to physical health outcomes, pediatric obesity is also associated with a range of negative psychosocial health outcomes. For example, a robust literature supports the associations of pediatric obesity with social difficulties, such as weight-based stigmatization and physical and relational victimization (Gray, Kahhan, & Janicke, 2009; Harriger & Thompson, 2012; Vander Wal & Mitchell, 2011). Regarding psychological or emotional difficulties, the literature is mixed concerning associations of pediatric obesity with decreased self-esteem and increased depressive symptoms (Harriger & Thompson, 2012; Pulgarón, 2013). Mond, Van den Berg, Boutelle, Hannan, and Neumark-Sztainer (2011) posited that the associations between obesity and emotional well-being (i.e., self-esteem and depressed mood) are due primarily to the effects of body dissatisfaction. Further, studies have shown that youth, especially females, with overweight/obesity are more likely to engage in disordered eating behaviors, again likely due to body dissatisfaction (Goldschmidt, Aspen, Sinton, Tanofsky-Kraff, & Wilfley, 2008). Overall, youth with obesity have lower quality of life than their healthy counterparts (Griffiths, Parsons, & Hill, 2010). In fact, the quality of life of children with obesity has been shown to be comparable to youth diagnosed with cancer (Schwimmer, Burwinkle, & Varni, 2003). Therefore, the negative psychosocial consequences of pediatric obesity cannot be ignored and should be targets of prevention and intervention.

It is noteworthy that these psychosocial factors are often bidirectionally related to pediatric obesity (Puder and Munsch, 2010). For example, children may experience increased stigmatization and teasing because of their weight status; these social factors may result in children withdrawing from peers, engaging in less physical activity, spending more time sedentary, and seeking food as comfort, which ultimately contribute to further weight gain (Niehoff, 2009; Sahoo et al., 2015). Alternatively, children may experience body dissatisfaction because they do not fit the thin ideal and may engage in unhealthy weight control behaviors, which can further contribute to increased weight gain (Neumark-Sztainer, Paxton, Hannan, Haines, & Story, 2006). Therefore, psychosocial factors can be seen as both predictors and outcomes of obesity.

Evidenced-Based Assessment Measures of Psychosocial Outcomes

Because rates of psychosocial difficulties vary for children with obesity, a thorough assessment of psychosocial functioning is recommended as a component of treatment. Standardized measures may serve as beneficial screeners of a range of symptoms. Examples of well-established rating scales of psychosocial functioning are as follows: *Child Behavior Checklist* (CBCL; Achenbach & Rescorla, 2001), the *Behavior Assessment Rating Scale, Second Edition* (BASC-3; Reynolds & Kamphaus, 2004), and the *Conners Parent and Teacher Rating Scales* (Conners, 2008). Additionally, health-related quality of life measures are often helpful to assess subjective ratings of the child's physical, emotional, social, and academic functioning. A generic measure of this construct is the *Pediatric Quality of Life Inventory* (PedsQL™ 4.0; Varni, Seid, & Kurtin, 2001); however, to examine how children's quality of life is impacted specifically by their weight or size, *Sizing Them Up* (Modi & Zeller, 2008) and *Sizing Me Up* (Zeller & Modi, 2009) are helpful tools. Finally, the *Youth Eating Disorders Examination Questionnaire* (YEDE-Q; Goldschmidt, Doyle, & Wilfley, 2007) and the *Children's Eating Attitudes Test* (ChEAT; Maloney, McGuire, & Daniels, 1988) are evidenced-based measures of disordered eating behaviors in children. For a comprehensive review of well-established measures of psychosocial adjustment of children with chronic illnesses, refer to Holmbeck et al. (2008). These measures, along with behavioral observations and diagnostic interviews, are recommended to understand the frequency, duration, severity, and impairment of the symptoms and to direct prevention and intervention efforts.

Prevention and Intervention

Because of multifactorial contributors and consequences of pediatric obesity, interprofessional collaboration aimed at preventing and reducing pediatric obesity is critical. Individual-, family-, healthcare-, school-, and community-level prevention and intervention approaches are described below.

Individual- and Family-Level Prevention

Evidence suggests that efforts to prevent pediatric obesity should begin prior to children even being born (Nader et al., 2012). As mentioned earlier, maternal weight status and excessive weight gain during pregnancy are risk factors for later childhood obesity due to the impacts on children's metabolic programing (Han et al., 2010; Lau et al., 2014; Luca et al., 2012; Nader et al., 2012). Additionally, high and low child birth weights, which are related to maternal obesity, are independent risk factors for childhood obesity (Han et al., 2010). Therefore, efforts focused on reducing obesity in women prior to conception, as well as preventing excessive weight gain during pregnancy, are important for preventing later obesity in children. Further, rapid weight gain early in infancy also increases risk for later obesity (Han et al., 2010); thus, infant weight and nutrition should be closely monitored in the first year of life (Nader et al., 2012). Overall, parents making healthy lifestyle choices for themselves prior to conception and during pregnancy, as well as facilitating healthy choices for young children after birth, can help prevent later childhood obesity.

Healthcare-Level Prevention and Intervention

Because children frequently visit medical settings for well-child visits and acute care, primary care settings offer unique opportunities for prevention and intervention of pediatric obesity. Barlow and the Expert Committee on Pediatric Overweight and Obesity (2007) and the US Preventive Services Task Force (USPSTF, 2010) set guidelines for the assessment, prevention, and treatment of pediatric obesity in medical settings. As a universal first step, both groups advised that primary care professionals should calculate and plot children's BMI at their annual well-child visit in order to identify children in need of weight management prevention and intervention efforts. After the initial screening and identification, Barlow and the Expert Committee (2007) recommended that primary care professionals conduct an assessment of medical risk (e.g., child history, child exam, parental obesity, family history), behavior risk (e.g., diet, physical activity, sedentary behavior), and attitudes (e.g., child and family concern and motivation). For those with average BMIs (5–85th percentile), and those with overweight and no identified health risks, it is recommended that prevention efforts are implemented. Prevention efforts include reviewing identified risks, encouraging behavior change when necessary, and praising current healthy choices. For children with overweight and identified health risks, and for children with obesity, intervention efforts are recommended in a stage-based approach (Barlow, 2007).

Primary care providers are instructed to proceed through the four stages of intervention as needed based on factors such as age, health risks, BMI, response to treatment, and motivation (Barlow, 2007). Stage 1 ("Prevention Plus") occurs within the primary care office and involves providers making basic healthy lifestyle recommendations, including increasing fruits/vegetables, physical activity, and family meals and decreasing sugar-sweetened beverages and sedentary behavior. In this first stage, providers engage in goal setting with the family and schedule follow-up visits to monitor behaviors. If progress is not made with Stage 1 interventions in 3–6 months, Stage 2 ("Structured Weight Management") is recommended. This stage also occurs within the primary care office, but involves more support and structure. Components of Stage 2 include detailed meal plans, structured meal schedules, scheduled physical activity, assigned tracking sheets, and planned reinforcement for goal achievement (Barlow, 2007).

In Stage 3 ("Comprehensive Multidisciplinary Intervention"), a referral is made to a comprehensive multidisciplinary team of specialists or a weight management program, which usually occurs outside of the primary care office (Barlow, 2007). Stage 3 involves structured behavior modifications to diet and activity in order to achieve negative energy balance. These approaches are typically family-based, especially for children under 12 years of age, and utilize a variety of behavioral strategies to facilitate change in dietary intake and physical and sedentary activity to ultimately impact improvements in weight status. These behavioral strategies include goal setting, monitoring, modeling, environment modification and stimulus control, positive parenting skills and contingency management, and problem solving. These interventions typically target both the parent and children for health behavior change and can be conducted in individual or group formats. Typically, programs with longer duration and greater contact hours result in greater BMI reduction. There are a number of studies showing small to medium effect sizes for these interventions in well-controlled settings (e.g., Ho et al., 2012; Janicke et al., 2014; Whitlock, O'Connor, Williams, Beil, & Lutz, 2010), but there is limited research showing the effectiveness and dissemination of these interventions in real-world and community settings (Janicke et al., 2014).

Stage 4 ("Tertiary Care Intervention") is usually recommended for children who have severe obesity and have had limited treatment response with the previous stages. One type of Stage 4 intervention is the use of pharmacotherapy to increase energy expenditure, suppress caloric intake, or limit nutrient absorption (Rogovik & Goldman, 2011; Shettar, Patel, & Kidambi, 2017). Common examples of medications used in children and adolescents are orlistat, metformin, topiramate, and phentermine. Orlistat is approved by the Food and Drug Administration (FDA) for treatment of obesity in children over age 12, and metformin is approved for treatment of obesity in children over age 10 with type 2 diabetes; topiramate and phentermine are typically reserved for older adolescents. These medications have been shown to result in clinically meaningful reductions in BMI, but it is generally recommended that these medications are used in combination with behavioral treatments for optimal results (Rogovik & Goldman, 2011; Shettar et al., 2017).

Another Stage 4 intervention for pediatric obesity is bariatric surgery. This option is sometimes considered for youth with BMI > 40 or with BMI > 35 and associated health risk (e.g., comorbid disease, inadequate success with non-operative procedures; International Pediatric Endosurgery Group, 2009). Common bariatric surgery procedures include Roux-en-Y gastric bypass, adjustable gastric band, sleeve gastrectomy, and biliopancreatic diversion operations, and they typically occur in the context of a multidisciplinary setting (Black, White, Viner, & Simmons, 2013; Hsia, Fallon, & Brandt, 2012). In a meta-analysis of the bariatric surgery literature (Black et al., 2013), results showed that bariatric surgery in children and adolescents leads to significant short-term (1 year) weight loss, and the highest weight loss was found for Roux-en-Y gastric bypass procedures. Further, a prospective study of multiple bariatric surgery centers found that Roux-en-Y gastric bypass and sleeve gastrectomy were associated with clinically meaningful reductions in weight and improvements in health conditions and quality of life 3 years after surgery (Inge et al., 2016). Although bariatric surgery procedures are associated with a number of positive outcomes, these procedures are also related with a number of complications (e.g., micronutrient deficiencies, need for future abdominal procedures); therefore, possible benefits and harms should be carefully weighed for children and adolescents (Black et al., 2013; Inge et al., 2016). For a comprehensive review of preoperative considerations and contraindications, procedures, and outcomes, see Hsia et al. (2012).

School-Level Prevention and Intervention

Schools are crucial for pediatric obesity prevention and intervention because children spend a large amount of time at school and often eat at least one meal there on weekdays (Karnik & Kanekar, 2012). Common elements of school prevention and intervention efforts include providing healthy food and drink options, eliminating unhealthy options, encouraging children to walk to school, lengthening the time children spend in physical education classes, interspersing breaks in sitting throughout the day, and providing education to parents. In a synthesis of multiple reviews and meta-analyses of school-based prevention and intervention programs, Khambalia, Dickinson, Hardy, Gill, and Baur (2012) found that programs that were long-term, targeted both diet and physical activity, and included a family component were associated with the greatest reductions in children's BMI.

Community-Level Prevention and Intervention

The availability and accessibility of foods within communities impact children's diet and energy consumption, and the perceived safety and availability of activity promoting facilities, equipment, and space impacts physical activity and sedentary behavior levels (Karnik & Kanekar, 2012). Therefore, these are important areas for prevention and intervention at the community level. Examples of community efforts to promote healthy lifestyle choices include providing healthy food festivals, affordable and accessible healthy foods, safe play grounds and bike paths, programs to promote safe active travel to school, and safe and affordable gymnasiums (Karnik & Kanekar, 2012).

Larger-scale community-level prevention and interventions involve implementing policies and media campaigns focused on healthy lifestyle choices (Han et al., 2010). For example, policies have pushed restaurants to label the caloric content of their menu items and for taxes to be placed on sugar-sweetened beverages. Further, marketing campaigns have been targeted at promoting physical activity and healthy foods. However, there is not adequate data on how these prevention efforts impact children's BMI (Han et al., 2010).

Case Study

Ana is an 8-year-old girl who presented to her annual well-child visit with a BMI at the 98th percentile. Ana's lab work revealed that she has at-risk glycated hemoglobin (HbA1c), elevated low-density lipoprotein (LDL) cholesterol, and decreased high-density lipoprotein (HDL) cholesterol. Ana and her mother completed a standard battery of psychosocial screening measures prior to the well-child visit, which was selected and incorporated within the primary care office in collaboration with a behavioral health specialist. Ana's scores revealed that she has been experiencing teasing from peers because of her weight. Given Ana's BMI, lab values, and impaired psychosocial functioning, Ana's pediatrician further assessed medical risk, behavioral risk, and family attitudes related to her weight status.

Ana's pediatrician learned that Ana lives with her mother (who has obesity) and two older female siblings (who do not have overweight/obesity). Ana wakes up around 6:00 am, and she rides the bus to and from school. Ana is enrolled in a public elementary school, and she participates in a physical education (PE) class at school 1 day per week. Afterschool, Ana's older siblings care for her until their mother gets home from work. Ana's mother is typically tired from her job and relies on quick and easy dinner options, including bringing home food from fast-food restaurants or making frozen meals. Ana watches television and plays video games until bedtime, and she usually falls asleep around 10:30 pm. Ana's mother indicated concern about Ana's lab values and teasing at school and requested recommendations.

Because Ana's mother had obesity prior to Ana's conception, it would have been most ideal if healthy lifestyle interventions were implemented for the family prior to Ana's birth or early in development. However, because her older sisters had average BMIs, Ana's mother assumed that Ana's elevated BMI was due to "baby fat" and that she would "grow out of it" throughout development. When Ana's weight trajectory persisted, her pediatrician provided basic healthy lifestyle recommendations to the family and followed up in multiple well-child visits. Ana's mother demonstrated adequate knowledge of healthy choices, but Ana's BMI remained in the obese category. Because more intensive services were needed, the pediatrician made a referral to a weight management program in a nearby medical center. The pediatrician informed the family that medication options are available to help with management of weight and HbA1c and that medications would be revisited if needed after engagement in the weight management program.

The weight management program, which included involvement from a physician, nurse, dietician, and psychologist, targeted healthy lifestyle changes for all members of the family and used behavioral strategies to alter Ana's energy balance. Specific dietary goals for the family included planning easy, healthy meals and snacks, reading food labels, and choosing healthy options when eating out. To increase physical activity and reduce sedentary behavior, the family began taking bike rides every evening after dinner and reducing screen time to 2 h per day. The family also talked to school staff about increasing the frequency and/or duration of Ana's PE classes and interspersing long periods of sitting with activity breaks. Additionally, because Ana receives fewer hours of sleep than is recommended by the National Sleep Foundation (Hirshkowitz et al., 2015), sleep hygiene goals were also emphasized within the family-based weight management program since sleep and BMI are strongly linked.

Conclusion and Future Directions

Over 30% of children and adolescents in the United States continue to struggle with excess weight (Ogden, Carroll, Kit, & Flegal, 2014), as well as the physical and psychosocial challenges associated with overweight and obesity. A multi-tiered and interdisciplinary approach is necessary for optimal screening, assessment, prevention, and intervention of this issue. For children requiring intervention services, behavioral family lifestyle interventions delivered by an interdisciplinary team of providers, with close communication to the child's primary care provider, is the recommended and most well-established intervention program.

However, many children struggle to attain or maintain recommended BMI goals, even within these programs. As such, additional research is needed to identify novel efficacious and effective interventions, as well as unique and cost-effective service delivery models. For example, innovative technologies (e.g., mobile devices, fit bits) can help families accurately and conveniently monitor lifestyle behaviors, a critical strategy related to optimal behavior change. The use of ecological momentary assessment protocol has the potential to help prompt adolescents when they are in less than optimal eating or activity environments and suggest alternative courses of action (Heron, Everhart, McHale, & Smith, 2017). Additionally, new insights into neurocognitive motivational and impulse control circuitry hold promise for development of novel interventions that can alter eating patterns (Carr, Daniel, Lin, & Epstein, 2011). Finally, many families struggle to overcome the many barriers to attend weight management intervention appointments on a regular basis, let alone completing daily monitoring or making the lifestyle changes necessary for improving weight status. Therefore, it is critical to develop and evaluate interventions that are feasible and effective for families and providers in real-world settings, especially those with less than optimal physical and financial resources (Janicke et al., 2014).

References

Abrams, P., & Katz, L. E. L. (2011). Metabolic effects of obesity causing disease in childhood. *Current Opinion in Endocrinology, Diabetes and Obesity, 18*, 23–27.

Achenbach, T. M., & Rescorla, L. A. (2001). *Manual for the ASEBA school-age forms & profiles*. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families.

Anderson, P. M., & Butcher, K. F. (2006). Childhood obesity: Trends and potential causes. *The Future of Children, 16*, 19–45.

Andreyeva, T., Kelly, I. R., & Harris, J. L. (2011). Exposure to food advertising on television: Associations with children's fast food and soft drink consumption and obesity. *Economics & Human Biology, 9*, 221–233.

Atay, Z., & Bereket, A. (2016). Current status on obesity in childhood and adolescence: Prevalence, etiology, co-morbidities and management. *Obesity Medicine, 3*, 1–9.

Barlow, S. E. (2007). Expert committee recommendations regarding the prevention, assessment, and treatment of child and adolescent overweight and obesity: Summary report. *Pediatrics, 120*, s164–s192.

Black, J. A., White, B., Viner, R. M., & Simmons, R. K. (2013). Bariatric surgery for obese children and adolescents: A systematic review and meta-analysis. *Obesity Reviews, 14*, 634–644.

Bronfrenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.

Budd, G. M., & Hayman, L. L. (2008). Addressing the childhood obesity crisis: A call to action. *The American Journal of Maternal/Child Nursing, 33*, 111–118.

Carr, K. A., Daniel, T. O., Lin, H., & Epstein, L. H. (2011). Reinforcement pathology and obesity. *Current Drug Abuse Reviews, 4*, 190–196.

Centers for Disease Control and Prevention [CDC]. (2016a). *Childhood obesity causes & consequences*. Retrieved from https://www.cdc.gov/obesity/childhood/causes.html

Centers for Disease Control and Prevention [CDC]. (2016b). *Defining childhood obesity*. Retrieved from https://www.cdc.gov/obesity/childhood/defining.html

Chen, X., Beydoun, M. A., & Wang, Y. (2008). Is sleep duration associated with childhood obesity? A systematic review and meta-analysis. *Obesity, 16*, 265–274.

Conners, C. K. (2008). *Conners manual* (3rd ed.). North Tonawanda, NY: Multi-Health Systems Inc.

Dunton, G. F., Kaplan, J., Wolch, J., Jerrett, M., & Reynolds, K. D. (2009). Physical environmental correlates of childhood obesity: A systematic review. *Obesity Reviews, 10*, 393–402.

Fisher, J. O., & Kral, T. V. (2008). Super-size me: Portion size effects on young children's eating. *Physiology & Behavior, 94*, 39–47.

Freedman, D. S., Horlick, M., & Berenson, G. S. (2013). A comparison of the Slaughter skinfold-thickness equations and BMI in predicting body fatness and cardiovascular disease risk factor levels in children. *American Journal of Clinical Nutrition, 98*, 1417–1424.

Freedman, D. S., & Sherry, B. (2009). The validity of BMI as an indicator of body fatness and risk among children. *Pediatrics, 124*, S23–S34.

Goldschmidt, A. B., Aspen, V. P., Sinton, M. M., Tanofsky-Kraff, M., & Wilfley, D. E. (2008). Disordered eating attitudes and behaviors in overweight youth. *Obesity, 16*, 257–264.

Goldschmidt, A. B., Doyle, A. C., & Wilfley, D. E. (2007). Assessment of binge eating in overweight youth using a questionnaire version of the Child Eating Disorder Examination with instructions. *International Journal of Eating Disorders, 40*, 460–467.

Gray, W. N., Kahhan, N. A., & Janicke, D. M. (2009). Peer victimization and pediatric obesity: A review of the literature. *Psychology in the Schools, 46*, 720–727.

Griffiths, L. J., Parsons, T. J., & Hill, A. J. (2010). Self-esteem and quality of life in obese children and adolescents: A systematic review. *Pediatric Obesity, 5*, 282–304.

Gurnani, M., Birken, C., & Hamilton, J. (2015). Childhood obesity: Causes, consequences, and management. *Pediatric Clinics, 62*, 821–840.

Hales, C. M., Carroll, M. D., Fryar, C. D., & Ogden, C. L. (2017). Prevalence of obesity among adults and youth: United States, 2015–2016. *NCHS Data Brief, 288*, 1–8.

Han, J. C., Lawlor, D. A., & Kimm, S. Y. (2010). Childhood obesity. *The Lancet, 375*, 1737–1748.

Harriger, J. A., & Thompson, J. K. (2012). Psychological consequences of obesity: Weight bias and body image in overweight and obese youth. *International Review of Psychiatry, 24*, 247–253.

Harrington, D. M., Staiano, A. E., Broyles, S. T., Gupta, A. K., & Katzmarzyk, P. T. (2013). BMI percentiles for the identification of abdominal obesity and metabolic risk in children and adolescents: Evidence in support of the CDC 95th percentile. *European Journal of Clinical Nutrition, 67*, 218–222.

Harris, J. L., Pomeranz, J. L., Lobstein, T., & Brownell, K. D. (2009). A crisis in the marketplace: How food marketing contributes to childhood obesity and what can be done. *Annual Review of Public Health, 30*, 211–225.

Hart, C. N., Cairns, A., & Jelalian, E. (2011). Sleep and obesity in children and adolescents. *Pediatric Clinics of North America, 58*, 715–733.

Heron, K. E., Everhart, R. S., McHale, S. M., & Smith, J. M. (2017). Using mobile-technology-based ecological momentary assessment (EMA) methods with youth: A systematic review and recommendations. *Journal of Pediatric Psychology, 42*, 1087–1107.

Hirshkowitz, M., Whiton, K., Albert, S. M., Alessi, C., Bruni, O., DonCarlos, L., … Kheirandish-Gozal, L. (2015). National Sleep Foundation's updated sleep duration recommendations. *Sleep Health, 1*, 233–243.

Ho, M., Garnett, S. P., Baur, L., Burrows, T., Stewart, L., Neve, M., & Collins, C. (2012). Effectiveness of lifestyle interventions in child obesity: Systematic review with meta-analysis. *Pediatrics, 130*, e1647–e1671.

Holmbeck, G. N., Thill, A. W., Bachanas, P., Garber, J., Miller, K. B., Abad, M., … Zukerman, J. (2008). Evidence-based assessment in pediatric psychology: Measures of psychosocial adjustment and psychopathology. *Journal of Pediatric Psychology, 33*, 958–980.

Hsia, D. S., Fallon, S. C., & Brandt, M. L. (2012). Adolescent bariatric surgery. *Archives of Pediatrics & Adolescent Medicine, 166*, 757–766.

Hu, F. B. (2008). Measurements of adiposity and body composition. In F. B. Hu (Ed.), *Obesity epidemiology* (pp. 53–83). New York, NY: Oxford University Press.

Inge, T. H., Courcoulas, A. P., Jenkins, T. M., Michalsky, M. P., Helmrath, M. A., Brandt, M. L., … Horlick, M. (2016). Weight loss and health status 3 years after bariatric surgery in adolescents. *New England Journal of Medicine, 374*, 113–123.

International Pediatric Endosurgery Group [IPEG]. (2009). IPEG guidelines for surgical treatment of extremely obese adolescents. *Journal of Laparoendoscopic & Advanced Surgical Techniques, 19*, 1–3.

Janicke, D. M., Steele, R. G., Gayes, L. A., Lim, C. S., Clifford, L. M., Schneider, E. M., … Westen, S. (2014). Systematic review and meta-analysis of comprehensive behavioral family lifestyle interventions addressing pediatric obesity. *Journal of Pediatric Psychology, 39*, 809–825.

Karnik, S., & Kanekar, A. (2012). Childhood obesity: A global public health crisis. *International Journal of Preventive Medicine, 3*, 1–7.

Khambalia, A. Z., Dickinson, S., Hardy, L. L., Gill, T. A., & Baur, L. A. (2012). A synthesis of existing systematic reviews and meta-analyses of school-based behavioural interventions for controlling and preventing obesity. *Obesity Reviews, 13*, 214–233.

Kramer, M. S., Matush, L., Vanilovich, I., Platt, R. W., Bogdanovich, N., Sevkovskaya, Z., … Smith, G. D. (2007). Effects of prolonged and exclusive breastfeeding on child height, weight, adiposity, and blood pressure at age 6.5 y: Evidence from a large randomized trial. *The American Journal of Clinical Nutrition, 86*, 1717–1721.

Kramer, M. S., Matush, L., Vanilovich, I., Platt, R. W., Bogdanovich, N., Sevkovskaya, Z., … Smith, G. D. (2009). A randomized breast-feeding promotion intervention did not reduce child obesity in Belarus. *The Journal of Nutrition, 139*, 417S–421S.

Lau, E. Y., Liu, J., Archer, E., McDonald, S. M., & Liu, J. (2014). Maternal weight gain in pregnancy and risk of obesity among offspring: A systematic review. *Journal of Obesity, 2014*, 1–16.

Luca, P., Birken, C., Grewal, P., Dettmer, E., & Hamilton, J. (2012). Complex obesity. *Current Pediatric Reviews, 8*, 179–187.

Maloney, M. J., McGuire, J. B., & Daniels, S. R. (1988). Reliability testing of a children's version of the Eating Attitude Test. *Journal of the American Academy of Child & Adolescent Psychiatry, 27*, 541–543.

Modi, A. C., & Zeller, M. H. (2008). Validation of a parent-proxy, obesity-specific quality-of-life measure: Sizing Them Up. *Obesity, 16*, 2624–2633.

Mond, J., Van den Berg, P., Boutelle, K., Hannan, P., & Neumark-Sztainer, D. (2011). Obesity, body dissatisfaction, and emotional well-being in early and late adolescence: Findings from the project EAT study. *Journal of Adolescent Health, 48*, 373–378.

Nader, P. R., Huang, T. T. K., Gahagan, S., Kumanyika, S., Hammond, R. A., & Christoffel, K. K. (2012). Next steps in obesity prevention: Altering early life systems to support healthy parents, infants, and toddlers. *Childhood Obesity, 8*, 195–204.

Neumark-Sztainer, D., Paxton, S. J., Hannan, P. J., Haines, J., & Story, M. (2006). Does body satisfaction matter? Five-year longitudinal associations between body satisfaction and health behaviors in adolescent females and males. *Journal of Adolescent Health, 39*, 244–251.

Niehoff, V. (2009). Childhood obesity: A call to action. *Bariatric Nursing and Surgical Patient Care, 4*, 17–23.

Ogden, C. L., Carroll, M. D., Kit, B. K., & Flegal, K. M. (2014). Prevalence of childhood and adult obesity in the United States, 2011-2012. *Journal of the American Medical Association, 311*, 806–814.

Ogden, C. L., Carroll, M. D., Lawman, H. G., Fryar, C. D., Kruszon-Moran, D., Kit, B. K., & Flegal, K. M. (2016). Trends in obesity prevalence among children and adolescents in the United States, 1988-1994 through 2013-2014. *Journal of the American Medical Association, 315*, 2292–2299.

Patrick, H., & Nicklas, T. A. (2005). A review of family and social determinants of children's eating patterns and diet quality. *Journal of the American College of Nutrition, 24*, 83–92.

Piernas, C., & Popkin, B. M. (2011). Food portion patterns and trends among US children and the relationship to total eating occasion size, 1977–2006. *The Journal of Nutrition, 141*, 1159–1164.

Puder, J. J., & Munsch, S. (2010). Psychological correlates of childhood obesity. *International Journal of Obesity, 34*, S37–S43.

Pulgarón, E. R. (2013). Childhood obesity: A review of increased risk for physical and psychological comorbidities. *Clinical Therapeutics, 35*, A18–A32.

Reilly, J. J., & Kelly, J. (2011). Long-term impact of overweight and obesity in childhood and adolescence on morbidity and premature mortality in adulthood: Systematic review. *International Journal of Obesity, 35*, 891–898.

Reynolds, C. R., & Kamphaus, R. W. (2004). *Behavior assessment system for children manual* (3rd ed.). Circle Pines, MN: AGS Publishing.

Rogovik, A. L., & Goldman, R. D. (2011). Pharmacologic treatment of pediatric obesity. *Canadian Family Physician, 57*, 195–197.

Sahoo, K., Sahoo, B., Choudhury, A. K., Sofi, N. Y., Kumar, R., & Bhadoria, A. S. (2015). Childhood obesity: Causes and consequences. *Journal of Family Medicine and Primary Care, 4*, 187.

Schwimmer, J. B., Burwinkle, T. M., & Varni, J. W. (2003). Health-related quality of life of severely obese children and adolescents. *Journal of the American Medical Association, 289*, 1813–1819.

Shettar, V., Patel, S., & Kidambi, S. (2017). Epidemiology of obesity and pharmacologic treatment options. *Nutrition in Clinical Practice, 32*, 441–462.

Skinner, A. C., Perrin, E. M., Moss, L. A., & Skelton, J. A. (2015). Cardiometabolic risks and severity of obesity in children and young adults. *New England Journal of Medicine, 373*, 1307–1317.

US Preventive Services Task Force [USPSTF]. (2010). Screening for obesity in children and adolescents: US Preventive Services Task Force recommendation statement. *Pediatrics, 125*, 361–367.

Vander Wal, J. S., & Mitchell, E. (2011). Psychological complications of pediatric obesity. *Pediatric Clinics of North America, 58*, 1393–1401.

Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL (TM) 4.0: Reliability and validity of the Pediatric Quality of Life Inventory (TM) Version 4.0 Generic Core Scales in healthy and patient populations. *Medical Care, 39*, 800–812.

Whitlock, E. P., O'Connor, E. A., Williams, S. B., Beil, T. L., & Lutz, K. W. (2010). Effectiveness of weight management interventions in children: A targeted systematic review for the USPSTF. *Pediatrics, 125*, e396–e418.

Wohlfahrt-Veje, C., et al. (2014). Body fat throughout childhood in 2647 healthy Danish children: Agreement of BMI, waist circumference, skinfolds with dual X-ray absorptiometry. *European Journal of Clinical Nutrition, 68*, 664–670.

World Health Organization [WHO]. (2017). *Obesity and overweight*. Retrieved from http://www.who.int/mediacentre/factsheets/fs311/en/

Zeller, M. H., & Modi, A. C. (2009). Development and initial validation of an obesity-specific quality-of-life measure for children: Sizing Me Up. *Obesity, 17*, 1171–1177.

Zlatevska, N., Dubelaar, C., & Holden, S. S. (2014). Sizing up the effect of portion size on consumption: A meta-analytic review. *Journal of Marketing, 78*, 140–154.

Diabetes

5

Kathy L. Bradley-Klug and Emily Shaffer-Hudkins

Abstract

Pediatric diabetes is on the rise in the United States. According to the National Diabetes Statistics Report, the estimated number of new cases of diabetes annually was 17,900 for Type 1 diabetes (children and adolescents under 20 years of age) and 5,300 for Type 2 diabetes (children and adolescents between 10 and 19 years of age) (Centers for Disease Control and Prevention. 2017. *National Diabetes Statistics Report*. Atlanta, GA: U.S. Dept of Health and Human Services). The focus of this chapter is to provide an overview of pediatric diabetes including background information, prevalence, psychosocial concomitants and consequences, prevention and intervention strategies, and implications for interprofessional care. This chapter will conclude with a case study to illustrate the practical application of the information presented.

Pediatric diabetes is on the rise in the United States. According to the National Diabetes Statistics Report, the estimated number of new cases of diabetes annually was 17,900 for Type 1 diabetes (children and adolescents under 20 years of age) and 5,300 for Type 2 diabetes (children and adolescents between 10 and 19 years of age) (Centers for Disease Control and Prevention, 2017). The focus of this chapter is to provide an overview of pediatric diabetes including background information, prevalence, psychosocial concomitants and consequences, prevention and intervention strategies, and implications for interprofessional care. The chapter will conclude with a case study to illustrate the practical application of the information presented.

Background

Definition and Etiology

There are two primary types of diabetes that affect children and youth: Type 1 diabetes (juvenile-onset, insulin dependent) and Type 2 diabetes (noninsulin-dependent). Type 1 diabetes, defined as an autoimmune disease, is characterized by abnormally high blood glucose levels. Specifically, the pancreas produces an insufficient amount of insulin, causing sugar to build up in the blood which results in insulin-producing beta cells in the pancreas and makes it difficult

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for the body to use glucose and break down foods into simple sugars. Without insulin, dangerous levels of unabsorbed glucose build up in the body. As a result, individuals with Type 1 diabetes have to monitor their blood sugar and use insulin therapy, regular exercise and a healthy diet to effectively manage their condition. Researchers believe that Type 1 diabetes is caused by a combination of genetic and environmental factors out of an individual's control (Silverstein et al., 2005). To date there is no cure for Type 1 diabetes; thus these individuals need to manage their chronic health condition for the remainder of their lives.

The incidence of Type 2 diabetes in adolescents has increased substantially in the last 10 years and is associated with the rise of childhood overweight and obesity (Anderson & McKay, 2011). Type 2 diabetes can be defined as a progressive disease related to insulin resistance. The onset of Type 2 diabetes often coincides with the beginning of puberty. With Type 2 diabetes the body does produce insulin, but struggles to regulate the insulin to keep blood sugar levels normal (D'Adamo & Caprio, 2011). Treatment for Type 2 diabetes includes diet and lifestyle choices as well as medication, such as insulin or metformin (Copeland et al., 2013; Reinehr, 2013). Screening for Type 2 diabetes is particularly recommended for children and adolescents who are overweight and have a family history of diabetes.

The most common symptoms of these complex, chronic conditions may include frequent urination, excessive thirst, unexplained weight loss, sudden vision changes, and fatigue. Additional symptoms specific to Type 1 diabetes include extreme hunger, fruity smelling breath, and yeast infections in females. The symptoms for Type 1 diabetes typically develop quickly while those of Type 2 diabetes may develop much more gradually (D'Adamo & Caprio, 2011). The symptoms for both types of diabetes are often mistaken for other, more minor or temporary health conditions, particularly in youth. As such, it is important for caregivers and medical professionals to look for these symptoms and request diagnostic assessments if such symptoms appear and persist.

Significant and debilitating complications may arise from Type 1 and Type 2 diabetes if the disease is not managed. Examples of chronic complications include kidney disease, hypertension, cardiovascular disease, retinopathy, foot problems, thyroid disease, and celiac disease (Silverstein et al., 2005). Type 2 diabetes in youth may have additional, negative physical health outcomes due to the association with overweight and obesity. Specifically, these youth may be at even greater risk for cardiovascular problems (D'Adamo & Caprio, 2011). Because of these potential complications, it is critical for patients and families to receive diabetes education and have regularly scheduled follow-up appointments with their physicians. It also is recommended that individuals wear an ID that identifies them as having diabetes, especially if they are active in sports so that they can be carefully monitored and appropriate medical attention can be provided in the case of acute complications (Silverstein et al., 2005).

Diagnosis

Diabetes, both Type 1 and Type 2, is diagnosed using blood tests to check for glucose levels. Examples of these tests include random blood sugar tests, glycated hemoglobin (A1C) test, and a fasting blood sugar test. If diabetes is suspected in youth, a common practice is for a pediatrician to refer a family to a pediatric endocrinologist for further testing and development of a treatment plan.

Prevalence

According to the Diabetes 2017 Report Card, the prevalence and incidence of both Type 1 and Type 2 diabetes in youth has increased over the last 15–20 years. Data indicate that "the annual relative increase for type 1 diabetes was 1.8%, while the increase for type 2 diabetes was about 4.8%" (Centers for Disease Control and Prevention, 2018, p. 7). The most significant increase of new cases of Type 1 diabetes was reported in non-Hispanic whites while the highest increase of new cases of Type 2 diabetes in youth was reported across racial and ethnic minority groups. Although deaths related to diabetes in children and youth decreased during this same time period, data from 2012 to 2014 show the death rate among non-Hispanic black youth to be two times that of the non-Hispanic white youth. These data speak to the continued need for research across diverse populations of youth with diabetes, with a specific focus on disparities in healthcare.

Psychosocial Concomitants and Consequences

Academics

As with any chronic health condition, it is critical that educators be knowledgeable of pediatric diabetes, the daily management requirements of students with diabetes, and the steps to take in case of an emergency. Fluctuations in blood glucose levels may affect students in a number of ways including decreased focus and attention, excessive absences, and readiness to learn (Wodrich & Cunningham, 2008). A study conducted by McCarthy, Lindgren, Mengeling, Tsalikian, and Engvall (2002) investigating the reported neuropsychological deficits in children with Type 1 diabetes found that students with this chronic condition did not demonstrate long-term decreased academic performance as compared to their healthy siblings or classmates. What they did report was that youth who experienced increased episodes of hypoglycemia, particularly with seizures or coma, were at risk for negative complications related to cognition. It is recommended that students with diabetes have a Diabetes Health Care Plan in place. This plan specifies the responsibilities of the individual with diabetes, his/her caregivers, and educators/school personnel (American Diabetes Association, 2003). Additional details related to school management of diabetes are discussed later in this chapter.

Mental Health

Individuals with Type 1 diabetes are more likely to be diagnosed with a psychiatric disorder including adjustment disorder, anxiety, depression, and disordered/unhealthy eating habits (Commissariat et al., 2018). Youth are most vulnerable to mental health concerns during the time between adolescence and adulthood, coinciding with the onset of developmental stressors typical of this age range including school transitions, academic stressors, and increased focus on peer acceptance (Stahl-Pehe et al., 2017).

A study conducted by Commissariat et al. (2018) found a direct relationship between the endorsement of stressful life events in teens and diabetes care management. Specifically, an increase in the number of stressful life events was correlated with a decrease in treatment adherence, self-efficacy, and quality of life. These authors emphasize the importance of screening for stressful life events in youth and young adults with diabetes so that interventions may be implemented to assist in care management and prevent or minimize negative physical disease-related outcomes. In contrast, a review of the literature conducted by Yi-Frazier, Hilliard, Cochrane, and Hood (2012) found a positive relationship between self-esteem, self-efficacy, and resilience and disease management and overall outcomes for youth with diabetes. These authors recommend turning to the positive psychology literature and incorporating screening measures to assess overall well-being and quality of life in youth with diabetes.

Impact on Others

Through their involvement with the individual living with diabetes, caregivers also are impacted by the disease and their lives may be changed as well. The roles of these caregivers may range from verbal support to 24-h care. Caregivers are at risk for psychosocial challenges including fear, anxiety, and depression. Specifically, diabetes management can affect the quality of life of a family, with parents of children with diabetes often reporting feelings of stress, frustration, isolation, and fatigue (Erie et al., 2017). They also wrestle with control and safety concerns for their child and must carefully negotiate life stage transitions that occur throughout their child's development (Johnson & Melton, 2015).

Similarly, siblings of youth with diabetes are affected by this condition. Siblings often report feeling the need to take on the role of protector and experience fear over the health of the child with diabetes. Siblings also may experience low academic and cognitive scores, low ratings of self-worth, and may engage in few peer-related activities as compared to their peers (Herrman, 2010). In some cases, these siblings do not feel as though they can share their feelings with the family because it would lead to additional stress.

Despite these potentially negative impacts, Herrman (2010) reports that living with this condition can result in positive outcomes such as family resilience, support and coping, altruism and the ability to focus on others, and the development of a healthier lifestyle of the entire family. Families who engage in communication and collaborative disease management, as well as those who maintain optimism in the face of disease complications report overall positive diabetes outcomes as compared to families who report less positive interactions (Yi-Frazier, 2012).

Prevention and Intervention

Prevention

Learning about and coping with a new diagnosis of diabetes. Until two decades ago, research on prevention and intervention for youth with diabetes focused almost exclusively on Type 1. Due to rising rates of Type 2 among youth over the past 20 years, large-scale national studies have focused on prevention and intervention practices that address the factors and challenges specific to Type 2 as well (Anderson & McKay, 2011). Although some self-management overlaps in regard to diet, physical activity, and glucose monitoring, it is important to recognize many of the distinctions between Type 1 and Type 2 diabetes. The demographics of the populations differ, along with the primary treatment mechanism (insulin vs. metformin), and the impetus for the diagnosis (i.e., the link between childhood obesity and T2D) (National Institute of Diabetes and Digestive and Kidney Diseases, 2013). However, learning to manage one's monitoring and care, coping with this life-altering disease, and garnering the necessary supports across settings overarches both types of diabetes. The below synthesis of the psychosocial prevention and intervention strategies for diabetes among youth encompasses many strategies that are cross-cutting to both Type 1 and Type 2 diabetes. Distinctions between each type specific to certain studies or implications for care are made when relevant.

Given the complex regimen of daily monitoring and treatment that diabetes entails, this disease can have a cascading impact on many facets of life; thus, providing high-quality psychosocial prevention and intervention is critical. Prevention strategies are most often considered at the time that a patient is newly diagnosed, including learning about one's diagnosis and care plan. However, prevention also is important during various developmental transitions, such as when a preadolescent begins to take more responsibility of his or her treatment regimen, or when a young adult is transitioning to college or out on their own. During these periods, prevention should include anticipatory guidance for managing both physical and psychosocial aspects of diabetes management along with a strong and consistent message that support is available and how to access it (friends, family, educational and community settings). A recent synthesis of studies examining the key factors impacting successful diabetes self-management for youth highlighted three overarching themes: understanding diabetes and one's involvement in care, learning to get on with everyday life while managing diabetes, and support from friends and management of psychosocial stressors (Rankin, Harden, Jepson, & Lawton, 2017). Other studies have highlighted the importance of educational and family supports as well (Kise, Hopkins, & Burke, 2017; Sweenie, Mackey, & Streisand, 2014). Each of these areas will be addressed in the sections below.

Learning about and coping with a diagnosis of diabetes is a long-term, fluid process that changes with development and environmental circumstances. With Type 1 diabetes typically diagnosed early in life, prior to adulthood, and Type 2 diabetes now much more prevalent among children and teens, parents and caregivers must be readily involved in education and acceptance of disease management. Both youth and their caregivers must demonstrate adequate health literacy in regard to the three levels: functional, communicative, and critical (Freebody & Luke, 1990). Critical health literacy for a patient with diabetes or their parent involves truly understanding the physical mechanisms of diabetes and how to problem-solve issues with self-management. Higher levels of diabetes health literacy and perceived self-efficacy to manage the disease are associated with improved glycemic control (HbA1c; Pulgaron et al., 2014). Critical health literacy has been reported as a steep "learning curve" upon initial diagnosis, particularly as parents or youth themselves adapt to the initial news, while also balancing a disease that can quickly turn life-threatening if not managed properly (Sparling, 2014).

Psychoeducation and support for beginning a new treatment regimen. Due to the complex monitoring and treatment regimens required for successful management of diabetes, health professionals and other caregivers in a youth's life must provide comprehensive education and support for learning to master the daily care requirements. Topics for diabetes care should include healthy eating and physical activity and how these relate to glycemic control, best practices and latest technology for monitoring blood glucose (HbA1c), and administration of insulin or oral medication. Practitioners should incorporate psychoeducation around these topics throughout the course of disease management, discussing potential barriers or risk factors, existing barriers, and ways to problem-solve the individual concerns of each patient and family (American Diabetes Association, 2015). Physicians and nurses often provide a great deal of information in brief medical appointments, with research showing that patients and/or caregivers forget 40–80% of the information provided (Kessels, 2003). The teach-back method is a well-researched strategy that health providers can use to confirm that a patient understands aspects of their disease and associated management by having him or her repeat the explanation back (Agency for Healthcare Research and Quality, 2010). This method also helps providers understand the best communication style to aid in patient's understanding over time. Teach-back has demonstrated improved health literacy of diabetes and required management among adults, but further testing of its effectiveness for youth with diabetes is still needed (Dinh et al., 2016).

The use of multimedia for psychoeducation of diabetes and other chronic illnesses has rapidly increased over the past few years. Brief, online learning modules with associated graphics, text, audio, and video can provide a multimedia approach that taps into many different learning styles of patients. Internet-based education also has the potential to reach a much larger number of youth living with diabetes, particularly those in rural or lower economic areas where many barriers may prevent access to routine, high-quality diabetes healthcare visits. For example, an initial investigation of one multimedia learning program, Managing Diabetes, showed improvements in quality of life following completion of five sessions; further testing is needed to determine long-term impact on HbA1c and other psychosocial outcomes (Grey et al., 2013). Internet-based programs can also be used to aid in building a "diabetes community" for many youth or parents that feel alone in their daily journey (Sparling, 2014). In addition, social or online media outlets provide enhanced accountability of diabetes self-management, which will be covered in the intervention section below.

Reintegration back into school and daily routines. Following the initial diagnosis and intense focus on understanding diabetes and the necessary care, entry back into "regular life" is the next step. For children and adolescents, the educational setting is a primary focus for prevention and intervention, both academic and psychosocial. Following an initial diagnosis, prevention should include a focus on reintegrating back into school and daily routines. Many members of the school team are essential for assisting with successful reintegration. Ideally, the team would include the child or adolescent student, his or her parents, teachers, the school nurse, school psychologist, a school administrator, and 504/IEP coordinator. Other school personnel that may need to be involved include coaches, lunchroom staff, or extracurricular teachers. Each team member is involved in areas pertinent to their specific work and interactions with a student, but all team members should be educated on diabetes and available for open communication and collaboration to ensure that the student has maximum support throughout the school day (U.S. Department of Health and Human Services, 2003). Of utmost importance is development of an individualized healthcare plan, facilitated by the school nurse under the guidance of orders from the child or adolescent's healthcare provider which may include a plan for maintaining the student's blood glucose within a target range, supplies needed and where they are kept, and any nutritional needs (Kaufman, Jackson, & Bobo, 2010). In addition, an emergency care plan should be developed by the school professionals along with the student and his or her parents. Educational plans may include any academic accommodations or interventions needed, such as addressing missed school days or alternate times for tests and exams due to out of range HbA1c levels. Many students with Type 1 and Type 2 diabetes require a Sect. 504 Plan in order to document the specific accommodations the school will provide. The American Diabetes Association offers a "Model 504 Plan" on their website for parents to use as a guide when meeting with educational personnel about modifications and actions to be included on the plan for their child.

Education for school personnel regarding the child's diagnosis of diabetes and related care involves three levels of training: (1) school personnel receive training in identifying and responding to diabetes symptoms, (2) any school personnel interacting with students with diabetes receive additional emergency training such as how to recognize signs of hypo- and hyperglycemia, and (3) one or more school personnel receive additional in-depth training from healthcare professional about routine and emergency care for each student with diabetes (Kucera & Sullivan, 2011). In an analog experiment, teachers who were informed of a student's diabetes diagnosis were less apt to make mistaken assumptions about the true cause of his or her classroom problems (Wodrich, 2005). Often, symptoms of inattention, tremors, sweating, lightheadedness, irritability, confusion, and drowsiness can be misperceived as other health or behavioral problems if teachers and staff are not well informed about potential issues related to diabetes. At the most basic level, educators must understand what affects blood glucose levels, that is, food raises it and activity and insulin lower it. A follow-up study found that increasing information about diabetes and its potential classroom impact improved the quality of classroom instructional accommodations made by teachers when hypothetical students with diabetes encountered various instructional problems (Cunningham & Wodrich, 2006).

Targeted Interventions

Health resiliency for youth with diabetes includes the intrapersonal and interpersonal supports and resources that an individual can access to better cope and manage the disease. It is operationalized broadly throughout the literature, and includes positive coping styles, optimism connectedness, and family member support, among many other factors (Jenson & Fraser, 1994; Rew & Horner, 2003). Most interventions focused on adjusting or readjusting to a diabetes diagnosis, learning to cope with psychosocial stressors, and successful management tap into one or more of these resiliency factors.

Many of the targeted interventions summarized below that promote diabetes self-management are grounded in behavioral intervention theories, including social cognitive theory, family systems theory, and the social ecological model (Hilliard, Powell, & Anderson, 2016). In regard to social cognitive theory, children learn to be proficient with self-care from social observation and feedback, and build self-efficacy over time with the proper influences. Family systems theory comes into play based on empirical knowledge of how family factors predict child health outcomes; parent involvement and communication about diabetes care is a key component of interventions (Wiebe, Helgeson, & Berg, 2016). Finally, although the key outcome is improved biomarkers such as glycemic control, targeted interventions must consider the multiple contexts (home, school, friendships, socioeconomic) within a social ecological model that impact self-management of diabetes.

Treatment adherence and self-management. Many children and adolescents have periods of struggle or even long-term difficulties with adherence to the strict daily regimen required for successful diabetes care. Due to the invasive and unrelenting aspects of self-management, many youth and even their caregivers become overwhelmed and discouraged to maintain adherence. Behavioral supports, positive and balanced parental oversight, and motivational enhancements are all well-researched strategies for addressing difficulties with a care regimen (Hilliard et al., 2016). Behavioral supports include prompts, organizational systems, and communication systems to aid in successful management. For some children, environmental cues are helpful to prompt glucose monitoring. For example, a child may have a visual reminder to check his or her glucose levels 30 min before lunch. Behavior contracts and contingency plans provide a more detailed strategy for monitoring and reinforcing a child to adhere. Daily tracking sheets can be used as a visual means of self-monitoring. Children may also benefit from functional communication training to reinforce self-advocacy related to their diabetic needs. One example of this type of training would be to review and role-play ways in which the child can ask for restroom time or snacks during the school day. Finally, a communication system set up across settings, such as between school and home or home and sports team, can aid in quickly identifying and problem-solving issues that arise with diabetes management.

Adhering to daily monitoring, healthy eating, and medication administration yield very few immediate benefits to patients with diabetes; thus, positive reinforcement for treatment adherence can be very important in order to provide these direct benefits or “rewards” for youth (Stoeckel & Duke, 2015). One evidence-based motivation strategy that has been researched in the educational setting for students with diabetes is the Mystery Motivator (Jenson, Rhode, & Reavis, 1995). This system uses positive reinforcement, performance feedback, and randomized contingencies to maintain treatment adherence. An envelope labeled with a question mark conceals a card listing a highly reinforcing reward. Students obtain the mystery award if they meet a daily individualized goal. The mystery motivator has been shown to be effective in improving academic and behavior goals among students with Type 1 diabetes (Lasecki, Olympia, Clark, Jenson, & Heathfield, 2008). Another well-known strategy to motivate an individual to engage in behavior change such as with diabetes self-management is motivational interviewing (MI; Gregory & Channon, 2009). MI involves the use of open questions, reflective listening, agenda setting, and summarizing. Finally, the use of multimedia and online support for diabetes self-management has expanded considerably in the past decade as means to encourage and connect youth with resources to successfully manage their disease. One example of this is YourWay, an online diabetes self-management program developed by a team of researchers for adolescents with Type 1 diabetes (Mulvaney, Rothman, Wallston, Lybarger, & Dietrich, 2010). Over the course of 11 weeks, patients viewed multimedia stories that depicted typical issues related to diabetes care (e.g., time constraints) and potential ways to problem-solve these situations. Social networking with other patients and help from a diabetes “care expert” also were components of the internet-based intervention. “Lower tech” support and accountability for care also have been shown to be effective, including telephone case management involving weekly reminders, follow-up, and reinforcement (Howe et al., 2005).

As children reach the pre-adolescent and adolescent years, a significant transition typically occurs in the responsibility of diabetes self-management, with more daily responsibility placed on the youth. This transitional period has been well documented as often being a challenging time between teens and their parents, as roles change and parents struggle to back away from the care monitoring they have been so closely involved with for years (Wolpert, Weissberg-Benchell, & Anderson, 2009). Research has demonstrated the need for attention to be paid to self-determination, development of overall life skills, and autonomy of adolescents in order to see improvements in diabetes self-care (Husted, Esbensen, Hommel, Thorsteinsson, & Zoffmann, 2014). When routinely scheduled healthcare visits included time for written patient self-reflection on topics such as diabetes now and in the future and new ways to self-manage, along with guided discussion on these responses in which youth were prompted to respond prior to any caregivers present, adolescents demonstrated more skill in problem-solving related to their diabetes care (Husted et al.). Studies of youth with both Type 1 and Type 2 demonstrate that more autonomy and parental responsiveness when requested by youth, balanced with less parental control in their daily care, are linked to better treatment adherence (Goethals et al., 2017; Saletsky, Trief, Anderson, Rosenbaum, & Weinstock, 2014). Further research is needed to determine impacts of such improved motivation and self-determination related to glycemic control.

Educational accommodations. Considering that youth spend a majority of their day in the school setting, assisting with successful management of diabetes in school as well as ensuring that students still achieve academic success in light of medical and psychosocial stressors is imperative. Well-controlled diabetes in the educational setting is associated with higher quality of life and improved academic outcomes (Wagner, Heapy, James, & Abbott, 2006). Diabetes can result in a myriad of both direct and indirect factors that hinder academic success. For instance, a student may struggle with focus and concentration in the classroom due to intermittent hypoglycemia or even due to psychosocial stressors associated with their diabetes. Accommodations needed may include varied work formats (e.g., oral vs. written responses, games, and small group activities) and enhanced instructions (e.g., "repeat back," record instructions in an audio recorder for homework later), and environmental changes such as moving the child to a seat with fewer distractions (Kucera & Sullivan, 2011). Many youth with diabetes also struggle with more frequent absences than their peers and sometimes miss work or have an inconsistent performance in the classroom due to the ups and downs of diabetes self-management. Monitoring and tracking systems can be useful to record how a student feels and behaves throughout the day to better understand effects of high or low blood sugar levels on their performance. This tracking data can be used to modify a student's schedule to accommodate blood sugar fluctuations and plan activities that require greater concentration or effort during the best times of day (Wodrich & Cunningham, 2008). The behavioral strategies described previously, including positive reinforcement and contingency plans for self-monitoring, can also be useful to prompt a student's appropriate glucose monitoring during the school day.

Coping Skills Training. Skills training for youth with diabetes and other chronic illnesses has a growing evidence base for enhanced treatment adherence and overall quality of life. Instead of simply giving a child or teen factual knowledge about their illness, skills training increases competence and positive coping by restricting thoughts and training new patterns of behavior (Grey, 2011). Specific skills emphasized include social problem-solving, communication skills, and stress management. Examples of topics addressed in skills training related to diabetes and other chronic illness include peer acceptance, peer pressure, teasing, assertiveness, and handling medical treatments. Coping Skills training (CST) is among the most well-research programs for diabetes self-care (Davidson, Boland, & Grey, 1997; Grey, Boland, Davidson, Li, & Tamborlane, 2000). CST utilizes a problem-solving model to look at potential ways of handling situations and possible consequences of decisions. Youth are taught to follow a typical problem-solving sequence in which they identify the problem, determine goals, generate alternative solutions, examine potential consequences, choose the solution, and finally evaluate the outcome. The primary purpose is to empower youth to approach diabetes-related challenges using adaptive coping strategies and improve self-efficacy. When a child cannot cope effectively with a problem or "high risk" situation, their confidence is decreased for dealing with the next problem, and so a less effective coping strategy may be used. Because of the higher rate of psychosocial maladjustment in children with diabetes, these youth may be more at risk to utilize dysfunctional strategies to cope.

Skills training has demonstrated both short-term and long-term benefits for youth with diabetes and many other chronic illnesses. Youth report increased ability to cope with their disease and less negative impact on overall quality of life (Grey, 2011). Glycemic control was also significantly improved in several samples, even with long-term effects of over one year following completion of CST (Grey et al., 2000). This highlights the importance for routine care of youth with diabetes to include teaching positive coping styles and a systematic problem-solving approach to the numerous daily hassles and stressors associated with the disease.

Crisis Intervention. By implementing appropriate preventions regarding proper diabetes self-management along with providing targeted interventions related to psychosocial and educational needs, professionals and caregivers working with youth with diabetes aim to promote success, resilience, and overall quality of life. However, even when supports are in place, due to the swift and life-threatening turns that diabetes can pose, parents and professionals must be trained and ready to provide crisis intervention if needed. Crisis situations could include a severe hypoglycemic episode in the classroom setting or a teen expressing suicidal thoughts after experiencing peer rejection or isolation as a result of the disease. Health providers and behavioral health providers across settings should discuss potential scenarios, warning signs, and ways to address specific situations, including the child or adolescent in such discussions whenever appropriate (Kaufman et al., 2010). When a crisis does occur, caregivers should follow pre-set guidelines to the best of their ability, inform other team members to ensure appropriate follow-up monitoring and care is provided, and discuss potential interventions needed to avoid further complications or crisis episodes moving forward. For instance, in the case of hypoglycemia, all school staff interacting with a child should learn the warning signs, and appropriate actions to take and to carefully avoid (such as force feeding). If a hypoglycemic event does occur, appropriate members of the school team and child's family should meet following the occurrence to develop a more targeted plan for glucose monitoring throughout the school day to avoid future crises.

Tailoring interventions to meet unique individual needs. Diabetes impacts children and adolescents from all different backgrounds and walks of life, including diverse races and ethnicities, socioeconomic statuses, and cultures. As with all chronic illnesses, each child or teen with diabetes has a unique personality, family dynamic, and overall cultural expectations specific to their life. In addition, barriers to ongoing and beneficial care are more prevalent in rural and high poverty areas, which can significantly impact the success a youth has in managing their diabetes. Providers must always keep the individual needs of youth in mind when finding the most appropriate communication style and when planning and implementing preventions and interventions. One of the most common barriers youth reported to successful diabetes management was lack of contextual care from their healthcare providers that accounted for their personal and family factors (Valenzuela et al., 2014). For instance, some youth may need more involvement of family members in their self-management and therapeutic interventions, while others may thrive more with an individualized and autonomous focus.

Diabetes may be more accepted in certain social contexts, making self-advocacy and coping with peer stressors more relevant for certain patients versus others. Providers should both formally and informally assess a child's response to how information is communicated and the supports put in place in order to determine strategies that are most successful for each individual.

Implications for Interprofessional Care

Diabetes is one of the most complex and expensive chronic illnesses to manage, with only a small percentage of patients meeting healthcare goals for disease management such as targeted glucose, blood pressure, and weight (Bojadzievski & Gabbay, 2011). Such statistics highlight the need for enhanced and interdisciplinary care that better meets the multitude of factors associated with diabetes. A medical home that offers interdisciplinary care coordination and a "whole person" approach has been posed as an ideal model for diabetes care (Tsai, Morton, Mangione, & Keeler, 2005). Although a medical home for each patient with diabetes may be a long-term goal, most current diabetes healthcare is not integrated or even co-located. Even though the logistics of a medical home may not be possible for many patients with diabetes, professionals must still team together by engaging in interdisciplinary communication and collaboration to integrate care across settings. Various models have been presented in the literature as a guide for facilitating interprofessional care. Once such model is Conjoint Behavioral Consultation (CBC). CBC consists of problem identification and intervention development that entails the perspectives of the entire healthcare team (Lasecki et al., 2008). Professionals across all settings that a child or teen participates in work together to identify the most important priorities for intervention and how to incorporate elements of support in each aspect of the child's life. Research supports that interventions implemented via CBC are more feasible, and result in greater improvements than those developed solely in one setting (Galloway & Sheridan, 1994). This type of framework for intervention is particularly relevant for diabetes, as the disease has multifaceted impacts across many areas of functioning. A similar model is the Biopsychoeducational Model (Grier & Bradley-Klug, 2011), which also draws from ecological and behavior change theories, but has specific considerations for children with chronic illnesses such as diabetes. Using this model, professionals and caregivers determine how the interactions between systems either help or hinder success for a child with diabetes. For instance, educational professionals may seek to involve family members in a plan for improving a teenager's glucose monitoring at school, but without considering the family's potential resistance or apprehension to collaborating with the school, the plan could be quite unsuccessful due to lack of reinforcement at home. Application and empirical testing of both the CBC and biopsycheducational models applied to intervention for youth with diabetes is still needed. Often times interprofessional care is limited due to common barriers noted in the literature, including time constraints, lack of reimbursement, and misperceptions of roles in other settings. One key strategy to address some of these barriers is to designate a professional such as the school psychologist with expertise across settings to serve as the liaison for facilitating collaboration among team members. Each team member must be open to partnering together to the extent possible in order for this to be successful. Training and professional development in the benefits of collaboration is also important in order to provide the knowledge and motivation for all professionals to participate.

Case Study

The following case study illustrates some of the specific stressors that youth with diabetes may face, and the need for behavioral health providers to be ready to address concerns across multiple domains of a patient's life. Katelyn is a 17-year-old high school student who was diagnosed with Type 1 diabetes at the age of 10. Her parents have been integrally involved in overseeing Katelyn's monitoring and insulin management, along with encouraging her to remain active by playing soccer and being involved with friends outside of school. During her routine checkup with her endocrinologist, lab results showed high HbA1c, which had been slightly elevated at the previous appointment as well. Upon further consultation, Katelyn's physician learned that she was struggling with monitoring her glucose regularly.

Given some concern about her levels, the physician referred Katelyn to the clinic's behavioral health provider (BHP) for further assessment and consideration of the need for a treatment plan. Until this current school year, Katelyn was managing her disease without difficulty. Now, in her senior year, there are a number of competing priorities that may be interfering with her attention to her health needs. Katelyn shares that between completing college applications and entrance exams as well as the increase in social events during this last year of high school, she has difficulty prioritizing the management of her health needs. In addition, Katelyn's parents have taken a step back from her care in preparation for her next life transition and given her more independence with her diabetes management. Although Katelyn appreciates the autonomy, she is feeling overwhelmed by all of her responsibilities and believes that more reminders from her parents may actually be helpful. Additionally, consultation with the behavioral health provider revealed that Katelyn has missed several school days over the past couple of months due to feeling fatigued and stressed, which is being perceived by her teachers as "senioritis." She is struggling to maintain a high GPA in order to be competitive for her college applications. Katelyn also expressed concerns related to just wanting to fit in with her friends and classmates and not continuously have to worry about her health.

The BHP shares with Katelyn that many of the life stressors she is currently experiencing impact disease management for many youth with diabetes, and discusses some of the most common issues related to "emerging adulthood" that older teens experience as a way to improve Katelyn's health literacy around this aspect of diabetes care and normalize her experience. Katelyn and the BHP prioritize support for her disease management as the initial focus of treatment. They agree that it would be important to include her parents in an upcoming session to discuss ways in which they can be supportive in her diabetes care during this busy year, as well as in preparation for when she begins college. They discuss the need for her parents to still give her autonomy, but also provide regular check-ins to help monitor her progress and problem-solve any challenges.

With Katelyn's permission, the BHP will connect with the school psychologist at Katelyn's high school to share with her teachers the underlying health concerns contributing to her frequent absences. The provider also will share a brief handout on Type 1 diabetes in "emerging adulthood" with the school psychologist in order for the teachers to better understand the impact this disease may be having for Katelyn. Katelyn also agrees to meet with the school nurse within the next 2 weeks to discuss ways that she can assist Katelyn with reminders for monitoring her diabetes while at school. The BHP uses scheduled follow-up sessions with Katelyn to further explore the specific situations related to peer relationships that are causing her to feel stressed. Using strategies from coping skills training, together they discuss and role-play social scenarios Katelyn is struggling with, such as how to handle peer pressure around drinking, and ways to excuse herself from social situations to check her glucose. In order to monitor the success of these various strategies, Katelyn and the provider schedule monthly sessions. Based on both her health and psychosocial priorities, monitoring will include Katelyn's perceptions of how things are going, HbA1c tracking via her bimonthly physician visits, and the number of school days missed and general academic outcomes as provided by the school psychologist, with Katelyn and her parent's consent. Strategies that aren't successful will be revised as needed. Due to the upcoming move to college Katelyn will have in several months, the BHP emphasizes that all of the strategies can be used as ways to ensure success and prevent potential challenges when she transitions to living away from home.

Conclusions and Future Directions

Diabetes, both Type 1 and Type 2, is a disease that presents with a high level of variability in daily life and not much stability. The intensive monitoring and treatment involved can pose challenges. A new “routine” must be established for each youth that is diagnosed as well as their caregivers. Behavioral health providers must be aware of the multifaceted impact of diabetes across each area of life for a child or adolescent, and be positioned to coordinate the supports needed for youth to adjust to the demands of this disease.

The current state of healthcare, psychosocial support, and research agendas for youth with diabetes highlight some significant growth in the last decade. Specifically, more attention is being paid to the need for interdisciplinary care specific to diabetes, which includes behavioral health expertise and direct links between the healthcare and academic settings. In addition, expanded use of technology and social media allows for a larger population of young people with diabetes to access education and support. Many of these online programs have been shown to provide a sense of diabetes community that youth need in order to feel empowered in their care and accountable for their self-management. However, there is still empirical and clinical progress to be made in order to best meet the needs of youth with diabetes. Given the high stakes of academics for later life success along with the amount of time that youth spend in their school setting, there is a great need for school personnel to be better educated on the needs of students with Type 1 and Type 2 diabetes, and to serve as support and be partners in the care and success of each child in their school. Although research highlights the importance of interprofessional care, the actual use of integrated care and interprofessional collaboration needs to be expanded in most areas of the country in order to best meet the multifaceted needs of pediatric diabetes. Children and adolescents with diabetes must continue to be encouraged to be self-advocates for their health needs, and future research on the effectiveness of parental and therapeutic strategies to promote self-advocacy for youth with diabetes is necessary. Behavioral health providers should be mindful to involve a patient’s entire family in some aspect, and be especially sensitive to the transition of diabetes self-management during certain developmental periods. Finally, while evidence-based practices need to be used for prevention and intervention strategies for those with diabetes, clinicians must always keep in mind the importance of ensuring that discussions and recommendations are individualized and culturally sensitive in order to best meet the needs of each child and adolescent.

References

Agency for Healthcare Research and Quality (AHRQ). (2010). *The teach-back method: Tool 5*. Retrieved from www.nchealthliteracy.org/toolkit/tool5.pdf.

American Diabetes Association. (2003). Care of children with diabetes in the school and day care setting. *Diabetes Care, 26*, S131–S135.

American Diabetes Association. (2015). Initial evaluation and diabetes management planning. *Diabetes Care, 38*(Suppl 1), S17–S19.

Anderson, B. J., & McKay, S. V. (2011). Barriers to glycemic control in youth with type 1 diabetes and type 2 diabetes. *Pediatric Diabetes, 12*, 197–205.

Bojadzievski, T., & Gabbay, R. A. (2011). Patient-centered medical home and diabetes. *Diabetes Care, 34*, 1047–1053.

Centers for Disease Control and Prevention. (2017). *National Diabetes Statistics Report*. Atlanta, GA: U.S. Dept of Health and Human Services.

Centers for Disease Control and Prevention. (2018). *Diabetes report card 2017*. Atlanta, GA: Centers for Disease Control and Prevention, US Department of Health and Human Services.

Commissariat, P. V., Volkening, L. K., Guo, Z., Elbach, J. L., Butler, D. A., & Laffel, L. M. (2018). Associations between major life events and adherence, glycemic control, and psychosocial characteristics in teens with type 1 diabetes. *Pediatric Diabetes, 19*, 85–91.

Copeland, K. C., Silverstein, J., Moore, K. R., Prazar, G. E., Raymer, T., Shiffman, R. N., … Flinn, S. K. (2013). Management of newly diagnosed type 2 diabetes mellitus (T2DM) in children and adolescents. *Pediatrics, 131*, 364–382.

Cunningham, M. M., & Wodrich, D. L. (2006). The effect of sharing health information on teachers’ production of classroom accommodations. *Psychology in the Schools, 43*(5), 553–564.

D’Adamo, E., & Caprio, S. (2011). Type 2 diabetes in youth: Epidemiology and pathophysiology. *Diabetes Care, 34*, S161–S165.

Davidson, M., Boland, E. A., & Grey, M. (1997). Teaching teens to cope: Coping skills training for adolescents with insulin-dependent diabetes mellitus. *Journal for Specialists in Pediatrics Nursing, 2*(2), 65–72.

Dinh, H., Thuy, T., Bonner, A., Clark, R., Ramsbotham, J., & Hines, S. (2016). The effectiveness of the teach-back method on adherence and self-management in health education for people with chronic disease: A systematic review. *JBI Database of Systematic Reviews and Implementation Reports, 14*(1), 210–247.

Erie, C., Van Name, M. A., Weyman, K., Wienzimer, S. A., Finnegan, J., Sikes, K., … Sherr, J. L. (2017). Schooling diabetes: Use of continuous glucose monitoring and remote monitors in the home and school settings. *Pediatric Diabetes, 19*(1), 92–97.

Freebody, P., & Luke, A. (1990). Literacites programs: Debates and demands in cultural context. *Prospect, 5*, 7–16.

Galloway, J., & Sheridan, S. M. (1994). Implementing scientific practices through case studies: Examples using home-school intervention and consultation. *Journal of School Psychology, 32*, 385–413.

Goethals, E. R., Oris, L., Soenens, B., Berg, C. A., Prikken, S., Van Broeck, N., … Luyckx, K. (2017). Parenting and treatment adherence in type 1 diabetes throughout adolescence and emerging adulthood. *Journal of Pediatric Psychology, 42*(9), 922–932.

Gregory, J. W., & Channon, S. (2009). Motivational interviewing to improve blood glucose control in childhood diabetes. *Paediatrics and Child Health, 19*(7), 331–334.

Grey, M. (2011). Coping skills training for youth with diabetes. *Diabetes Spectrum, 24*(2), 70–76.

Grey, M., Boland, E. A., Davidson, M., Li, J., & Tamborlane, W. V. (2000). Coping skills training for youth with diabetes mellitus has long-lasting effects on metabolic control and quality of life. *The Journal of Pediatrics, 137*, 107–113.

Grey, M., Whittemore, R., Jeon, S., Murphy, K., Faulkner, M., & Delamater, A. (2013). Internet psycho-education programs improves outcomes in youth with type 1 diabetes. *Diabetes, Care, 36*(9), 2475–2482.

Grier, B. C., & Bradley-Klug, K. (2011). Collaborative consultation to support children with pediatric health issues: A review of the biopsychoeducational model. *Journal of Educational and Psychological Consultation, 21*, 88–105.

Herrman, J. (2010). Siblings' perceptions of the costs and rewards of diabetes and its treatment. *Journal of Pediatric Nursing, 25*, 428–437.

Hilliard, M. E., Powell, P. W., & Anderson, B. J. (2016). Evidence-based behavioral interventions to promote diabetes management in children, adolescents, and families. *American Psychologist, 71*(7), 590–601.

Howe, C. J., Jawad, A. F., Tuttle, A. K., Moser, J. T., Preis, C., Buzby, M., & Murphy, K. M. (2005). Education and telephone case management for children with type 1 diabetes: A randomized controlled trial. *Journal of Pediatric Nursing, 20*(2), 83–95.

Husted, G. R., Esbensen, B. A., Hommel, E., Thorsteinsson, B., & Zoffmann, V. (2014). Adolescents developing life skills for managing type 1 diabetes: A qualitative, realistic evaluation of a guided self-determination-youth intervention. *Journal of Advanced Nursing, 70*(11), 2634–2650.

Jenson, J. M., & Fraser, M. W. (1994). A risk and resilience framework for child, youth, and family policy. In J. M. Jenson & M. W. Fraser (Eds.), *Social policy for children and families: A risk and resilience perspective*. Thousand Oaks, CA: Sage.

Jenson, W. R., Rhode, G., & Reavis, H. K. (1995). *The tough kid toolbox*. Longmont, CO: Sopris West.

Johnson, N., & Melton, S. T. (2015). Partner perspective on life with a person with type 1 diabetes. *People Living with and Inspired by Diabetes, 1*, 32–39.

Kaufman, F. R., Jackson, C., & Bobo, N. (2010). Health care plans to manage diabetes at school. *NASN School Nurse, 25*(6), 276–278.

Kessels, R. P. (2003). Patients' memory for medical information. *Journal of the Royal Society of Medicine, 96*(5), 219–222.

Kise, S. S., Hopkins, A., & Burke, S. (2017). Improving school experiences for adolescents with type 1 diabetes. *Journal of School Health, 87*, 363–375.

Kucera, M., & Sullivan, A. L. (2011). The educational implications of type 1 diabetes mellitus: A review of research and recommendations for school psychological practice. *Psychology in the Schools, 48*(6), 587–603.

Lasecki, K., Olympia, D., Clark, E., Jenson, W., & Heathfield, L. T. (2008). Using behavioral interventions to assist children with type 1 diabetes manage blood glucose levels. *School Psychology Quarterly, 23*, 389–406.

McCarthy, A. M., Lindgren, S., Mengeling, M. A., Tsalikian, E., & Engvall, J. C. (2002). Effects of diabetes on learning in children. *Pediatrics, 109*, e9.

Mulvaney, S. A., Rothman, R. L., Wallston, K. A., Lybarger, C. L., & Dietrich, M. S. (2010). An internet-based program to improve self-management in adolescents with type 1 diabetes. *Diabetes Care, 33*(3), 602–604.

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDKD). (2013). Your guide to diabetes: Type 1 and Type 2. *National Institute of Health Publication No. 14–4016.*

Pulgaron, E. R., Sanders, L. M., Patino-Fernandez, A. M., Wile, D., Sanchez, J., Rothman, R. L., & Delamater, A. M. (2014). Glycemic control in young children with diabetes: The role of parental health literacy. *Patient Education and Counseling, 94*(1), 67–70.

Rankin, D., Harden, J., Jepson, R., & Lawton, J. (2017). Children's experiences of managing type 1 diabetes in everyday life: A thematic synthesis of qualitative studies. *Diabetic Medicine, 34*(8), 1050–1060.

Reinehr, T. (2013). Type 2 diabetes mellitus in children and adolescents. *World Journal of Diabetes, 15*, 270–281.

Rew, L., & Horner, S. D. (2003). Youth resilience framework for reducing health-risk behaviors in adolescents. *Journal of Pediatric Nursing, 18*, 379–388.

Saletsky, R. D., Trief, P. M., Anderson, B. J., Rosenbaum, P., & Weinstock, R. S. (2014). Parenting style, parent-youth conflict, and medication adherence in youth with type 2 diabetes participating in an intensive lifestyle change intervention. *Families, Systems, & Health, 32*(2), 176–185.

Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., … Clark, N. (2005). Care of children and adolescents with type 1 diabetes: A statement of the American Diabetes Association. *Diabetes Care, 28*, 186–212.

Sparling, K. (2014). *Balancing diabetes: Conversations about finding happiness and living well*. New York: Spry Publishing LLC.

Stahl-Pehe, A., Landwehr, S., Lange, K. S., Bachle, C., Castillo, K., Yossa, R., … Rosenbauer, J. (2017). Impact of quality of life (QoL) on glycemic control (HbA1c) among adolescents and emerging adults with long-duration type 1 diabetes: A prospective cohort-study. *Pediatric Diabetes, 18*, 808–816.

Stoeckel, M., & Duke, D. (2015). Diabetes and behavioral learning principles: Often neglected by well-known and empirically validated means of optimizing diabetes care behavior. *Current Diabetes Reports, 15*(7), 1–8.

Sweenie, R., Mackey, E. R., & Streisand, R. (2014). Parent-child relationships in type 1 diabetes: Associations among child behavior, parenting behavior, and pediatric parenting stress. *Families, Systems, & Health, 32*(1), 31–42.

Tsai, A. C., Morton, S. C., Mangione, C. M., & Keeler, E. B. (2005). A meta-analysis of interventions to improve care for chronic illnesses. *The American Journal of Managed Care, 11*(8), 478–488.

U.S. Department of Health and Human Services. (2003). *Helping the student with diabetes succeed: A guide for school personnel*. Washington, DC: National Institutes of Health, Centers for Disease Control and Prevention.

Valenzuela, J. M., Seid, M., Waitzfelder, B., Anderson, A. M., Beavers, D. P., Dabelea, D. M., … Yi-Frazier, J. (2014). Prevalence of and disparities in barriers to care experienced by youth with type 1 diabetes. *The Journal of Pediatrics, 164*(6), 1369–1375.

Wagner, J., Heapy, A., James, A., & Abbott, G. (2006). Glycemic control, quality of life, and school experiences among students with diabetes. *Journal of Pediatric Psychology, 31*(8), 764–769.

Wiebe, D. J., Helgeson, V., & Berg, C. A. (2016). The social context of managing diabetes across the life span. *American Psychologist, 71*, 526–538.

Wodrich, D. L. (2005). Disclosing information about epilepsy and type 1 diabetes mellitus: The effect on teachers' understanding of classroom behavior. *School Psychology Quarterly, 20*(3), 288–303.

Wodrich, D. L., & Cunningham, M. M. (2008). School-based tertiary and targeted interventions for students with chronic medical conditions: Examples from type 1 diabetes mellitus and epilepsy. *Psychology in the Schools, 45*(1), 52–62.

Wolpert, H., Weissberg-Benchell, J., & Anderson, B. J (2009). *Transitions in care: Meeting the challenges of type 1 diabetes in young adults*. New York: American Diabetes Association.

Yi-Frazier, J. P., Hilliard, M., Cochrane, K., & Hood, K. K. (2012). The impact of positive psychology on diabetes outcomes: A review. *Psychology, 3*, 1116–1124.

6

Asthma

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Abstract

Asthma is the most common chronic illness of childhood, affecting over 8% of youth. The economic impact of asthma is estimated to be over $37 billion dollars per year in the United States due to the cost of medications, increased healthcare utilization, and missed school and work days. Asthma represents a significant public health burden; it is associated with 2.3% of emergency department visits, 5.6% of hospitalizations, and 14 million missed school days among children. This chapter provides an overview of an interdisciplinary and collaborative approach to prevention, evaluation, and management of asthma. A case study is provided and future directions for research and practice are also discussed.

Background

Asthma is the most common chronic illness of childhood, affecting over 8% of youth (Akinbami, Simon, & Rossen, 2016). The economic impact of asthma is estimated to be over $37 billion dollars per year in the United States (Kamble & Bharmal, 2009) due to the cost of medications, increased healthcare utilization, and missed school and work days (Bahadori et al., 2009). Asthma represents a significant public health burden; it is associated with 2.3% of emergency department (ED) visits, 5.6% of hospitalizations (Akinbami, Moorman, Garbe, & Sondik, 2009), and 14 million missed school days among children (Bloom & Simpson, 2016).

Definition

Asthma affects the airways and is characterized by the triad of bronchial hyper-responsiveness, inflammation, and airflow obstruction (National Heart, Lung, and Blood Institute [NHLBI], 2007). In response to an allergen or trigger, the smooth airway muscles constrict causing airway narrowing and subsequent airflow limitation. In persistent asthma, inflammation is prominent, leading to overproduction of mucus and airway edema, which further limits airflow. Airflow limitation manifests in variable and recurring

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symptoms including cough, wheeze, chest tightness, and shortness of breath. Asthma symptoms are chronic and the underlying inflammation and predisposition to allergic responses are present even when symptoms are not.

Etiology

The role of genetics in asthma has not been fully identified although a family history of asthma or other allergic/atopic conditions increases the likelihood that a child may develop asthma (Subbarao, Mandhane, & Sears, 2009). Children who have one parent with asthma are 2.6 times more likely to have asthma; children with two parents with asthma are 5.2 times as likely to have asthma (Dold, Wjst, Von Mutius, Reitmeir, & Stiepel, 1992). The hygiene hypothesis and, relatedly, the microbiome theory are suggested etiological mechanisms of asthma, which posit that early exposure to microbes may support development of appropriate immune responses to the environment (Liu, 2015). There are a number of prenatal risk factors associated with onset of asthma including tobacco use, diet and nutrition, high levels of maternal stress, antibiotic treatment, and emergency cesarean section delivery (Subbarao et al., 2009).

Diagnosis

National guidelines (NHLBI, 2007) specify that an asthma diagnosis be based on medical history, physical examination, and, when possible, spirometry to assess lung function. Common medical history components include symptom pattern and frequency, activity limitations, precipitating triggers and environmental factors, risk factors (e.g., eczema, allergies, family history of asthma, maternal smoking), response to medication, and comorbidities. Asthma severity is determined by current frequency of symptoms, nighttime awakenings, frequency of medication use, activity limitations, and lung function. Asthma severity is classified as either intermittent or persistent, and among youth with persistent asthma, symptoms are further characterized as being mild, moderate, or severe.

Prevalence

Prevalence rates in pediatric asthma rose quickly from 1980 to 1996, with a yearly percentage increase of 3.8%, followed by a period of slowing between 2001 and 2010 (Akinbami, Moorman, & Liu, 2011). Currently 8.4% of children are reported to have asthma (Bloom & Simpson, 2016). While overall asthma prevalence rates have recently plateaued, increases continue within several subgroups, including adolescents, youth from low socioeconomic backgrounds, and those from the Southern portion of the United States (Akinbami et al., 2016). Children younger than 4 years old have a prevalence rate of 4.7%, while the prevalence rates range from 9.8% to 10.3% in adolescents. African Americans under the age of 18 are nearly twice as likely to have asthma as Caucasian children in this age group (13.4% vs. 7.4%). Among Hispanic children, the prevalence is 8%, but it is notably higher among Puerto Rican children (13.9%). Further, there is a higher prevalence rate of asthma among individuals below the federal poverty line (11.6%; Akinbami et al., 2011). Recent evidence suggests that asthma prevalence rates are comparable among urban and rural youth (Ownby et al., 2015), as well as rural and non-rural youth (Fedele, Barnett, Everhart, Lawless, & Forrest, 2014).

Physical Health Outcomes

The course of asthma varies among individuals. Some young children wheeze only after they have had a viral illness (i.e., viral-induced asthma). For children whose symptoms are not viral-induced, triggers can include exercise, pollutants (e.g., cleaning chemicals), secondhand smoke exposure (Mannino, Moorman, Kingsley, Rose, & Repace, 2001), and weather changes (Mireku, Wang, Ager, Reddy, & Baptist, 2009). Stress is an important consideration for youth with asthma given the impact of stress on the body's immune response resulting in increased risk for asthma exacerbation following exposure to triggers (Chen & Miller, 2007). Among children whose asthma is not viral-induced, asthma is classified into non-atopic (non-allergic) and atopic (allergic) asthma. The mechanism of non-atopic asthma is less well understood than that of atopic asthma. Children with atopic asthma develop symptoms primarily in response to allergens. These children have positive skin prick tests, show elevated immunoglobulin E or antibodies in response to allergens, and often have other types of allergies. Children with atopic asthma frequently have a positive family history of asthma, other allergies, and more persistent asthma symptoms (Matricardi et al., 2008), and symptoms are typically triggered by exposure to allergens (e.g., dust mites, pollen; Erbas et al., 2012; Matsui, Abramson, & Sandel, 2016).

Death from asthma is rare (3.8 per 1,000,000; Akinbami & Schoendorf, 2002) and life expectancy is not shortened by asthma alone (McFadden, 2000). Approximately 4 million children experience an asthma exacerbation annually, accounting for an estimated 14 million missed school days and more than 1.8 million ED visits each year (Bloom & Simpson, 2016). There are significant disparities in rates of emergency room use, hospitalization, and mortality related to pediatric asthma (Akinbami et al., 2016; Stewart et al., 2010).

Comorbid medical conditions are common in pediatric asthma and can be associated with greater asthma severity. Allergic rhinitis and atopic dermatitis are atopic diseases which share with asthma an allergic oversensitivity leading to allergic inflammation and are often present in children with asthma (Zheng, Yu, Oh, & Zhu, 2011). Chronic rhinosinusitis is often present in youth with asthma and is an independent risk factor for asthma exacerbations. Gastroesophageal reflux disease is also common and can affect asthma through the activation of vagal reflexes and/or microaspiration especially in youth with severe or difficult to treat asthma (Harding & Sontag, 2000). Obstructive sleep apnea may occur along with asthma, especially as the two conditions share predisposing factors (e.g., airway inflammation; Malakasioti, Gourgoulianis, Chrousos, & Kaditis, 2011). Vocal cord dysfunction (VCD) is a functional disorder in which the vocal cords close abnormally during inhalation, which may be diagnosed as treatment-resistant asthma (Dunn, Katial, & Hoyte, 2015). While asthma and VCD sometimes co-exist, the treatments are different and asthma medications will not improve VCD. Finally, asthma and obesity are highly comorbid, and further, these youth experience greater asthma severity and poorer asthma-related outcomes (e.g., more frequent symptoms, ED visits) than their non-obese peers with asthma (Belamarich et al., 2000; Black, Smith, Porter, Jacobsen, & Koebnick, 2012; Cassol et al., 2006; Michelson, Williams, Benjamin, & Barnato, 2009). Obesity may be a risk factor for asthma due to the generation of unique inflammatory mediators (e.g., leptin, C-reactive protein) that lead to airway dysfunction (Mai, Bottcher, & Leijon, 2004). This is compounded by the fact that children with asthma may refrain from exercise, leading to weight gain (Eneli, Skybo, & Camargo Jr., 2008).

Psychosocial Concomitants and Consequences

Adjustment difficulties are common among youth with asthma, particularly as asthma severity increases (Klinnert, McQuaid, McCormick, Adinoff, & Bryant, 2000). Increased asthma symptomology is associated with greater prevalence of anxiety and depressive disorders (Richardson et al., 2006) and youth with more severe asthma have poorer quality of life (Everhart & Fiese, 2009). Youth with severe asthma are more likely to experience panic attacks (Goodwin, Pine, & Hoven, 2003), which may be due, in part, to overlapping symptomology such as shortness of breath (Katon et al., 2007). Mood disorders among youth with asthma are associated with poorer treatment adherence and increased risk taking behaviors, like smoking, which may further exacerbate symptoms (Bender, 2006). Compared to peers, youth with asthma are at-risk for increased behavioral symptoms (McQuaid, Kopel, & Nassau, 2001). Rates of externalizing problems, such as Attention-deficit/Hyperactivity Disorder (ADHD), are elevated among youth with asthma, which may be associated with overlap in asthma symptoms, as well as side effects from asthma medication (Blackman & Gurka, 2007).

The family context is an important component of pediatric asthma self-management that impacts asthma outcomes (Kaugars, Klinnert, & Bender, 2004). Parent psychological functioning is associated with adherence to asthma treatment (Drotar & Bonner, 2009). Family beliefs regarding asthma medication (e.g., importance of, concern related to side effects; Conn, Halterman, Lynch, & Cabana, 2007) or the use of complementary and alternative medicine (McQuaid et al., 2014) can impact adherence to treatment. Similarly, family routines (Fiese, Wamboldt, & Anbar, 2005) and age appropriate division of responsibility for asthma management (McQuaid, Kopel, Klein, & Fritz, 2003) promote treatment regimen adherence. Finally, youth and families from lower socioeconomic backgrounds may experience increased risk for asthma exacerbations due to chronic stress (Chen et al., 2006), greater exposure to environmental triggers (e.g., mold, cockroaches), and higher likelihood of engaging in risk behaviors that may exacerbate symptoms (e.g., smoking; Canino, McQuaid, & Rand, 2009).

Psychosocial Screening and Assessment/Evaluation

A variety of screening measures are utilized to assess asthma symptomology and related psychosocial concerns, as well as to guide clinical decision-making. Measures examining asthma status are useful in identifying youth that may benefit from further intervention. Child and parent self-report measures of asthma control, including the Childhood Asthma Control Test (Liu et al., 2007), are widely used to assess changes in asthma symptomology and activity limitations (e.g., coughing, wheezing, asthma symptoms during play). Likewise, the Pediatric Asthma Control and Communication Instrument (Okelo et al., 2013) is available in both English and Spanish and provides information related to asthma status and patient–provider communication to inform treatment decisions. The Family Asthma Management System Scale (McQuaid, Walders, Kopel, Fritz, & Klinnert, 2005) provides insight into family-level asthma management.

Asthma-specific measures of psychosocial functioning have utility in assessing quality of life, identifying youth that may be struggling with the burden of disease management, have limited asthma knowledge, or low self-efficacy. Measures examining quality of life include the Pediatric Asthma Quality of Life Questionnaire (Juniper et al., 1996) which may be used to examine the impact of asthma symptoms on daily activities. Similarly, the PedsQL Asthma Module (Varni, Burwinkle, Rapoff, Kamps, & Olson, 2004) assesses health-related quality of life by examining asthma symptomology and treatment burden. The Pediatric Asthma Impact Scale (Yeatts et al., 2010), which was developed as a part of the Patient-Reported Outcomes Measurement Information System (PROMIS), is a brief questionnaire measuring asthma severity and control. There are also a number of measures examining asthma knowledge (Fitzclarence & Henry, 1990; Ho et al., 2003) and self-efficacy, like the Child and Parent Asthma Self-Efficacy Scales (Bursch, Schwankovsky, Gilbert, & Zeiger, 1999), which assess beliefs about ability to complete self-management tasks. Finally, the Asthma-Related Anxiety Scale (Bruzzese, Unikel, Shrout, & Klein, 2011) examines youth and parent adjustment to asthma symptoms.

Measures traditionally used to assess psychological functioning in youth may also have utility in pediatric asthma. The Multidimensional Anxiety Scale for Children (March, Parker, Sullivan, Stallings, & Conners, 1997) assesses clinical symptoms of anxiety, whereas the Child Depression Inventory (Helsel & Matson, 1984) is a widely used measure to screen for depressive symptoms. The Child Behavioral Checklist (Achenbach & Ruffle, 2000) or Behavior

Assessment System for Children (Reynolds, Kamphaus, & Vannest, 2011) may be helpful in assessing for emotional and behavioral problems, particularly given the high prevalence of ADHD and behavior problems among youth with asthma. Behaviorally, it is important to assess for side effects related to some asthma medications (i.e., oral steroids) due to their reported association with aggressive behavior and anxiety (Kayani & Shannon, 2002).

Prevention and Intervention

The goals of asthma management are to reduce impairment (e.g., frequency and severity of asthma symptoms) and risk of morbidity and mortality (NHLBI, 2007). National guidelines (NHLBI, 2007) call for a stepwise approach to asthma management based on regular assessment of an individual's asthma control. Asthma control is comprised of frequency of asthma symptoms, need for rescue medications, nighttime awakening from asthma, ability to perform daily tasks (including physical activity and school attendance), reliance on oral steroids for symptom management, rates of ED visits or hospitalizations, and patient satisfaction.

Medications

Medications, as well as the dose, and frequency of administration, may be increased or decreased based on reported control at each visit (NHLBI, 2007). Asthma medications are divided into short-acting beta agonists (SABA), which treat acute exacerbations, and inhaled corticosteroids (ICSs), which address the chronic symptoms of asthma. SABAs, also known as rescue medication, open the airways and are taken as needed and provide symptom relief during an acute exacerbation. ICSs, or preventive medication, must be taken daily to reduce inflammation, thereby reducing predisposition to asthma triggers. While most preventive medications are comprised of ICSs, some consist of a combination with a long-acting beta agonist (LABA), which loosens the muscles around the airways. Montelukast, a leukotriene receptor antagonist, may be used as an add-on therapy for youth whose asthma is poorly controlled with an ICS or for youth who are unable or unwilling to take an ICS. During severe exacerbations, children may be placed on a 5-day course of oral steroids or given an injection of depomedrol, an anti-inflammatory glucocorticoid. Immunotherapy has opened recent options for select youth with persistent allergic asthma with well-documented specific sensitizations to airborne allergens (Calderón et al., 2011). These medications (e.g., omalizumab, mepolizumab) are available only as injections. Asthma "action plans" are essential to promoting appropriate symptom response and provide youth with asthma and their families information about how medications should be used or direction about seeking healthcare services during an exacerbation (Zemek, Bhogal, & Ducharme, 2008).

Environmental Control

Environmental control is an essential aspect of asthma treatment and should be applied in all environments in which the child spends time (e.g., school or daycare, afterschool program, relatives' homes; NHLBI, 2007). Any triggers to which the child is allergic should be taken away. Smoke exposure should be eliminated. Mattress and pillow covers reduce the impact of dust mites and carpets, stuffed animals, and other dust mite hosts should be removed where possible. It is important to note that for children with exercise-induced asthma, avoidance of exercise is not desirable. Exercise has significant benefit, especially in children with asthma who may be overweight (Lang, 2014). Youth and families must learn to identify and avoid their unique triggers, to understand the value of prevention, and to respond quickly to respiratory symptoms. Home-based interventions targeting environmental factors that contribute to asthma symptomology have demonstrated improvements in quality of life, including reduction of asthma symptoms and missed school days (Crocker et al., 2011).

Education

Education programs promoting asthma self-management are associated with improvements in lung function and self-efficacy, as well as reducing missed school days, activity limitations, and healthcare utilization (Guevara, Wolf, Grum, & Clark, 2003). There are a number of modalities that serve as a feasible point of intervention to provide accessible asthma education; however, asthma self-management education should routinely occur at the point of care. Interventions providing school-based education related to inhaler technique, supporting the development of problem-solving skills for asthma management scenarios and coping skills using group discussions or relaxation strategies, and symptom assessment yielded improvements in asthma management skills and asthma severity (Horner & Brown, 2014), as well as improvements in asthma self-management and quality of life, as well as decreased healthcare utilization (Bruzzese et al., 2011). School staff should be familiar with administration of asthma medications, particularly since delivery of ICS medication at school may be a useful strategy to promote medication use among youth with poor adherence (Jones, Wheeler, Smith, & McManus, 2009).

Psychosocial Interventions

Adherence to ICS among youth with asthma is often poor (Bender, 2016). The use of a brief motivational interviewing (MI) intervention is one method for increasing youth and parent motivation to engage in asthma self-management (Riekert, Borrelli, Bilderback, & Rand, 2011). MI is a method of encouraging changes in health behaviors that includes helping individuals consider the benefits and consequences of behaviors, supports the development of intrinsic motivation, and aids in collaborative decision-making. Engaging in family-based self-monitoring and receiving feedback on ICS use from health providers is associated with decreased ED visits and increased rates of ICS refills (Otsuki et al., 2009), as well as improvements in adherence (Spaulding, Devine, Duncan, Wilson, & Hogan, 2012). Interventions promoting adaptive family asthma management are also important. A teamwork intervention for youth and parents was associated with increased medication adherence (Duncan et al., 2013). Multisystemic therapy (MST), an intensive family treatment conducted both at home and community sessions for youth with behavioral problems, has been adapted for asthma and was shown to enhance adherence and lung function (Naar-King et al., 2014). MST adapted for healthcare settings focuses on difficulties adolescents with chronic health problems may have in managing their condition by providing tailored intervention across systems, including the child, family, peer, school, and healthcare provider.

A number of psychosocial interventions may benefit youth with asthma experiencing comorbid symptoms of depression, anxiety, or behavioral problems. Behavioral interventions including breathing exercises, relaxation training, biofeedback, and training in perception of airway obstruction have utility in addressing symptoms of panic and anxiety, particularly for youth with difficulty discerning these from asthma symptoms (Ritz, Meuret, Trueba, Fritzsche, & von Leupoldt, 2013). Similarly, cognitive behavioral treatment providing coping skills (e.g., relaxation strategies, breathing exercises, cognitive restructuring, problem-solving skills, symptom monitoring) and exposures to anxiety-provoking situations, in combination with asthma education, have led to reductions in anxious symptoms and improvements in asthma management (Ritz et al., 2013). General lifestyle interventions may also be important for some youth in order to promote regular physical activity, healthy diet, and reduce risky health behaviors, particularly smoking.

Implications for Interprofessional Care

Asthma-related difficulties can stem from a range of factors including low asthma self-management knowledge or skills, poor inhaler technique, difficulties accessing care, and psychosocial concerns impacting disease management. For these reasons, optimal care consists of an interprofessional approach to treatment that leverages the unique knowledge and skills of physicians, nurses, respiratory therapists, pharmacists, social workers, and psychologists. The need for close collaboration between providers to offer integrated care is illustrated in the below case study.

Case Study

William Maxwell was a 16-year-old African-American male with a significant family history of asthma. William had a diagnosis of severe persistent asthma and his medication regimen consisted of an ICS/LABA, and SABA (as needed). Review of William's medical records indicated that he had several courses of oral corticosteroids to treat exacerbations in the past year and a history of asthma-related ICU admissions. Furthermore, his asthma was poorly controlled as indicated by recent pulmonary function test results and his asthma control test score of 8 (a cut-off score of ≤19 indicates poorly controlled asthma). His declining trajectory occurred despite frequent pulmonary clinic appointments, titration of his medication regimen, a current asthma action plan, and review of inhaler technique by respiratory therapy. William's low level of treatment adherence prompted the medical team to contact his school and request that the school nurse administer his ICS medications on school days.

William was referred to behavioral medicine from the Pediatric Pulmonary Division primarily due to low adherence to his asthma regimen. William and his mother participated in an initial intake appointment with a pediatric psychologist. William reported that he resided with his mother and a younger sibling. William indicated that he has frequent activity limitations (e.g., no longer engages in sports), nighttime awakenings, and was increasingly missing school days, in part, due to asthma symptoms. Despite a high level of impairment, William was largely ambivalent about his asthma regimen, reporting that he was not motivated to take medications. William's mother reported that William was defiant at home and school, often refusing to complete school assignments, follow house rules, or her requests. She expressed feeling overwhelmed due to her demanding work schedule and William's oppositional behavior.

The psychologist initially targeted William's ambivalent feelings regarding asthma medications via motivational interviewing. This patient-centered technique involved listening to William's frustrations surrounding his asthma regimen and supporting his autonomy as an adolescent. The psychologist reinforced William's change talk (e.g., desire to engage in sports with friends) and gently noted discrepancies between his current behavior and future goals. Once William reported a higher level of motivation, he agreed to collaboratively engage in problem-solving barriers to taking his ICS medication regularly and set goals to progressively increase his medication adherence.

Concurrently, social work completed a series of home visits with William's family. The social worker provided supportive counseling to William's mother and reinforced the progress the family was making in therapy. During the home visits, the social worker identified a number of potential asthma triggers that were occurring in the family's apartment complex (e.g., secondhand smoke exposure). This led to the social worker assisting William's mother in ongoing tenant efforts to implement a complex-wide smoking ban. Further, the social worker was able to troubleshoot transportation difficulties that were interfering with the family's ability to attend pulmonary clinic visits as frequently as the medical team thought necessary.

William's adherence to ICS and his asthma control steadily increased in the context of this coordinated, interdisciplinary treatment approach. William reported less frequent asthma symptoms and began playing high school basketball during the following school year. In the context of William's improved health, the pediatric psychologist and social worker transitioned to briefly meeting with the family during quarterly outpatient medical appointments at the pediatric pulmonary clinic. These visits were intended to serve as brief booster sessions and facilitated ongoing interprofessional care.

Conclusions and Future Directions

Asthma remains the most common pediatric chronic illness and is a significant public health burden in the United States. As illustrated in the above case study, interprofessional care can be helpful in promoting optimal asthma self-management in children and adolescents. Interdisciplinary teams should continue to collaborate to facilitate disease management in youth with asthma (e.g., Walders et al., 2006). There have been calls for interventions where behavioral health providers serve as coaches to medical providers readily available at the point of care (Rohan et al., 2013), an ongoing emphasis on personalized, developmentally appropriate asthma management from the interdisciplinary team (Costello et al., 2016), and an increased focus on considering cost-effectiveness as a key intervention component (van Boven et al., 2016). Additionally, given the effectiveness of mobile health interventions for pediatric chronic illnesses (Fedele, Cushing, Fritz, Amaro, & Ortega, 2017), mobile technology interventions show promise as a means to improve adherence to treatment and clinically relevant asthma outcomes (Miller, Schüz, Walters, & Walters, 2017). For instance, mobile technology using methods for behavior change can be leveraged to support patients in self-monitoring symptoms, obtaining asthma education, creating tailored asthma action plans, or connecting to healthcare providers.

References

Achenbach, T. M., & Ruffle, T. M. (2000). The child behavior checklist and related forms for assessing behavioral/emotional problems and competencies. *Pediatrics in Review, 21*, 265–271.

Akinbami, L. J., Moorman, J. E., Garbe, P. L., & Sondik, E. J. (2009). Status of childhood asthma in the United States, 1980–2007. *Pediatrics, 123*, S131–S145.

Akinbami, L. J., Moorman, J. E., & Liu, X. (2011). Asthma prevalence, health care use, and mortality: United States, 2005-2009. *National Health Statistics Reports, 12*, 1–14.

Akinbami, L. J., & Schoendorf, K. C. (2002). Trends in childhood asthma: Prevalence, health care utilization, and mortality. *Pediatrics, 110*, 315–322.

Akinbami, L. J., Simon, A. E., & Rossen, L. M. (2016). Changing trends in asthma prevalence among children. *Pediatrics, 137*, 2015–2354.

Bahadori, K., Doyle-Waters, M. M., Marra, C. A., Lynd, L. D., Alasaly, K., Swiston, J., & FitzGerald, J. M. (2009). Economic burden of asthma: A systematic review. *BMC Pulmonary Medicine, 9*, 24.

Belamarich, P. F., Luder, E., Kattan, M., Mitchell, H. E., Islam, S., Lynn, H., & Crain, E. F. (2000). Do obese inner-city children with asthma have more symptoms than nonobese children with asthma? *Pediatrics, 106*, 1436–1441.

Bender, B. G. (2006). Risk taking, depression, adherence, and symptom control in adolescents and young adults with asthma. *American Journal of Respiratory and Critical Care Medicine, 173*, 953–957.

Bender, B. G. (2016). Nonadherence to asthma treatment: Getting unstuck. *The Journal of Allergy and Clinical Immunology: In Practice, 4*, 849–851.

Black, M. H., Smith, N. A., Porter, A. H., Jacobsen, S. J., & Koebnick, C. (2012). Higher prevalence of obesity among children with asthma. *Obesity, 20*, 1041–1047.

Blackman, J. A., & Gurka, M. J. (2007). Developmental and behavioral comorbidities of asthma in children. *Journal of Developmental and Behavioral Pediatrics, 28*, 92–99.

Bloom, B., & Simpson, J. (2016). Tables of summary health statistics for U.S. children: 2015 National Health Interview Survey.

Bruzzese, J. M., Sheares, B. J., Vincent, E. J., Du, Y., Sadeghi, H., Levison, M. J., … Evans, D. (2011). Effects of a school-based intervention for urban adolescents with asthma: A controlled trial. *American Journal Respiratory Critical Care Medicine, 183*, 998–1006.

Bruzzese, J. M., Unikel, L. H., Shrout, P. E., & Klein, R. G. (2011). Youth and parent versions of the Asthma-Related Anxiety Scale: Development and initial testing. *Pediatric Allergy, Immunology, and Pulmonology, 24*, 95–105.

Bursch, B., Schwankovsky, L., Gilbert, J., & Zeiger, R. S. (1999). Construction and validation of four childhood asthma self-management scales: Parent barriers, child and parent self-efficacy and parent belief in treatment efficacy. *Journal of Asthma, 36*, 115–128.

Calderón, M. A., Casale, T. B., Togias, A., Bousquet, J., Durham, S. R., & Demoly, P. (2011). Allergen-specific immunotherapy for respiratory allergies: From meta-analysis to registration and beyond. *Journal of Allergy and Clinical Immunology, 127*, 30–38.

Canino, G., McQuaid, E. L., & Rand, C. S. (2009). Addressing asthma health disparities: A multilevel challenge. *Journal of Allergy and Clinical Immunology, 123*, 1209.

Cassol, V. E., Rizzato, T. M., Teche, S. P., Basso, D. F., Centenaro, D. F., Maldonado, M., … Menna-Barreto,

S. S. (2006). Obesity and its relationship with asthma prevalence and severity in adolescents from southern Brazil. Journal of Asthma, 43, 57–60.

Chen, E., Hanson, M. D., Paterson, L. Q., Griffin, M. J., Walker, H. A., & Miller, G. E. (2006). Socioeconomic status and inflammatory processes in childhood asthma: The role of psychological stress. *Journal of Allergy and Clinical Immunology, 117*, 1014–1020.

Chen, E., & Miller, G. E. (2007). Stress and inflammation in exacerbations of asthma. *Brain, Behavior, and Immunity, 21*, 993–999.

Conn, K. M., Halterman, J. S., Lynch, K., & Cabana, M. D. (2007). The impact of parents' medication beliefs on asthma management. *Pediatrics, 120*, e521–e526.

Costello, R. W., Foster, J. M., Grigg, J., Eakin, M. N., Canonica, G. W., Yunus, F., & Ryan, D. (2016). The seven stages of man: The role of developmental stage on medication adherence in respiratory diseases. *The Journal of Allergy and Clinical Immunology: In Practice, 4*, 813–820.

Crocker, D. D., Kinyota, S., Dumitru, G. G., Ligon, C. B., Herman, E. J., Ferdinands, J. M., … Sipe, T. A. (2011). Effectiveness of home-based, multi-trigger, multicomponent interventions with an environmental focus for reducing asthma morbidity a community guide systematic review task force on community preventive services. *American Journal of Preventive Medicine, 41*, S5–S32.

Dold, S., Wjst, M., Von Mutius, E., Reitmeir, P., & Stiepel, E. (1992). Genetic risk for asthma, allergic rhinitis, and atopic dermatitis. *Archives of Disease in Childhood, 67*, 1018–1022.

Drotar, D., & Bonner, M. S. (2009). Influences on adherence to pediatric asthma treatment: A review of correlates and predictors. *Journal of Developmental and Behavioral Pediatrics, 30*, 574–582.

Duncan, C. L., Hogan, M. B., Tien, K. J., Graves, M. M., Chorney, J. M., Zettler, M. D., … Portnoy, J. (2013). Efficacy of a parent-youth teamwork intervention to promote adherence in pediatric asthma. *Journal of Pediatric Psychology, 38*(6), 617–628.

Dunn, N. M., Katial, R. K., & Hoyte, F. C. L. (2015). Vocal cord dysfunction: A review. *Asthma Research and Practice, 1*, 9.

Eneli, I. U., Skybo, T., & Camargo, C. A., Jr. (2008). Weight loss and asthma: A systematic review. *Thorax, 63*, 671–676.

Erbas, B., Akram, M., Dharmage, S. C., Tham, R., Dennekamp, M., Newbigin, E., … J, M. (2012). The role of seasonal grass pollen on childhood asthma emergency department presentations. *Clinical & Experimental Allergy, 42*, 799–805.

Everhart, R. S., & Fiese, B. H. (2009). Asthma severity and child quality of life in pediatric asthma: A systematic review. *Patient Education and Counseling, 75*, 162–168.

Fedele, D. A., Barnett, T. E., Everhart, R. S., Lawless, C., & Forrest, J. R. (2014). Comparison of asthma prevalence and morbidity among rural and nonrual youth. *Annals of Allergy, Asthma, and Immunology, 52*, 2013–2014.

Fedele, D. A., Cushing, C. C., Fritz, A., Amaro, C. M., & Ortega, A. (2017). Mobile health interventions for improving health outcomes in youth. *JAMA Pediatrics, 171*, 461.

Fiese, B. H., Wamboldt, F. S., & Anbar, R. D. (2005). Family asthma management routines: Connections to medical adherence and quality of life. *The Journal of Pediatrics, 146*, 171–176.

Fitzclarence, C. A. B., & Henry, R. L. (1990). Validation of an asthma knowledge questionnaire. *Journal of Paediatrics and Child Health, 26*, 200–204.

Goodwin, R. D., Pine, D. S., & Hoven, C. W. (2003). Asthma and panic attacks among youth in the community. *Journal of Asthma, 40*, 139–145.

Guevara, J. P., Wolf, F. M., Grum, C. M., & Clark, N. M. (2003). Effects of educational interventions for self management of asthma in children and adolescents: Systematic review and meta-analysis. *British Medical Journal, 326*, 1308–1309.

Harding, S. M., & Sontag, S. J. (2000). Asthma and gastroesophageal reflux. *The American Journal of Gastroenterology, 95*, S23–S32.

Helsel, W. J., & Matson, J. L. (1984). The assessment of depression in children: The internal structure of the child depression inventory (CDI). *Behaviour Research and Therapy, 22*, 289–298.

Ho, J., Bender, B. G., Gavin, L. A., O'Connor, S. L., Wamboldt, M. Z., & Wamboldt, F. S. (2003). Relations among asthma knowledge, treatment adherence, and outcome. *Journal of Allergy and Clinical Immunology, 111*, 498–502.

Horner, S. D., & Brown, A. (2014). Evaluating the effect of an asthma self-management intervention for rural families. *Journal of Asthma, 51*, 168–177.

Jones, S. E., Wheeler, L. S., Smith, A. M., & McManus, T. (2009). Adherence to National Asthma Education and Prevention Program's "How Asthma-Friendly Is Your School?" recommendations. *The Journal of School Nursing, 25*, 382–394.

Juniper, E. F., Guyatt, G. H., Feeny, D. H., Ferrie, P. J., Griffith, L. E., & Townsend, M. C. (1996). Measuring quality of life in children with asthma. *Quality of Life Research, 5*, 35–46.

Kamble, S., & Bharmal, M. (2009). Incremental direct expenditure of treating asthma in the United States. *Journal of Asthma, 46*, 73–80.

Katon, W. J., Lozano, P., Russo, J., McCauley, E., Richardson, L. P., & Bush, T. (2007). The prevalence of DSM-IV anxiety and depressive disorders in youth with asthma compared with controls. *Journal of Adolescent Health, 41*, 455–463.

Kaugars, A. S., Klinnert, M. D., & Bender, B. G. (2004). Family influences on pediatric asthma. *Journal of Pediatric Psychology, 29*, 475–491.

Kayani, S., & Shannon, D. C. (2002). Adverse behavioral effects of treatment for acute exacerbation of asthma in children: A comparison of two doses of oral steroids. *Chest, 122*, 624–628.

Klinnert, M. D., McQuaid, E. L., McCormick, D. P., Adinoff, A. D., & Bryant, N. E. (2000). A multimethod assessment of behavioral and emotional adjustment in children with asthma. *Journal of Pediatric Psychology, 25*, 35–46.

Lang, J. E. (2014). Obesity and asthma in children: Current and future therapeutic options. *Paediatric Drugs, 16*, 179–188.

Liu, A. H. (2015). Revisiting the hygiene hypothesis for allergy and asthma. *Journal of Allergy and Clinical Immunology, 136*, 860–865.

Liu, A. H., Zeiger, R. S., Sorkness, C. A., Mahr, T., Ostrom, N. K., Burgess, S., … Manjunath, R. (2007). Development and cross-sectional validation of the Childhood Asthma Control Test. *Journal of Allergy and Clinical Immunology, 119*, 817–825.

Mai, X. M., Bottcher, M. F., & Leijon, I. (2004). Leptin and asthma in overweight children at 12 years of age. *Pediatric Allergy and Immunology, 15*, 523–530.

Malakasioti, G., Gourgoulianis, K., Chrousos, G., & Kaditis, A. (2011). Interactions of obstructive sleep-disordered breathing with recurrent wheezing or asthma and their effects on sleep quality. *Pediatric Pulmonology, 46*, 1047–1054.

Mannino, D. M., Moorman, J. E., Kingsley, B., Rose, D., & Repace, J. (2001). Health effects related to environmental tobacco smoke exposure in children in the United States. *Archives of Pediatrics & Adolescent Medicine, 155*, 36.

March, J. S., Parker, J. D. A., Sullivan, K., Stallings, P., & Conners, C. K. (1997). The Multidimensional Anxiety Scale for Children (MASC): Factor structure, reliability, and validity. *Journal of the American Academy of Child and Adolescent Psychiatry, 36*, 554–565.

Matricardi, P. M., Illi, S., Grüber, C., Keil, T., Nickel, R., Wahn, U., & Lau From, S. (2008). Wheezing in childhood: Incidence, longitudinal patterns and factors predicting persistence. *European Respiratory Journal, 32*, 585–592.

Matsui, E. C., Abramson, S. L., & Sandel, M. T. (2016). Indoor environmental control practices and asthma management. *Pediatrics, 138*, e20162589.

McFadden, E. R. J. (2000). Natural history of chronic asthma and its long-term effects on pulmonary function. *The Journal of Allergy and Clinical Immunology, 105*, S535–S539.

McQuaid, E. L., Fedele, D. A., Adams, S. K., Koinis-Mitchell, D., Mitchell, J. H., Kopel, S. J., … Canino, G. (2014). Complementary and alternative medicine use and adherence to asthma medications among Latino and non-Latino white families. *Academic Pediatrics, 14*, 192–199.

McQuaid, E. L., Kopel, S. J., Klein, R. B., & Fritz, G. K. (2003). Medication adherence in pediatric asthma: Reasoning, responsibility, and behavior. *Journal of Pediatric Psychology, 28*, 323–333.

McQuaid, E. L., Kopel, S. J., & Nassau, J. (2001). Behavioral adjustment in children with asthma: A meta-analysis. *Journal of Developmental and Behavioral Pediatrics, 22*, 430–439.

McQuaid, E. L., Walders, N., Kopel, S. J., Fritz, G. K., & Klinnert, M. D. (2005). Pediatric asthma management in the family context: The family asthma management system scale. *Journal of Pediatric Psychology, 30*, 492–502.

Michelson, P. H., Williams, L. W., Benjamin, D. K., & Barnato, A. E. (2009). Obesity, inflammation, and asthma severity in childhood: Data from the National Health and Nutrition Examination Survey 2001-2004. *Annals of Allergy, Asthma & Immunology, 103*, 381–385.

Miller, L., Schüz, B., Walters, J., & Walters, E. H. (2017). Mobile technology interventions for asthma self-management: Systematic review and meta-Analysis. *Journal of Medical Internet Research mHealth and uHealth, 5*, e57.

Mireku, N., Wang, Y., Ager, J., Reddy, R. C., & Baptist, A. P. (2009). Changes in weather and the effects on pediatric asthma exacerbations. *Annal of Allergy, Asthma, and Immunology, 103*, 220–224.

Naar-King, S., Ellis, D. A., King, P. S., Lam, P., Cunningham, P. B., Secord, E., … Templin, T. (2014). Multisystemic therapy for high-risk African American adolescents with asthma: A randomized clinical trial. *Journal of Consulting and Clinical Psychology, 82*, 536–545.

National Heart, Lung, and Blood Institute. (2007). *Guidelines for the diagnosis and management of asthma*. Retrieved from https://www.nhlbi.nih.gov/health-topics/guidelines-for-diagnosis-management-of-asthma

Okelo, S. O., Eakin, M. N., Patino, C. M., Teodoro, A. P., Bilderback, A. L., Thompson, D. A., … A, K. (2013). The Pediatric Asthma Control and Communication Instrument asthma questionnaire: For use in diverse children of all ages. *Journal of Allergy and Clinical Immunology, 132*, 55–62.

Otsuki, M., Eakin, M. N., Rand, C. S., Butz, A. M., Hsu, V. D., Zuckerman, I. H., … Riekert, K. A. (2009). Adherence feedback to improve asthma outcomes among inner-city children: A randomized trial. *Pediatrics, 124*, 1513–1521.

Ownby, D. R., Tingen, M. S., Havstad, S. L., Waller, J. L., Johnson, C. C., & Joseph, C. L. M. (2015). Comparison of asthma prevalence among African American teenage youth attending public high schools in rural Georgia and urban Detroit. *Journal of Allergy and Clinical Immunology, 136*(3), 595–600 e3.

Reynolds, C. R., Kamphaus, R. W., & Vannest, K. J. (2011). Behavior Assessment System for Children (BASC). In J. S. Kreutzer, J. DeLuca, & B. Caplan (Eds.), *Encyclopedia of clinical neuropsychology* (pp. 366–371). New York, NY: Springer.

Richardson, L. P., Lozano, P., Russo, J., McCauley, E., Bush, T., & Katon, W. J. (2006). Asthma symptom burden: Relationship to asthma severity and anxiety and depression symptoms. *Pediatrics, 118*, 1042–1051.

Riekert, K. A., Borrelli, B., Bilderback, A. L., & Rand, C. S. (2011). The development of a motivational interviewing intervention to promote medication adherence among inner-city, African-American adolescents with asthma. *Patient Education and Counseling, 82*, 117–122.

Ritz, T., Meuret, A. E., Trueba, A. F., Fritzsche, A., & von Leupoldt, A. (2013). Psychosocial factors and behavioral medicine interventions in asthma. *Journal of Consulting and Clinical Psychology, 81*(2), 231–250.

Rohan, J. M., Drotar, D., Perry, A. R., McDowell, K. M., Malkin, J., & Kercsmar, C. M. (2013). Training health care providers to conduct adherence promotion in pediatric settings: An example with pediatric asthma. *Clinical Practice in Pediatric Psychology, 1*, 314–325.

Spaulding, S. A., Devine, K. A., Duncan, C. L., Wilson, N. W., & Hogan, M. B. (2012). Electronic monitoring and feedback to improve adherence in pediatric asthma. *Journal of Pediatric Psychology, 37*, 64–74.

Stewart, K. A., Higgins, P. C., McLaughlin, C. G., Williams, T. V., Granger, E., & Croghan, T. W. (2010). Differences in prevalence, treatment, and outcomes of asthma among a diverse population of children with equal access to care. *Archives of Pediatrics & Adolescent Medicine, 164*, 720–726.

Subbarao, P., Mandhane, P. J., & Sears, M. R. (2009). Asthma: Epidemiology, etiology and risk factors. *Canadian Medical Association Journal, 181*, E181–E190.

van Boven, J. F. M., Ryan, D., Eakin, M. N., Canonica, G. W., Barot, A., & Foster, J. M. (2016). Enhancing respiratory medication adherence: The role of health care professionals and cost-effectiveness considerations. *The Journal of Allergy and Clinical Immunology: In Practice, 4*, 835–846.

Varni, J. W., Burwinkle, T. M., Rapoff, M. A., Kamps, J. L., & Olson, N. (2004). The PedsQL in pediatric asthma: Reliability and Validity of the Pediatric Quality of Life Inventory Generic Core Scales and asthma module. *Journal of Behavioral Medicine, 27*, 297–318.

Walders, N., Kercsmar, C. M., Schluchter, M., Redline, S., Kirchner, H. L., & Drotar, D. (2006). An interdisciplinary intervention for undertreated pediatric asthma. *Chest, 129*, 292–299.

Yeatts, K. B., Stucky, B., Thissen, D., Irwin, D., Varni, J. W., DeWitt, E. M., … DeWalt, D. A. (2010). Construction of the Pediatric Asthma Impact Scale (PAIS) for the Patient-Reported Outcomes Measurement Information System (PROMIS). *The Journal of Asthma, 47*, 295–302.

Zemek, R. L., Bhogal, S. K., & Ducharme, F. M. (2008). Systematic review of randomized controlled trials examining written action plans in children: What is the plan? *Archives of Pediatrics & Adolescent Medicine, 162*, 157–163.

Zheng, T., Yu, J., Oh, M. H., & Zhu, Z. (2011). The atopic march: Progression from atopic dermatitis to allergic rhinitis and asthma. *Allergy, Asthma and Immunology Research, 3*(2), 67.

Epilepsy

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Abstract

Pediatric epilepsy affects 460,000 youth between 0 and 17 years of age in the United States and is one of the most common pediatric neurological disorders, affecting 1% of youth. Epilepsy is increasingly being recognized as a spectrum disorder that goes beyond seizures, as 50% of individuals also experience cognitive and psychiatric comorbidities. Given the multifactorial nature of epilepsy, the role of interdisciplinary care is critically important to the well-being and comprehensive care of youth with epilepsy (YWE). This chapter covers the diagnosis and treatment of epilepsy, as well as the most common psychological comorbidities. For each of the comorbidities, the chapter discusses the prevalence, evidence-based assessment, risk factors, and evidence-based treatment guidelines from the literature. The chapter concludes with a discussion regarding the importance of interdisciplinary care for YWE, and future directions.

Epilepsy

Pediatric epilepsy affects 460,000 youth between 0 and 17 years of age in the United States (Zack & Kobau, 2017) and is one of the most common pediatric neurological disorders, affecting 1% of youth (Russ, Larson, & Halfon, 2012). Epilepsy is increasingly being recognized as a spectrum disorder that goes beyond seizures, as 50% of individuals also experience cognitive and psychiatric comorbidities (Jensen, 2011). Given the multifactorial nature of epilepsy, the role of interdisciplinary care is critically important to the well-being and comprehensive care of youth with epilepsy (YWE) (Guilfoyle et al., 2017). This chapter will cover the diagnosis and treatment of epilepsy, as well as the most common psychological comorbidities. For each of the comorbidities, this chapter includes a discussion of the prevalence, evidence-based assessment, risk factors, and evidence-based treatment guidelines from the literature. This chapter concludes with a discussion regarding the importance of interdisciplinary care for YWE, and future directions.

Diagnosis and Treatment

The International League Against Epilepsy (ILAE) revised the terminology and definitions related to the diagnosis of epilepsy in 2010 (Berg et al., 2010). Specifically, an individual must have

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had: (1) at least two unprovoked seizures >24 h apart, or (2) one unprovoked seizure and the probability of having further seizures, or (3) the diagnosis of an epilepsy syndrome. Seizures are the hallmark symptom of epilepsy and are caused by abnormal electrical activity in the brain. They can be classified into three primary types (i.e., focal, generalized, or unclassified). Focal seizures occur in one or more localized regions of the brain and may or may not result in lost consciousness. Generalized seizures affect both sides of the brain. Pediatric syndromes in which generalized seizures are common include childhood absence epilepsy, characterized by staring spells and in some cases, infrequent generalized tonic-clonic seizures, and juvenile myoclonic epilepsy, characterized by three seizure types that include absence seizures, generalized tonic-clonic seizures, and sudden jerking of the extremities. Unclassified seizures are those with unknown or unclear onset. Any of these three seizure types can be associated with pre-ictal (i.e., pre-seizure) symptoms or auras that signal an impending seizure, though many people experience no aura. Auras may include sensations (e.g., altered taste or vision) or mood/behavioral changes (e.g., anger outbursts) (Nakken et al., 2009).

Children with epilepsy can manifest one type of seizure or several seizure types. If a child has a seizure that lasts longer than 5 min or two seizures with no return to baseline functioning between the seizures, it is classified as status epilepticus (Wasterlain & Chen, 2006). The etiology of seizures can be genetic (i.e., presumed genetic defect), structural-metabolic (i.e., co-occurs with a structural or metabolic disorder), immune-infectious (i.e., due to an immune-mediated or infection of the central nervous system), or unknown (i.e., unidentified or unrecognized genetic or other disorder) (Berg et al., 2010). Epilepsy etiology is unknown in 33% of patients with epilepsy (Berg et al., 2010).

The diagnosis of epilepsy is made based on a clinical description of the seizures, comprehensive history of the patient, electroencephalogram (EEG), and neuroimaging (e.g., magnetic resonance imaging [MRI]). The EEG and MRI detect abnormal electrographic activity (i.e., seizures) and any other brain abnormalities or structural defects that may cause seizures (Smith, Wagner, & Edwards, 2015a). Once an epilepsy diagnosis is made, initial treatment is antiepileptic drugs (AEDs). There are approximately 25 AEDs on the market, including both older and newer generation drugs. Notably, AED side effects are quite common in YWE, including altered mood, fatigue, behavioral changes, cognitive slowing, weight gain, and motor changes (Glauser, 2004a, 2004b; Guilfoyle et al., 2018; Morita, Glauser, & Modi, 2012). AED monotherapy is effective at stopping seizures for approximately two-thirds of the epilepsy population (Holland & Glauser, 2007; Holland, Monahan, Morita, Vartzelis, & Glauser, 2010). Unfortunately, one-third of the YWE will continue to have seizures after two or more appropriate and adequately trialed AEDs, indicating the child is treatment-resistant. Children who have treatment-resistant epilepsy may need polytherapy or be candidates for more expensive and invasive treatments, including neurosurgery, neurostimulation (i.e., vagal nerve stimulation), or dietary changes (i.e., modified Atkins or ketogenic diet) (Smith, Wagner, & Edwards, 2015b).

The symptoms and treatment for epilepsy can have a significant negative impact on the health-related quality of life (HRQOL) of both children and their caregivers (Baca, Vickrey, Caplan, Vassar, & Berg, 2011; Ferro, 2014; Ferro et al., 2013; Loiselle, Ramsey, Rausch, & Modi, 2016; Modi et al., 2017; Ramsey, Loiselle, Rausch, Harrison, & Modi, 2016). In fact, studies have demonstrated that both seizures and side effects are significant predictors of HRQOL. HRQOL is further compromised by high rates of psychological comorbidities (Austin et al., 2011; Salpekar & Dunn, 2007). For example, YWE are at three to sixfold increased risk for psychological disorders (Ott et al., 2001, 2003). A population-based study in children with active epilepsy found that 80% of children met DSM-IV-TR criteria for a cognitive or behavioral disorder (Reilly et al., 2014). The same study found that 2/3 of children meeting criteria for a behavioral disorder were previously undiagnosed. The lack of proper diagnosis and treatment in YWE is of particular concern given that psychological comorbidities are associated with poorer disease management and prognosis, higher mortality rates, increased risk for psychiatric side effects of treatment, increased risk for suicide, poorer HRQOL, and greater economic burden (Kanner, 2017). Shared neuropathological or genetic pathways (Glasgow, Goldstein, Ockene, & Pronk, 2004), AED side effects (Glauser, 2004b), or typical developmental processes (Pellock, 2004) can contribute to psychological comorbidities. There is also evidence that psychological comorbidities (e.g., depression) can present prior to seizure onset, further elucidating the shared neurobiological pathways (Kanner et al., 2012). Thus, YWE require a comprehensive and interdisciplinary approach to their care (Guilfoyle et al., 2017). Provider awareness of common comorbidities, risk factors, and treatments in pediatric epilepsy may improve HRQOL in this vulnerable population.

Psychological Comorbidities

Neurodevelopmental Disorders

Definitions and prevalence. Neurodevelopmental disorders include intellectual disability, learning disorders, and developmental delays, such as autism spectrum disorders (ASD). YWE have a substantially increased risk for intellectual disabilities and learning disorders compared to healthy children (Leonard & George, 1999). Intellectual disability has been estimated to affect 40% of YWE (Reilly et al., 2014). The prevalence of learning disorders in pediatric epilepsy is also quite high (Russ et al., 2012). One study noted that 23% of YWE between 4 and 15 years of age had learning disabilities despite normative IQ, with 19% having reading disorders, 18% writing disorders, and 15% math disorders (Sillanpaa, 1992). Furthermore, 10% of all YWE have repeated a grade, 30% endorsed school problems, and 75% received special education services such as a Section 504 Plan or Individualized Educational Plan (Russ et al., 2012). Developmental milestones not met within a normative time frame (i.e., developmental delays) are also common in YWE, with approximately 50% demonstrating a delay in one or more domains (e.g., cognitive, motor, language) (Russ et al., 2012). ASD occur in 15–30% of YWE (Clarke et al., 2005; Russ et al., 2012; Tuchman, Alessandri, & Cuccaro, 2010).

Evidence-based assessment. Neurodevelopmental assessment is best accomplished by an interdisciplinary team, which may consist of developmental pediatricians, neuropsychologists or clinical psychologists, speech-language pathologists, occupational therapists, physical therapists, and education specialists, depending on presenting concerns. This is especially important in the diagnosis of ASD, since multiple disorders can masquerade as autism (e.g., intellectual disability, language disorder, selective mutism, severe inattention). Assessment typically combines a detailed clinical interview, child-focused comprehensive testing, including intelligence and achievement-based tests, and standardized parent and child questionnaires. Neuropsychological testing can be particularly useful in identifying cognitive strengths and weaknesses in children with brain-based disorders, and is more comprehensive than what is typically accomplished through school-based testing.

Risk factors. Researchers have hypothesized that epilepsy and neurodevelopmental disorders may share some common pathophysiological mechanisms that explain their high co-occurrence; however, further research is needed to elucidate these hypotheses, including the role of gene mutations (Brooks-Kayal, 2010). The co-occurrence of epilepsy and neurodevelopmental disorders is often associated with intellectual disability, particularly when seizures occur in the first year of life (Saemundsen, Ludvigsson, Hilmarsdottir, & Rafnsson, 2007). Seizure frequency and multiple seizure types are risk factors for learning disorders (Seidenberg et al., 1986). Earlier seizure onset (Fastenau, Jianzhao, Dunn, & Austin, 2008), generalized non-absence seizures (Fastenau et al., 2008), and symptomatic epilepsies (Giovagnoli & Avanzini, 1999) are also associated with learning disorders. The area of seizure involvement may play a differential role in learning disorders (Butterbaugh et al., 2004). For example, youth with temporal lobe epilepsy in the left hemisphere may have more verbal deficits given that region's involvement in language and communication (Janecek et al., 2013). The presence of mood disorders (Beghi, Cornaggia, Frigeni, & Beghi, 2006) and Attention-Deficit Hyperactivity Disorder (ADHD) (Fastenau et al., 2008) are also associated with increased risk for learning disorders in YWE. No evidence exists that specific AEDs impact the development of learning disorders; however, AED side effects may affect processing speed and word retrieval (Hessen, Lossius, Reinvang, & Gjerstad, 2006; Lagae, 2006).

Evidence-based treatment. Early identification and intensive intervention are essential for neurodevelopmental disorders. YWE and neurodevelopmental disorders may qualify for several academic services. For example, state funded early intervention programs provide therapies (e.g., speech, occupational, physical, and behavioral) to youth 0–3 years of age who are at risk for neurodevelopmental disorders. The Individuals with Disabilities Education Improvement Act requires that public schools provide appropriate education supports when a child has a disability (Department of Education, 2010), starting with preschool. An Individualized Education Plan and/or 504 Plan should be developed that specifies the exact support the student will receive. Common 504 Plan accommodations for youth with comorbid epilepsy and neurodevelopmental disorders include preferential seating, increased one-on-one or small group instruction, behavioral intervention and monitoring, extended time for tests or homework, organizational supports, and presentation of information in multiple formats (e.g., written, verbal). Regarding developmental disorders, studies have demonstrated that early (Tuchman et al., 2010), structured, intensive individualized treatment programs are the most effective (Howlin, 2008). These interventions are primarily psychosocial in nature and can include applied behavioral analysis, occupational therapy, physical therapy, speech and language therapy, vision therapy, and developmental interventions (Seida et al., 2009). Medications, including AEDs (Tuchman et al., 2010), can also be used to treat the myriad of behavioral or emotional symptoms associated with neurodevelopmental disorders. However, there are no evidence-based pharmacological treatments with demonstrated efficacy for social and language impairments.

Internalizing Disorders

Definitions and prevalence. Internalizing disorders, including depression and anxiety, are highly prevalent in pediatric epilepsy, even when compared to children with other chronic conditions (Moreira et al., 2013). Internalizing symptoms are associated with increased healthcare utilization in pediatric epilepsy (Puka, Smith, Moineddin, Snead, & Widjaja, 2016). Depression occurs in 21–26% of YWE, and symptoms include persistent irritable mood, anger, academic decline, sleep and appetite disruptions, and tearfulness without reason (Plioplys, 2003). Psychomotor agitation, regressive behaviors (e.g., separation anxiety), vegetative symptoms (e.g., lethargy), and somatic complaints (e.g., stomachaches) are also common (McCauley, Carlson, & Calderon, 1991; Weller, Weller, Rowan, & Svadjian, 2000). Anhedonia, hypersomnia, weight fluctuations, and substance abuse are more common in older youth (Birmaher et al., 2004). In 2008, the Food and Drug Administration (U.S. Food and Drug Administration, 2008) identified a potential link between suicidal behavior and AEDs. Rates of suicidal ideation within pediatric epilepsy are 14–27% (Guilfoyle, Monahan, Wesolowski, & Modi, 2015; Wagner, Ferguson, & Smith, 2012), with risk increasing when a psychiatric disorder is present (Jones, Siddarth, Gurbani, Shields, & Caplan, 2013).

Recent pediatric epilepsy studies have detected high rates of anxiety (5–47%) (Alwash, Hussein, & Matloub, 2000; Berg, Caplan, & Hesdorffer, 2011; Schraegle & Titus, 2017a) which has a negative impact on HRQOL (Beyenburg, Mitchell, Schmidt, Elger, & Reuber, 2005; Plioplys, 2003). The prevalence of anxiety subtypes are variable: obsessive-compulsive disorder (11%), specific phobia (8%), social phobia (8%), and separation anxiety (2%) (Jones et al., 2007). Anxiety about having seizures may present as different forms of anxiety, such as concern about having a seizure in public (social phobia), fear of being away from parents in case of seizure (separation anxiety), or general worries about health and safety (generalized anxiety) (Ekinci, Titus, Rodopman, Berkem, & Trevathan, 2009; Newsom-Davis, Goldstein, & Fitzpatrick, 1998). Seizure-related anxiety may lead to avoidance of typically expected activities, such as skipping field trips, co-sleeping, or staying near a caregiver all the time. YWE who have comorbid anxiety may overestimate risks and underestimate their ability to manage life-threatening or stressful situations because of potential seizure activity. They may also excessively limit activities and impede age-appropriate autonomy, which is of particular importance for YWE who gain independence at a slower rate than healthy peers (Brna, Gordon, Woolridge, Dooley, & Wood, 2017).

Risk factors. Numerous factors have been inconsistently associated with increased risk for anxiety and depression in youth with epilepsy (Ekinci et al., 2009). Older age is a risk factor for symptoms of depression and anxiety in YWE (Guilfoyle et al., 2015; Oguz, Kurul, & Dirik, 2002). Depression and anxiety are equally common in males and females (Ettinger et al., 1998; Oguz et al., 2002; Williams et al., 2003). Family history of depression (Thome-Souza et al., 2004), temporal lobe epilepsy (Salpekar et al., 2013; Schraegle & Titus, 2017b; Titus, Kanive, Sanders, & Blackburn, 2008), seizure recurrence (Austin et al., 2002), age of seizure onset (Sabbagh, Soria, Escolano, Bulteau, & Dellatolas, 2006), AEDs (Guilfoyle et al., 2015), and duration of epilepsy are associated with depression, but further investigation is warranted (Austin et al., 2001; Barry et al., 2008; Caplan et al., 2005; Dunn, Austin, & Huster, 1997; Plioplys, Dunn, & Caplan, 2007; Thome-Souza et al., 2004). Seizure frequency (Alwash et al., 2000; Oguz et al., 2002), learning deficits (Caplan et al., 2005; Williams et al., 2003), and AED polytherapy (Fujikawa et al., 2015; Oguz et al., 2002; Schraegle & Titus, 2017a) are risk factors for anxiety. However, the link between AED polytherapy and anxiety in pediatric epilepsy may be secondary to seizure intractability (Ekinci et al., 2009). Notably, internalizing symptoms maintain even after seizure control is improved (Gatta et al., 2017). Recent research suggests a brain-based shared pathogenic mechanism between anxiety (Garcia-Ramos et al., 2016), and depression (Kanner et al., 2012) in epilepsy. Seizure type (Ettinger et al., 1998; Williams et al., 2003) and cultural/socioeconomic factors require further investigation as anxiety risk factors.

Evidence-based assessment. Screening for internalizing disorders is strongly recommended in pediatric epilepsy (Kwong et al., 2016). Although difficult to implement in clinic settings, systematic screening can improve HRQOL and decrease symptoms of depression (Guilfoyle et al., 2015). While screening can be as simple as inquiring about symptoms of anxiety or depression during the clinical encounter, ideally, disease-specific measures are used to identify depression and anxiety in pediatric epilepsy, which may help to capture a greater range of symptoms in the context of developmental norms. The Neurological Disorders Depression Inventory for Epilepsy-Youth has been validated within pediatric epilepsy (Wagner, Kellermann, et al., 2016). There are no epilepsy-specific assessment tools for anxiety. Broader screening tools, particularly self-reporting versions, may offer utility to assess depression and anxiety within pediatric epilepsy (see Table 7.1). The Childhood Depression Inventory-2nd edition (Kovacs, 2010a) is a good screening instrument for assessing depressive symptoms. The Revised Children's Manifest Anxiety Scale-2nd edition (Reynolds & Richmond, 2008) and Multidimensional Anxiety Scale for Children-2nd edition (MASC2) (March, 2013) can be used for anxiety screening. Broadband psychological instruments (e.g., Behavior Assessment System

Table 7.1 Commonly used screening measures for comorbidities

Measures	Respondent/ number of	Age range	Time to complete in minutes
Broadband Emotional and Behavioral functioning			
Behavior Assessment Schedule for Children: 3rd edition (Reynolds & Kamphaus, 2015)	*Parent:* 139–175 *Self:* 137–189	2–21 years old 8–21 years old	10–20 30
Vanderbilt ADHD Diagnostic Parent and Teacher Rating Scale (Wolraich et al., 2003, 2011)	*Parent:* 55 *Teacher:* 43	2–18 years old	10
Pediatric Symptom Checklist (Jellinek et al., 1988)	*Parent:* Short form: 17 Long form: 35	4–18 years old	5–10
Attention-Deficit Hyperactivity Disorder			
Vanderbilt ADHD Diagnostic Parent and Teacher Rating Scale (Wolraich et al., 2003, 2011)	*Parent:* 55 *Teacher:* 43	5–18 years old	10
Depression			
Children's Depression Inventory: 2nd edition (Kovacs, 2010a, 2010b)	*Parent:* 17 *Self:* Long form: 28 *Self:* Short form: 12	7–17 years old	5 <5
Neurological Disorders Depression Inventory for Epilepsy-Youth (Wagner, Smith, Ferguson, & Fedele, 2013)	*Self:* 11	10–17 years old	5
Anxiety			
Revised Children's Manifest Anxiety Scale (Reynolds & Richmond, 1978)	*Self:* 37	6–19 years old	10–15
Multidimensional Anxiety Scale for Children-2nd Edition (March, 2013)	*Parent:* 50 *Self:* 50	8–19 years old	15
Health-related quality of life			
Pediatric Quality of Life-Epilepsy Module (Modi et al., 2017)	*Parent* : 22–29 *Self:* 28–29	2–25 years old 5–25 years old	7–8
Quality of Life in Epilepsy-Adolescents (Cramer et al., 1999)	*Self:* 48	11–18 years old	15
Quality of Life in Childhood Epilepsy (Sabaz et al., 2003)	*Parent:* 77	4–18 years old	20

Note: All measures described are recommended to screen for psychological symptoms but cannot be used to make a formal diagnosis. Further assessment is typically required by trained professionals, including neuro/clinical psychologists and/or primary care providers.

for Children; BASC-3) (Reynolds & Kamphaus, 2015) are also viable options to assess internalizing symptoms; however, a full clinical assessment is typically necessary for diagnosis.

Evidence-based treatment. The most efficacious interventions for both moderate to severe depression and anxiety include a combination of pharmacotherapy (e.g., selective serotonin reuptake inhibitors) and cognitive-behavioral treatment to reduce symptom frequency and impairment (Jones, Blocher, Jackson, Sung, & Fujikawa, 2014). Cognitive-behavioral treatments aim to teach children behavioral activation, self-monitoring, behavioral relaxation, problem-solving skills, and techniques to challenge maladaptive or unrealistic thoughts or beliefs (Jones, 2014). Selective serotonin reuptake inhibitors have been deemed efficacious and safe for treatment of depression in YWE (Thome-Souza, Kuczynski, & Valente, 2007). No studies have examined the efficacy and safety of these medications for anxiety in pediatric epilepsy. When mild depressive or anxiety symptoms are present, cognitive-behavioral treatment is often the first line of treatment. One computer-assisted cognitive-behavioral treatment for 8–13-year-olds with epilepsy and internalizing symptoms resulted in a significant reduction in anxiety and depressive symptoms as well as behavior problems (Blocher, Fujikawa, Sung, Jackson, & Jones, 2013). The 12-week program used a combination of computer-based skills training and therapist guided skill application and exposures to teach cognitive behavioral therapy (CBT) principles including relaxation, emotion identification, cognitive modification, problem-solving, exposure, and reinforcement. Reductions in emotional and behavioral symptoms were maintained at the 3-month follow-up. There is evidence that clinic-based integrated behavioral medicine services are an effective method of delivering evidence-based care (Guilfoyle et al., 2015) and preferable compared to outpatient referral models that require additional hospital visits, which can be challenging for families (Wagner, Ferguson, Kellermann, Smith, & Brooks, 2016).

Externalizing Disorders

Definitions and prevalence. Externalizing disorders, including ADHD, oppositional defiant disorder (ODD), and conduct disorder, impact approximately 1/3 of YWE (Jones et al., 2007; Russ et al., 2012) and are strong predictors of HRQOL (Brunklaus, Dorris, & Zuberi, 2011). Rates of ADHD are 33% in pediatric epilepsy (Reilly et al., 2014) compared to 3–6% in the general population (Socanski, Aurlien, Herigstad, Thomsen, & Larsen, 2013) and are equally prevalent in males and females (Cohen et al., 2013; Jones et al., 2007) compared to the general population exhibiting higher rates in males. Notably, inattention and distractibility can be difficult to differentiate from seizures (Salpekar & Mishra, 2014), with absence seizures in particular being mistaken for, or confused with, inattention or daydreaming. Thus, a careful assessment of symptom onset and seizure semiology is needed. The prevalence rates of ODD and conduct disorder in pediatric epilepsy are 13–16% (Jones et al., 2007; Russ et al., 2012).

Evidence-based assessment. The Vanderbilt ADHD Diagnostic Parent and Teacher Rating Scales (Subcommittee on Attention-Deficit/Hyperactivity Disorder & Management, 2011; Wolraich et al., 2003) are the hallmark measures for ADHD assessment (see Table 7.1). The Vanderbilt also has a subscale to assess ODD. The Vanderbilt is commonly used in pediatric primary care practices (Langberg, Froehlich, Loren, Martin, & Epstein, 2008) and can be used during epilepsy clinic visits to assess diagnostic criteria, track externalizing symptoms over time, and evaluate response to treatment. Broadband psychological instruments, such as the BASC-3, are viable options to assess externalizing symptoms and may be particularly helpful prior to AED initiation (Guilfoyle, Wagner, Smith, & Modi, 2012) to help distinguish premorbid behavioral symptoms (Jones et al., 2007) and AED side effects to enhance clinical decision making.

Risk factors. Seizure frequency and AED side effects are risk factors for externalizing symptoms after epilepsy onset (Goldberg & Burdick, 2001; Kanemura, Sano, Sugita, & Aihara, 2013; Tovia et al., 2011). For youth with benign childhood epilepsy with centrotemporal spikes, febrile convulsions, male gender, high index spike on sleep-deprived EEG, and frequent seizures have been documented as risk factors for ADHD (Kim, Yum, Kim, & Ko, 2014). Links between AEDs and behavior are variable. Some AEDs may exacerbate inattention and comprehension difficulties in YWE (Goldberg & Burdick, 2001), whereas others are associated with a decrease in ADHD symptoms (Kanemura et al., 2013) subsequent to AED initiation and improved seizure control. When considering seizure localization, youth with temporal lobe epilepsy have worse behavioral disruptions than youth with frontal lobe epilepsy (Andresen et al., 2014). Although the above data indicate a link between epilepsy-related factors (i.e., seizure frequency, AEDs, seizure localization) and externalizing symptoms, recent studies have not supported these associations (Reilly et al., 2014; Salpekar et al., 2013; Socanski et al., 2013).

Evidence-based treatment. Evidence-based treatment for ADHD includes a combination of neurostimulant medication and parent-based behavioral treatment. Recent data suggest that neurostimulant medications are well tolerated and effective for comorbid ADHD and epilepsy (Fosi, Lax-Pericall, Scott, Neville, & Aylett, 2013; Salpekar & Mishra, 2014). However, behavioral treatment is an effective first step if neurostimulant medications are not preferred (Pelham & Fabiano, 2008). Evidence-based treatment for ODD includes parent-based behavioral treatment targeting behavioral principles and contingency management, age-appropriate supervision, and problem-solving skills (Eyberg, Nelson, & Boggs, 2008). School-based accommodations, including behavioral strategies to optimize attention, compliance, organization, and task completion, can be developed in collaboration with schools.

Interdisciplinary Epilepsy Care

Expert consensus statements recommend routine psychosocial screening for YWE (Barry et al., 2008). An interdisciplinary, team-based approach to care can include epileptologists, specialist nurse practitioners, nurses, psychologists, pharmacists, psychiatrists, social workers, and medical assistants. The holistic approach to interdisciplinary care acknowledges the unique expertise of all disciplines that are critical to optimal epilepsy care. Given the high prevalence of psychological comorbidities, integrated pediatric psychologists can conduct routine psychosocial screening to monitor cognitive, emotional, and behavioral symptoms and provide clinical recommendations that are complementary to their epilepsy care. When cognitive, emotional, or behavioral difficulties are identified, pediatric psychologists can offer brief cognitive and behavioral treatment and recommendations that address subclinical symptoms and, thus, reduce the need for behavioral medicine referrals outside of routine epilepsy care (Guilfoyle et al., 2015; Guilfoyle, Follansbee-Junger, & Modi, 2013), which often leads to lack of follow-up (Wagner, Ferguson, et al., 2016). This type of interdisciplinary model has the potential to decrease healthcare utilization and medical costs (Ryan et al., 2015, 2016).

Despite recommendations of integrating behavioral medicine services into epilepsy care, only 20–30% of YWE receive behavioral medicine services (Caplan et al., 2005; Wagner, Ferguson, et al., 2016). This disconnect between ideal practice and patient access is related in part to lack of service availability/accessibility and/or lack of knowledge about, or stigma of, behavioral medicine services and mental health conditions. Integrating pediatric psychologists into routine epilepsy care offers a novel opportunity to demystify behavioral health services and increase patient access to clinically warranted services that can optimize epilepsy management and improve HRQOL.

In addition to working with families and medical providers, psychosocial providers (e.g., psychologists, social workers) can also help families manage epilepsy and comorbidities in community settings, such as at school. This may include facilitating school-based accommodations (i.e., Section 504 plan, Individualized Education Plans) to address developmental and learning disorders, or referrals to other community-based resources (e.g., Department of Developmental Disabilities, Epilepsy Foundation) for advocacy, support, and information. Pediatric psychologists can also support families and schools in maximizing each child's autonomy (e.g., attending field trips, participating in extracurricular activities, maximizing time in school). Although interdisciplinary care is optimal, many epilepsy providers do not have access to behavioral medicine specialists nor the time to use screening instruments. Thus, identification of local behavioral medicine providers is critical.

Case Study: An Example of Interdisciplinary Epilepsy Care

Juan, a 5-year-old Hispanic male with new-onset epilepsy, provides an exemplar of interdisciplinary teamwork, including epilepsy medical specialists, behavioral medicine, pharmacy, and social work. Juan was recently diagnosed with new-onset epilepsy and prescribed a liquid AED. At this diagnosis visit, the BASC-3 was completed by the father to ascertain psychological functioning prior to AED initiation, which revealed subclinical aggression and hyperactivity symptoms. Approximately one month later, he was seen for his initial epilepsy follow-up visit where his father reported continued seizures, increased aggression and low frustration tolerance following AED initiation, and concern that Juan is not gaining academic skills at the same rate as peers.

Discussion during the visit included recognition of his premorbid behavioral concerns, but father expressed that his premorbid behavioral difficulties worsened with the start of the AED. However, father also acknowledged that he has had difficulty understanding whether his son's aggression and hyperactivity were different from other boys, along with expressing wariness to discipline for fear of provoking seizures. Juan also has taste aversion to the liquid AED and often resisted his father's request to take the AED; his father sometimes acquiesced leading to missed AED doses. After the epilepsy provider, pharmacist, and psychologist discussed Juan's presenting concerns, comprehensive recommendations were made. Specifically, the pediatric psychologist (1) provided education about the links between behavior, learning, and epilepsy and its treatment, (2) provided cognitive and behavioral recommendations to target AED adherence, behavioral compliance, and emotion regulation, (3) emphasized the importance of maintaining health habits, such as adequate sleep, and (4) initiated a neuropsychology referral for assessment of possible ADHD and learning needs. The psychologist then engaged the social worker to liaison with school to develop preliminary learning accommodations. At the subsequent visit, Juan had improved seizure control, reduced AED behavioral side effects, and a 504 plan in place to address hyperactivity and learning needs at school.

Conclusions and Future Directions

YWE are at increased risk for psychosocial comorbidities, which when present, are associated with poorer HRQOL, poorer disease management, increased morbidity and mortality, and increased healthcare utilization. Psychosocial providers are ideally trained to intervene with this vulnerable population given their expertise in typical and atypical child development, treatment of a wide range of childhood disorders, understanding of the biopsychosocial model, and competence working within the medical system with chronically ill youth. In recognition of the need to consider psychosocial functioning as part of epilepsy care, the ILAE updated practice guidelines in 2011 to include psychosocial assessment of YWE (Kerr et al., 2011). Despite this, YWE remain underserved regarding psychosocial care. Ideally, an interdisciplinary model including pediatric psychologists at point of care would offer comprehensive treatment to optimize HRQOL by targeting both the medical and psychosocial aspects of the disease concurrently while at the same time reducing access barriers to behavioral health professionals and stigma surrounding mental health. When interdisciplinary models are not feasible, neurological provider knowledge about comorbidities, referral streams, and evidence-based treatment can help to connect families to appropriate care outside of the neurology clinic setting. Providing families with education on the benefits of psychosocial care, specific information about how to identify providers (e.g., call insurance company, ask pediatrician), brainstorming a range of options that take into consideration access issues (e.g., community, school-based options, co-located services), initiating referrals during office visits, and sending a letter back to the pediatrician outlining recommendations may be ways to encourage better follow-up with psychosocial care.

References

Alwash, R. H., Hussein, M. J., & Matloub, F. F. (2000). Symptoms of anxiety and depression among adolescents with seizures in Irbid, Northern Jordan. *Seizure, 9*, 412–416.

Andresen, E. N., Ramirez, M. J., Kim, K. H., Dorfman, A. B., Haut, J. S., Klaas, P. A., … Busch, R. M. (2014). Effects of surgical side and site on mood and behavior outcome in children with pharmacoresistant epilepsy. *Frontiers in Neurology, 5*, 18.

Austin, J. K., Dunn, D. W., Caffrey, H. M., Perkins, S. M., Harezlak, J., & Rose, D. F. (2002). Recurrent seizures and behavior problems in children with first recognized seizures: A prospective study. *Epilepsia, 43*, 1564–1573.

Austin, J. K., Harezlak, J., Dunn, D. W., Huster, G. A., Rose, D. F., & Ambrosius, W. T. (2001). Behavior problems in children before first recognized seizures. *Pediatrics, 107*, 115–122.

Austin, J. K., Perkins, S. M., Johnson, C. S., Fastenau, P. S., Byars, A. W., deGrauw, T. J., & Dunn, D. W. (2011). Behavior problems in children at time of first recognized seizure and changes over the following 3 years. *Epilepsy and Behavior, 21*, 373–381.

Baca, C. B., Vickrey, B. G., Caplan, R., Vassar, S. D., & Berg, A. T. (2011). Psychiatric and medical comorbidity and quality of life outcomes in childhood-onset epilepsy. *Pediatrics, 128*, e1532–e1543.

Barry, J. J., Ettinger, A. B., Friel, P., Gilliam, F. G., Harden, C. L., Hermann, B. P., … Jones, J. (2008). Consensus statement: The evaluation and treatment of people with epilepsy and affective disorders. *Epilepsy and Behavior, 13*, S1–S29.

Beghi, M., Cornaggia, C. M., Frigeni, B., & Beghi, E. (2006). Learning disorders in epilepsy. *Epilepsia, 47*, 14–18.

Berg, A. T., Berkovic, S. F., Brodie, M. J., Buchhalter, J., Cross, J. H., van Emde Boas, W., … Scheffer, I. E. (2010). Revised terminology and concepts for organization of seizures and epilepsies: Report of the ILAE Commission on Classification and Terminology, 2005-2009. *Epilepsia, 51*, 676–685.

Berg, A. T., Caplan, R., & Hesdorffer, D. C. (2011). Psychiatric and neurodevelopmental disorders in childhood-onset epilepsy. *Epilepsy and Behavior, 20*, 550–555.

Beyenburg, S., Mitchell, A. J., Schmidt, D., Elger, C. E., & Reuber, M. (2005). Anxiety in patients with epilepsy: Systematic review and suggestions for clinical management. *Epilepsy and Behavior, 7*, 161–171.

Birmaher, B., Williamson, D. E., Dahl, R. E., Axelson, D. A., Kaufman, J., Dorn, L. D., & Ryan, N. D. (2004). Clinical presentation and course of depression in youth: Does onset in childhood differ from onset in adolescence? *Journal of the American Academy of Child and Adolescent Psychiatry, 43*, 63–70.

Blocher, J. B., Fujikawa, M., Sung, C., Jackson, D. C., & Jones, J. E. (2013). Computer-assisted cognitive behavioral therapy for children with epilepsy and anxiety: A pilot study. *Epilepsy and Behavior, 27*, 70–76.

Brna, P. M., Gordon, K. E., Woolridge, E., Dooley, J. M., & Wood, E. (2017). Perceived need for restrictions on activity for children with epilepsy. *Epilepsy and Behavior, 73*, 236–239.

Brooks-Kayal, A. (2010). Epilepsy and autism spectrum disorders: Are there common developmental mechanisms? *Brain Development, 32*, 731–738.

Brunklaus, A., Dorris, L., & Zuberi, S. M. (2011). Comorbidities and predictors of health-related quality of life in Dravet syndrome. *Epilepsia, 52*, 1476–1482.

Butterbaugh, G., Olejniczak, P., Roques, B., Costa, R., Rose, M., Fisch, B., … Skinner, J. (2004). Lateralization of temporal lobe epilepsy and learning disabilities, as defined by disability-related civil rights law. *Epilepsia, 45*, 963–970.

Caplan, R., Siddarth, P., Gurbani, S., Hanson, R., Sankar, R., & Shields, W. D. (2005). Depression and anxiety disorders in pediatric epilepsy. *Epilepsia, 46*(5), 720–730.

Clarke, D. F., Roberts, W., Daraksan, M., Dupuis, A., McCabe, J., Wood, H., … Weiss, S. K. (2005). The prevalence of autistic spectrum disorder in children surveyed in a tertiary care epilepsy clinic. *Epilepsia, 46*, 1970–1977.

Cohen, R., Senecky, Y., Shuper, A., Inbar, D., Chodick, G., Shalev, V., & Raz, R. (2013). Prevalence of epilepsy and attention-deficit hyperactivity (ADHD) disorder: A population-based study. *Journal of Child Neurology, 28*, 120–123.

Cramer, J. A., Westbrook, L. E., Devinsky, O., Perrine, K., Glassman, M. B., & Camfield, C. (1999). Development of the quality of life in epilepsy inventory for adolescents: The QOLIE-AD-48. *Epilepsia, 40*, 1114–1121.

Department of Education. (2010). *Building the legacy: IDEA 2004*. Retrieved January 28, 2011, from http://idea.ed.gov/.

Dunn, D. W., Austin, J. K., & Huster, G. A. (1997). Behaviour problems in children with new-onset epilepsy. *Seizure, 6*, 283–287.

Ekinci, O., Titus, J. B., Rodopman, A. A., Berkem, M., & Trevathan, E. (2009). Depression and anxiety in children and adolescents with epilepsy: Prevalence, risk factors, and treatment. *Epilepsy and Behavior, 14*, 8–18.

Ettinger, A. B., Weisbrot, D. M., Nolan, E. E., Gadow, K. D., Vitale, S. A., Andriola, M. R., … Hermann, B. P. (1998). Symptoms of depression and anxiety in pediatric epilepsy patients. *Epilepsia, 39*, 595–599.

Eyberg, S. M., Nelson, M. M., & Boggs, S. R. (2008). Evidence-based psychosocial treatments for children and adolescents with disruptive behavior. *Journal* *of Clinical Child and Adolescent Psychology, 37*, 215–237.

Fastenau, P. S., Jianzhao, S., Dunn, D. W., & Austin, J. K. (2008). Academic underachievement among children with epilepsy: Proportion exceeding psychometric criteria for learning disability and associated risk factors. *Journal of Learning Disabilities, 41*(3), 195–207.

Ferro, M. A. (2014). Risk factors for health-related quality of life in children with epilepsy: A meta-analysis. *Epilepsia, 55*, 1722–1731.

Ferro, M. A., Camfield, C. S., Levin, S. D., Smith, M. L., Wiebe, S., Zou, G., & Speechley, K. N. (2013). Trajectories of health-related quality of life in children with epilepsy: A cohort study. *Epilepsia, 54*, 1889–1897.

Fosi, T., Lax-Pericall, M. T., Scott, R. C., Neville, B. G., & Aylett, S. E. (2013). Methylphenidate treatment of attention deficit hyperactivity disorder in young people with learning disability and difficult-to-treat epilepsy: Evidence of clinical benefit. *Epilepsia, 54*, 2071–2081.

Fujikawa, M., Kishimoto, Y., Kakisaka, Y., Jin, K., Kato, K., Iwasaki, M., & Nakasato, N. (2015). Obsessive-compulsive behavior induced by levetiracetam. *Journal of Child Neurology, 30*, 942–944.

Garcia-Ramos, C., Lin, J. J., Bonilha, L., Jones, J. E., Jackson, D. C., Prabhakaran, V., & Hermann, B. P. (2016). Disruptions in cortico-subcortical covariance networks associated with anxiety in new-onset childhood epilepsy. *NeuroImage: Clinical, 12*, 815–824.

Gatta, M., Raffagnato, A., Mannarini, S., Balottin, L., Toldo, I., Vecchi, M., & Boniver, C. (2017). Pediatric epilepsy and psychiatric comorbidity: Preliminary observational data from a prospective study. Minerva Pediatrica.

Giovagnoli, A. R., & Avanzini, G. (1999). Learning and memory impairment in patients with temporal lobe epilepsy: Relation to the presence, type, and location of brain lesion. *Epilepsia, 40*, 904–911.

Glasgow, R. E., Goldstein, M. G., Ockene, J. K., & Pronk, N. P. (2004). Translating what we have learned into practice. Principles and hypotheses for interventions addressing multiple behaviors in primary care. *American Journal of Preventative Medicine, 27*, 88–101.

Glauser, T. A. (2004a). Behavioral and psychiatric adverse events associated with antiepileptic drugs commonly used in pediatric patients. *Journal of Child Neurology, 19*, S25–S38.

Glauser, T. A. (2004b). Effects of antiepileptic medications on psychiatric and behavioral comorbidities in children and adolescents with epilepsy. *Epilepsy and Behavior, 5*, S25–S32.

Goldberg, J. F., & Burdick, K. E. (2001). Cognitive side effects of anticonvulsants. *Journal of Clinical Psychiatry, 62*, 27–33.

Guilfoyle, S. M., Follansbee-Junger, K., & Modi, A. C. (2013). Development and preliminary implementation of a psychosocial service into standard medical care for pediatric epilepsy. *Clinical Practice in Pediatric Psychology, 1*, 276–288.

Guilfoyle, S. M., Follansbee-Junger, K., Smith, A. W., Combs, A., Ollier, S., Hater, B., & Modi, A. C. (2018). Antiepileptic drug behavioral side effects and baseline hyperactivity in children and adolescents with new-onset epilepsy. *Epilepsia., 59*, 146–154.

Guilfoyle, S. M., Monahan, S., Wesolowski, C., & Modi, A. C. (2015). Depression screening in pediatric epilepsy: Evidence for the benefit of a behavioral medicine service in early detection. *Epilepsy and Behavior, 44*, 5–10.

Guilfoyle, S. M., Wagner, J. L., Modi, A. C., Junger, K. F., Barrett, L. E., Riisen, A. C., … Weyand, C. (2017). Pediatric epilepsy and behavioral health: The state of the literature and directions for evidence-based interprofessional care, training, and research. *Clinical Practice in Pediatric Psychology, 5*, 79–90.

Guilfoyle, S. M., Wagner, J. L., Smith, G., & Modi, A. C. (2012). Early screening and identification of psychological comorbidities in pediatric epilepsy is necessary. *Epilepsy and Behavior, 25*, 495–500.

Hessen, E., Lossius, M. I., Reinvang, I., & Gjerstad, L. (2006). Influence of major antiepileptic drugs on attention, reaction time, and speed of information processing: Results from a randomized, double-blind, placebo-controlled withdrawal study of seizure-free epilepsy patients receiving monotherapy. *Epilepsia, 47*, 2038–2045.

Holland, K. D., & Glauser, T. A. (2007). Response to carbamazepine in children with newly diagnosed partial onset epilepsy. *Neurology, 69*, 596–599.

Holland, K. D., Monahan, S., Morita, D., Vartzelis, G., & Glauser, T. A. (2010). Valproate in children with newly diagnosed idiopathic generalized epilepsy. *Acta Neurologica Scandinavica, 121*(3), 149–153.

Howlin, P. (2008). Identifying effective interventions for young children with autism spectrum disorders. *Journal of Intellectual Disability Research, 52*, 817.

Janecek, J. K., Winstanley, F. S., Sabsevitz, D. S., Raghavan, M., Mueller, W., Binder, J. R., & Swanson, S. J. (2013). Naming outcome after left or right temporal lobectomy in patients with bilateral language representation by Wada testing. *Epilepsy and Behavior, 28*, 95–98.

Jellinek, M. S., Murphy, J. M., Robinson, J., Feins, A., Lamb, S., & Fenton, T. (1988). Pediatric Symptom Checklist: Screening school-age children for psychosocial dysfunction. *Journal of Pediatrics, 112*, 201–209.

Jensen, F. E. (2011). Epilepsy as a spectrum disorder: Implications from novel clinical and basic neuroscience. *Epilepsia, 52*, 1–6.

Jones, J. E. (2014). Treating anxiety disorders in children and adolescents with epilepsy: What do we know? *Epilepsy and Behavior, 39*, 137–142.

Jones, J. E., Blocher, J. B., Jackson, D. C., Sung, C., & Fujikawa, M. (2014). Social anxiety and self-concept in children with epilepsy: A pilot intervention study. *Seizure, 23*, 780–785.

Jones, J. E., Siddarth, P., Gurbani, S., Shields, W. D., & Caplan, R. (2013). Screening for suicidal ideation in children with epilepsy. *Epilepsy and Behavior, 29*, 521–526.

Jones, J. E., Watson, R., Sheth, R., Caplan, R., Koehn, M., Seidenberg, M., & Hermann, B. P. (2007). Psychiatric comorbidity in children with new onset epilepsy. *Developmental Medicine and Child Neurology, 49*(7), 493–497.

Kanemura, H., Sano, F., Sugita, K., & Aihara, M. (2013). Effects of levetiracetam on seizure frequency and neuropsychological impairments in children with refractory epilepsy with secondary bilateral synchrony. *Seizure, 22*, 43–47.

Kanner, A. M. (2017). Psychiatric comorbidities in new onset epilepsy: Should they be always investigated? *Seizure, 49*, 79–82.

Kanner, A. M., Schachter, S. C., Barry, J. J., Hesdorffer, D. C., Mula, M., Trimble, M., … LaFrance, W. C., Jr. (2012). Depression and epilepsy: Epidemiologic and neurobiologic perspectives that may explain their high comorbid occurrence. *Epilepsy and Behavior, 24*, 156–168.

Kerr, M. P., Mensah, S., Besag, F., de Toffol, B., Ettinger, A., Kanemoto, K., … Wilson, S. J. (2011). International consensus clinical practice statements for the treatment of neuropsychiatric conditions associated with epilepsy. *Epilepsia, 52*, 2133–2138.

Kim, E. H., Yum, M. S., Kim, H. W., & Ko, T. S. (2014). Attention-deficit/hyperactivity disorder and attention impairment in children with benign childhood epilepsy with centrotemporal spikes. *Epilepsy and Behavior, 37*, 54–58.

Kovacs, M. (2010a). *The children's depression inventory 2 (CDI 2) manual*. North Tonawanda, NY: Multi-Health Systems.

Kovacs, M. (2010b). *The children's depression inventory 2 (CDI 2): Self-report (short) version (CDI 2:SR[S])*. North Tonawanda, NY: Multi-Health Systems.

Kwong, K. L., Lam, D., Tsui, S., Ngan, M., Tsang, B., Lai, T. S., & Lam, S. M. (2016). Anxiety and depression in adolescents with epilepsy. *Journal of Child Neurology, 31*, 203–210.

Lagae, L. (2006). Cognitive side effects of anti-epileptic drugs. The relevance in childhood epilepsy. *Seizure, 15*(4), 235–241. https://doi.org/10.1016/j.seizure.2006.02.013

Langberg, J. M., Froehlich, T. E., Loren, R. E., Martin, J. E., & Epstein, J. N. (2008). Assessing children with ADHD in primary care settings. *Expert Review of Neurotherapeutics, 8*, 627–641.

Leonard, E. L., & George, M. R. (1999). Psychosocial and neuropsychological function in children with epilepsy. *Pediatric Rehabilitation, 3*, 73–80.

Loiselle, K. A., Ramsey, R. R., Rausch, J. R., & Modi, A. C. (2016). Trajectories of health-related quality of life among children with newly diagnosed epilepsy. *Journal of Pediatric Psychology, 41*, 1011–1021.

March, J. S. (2013). *Multidimensional Anxiety Scale for Children 2nd Edition (MASC 2)*. North Tonawanda, NY: Multi-Health Systems Inc.

McCauley, E., Carlson, G. A., & Calderon, R. (1991). The role of somatic complaints in the diagnosis of depression in children and adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry, 30*, 631–635.

Modi, A. C., Junger, K. F., Mara, C. A., Kellermann, T., Barrett, L., Wagner, J., … Varni, J. W. (2017). Validation of the PedsQL Epilepsy Module: A pediatric epilepsy-specific health-related quality of life measure. *Epilepsia, 58*(11), 1920–1930.

Moreira, H., Carona, C., Silva, N., Frontini, R., Bullinger, M., & Canavarro, M. C. (2013). Psychological and quality of life outcomes in pediatric populations: A parent-child perspective. *Journal of Pediatrics, 163*, 1471–1478.

Morita, D. A., Glauser, T. A., & Modi, A. C. (2012). Development and validation of the pediatric epilepsy side effects questionnaire. *Neurology, 79*, 1252–1258.

Nakken, K. O., Solaas, M. H., Kjeldsen, M. J., Friis, M. L., Pellock, J. M., & Corey, L. A. (2009). The occurrence and characteristics of auras in a large epilepsy cohort. *Acta Neurologica Scandinavica, 119*, 88–93.

Newsom-Davis, I., Goldstein, L. H., & Fitzpatrick, D. (1998). Fear of seizures: An investigation and treatment. *Seizure, 7*, 101–106.

Oguz, A., Kurul, S., & Dirik, E. (2002). Relationship of epilepsy-related factors to anxiety and depression scores in epileptic children. *Journal of Child Neurology, 17*, 37–40.

Ott, D., Caplan, R., Guthrie, D., Siddarth, P., Komo, S., Shields, W. D., … Chayasirisobhon, S. (2001). Measures of psychopathology in children with complex partial seizures and primary generalized epilepsy with absence. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*(8), 907–914.

Ott, D., Siddarth, P., Gurbani, S., Koh, S., Tournay, A., Shields, W. D., & Caplan, R. (2003). Behavioral disorders in pediatric epilepsy: Unmet psychiatric need. *Epilepsia, 44*, 591–597.

Pelham, W. E., Jr., & Fabiano, G. A. (2008). Evidence-based psychosocial treatments for attention-deficit/hyperactivity disorder. *Journal of Clinical Child and Adolescent Psychology, 37*, 184–214.

Pellock, J. M. (2004). Defining the problem: Psychiatric and behavioral comorbidity in children and adolescents with epilepsy. *Epilepsy and Behavior, 5*, 3–9.

Plioplys, S. (2003). Depression in children and adolescents with epilepsy. *Epilepsy and Behavior, 4*, S39–S45.

Plioplys, S., Dunn, D. W., & Caplan, R. (2007). 10-year research update review: Psychiatric problems in children with epilepsy. *Journal of the American Academy of Child and Adolescent Psychiatry, 46*, 1389–1402.

Puka, K., Smith, M. L., Moineddin, R., Snead, O. C., & Widjaja, E. (2016). Health resource utilization varies by comorbidities in children with epilepsy. *Epilepsy and Behavior, 57*, 151–154.

Ramsey, R. R., Loiselle, K., Rausch, J. R., Harrison, J., & Modi, A. C. (2016). Predictors of trajectories of epilepsy-specific quality of life among children newly diagnosed with epilepsy. *Epilepsy and Behavior, 57*, 202–210.

Reilly, C., Atkinson, P., Das, K. B., Chin, R. F., Aylett, S. E., Burch, V., … Neville, B. G. (2014). Neurobehavioral comorbidities in children with active epilepsy: A population-based study. *Pediatrics, 133*, e1586–e1593.

Reynolds, C. R., & Kamphaus, R. W. (2015). *Behavior assessment system for children: Third edition*. Bloomington, MN: Pearson.

Reynolds, C. R., & Richmond, B. O. (1978). What I think and feel: A revised measure of children's manifest anxiety. *Journal of Abnormal Child Psychology, 6*, 271–280.

Reynolds, C. R., & Richmond, B. O. (2008). *Revised Children's Manifest Anxiety Scale: Second edition*. Torrance: Western Psychological Services.

Russ, S. A., Larson, K., & Halfon, N. (2012). A national profile of childhood epilepsy and seizure disorder. *Pediatrics, 129*, 256–264.

Ryan, J. L., McGrady, M. E., Guilfoyle, S. M., Follansbee-Junger, K., Peugh, J. L., Loiselle, K. A., … Modi, A. C. (2016). Quality of life changes and health care charges among youth with epilepsy. *Journal of Pediatric Psychology, 41*, 888–897.

Ryan, J. L., McGrady, M. E., Guilfoyle, S. M., Junger, K., Arnett, A. D., & Modi, A. C. (2015). Health care charges for youth with newly diagnosed epilepsy. *Neurology, 85*, 490–497.

Sabaz, M., Lawson, J. A., Cairns, D. R., Duchowny, M. S., Resnick, T. J., Dean, P. M., & Bye, A. M. (2003). Validation of the quality of life in childhood epilepsy questionnaire in American epilepsy patients. *Epilepsy and Behavior, 4*, 680–691.

Sabbagh, S. E., Soria, C., Escolano, S., Bulteau, C., & Dellatolas, G. (2006). Impact of epilepsy characteristics and behavioral problems on school placement in children. *Epilepsy and Behavior, 9*, 573–578.

Saemundsen, E., Ludvigsson, P., Hilmarsdottir, I., & Rafnsson, V. (2007). Autism spectrum disorders in children with seizures in the first year of life—A population-based study. *Epilepsia, 48*, 1724–1730.

Salpekar, J. A., Berl, M. M., Havens, K., Cushner-Weinstein, S., Conry, J. A., Pearl, P. L., … Gaillard, W. D. (2013). Psychiatric symptoms in children prior to epilepsy surgery differ according to suspected seizure focus. *Epilepsia, 54*, 1074–1082.

Salpekar, J. A., & Dunn, D. W. (2007). Psychiatric and psychosocial consequences of pediatric epilepsy. *Seminars in Pediatric Neurology, 14*, 181–188.

Salpekar, J. A., & Mishra, G. (2014). Key issues in addressing the comorbidity of attention deficit hyperactivity disorder and pediatric epilepsy. *Epilepsy and Behavior, 37*, 310–315.

Schraegle, W. A., & Titus, J. B. (2017a). The influence of endophenotypic, disease-specific, and environmental variables on the expression of anxiety in pediatric epilepsy. *Epilepsy and Behavior, 75*, 90–96.

Schraegle, W. A., & Titus, J. B. (2017b). The relationship of seizure focus with depression, anxiety, and health-related quality of life in children and adolescents with epilepsy. *Epilepsy and Behavior, 68*, 115–122.

Seida, J. K., Ospina, M. B., Karkhaneh, M., Hartling, L., Smith, V., & Clark, B. (2009). Systematic reviews of psychosocial interventions for autism: An umbrella review. *Developmental Medicine and Child Neurology, 51*, 95–104.

Seidenberg, M., Beck, N., Geisser, M., Giordani, B., Sackellares, J. C., Berent, S., … Boll, T. J. (1986). Academic achievement of children with epilepsy. *Epilepsia, 27*, 753–759.

Sillanpaa, M. (1992). Epilepsy in children: Prevalence, disability, and handicap. *Epilepsia, 33*, 444–449.

Smith, G., Wagner, J. L., & Edwards, J. C. (2015a). CE: epilepsy update, part 1: Refining our understanding of a complex disease. *American Journal of Nursing, 115*, 40–47.

Smith, G., Wagner, J. L., & Edwards, J. C. (2015b). CE: Epilepsy update, part 2: Nursing care and evidence-based treatment. *American Journal of Nursing, 115*, 34–44.

Socanski, D., Aurlien, D., Herigstad, A., Thomsen, P. H., & Larsen, T. K. (2013). Epilepsy in a large cohort of children diagnosed with attention deficit/hyperactivity disorders (ADHD). *Seizure, 22*, 651–655.

Subcommittee on Attention-Deficit/Hyperactivity Disorder, & Steering Committee on Quality Improvement, & Management. (2011). ADHD: Clinical practice guideline for the diagnosis, evaluation, and treatment of attention-deficit/hyperactivity disorder in children and adolescents. *Pediatrics, 128*, 1007–1022.

Thome-Souza, M. S., Kuczynski, E., & Valente, K. D. (2007). Sertraline and fluoxetine: Safe treatments for children and adolescents with epilepsy and depression. *Epilepsy and Behavior, 10*, 417–425.

Thome-Souza, S., Kuczynski, E., Assumpcao, F., Jr., Rzezak, P., Fuentes, D., Fiore, L., & Valente, K. D. (2004). Which factors may play a pivotal role on determining the type of psychiatric disorder in children and adolescents with epilepsy? *Epilepsy and Behavior, 5*, 988–994.

Titus, J. B., Kanive, R., Sanders, S. J., & Blackburn, L. B. (2008). Behavioral profiles of children with epilepsy: Parent and teacher reports of emotional, behavioral, and educational concerns on the BASC-2. *Psychology in the schools, 45*, 892–903.

Tovia, E., Goldberg-Stern, H., Ben Zeev, B., Heyman, E., Watemberg, N., Fattal-Valevski, A., & Kramer, U. (2011). The prevalence of atypical presentations and comorbidities of benign childhood epilepsy with centrotemporal spikes. *Epilepsia, 52*, 1483–1488.

Tuchman, R., Alessandri, M., & Cuccaro, M. (2010). Autism spectrum disorders and epilepsy: Moving towards a comprehensive approach to treatment. *Brain Development, 32*, 719–730.

U.S. Food and Drug Administration. (2008, August 15). *Information for healthcare professionals: Suicidal behavior and ideation and antiepileptic drugs*. Retrieved August 29, 2014, from http://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/ucm100192.htm.

Wagner, J. L., Ferguson, P. L., Kellermann, T., Smith, G., & Brooks, B. (2016). Behavioral health referrals in pediatric epilepsy. *Epilepsy Research, 127*, 72–77.

Wagner, J. L., Ferguson, P. L., & Smith, G. (2012). The relationship of coping behaviors to depressive symptoms in youth with epilepsy: An examination of caregiver and youth proxy report. *Epilepsy and Behavior, 24*, 86–92.

Wagner, J. L., Kellermann, T., Mueller, M., Smith, G., Brooks, B., Arnett, A., & Modi, A. C. (2016). Development and validation of the NDDI-E-Y: A screening tool for depressive symptoms in pediatric epilepsy. *Epilepsia, 57*, 1265–1270.

Wagner, J. L., Smith, G., Ferguson, P. L., & Fedele, D. A. (2013). Preliminary psychometrics of the neurological disorders depression inventory for epilepsy-youth. *Journal of Child Neurology, 28*, 1392–1399.

Wasterlain, C. G., & Chen, J. W. (2006). Definition and classification of status epilepticus. In C. G. Wasterlain & D. M. Treiman (Eds.), *Statsus epilepticus: Mechanisms and management* (pp. 11–16). Cambridge, MA: The MIT Press.

Weller, E. B., Weller, R. A., Rowan, A. B., & Svadjian, H. (2000). Depressive disorders in children and adolescents). In M. Lewis (Ed.), *Child and adolescent psychiatry: A comprehensive textbook* (pp. 767–781). Philadelphia, PA: Lippincott Williams & Wilkins Publishers.

Williams, J., Steel, C., Sharp, G. B., DelosReyes, E., Phillips, T., Bates, S., … Griebel, M. L. (2003). Anxiety in children with epilepsy. *Epilepsy and Behavior, 4*, 729–732.

Wolraich, M. L., Brown, L., Brown, R. T., DuPaul, G., Earls, M., Feldman, H. M., … Visser, S. (2011). ADHD: Clinical practice guideline for the diagnosis, evaluation, and treatment of attention-deficit/hyperactivity disorder in children and adolescents. *Pediatrics, 128*, 1007–1022.

Wolraich, M. L., Lambert, W., Doffing, M. A., Bickman, L., Simmons, T., & Worley, K. (2003). Psychometric properties of the Vanderbilt ADHD diagnostic parent rating scale in a referred population. *Journal of Pediatric Psychology, 28*, 559–567.

Zack, M. M., & Kobau, R. (2017). National and state estimates of the numbers of adults and children with active epilepsy—United States, 2015. *Morbidity and Mortality Weekly Report, 66*, 821–825.

8

Traumatic Brain Injury/Concussions

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Abstract

This chapter focuses on pediatric behavioral health issues associated with traumatic brain injuries (TBIs), including concussions. Children and adolescents who have sustained TBIs often experience significant and persistent cognitive, social, emotional, and behavioral consequences; these can be magnified if the children had pre-existing difficulties. In addition to describing how TBIs can affect children, the chapter emphasizes interdisciplinary collaboration and care coordination across systems, including the home, school, community, and healthcare settings.

Introduction

This chapter focuses on pediatric behavioral health issues associated with traumatic brain injuries (TBIs), including concussions. Children and adolescents who have sustained TBIs often experience significant and persistent cognitive, social, emotional, and behavioral consequences; these can be magnified if the children had pre-existing difficulties. In addition to describing how TBIs can affect children, the chapter emphasizes interdisciplinary collaboration and care coordination across systems, including the home, school, community, and healthcare settings.

Background

Definition

A traumatic brain injury (TBI) is a brain dysfunction caused by an external bump, blow, or jolt to the head. There are two common types of TBI: closed head injuries and penetrating head injuries, often called “open” head injuries. A closed head injury occurs when the impact of an object or a sudden jolt of the head causes the brain to knock against the skull. Strong blows to the head can lead to brain swelling and intracranial pressure, and they can permanently destroy delicate brain tissue and nerve cells (Brain Injury Association of America, 2017).

Etiology

Negative effects of a TBI can appear immediately after the injury, or they may manifest over time. *Primary injuries* result immediately from the initial trauma and may include axonal shearing, destruction of brain tissues, hemorrhaging, contusions, and the leaking of cerebrospinal fluid.

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Secondary injuries typically appear in the days or weeks after the initial trauma and may include swelling, restricted blood flow to the brain, blood clotting, fever, insufficient oxygen reaching the brain, increased intracranial pressure, loss of brain cells, and infection (Arake, Yokota, & Morita, 2017). The effects of secondary injuries often aggravate the effects of primary damage.

Prevalence

TBI is the leading cause of death and disability in children and young adults worldwide (Thurman, 2016). In the United States, an estimated 90 out of 100,000 people will be hospitalized as a result of a TBI each year (Faul & Coronado, 2015). Among those aged 0–19, approximately 62,000 children will require hospitalization as a result of motor vehicle crashes, falls, sport injuries, physical abuse, and other causes. About 1 in 550 of these youth will experience a TBI severe enough to result in long-term disability (Arroyos-Jurado, Paulsen, Ehly, & Max, 2006).

Student-athletes are particularly vulnerable to TBIs because of the nature of such contact sports as football, basketball, soccer, and wrestling. While many athletes—particularly those participating in contact sports—receive training at the start of each season on the symptoms, long-term risks, and prevention techniques for concussions, concussions continue to be under-reported (Cusimano et al., 2017). This makes it quite difficult to ascertain the true prevalence rates of TBI, particularly mild TBIs such as concussions. Factors contributing to this under-reporting include players' and coaches' motivation to win, group dynamics, parents' personal financial interest, and worry over future career prospects (Kroshus, Garnett, Hawrilenko, Baugh, & Calzo, 2015). Athletes who fail to report symptoms of a suspected concussion and who continue play are at risk for worsened symptoms and for potentially catastrophic neurologic consequences if another impact is sustained during this vulnerable period.

Specific prevalence rates are also difficult to determine due to inconsistency in reporting and differing definitions among the medical community (Brain Injury Association of American [BIAA], 2017). Although the Glasgow Coma Scale is commonly used, there is no universal system in place for determining when a head injury warrants a diagnosis of TBI, nor is there a definitive and universally accepted definition as to what constitutes a TBI. Further, symptoms can be difficult to recognize, and patients are more likely to visit an outpatient clinic or a doctor's office, where TBI prevalence is not reported, than visit a hospital for treatment.

Diagnosis

To diagnose a TBI, healthcare providers may use one or more tests that assess a person's physical injuries, brain and nerve functioning, and level of consciousness. TBI severity is generally described as *mild, moderate*, or *severe*. This classification is typically based on the Glasgow Coma Scale, a 15-point scale which measures a patient's ability to speak, ability to open eyes, and ability to move, along with reports and observations on the duration of loss of consciousness, post-traumatic amnesia, and brain imaging results. A mild TBI may (or may not) include a brief loss of consciousness or change in mental status. A moderate TBI may include loss of consciousness for up to 1 day or abnormal brain imaging results. A severe TBI generally includes an extended period of unconsciousness, abnormal imaging results, and memory loss following the injury (BIAA, 2017).

Neuroimaging is useful to determine the severity, location, and type of injury. Commonly used imaging techniques include computerized tomography (CT) scans that take X-rays from many angles to quickly find any bleeding in the brain, bruised brain tissue, or other damage; magnetic resonance imaging (MRI), which uses magnets and radio waves to produce more detailed images than CT scans; and intracranial pressure (ICP) monitoring to detect any swelling of the brain. While imaging is useful to detect issues related to moderate to severe TBIs, it is important to note that scans are generally unremarkable in mild TBI cases.

Concussions are a type of mild TBI. Although there has been a marked increase in scientific investigation of concussions in recent years, the diagnosis of a concussion remains primarily based on observable signs and reported symptoms rather than on a definitive medical test. However, such imaging can help rule out a more significant injury, including bleeding or swelling in the brain.

Educators and behavioral health providers are key recipients of diagnostic information from the medical community. School personnel do not "diagnose" medical issues, including TBIs; however, they do identify various disorders to determine whether students are eligible for special education services. The Individuals with Disabilities Education Act (IDEA) describes a TBI as "an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance" (IDEA, 2004). Public school-based evaluation teams determine whether students who have sustained TBIs meet this definition; if so, these students are eligible for an Individualized Education Plan (IEP). Thus, although a student may receive a TBI diagnosis from a medical provider, this diagnosis does not necessarily mean the student will be eligible for special education services. There must be impairment and an adverse effect on educational performance that is deemed significant enough to require special education services. Behavioral health providers, including clinical psychologists, social workers, and counselors, can often help bridge the gap between medical services and educational services, given their shared electronic medical records and their training in systems theory.

Physical Health Outcomes

Damage to different parts of the brain can result in variable outcomes and recovery trajectories. Children and adolescents with brain injuries may suffer from a range of physical problems that includes loss of consciousness, seizures, headaches, dizziness, nausea or vomiting, and fatigue. These symptoms are most common at the onset of the injury, but some physical symptoms—particularly headaches—can last throughout the recovery period.

Physical health issues experienced after a TBI are often associated with the part of the brain that was most affected by the injury. Reduced muscle strength (paresis or paralysis), and impairments in movement, balance, or coordination may be caused by damage to the *frontal lobe,* which is located at the front of the cerebral cortex, and is the area responsible for voluntary movement. Sensory deficits can also arise in children after a TBI. A child may become less or more sensitive to sensations, they may experience altered sensations, or they may be unable to synthesize sensations to identify their own location in space. This may be a result of damage to the *temporal lobe* or *parietal lobe*, responsible for the organization of sensory input. Another area of concern is located at the back of the brain; the *occipital lobe* is responsible for visual perception. Damage here may thus result in loss of visual capability and hallucinations. All of these physical and sensory issues can frustrate the child and can contribute to psychosocial difficulties.

Psychosocial Concomitants and Consequences

Similar to physical health issues, psychosocial issues post-TBI may be partially attributed to the part of the brain that was injured. Further, brain injuries can lead to situational variables that adversely affect a child's social and emotional well-being as well as his or her academic performance. For example, a student-athlete may no longer be able to play a sport that was the main source of her friendships, or an honors student may have missed a great deal of school and as a result need to drop his Advanced Placement courses, which also may lead to depression and social isolation.

Cognitive and Academic Issues

A brain injury can affect the way a person thinks, learns, and remembers. These include skills such as speed of thought, understanding, concentration, problem-solving, and use of language. For example, problems with memory—particularly short-term memory—are common after a brain injury; some children may have difficulty remembering new faces or names, what they have read, or what has been said to them (Daisley, Tams, & Kischka, 2008). New learning is often most affected, while previously learned skills may still be intact. Language loss, or *aphasia*, may affect receptive language, so a student with TBI may have difficulty processing what is said or read. Or a student's expressive language may be adversely affected, resulting in difficulty finding the right words to say or write, or both.

Frontal lobe damage is frequently associated with impaired executive functioning, which is the brain's self-management system. Issues with executive functioning, such as problem-solving and rational thinking, can lead to poor decision-making. Reduced ability in processing information results in difficulty organizing facts, particularly if there are also memory problems. Students with TBI can also quickly reach "information overload," which in turn can cause frustration and anger. Impaired reasoning may affect a person's ability to think logically, to understand rules, or to follow discussions. Further, impaired insight and empathy can cause difficulties in accurately perceiving and interpreting one's own and other people's behavior and feelings. Difficulties also arise with the ability to observe and reflect on one's own thoughts and actions (Daisley et al., 2008). Families and friends can find this particularly problematic because the survivors of brain injury may behave inappropriately—without being aware that there is anything wrong with their actions.

Emotional, Social, and Behavioral Difficulties

Emotional and behavioral changes, as well as changes in relationships, are frequent sources of difficulties and stress for individuals who have sustained TBIs. Parents and caregivers often report personality changes in their children after a TBI (Degeneffe, Chan, Dunlap, Man, & Sung, 2011). A child may be more (or less) outgoing, irritable, or active; there may be a loss of interest in activities the child enjoyed before the injury. Following a TBI, the injured person may be seen as short-tempered, quick to become angry or frustrated. He or she may seem less patient, intolerant of change, and verbally or physically aggressive. Another post-TBI difficulty is flat affect, which is a severe reduction in emotional expressiveness. The injured individual may also experience depression or anxiety. All of these symptoms may be associated with the physiological effects of the injury, but they may also reflect problems adjusting to cognitive, physical, or behavioral difficulties that arise as a result of the injury.

Individuals may also experience fear or anxiety in situations related to the TBI (e.g., playing with their sports team after a fall). Changes in their sense of self or their self-identity can also be a source of distress. If students who have suffered a brain injury are kept from finishing a sports season with the teams they were on, they might see this situation affect their friendships with their teammates, they may worry about their future endeavors regarding sports in high school or college, and they may experience drops in their self-confidence levels. With such concerns, students may feel isolated and withdrawn from what used to be a source of joy or excitement. The following typical scenario describes one such student's narrative:

> *Billy sustained a concussion during soccer practice. His doctors recommended that he sit the rest of the season out. Billy's mom noticed that he was not talking about friends as much and did not want to socialize . He had also lost interest in watching soccer games with his father, an event that he typically looked forward to each week. Billy confided in his mother that talking to his friends and watching soccer just made him sad that he had to sit the season out. He didn't know who he was without soccer.*

Problems with skills associated with effective interpersonal communication may also occur, including reciprocal interactions, use of appropriate eye contact, and awareness of and appropriate use of non-verbal communication skills (Daisley et al., 2008). Following a TBI, individuals may be less sensitive to social norms and to others' feelings. They may use inappropriate language or behave in a socially unaccepted way at home and in public. This might include demonstrating reduced self-control and increased impulsivity:

> *Sara sustained a TBI after accidentally driving her bike into a mailbox. She also broke her nose. When she went back to school, a few girls teased Sara about the bandage she had across her nose. Sara asked them to stop, but when they didn't, she felt furious. Sara was never bothered by teasing before, but this time, she had trouble controlling her anger. The next time one of the girls teased her, she pushed her down and burst into tears.*

An additional consequence of a child's TBI can be the profound grief that his or her family may be experiencing. While many of the medical issues discussed in this text relate to illnesses that worsen over time or to disabilities that become apparent over time, a TBI is an instantaneous event, resulting in a family's rapid introduction to medical and rehabilitative care. Because a TBI can result in a student's significant cognitive and personality change, parents may be grieving the loss of the child they once had, feeling guilty about the cause of the TBI, or experiencing panic over medical bills. As a result, parents may have difficulty taking the lead in the care process. Clearly, medical practitioners, behavioral health providers, and educators who are sensitive to this issue and who can guide parents toward appropriate solutions and services become essential sources of support.

Psychosocial Screening and Assessment and Evaluation

The optimal care of a child with TBI requires a multidisciplinary approach in each phase of management, beginning with evaluation. Because it is common to see uneven patterns of strengths and weaknesses, patterns that can change rapidly during recovery, medical and educational service providers are encouraged to open with a discussion of the child's strengths and skills when communicating assessment results to families. Such strengths can be critical in the eventual development of interventions and compensatory strategies.

Professionals involved in psychosocial assessment and evaluation are encouraged to gather input from the family, the medical community, behavioral health providers, and educators to gain a comprehensive picture of the child's functioning across settings and tasks. It is critical to gather data on the child's pre-injury cognitive, academic, social, emotional, and behavioral skills. For example, a student may have significant post-injury attention deficits, but evaluators cannot determine the gravity of this issue without knowing how well the student sustained attention to tasks before the TBI. The following assessment approaches are keys to such a comprehensive evaluation.

Observations should be conducted by multiple observers at different points in time and in various contexts, including school settings, social venues, and the natural home environment. Both systematic and semi-structured techniques are useful. Observers are encouraged to note both individual behaviors and interactions with family, teachers, peers, and the environments.

Interviews with parents, teachers, support staff, medical providers, and the affected individual can provide information about pre-injury academic, medical, and social functioning, health habits (i.e., sleep, diet, exercise), peer and sibling relationships, and such other relevant factors as pre-existing conditions and previous head injuries. Interviews can also provide a more detailed review of particular cognitive and emotional challenges. These interviews can be unstructured, semi-structured, or formal. For example, the *Vineland Adaptive Behavior Scales, Third edition* (Vineland-3) result in standard scores that allow for comparisons to typical same-age peers (Sparrow, Cicchetti, & Saulnier, 2016).

Checklists and rating scales also provide a means of evaluating social skills, adaptive behavior, and executive functioning. In TBI cases, these scales typically involve checking off whether or not a child exhibits a skill, behavior, or physical symptom, such as memory loss, brain fog, headaches, fatigue, or difficulty with receptive or expressive language (Gioia, Isquith, Schneider, & Vaughan, 2009). This information helps guide observations and interventions; checklists and rating scales also provide an efficient and cost-effective means of monitoring intervention efficacy.

Standardized, norm-referenced tests provide a systematic way to evaluate a child's skills and abilities in comparison to typical same-age peers. Such tests should be administered and interpreted with caution in TBI cases. Typically, standardized test scores are relatively stable; however, they often fluctuate in TBI cases due to recovery. Therefore, scores may not be reliable. Scores also may not be consistent with daily functioning. For example, a student may score relatively well on an IQ test because he or she is still able to demonstrate previously learned material, but that same student may have difficulty learning new material and focusing in the classroom after a TBI, resulting in poor grades and an increasing deficit in comparison to peers. Yet, despite these limitations, such tests can still help identify specific areas of impairment, as well as relative strengths.

Computer-based neurocognitive tests are often used with students who are at a higher risk of TBI, such as student-athletes. Such tests can establish a baseline level of functioning pre-injury (typically "pre-season"), which is then compared to post-injury functioning. Administered by trained clinicians familiar with principles of testing, these tests are administered on a computer or tablet. Advantages of computer-based neurocognitive testing include time efficiency, precise reaction time, and the ability to be easily modified to increase sensitivity to mild cognitive dysfunction (Gioia et al., 2009).

Functional behavior assessments (FBAs) help determine triggers and conditions that predict and maintain maladaptive behaviors, often referred to as *antecedents* and *consequences*. FBAs are typically used as the basis for behavior intervention plans. For example, Janie may regularly ask to go to the nurse's office during math class. While one might initially assume it is because she wants to escape a disliked academic subject, a closer evaluation of the situation might reveal that the classroom is very bright and noisy, with buzzing lights and a shrill teacher that exacerbate Janie's headaches. The educational team might use that information to modify her environment or to give Janie strategies for managing the triggers.

Assessments may be conducted in a medical setting as well as in a school setting. When a school-based evaluation is conducted, particularly for special education eligibility, it is essential that the evaluation team receive all relevant medical and neuropsychological assessment data. Neuropsychological assessments are often used to obtain information about cognitive capabilities. These tests are specialized evaluations of brain-behavior relationships, evaluating higher cognitive functioning as well as basic sensory-motor processes (Rabin, Barr, & Burton, 2005).

Information and recommendations from medical and neuropsychological reports can then be integrated into the school-based evaluation and intervention planning. Consulting with the original report's author provides practitioners with a better understanding of the contents of the report. Such collaborative consultation can also facilitate the development of an ongoing consultative relationship with the practitioner who conducted the medical and neuropsychological assessments that can be utilized as intervention planning teams move forward, creating a more holistic view of the student and his or her injury. After the initial evaluation, monitoring is necessary to ensure that interventions are having their desired outcomes. This monitoring could be as simple as using a rating scale for behaviors that the teachers and parents fill out periodically. It is important to track changes in both behavior and academics because, as previously mentioned, a student recovering from a TBI may have uneven patterns of strengths and weaknesses that can change rapidly throughout recovery. Depending on the result found through the progress monitoring, strategies should be adjusted accordingly.

Prevention and Intervention

Educational, behavioral health, and medical professionals can collaborate with parents to help prevent TBIs, to minimize adverse effects of TBIs, and to create intervention plans to improve functioning post-TBI. Education about the risks of TBI, as well as TBI signs and symptoms, can help ensure that children receive prompt medical treatment. For example, school professionals might train preschool parents in TBI recognition and response. Or, to increase overall awareness of TBI, they might develop or disseminate resources from such programs as the Centers for Disease Control and Prevention's Heads Up Program (CDC, 2017) and the National Injury Prevention Foundation's ThinkFirst Program (Gerhardstein, 2017).

Prevention

Education, protective equipment, changes in legislation to address risk factors, and collaboration among community members can all help minimize the risk of TBIs. Such preventative efforts might include the following:

- *Safe recreation*, including protective equipment, such as properly fitted helmets for biking, skating, skateboarding, skiing, and horseback riding; and training in concussion recognition and response for parents, athletes, and coaches.
- *Safe driving*, including protective equipment such as seatbelts, airbags, and properly installed car seats; and community-based initiatives, such as teen driver safety week and campaigns to raise awareness of the risks of driving while distracted or impaired.
- *Violence prevention*, including awareness initiatives for shaken baby syndrome and adolescent dating violence.
- *Community support*, including support for creation of safe living spaces that use such preventive measures as window guards to keep young children from falling out of open windows; and playground surfaces made of shock-absorbing material, such as hardwood mulch or sand.

Policy and Legislative Initiatives

Recently, many states, schools, sports leagues, and organizations have created policies or action plans related to concussion in youth and high school sports. Most address education of athletes, coaches, and parents on concussion signs and symptoms; removal from play of an athlete suspected of sustaining a concussion; and guidelines for return to play. While these policy efforts show promise, more research is needed to discern their effects (Coronado et al., 2015). Some organizations, such as the National Conference of State Legislatures, have created online maps to track and update laws about concussion in sports by state. When managing an athlete with concussion, a healthcare professional's management plan should cover both returning to school and returning to play; it should monitor both physical and cognitive activities, consider concussion history, and be individualized to the athlete.

Intervention

The intervention process for students who have sustained TBIs should begin before they even return to school, and it should begin with a collaborative meeting of relevant medical professionals, behavioral health providers, educators, parents, and—if possible—the students. Intervention outcomes and reintegration to home, school, work, and community for children with TBI are best achieved when family members and caregivers play a central role. These individuals are responsible not only for making decisions that affect the child's life and education, but also for providing long-term support (Kim & Colantonio, 2010). Family members and caregivers can be frightened, stressed, and overwhelmed by the magnitude of the medical situation, by changes in their child's functioning, and by the process of learning to care for a child with TBI. Effective education, training, and counseling require sensitivity to these emotions.

One promising intervention is an online problem-solving intervention for families of adolescents with traumatic brain injury (Wade et al., 2012). The ten online modules are self-guided, with the occasional aid of a therapist to facilitate the problem-solving process. This online problem-solving intervention is well received by parents and may contribute to improvements in parental problem-solving, depression, and distress. Such findings add to the growing literature supporting the efficacy of interventions for parents of children sustaining a TBI and are helpful to the collaborative team in facilitating recovery.

Return-to-school. When children with TBI return to school, their educational and emotional needs are often different. Their injuries and resulting difficulties happened suddenly and sometimes traumatically. Vital to classroom support is a thoughtful return-to-school process, including a discussion of environmental and instructional modifications, such as a shortened school day, frequent breaks, modified (or excused) assignments, testing and homework accommodations, technological support, frequent repetition, and small group instruction. Other supports may include those that help minimize extraneous auditory, visual, and physical stimulation, as well as those that provide social and emotional support. A consistent schedule, a trusted adult at school, and a supportive group of friends can be incredibly reassuring, particularly during the initial stages of return-to-school.

Rehabilitation. In addition to school-based services, students who have sustained TBIs may receive rehabilitation in a medical setting. Rehabilitation generally includes teaching of strategies to compensate for impaired or lost functions and for optimization of the use of abilities as they return. An interdisciplinary approach to rehabilitation is essential because many of the strategies can be supported and replicated in the school and home settings.

Formalized school supports. IDEA (2004) mandates that all public schools receive federal funding to locate, identify, and evaluate all children with disabilities, from birth through the age of 21, who are in need of special education services or early intervention. A student with a brain injury may qualify for an Individualized Education Program (IEP) under the TBI category in cases that involve a disability severe enough to interfere with educational performance to such an extent that special services are required. However, students with TBI are often misidentified as having a specific learning disability, emotional disturbance, or an intellectual disability (Ettel, Glang, Todis, & Davies, 2016). In other cases, students are not identified at all. In such situations, the school-based evaluation team may not have been informed that the student sustained a TBI (e.g., if the student was injured as a preschooler and begins to show difficulties only later in school) or they may not recognize the child's academic or behavior problems as related to a TBI. As a result, these students may not receive the type of educational help and support they need. Thus, it is essential that school-based evaluation teams understand the unique ways in which TBIs can manifest.

Not all students who sustain TBIs require or qualify for special education services. Many have mild or transient difficulties that can be supported in other ways. Some may receive a Section 504 plan, which ensures that students who have physical or mental impairments receive accommodations that will ensure their academic success and access to the learning environment. Others may be supported through a multi-tiered system of support (MTSS), a process of systematically documenting the performance of students as evidence of the need for additional services after making changes in classroom instruction (Burns, Jimerson, VanDerHeyden, & Deno, 2016). MTSS is beneficial for students with TBI because their skills and abilities may change quickly and MTSS involves interventions that increase or decrease in intensity based upon student need (Davies, 2016).

Behavioral and emotional intervention. Children with persistent difficulties may remember how they were before the brain injury, which can elicit emotional and social challenges (Rowlands, 2001). The child's family, friends, and teachers may also recall what the child was like before the injury and have trouble changing or adjusting their expectations of the child. Thus, some interventions may focus on behavioral and social-emotional support, including clinical counseling.

Behavioral interventions often focus on reinforcing appropriate behaviors; however, in the case of a TBI, the student may no longer have the appropriate behavior within his or her skill set. In such cases, re-teaching the skills (e.g., through direct instruction) may be required. To put the issue in a different context, if someone does not know how to solve a quadratic equation, reinforcers such as candy or free time will not help; it may, in fact, only further frustrate the student. Likewise, if someone does not know how to appropriately join a playground game, he or she must first be taught how to do so.

Language intervention. Language intervention for children with TBI takes into account the interconnection between cognition and communication. Language intervention varies, depending on the child's developmental level at the time of injury and the pattern of deficits that require intervention (American Speech-Language Hearing Association [ASHA], 2017). For younger children, intervention tends to emphasize following directions, phonological awareness, vocabulary development, and word fluency for early literacy skills. For older children and adolescents, the emphasis is often on inferencing, higher-level comprehension, narrative and discourse processes, and academic or vocational literacy (ASHA, 2017). Regardless of a student's age at injury, treatment goals might also address the appropriate use of social language in different contexts and under varying demands.

Social communication intervention for children and adolescents with TBI frequently focuses on training the child's communication partners. Social communication intervention helps children develop conversation skills, learn appropriate pragmatic language norms, and practice impulse control necessary for improved social interactions.

Speech problems resulting from TBI can include dysarthria, apraxia, phonation, resonance, respiration, articulation, and/or fluency disorders (ASHA, 2017). Intervention for speech problems may focus on the individual speech subsystems of respiration, phonation, articulation, and velopharyngeal function or, more globally, on overall speech intelligibility, using behavioral and instrumental treatments, prosthetics, compensatory strategies, augmentative and alternative communication, and/or environmental modifications.

Motor intervention. Occupational therapy helps children develop fine motor skills as well as other adaptive behaviors. This may include teaching such memory compensation techniques as the use of daily planners, technological devices, checklists, and cueing systems. Therapy assists in developing effective schedules and routines. Occupational therapists can recommend environmental adaptations to assist with physical, perceptual, and cognitive functioning and provide training and adaptation for activities of daily living, such as dressing, bathing, and grooming (Kim & Colantonio, 2010). Students who have sustained severe TBIs may also require physical therapy, which may involve a combination of exercise, task-specific training, patient and family education, and training with different types of equipment to help the patient improve (APTA, 2017). Therapy goals often include maintenance of alertness and following commands; muscle and joint flexibility that may be reduced after inactivity; the ability to move around in bed, to sit without support, and to stand up; balance and coordination; strength and energy; and a return to sports and fitness activities.

Pharmacological interventions. Medications may be used to treat symptoms of TBI and to lower some associated risks. These medications may include, but are not limited to analgesics for pain relief and pain management; anti-anxiety agents to lessen feelings of uncertainty, nervousness, and fear; antidepressants to treat symptoms of depression; antipsychotics to target psychotic symptoms of combativeness, hostility, hallucinations, and sleep disorders; or stimulants to increase levels of alertness and attention. While medications can provide relief for many individuals, they do not always provide the desired level of efficacy. Further, impaired self-awareness, which is a common effect of TBI, may cause a student with a TBI to be an unreliable reporter of how well the medication is working. Collaboration and communication between school personnel, pediatricians, psychiatrists, and families regarding dosage, side effects, and effectiveness are essential.

Implications for Interprofessional Care

A collaborative team model can facilitate coordinated, medically approved return-to-activity decisions (Jantz, Davies, & Bigler, 2014). The team will share observations of symptoms, conduct comprehensive assessment, create and implement interventions, and monitor progress. This proactive collaboration among the family, medical community, psychological/behavioral health community, rehabilitation specialists, outpatient therapists, the educational community, and the athletic community (if applicable) ensures that multiple people are watching and helping the student, and helps determine appropriate adjustments to the educational environment.

It is recommended that this "TBI team" have a leader, someone who serves as the primary point of contact for all team members. This point person conducts team meetings, coordinates communication among team members, and facilitates implementation of accommodations for the student. Parents are key providers and recipients of medical and academic information. They can provide professionals with important information regarding how their child's physical, cognitive, and social emotional functioning have changed as a result of TBI; they can also provide information on how well intervention strategies are working. Finally, the student should participate on the team to whatever degree possible; this participation may increase as recovery progresses. For example, the student might log symptoms to track progress, which can bolster a sense of control over recovery.

School personnel, including teachers, school psychologists, school counselors, school nurses, school-based therapists, and administrators, assess the student's levels of functioning, identify appropriate resources, and implement the provision of educational services. They also create academic adjustments and provide emotional support for the student and the family. Schools should keep close contact with the families of students with TBI to report any changes of symptoms on a day-to day-basis; this is particularly important for a student with TBI because of how rapidly recovery can progress. The role of medical personnel involved with the child's case is typically to provide records and supporting documentation that describe and define the nature of the student's TBI, as well as to provide recommendations for treatment and accommodations. Behavioral health providers can facilitate all of these tasks and serve as a crucial liaison among team members, including the family. The team's ongoing monitoring of symptoms and intervention efficacy is critical to ensure that strategies are intensified, changed, continued, or discontinued as needed.

Confidentiality

Any time there is sharing of sensitive information, professionals must be mindful about student privacy, considering how and why they are sharing information. Information about a student's health is protected by the Health Insurance Portability and Accountability Act of 1996 (HIPAA). A signed release is essential for the school to receive and discuss information related to a student's brain injury; it is recommended that the TBI team leader secure such consent as soon as a student's TBI is made known to the school.

In addition, information about a student's academic record is protected under the Family Educational Rights and Privacy Act of 1974 (FERPA). Staff members should be regularly reminded only to discuss information that is necessary to manage a student's situation; they should also carefully consider how sensitive information is being stored and shared. While electronic transmission is quick and easy, particularly for interprofessional coordination of care, it is not always secure.

Case Study

Emily was a smart and successful 14-year-old eighth grader. She had many friends, earned good grades, worked hard in school, and was involved in the drama club. A week before holiday break, Emily was in a car accident that resulted in a moderate traumatic brain injury. She was hospitalized for 3 days. Emily's doctors recommended that she stay home and rest until the beginning of the next semester. Emily was anxious, though, because she would not be present for her end-of-semester exams, and she worried about how that would affect her grades.

Emily's school nurse, Mr. Janning, was the school-based TBI team leader. He coordinated a brief meeting between Emily's mother, the principal, her core teachers, and the school psychologist to discuss how to help Emily finish the semester and transition back to school in January; Emily's physician participated in this meeting via secure video conference. Emily's teachers agreed to excuse her from final exams based on her semester grades and the work completed thus far. Emily's mother agreed to monitor Emily's symptoms, under the guidance of her physician, to ensure she was ready to resume full days of school in January. Because of the likelihood of a great deal of recovery and resolution of symptoms during the break, the team decided that Mr. Janning would meet with Emily when school resumed to help discern which school-based adjustments would be beneficial.

Emily no longer had severe symptoms when school resumed, but she complained of severe headaches, fatigue, and feeling mentally "foggy"; further, she often exhibited short-tempered behavior, which was uncharacteristic of her. Her mother reported that Emily had isolated herself from friends during the break, but she was unsure whether it was Emily's choice or because friends were not reaching out to her.

Mr. Janning completed a symptom inventory with Emily to help determine the intensity of her symptoms. This rating scale was administered on a weekly basis until her symptoms resolved substantially. With the assistance of the school psychologist, school-based adjustments were selected to help compensate for her symptoms. Emily was permitted rest periods in the clinic during non-core classes, she was given modified or reduced work in each class, and her teachers provided her with written instructions and guided notes. The school counselor assisted Emily with anger management and coping strategies, including how to talk with her friends about her TBI.

After several weeks, Emily experienced some persistent difficulties: she got headaches more frequently than she did before the injury, she took a long time to complete assignments, and she had difficulty with reading comprehension. However, with class and test accommodations, including additional time to complete work, chunking large assignments into smaller parts, and avoidance of high-pressure situations, she was able to maintain her high grade point average and to resume her normal activities. These accommodations were written into a Section 504 plan, which would continue at the high school the following year if needed.

Conclusions and Future Directions

New research continues to inform professionals about effective brain injury diagnosis, prevention, and treatment. Because of medical advances, many children who previously would not have survived their injuries now recover and return to school. Many such students return with significant disabilities. Others sustain mild TBIs and return to school "looking" fine, but struggle with invisible issues, such as memory problems, headaches, or anxiety. Effective response to students with TBIs of all severity levels requires thoughtful, collaborative interprofessional care.

In the future, more sensitive and advance neuroimaging techniques will likely help us better understand areas of damage and potential implications; the medical community can help educators interpret such information. Likewise, the educational community can share research-based academic interventions. Effective use of technology will likely be a key source of support for children and adolescents with TBI, particularly in remote rural communities.

As information on concussions continues to be at the forefront in popular media outlets, a cultural shift seems to be underway, one that encourages reporting of known and suspected concussions. Educational and medical professionals are encouraged to collaborate with athletic personnel to facilitate this perceptual shift from seeing concussions as a rite of passage to seeing them as what they are—brain injuries.

Professionals can collaborate with families to encourage children's self-advocacy and health literacy. Placed at the center of this team-based approach, the child can be a strong participant in conversations about his or her recovery and treatment. This, in turn, can help the child better understand TBI-related issues and make positive health decisions in the future.

References

American Physical Therapy Association (APTA). (2017). *Traumatic Brain Injury*. Retrieved November 9, 2017, from http://www.moveforwardpt.com/SymptomsConditionsDetail.aspx?cid=0ed75eb1-1d47-41a1-98da-795289c0c02a

American Speech-Language Hearing Association (ASHA). (2017). *Traumatic Brain Injury (TBI)*. Asha.org. Retrieved November 15, 2017, from https://www.asha.org/public/speech/disorders/TBI/

Arake, T., Yokota, H., & Morita, A. (2017). Pediatric traumatic brain injury: Characteristic features, diagnosis, and management. *Neurologia Medico-Chirurgica, 57*, 82–93.

Arroyos-Jurado, E., Paulsen, J. S., Ehly, S., & Max, J. E. (2006). Traumatic brain injury in children and adolescents: academic and intellectual outcomes following injury. *Exceptionality, 14*, 125–140.

Brain Injury Association of America. (2017). *About Brain Injury*. Retrieved November 9, 2017, from http://www.biausa.org/about-brain-injury.htm

Burns, M., Jimerson, S., VanDerHeyden, A., & Deno, S. (2016). Toward a unified response-to-intervention model: Multi-tiered systems of support. In S. Jimerson, M. Burns, & A. VanDerHeyden (Eds.), *Handbook of response to intervention*. Boston, MA: Springer.

Center for Disease Control (CDC). (2017). *Managing Return to Activities | HEADS UP | Center for Disease Control Injury Center*. Retrieved November 9, 2017, from https://www.cdc.gov/headsup/providers/return_to_activities.html

Coronado, V. G., Haileyesus, T., Cheng, T. A., Bell, J. M., Haarbauer-Krupa, J., Lionbarger, M. R., … Gilchrist, J. (2015). Trends in sports- and recreation-related traumatic brain injuries treated in US emergency departments: The National Electronic Injury Surveillance System-All Injury Program (NEISS-AIP) 2001-2012. *Journal of Head Trauma Rehabilitation, 30*, 185–197.

Cusimano, M., Topolovec-Vranic, J., Zhang, S., Mullen, S., Wong, M., & Ilie, G. (2017). Factors influencing the underreporting of concussion in sports. *Clinical Journal of Sport Medicine, 27*, 375–380.

Daisley, A., Tams, R., & Kischka, U. (2008). *Head injury: The facts*. Oxford: Oxford University Press.

Davies, S. C. (2016). School-based traumatic brain injury program and concussion management team. *Psychology in the Schools, 53*, 567–582.

Degeneffe, C. E., Chan, F., Dunlap, L., Man, D., & Sung, C. (2011). Development and validation of the caregiver empowerment scale: A resource for working with family caregivers of persons with traumatic brain injury. *Rehabilitation Psychology, 56*, 243–250.

Ettel, D., Glang, A. E., Todis, B., & Davies, S. C. (2016). Traumatic brain injury: Persistent misconceptions and knowledge gaps among educators. *Exceptionality Education International, 26*, 1–18.

Family Educational Rights and Privacy Act of 1974, 20 U.S.C. § 1232g.

Faul, M., & Coronado, V. G. (2015). Epidemiology of traumatic brain injury. *Handbook of Clinical Neurology, 127*, 3–13.

Gerhardstein, D. (2017). ThinkFirst: Primary prevention that makes a difference. *ThinkFirst Foundation*. Retrieved December 6, 2017, from http://thinkfirst.org/sites/default/files/About%20ThinkFirst.pdf

Gioia, G. A., Isquith, P. K., Schneider, J. C., & Vaughan, C. G. (2009). New approaches to assessment and monitoring of concussion in children. *Topics in Language Disorders, 29*, 266–281.

Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191.

Individuals with Disabilities Education Act of 2004, 20 U.S.C. §§ 1401 (2004).

Jantz, P. B., Davies, S. C., & Bigler, E. D. (2014). *Working with traumatic brain injury in schools: Transition, assessment, and intervention*. New York, NY: Routledge.

Kim, H., & Colantonio, A. (2010). Effectiveness of rehabilitation in enhancing community integration after acute traumatic brain injury: A systematic review. *American Journal of Occupational Therapy, 64*, 709–719.

Kroshus, E., Garnett, B., Hawrilenko, M., Baugh, C., & Calzo, J. (2015). Concussion under-reporting and pressure from coaches, teammates, fans, and parents. *Social Science & Medicine, 134*, 66–75.

Rabin, L., Barr, W., & Burton, L. (2005). Assessment practices of clinical neuropsychologists in the United States and Canada: A survey of INS, NAN, and APA division 40 members. *Archives of Clinical Neuropsychology, 20*, 33–65.

Rowlands, A. (2001). Ability or disability? Strengths-based practice in the area of traumatic brain injury. *Families in Society: The Journal of Contemporary Social Services, 82*, 273–286.

Sparrow, S. S., Cicchetti, D. V., & Saulnier, C. A. (2016). Vineland adaptive behavior scales (3rd ed. (Vineland—3)). Bloomington, MN: Pearson.

Thurman, D. J. (2016). The epidemiology of traumatic brain injury in children and youths; a review of research since 1990. *Journal of Child Neurology, 31*, 20–27.

Wade, S. L., Walz, N. C., Carey, J., McMullen, K. M., Cass, J., Mark, E., & Yeates, K. O. (2012). A randomized trial of teen online problem solving: Efficacy in improving caregiver outcomes after brain injury. *Health Psychology, 31*, 767–776.

9

Cancer

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Abstract

Five-year survival rates for children with cancer have increased dramatically since the 1970s, but cancer remains a traumatic experience for many children with cancer and their families. Moreover, many treatment options for children with cancer remain highly toxic, with lifelong medical and neurocognitive consequences. In addition to the child with cancer, parents and siblings also commonly report psychosocial distress related to cancer diagnosis and treatment. Psychosocial screening helps to identify areas of concern for children with cancer and their families, and psychosocial interventions provide critical support to help families navigate the many challenges associated with cancer diagnosis and treatment. Psychosocial cancer care must extend beyond diagnosis and treatment into survivorship and, when indicated, through death and bereavement. Interdisciplinary collaboration is essential when providing holistic cancer care, and multidisciplinary care teams often include individuals with medical and psychosocial backgrounds, as well as members of the community, such as teachers. Future directions for pediatric cancer care include the development of new medical treatments to improve outcomes and decrease adverse side effects, and a greater reliance on technology for the provision of psychosocial and follow-up care.

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Background

Over 15,000 children under age 19 are diagnosed with cancer each year in the United States (Siegel, Miller, & Jemal, 2017). Five-year survival rates in children with cancer increased dramatically from 58% in the mid-1970s to 83% in the early 2010s (Siegel et al., 2017). Due to these advances in treatment, there are over 400,000 survivors of childhood cancer in the United States (Howlader et al., 2017). However, treatment remains toxic and cancer remains the leading cause of death from disease in childhood (Siegel et al., 2017). Treatments may include combinations of chemotherapy, immunotherapy, radiation therapy, surgery, and stem cell transplantation and are tailored to the specific cancer type and stage. Duration of cancer therapy can last from several weeks to many years.

The types of cancer diagnosed in children vary by age. The most common cancers for children aged 0–14 years include leukemia (29%), brain and central nervous system cancers (26%), lymphomas (11%), soft tissue sarcomas (6%), neuroblastoma (6%), and kidney cancers (5%). Lymphomas (21%), brain and central nervous system tumors (17%), leukemias (14%), germ cell and gonadal tumors (12%), thyroid cancer (11%), and melanoma (5%) are most common in adolescents aged 15–19 years.

Direct toxic effects of chemotherapy occur in every organ system (Chavhan, Babyn, Nathan, & Kaste, 2016; Cordelli et al., 2017; Riachy et al., 2014; Thu Huynh & Bergeron, 2017). Short-term side effects typically resolve quickly and often include nausea, vomiting, hair loss, and increased susceptibility to infection. Radiation toxicity is dose and location dependent but includes fatigue, bone marrow suppression, and direct damage to surrounding tissue (Selo et al., 2010). Surgical treatment to remove a tumor results in postoperative pain and physical changes from scarring or amputation.

"Late effects" are long-term side effects that do not resolve after completion of therapy or may not appear until months or years later. Late effects vary based on age, type of cancer, type of treatment and may be physical, cognitive, or psychosocial. Potential late effects may impact every organ system (Bottomley & Kassner, 2003; Diller et al., 2009) and may include learning disabilities or other neurologic problems (Cheung et al., 2018), abnormal growth or development (Chow et al., 2007), hearing loss (Bass et al., 2016), cardiac dysfunction (Scholz-Kreisel et al., 2017), impaired fertility or reproductive health (Overbeek et al., 2017), and increased risk of secondary cancers (Neglia et al., 2001). Like chemotherapy, the late effects of radiation therapy depend on dose, location, and age of child (Ishida et al., 2010).

As the number of long-term cancer survivors increases, attention to late effects is critical. Because of this, the Children's Oncology Group created long-term follow-up guidelines for survivors of childhood cancer (http://www.survivorshipguidelines.org/) and recommends ongoing monitoring by someone familiar with pediatric oncology and late effects. Though the cause of most pediatric cancers is unknown, more than 5–10% of children with cancer may have a cancer predisposition syndrome such as LiFraumeni syndrome (Brodeur, Nichols, Plon, Schiffman, & Malkin, 2017). In addition to monitoring for relapse of disease and long-term side effects from initial cancer therapy, children with cancer predisposition syndromes often require additional screening measures. As therapies advance, efforts to decrease toxicity while increasing survival continue.

Psychosocial Concomitants and Consequences

Despite improvements in survival rates for children with cancer, the perceived life threat, physical toll, and logistical demands of treatment have psychosocial implications for the entire family. Qualitative research provides vivid accounts of families' experiences with pediatric cancer diagnosis, treatment, and survivorship, highlighting great uncertainty, feelings of chaos and helplessness, distress, physical and emotional pain, fatigue, and social isolation (e.g., Gibbins, Steinhardt, & Beinart, 2012; Hedstrom, Haglund, Skolin, & Von Essen, 2003; Wakefield, McLoone, Butow, Lenthen, & Cohn, 2011; Yang, Mu, Sheng, Chen, & Hung, 2016).

The experience often starts prior to diagnosis with concern and uncertainty regarding the child's sometimes vague or common symptoms, repeated medical appointments before cancer is suspected, and then invasive, painful and/or frightening diagnostic tests, usually in an unfamiliar medical setting. When a cancer diagnosis is made, the threat to the child's life becomes real and shock and devastation sets in. The intense treatment has many physical side effects, may disrupt school attendance, and requires changes in family roles and responsibilities (e.g., parental employment; household tasks) to accommodate frequent appointments and hospitalizations. Eventually, routines are established and most families adapt to their new situation; however, managing treatment is difficult for families to sustain and it is often punctuated with stressful events (e.g., invasive procedures, waiting for test results), emergencies, and other possible set-backs.

Once the cancer is eradicated and the treatment protocol completed, the end of treatment is often an ambivalent time—the joy of completing treatment and conquering the cancer is combined with fear that stopping treatment may result in relapse, that late effects may now emerge, and that these new challenges may arise without the safety net of the healthcare team. Finally, as the patient and family moves into survivorship, they need to establish a "new normal" and integrate the cancer experience into the continuing evolution of their family.

Given the stressful nature of the cancer experience, much attention has been paid to the psychosocial consequences for children with cancer and their family members. Some treatments that children with cancer receive (i.e., corticosteroids) are linked to side effects such as mood swings, irritability, depression, anxiety, and problems with behavior (Hochhauser, Lewis, Kamen, & Cole, 2005; Mrakotsky et al., 2011). Repeated, painful, invasive procedures often result in procedural distress (Shockey et al., 2013). Physical decline related to cancer, treatment side effects, and physical late effects leads to decrements in quality of life (Momani, Hathaway, & Mandrell, 2016). Absences from school and cognitive effects of treatment raise concerns about social functioning and long-term educational achievement (Lum et al., 2017; Pinquart & Tuebert, 2012). However, children with cancer and childhood cancer survivors are typically resilient; meta-analyses indicate that, on average, as a group, they score within normal ranges on standardized measures of emotional, social, and behavioral problems (e.g., Pinquart & Shen, 2011; Wechsler & Sánchez-Iglesias, 2013).

Still, there is a subset that experiences difficulties. Prospective studies reveal that the percentage of children with cancer experiencing at-risk/clinical levels of anxiety, depression symptoms, and poor quality of life is significantly elevated within one month following diagnosis (Furlong et al., 2012; Jorngarten, Mattsson, & von Essen, 2007; Marcoux, Robaey, Krajinovic, Moghrabi, & Laverdière, 2012; Mitchell et al., 2016; Myers et al., 2014; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). Generally, improvements are seen with time, but 20–30% continue to experience depressive symptoms and decrements in quality of life throughout treatment and into early survivorship (Kunin-Batson et al., 2016; Mitchell et al., 2016; Myers et al., 2014). After a decline to normative levels, there also seems to be an increase in anxiety after treatment ends (Ander et al., 2016; Kunin-Batson et al., 2016). This anxiety may persist or re-emerge for survivors during specific developmental stages or transitions (McDonnell et al., 2017). Cancer-related posttraumatic stress symptoms also occur in approximately 20% of children who have been diagnosed with cancer (Kazak et al., 2004; Bruce, 2006; Price, Kassam-Adams, Alderfer, Christofferson, & Kazak, 2016).

Childhood cancer is stressful for parents. They must take in complicated information, make difficult treatment decisions, ensure adherence, reorganize their lives to accommodate treatment among their other demands, and face financial burdens while fearing for the life of their child. As a group, parents of children with cancer demonstrate elevated scores on indices of anxiety, depression, and cancer-related traumatic stress around the time of diagnosis. Most are resilient and improve with time; however, it can take months or years before distress levels return to normal and a substantial subset is at-risk for marked, prolonged distress (Kearney, Salley, & Muriel, 2015). For example, estimates indicate that 40–83% of parents report significant traumatic stress near the time of diagnosis (Price et al., 2016) with 20–41% reporting these levels during and after treatment (Ljungman et al., 2014). Marital and family strains (e.g., conflict) are also common, but with time, most are resilient (Van Schoors, Caes, Alderfer, Goubert, & Verhofstadt, 2017; Van Schoors, Caes, Verhofstadt, Goubert, & Alderfer, 2015).

Siblings of children with cancer are also impacted by the cancer diagnosis and treatment (Alderfer et al., 2010; Gerhardt, Lehmann, Long, & Alderfer, 2015). Like children with cancer, on average, as a group, siblings score within norms on standardized measures of emotional, social, and behavioral problems; however, an important subset reports cancer-related traumatic stress (Kaplan, Kaal, Bradley, & Alderfer, 2013), anxiety, depression and poor quality of life (Gerhardt et al., 2015), poor academic functioning (Alderfer et al., 2015), various unmet needs related to social and emotional support, cancer-related information, and treatment involvement (O'Shea, Shea, Robert, & Cavanaugh, 2012; Patterson et al., 2014; Samson, Rourke, & Alderfer, 2016)

Standards for Psychosocial Care for Children with Cancer and Their Families

Psychosocial care has long been recognized as an important component of pediatric cancer care, and psychosocial staff have been important partners in providing clinical care and shaping research agendas in pediatric cancer for several decades (Kazak & Noll, 2015). However, research has described great variability between sites with regard to the provision of care (Selove, Kroll, Coppes, & Cheng, 2012). In order to develop a set of evidence-based standards for providing optimal psychosocial care for children with cancer and their families, the multidisciplinary Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) was initiated in 2012 (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). Supported by the Mattie Miracle Foundation (www.mattiemiracle.com), this workgroup conducted comprehensive literature reviews that supported 15 standards for psychosocial care that can be used to develop and evaluate psychosocial programs at pediatric cancer centers. Several of these standards focus on screening, assessment, and intervention in this population, which are discussed in more detail later in this chapter. Refer to Table 9.1 for a complete list of the psychosocial standards. These standards were published as a special issue of *Pediatric Blood & Cancer* in 2015 (http://onlinelibrary.wiley.com/doi/10.1002/pbc.v62.S5/issuetoc).

Psychosocial Screening and Assessment

When considering "core" psychosocial services that are often offered to children with cancer and their families, screening and assessment is important as it identifies patient and family needs and guides the provision of psychosocial care to the family. Data suggests that screening is most often provided via informal discussion, followed by the use of structured interviews and evidence-based assessment tools, such as the Psychosocial Assessment Tool (Pai et al., 2008) and Distress Thermometer (National Comprehensive Cancer Network, 2013; Scialla et al., 2017a). While many pediatric cancer centers report that screening and assessment of psychosocial need occurs at diagnosis, the majority of centers indicated that assessment occurs in response to an identified problem (Scialla et al., 2017a). This is potentially problematic, as identifying potential problems preemptively allows for faster and more effective provision of services. Additionally, a lack of systematic screening procedures allows some families with difficulties that could be remedied to "fall through the cracks."

Psychosocial and neurocognitive screening through survivorship is also critically important.

Table 9.1 Psychosocial standards of care for children with cancer and their families

Psychosocial standards
Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial healthcare needs
Patients with brain tumors and others at high risk for neuropsychological deficits as a result of cancer treatment should be monitored for neuropsychological deficits during and after treatment
Long-term survivors of child and adolescent cancers should receive yearly psychosocial screening for: (a) adverse educational and/or vocational progress, social and relationship difficulties; (b) distress, anxiety, and depression, and (c) risky health behaviors. Adolescent and young adult survivors and their parents should receive anticipatory guidance on the need for life-long follow-up care by the time treatment ends and repeated at each follow-up visit
Youth with cancer and their family members should have access to psychosocial support and interventions throughout the cancer trajectory and access to psychiatry as needed
Assessment of risk for financial hardship should be incorporated at time of diagnosis for all pediatric oncology families… Targeted referral for financial counseling and supportive resources (including both governmental and charitable supports) should be offered based on results of family assessment. Longitudinal reassessment and intervention should occur throughout the cancer treatment trajectory and into survivorship or bereavement
Parents and caregivers of children with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimize parent, child, and family well-being
Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation. Guidance should be tailored to the specific needs and preferences of individual patients and families and be provided throughout the trajectory of cancer care
Youth with cancer should receive developmentally appropriate preparatory information about invasive medical procedures. All youth should receive psychological interventions for these procedures
Children and adolescents with cancer should be provided opportunities for social interaction during cancer therapy and into survivorship following careful consideration of the patients' unique characteristics, including developmental level, preferences for social interaction, and health status
Siblings of children with cancer are a psychosocially at-risk group and should be provided with appropriate supportive services
In collaboration with parents, school-age youth diagnosed with cancer should receive school reentry support that focuses on providing information to school personnel about the patient's diagnosis, treatment, and implications for the school environment and provides recommendations to support the child's school experience
Adherence should be assessed routinely and monitored throughout treatment
Youth with cancer and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status. When necessary, youth and families should receive developmentally appropriate end of life care [which includes bereavement care after the child's death]
A member of the healthcare team should contact the family after a child's death to assess family needs, to identify those for negative psychosocial sequelae, to continue care, and to provide resources for bereavement support
Open, respectful communication and collaboration among medical and psychosocial providers, patients, and families is essential to effective patient- and family-centered care. Psychosocial professionals should be integrated into pediatric oncology care settings as integral team members and be participants in patient care rounds/meetings… Pediatric psychosocial providers must have specialized training and education and be credentialed in their discipline to provide developmentally appropriate assessment and treatment for children with cancer and their families. Experience working with children with serious, chronic illness is crucial as well as ongoing relevant supervision/peer support

Note: Adapted and abbreviated from Pediatric Blood & Cancer, Volume 62, Issue S5

Survivors of pediatric cancer are at high risk for a number of adverse educational, vocational, social, and psychosocial difficulties. In addition, survivors of pediatric cancer report levels of risky health behavior (e.g., heavy drinking, tobacco use) that are often similar to national norms, despite increased risk for adverse health outcomes such as secondary malignancies (Hudson et al., 2003; Lown, Phillips, Schwartz, Rosenberg, & Jones, 2015). Systematic psychosocial screening allows for the identification of problems and the provision of appropriate services. Abbreviated neurocognitive batteries have proven to be feasible (Pejnovic et al., 2012; Embrey et al., 2012) and useful in terms of identifying potential neurocognitive and neurobehavioral concerns early in treatment (Pejnovic et al., 2012) and into survivorship (Krull et al., 2008).

Psychosocial Intervention

Preventive interventions and evidence-based interventions are critical components of psychosocial care for children with cancer and their families, as these services help families cope with the significant stress associated with pediatric cancer. Moreover, some of these symptoms may persist long after the conclusion of cancer treatment, highlighting the need for appropriate support and intervention through treatment.

Interventions vary greatly between and among sites, depending on factors such as patient needs, staffing, and resources. Data suggests that pediatric cancer centers deliver psychosocial interventions via a range of different approaches, although many centers rely most commonly on informal discussion as opposed to evidence-based interventions. Many centers also report utilizing supportive psychotherapy and cognitive behavioral therapy (Scialla et al., 2017a). Problem-Solving Skills Training is a highly utilized intervention strategy with a strong evidence-base supporting its efficacy for mothers of newly diagnosed patients (Sahler et al., 2005, 2013). This intervention consists of eight 1-h intervention sessions that are focused on learning and practicing a structured approach to identifying and solving problems (Sahler et al., 2002). The treatment manual is available through the National Cancer Institute's Research-Tested Intervention Programs (RTIPs) website (Varni et al., 2002; https://rtips.cancer.gov/rtips/programDetails.do?programId=546012). The Surviving Cancer Competently Intervention Program (SCCIP) and Surviving Cancer Competently Intervention Program—Newly Diagnosed (SCCIP-ND) are additional research-based interventions which incorporate cognitive-behavioral skills and family systems therapy to help parents cope with pediatric cancer (Kazak et al., 1999, 2005). SCCIP is a group intervention, and SCCIP-ND utilizes a pre-recorded multifamily video discussion group as a proxy for a group session. Both interventions include cognitive-behavioral skills such as thought reframing.

Intervention services should follow the child and family beyond the cancer diagnosis and treatment, extending to include survivorship or bereavement care. While data suggests that there is great variability in terms of how and when this care is delivered, most pediatric cancer centers reported providing survivorship care via informal discussion as opposed to utilizing a standardized program or approach (Scialla et al., 2017a). The lack of formalized approaches to survivorship care is unfortunately not surprising, as data suggests that many childhood cancer survivors do not receive recommended cancer-related follow-up care as they transition to young adulthood (e.g., Szalda et al., 2016). Encouragingly, there is important work being done to develop and test models of care for successfully transitioning survivors of pediatric cancer into the adult healthcare sphere (e.g., the social-ecological model of adolescent and young adult readiness to transition; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). Several intervention programs are also available and in development to help improve modifiable health behaviors of adolescent and young adult cancer survivors given their increased risk for ongoing chronic health conditions (Kopp et al., 2016).

Despite recommendations to integrate palliative care into cancer treatment regardless of prognosis—for example, introducing palliative care early on to assist with medical decision making, symptom alleviation and provide pain management support—this is not a widespread practice in pediatric oncology care. Grounded in a comprehensive literature review, the psychosocial standard related to palliative care underscores the importance of early integration of palliative care concepts to reduce suffering and help with symptom management (Weaver et al., 2015). Recent work by Weaver et al. (2016) introduces a conceptual framework for moving towards standardized interventions in psychosocial pediatric palliative cancer care. This framework highlights five "quality care factors" (i.e., communication, symptom control, cognitive understanding, pragmatic needs, and maintaining relationships) as they relate to the patient, parent, family, and clinician. Additionally, and of critical importance, palliative care support should be tantamount when providing end of life and bereavement care to the child with cancer and his/her family (Lichtenthal et al., 2015; Weaver et al., 2015). Many bereaved family members are at-risk for long-lasting negative psychosocial outcomes following the death of a child from cancer, and indicate that continued contact with the healthcare team is desired (Lichtenthal et al., 2015). Despite this, data suggests that many centers send a card or letter following the death of a child, while only a small minority offer in person meetings or therapy (Scialla et al., 2017a). While it is likely challenging for staff to manage the needs of bereaved families in addition to the needs of current patients, this is an area of critical importance that should be included in comprehensive cancer care plans.

Implications for Interprofessional Care

In addition to the child with cancer and their family, there are a number of other individuals who are central to the treatment and adjustment of the family system after a cancer diagnosis (e.g., oncologists, social workers, teachers). As the healthcare landscape in the United States continues to shift and alternative models for service delivery and reimbursement are considered, the importance of interdisciplinary care becomes apparent. Interdisciplinary care, highlighted as an integral component of a changing healthcare system almost two decades ago (Institute of Medicine, 2001), utilizes a team-based approach where providers from different disciplines (e.g., oncology, psychology, social work, nutrition) collaborate to provide holistic care for patients. For children with cancer, these interdisciplinary teams are often comprised of a number of individuals from different psychosocial disciplines (e.g., social work, psychology, child life), although teams vary greatly across sites (Selove et al., 2012; Scialla et al., 2017b). Recent data suggests that the "typical" psychosocial team is comprised of two social workers, one psychologist, and two child life specialists (Scialla et al., 2017b). Work patterns also vary greatly between sites, with the level of integration between the medical and psychosocial team predicting perceptions of providing "state of the art" psychosocial care (Scialla et al., 2017a). These data highlight the importance of providing integrated, interprofessional care to children with cancer and their families.

In addition to interdisciplinary care within the hospital system, a systems-level approach to healthcare mandates the consideration of the life of the child and family outside of and beyond the cancer diagnosis. A thorough assessment of the other systems affecting the child and family allows the interdisciplinary team to better understand the family's needs and provide care that is consistent with these needs. Recent data from Scialla et al. (2017a) again highlights the wide range of methods used to understand and assess each family's unique background following the initial cancer diagnosis. For example, some centers reported relying on structured interviews or institution specific tools to evaluate family needs and identify areas where additional support would be useful. In contrast, many centers reported relying on informal discussion to evaluate the strengths and needs of a family following a cancer diagnosis. In order to facilitate and coordinate care within and between systems (e.g., hospital, school, community), as well as to ensure that all families are treated with the same level of care, standardized instruments and/or procedures are likely beneficial.

One particularly salient example of interprofessional care and collaboration for children with cancer involves the interface between the school and hospital system. School is often described as the most essential "job" of childhood, as this is the primary sphere where children learn and develop critical social skills. Data suggests that children with cancer miss many days of school during cancer treatment (Charlton et al., 1991) and into survivorship (French et al., 2013). This can contribute to social and emotional challenges, as children are often isolated from peers when they are not able to attend school consistently or participate fully in activities with peers. Moreover, while several models for school reentry programs exist (Harris, 2009; Power, DuPaul, Shapiro, & Kazak, 2003), school is not always a high priority in the context of working to save the child's life and addressing more "pressing" psychosocial concerns. Meta-analytic data also suggests that knowledge may be more amenable to change than attitudes for peers of children with cancer, which may further complicate the return to school (Canter & Roberts, 2012). For example, there may be social and emotional challenges if classmates are unsure about how to interact with the child with cancer when they return to the classroom. An increased reliance on technology in the classroom may facilitate more integration of the child with cancer into the classroom, although this remains an understudied area. Video conferencing programs may allow children with cancer to "join" their classmates from home or the hospital, and online platforms are utilized by many schools to assign and complete work.

An Example of Standardization of Care: Assessment of Psychosocial Needs at Nemours

The Psychosocial Assessment Tool (PAT; Pai et al., 2008) is a brief parent report screening instrument guided by social ecological approaches to child health to assess psychosocal risk in families of children with cancer. The PAT is used at 28.9% of cancer programs in the United States (Scialla et al., 2017a). In addition to a total score, the PAT has seven subscales: Family Structure and Resources, Family Social Support, Family Problems, Parent Stress Reactions, Family Beliefs, Child Problems, and Sibling Problems (Pai et al., 2008). The PAT is guided by the Pediatric Psychosocial Preventative Health Model (PPPHM; Kazak, 2006), which utilizes a pyramid model to categorize families into levels of psychosocial risk. Families at the base of the pyramid, or the *Universal* level, are resilient despite some expected distress at diagnosis. Families in the middle of the pyramid, described as the *Targeted* level, have some risk factors present and likely experience acute distress. The most high-risk families, who have persistent and/or escalating distress, are categorized at the *Clinical* level. Data indicates that the majority of families who have a child with cancer fall into the *Universal* level, with fewer families at the *Targeted* and *Clinical* levels (Kazak, Schneider, Didonato, & Pai, 2015). Levels of intervention, ranging from providing general support to specialized psychosocial intervention, vary based on risk classification.

The PAT is used at our instituation, Nemours/Alfred I. duPont Hospital for Children, as a clinical screening tool to evaluate family risk and resilience following a cancer diagnosis. The PAT is available in English and Spanish and is offered to the parents of all newly diagnosed patients who are fluent in either language. The PAT is presented to families as a routine part of care within 45 days of the cancer diagnosis, which normalizes the assessment process and sets the stage for the integration of psychosocial care throughout cancer treatment.

Each eligible family is first identified by social work staff, who approach the family about the PAT within 45 days of cancer diagnosis. The PAT is given online, using a secure web application for research and survey administration (i.e., REDCap), on an iPad and takes 10–15 min to complete. After completion of the PAT, a report including an overall risk score and individual subscale scores is automatically generated. Information about specific item endorsements (e.g., "the caregiver reports that it is 'very true' for me that [the cancer diagnosis] is a disaster") is also provided in this report. A note with information about the instrument and family risk profile is entered into the electronic medical record, and information about psychosocial risk and resilience is discussed during weekly team rounds. If a high-risk item is endorsed (e.g., a question about suicidality) and/or a family screens into the clinical range, a member of the psychosocial team is immediately notified and meets with the family as quickly as possible. Parents typically complete the PAT during an initial inpatient admission, which facilitiates rapid identification of any urgent needs and allows the

the psychosocial staff to more readily follow up about any areas of concern. While item endorsements and levels of risk vary greatly, problems related to finances, employment, parental emotional health, and child behavior changes are commonly endorsed. Utilizing the PAT early in the treatment process allows for the psychosocial team to identify appropriate members of the care team to work with individual families. The inclusion of the PAT scores in the EMR also allows the medical team to view critical psychosocial information and address relevant concerns.

Conclusions and Future Directions

Advances in medical treatment have greatly improved the prognosis for many children diagnosed with cancer, although treatment remains highly toxic and the medical and psychosocial impact of cancer on the child and family often persist long into remission. Holistic, interdisciplinary care models help address the many needs of children and families through cancer treatment and into survivorship. Critical roles for psychosocial team members include the provision of assessment and intervention services for the child with cancer, siblings, and caregivers from diagnosis into treatment, survivorship, and bereavement care when needed. Evidence suggests that “best practice” psychosocial care should be research-based and standardized, and should follow patients and their families from diagnosis into survivorship or, if necessary, bereavement. While models and methods of care delivery will undoubtedly change as the healthcare landscape continues to shift, the long history of integration between psychosocial and medical care in pediatric cancer ensures that integrated care will remain a hallmark of pediatric cancer treatment in the future.

References

Alderfer, M. A., Long, K. A., Lown, E. A., Marsland, A. L., Ostrowski, N. L., Hock, J. M., & Ewing, J. (2010). Psychosocial adjustment of siblings of children with cancer: a systematic review. *Psychooncology, 19*, 789–805.

Alderfer, M. A., Stanley, C., Conroy, R., Long, K. A., Fairclough, D. L., Kazak, A. E., & Noll, R. B. (2015). The social functioning of siblings of children with cancer: A multi-informant investigation. *Journal of Pediatric Psychology, 40*, 309–319.

Ander, M., Grönqvist, H., Cernvall, M., Engvall, G., Hedström, M., Ljungman, G., … von Essen, L. (2016). Development of health-related quality of life and symptoms of anxiety and depression among persons diagnosed with cancer during adolescence: A 10-year follow-up study. *Psychooncology, 25*, 582–589.

Bass, J. K., Knight, K. R., Yock, T. I., Chang, K. W., Cipkala, D., & Grewal, S. S. (2016). Evaluation and Management of Hearing Loss in Survivors of Childhood and Adolescent Cancers: A Report From the Children's Oncology Group. *Pediatric Blood & Cancer, 63*, 1152–1162.

Bottomley, S. J., & Kassner, E. (2003). Late effects of childhood cancer therapy. *Journal of Pediatric Nursing, 18*, 126–133.

Brodeur, G. M., Nichols, K. E., Plon, S. E., Schiffman, J. D., & Malkin, D. (2017). Pediatric cancer predisposition and surveillance: An overview, and a tribute to Alfred G. Knudson Jr. *Clinical Cancer Research, 23*, e1–e5.

Bruce, M. (2006). A systematic and conceptual review of posttraumatic stress in childhood cancer survivors and their parents. *Clinical Psychology Review, 26*, 233–256.

Canter, K. S., & Roberts, M. C. (2012). A systematic and quantitative review of interventions to facilitate school reentry for children with chronic health conditions. *Journal of Pediatric Psychology, 37*, 1065–1075.

Charlton, A., Larcombe, I. J., Meller, S. T., Morris Jones, P. H., Mott, M. G., Potton, M. W., … Walker, J. J. (1991). Absence from school related to cancer and other chronic conditions. *Archives of Disease in Childhood, 66*, 1217–1222.

Chavhan, G. B., Babyn, P. S., Nathan, P. C., & Kaste, S. C. (2016). Imaging of acute and subacute toxicities of cancer therapy in children. *Pediatric Radiology, 46*, 9–20.

Cheung, Y. T., Brinkman, T. M., Li, C., Mzayek, Y., Srivastava, D., Ness, K. K., … Krull, K. R. (2018). Chronic health conditions and neurocognitive function in aging survivors of childhood cancer: A report from the childhood cancer survivor study. *Journal of the National Cancer Institute, 110*(4), 411–419.

Chow, E. J., Friedman, D. L., Yasui, Y., Whitton, J. A., Stovall, M., Robison, L. L., … Sklar, C. A. (2007). Decreased adult height in survivors of childhood acute lymphoblastic leukemia: a report from the childhood cancer survivor study. *Journal of Pediatrics, 150*(370-375), e371.

Cordelli, D. M., Masetti, R., Zama, D., Toni, F., Castelli, I., Ricci, E., … Pession, A. (2017). Central nervous system complications in children receiving chemotherapy or hematopoietic stem cell transplantation. *Frontiers in Pediatrics, 5*, 105.

Diller, L., Chow, E. J., Gurney, J. G., Hudson, M. M., Kadin-Lottick, N. S., Kawashima, T. I., … Sklar,

C. A. (2009). Chronic disease in the childhood cancer survivor study cohort: A review of published findings. *Journal of Clinical Oncology, 27*, 2339–2355.

Embrey, L., Annett, R. D., Kunin-Batson, A., Patel, S. K., Sands, S., Reaman, G., & Noll, R. B. (2012). Implementation of multi-site neurocognitive assessments within a pediatric cooperative group: Can it be done? *Pediatric Blood & Cancer, 59*, 536–539.

French, A. E., Tsangaris, E., Barrera, M., Guger, S., Brown, R., Urbach, S., … Nathan, P. C. (2013). School attendance in childhood cancer survivors and their siblings. *Journal of Pediatrics, 162*, 160–165.

Furlong, W., Rae, C., Feeny, D., Gelber, R., Laverdiere, C., Michon, B., … Barr, R. (2012). Health-related quality of life among children with acute lymphoblastic leukemia. *Pediatric Blood & Cancer, 59*, 717–724.

Gerhardt, C. A., Lehmann, V., Long, K. A., & Alderfer, M. A. (2015). Supporting siblings as a standard of care in pediatric oncology. *Pediatric Blood & Cancer, 62*, S750–S804.

Gibbins, J., Steinhardt, K., & Beinart, H. (2012). A systematic review of qualitative studies exploring the experience of parents whose child is diagnosed and treated for cancer. *Journal of Pediatric Oncology Nursing, 29, 253–271.*

Harris, M. S. (2009). School reintegration and adolescents with cancer: The role of school psychologists. *Psychology in the Schools, 46*, 579–592.

Hedstrom, M., Haglund, K., Skolin, I., & Von Essen, L. (2003). Distressing events for children and adolescents with cancer: Child, parent, and nurse perceptions. *Journal of Pediatric Oncology Nursing, 20*, 120–132.

Hochhauser, C. J., Lewis, M., Kamen, B. A., & Cole, P. D. (2005). Steroid-induced alterations of mood and behavior in children during treatment for acute lymphoblastic leukemia. *Supportive Care in Cancer, 13*, 967–974.

Howlader, N., Noone, A. M., Krapcho, M., Miller, D., Bishop, K., Kosary, C. L., … Cronin KA. (2017). *SEER Cancer Statistics Review, 1975-2014*. Retrieved from https://seer.cancer.gov/csr/1975_2014/

Hudson, M. M., Mertens, A. C., Yasui, Y., Hobbie, W., Chen, H., Gurney, J. G., … Childhood Cancer Survivor Study Investigators. (2003). Health status of adult long-term survivors of childhood cancer: A report from the childhood cancer survivor study. *JAMA, 290*, 1583–1592.

Institute of Medicine (U.S.). Committee on Quality of Health Care in America. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, D.C.: National Academy Press.

Ishida, Y., Sakamoto, N., Kamibeppu, K., Kakee, N., Iwai, T., Ozono, S., … Horibe, K. (2010). Late effects and quality of life of childhood cancer survivors: Part 2. Impact of radiotherapy. *International Journal of Hematology, 92*, 95–104.

Jorngarten, A., Mattsson, E., & von Essen, L. (2007). Health-related quality of life, anxiety and depression among adolescents and young adults with cancer: A prospective longitudinal study. *European Journal of Cancer, 43*, 1952–1958.

Kaplan, L. M., Kaal, K. J., Bradley, L., & Alderfer, M. A. (2013). Cancer-related traumatic stress reactions in siblings of children with cancer. *Family Systems & Health, 31*, 205–217.

Kazak, A. E. (2006). Pediatric Psychosocial Preventative Health Model (PPPHM): Research, practice, and collaboration in pediatric family systems medicine. *Families, Systems, & Health, 24*, 381–395.

Kazak, A. E., Alderfer, M., Rourke, M. T., Simms, S., Streisand, R., & Grossman, J. R. (2004). Posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in families of adolescent childhood cancer survivors. *Journal of Pediatric Psychology, 29*, 211–219.

Kazak, A. E., & Noll, R. B. (2015). The integration of psychology in pediatric oncology research and practice: Collaboration to improve care and outcomes. *American Psychologist, 70*, 146–158.

Kazak, A. E., Schneider, S., Didonato, S., & Pai, A. L. (2015). Family psychosocial risk screening guided by the Pediatric Psychosocial Preventative Health Model (PPPHM) using the Psychosocial Assessment Tool (PAT). *Acta Oncologica, 54*, 574–580.

Kazak, A. E., Simms, S., Alderfer, M. A., Rourke, M. T., Crump, T., McClure, K., … Reilly, A. (2005). Feasibility and preliminary outcomes from a pilot study of a brief psychological intervention for families of children newly diagnosed with cancer. *Journal of Pediatric Psychology, 30*, 644–655.

Kazak, A. E., Simms, S., Barakat, L. B., Hobbie, W., Foley, B., Golomb, V., & Best, M. (1999). Surviving cancer competently intervention program (SCCIP): A cognitive-behavioral and family therapy intervention for adolescent survivors of childhood cancer and their families. *Family Process, 38*, 176–191.

Kearney, J. A., Salley, C. G., & Muriel, A. C. (2015). Standards of psychosocial care for parents of children with cancer. *Pediatric Blood & Cancer, 62*, S632–S683.

Kopp, L. M., Gastelum, Z., Guerrero, C. H., Howe, C. L., Hingorani, P., & Hingle, M. (2016). Lifestyle behavior interventions delivered using technology in childhood, adolescent, and young adult cancer survivors: A systematic review. *Pediatric Blood & Cancer, 64*, 1–17.

Krull, K. R., Okcu, F., Poter, B., Jain, N., Dreyer, Z., Kamdar, K., & Brouwers, P. (2008). Screening for neurocognitive impairment in pediatric cancer long-term survivors. *Journal of Clinical Oncology, 26*, 4138–4143.

Kunin-Batson, A., Lu, X., Balsamo, L., Graber, K., Devidas, M., Hunger, S., … Kadan-Lottick, N. (2016). Prevalence and predictors of anxiety and depression after completion of chemotherapy for childhood acute lymphoblastic leukemia: A prospective longitudinal study. *Cancer, 122*, 1608–1617.

Lichtenthal, W. G., Sweeney, C. R., Roberts, K. E., Corner, G. W., Donovan, L. A., Prigerson, H. G., & Wiener, L. (2015). Bereavement follow-up after the death of a child as a standard of care in pediatric oncology. *Pediatric Blood & Cancer, 62*, S834–S869.

Ljungman, L., Cernvall, M., Grönqvist, H., Ljótsson, B., Ljungman, G., & von Essen, L. (2014). Long-term positive and negative psychological late effects for parents of childhood cancer survivors: A systematic review. *PLOS One, 9*, e103340.

Lown, E. A., Phillips, F., Schwartz, L. A., Rosenberg, A. R., & Jones, B. (2015). Psychosocial follow-up in survivorship as a standard of care in pediatric oncology. *Pediatric Blood & Cancer, 62*, S514–S584.

Lum, A., Wakefield, C., Donnan, B., Burns, M., Fardell, J., & Marshall, G. (2017). Understanding the school experiences of children and adolescents with serious chronic illness: a systematic meta-review. *Child: Care, Health, and Development, 43*(5), 645–662.

Marcoux, S., Robaey, P., Krajinovic, M., Moghrabi, A., & Laverdière, C. (2012). Predictive factors of internalized and externalized behavioral problems in children treated for acute lymphoblastic leukemia. *Pediatric Blood & Cancer, 58*, 971–977.

McDonnell, G., Salley, C., Barnett, M., DeRosa, A., Werk, R., Hourani, A., … Ford, J. (2017). Anxiety among adolescent survivors of pediatric cancer. *Journal of Adolescent Health, 61*, 409–423.

Mitchell, H., Lu, X., Myers, R., Sung, L., Balsamo, L., Carroll, W., … Kadan-Lottick, N. (2016). Prospective, longitudinal assessment of quality of life in children from diagnosis to 3 months off treatment for standard risk acute lymphoblastic leukemia: Results of Children's Oncology Group study AALL0331. *International Journal of Cancer, 138*, 332–339.

Momani, T., Hathaway, D., & Mandrell, B. (2016). Factors affecting health-related quality of life in children undergoing curative treatment for cancer: A review of the literature. *Journal of Pediatric Oncology Nursing, 33*, 228–240.

Mrakotsky, C. M., Silverman, L. B., Dahlberg, S. E., Alyman, M. C., Sands, S. A., Queally, J. T., … Waber, D. P. (2011). Neurobehavioral side effects of corticosteroids during active treatment for acute lymphoblastic leukemia in children are age-dependent: report from Dana-Farber Cancer Institute ALL Consortium Protocol 00-01. *Pediatric Blood & Cancer, 57*, 492–498.

Myers, R. M., Balsamo, L., Lu, X., Devidas, M., Hunger, S., Carroll, W., … Kadan-Lottick, N. (2014). A prospective study of anxiety, depression, and behavioral changes in the first year after a diagnosis of childhood acute lymphoblastic leukemia: a report from the Children's Oncology Group. *Cancer, 120*, 1417–1425.

National Comprehensive Cancer Network. (2013). Distress management: Clinical practice guidelines. *Journal of the National Comprehensive Cancer Network, 1*, 344–374.

Neglia, J. P., Friedman, D. L., Yasui, Y., Mertens, A. C., Hammond, S., Stovall, M., … Robison, L. L. (2001). Second malignant neoplasms in five-year survivors of childhood cancer: childhood cancer survivor study. *Journal of the National Cancer Institute, 93*, 618–629.

O'Shea, E. R., Shea, J., Robert, T., & Cavanaugh, C. (2012). The needs of siblings of children with cancer: A nursing perspective. *Journal of Pediatric Oncology Nursing, 29*, 221–231.

Overbeek, A., van den Berg, M. H., van Leeuwen, F. E., Kaspers, G. J., Lambalk, C. B., & van Dulmen-den Broeder, E. (2017). Chemotherapy-related late adverse effects on ovarian function in female survivors of childhood and young adult cancer: A systematic review. *Cancer Treatment Reviews, 53*, 10–24.

Pai, A. L. H., Patiño-Fernández, A. M., McSherry, M., Beele, D., Alderfer, M. A., Reilly, A. T., … Kazak, A. E. (2008). The Psychosocial Assessment Tool (PAT2.0): Psychometric properties of a screener for psychosocial distress in families of children newly diagnosed with cancer. *Journal of Pediatric Psychology, 33*, 50–62.

Patterson, P., McDonald, F. E., Butow, P., White, K. J., Costa, D. S., Millar, B., … Cohn, R. J. (2014). Psychometric evaluation of the sibling cancer needs instrument (SCNI): An instrument to assess the psychosocial unmet needs of young people who are siblings of cancer patients. *Supportive Care in Cancer, 22*, 653–665.

Pejnovic, L. P., De Luca, C. R., Gentle, E., Anson, K., Ashley, D. M., Anderson, V. A., & McCarthy, M. C. (2012). Feasibility of neurobehavioral screening following diagnosis of pediatric cancer. *Pediatric Blood & Cancer, 59*, 295–300.

Pinquart, M., & Shen, Y. (2011). Behavior problems in children and adolescents with chronic physical illness: a meta-analysis. *Journal of Pediatric Psychology, 36*(9), 1003–1016.

Pinquart, M., & Tuebert, D. (2012). Academic, physical, and social functioning of children and adolescents with chronic physical illness: a meta-analysis. *Journal of Pediatric Psychology, 37*(4), 376–389.

Power, T. J., DuPaul, G. J., Shapiro, E. S., & Kazak, A. E. (2003). *Promoting children's health: Integrating health, school, family, and community systems*. New York: Guilford.

Price, J., Kassam-Adams, N., Alderfer, M. A., Christofferson, J., & Kazak, A. E. (2016). Systematic Review: A reevaluation and update of the integrative (trajectory) model of pediatric medical traumatic stress. *Journal of Pediatric Psychology, 41*, 86–97.

Riachy, E., Krauel, L., Rich, B. S., McEvoy, M. P., Honeyman, J. N., Boulad, F., … La Quaglia, M. P. (2014). Risk factors and predictors of severity score and complications of pediatric hemorrhagic cystitis. *The Journal of Urology, 191*, 186–192.

Sahler, O. J. Z., Dolgin, M. J., Phipps, S., Fairclough, D. L., Askins, M. A., Katz, E. R., … Butler, R. W. (2013). Specificity of problem-solving skills training in mothers of children newly diagnosed with cancer: Results of a multisite randomized clinical trial. *Journal of Clinical Oncology, 31*, 1329–1335.

Sahler, O. J. Z., Fairclough, D. L., Phipps, S., Mulhern, R. K., Dolgin, M. J., Noll, R. B., & Butler, R. W. (2005). Using problem-solving skills training to reduce negative affectivity in mothers of children with newly diagnosed cancer: report of a multisite randomized trial. *Journal of Consulting and Clinical Psychology, 73*, 272–283.

Sahler, O. J. Z., Varni, J. W., Fairclough, D. L., Butler, R. W., Noll, R. B., Dolgin, M. J., … Mulhern, R. K. (2002). Problem-solving skills training for mothers of children with newly diagnosed cancer: A randomized trial. *Journal of Developmental and Behavioral Pediatrics, 23*, 77–86.

Samson, K., Rourke, M. T., & Alderfer, M. A. (2016). A qualitative analysis of the impact of childhood cancer on the lives of siblings at school, in extra-curricular activities and with friends. *Clinical Practice in Pediatric Psychology, 4*, 362–372.

Sawyer, M., Antoniou, G., Toogood, I., Rice, M., & Baghurst, P. (2000). Childhood cancer: a 4-year prospective study of the psychological adjustment of children and parents. *Journal of Pediatric Hematology & Oncology, 22*, 214–220.

Scholz-Kreisel, P., Spix, C., Blettner, M., Eckerle, S., Faber, J., Wild, P., … Hennewig, U. (2017). Prevalence of cardiovascular late sequelae in long-term survivors of childhood. *Pediatric Blood & Cancer, 64*, e26428.

Schwartz, L. A., Tuchman, L. K., Hobbie, W. L., & Ginsberg, J. P. (2011). A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child: Care, Health and Development, 37*, 883–895.

Scialla, M. A., Canter, K. S., Chen, F. F., Kolb, A. E., Sandler, E., Wiener, L., & Kazak, A. E. (2017a). Delivery of care consistent with the Psychosocial Standards in Pediatric Cancer: Current practices in the United States. *Pediatric Blood & Cancer, 65*, e26869.

Scialla, M. A., Canter, K. S., Chen, F. F., Kolb, E. A., Sandler, E., Wiener, L., & Kazak, A. E. (2017b). Implementing the psychosocial standards in pediatric cancer: Current staffing and services available. *Pediatric Blood & Cancer, 64*, e26634.

Selo, N., Bolling, T., Ernst, I., Pape, H., Martini, C., Rube, C., … Willich, N. (2010). Acute toxicity profile of radiotherapy in 690 children and adolescents: RiSK data. *Radiotherapy and Oncology, 97*, 119–126.

Selove, R., Kroll, T., Coppes, M., & Cheng, Y. (2012). Psychosocial services in the first 30 days after diagnosis: Results of a web-based survey of Children's Oncology Group (COG) member institutions. *Pediatric Blood & Cancer, 58*, 435–440.

Shockey, D., Menzies, V., Glick, D., Taylor, A., Boitnott, A., & Rovnyak, V. (2013). Preprocedural distress in children with cancer: An intervention using biofeedback and relaxation. *Journal of Pediatric Oncology Nursing, 30*, 129–138.

Siegel, R. L., Miller, K. D., & Jemal, A. (2017). Cancer Statistics, 2017. *CA: A Cancer Journal for Clinicians, 67*(1), 7–30.

Szalda, D., Pierce, L., Hobbie, W., Ginsberg, J. P., Brumley, L., Wasik, M., … Schwartz, L. (2016). Engagement and experience with cancer-related follow-up care among young adult survivors of childhood cancer after transfer to adult care. *Journal of Cancer Survivorship, 10*, 342–350.

Thu Huynh, V., & Bergeron, S. (2017). Asparaginase toxicities: Identification and management in patients with acute lymphoblastic leukemia. *Clinical Journal of Oncology Nursing, 21*, e248–e259.

Van Schoors, M., Caes, L., Alderfer, M. A., Goubert, L., & Verhofstadt, L. L. (2017). Couple functioning after pediatric cancer diagnosis: A systematic review. *Psycho-Oncology, 26*, 608–616.

Van Schoors, M., Caes, L., Verhofstadt, L. L., Goubert, L., & Alderfer, M. A. (2015). Systematic review: Family resilience after pediatric cancer diagnosis. *Journal of Pediatric Psychology, 40*, 856–868.

Varni, J.W., Sahler, O. J., Mulhern, R. K., Katz, E. R., Copeland, D. R., Noll, R., … & Roghmann, K. (2002). *Maternal problem solving skills training in childhood cancer (CR01): Instructor's manual*. Retrieved from https://rtips.cancer.gov/rtips/programDetails.do?programId=546012

Wakefield, C. E., McLoone, J. K., Butow, P., Lenthen, K., & Cohn, R. J. (2011). Parental adjustment to the completion of their child's cancer treatment. *Pediatric Blood & Cancer., 56*, 524–531.

Weaver, M. S., Heinze, K. E., Bell, C. J., Wiener, L., Garee, A. M., Casey, R. L., … Pediatric Palliative Care Special Interest Group at Children's National Health System. (2016). Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review. *Palliative Medicine, 30*(3), 212–223.

Weaver, M. S., Heinze, K. E., Kelly, K. P., Wiener, L., Casey, R. L., Bell, C. J., … Hinds, P. S. (2015). Palliative care as a standard of care in pediatric oncology. *Pediatric Blood & Cancer, 62*, S829–S833.

Wechsler, A. M., & Sánchez-Iglesias, I. (2013). Psychological adjustment of children with cancer as compared with healthy children: a meta-analysis. *European Journal of Cancer Care, 22*, 314–325.

Wiener, L., Kazak, A. E., Noll, R. B., Patenaude, A. F., & Kupst, M. J. (2015). Standards for the psychosocial care of children with cancer and their families: An introduction to the special issue. *Pediatric Blood & Cancer, 62*, S419–S424.

Yang, H. C., Mu, P. F., Sheng, C. C., Chen, Y. W., & Hung, G. Y. (2016). A systematic review of the experiences of siblings of children with cancer. *Cancer Nursing, 39*, e12–e21.

Chronic and Recurrent Pain

10

Joanne Dudeney and Emily F. Law

Abstract

Chronic and recurrent pain is defined as pain that persists or recurs for longer than 3 months. Chronic pain is common in childhood, impacting at least one in four youth. The etiology of chronic pain is best understood within a biopsychosocial framework, which emphasizes the intersection of biological processes, psychological factors, and social/environmental influences in both the onset and maintenance of chronic pain. Children and adolescents with chronic pain can experience disability of physical function, psychological distress, family conflict, and difficulties in school and social functioning. Given the degree of potential physical and psychosocial consequences, assessment and treatment of pediatric chronic pain typically involves an interprofessional team including physicians, psychologists, and physical/occupational therapists who specialize in pediatric pain medicine. In this chapter, we use a biopsychosocial framework to describe the evaluation and treatment of chronic pain in childhood. Implications for interprofessional care and future directions are also discussed.

Background

Definition

Chronic or recurrent pain is defined as pain that recurs or persists for 3 months or more (IASP Taxonomy Working Group, 2011). Children and adolescents can experience chronic pain due to an underlying medical condition (e.g., inflammatory bowel disease, sickle cell disease, rheumatoid arthritis), or where the pain itself is the disorder (e.g., functional abdominal pain). The most common types of chronic pain in childhood include headache, abdominal pain, and musculoskeletal pain (e.g., leg pain, back pain). Youth can also experience chronic neuropathic pain conditions such as complex regional pain syndrome (CRPS), a type of neuropathic pain condition that has autonomic features and can occur when no major nerve injury is identified (CRPS type I) or when there is identifiable nerve damage (CRPS type II).

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Prevalence

Chronic pain is a common problem, impacting 25–35% of children and adolescents worldwide (King et al., 2011). The prevalence of chronic pain in childhood increases with age, peaking during adolescence and typically affecting more girls than boys (Swain et al., 2014). Approximately 5–7% of youth with chronic pain experience severe pain-related impairments in physical, emotional, social, and family functioning (King et al., 2011). Chronic pain is among the most costly chronic medical conditions in childhood with an estimated cost to society of $11.8 billion annually in the United States (Groenewald, Wright, & Palermo, 2015).

Etiology

Several conceptual models have been developed to understand the complex etiology of chronic pain in childhood with varying foci, including developmental factors (Palermo, Valrie, & Karlson, 2014), parent and family factors (Palermo & Chambers, 2005; Stone & Wilson, 2016), and the role of fear-avoidance (Asmundson, Noel, Petter, & Parkerson, 2012). Common across these conceptual models is a biopsychosocial framework, which emphasizes the intersection of biological processes, psychological factors, and social/environmental influences in both the onset and maintenance of chronic pain.

Diagnosis

An initial evaluation for chronic pain should include a complete medical and pain history, physical and neurological examination, and review of any prior diagnostic workup. Psychosocial assessments will be described in more detail below, and generally focus on the child's emotional status, sleep, academic and social performance, physical activities, and family functioning. The standard of care for evaluation and diagnosis of chronic pain in childhood is through a pediatric pain clinic, which specializes in the assessment and management of chronic pain. Pediatric pain clinics are typically located in tertiary care medical centers and are staffed by providers from disciplines including physicians, psychologists, physical and occupational therapists, and nurses.

Physical Health Outcomes

Youth with chronic pain may experience functional disability which can impact nearly all aspects of daily life including schooling (Vervoort, Logan, Goubert, De Clercq, & Hublet, 2014), social activities (Forgeron et al., 2010), and sports and other extracurricular activities (Palermo, 2008). Longitudinal research indicates that pediatric chronic pain can persist into adulthood and can increase risk for the onset of new types of pain, other physical symptoms, and mental health conditions (Fearon & Hotopf, 2001; Walker, Sherman, Bruehl, Garber, & Smith, 2012). Thus, appropriate assessment and treatment of chronic pain in childhood could prevent trajectories of pain and disability in adulthood.

Psychosocial Concomitants and Consequences

Psychological

Youth with chronic pain report higher symptoms of general anxiety, pain-specific anxiety, depression, and post-traumatic stress symptoms than youth without chronic pain (Cunningham et al., 2015; Noel et al., 2016). Psychological difficulties in youth with chronic pain can negatively impact the intensity and duration of pain and have been associated with greater impairments in physical function, sleep, school, and peer/social interactions (Kashikar-Zuck et al., 2013). Epidemiological studies have shown that people with a history of chronic pain in adolescence are at a higher lifetime risk for anxiety and depressive disorders, as compared with individuals without a history of adolescent chronic pain (Noel et al., 2016).

Social/Environmental

The experience of chronic pain affects not only the child, but also the family system. Research indicates that families of youth with chronic pain have poorer cohesion and communication, and increased conflict, when compared to families of healthy youth (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010). Further, parents report higher rates of distress, maladaptive parenting behaviors, and financial strain (Palermo et al., 2014). Bi-directional associations between parent distress and behavior and children's adaptation to chronic pain have been proposed, and results from cross-sectional and longitudinal studies have indicated that parental distress and maladaptive parenting behaviors are associated with increased child functional disability (Palermo et al., 2014).

Environmental contexts outside of the home are also important for children and adolescents with chronic pain. For example, youth with chronic pain commonly report greater school absenteeism, poorer academic achievement, decreased participation in extracurricular activities, and increased social isolation, compared to age-matched peers (Assa, Ish-Tov, Rinawi, & Shamir, 2015; Forgeron, MacLaren Chorney, Carlson, Dick, & Plante, 2015). There is limited research examining the effects of sociodemographic differences on chronic pain. Related research in adults with chronic pain shows relationships between lower SES and both chronic pain prevalence (Westergaard, Glümer, Hansen, & Jensen, 2014) and interference (Fitzcharles, Rampakakis, Ste-Marie, Sampalis, & Shir, 2014). Research is needed to understand whether similar patterns exist for youth with chronic pain conditions.

Cognitive

Youth with chronic pain report greater impairments in executive functioning (Weiss et al., 2017) and demonstrate poorer performance on experimental tasks of working memory and attention compared to their healthy peers (Costa-Silva, Prado, Souza, Gomez, & Teixeira, 2016), despite being no more likely to meet criteria for a learning disability or show differences in IQ (Dick & Pillai Riddell, 2010). Although the exact pathophysiology is unclear, these cognitive problems may be a symptom of chronic pain conditions (e.g., migraine or fibromyalgia), a consequence of competing attention from pain symptoms (Heathcote et al., 2015), and/or a medication side-effect (Powers et al., 2017). Cognitive difficulties can interfere with school productivity and health-related quality of life, and have been shown to contribute to functional disability in youth with chronic pain (Torkamani et al., 2015).

Psychosocial Screening and Assessment

Within a pediatric pain clinic, psychosocial assessment is conducted by licensed psychologists with specialized training in pediatric pain. The majority of information comes from a semi-structured psychosocial assessment clinical interview, which can be supplemented by questionnaire measures. Consistent with the biopsychosocial model, domains of assessment should include pain history and symptoms, emotional and cognitive functioning, and social and family functioning. Importantly, findings from the psychosocial assessment must be considered in the context of other evaluations including medical status and physical functioning (as evaluated by a physician and physical therapist). Here, we briefly describe the domains that should be included in a psychosocial assessment clinical interview. For clinicians interested in more detailed guidance on conducting psychosocial assessments with youth who have chronic pain, please see *Cognitive-Behavioral Therapy for Chronic Pain in Children and Adolescents* (Palermo, 2012).

Pain History

This includes asking the child and parents to describe how and when the child's pain started and how it has changed over time, as well as characteristics of the pain including location, frequency, and intensity. It is important to understand patterns, exacerbating factors, and ameliorating factors for the pain. See Stinson, Kavanagh, Yamada, Gill, and Stevens (2006) and Cohen et al. (2008) for systematic reviews of self-report measures for evaluating pain symptoms in youth.

Physical Functioning

The clinical interview should identify domains of pain-related interference that may be targeted in treatment, including daily living activities (e.g., walking, grooming), physical activities (e.g., organized sports, hobbies), family activities (e.g., chores, family events), school attendance (e.g., days missed due to pain), academic performance (e.g., grades, learning and behavior problems), and peer relationships (e.g., social activities, exposure to bullying). Questionnaire measures of activity limitations due to pain can supplement the clinical interview (e.g., Child Activity Limitations Interview; Palermo, Riley, & Mitchell, 2008). Clinicians may also consider questionnaires that assess the broad impact of chronic pain on the child, parent, and family (e.g., Bath Adolescent Pain Questionnaire; Eccleston et al., 2005).

Emotional Functioning

Evaluation should include the child's current and past emotional status (e.g., depression, anxiety, post-traumatic stress, and other relevant symptoms), exposure to psychosocial stressors, and typical coping strategies. Depending on the severity of the child's psychological symptoms, referral to other mental health professionals for further evaluation and treatment may be required. Questionnaire measures that include scoring guidelines with clinical cut-offs for mental health disorders can be useful to integrate with the clinical interview (e.g., Revised Child Anxiety and Depression Scale, Chorpita, Moffitt, & Gray, 2005).

Sleep

Clinicians should seek to understand the child's sleep schedule, sleep habits, and use of medications that may influence sleep (e.g., melatonin). Referral to a specialty sleep clinic may be required for specific concerns, such as obstructive sleep apnea. See Lewandowski, Toliver-Sokol, and Palermo (2011) for a comprehensive review of questionnaires to assess sleep.

Family Functioning

Families can be asked about cohesion and conflict, the impact of the pain on the family (e.g., parent distress, marital conflict), how different family members respond to the pain (e.g., distraction, attention, or hostility), and the child's independence in pain management. Clinicians can incorporate questionnaire measures of parental responses to their child's pain (Adult Responses to Children's Pain Symptoms; Van Slyke & Walker, 2006), as well as general measures of family functioning (e.g., Family Assessment Device; Miller, Epstein, Bishop, & Keitner, 1985).

Prevention and Intervention

Prevention

There is growing interest in identifying youth who are at risk for developing chronic pain conditions, allowing for early intervention. For example, research indicates that youth who have undergone major surgery may be at increased risk for developing chronic pain if they have elevated symptoms of anxiety, poor coping skills, or higher pain intensity prior to surgery (Rabbitts, Fisher, Rosenbloom, & Palermo, 2017). Recent research has also sought to identify risk factors for the development of chronic pain among youth who have experienced a recent orthopedic injury, and preliminary results indicate that being female and having poor ability to inhibit pain modulation may increase risk (Holley, Wilson, & Palermo, 2017). Youth whose parents have chronic pain may also be at increased risk, although the exact mechanisms of this relationship are unclear (Higgins et al., 2015). This area of research is still in its infancy. To our knowledge, there have not been studies evaluating prevention programs for youth who are potentially at risk for developing chronic pain.

Intervention

Treatment for youth with chronic pain conditions is typically multidisciplinary and includes psychological interventions, physical and occupational therapies, pharmacological interventions, and complimentary health approaches. These are summarized below.

Psychological Interventions

Psychological interventions for pediatric pain management are typically brief, goal-oriented, and focused on decreasing pain and increasing activity participation. Cognitive-behavioral therapy (CBT) is currently the prevailing psychological treatment for children and adolescents with chronic pain (Eccleston et al., 2014). The latest systematic review on psychological therapies for youth with chronic pain included 43 RCTs conducted over the past 30 years (Eccleston et al., 2014). Results indicated that psychological therapies have moderate benefits for decreasing pain, disability, and anxiety symptoms for youth with a variety of chronic pain conditions.

CBT is based in behavioral, cognitive, and social learning theories (Palermo, 2012), and typically provides youth with instruction in a broad range of pain self-management strategies. Parents may also receive training in operant strategies to support their child in skills practice and reduce unnecessary attention to pain at home. Currently, there is no consensus in the sequence, dose, or particular combination of strategies that produce the most benefits for youth with chronic pain. For a detailed CBT protocol for pediatric chronic pain management, see Palermo (2012). The most common components of CBT treatment packages are reviewed below, including pain education, relaxation skills, cognitive strategies, and behavioral strategies (Law, Beals-Erickson, Fisher, Lang, & Palermo, 2017).

Pain education teaches children and their parents about the biopsychosocial model of pediatric chronic pain. This includes basic education about neurophysiology of pain processing, which emphasizes that the child's pain experience is real although does not necessarily indicate ongoing damage to the body. Associations between pain and psychological and social factors are also discussed, as is the role of cognitive and behavioral strategies in helping with pain modulation and return to function.

Relaxation methods aim to decrease physiological arousal (including pain perception), increase feelings of well-being, and decrease emotional distress. Relaxation methods for pain management commonly include deep breathing, progressive muscle relaxation, and guided imagery (Law, Beals-Erickson, et al., 2017). These strategies may also be used in conjunction with biofeedback training or hypnosis. *Biofeedback* combines training in relaxation methods with visual and/or auditory feedback (from biofeedback devices) about the child's physiological functioning (e.g., respiration rate, finger temperature, blood flow, heart rate variability), and is commonly used in youth with headache pain (Law, Beals-Erickson, et al., 2017). *Hypnosis* also relies on relaxation methods and incorporates analgesic suggestion to relieve pain and/or increase comfort, and has demonstrated preliminary efficacy for youth with abdominal pain (Gulewitsch, Muller, Hautzinger, & Schlarb, 2013).

Cognitive strategies include cognitive reframing and positive self-statements. First, youth learn to identify maladaptive beliefs about pain and the role and impact of pain in their life. In cognitive reframing, children are taught to challenge these negative beliefs by examining their accuracy (e.g., listing out evidence in support of the thought vs. against it) or by conducting behavioral experiments to test its validity. Positive self-statements is a related coping skill in which youth focus on their ability to cope with pain and participate in valued activities.

Behavioral skills assist the child to reengage in activities, even when experiencing pain. These include graded exposure and activity pacing. Graded exposure involves gradually increasing exposure to a feared situation, often by starting with the least-feared activity and, over time, engaging in activities that are more anxiety- or pain-provoking (Simons, Kaczynski, Conroy, & Logan, 2012). Relaxation methods and cognitive skills can help to decrease anxiety and pain symptoms during exposures. For activity pacing, participation in a goal-directed activity is built up over time by alternating active periods with rest breaks. Over time, the duration of rest breaks is decreased as the child's ability to participate in the activity increases.

Physical and Occupational Therapies

Physical therapy (PT) aims to increase physical endurance, mobility, strength, and flexibility, all of which may be impacted by the chronic pain condition. Pain-specific techniques include pain-physiology education, graded activity exposure, and desensitization (see Tupper, Swiggum, O'Rourke, & Sangster, 2014, for a review of these treatment approaches). *Occupational therapy* (OT) aims to improve participation in activities related to self-care (e.g., grooming, dressing, chores), productivity (e.g., ability to sit in a chair comfortably at school), and leisure (Holsti, Backman, & Engel, 2014). Research investigating the unique effects of PT and OT on children and adolescent's pain and disability outcomes is needed, as most prior research has examined these modalities within the context of broader pediatric pain treatment programs (Simons et al., 2018).

Pharmacological Treatments

Pharmacological approaches are typically used to reduce pain symptoms in order to support children and adolescents in engaging in other treatment modalities (e.g., PT/OT). Over-the-counter medications include analgesics such as acetaminophen and non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen and aspirin. Both have pain-relieving properties and may be indicated for mild to moderate pain such as musculoskeletal pain and headache. For moderate to severe pain, including neuropathic pain, common medication classes include anticonvulsants (e.g., gabapentin, pregabalin) and antidepressants (e.g., amitriptyline, duloxetine). Topical agents (e.g., lidocaine, diclofenac) may be prescribed for focal pain conditions. Opioid medications (e.g., codeine, morphine, oxycodone) and interventional procedures (e.g., nerve blocks) are used less frequently in the treatment of chronic pain in youth.

There is a paucity of evidence regarding the safety or efficacy of pharmacological interventions for the treatment of chronic pain in youth. For example, no randomized controlled trials evaluating the safety or efficacy of acetaminophen or opioids have been conducted in pediatric chronic pain populations (Cooper, Fisher, Anderson, et al., 2017; Cooper, Fisher, Gray, et al., 2017). A few randomized controlled trials have been conducted for other medication classes (i.e., NSAIDs, antidepressants) and recent systematic reviews concluded that, in light of the low number of trials currently available, we cannot be certain of the safety or efficacy of these approaches for treating childhood chronic pain (Cooper, Heathcote, et al., 2017; Eccleston, Cooper, Fisher, Anderson, & Wilkinson, 2017).

Complementary Health Approaches

These include natural products (e.g., vitamins, minerals, probiotics) as well as mind body practices (e.g., acupuncture, yoga, massage). Parents of children and adolescents with chronic pain have indicated a variety of reasons for seeking complimentary health approaches for their child including reluctance to persist with pain medication schedules, desire for an integrated approach to pain management, and beliefs about the inefficiency of conventional medicine (Dalla Libera, Colombo, Pavan, & Comi, 2014). The limited available research regarding the safety and efficacy of complimentary health approaches for youth with chronic pain has yielded some conflicting findings (Evans et al., 2014; Hainsworth et al., 2014), and further research in this area is needed.

Implications for Interprofessional Care

Within a pediatric pain medicine clinic, various strategies are employed to facilitate the provision of interprofessional care. For example, new patient evaluations are commonly conducted by multiple members of the treatment team, which allows for a coordinated and collaborative approach to formulating an assessment and recommending treatment. During treatment, regular case conference meetings and scheduling return visit appointments for patients with multiple members of the treatment team can facilitate ongoing interprofessional care. Intensive day treatment or inpatient pain rehabilitation programs are also available and are typically recommended to patients who live too far away from a specialized pain clinic to receive treatment, patients with certain types of pain conditions that require intensive physical therapy (e.g., CRPS), and those who have not had a successful outcome with outpatient treatment. Patients are typically enrolled in these programs for several weeks and participate in intensive physical and occupational therapy, pain psychology, and management by a pain physician (see Hechler et al., 2015 for a review of published data from these programs). The American Pain Society and the Canadian Pain Coalition maintain listings of dedicated interprofessional pediatric pain medicine programs in North America (http://americanpainsociety.org/get-involved/shared-interest-groups/pediatric-adolescent-pain; http://prc.canadianpaincoalition.ca/en/pediatric_pain_treatment_facilities.html).

Interprofessional care for youth with chronic pain can also occur between the pain medicine clinic and a variety of child-serving systems including primary care clinics, other specialty medical care clinics, mental health care providers, and school systems. For youth with chronic pain, care coordination between these systems is typically managed by the child's primary care physician with the specialty care pain medicine team serving in a consulting role. For example, the pain physician may liaise with the primary care physician and other relevant providers upon completion of the diagnostic evaluation to relay recommendations for treatment, and then on an as-needed basis as treatment progresses. For youth who experience disease-related chronic pain (e.g., from cancer or diabetes), medical management of the disease will be led by the specialty provider (e.g., oncologist, endocrinologist) and the pain clinic team will serve in a consulting role, focusing on the pain management component of the child's treatment plan. The pain psychologist will typically liaise with the child's local mental health providers and school staff. Interactions may be limited to a letter from the pain medicine team documenting the child's pain condition, or may be more intensive and involve direct contact with mental health providers or school officials. For example, the pain psychologist may request a psychoeducational evaluation to identify potential cognitive or learning disabilities, advocate for specific accommodations to support school re-entry (e.g., rest periods or later school start times), or employ strategies to enhance rapport and communication between parents and school staff.

Recently, there has been growing interest in more intensive approaches for the subset of youth with chronic pain who are at highest risk for disproportionate use of health care services (e.g., repeated avoidable hospitalizations due to pain). For example, Harris et al. (2015) developed an intensive behavioral health intervention for youth with chronic pain and high health care utilization that combines psychological treatment with intensive care coordination and case management. Similar programs have reduced avoidable hospitalizations and improved psychosocial outcomes among youth with other complex medical conditions (Naar-King et al., 2014). Further research needs to evaluate the feasibility, efficacy, and cost-effectiveness of this approach for youth with chronic pain.

Case Study

Angelina is 16 years old with abdominal pain and headaches that occur most days of the week. Her pain is worse in the mornings and *because of this, Angelina has missed close to 100 days of school in the past year. She used to be an elite soccer player, but has not played in the past 12 months because of her pain. She has seen her primary care provider and a variety of specialists, but no one has been able to provide the family with a conclusive explanation for her pain. As Angelina's ability to participate in daily activities has become more limited, her parents have noticed that she is increasingly irritable, withdrawn, and depressed. Angelina herself describes a high level of distress about her grades and worry that her pain will get worse if she attempts to go to school or play soccer.*

Angelina and her family were relieved when they were seen at the pain medicine clinic at their local children's hospital. They learned that Angelina's pain was real but not dangerous. Recommendations from the pain clinic focused on reducing Angelina's pain as much as possible and helping her to participate in activities that are important to her and her family, including returning to school and sports. Angelina began working with a physical therapist to increase her strength and endurance. She decided she was not ready to go back to soccer, but started swimming and taking a yoga class that she enjoyed. She began cognitive-behavioral therapy for pain management as well, and found that a few minutes of relaxation exercises in the mornings helped her to feel well enough to attend school. Being in school wasn't easy, and her pain psychologist worked with her parents and the school counselor to coordinate accommodations that helped her to feel more comfortable during the school day. As she spent more time in school, she noticed that her worry about school decreased. Her friends started inviting her to do things with them again, and her parents noticed that she was more cheerful and "like her old self." Angelina still had what she called "good pain days and bad pain days" but noticed that the number of bad pain days was getting less and less.

Conclusions and Future Directions

Although we continue to deepen our understanding of chronic pain in childhood, research is needed to address several existing gaps in current models of care. For example, interdisciplinary treatment is the standard of care for pediatric chronic pain; however, many youth do not receive this care due to barriers including distance from specialty care clinics, access, and cost. Remotely delivered psychological treatments have been developed in order to address these barriers to care. These include treatment via the telephone (Levy et al., 2017) or via technology such as the Internet (Palermo et al., 2016). The evidence for these technology-delivered treatments is preliminary but small effects in reducing children and adolescent's pain and disability have been demonstrated (Fisher, Law, Palermo, & Eccleston, 2014). Within the field of pediatric psychology, there is also a growing interest in innovative clinical models that embed psychologists within primary care settings (Stancin, 2016). This type of care model may have the potential to address some of the current gaps in service delivery for youth with chronic pain, particularly those who live far away from tertiary care medical centers. Research regarding the feasibility and acceptability of implementing these care models to address the treatment needs of youth with chronic pain is needed.

Second, little is known about best approaches for addressing the treatment needs of youth with chronic pain who have co-occurring conditions. This is an important consideration because mental and physical health comorbidities may impact response to treatment. For example, pre-treatment insomnia and anxiety symptoms have been associated with poorer response to cognitive-behavioral therapy for pain management (Cunningham et al., 2016; Fales, Palermo, Law, & Wilson, 2015). Recent pilot clinical trials have evaluated the feasibility and acceptability of psychological interventions to address co-occurring insomnia (Palermo, Beals-Erickson, Bromberg, Law, & Chen, 2017) and anxiety disorders (Cunningham et al., 2018) among youth with chronic pain; however, full-scale randomized trials are needed.

Third, there has been growing interest in identifying optimal strategies for involving parents in their child's chronic pain treatment. The majority of CBT protocols focus on delivering intervention to the child with little or no intervention delivered to the parent. However, recent longitudinal studies have indicated that youth demonstrate a poorer response to pain treatment when their parents have higher distress and maladaptive behaviors at pre-treatment (Chow, Otis, & Simons, 2016; Law, Fisher, et al., 2017). Recently, interventions have also been developed to deliver psychological treatment only to parents in order to address maladaptive parenting behaviors and decrease parent distress, including social-learning CBT (Levy et al., 2017), and problem-solving therapy (Palermo et al., 2016). These parent-only interventions have demonstrated preliminary efficacy in improving parenting behaviors and reducing parental distress, as well as improving pain-related disability and emotional distress in youth. Further research needs to expand this evidence base and to understand which families would benefit from parent-only vs. child-only vs. family-based psychological interventions for pain management.

In conclusion, chronic pain is a common condition in childhood that is best understood within a biopsychosocial framework. As such, standard of care for assessment and treatment is recommended to be interprofessional. Collaboration across varying disciplines and settings will provide the best opportunity for youth with chronic pain to receive evidence-based approaches that can reduce pain and associated functional impairment, emotional distress, and family dysfunction.

References

Asmundson, G. J., Noel, M., Petter, M., & Parkerson, H. A. (2012). Pediatric fear-avoidance model of chronic pain: Foundation, application and future directions. *Pain Research and Management, 17*(6), 397–405.

Assa, A., Ish-Tov, A., Rinawi, F., & Shamir, R. (2015). School attendance in children with functional abdominal pain and inflammatory bowel diseases. *Journal of Pediatric Gastroenterology and Nutrition, 61*(5), 553–557.

Chorpita, B. F., Moffitt, C. E., & Gray, J. (2005). Psychometric properties of the Revised Child Anxiety and Depression Scale in a clinical sample. *Behaviour Research and Therapy, 43*(3), 309–322.

Chow, E. T., Otis, J. D., & Simons, L. E. (2016). The longitudinal impact of parent distress and behavior on functional outcomes among youth with chronic pain. *Journal of Pain, 17*(6), 729–738.

Cohen, L. L., Lemanek, K., Blount, R. L., Dahlquist, L. M., Lim, C. S., Palermo, T. M., … Weiss, K. E. (2008). Evidence-based assessment of pediatric pain. *Journal of Pediatric Psychology, 33*(9), 939–955.

Cooper, T. E., Fisher, E., Anderson, B., Wilkinson, N. M., Williams, D. G., & Eccleston, C. (2017). Paracetamol (acetaminophen) for chronic non-cancer pain in children and adolescents. *Cochrane Database of Systematic Reviews, 8*, CD012539.

Cooper, T. E., Fisher, E., Gray, A. L., Krane, E., Sethna, N., van Tilburg, M. A., … Wiffen, P. J. (2017). Opioids for chronic non-cancer pain in children and adolescents. *Cochrane Database of Systematic Reviews, 7*, CD012538.

Cooper, T. E., Heathcote, L. C., Clinch, J., Gold, J. I., Howard, R., Lord, S. M., … Wiffen, P. J. (2017). Antidepressants for chronic non-cancer pain in children and adolescents. *Cochrane Database of Systematic Reviews, 8*, CD012535.

Costa-Silva, M. A., Prado, A. C. d. A., Souza, L. C. d., Gomez, R. S., & Teixeira, A. L. (2016). Cognitive functioning in adolescents with migraine. *Dementia & Neuropsychologia, 10*, 47–51.

Cunningham, N. R., Cohen, M. B., Farrell, M. K., Mezoff, A. G., Lynch-Jordan, A., & Kashikar-Zuck, S. (2015). Concordant parent-child reports of anxiety predict impairment in youth with functional abdominal pain. *Journal of Pediatric Gastroenterology and Nutrition, 60*(3), 312–317.

Cunningham, N. R., Jagpal, A., Tran, S. T., Kashikar-Zuck, S., Goldschneider, K. R., Coghill, R. C., & Lynch-Jordan, A. M. (2016). Anxiety adversely impacts response to cognitive behavioral therapy in children with chronic pain. *Journal of Pediatrics, 171*, 227–233.

Cunningham, N. R., Nelson, S., Jagpal, A., Moorman, E., Farrell, M., Pentiuk, S., & Kashikar-Zuck, S. (2018). Development of the Aim to Decrease Anxiety and Pain Treatment (ADAPT) for pediatric functional abdominal pain disorders. *Journal of Pediatric Gastroenterology and Nutrition, 66*(1), 16–20.

Dalla Libera, D., Colombo, B., Pavan, G., & Comi, G. (2014). Complementary and alternative medicine (CAM) use in an Italian cohort of pediatric headache patients: The tip of the iceberg. *Neurological Sciences, 35*(Suppl 1), 145–148.

Dick, B. D., & Pillai Riddell, R. (2010). Cognitive and school functioning in children and adolescents with chronic pain: A critical review. *Pain Research and Management, 15*(4), 238–244.

Eccleston, C., Cooper, T. E., Fisher, E., Anderson, B., & Wilkinson, N. M. (2017). Non-steroidal anti-inflammatory drugs (NSAIDs) for chronic non-cancer pain in children and adolescents. *Cochrane Database of Systematic Reviews, 8*, CD012537.

Eccleston, C., Jordan, A., McCracken, L. M., Sleed, M., Connell, H., & Clinch, J. (2005). The Bath Adolescent Pain Questionnaire (BAPQ): Development and preliminary psychometric evaluation of an instrument to assess the impact of chronic pain on adolescents. *Pain, 118*(1–2), 263–270.

Eccleston, C., Palermo, T. M., Williams, A. C., Lewandowski Holley, A., Morley, S., Fisher, E., & Law, E. (2014). Psychological therapies for the management of chronic and recurrent pain in children and adolescents. *Cochrane Database of Systematic Reviews, 5*, CD003968.

Evans, S., Lung, K. C., Seidman, L. C., Sternlieb, B., Zeltzer, L. K., & Tsao, J. C. (2014). Iyengar yoga for adolescents and young adults with irritable bowel syndrome. *Journal of Pediatric Gastroenterology and Nutrition, 59*(2), 244–253.

Fales, J., Palermo, T. M., Law, E. F., & Wilson, A. C. (2015). Sleep outcomes in youth with chronic pain participating in a randomized controlled trial of online cognitive-behavioral therapy for pain management. *Behavioral Sleep Medicine, 13*(2), 107–123.

Fearon, P., & Hotopf, M. (2001). Relation between headache in childhood and physical and psychiatric symptoms in adulthood: National birth cohort study. *British Medical Journal, 322*(7295), 1145.

Fisher, E., Law, E., Palermo, T. M., & Eccleston, C. (2014). Psychological therapies (remotely delivered) for the management of chronic and recurrent pain in children and adolescents. *Cochrane Database of Systematic Reviews, 2014*, CD011118.

Fitzcharles, M.-A., Rampakakis, E., Ste-Marie, P. A., Sampalis, J. S., & Shir, Y. (2014). The association of socioeconomic status and symptom severity in persons with fibromyalgia. *The Journal of Rheumatology, 41*(7), 1398–1404.

Forgeron, P. A., King, S., Stinson, J. N., McGrath, P. J., MacDonald, A. J., & Chambers, C. T. (2010). Social functioning and peer relationships in children and adolescents with chronic pain: A systematic review. *Pain Research and Management, 15*(1), 27–41.

Forgeron, P. A., MacLaren Chorney, J., Carlson, T. E., Dick, B. D., & Plante, E. (2015). To befriend or not: Naturally developing friendships amongst a clinical group of adolescents with chronic pain. *Pain Management Nursing, 16*(5), 721–732.

Groenewald, C. B., Wright, D. R., & Palermo, T. M. (2015). Health care expenditures associated with pediatric pain-related conditions in the United States. *Pain, 156*(5), 951–957.

Gulewitsch, M. D., Muller, J., Hautzinger, M., & Schlarb, A. A. (2013). Brief hypnotherapeutic-behavioral intervention for functional abdominal pain and irritable bowel syndrome in childhood: A randomized controlled trial. *European Journal of Pediatrics, 172*(8), 1043–1051.

Hainsworth, K. R., Salamon, K. S., Khan, K. A., Mascarenhas, B., Davies, W. H., & Weisman, S. J. (2014). A pilot study of yoga for chronic headaches in youth: Promise amidst challenges. *Pain Management Nursing, 15*(2), 490–498.

Harris, M. A., Wagner, D. V., Wilson, A. C., Spiro, K., Heywood, M., & Hoehn, D. (2015). Novel interventions in children's healthcare for youth hospitalized for chronic pain. *Clinical Practice in Pediatric Psychology, 3*(1), 48–58.

Heathcote, L. C., Vervoort, T., Eccleston, C., Fox, E., Jacobs, K., Van Ryckeghem, D. M., & Lau, J. Y. (2015). The relationship between adolescents' pain catastrophizing and attention bias to pain faces is moderated by attention control. *Pain, 156*(7), 1334–1341.

Hechler, T., Kanstrup, M., Holley, A. L., Simons, L. E., Wicksell, R., Hirschfeld, G., & Zernikow, B. (2015). Systematic review on intensive interdisciplinary pain treatment of children with chronic pain. *Pediatrics, 136*(1), 115–127.

Higgins, K. S., Birnie, K. A., Chambers, C. T., Wilson, A. C., Caes, L., Clark, A. J., … Campbell-Yeo, M. (2015). Offspring of parents with chronic pain: A systematic review and meta-analysis of pain, health, psychological, and family outcomes. *Pain, 156*(11), 2256–2266.

Holley, A. L., Wilson, A. C., & Palermo, T. M. (2017). Predictors of the transition from acute to persistent musculoskeletal pain in children and adolescents: A prospective study. *Pain, 158*(5), 794–801.

Holsti, L., Backman, C. L., & Engel, J. M. (2014). Occupational therapy. In P. J. McGrath, B. Stevens, S. M. Walker, & W. T. Zempsky (Eds.), *Oxford textbook of pediatric pain*. Oxford: Oxford University Press.

IASP Taxonomy Working Group. (2011). *Classification of chronic pain* (2nd ed.). Retrieved October 20, 2017, from http://www.iasp-pain.org/PublicationsNews/Content.aspx?Itemnumber=1673&navItemNumber=677.

Kashikar-Zuck, S., Zafar, M., Barnett, K. A., Aylward, B. S., Strotman, D., Slater, S. K., … Powers, S. W. (2013). Quality of life and emotional functioning in youth with chronic migraine and juvenile fibromyalgia. *Clinical Journal of Pain, 29*(12), 1066–1072.

King, S., Chambers, C. T., Huguet, A., MacNevin, R. C., McGrath, P. J., Parker, L., & MacDonald, A. J. (2011). The epidemiology of chronic pain in children and adolescents revisited: A systematic review. *Pain, 152*(12), 2729–2738.

Law, E. F., Beals-Erickson, S. E., Fisher, E., Lang, E. A., & Palermo, T. M. (2017). Components of effective cognitive-behavioral therapy for pediatric headache: A mixed-methods approach. *Clinical Practice in Pediatric Psychology, 5*(4), 376–391.

Law, E. F., Fisher, E., Howard, W. J., Levy, R., Ritterband, L., & Palermo, T. M. (2017). Longitudinal change in parent and child functioning after internet-delivered cognitive-behavioral therapy for chronic pain. *Pain, 58*(10), 1992–2000.

Levy, R. L., Langer, S. L., van Tilburg, M. A., Romano, J. M., Murphy, T. B., Walker, L. S., … Feld, A. D. (2017). Brief telephone-delivered cognitive behavioral therapy targeted to parents of children with functional abdominal pain: A randomized controlled trial. *Pain, 158*(4), 618–628.

Lewandowski, A. S., Palermo, T. M., Stinson, J., Handley, S., & Chambers, C. T. (2010). Systematic review of family functioning in families of children and adolescents with chronic pain. *Journal of Pain, 11*(11), 1027–1038.

Lewandowski, A. S., Toliver-Sokol, M., & Palermo, T. M. (2011). Evidence-based review of subjective pediatric sleep measures. *Journal of Pediatric Psychology, 36*(7), 780–793.

Miller, I. W., Epstein, N. B., Bishop, D. S., & Keitner, G. I. (1985). The McMaster family assessment device: Reliability and validity. *Journal of Marital and Family Therapy, 11*(4), 345–356.

Naar-King, S., Ellis, D., King, P. S., Lam, P., Cunningham, P., Secord, E., … Templin, T. (2014). Multisystemic therapy for high-risk African American adolescents with asthma: A randomized clinical trial. *Journal of Consulting and Clinical Psychology, 82*(3), 536–545.

Noel, M., Wilson, A. C., Holley, A. L., Durkin, L., Patton, M., & Palermo, T. M. (2016). Post-traumatic stress disorder symptoms in youth with versus without chronic pain. *Pain, 157*(10), 2277–2284.

Palermo, T. M. (2008). Validation of a self-report questionnaire version of the Child Activity Limitations Interview (CALI): The CALI-21. *Pain Research and Management, 139*(3), 644–652.

Palermo, T. M. (2012). *Cognitive-behavioral therapy for chronic pain in children and adolescents*. New York, NY: Oxford University Press.

Palermo, T. M., Beals-Erickson, S., Bromberg, M., Law, E., & Chen, M. (2017). A single arm pilot trial of brief cognitive behavioral therapy for insomnia in adolescents with physical and psychiatric comorbidities. *Journal of Clinical Sleep Medicine, 13*(3), 401–410.

Palermo, T. M., & Chambers, C. T. (2005). Parent and family factors in pediatric chronic pain and disability: An integrative approach. *Pain, 119*(1–3), 1–4.

Palermo, T. M., Law, E. F., Bromberg, M., Fales, J., Eccleston, C., & Wilson, A. C. (2016). Problem-solving skills training for parents of children with chronic pain: A pilot randomized controlled trial. *Pain, 157*(6), 1213–1223.

Palermo, T. M., Law, E. F., Fales, J., Bromberg, M. H., Jessen-Fiddick, T., & Tai, G. (2016). Internet-delivered cognitive-behavioral treatment for adolescents with chronic pain and their parents: A randomized controlled multicenter trial. *Pain, 157*, 174–185.

Palermo, T. M., Riley, C. A., & Mitchell, B. A. (2008). Daily functioning and quality of life in children with sickle cell disease pain: Relationship with family and neighborhood socioeconomic distress. *Journal of Pain, 9*, 833–840.

Palermo, T. M., Valrie, C. R., & Karlson, C. W. (2014). Family and parent influences on pediatric chronic pain: A developmental perspective. *American Psychologist, 69*, 142–152.

Powers, S. W., Coffey, C. S., Chamberlin, L. A., Ecklund, D. J., Klingner, E. A., Yankey, J. W., … CHAMP Investigators. (2017). Trial of amitriptyline, topiramate, and placebo for pediatric migraine. *New England Journal of Medicine, 376*, 115–124.

Rabbitts, J. A., Fisher, E., Rosenbloom, B. N., & Palermo, T. M. (2017). Prevalence and predictors of chronic postsurgical pain in children: A systematic review and meta-analysis. *Journal of Pain, 18*, 605–614.

Simons, L. E., Kaczynski, K. J., Conroy, C., & Logan, D. E. (2012). Fear of pain in the context of intensive pain rehabilitation among children and adolescents with neuropathic pain: Associations with treatment response. *Journal of Pain, 13*, 1151–1161.

Simons, L. E., Sieberg, C. B., Conroy, C., Randall, E. T., Shulman, J., Borsook, D., … Logan, D. E. (2018). Children with chronic pain: Response trajectories following intensive pain rehabilitation treatment. *Journal of Pain, 19*(2), 207–218.

Stancin, T. (2016). Commentary: Integrated pediatric primary care: Moving from why to how. *Journal of Pediatric Psychology, 41*, 1161–1164.

Stinson, J. N., Kavanagh, T., Yamada, J., Gill, N., & Stevens, B. (2006). Systematic review of the psychometric properties, interpretability and feasibility of self-report pain intensity measures for use in clinical trials in children and adolescents. *Pain, 125*(1–2), 143–157.

Stone, A. L., & Wilson, A. C. (2016). Transmission of risk from parents with chronic pain to offspring: An integrative conceptual model. *Pain, 157*, 2628–2639.

Swain, M. S., Henschke, N., Kamper, S. J., Gobina, I., Ottova-Jordan, V., & Maher, C. G. (2014). An international survey of pain in adolescents. *BMC Public Health, 14*, 447.

Torkamani, M., Ernst, L., Cheung, L. S., Lambru, G., Matharu, M., & Jahanshahi, M. (2015). The neuropsychology of cluster headache: Cognition, mood, disability, and quality of life of patients with chronic and episodic cluster headache. *Headache, 55*, 287–300.

Tupper, S. M., Swiggum, M. S., O'Rourke, D., & Sangster, M. (2014). Physical therapy interventions for pain in childhood and adolescence. In P. McGrath, B. Stevens, S. Walker, & B. Zempsky (Eds.), *Oxford textbook of paediatric pain* (pp. 581–589). Oxford: Oxford University Press.

Van Slyke, D. A., & Walker, L. S. (2006). Mothers' responses to children's pain. *Clinical Journal of Pain, 22*, 387–391.

Vervoort, T., Logan, D. E., Goubert, L., De Clercq, B., & Hublet, A. (2014). Severity of pediatric pain in relation to school-related functioning and teacher support: An epidemiological study among school-aged children and adolescents. *Pain, 155*, 1118–1127.

Walker, L. S., Sherman, A. L., Bruehl, S., Garber, J., & Smith, C. A. (2012). Functional abdominal pain patient subtypes in childhood predict functional gastrointestinal disorders with chronic pain and psychiatric comorbidities in adolescence and adulthood. *Pain, 153*, 1798–1806.

Weiss, K. E., Harbeck-Weber, C., Zaccariello, M. J., Kimondo, J. N., Harrison, T. E., & Bruce, B. K. (2017). Executive Functioning in Pediatric Chronic Pain: Do Deficits Exist?. Pain Medicine, *19*(1), 60–67.

Westergaard, M. L., Glümer, C., Hansen, E. H., & Jensen, R. H. (2014). Prevalence of chronic headache with and without medication overuse: Associations with socioeconomic position and physical and mental health status. *Pain, 155*, 2005–2013.

Part III

Behavioral Health and Educational Problems: Physical Health Implications

11

Externalizing Disorders

Sean M. O'Dell, Jenna M. Marx, and Monika Parikh

Abstract

Youth with oppositional defiant disorder (ODD) and conduct disorder (CD), referred to together in this chapter as externalizing disorders (ED), represent a sizeable population of youth, and exhibit high rates of comorbidity with other psychiatric disorders, including anxiety disorders, depressive disorders, substance use disorders, and neurodevelopmental disorders such as attention-deficit/hyperactivity disorder. This chapter begins with a discussion of background and etiology of ODD and CD, including associated comorbid diagnoses and health-related behavior problems. We then review considerations for assessment under various real-world conditions. Next, we discuss the treatment literature for youth with ED, with an emphasis on implications for process-oriented intervention. We follow this section with considerations for working across systems to meet the unique and complex need of the population of youth with ED. Then, we provide a case vignette describing the course of treatment for a 9-year-old boy with ODD who was treated in an integrated primary care setting. Last, we close with a discussion of our conclusions and suggestions for future directions for working with families coping with ED.

Introduction

Youth with Oppositional Defiant Disorder (ODD) and Conduct Disorder (CD), referred to together in this chapter as Externalizing Disorders (ED), represent a sizeable population and exhibit high rates of comorbidity with other psychiatric disorders, including anxiety disorders, depressive disorders, substance use disorders, and neurodevelopmental disorders such as attention deficit hyperactivity disorder (ADHD). We maintain the scope of this chapter to focus on ED, and discuss comorbid disorders only to the extent necessary for describing topics within this chapter such as etiology and treatment indications.

This chapter begins with a discussion of background and etiology of ODD and CD, including associated comorbid diagnoses and health-related behavior problems. We then review considerations for assessment under various real-world conditions. Next, we discuss the treatment literature for youth with ED, with an emphasis on implications for process-oriented intervention. We follow this section with considerations for working across systems to meet the unique and

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complex need of the population of youth with ED. Then, we provide a case vignette describing the course of treatment for a 9-year-old boy with ODD who was treated in an integrated primary care setting. Last, we close with a discussion of conclusions and suggestions for future directions for working with families coping with ED.

Background

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association, 2013) criteria for ODD is based on a pattern of behavior including angry/irritable mood, argumentative/defiant behavior, or vindictiveness towards one or more individuals who are not siblings. The DSM-5 diagnostic criteria for CD include more serious norm violations, including aggression towards people and/or animals, destruction of property, deceitfulness or theft, and serious rule breaking. Of note, the DSM-5 added a diagnostic specifier within CD for so-called callous and unemotional (CU) traits, which include lack of empathy and fear, impaired ability to recognize stress in others, discounting of punishment relative to reward, and insensitivity to punishment following negative behaviors. For both ODD and CD, symptoms must be present before age 18 and accompanied by functional impairment in at least one setting to warrant diagnosis.

Prevalence and course. There is a dearth of population-based research to inform reliable and valid estimates of the prevalence rates of ODD and CD. One meta-analysis estimated that ODD and CD have a combined prevalence within the 0–18 population of 6.1% (confidence interval [CI] = 5.4–7.3%), with ODD estimated at 2.8% (CI = 2.1–3.7%) and CD prevalence at 3.5% (CI = 2.7–4.7%) (National Research Council [NRC] and Institute of Medicine [IOM], 2009). Lifetime prevalence is estimated substantially higher for both ODD and CD, although there is not as great a gender difference in lifetime prevalence for ODD between boys (11.2%) and girls (9.2%) as there is for boys (5%) and girls (3%) with CD (Nock, Kazdin, Hiripi, & Kessler, 2007). One factor known to affect the course of both ODD and CD is the timing of onset. Younger age of onset is predictive of a more severe and less remitting course of ODD and CD, as are presence of CU traits (Nock, Kazdin, Hiripi, & Kessler, 2006, 2007).

For youth diagnosed with ED, comorbidities are estimated in upwards of 92% of cases (Nock et al., 2007). For youth with an ED diagnosis, attention deficit hyperactivity disorder and substance use disorder are among the most common (NRC and IOM, 2009). High levels of antisocial behavior are associated with anxiety; however, when individuals also exhibit high levels of CU traits the opposite is true (Frick, Lilienfeld, Ellis, Loney, & Silverthorn, 1999). When both CU traits and anxiety are present in the context of high levels of antisocial behavior, higher rates of physical and sexual abuse histories are common (Frick, Ray, Thornton, & Kahn, 2014).

Etiology. As discussed previously, there is a great deal of overlap between ODD and CD symptoms and comorbidities. This leads to increased complexity in understanding the unique and common contributors to ODD and CD, and highlights the importance for the practicing clinician to be able to identify the heterotypic and homotypic continuity within and across the two disorders to intervene effectively.

The genetic contribution to ED overall appears to be quite high, as evidenced by a heritability factor for clinically significant externalizing symptoms as high as 0.81 (Krueger et al., 2002). With regard to the influence of family of origin, one model states that ED develop as part of coercive family process (i.e., ingrained patterns of family interactions in which individuals are mutually reinforced for engaging in antisocial behavior to get needs met) (Patterson, 1982). This research has since been replicated and shown to be valid for both boys and girls (Eddy, Leve, & Fagot, 2001). However, the implications for coercive family process seem to be central only for those youth who do not exhibit CU traits (Frick & Viding, 2009).

In fact, the mechanisms underlying CU traits are central to the issue of developmental trajectory of antisocial behavior in youth (Frick et al., 2014). Because youth exhibiting CU traits have a temperament marked by fearlessness and low physiological responsiveness to distress in others, CU traits are associated with more proactive aggression and positive expectations for outcomes of aggressive behavior (Thornton, Frick, Crapanzano, & Terranova, 2013). Because these youth do not exhibit the same aversive private experience in response to distress cues in others compared with non-disabled peers, it is thought that they also may not experience the behavioral learning necessary for development of empathic concern (Frick et al., 2014).

Less research has focused on the role that parenting may play in the development and maintenance of CU traits, and findings are inconsistent. A cross-sectional study by Willoughby, Mills-Koonce, Propper, and Waschbusch (2013) found the timing of harsh and intrusive parenting in the first year of life in combination with genetic factors predicted increased likelihood to exhibit CU traits. There are few studies investigating this phenomenon over time; however, the evidence so far suggests that CU traits precede the onset of harsh, inconsistent, and intrusive parenting practices over time (Hawes, Dadds, Frost, & Hasking, 2011; Muñoz, Pakalniskiene, & Frick, 2011). This trend is also seen in the ADHD population, where comorbid ODD and CD is more likely for youth with ADHD when maternal negative/ineffective discipline is present, and CD but not ODD is a more likely outcome when maternal warmth, paternal negative/ineffective discipline, and paternal antisocial personality disorder were present (Pfiffner, McBurnett, Rathouz, & Judice, 2005). Considering that not all heritability of these disorders is explained by genetic or environmental factors alone, gene by environment interactions are implicated in the expression of these behavioral phenotypes. These interactions have important implications for understanding ODD and CD and how it may be treated (Beauchaine, Neuhaus, Brenner, & Gatzke-Kopp, 2008).

Physical Health Implications

ED have been related to risky health behaviors. For example, one study of young adults (18–25 years) with alcohol dependence found that the risk of having ten or more sexual partners significantly increased for those with CD (Cavazos-Rehg et al., 2007). Research in school-aged children also found that elevated CD symptoms significantly increased risk of pregnancy by 12th grade, and that youth with CD symptoms and callous-unemotional traits (CU) were more likely to initiate sex by age 13 than their peers (Wymbs et al., 2013).

ED have also been linked to sleep problems. One study of children 9–16 years old found a reciprocal relationship between ODD and sleep problems, indicating that children who have difficulty falling asleep and have decreased quality of sleep are more likely to have ODD symptoms, and vice versa (Shanahan, Copeland, Angold, Bondy, & Costello, 2014). An extensive literature has linked sleep problems with negative health outcomes, including increased risk for overweight and obesity, high cortisol levels, and decreased metabolic function. One study of male adults diagnosed with CD as children identified several health conditions compared to the general population, including increased use of primary care provider (PCP) treatment, cardiovascular risk based on high-sensitivity C-reactive protein levels, smoking use and dependence, decreased lung function and increased chronic bronchitis, and increased decay of tooth surfaces and other dental problems (Odgers et al., 2007).

Behavioral Health Implications

Individuals with ED in adolescence are also at elevated risk for a range of negative health-related behavioral outcomes in adulthood. Individuals with ED and substance abuse disorders are more likely to drop out and have lower educational attainment than individuals with substance use disorders alone (Esch et al., 2014). These youth with dual diagnoses are also more likely to engage in bullying and relational aggression, although physical aggression is more common in young men compared with young women (Fite, Evans, Cooley, & Rubens, 2013).

Substance use within this population is thought to be associated with predisposition to short-term gratification and discounting of long-term negative outcomes (Grant, Contoreggi, & London, 2000). However, the presence of an ADHD diagnosis does not increase this risk (Serra-Pinheiro et al., 2012). Of note, a diagnosis of ED with earlier onset and without remission was predictive of increased risk for long-term negative outcomes, consistent within the literature (e.g., Esch et al., 2014; Odgers et al., 2007). Although youth with CD seem to be at a greater risk than their ODD peers, there does not appear to be enough research in this area to draw firm conclusions. In a sample of youth with CD and low levels of depressive symptoms, Mason, Hitchings, and Spoth (2008) found that those with lower levels of depression and CD symptoms were more likely to also report substance use. This counterintuitive finding is inconsistent with a study by Maslowsky and Schulenberg (2013), which showed that adolescents with high levels of depression and CD symptoms use substances more frequently, especially for boys.

Screening and Assessment/Evaluation

ED are difficult to precisely diagnose for several reasons, including: (a) wide breadth of symptoms, some of which occur infrequently; (b) many ED symptoms occur covertly and can therefore only be accessed by self-report, and this requires insight and honesty which can be impaired in this population; (c) high comorbidity rates, which exacerbate challenges in differential diagnosis; and (d) high prevalence of parent ED symptoms, which presents challenges for engaging families in treatment. Because discussion of issues related to measurement strategies per se is beyond the scope of this chapter, the following section will emphasize selection of measures and assessment practices aligned with facilitating population-based care, and targeted assessment and progress monitoring for outpatient psychotherapy in real-world settings. As discussed below, considering the goals of the evaluation can help to identify assessment strategies with high treatment utility and efficiency.

Population-based care. One potential method for identifying youth at risk for ED is universal screening (Wilson, Minnis, Puckering, & Gillberg, 2009). Brief screening tools can be used to identify all individuals with identifiable and modifiable risk factors in a population, and refer these families for further assessment, evaluation, and engagement with appropriate levels of services (Powell, Lochman, & Boxmeyer, 2007). Several validated screening instruments are available in the public domain to screen for pediatric mental health problems. The Pediatric Symptom Checklist (PSC) has a 35-item and 17-item version called the PSC-17 that is advantageous for screening purposes (Jellinek & Murphy, 2006), and assesses for internalizing, externalizing, and attention problems in youth aged 3–16. The psychometric properties of the PSC and PSC-17 correspond well to other validated instruments and have well-established criterion scores for its three factors (Gardner et al., 1999). In schools, brief behavior rating scales are commonly used, especially in schools that implement school-wide behavioral supports; however, the PSC-17 is rarely used in school settings. Perhaps the most widely researched and disseminated screener in youth from preschool through grade 12 in school settings is the Behavior and Emotional Screening System (Kamphaus & Reynolds, 2007). Single-item direct behavior rating scales have also been validated in elementary and middle school samples, although the tradeoff that comes with the efficiency of this measurement approach appears to be a reduced positive predictive power (Kilgus, Riley-Tillman, Chafouleas, Christ, & Welsh, 2014).

Targeted assessment and progress monitoring. In most real-world outpatient, community, and school settings, the unstructured clinical interview is a ubiquitous first-line assessment tool. In addition to clinical interviews, validated rating scales for ED or other comorbid disorders assess the frequency and intensity of behaviors relative to diagnostic criteria and allow for efficient early identification, early intervention, and progress monitoring. This is particularly helpful in a brief, solution-focused model where limited sessions are focused on a combination of skill acquisition and performance support aligned with collaborative treatment goals. Given the complexity of symptom presentation across several settings, data from raters in at least two settings are needed to provide a comprehensive summary of symptoms and impairment. One validated idiographic assessment tool is the Youth Top Problems inventory (Weisz et al., 2011), in which stakeholders identify the top three treatment goals and track progress towards these goals throughout treatment.

Assessment instruments completed by parent and teacher stakeholders include the Vanderbilt Assessment Scales, which have been shown by Becker, Langberg, Vaughn, and Epstein (2012) to have clinical utility as an assessment tool for ODD and CD. Although diagnosis using DSM-5 criteria requires 4 out of 8 symptoms listed for ODD and 3 out of 15 symptoms listed for CD, Lindhiem, Bennett, Hipwell, and Pardini (2015) advocate for the use of symptom profiles rather than symptom count, and demonstrated through their research that individuals with a lower symptom count often exhibit more severe behavioral problems than those with a higher symptom count. Clinicians and other professionals using rating scales should be familiar with the recommended diagnostic cutoffs as well as decision errors that may accompany strict adherence to these cutoffs.

Prevention and Intervention

The state of the science in youth psychotherapy is clear in terms of efficacy for the treatment of externalizing problems (Weisz et al., 2017), yet most youth do not have easy access to proven interventions in their community (Wang et al., 2005). A theory-driven, process-oriented, ecological, collaborative, multidisciplinary, and participatory approach is recommended to overcome these barriers (Greenhalgh, Robert, Macfarlane, & Bate, 2004); however, the scientific process for developing the empirically supported treatments for ED has focused more on developing standalone treatments. We first discuss programs with the most empirical support for treatment of externalizing problems in youth. Where possible, we label components of these treatments across *universal* (delivered to all individuals in a population), *targeted* (delivered to those at risk of a negative health outcome), and *indicated* (delivered to those who are assessed to meet criteria for a negative health outcome) levels of intervention to guide the reader as to where these interventions may fit within their unique practice settings. Then, we integrate this information with cross-cutting themes of relevance to the population of families and youth coping with ED.

PAX Good Behavior Game (PAX GBG). PAX GBG (see Embry, 2002, for review) is a teacher-led self-management intervention. Using interdependent group contingencies, groups of students earn at or below a predetermined number of rule violations (e.g., four) during the game to earn a prize. In this way, although all peers within a team are equally responsible for whether they earn a prize for their behavior, they are not competing against other teams. PAX GBG has demonstrated positive effects on classroom externalizing behavior shortly after implementation (Wilson, Hayes, Biglan, & Embry, 2014). The effects of PAX GBG are also long-lasting, as evidenced in a longitudinal study by Musci et al. (2013) in which effects of PAX GBG implementation in first grade on impulsive and aggressive behavior were evident 10 years later for youth who were genetically predisposed to these behaviors.

Positive Parenting Program (Triple P). Several family-based interventions targeting parent–child interactions have considerable evidence of improving externalizing problem behaviors, including Incredible Years (Webster-Stratton, 1998), Parent Management Training-Oregon

Model (Forgatch & Patterson, 2010), and Parent Child Interaction Therapy (Fernandez & Eyberg, 2009). However, none of these programs include components to address population-based challenges of scaling up such interventions for all families in a community. Triple P is a multicomponent parenting and family support intervention to prevent and treat conduct problems in youth up to 12 years of age. Triple P has been studied extensively across levels of intervention, modality of implementation, and in several countries. A recent meta-analysis showed that Triple P evidences substantial improvements across several domains when implemented across universal, targeted, and indicated levels of prevention, including child social-emotional outcomes, externalizing behavior, parenting practices, parenting self-efficacy, parental adjustment, and parent–child relationship (Sanders, Kirby, Tellegen, & Day, 2014). In a study including samples exclusively with conduct problems at age 3, results indicated that the face-to-face standard or enhanced Triple P, as well as the self-directed workbook version of Triple P, was efficacious compared to a waitlist control (Sanders, Carol, Tully, & Bor, 2000). A review of parent-based interventions also supported the conclusion that children with higher initial levels of conduct problems benefit as much or more than youth with lower levels of these challenging behaviors, and that these reductions in ineffective parenting behaviors are an important contributing factor to these changes (Shelleby & Shaw, 2014). Overall, parent-focused interventions based in social learning theory have considerable evidence in improving a range of child and parent outcomes relevant to ODD and CD.

Family Check-Up (FCU). FCU (Dishion, Kavanagh, Schneiger, Nelson, & Kaufman, 2002) is a multicomponent intervention for families coping with youth conduct problems, and includes a universal component of a family resource center that makes evidence-based information more accessible to families, provides paraprofessional support and guidance, and helps to establish and reinforce norms regarding family management practices. At the targeted level of intervention, FCU includes a brief, two-session intervention using motivational interviewing (Miller & Rollnick, 2013) to enhance motivation for change and facilitate engagement in the indicated multicomponent intervention based on a child's age. Initial testing of FCU with a cohort of sixth graders showed that families used relatively few targeted or indicated services, yet did evidence a reduction in substance use throughout middle school compared to control participants (Dishion et al., 2002). Treatment adherence is important to the effects of FCU, as evidenced by subsequent research demonstrating that families who engaged in FCU services, compared with those who were assigned to the FCU but did not engage, showed fewer signs of alcohol, tobacco, or marijuana dependence or abuse by age 23 (Véronneau et al., 2016).

More recent research shows that FCU is a viable treatment for ED across a broad range of age and risk factors. FCU has been shown to improve parenting and peer relationships in preschoolers that maintains in sixth grade (Chang, Shaw, Shelleby, Dishion, & Wilson, 2017). In a study with 2-year-olds from low-income families randomized to FCU or control, families with more impaired parenting behaviors and parental mental health issues benefitted more from FCU than families with fewer risk factors, suggesting that FCU may be an essential service as risk factors increase (Pelham III, Dishion, Tein, Shaw, & Wilson, 2017). Further highlighting long-term benefits of FCU, participants engaged in sixth grade evidenced reductions in suicidal risk that extended into early adulthood (Connell, McKillop, & Dishion, 2016).

Coping Power Program (CPP). CPP is a multicomponent indicated intervention for youth nearing the middle school transition who exhibit conduct problems, such as aggression (Lochman & Wells, 2002). Parents take part in co-led group sessions that cover a range of skills to improve challenging child behavior, homework routine, and manage stress. Parents also learn to support the use of social-cognitive problem-solving skills that are taught by facilitators during concurrent child group sessions. Child sessions address social-cognitive problem-solving deficits through establishing prosocial behavioral expectations for group, teaching emotion regulation strategies, and teaching social problem-solving strategies. Strategies are taught through a combination of video modeling of appropriate skill use, video self-modeling of self-talk and problem-solving skills, and direct instruction with performance support of skills to enhance behavioral inhibition, social skills, and coping with peer pressure. Group size is typically 10 families, and the entire CPP manual is intended to be delivered in 16 sessions. Overall, as a manualized intervention, CPP is recognized as a well-established treatment by the SAMHSA National Registry of Evidence-Based Programs. There is also evidence that CPP can be implemented individually with equal efficacy (Ludmer, Sanches, Propp, & Andrade, 2018). Furthermore, CPP has also been shown to be efficacious when adapted as a universal intervention to reduce aggressive behavior in elementary school students when delivered class-wide (Muratori et al., 2015).

Multisystemic Therapy (MST). An intensive family- and community-based treatment, MST has garnered substantial research evidence in treating ED in adolescence. The range of MST interventions is flexible, and components are meant to address factors at the level of individuals and dyads within families and peer groups. This includes services such as family therapy, parent training, individual psychotherapy, and school-based behavioral interventions. Of the five known randomized controlled trials of MST, all but one (i.e., Sundell et al., 2008) evidenced improvement in conduct problems compared with the comparison condition. However, there were implementation fidelity issues as well as potential confounds due to the content of the treatment as usual condition in the Sundell et al. (2008) study that should be considered. The Sundell et al. study was conducted in Sweden, where instead of a juvenile justice system comparison group often found in the US studies, the comparison group included access to services that are similar to MST content, such as individual and family therapy as well as other home- and community-based services. The US studies demonstrated a meaningful impact on externalizing problems, yet few improvements in serious conduct problems such as delinquency, drug use, violent legal offenses, or overall psychiatric symptoms (Epstein et al., 2015).

Cognitive Behavioral Therapy (CBT). Of note, a common element of all empirically supported treatments for ED is a focus on cognitive, affective, and/or behavioral bases of youth challenging behavior. A recent meta-analysis concluded that CBT is an effective treatment modality for ED across a range of outcomes (Battagliese et al., 2015). Lochman, Powell, Boxmeyer, and Jimenez-Camargo (2011) list the following components of CBT for ED: emotion awareness, perspective taking, anger management, social problem solving, and goal setting. These core components of CBT for ED are relatively distinct compared with CBT for internalizing disorders. Therefore, it seems unlikely that a CBT package developed and tested with youth with internalizing disorders would be sufficient to address the unique challenges of youth with ED, even when comorbid anxiety and depression are present. In the absence of clear empirical evidence to guide clinical decision-making regarding selection and implementation of CBT components for youth with comorbid internalizing disorders and ED, the reader is advised to carefully consider the core processes that selected manuals or modules are intended to address and to collect progress monitoring data to gauge treatment progress and adjust accordingly.

Research Synthesis and Multi-System Treatment Targets

Theoretical consistency and implementation fidelity. Although most interventions for ED claim a social learning theory orientation, few studies have empirically tested theoretical mechanisms of action. Of note, the CPP has been evaluated to be most beneficial for those youth whose parents improve in consistency and predictability of parenting behavior, and youth who evidence improvements in hostile attributional biases and anger during treatment (Lochman & Wells, 2002). Recent work by Lochman, Dishion, Boxmeyer, Powell, and Qu (2017) demonstrated that the behavior of group facilitators of the child group portion of CPP is important for youth outcomes. Facilitator modeling of self-regulation and warmth during sessions were a strong predictor of youth behavior during the 32 group sessions. Of note, in-session challenging behaviors were not related to baseline levels of challenging behaviors at home and school; however, in-session challenging behaviors did predict functioning on home and school outcomes at 1-year follow-up. This suggests that training group facilitators, and potentially parents and teachers, to become highly skilled in maintaining self-regulation in response to challenging behavior is an important social learning component of CPP and potentially other psychosocial treatments for ODD and CD.

Individual factors. As discussed previously, deficits in emotion regulation, executive functioning, and social information processing are common in youth with ED (Conner & Lochman, 2010). Emotion regulation is also considered central to ADHD (Barkley, 2016); however, research has shown that social-cognitive problem-solving difficulties within the ADHD population are no longer significant after controlling for ODD symptoms (Kofler, Larsen, Sarver, & Tolan, 2015). This suggests that emotion regulation may only be a core process of interest in intervention for those with ED and comorbid ADHD. It follows that those exhibiting emotion regulation deficits may benefit most from interventions targeting these processes, and under some circumstance may even require interventions specifically tailored to remediation of individual deficits in order to benefit (Matthys, Vanderschuren, Schutter, & Lochman, 2012). Language functioning is also an important factor to attend to in the treatment of youth with ED, as language impairments have been found to mediate the relationship between social information processing and externalizing psychopathology (Yaghoub Zadeh, Im-Bolter, & Cohen, 2007). For this reason, care should be taken during the intervention process to model and practice effective use of language for thought and emotion identification, as well as social problem solving. Expressive or receptive language impairments that are more pervasive likely warrant referral to a speech and language pathologist.

Peers. There is little research investigating the impact of peers on development of ED or treatment response (Frick et al., 2014). Most of the research conducted to date has focused on documenting the tendency of youths with elevated CU traits to associate with antisocial peers. However, no known research has demonstrated methods to influence how youths with elevated CU traits are perceived by their peers, the quality of their peer relationships, or the quality of their social skills through including peers in treatment.

Family. Given the high heritability estimates of ED, it is likely that parents of youth with ODD and CD were also raised in non-nurturing home environments and may be experiencing similar social information processing deficits that are influencing their parenting choices. Most research indicates that hostile and coercive parenting is more related to conduct problems in those with normative levels of CU traits (e.g., Frick & Viding, 2009). However, less research has focused on the role that parenting may play in the development and maintenance of CU traits. Given these gaps in clear evidence regarding the quality of parenting behavior in early childhood on development of CU traits, it seems warranted to recommend targeting increases in positive, warm parent–child interactions as well as reducing harsh and intrusive parenting behaviors in a family-based intervention with young children exhibiting externalizing challenging behaviors.

School. Nurturing school environments can be characterized by high quality early education and school-aged educational programming, positive school climate, engagement of child and family stakeholders in school activities, providing health education and preventive interventions, and afterschool activities (Komro, Flay, & Biglan, 2011). PAX GBG and PATHS curricula (Kelly, Longbottom, Potts, & Williamson, 2004) are positive examples of programs aligned with these ideals, and should be strongly considered by school-based practitioners for implementation. When schools employ high quality foundational programming and related services, youth with ED are more likely to benefit from instruction.

Implications for Interprofessional Care

Treatment modalities for ED have varied greatly in intensity, setting, and structure. This section will first outline historical barriers to treatment, then discuss suggestions for improving care delivery in school and medical settings.

Historical barriers. Substantial barriers to mental health care exist, including health disparities for rural and urban communities resulting from challenges in access, provider availability, transportation, and stigma (Human & Wasem, 1991). Even in areas where these specific issues are not a barrier to treatment, navigating the managed care system, in which behavioral health is often a carve-out insurance product, can create additional barriers stemming from complicated policy jargon, session limits, and exclusion of pre-existing conditions. Even for families that are successful in establishing treatment and obtaining workable insurance coverage, additional barriers may exist. For example, poor or absent communication between various care providers may lead to fragmentation of services, resulting in inefficient service delivery, possible conflict between providers that is confusing for families, and ultimately suboptimal outcomes.

Care delivered in the medical setting. Service delivery models using behavioral health providers integrated in primary care practices have promise to improve continuity and comprehensiveness of care for youth with ED. Asarnow, Rozenman, Wiblin, and Zeltzer (2015) conducted a meta-analysis of outcome studies for pediatric integrated care, and showed that for studies targeting ED and ADHD, there was a small to medium effect ($d = 0.51$), and that overall there was a 66% chance that youth would fare better if they received integrated care for an identified mental health concern versus treatment as usual. Tynan and Woods (2013) discuss policy and program recommendations for supporting integration of psychologists in a pediatric medical home service delivery model. The authors recommend training PCPs in behavioral health and development topics, implementation of validated screening instruments for medical professionals, opportunities for grant-funded training in implementation science for practice teams, and development of alternative payment structures that facilitate collaborative care. To this last point, alternative payment models such as reimbursement for specific CPT codes and capitation models have been proposed and tested, yet are still unavailable in most practice settings and may not result in financial sustainability even when implemented (e.g., Monson, Sheldon, Ivey, Kinman, & Beacham, 2012). Also, these changes may not be workable for rural areas, where the number of patients is not great enough for healthcare payers to manage financial risk (MacKinney, Mueller, & McBride, 2011). In all, research and policy in this area is in its infancy, and if comprehensive care in medical settings for youth with ED is to be brought to scale, these policy, organizational, and provider barriers will need to be solved along the way.

Care delivered in the school setting. Although 70–80% of youth with ED receive exclusively school-based mental health services, evidence of effectiveness is mixed (Allen, 2015). Simon (2016) posits that children, especially those with ED, benefit from structured environments that include outlining clear expectations, consistent consequences, and ongoing performance feedback. Simon also notes that specific interventions include the use of behavioral contracts, and school-wide positive behavior interventions and supports have a positive impact on student educational functioning. Home-school coordination of interventions can also have a positive impact. One method of improving home-school collaboration is the use of the daily behavior report card, which identifies clear behavioral expectations to be assessed multiple times throughout the day, with rewards provided at home for meeting predetermined goals (Evans, Owens, & Bunford, 2014). Another is the conjoint behavioral consultation model (Sheridan, Bovaird, Glover, Garbacz, & Witte, 2012), which ideally involves all natural stakeholders in a series of meetings to identify the problem, develop an intervention plan, and evaluate treatment response to determine next steps.

Case Study

Billy Joe Smith is a 9-year-old boy who lives with his biological parents, 2-year-old sister, 11-year-old brother, and paternal grandmother. Billy's pediatrician initiated a same-day brief consultation with the integrated behavioral health provider (BHP) while Billy and family were in the office for evaluation of flu-like symptoms and Billy's refusal to take medication. At this evaluation, the family reported to the BHP that these challenging behaviors were longstanding, and included physical aggression towards siblings, emotion dysregulation, and refusal to follow instructions. The family accepted an invitation from the BHP to complete a same-day behavioral health evaluation to determine the appropriate services to help with these concerns. During the evaluation, parents reported that these challenging behaviors first began when Billy Joe was 3 years old, and predominantly occurred at home. These challenging behaviors were perplexing for them in part because Billy's siblings have never exhibited these behaviors. Billy did not receive intervention services for these concerns in early childhood, but the family did consult with his pediatrician when Billy was 7 before the clinic had an integrated BHP and Billy was subsequently prescribed a low dose of risperidone. The family noticed an improvement in aggression, as well as negative side effects of rapid weight gain, no improvement in following instructions, and the family's concern of emotion dysregulation had been replaced by concerns the medication blunted his personality and Billy "just didn't seem like himself." Because of these concerns, the medication was discontinued after 6 months, and no other treatments were tried.

In addition to Billy's challenging behavior at home, these behaviors became problematic in the school setting within the last year. At the time of the evaluation, Billy was a third grade student in a public elementary school and was performing well academically in all classes except reading; Billy was reading on par with the average student at the beginning of second grade based on the most recent progress monitoring data communicated to the family. Billy reportedly got into a fight with another boy at recess after an argument about whether he was tagged in kickball, which resulted in 1 day of afternoon detention. More concerning to parents, Billy's mother reported Billy did not seem to show remorse for injuring the boy. Rather, Billy repeatedly denied responsibility for his actions and blamed the boy for "making him" become aggressive and "feel bad" for the boy when Billy saw the boy was injured. Billy's mother reported that homework "takes forever" and he becomes easily frustrated with reading tasks as evidenced by refusing to complete his work and breaking pencils. Billy has a consistent history of taking his brother's belongings without permission and at times destroying these items when prompted to give them back. When caught, Billy does not appear to display remorse for damaging his brother's belongings. Instead, Billy usually blames his brother stating, "he deserves it because he takes my stuff all the time." Additionally, Billy's mother reported frustration that Billy rarely admits to these behaviors even when caught in the act. Parents reported they tried explaining to Billy why these choices were wrong, yelling at him, grounding him from screen time for a week at a time, and spanking when he aggresses towards siblings; however, these strategies have not improved matters. Based on the facts presented by the family during the evaluation, Billy was diagnosed with ODD, and the BHP engaged the family in discussion about interventions that could be delivered through the clinic and through consultation with school personnel.

Billy and his family subsequently engaged in a behavioral parent training group intervention held weekly at the integrated primary care clinic. The group included parenting skills such as specific praise, token economy, planned ignoring, and punishments based on natural and logical consequences. Billy also learned social problem-solving skills such as emotion identification and regulation skills, perspective taking, and brainstorming solutions to problems before acting. In planning for school-based intervention, the BHP recommended that the school consider a reading fluency intervention, as Billy's lagging reading skills were likely exacerbating his challenging classroom behavior now that the curriculum has shifted from reading for the purpose of building fluency to reading for the purpose of learning academic content across all subjects. The BHP also engaged in bi-weekly, brief phone consultation with school personnel to assist with generalizing skills beyond the home setting and managing classroom behavior. Billy's teacher was willing to collaboratively develop and implement a daily behavior report card for the target behaviors of, (a) follow instructions the first time; (b) be respectful; and (c) keep hands and feet to self. In Billy's case, this strategy facilitated bidirectional communication between his parents and teachers to implement consistent practices across both settings, and making screen time at home contingent on meeting these goals at school worked well to improve Billy's motivation to adhere to these behavioral expectations. Within 6 months of the evaluation, the family reported that Billy's behavior at home and school was "a lot better, but he still has his moments," and the frequency and intensity of challenging behaviors was reduced and Billy has made one new friend at school. Billy was eventually referred to the reading specialist to engage in a reading fluency pre-referral intervention.

Commentary on case study. Billy's example is relatively uncommon in that he evidenced clinically significant ODD symptoms without comorbidity at the time of the evaluation with the BHP; however, the treatment components used in this vignette would apply to most boys his age if ODD was comorbid with other disorders. Given Billy' early onset and consistent course of ODD behaviors, Billy is at relatively high risk for a host of negative outcomes if this trajectory is not improved. Based on the history taken from the family in the unstructured clinical interview, it appears that Billy's more challenging temperament compared with his siblings interacted with negative and ineffective parenting behaviors to maintain and exacerbate these challenging behaviors over time. Before working with the BHP, Billy's parents mistakenly concluded that because their parenting style "worked" with the other siblings, that Billy was the only one who needed to change. In Billy's case, it appears that his apparent lack of remorse and unwillingness to accept responsibility for his actions is better explained by hostile attribution biases than CU traits, as evidenced by Billy's emotion dysregulation that typically precedes aggressive behavior, lack of other CD behaviors, ability to demonstrate age-appropriate empathy and affect when seeing his peer injured, and parental modeling of aggression in the form of spanking as an acceptable way to punish others' wrongdoing.

Sadly, Billy and his family endured daily stress and hardship for years before seeking help. Universal screening for these behaviors in the primary care clinic would have likely identified Billy as in need of intervention at preschool-age, but this was not available in the clinic at that time. It is common for primary care physicians to function as front-line behavioral health providers, and the use of atypical antipsychotics to manage disruptive behaviors is as common in primary care settings as it is unhelpful (Penfold et al., 2013). Years after the onset of the challenging behaviors, access to brief consultation and same-day evaluation in primary care helped the family gain access to evidence-based psychosocial treatment for ODD. Of note, Billy's case highlights the implications of language impairments common in ED for academic and behavioral functioning. Billy's lagging reading skills represented a tipping point for his challenging behavior to cause substantial behavioral problems in school as well as at home. Engaging in multimodal treatment for ODD combining outpatient behavioral parent training and social problem-solving skills training with school-based consultative intervention proved to be a helpful combination for Billy and his family. Parents improved in their consistent use of positive reinforcement techniques to increase the frequency of desirable behaviors, and reduced the frequency of negative and ineffective discipline by relying on natural and logical consequences as the primary class of punishment techniques. Working proactively with the school, the adult stakeholders could leverage Billy's strong preference for screen time as an extrinsic motivator to facilitate more behavior in school that would afford Billy both the opportunity to close the achievement gap in reading and benefit from ongoing instruction. Billy's case illustrates the negative impact of lack of access to proven treatments for ED. Without access to these services, Billy's future in terms of academic and social outcomes appeared bleak. This case also highlights the importance of shared decision-making and collaboration throughout the intervention process, as without active engagement from the family and school, access to services in primary care could not have yielded these results.

Conclusions and Future Directions

The constellation of behaviors comprising ED are multiply determined, and often require comprehensive assessment and interventions from a young age throughout the developmental course across multiple stakeholders and settings. The substantial challenge of successfully engaging stakeholders to treat ED is compounded by the high rates of comorbidity within this population across educational, behavioral, social-emotional, and physical health domains. Given that etiology of ED is well understood and there are several proven interventions across varying levels of intensity, the main challenges in addressing ED are those associated with eliminating the widespread difficulty accessing timely, effective interventions in real-world settings. To address these challenges, more systematic study of the factors that function as barriers and facilitators to the dissemination and implementation of these effective treatments is needed. Likewise, development and implementation of policies that strengthen capacity and collaboration within and across home, school, medical, and community settings are needed to support these efforts. Given the steep cost associated with failing to prevent or intervene with ED, it is imperative that coordinated and sweeping efforts work to close these historic and contemporary gaps.

References

Allen, K. (2015). Externalizing disorders: Assessment, treatment, and school-based interventions. In R. Flanagan, K. Allen, & E. Levine (Eds.), *Cognitive and behavioral interventions in the schools: Integrating theory and research into practice* (pp. 161–180). New York, NY: Springer.

American Psychiatric Assocation. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Assocation.

Asarnow, J. R., Rozenman, M., Wiblin, J., & Zeltzer, L. (2015). Integrated medical-behavioral care compared with usual primary care for child and adolescent behavioral health: A metaanalysis. *JAMA Pediatrics, 169*, 929–937.

Barkley, R. A. (2016). Recent longitudinal studies of childhood attention-deficit/hyperactivity disorder: Important themes and questions for further research. *Journal of Abnormal Psychology, 125*, 248–255.

Battagliese, G., Caccetta, M., Luppino, O. I., Baglioni, C., Cardi, V., Mancini, F., & Buonanno, C. (2015). Cognitive-behavioral therapy for externalizing disorders: A meta-analysis of treatment effectiveness. *Behaviour Research and Therapy, 75*, 60–71.

Beauchaine, T. P., Neuhaus, E., Brenner, S. L., & Gatzke-Kopp, L. (2008). Ten good reasons to consider biological processes in prevention and intervention research. *Development and Psychopathology, 20*, 745–774.

Becker, S. P., Langberg, J. M., Vaughn, A. J., & Epstein, J. N. (2012). Clinical utility of the Vanderbilt ADHD diagnostic parent rating scale comorbidity screening scales. *Journal of Developmental & Behavioral Pediatrics, 33*, 221–228.

Cavazos-Rehg, P. A., Spitznagel, E. L., Bucholz, K. K., Norberg, K., Reich, W., Nurnberger, J., & Bierut, L. J. (2007). The relationship between alcohol problems and dependence, conduct problems and diagnosis, and number of sex partners in a sample of young adults.

Alcoholism: Clinical and Experimental Research, 31, 2046–2052.

Chang, H., Shaw, D. S., Shelleby, E. C., Dishion, T. J., & Wilson, M. N. (2017). The long-term effectiveness of the family check-up on peer preference: Parent-child interaction and child effortful control as sequential mediators. *Journal of Abnormal Child Psychology, 45*, 705–717.

Connell, A. M., McKillop, H. N., & Dishion, T. J. (2016). Long-term effects of the family check-up in early adolescence on risk of suicide in early adulthood. *Suicide and Life-threatening Behavior, 46*, S15–S22.

Conner, B. T., & Lochman, J. E. (2010). Comorbid conduct disorder and substance use disorders. *Clinical Psychology: Science and Practice, 17*, 337–350.

Dishion, T. J., Kavanagh, K., Schneiger, A., Nelson, S., & Kaufman, N. K. (2002). Preventing early adolescent substance use: A family-centered strategy for the public middle school. *Prevention Science, 3*, 191–201.

Eddy, J. M., Leve, L. D., & Fagot, B. I. (2001). Coercive family processes: A replication and extension of Patterson's coercion model. *Aggressive Behavior, 27*, 14–25.

Embry, D. D. (2002). The Good Behavior Game: A best practice candidate as a universal behavioral vaccine. *Clinical Child and Family Psychology Review, 5*, 273–297.

Epstein, R., Fonnesbeck, C., Williamson, E., Kuhn, T., Lindegren, M. L., Rizzone, K., … McPheeters, M.. (2015). Psychosocial and pharmacologic interventions for disruptive behavior in children and adolescents. Comparative Effectiveness Review No. 154. (Prepared by the Vanderbilt Evidence-based Practice Center under contract no. 290-2012-00009-I.) AHRQ publication no. 15(16)-EHC019-EF. Rockville, MD: Agency for Healthcare Research and Quality; October 2015. Retrieved from www.effectivehealthcare.ahrq.gov/reports/final.cfm.

Esch, P., Bocquet, V., Pull, C., Couffignal, S., Lehnert, T., Graas, M., … Ansseau, M. (2014). The downward spiral of mental disorders and educational attainment: A systematic review on early school leaving. *BMC Psychiatry, 14*, 237.

Evans, S. W., Owens, J. S., & Bunford, N. (2014). Evidence-based psychosocial treatments for children and adolescents with attention-deficit/hyperactivity disorder. *Journal of Clinical Child & Adolescent Psychology, 43*, 527–551.

Fernandez, M., & Eyberg, S. (2009). Predicting treatment and follow-up attrition in Parent–Child Interaction Therapy. *Journal of Abnormal Child Psychology, 37*, 431–441.

Fite, P. J., Evans, S. C., Cooley, J. L., & Rubens, S. L. (2013). Further evaluation of associations between attention-deficit/hyperactivity and oppositional defiant disorder symptoms and bullying-victimization in adolescence. *Child Psychiatry & Human Development, 45*, 32–41.

Forgatch, M. S., & Patterson, G. R. (2010). Parent Management Training-Oregon Model: An intervention for antisocial behavior in children and adolescents. In J. R. Weisz & A. E. Kazdin (Eds.), *Evidence-based psychotherapies for children and adolescents* (2nd ed., pp. 159–178). New York, NY: Guilford.

Frick, P. J., Lilienfield, S. O., Ellis, M., Loney, B., & Silverthorn, P. (1999). The association between anxiety and psychopathy dimensions in children. *Journal of Abnormal Child Psychology, 27*, 383–392.

Frick, P. J., Ray, J. V., Thornton, L. C., & Kahn, R. E. (2014). Can callous-unemotional traits enhance the understanding, diagnosis, and treatment of serious conduct problems in children and adolescents? A comprehensive review. *Psychological Bulletin, 140*, 1–57.

Frick, P. J., & Viding, E. M. (2009). Antisocial behavior from a developmental psychopathology perspective. *Development and Psychopathology, 21*, 1111–1131.

Gardner, W., Murphy, J. M., Childs, G., Kelleher, K., Pagano, M., Jellinek, M., … Chiappetta, L. (1999). The PSC-17: A brief Pediatric Symptom Checklist with psychosocial problem subscales. A report from PROS and ASPN. *Ambulatory Child Health, 5*, 225–236.

Grant, S., Contoreggi, C., & London, E. D. (2000). Drug abusers show impaired performance in a laboratory test of decision making. *Neuropsychologia, 38*, 1180–1187.

Greenhalgh, T., Robert, G., Macfarlane, F., & Bate, P. (2004). Diffusion of innovations in service organizations: Systematic review and recommendations. *Milbank Quarterly, 82*, 581–629.

Hawes, D. J., Dadds, M. R., Frost, A. D. J., & Hasking, P. A. (2011). Do childhood callous-unemotional traits drive change in parenting practices? *Journal of Clinical Child and Adolescent Psychology, 40*, 507–518.

Human, J., & Wasem, C. (1991). Rural mental health in America. *American Psychologist, 46*, 232–239.

Jellinek, M. S., & Murphy, J. M. (2006). *Pediatric symptoms checklist–17* [Instrument]. Retrieved from http://www.massgeneral.org/psychiatry/assets/PSC-17_English.pdf.

Kamphaus, R. W., & Reynolds, C. R. (2007). *Behavior assessment system for children—2nd ed. (BASC–2): Behavioral and emotional screening system (BESS)*. Bloomington, MN: Pearson.

Kelly, B., Longbottom, J., Potts, F., & Williamson, J. (2004). Applying emotional intelligence: Exploring the Promoting Alternative Thinking Strategies curriculum. *Educational Psychology in Practice, 20*, 221–240.

Kilgus, S. P., Riley-Tillman, T. C., Chafouleas, S. M., Christ, T. J., & Welsh, M. E. (2014). Direct behavior rating as a school-based behavior universal screener: Replication across sites. *Journal of School Psychology, 52*, 63–82.

Kofler, M. J., Larsen, R., Sarver, D. E., & Tolan, P. H. (2015). Developmental trajectories of aggression, prosocial behavior, and social–cognitive problem solving in emerging adolescents with clinically elevated attention-deficit/hyperactivity disorder symptoms. *Journal of Abnormal Psychology, 124*, 1027–1042.

Komro, K. A., Flay, B. R., & Biglan, A. (2011). Creating nurturing environments: A science-based framework for promoting child health and development within high-poverty neighborhoods. *Clinical Child and Family Psychology Review, 14*, 111–134.

Krueger, R. F., Hicks, B. M., Patrick, C. J., Carlson, S. R., Iacono, W. G., & McGue, M. (2002). Etiological connections among substance dependence, antisocial behavior, and personality: Modeling the externalizing spectrum. *Journal of Abnormal Psychology, 111*, 411–424.

Lindhiem, O., Bennett, C. B., Hipwell, A. E., & Pardini, D. A. (2015). Beyond symptom counts for oppositional defiant disorder and conduct disorder? *Journal of Abnormal Child Psychology, 43*, 1379–1387.

Lochman, J. E., Dishion, T. J., Boxmeyer, C. L., Powell, N. P., & Qu, L. (2017). Variation in response to evidence-based group preventive intervention for disruptive behavior problems: A view from 938 Coping Power sessions. *Journal of Abnormal Child Psychology, 45*, 1271–1284.

Lochman, J. E., Powell, N. P., Boxmeyer, C. L., & Jimenez-Camargo, L. (2011). Cognitive-behavioral therapy for externalizing disorders in children and adolescents. *Child and Adolescent Psychiatric Clinics of North America, 20*, 305–318.

Lochman, J. E., & Wells, K. C. (2002). Contextual social-cognitive mediators and child outcome: A test of the theoretical model in the Coping Power program. *Development and Psychopathology, 14*, 945–967.

Ludmer, J. A., Sanches, M., Propp, L., & Andrade, B. F. (2018). Comparing the multicomponent coping power program to individualized parent–child treatment for improving the parenting efficacy and satisfaction of parents of children with conduct problems. *Child Psychiatry and Human Development, 49*, 100–108.

MacKinney, A. C., Mueller, K. J., & McBride, T. D. (2011). The march to accountable care organizations-how will rural fare? *The Journal of Rural Health, 27*, 131–137.

Maslowsky, J., & Schulenberg, J. E. (2013). Interaction matters: Quantifying Conduct Problem Depressive Symptoms interaction and its association with adolescent alcohol, cigarette, and marijuana use in a national sample. *Development and Psychopathology, 25*, 1029–1043.

Mason, W. A., Hitchings, J. E., & Spoth, R. L. (2008). The interaction of conduct problems and depressed mood in relation to adolescent substance involvement and peer substance use. *Drug and Alcohol Dependence, 96*, 233–248.

Matthys, W., Vanderschuren, L. J. M. J., Schutter, D. J. L. G., & Lochman, J. E. (2012). Impaired neurocognitive functions affect social learning processes in oppositional defiant disorder and conduct disorder: Implications for interventions. *Clinical Child and Family Psychology Review, 15*, 234–246.

Miller, W. R., & Rollnick, S. (2013). *Motivational interviewing: Helping people change*. New York, NY: Guilford Press.

Monson, S. P., Sheldon, J. C., Ivey, L. C., Kinman, C. R., & Beacham, A. O. (2012). Working toward financial sustainability of integrated behavioral health services in a public health care system. *Families, Systems & Health, 30*, 181–186.

Muñoz, L. C., Pakalniskiene, V., & Frick, P. J. (2011). Parental monitoring and youth behavior problems: Moderation by callous-unemotional traits over time. *European Child & Adolescent Psychiatry, 20*, 261–269.

Muratori, P., Bertacchi, I., Giuli, C., Lombardi, L., Bonetti, S., Nocentini, A., … Lochman, J. E. (2015). First adaptation of coping power program as a classroom-based prevention intervention on aggressive behaviors among elementary school children. *Prevention Science, 16*, 432–439.

Musci, R. J., Bradshaw, C. P., Maher, B., Uhl, G. R., Kellam, S. G., & Ialongo, N. S. (2013). Reducing aggression and impulsivity through school-based prevention programs: A gene by intervention interaction. *Prevention Science, 15*, 1–10.

National Research Council and Institute of Medicine. (2009). Preventing mental, emotional, and behavioral disorders among young people: Progress and possibilities. Committee on the prevention of mental disorders and substance abuse among children, youth, and young adults: Research advances and promising interventions. In M. E. O'Connell, T. Boat, & K. E. Warner (Eds.), *Board on Children, Youth, and Families, Division of Behavioral and Social Sciences and Education*. Washington, DC: The National Academies Press.

Nock, M. K., Kazdin, A. E., Hiripi, E., & Kessler, R. C. (2006). Prevalence, subtypes, and correlates of DSM-IV conduct disorder in the National Comorbidity Survey Replication. *Psychological Medicine, 36*, 699–710.

Nock, M. K., Kazdin, A. E., Hiripi, E., & Kessler, R. C. (2007). Lifetime prevalence, correlates, and persistence of oppositional defiant disorder: Results from the National Comorbidity Survey Replication. *Journal of Child Psychology and Psychiatry, 48*, 703–713.

Odgers, C. L., Caspi, A., Broadbent, J. M., Dickson, N., Hancox, R. J., Harrington, H., & Moffitt, T. E. (2007). Prediction of differential adult health burden by conduct problem subtypes in males. *Archives of General Psychiatry, 64*, 476.

Patterson, G. R. (1982). *Coercive family process*. Eugene, OR: Castalia.

Pelham, W. E., III, Dishion, T. J., Tein, J. Y., Shaw, D. S., & Wilson, M. N. (2017). What doesn't work for whom? Exploring heterogeneity in responsiveness to the family check-up in early childhood using a mixture model approach. *Prevention Science, 18*, 911–922.

Penfold, R. B., Stewart, C., Hunkeler, E. M., Madden, J. M., Cummings, J. R., Owen-Smith, A. A., … Simon, G. E. (2013). Use of antipsychotic medications in pediatric populations: What do the data say? *Current Psychiatry Reports, 15*, 426–436.

Pfiffner, L. J., McBurnett, K., Rathouz, P. J., & Judice, S. (2005). Family correlates of oppositional and conduct disorders in children with attention deficit/hyperactivity disorder. *Journal of Abnormal Child Psychology, 33*, 551–563.

Powell, N. R., Lochman, J. E., & Boxmeyer, C. L. (2007). The prevention of conduct problems. *International Review of Psychiatry, 19*, 597–605.

Sanders, M. R., Carol, M. D., Tully, L. A., & Bor, W. (2000). The Triple P-Positive Parenting Program: A comparison of enhanced, standard, and self-directed behavioral family intervention for parent of children with early onset conduct problem. *Journal of Consulting and Clinical Psychology, 68*, 624–640.

Sanders, M. R., Kirby, J. N., Tellegen, C. L., & Day, J. J. (2014). The Triple P-Positive Parenting Program: A systematic review and meta-analysis of a multi-level system of parenting support. *Clinical Psychology Review, 34*, 337–357.

Serra-Pinheiro, M. A., Coutinho, E. S. F., Souza, I. S., Pinna, C., Fortes, D., Araujo, C., … Mattos, P. (2012). Is ADHD a risk factor independent of conduct disorder for illicit substance use? A meta-analysis and metaregression investigation. *Journal of Attention Disorders, 17*, 459–369.

Shanahan, L., Copeland, W. E., Angold, A., Bondy, C. L., & Costello, E. J. (2014). Sleep problems predict and are predicted by generalized anxiety/depression and oppositional defiant disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 53*, 550–558.

Shelleby, E. C., & Shaw, D. S. (2014). Outcomes of parenting interventions for child conduct problems: A review of differential effectiveness. *Child Psychiatry and Human Development, 45*, 628–645.

Sheridan, S. M., Bovaird, J. A., Glover, T. A., Garbacz, S. A., & Witte, A. (2012). A randomized trial examining the effects of conjoint behavioral consultation and the mediating role of the parent-teacher relationship. *School Psychology Review, 41*, 23–46.

Simon, D. J. (2016). Disruptive Behavior Disorders. In *School-centered interventions: Evidence-based strategies for social, emotional, and academic success* (pp. 105–144). Washington, DC: American Psychological Association.

Sundell, K., Hansson, K., Lofholm, C. A., Olsson, T., Gustle, L. H., & Kadesjo, C. (2008). The transportability of multisystemic therapy to Sweden: Short-term results from a randomized trial of conduct-disordered youths. *Journal of Family Psychology, 22*, 550–560.

Thornton, L. C., Frick, P. J., Crapanzano, A. M., & Terranova, A. M. (2013). The incremental utility of callous-unemotional traits and conduct problems in predicting aggression and bullying in a community sample of boys and girls. *Psychological Assessment, 25*, 366–378.

Tynan, W. D., & Woods, K. E. (2013). Emerging issues: Psychology's place in the primary care pediatric medical home. *Clinical Practice in Pediatric Psychology, 1*, 380–385.

Véronneau, M., Dishion, T. J., Connell, A. M., Kavanagh, K., Véronneau, M., Dishion, T. J., … Kavanagh, K. (2016). A randomized, controlled trial of the family check-up model in public secondary schools: Examining links between parent engagement and substance use progressions from early adolescence to adulthood. *Journal of Consulting and Clinical Psychology, 84*, 526–543.

Wang, P. S., Berglund, P., Olfson, M., Pincus, H. A., Wells, K. B., & Kessler, R. C. (2005). Failure and delay in initial treatment contact after first onset of mental disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry, 62*, 603–613.

Webster-Stratton, C. (1998). Preventing conduct problems in Head Start children: Strengthening parenting competencies. *Journal of Consulting and Clinical Psychology, 66*, 715–730.

Weisz, J. R., Chorpita, B. F., Frye, A., Ng, M. Y., Lau, N., Bearman, S. K., … Hoagwood, K. E. (2011). Youth top problems: Using idiographic, consumer-guided assessment to identify treatment needs and to track change during psychotherapy. *Journal of Consulting and Clinical Psychology, 79*, 369–380.

Weisz, J. R., Kuppens, S., Ng, M. Y., Eckshtain, D., Ugueto, A. M., Vaughn-Coaxum, R., … Fordwood, S. R. (2017). What five decades of research tells us about the effects of youth psychological therapy: A multilevel meta-analysis and implications for science and practice. *American Psychologist, 72*, 79–117.

Willoughby, M. T., Mills-Koonce, R., Propper, C. B., & Waschbusch, D. A. (2013). Observed parenting behaviors interact with a polymorphism of the brain-derived neurotrophic factor gene to predict the emergence of oppositional defiant and callous-unemotional behaviors at age 3 years. *Development and Psychopathology, 25*, 903–917.

Wilson, D. S., Hayes, S. C., Biglan, A., & Embry, D. D. (2014). Evolving the future: Toward a science of intentional change. *The Behavioral and Brain Sciences, 37*, 395–460.

Wilson, P., Minnis, H., Puckering, C., & Gillberg, C. (2009). Should we aspire to screen preschool children for conduct disorder? *Archives of Disease in Childhood, 94*, 812–816.

Wymbs, B. T., McCarty, C. A., Baer, J. S., King, K. M., Stoep, A. V., & McCauley, E. (2013). Callous-unemotional traits and conduct disorder symptoms as prospective risk factors for adolescent sexual activity. *Journal of Clinical Child & Adolescent Psychology, 42*, 693–699.

Yaghoub Zadeh, Z., Im-Bolter, N., & Cohen, N. J. (2007). Social cognition and externalizing psychopathology: An investigation of the mediating role of language. *Journal of Abnormal Child Psychology, 35*, 141–152.

Internalizing Disorders

12

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Abstract

Internalizing symptoms are a collection of feelings, behaviors, and physiological responses associated with a host of conditions that include anxiety disorders (generalized, separation, social), depression, post-traumatic stress disorder, panic disorder, and other somatic conditions. These symptoms are highly prevalent in childhood and adolescence and have been associated with a host of negative outcomes across domains of functioning. As these symptoms are often expressed internally, identification poses a unique challenge for clinicians. In the absence of prevention or intervention efforts, internalizing symptoms can be exacerbated and lead to functional impairment that can persist into adulthood. This chapter underscores the importance of understanding and addressing internalizing symptoms in youth from an integrated behavioral health perspective. The first section of this chapter addresses the prevalence and etiology of internalizing symptoms and disorders. The second section focuses on identification, prevention, and treatment. The final section provides a case example and strategies for integrated behavioral health specific to internalizing conditions.

Internalizing Disorders

Internalizing problems is an umbrella term that encompasses a range of responses and feelings that are focused inward towards the self, as opposed to outward towards others. Symptoms include feelings such as sadness, guilt, and worry and are typically expressed through behaviors such as loss of enjoyment in activities, withdrawal, and avoidance. There may also be physiological responses such as general arousal, nausea, and fatigue (Whitcomb & Merrell, 2013). These symptoms can exist in isolation, but may also be indicative of larger problems or may lead to clinically significant psychological disorders (Eklund, Tanner, Stoll, & Anway, 2015). A number of psychiatric diagnoses include the internalizing symptoms, with the most common being anxiety and mood disorders. Although these disorders are diagnosed as distinct conditions based on separate criteria, they frequently co-occur. Internalizing symptoms have also been shown to increase risk for suicide, which is the third

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Table 12.1 Prevalence of internalizing disorders in childhood and adolescence

Disorder	Prevalence	Primary Symptoms
Generalized Anxiety Disorder[a]	1.8% in children; 4% in adolescents	Excessive worry/anxiety; restlessness; irritability; difficulty concentrating; easily fatigued; muscle tension
Separation Anxiety Disorder[a]	4.6% in children; 0.4% in adolescents	Distress related to separation from an attachment figure; refusal to separate; nightmares about separation; fear of being alone
Panic Disorder[a]	0.2% in children; 3% in adolescents	Recurrent unexpected panic attacks associated with a fear of future occurrence
Social Anxiety Disorder[b]	9%	Fear and anxiety specific to social settings; distress in social interaction; avoidance or discomfort in social interactions
Disruptive Mood Dysregulation Disorder[c]	2–5%	Severe, recurrent temper outbursts or physically aggressivity
Major Depressive Disorder[d]	1–3%	Depressed or irritable mood; reduced interest or pleasure, weight loss/gain; insomnia/hypersomnia; psychomotor agitation or retardation; fatigue or loss of energy; feelings of worthlessness or guilt; difficulty concentrating or making decisions; suicidality
Persistent Depressive Disorder[c]	0.5%	Depressed or irritable mood present for 2 years with accompanying depressive symptoms
Posttraumatic Stress Disorder[e]	5–14%	Exposure to a stressor (either witnessed or indirectly experienced) with a specified number of symptoms in the following clusters: intrusion (1); avoidance (1); negative thought or mood (2); arousal and reactivity (2)
Bipolar Disorder[d]	0–2.1%	Abnormal and persistent elevated or irritable mood; inflated self-esteem; decreased need to for sleep; pressured speech; racing thoughts; distractibility; high risk behaviors; increased in goal directed activity

[a] Bittner et al. (2007)
[b] Burstein et al. (2011)
[c] American Psychiatric Association (2013)
[d] Merikangas, Nakamura, and Kessler (2009)
[e] Donnelly and Amaya-Jackson (2002)

leading cause of death in children and adolescents (Martin et al., 2008). In the United States, it is estimated that approximately 10.6% of children and adolescents have mood-related problems, whereas 15–16% experience difficulties related to anxiety (Beesdo, Knappe, & Pine, 2009). The individual prevalence rates and main symptoms of the most common internalizing disorders are presented in Table 12.1.

Etiology

Although highly comorbid, research has indicated different etiologies for depression and anxiety. It is important to recognize that at its core, anxiety is considered adaptive. Depending on the age of the child and the situation, experiencing anxiety is considered developmentally appropriate (e.g., stranger anxiety). However, clinicians should not disregard reports of internalizing symptoms in youth based on the belief that they are normal or temporary. Even mild symptoms have been shown to be predictive of later psychopathology, and a large percentage of internalizing disorders diagnosed in childhood remain into adulthood. Thus, it is critical to assess internalizing symptoms to determine whether problems are clinically significant, persistent, and causing functional impairment that warrant treatment.

In general, the development of an internalizing disorder is considered to be partially due to heritability and genetic loading accompanied by environmental factors and intra-individual characteristics. In the general population, internalizing symptoms are more prevalent in girls as compared to boys (Crick & Zahn–Waxler, 2003). The risk of developing an anxiety disorder is estimated to be seven times greater for a child whose parent has a diagnosis (Woodruff-Borden, Morrow, Bourland, & Cambron, 2002). Similarly, children are 26.1% more likely to develop depression themselves if one parent has a diagnosis of major depressive disorder and 28.5% more likely if both parents do (Mattejat & Remschmidt, 2008). Individual personality traits such as neuroticism (e.g., high emotionality and reactivity to stress) have been implicated as an individual risk factor for anxiety, while negative affectivity is related to the development of depression (Beesdo et al., 2009). Environmental factors also play a critical role; high rates of familial stress and conflict or exposure to trauma are risk factors for developing internalizing symptoms. Thus, clinicians should assess for family history and exposure to environmental risk factors when assessing for internalizing symptoms.

Identification and Classification

In youth, internalizing symptoms can be conceptualized as existing on a continuum instead of an all or nothing diagnosis (Hankin, Fraley, Lahey, & Waldman, 2005). Many of the symptoms may occur in isolation, be transient, or manifest in a way that does not significantly impair functioning. Diagnosis of internalizing disorders is typically warranted when multiple symptoms are present for an extended amount of time and accompanied by functional impairment. However, research has demonstrated that youth do not need to meet full criteria for an internalizing disorder to experience negative outcomes. Instead, the presence of subclinical depressive or anxiety symptoms (i.e., endorsing core symptoms but not meeting full criteria with regard to number of symptoms or duration) has been found to be just as disabling in youth as diagnosable disorders (Lewinsohn, Solomon, Seeley, & Zeiss, 2000).

There is a distinction between a clinical diagnosis and educational classification. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is typically utilized by behavioral health providers to diagnose internalizing disorders, although overlapping disorders are present in the International Statistical Classification of Diseases and Related Health Problems (ICD-10), which is the naming system used within many medical systems. Internalizing symptoms may also qualify children and adolescents for school-based services. Within the education system, services are based on categories outlined in the Individuals with Disabilities Education Improvement Act (IDIEA), as opposed to diagnoses. Students may receive an individualized education plan (IEP) under the category of Other Health Impairment (OHI) under IDEA that may be used to qualify students with anxiety for services. To qualify for OHI, the student must demonstrate, "limited strength, vitality, or alertness to the educational environment…that is due to a chronic or acute health problem…and adversely affects…educational performance" Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004). Depending on the level of impairment, a child with internalizing symptoms may qualify under the category of emotional disturbance (ED). Specifically, they would demonstrate "inappropriate types of behavior or feelings under normal circumstances, a general pervasive mood of unhappiness or depression, a tendency to develop physical symptoms or fears associated with personal or school problems…" (Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004). Alternatively, students can also receive accommodations under Section 504 of the Rehabilitation Act of 1973. Under an IEP, the child receives special education services and must meet strict criteria, while a 504 plan outlines accommodations and/or services required to allow them to access the general education curriculum. Eligibility for a 504 plan is based on whether their condition "causes a substantial limitation on the student's ability to learn or [to complete] another major life activity," which is defined broadly to include impacts on learning, concentration, communication, or physical activities. The accommodations a student receives are largely based on the presentation and severity of their symptoms and may include allowing students additional time on exams or the ability to take tests in a separate location. Students might also require counseling to help cope with their anxiety or social skills training.

In general, diagnoses/classifications are based on meeting criteria outlined for each condition. However, the use of multiple distinct systems for classifying symptoms can create confusion across disciplines. Furthermore, the presentation of symptoms may differ from adult criteria. Specifically, irritability and disruptive behaviors can be indicative of underlying mood disorders in children. Thus, a core component of an integrated and collaborative approach is to clarify terms specific to fields to promote effective communication across systems and providers.

Social, Cognitive, and Educational Implications

Research has suggested that internalizing symptoms can impair functioning though outcomes may differ based on symptom and severity. Further, conclusions drawn from prior research are complicated by the fact that studies vary in the degree of internalizing symptoms participants may have, from experiencing subclinical symptoms versus meeting clinical criteria (e.g., having a diagnosis).

Cognitive and academic impact. With regard to anxiety, children with symptoms of anxiety have been shown to struggle within the educational setting, particularly on exams, public speaking, and overall academic performance (Grover, Ginsburg, & Ialongo, 2007). Although some differences exist, the effects of anxiety on school performance have been documented across different genders, ethnicities, socioeconomic statuses, and populations (general and clinical samples). A longitudinal study indicated that children with high anxiety were nearly three times as likely to score in the lower third on academic achievement tests when compared to youth without anxiety, and these differences remained over time (Grover et al., 2007). Furthermore, youth with anxiety are more likely to experience concentration and attention difficulties in school than students without anxiety, which can be misattributed to attention-deficit/hyperactivity disorder (ADHD; McLoone, Hudson, & Rapee, 2006). Children with anxiety are also at a higher risk for school withdrawal. A study of individuals with anxiety disorders reported that almost 50% of the sample population left school prematurely, with 24% citing anxiety as the primary reason for withdrawal (Van Ameringen, Mancini, & Farvolden, 2003). Similarly, children and adolescents with depression, even mild levels, have been shown to experience functional impairment across domains (Georgiades, Lewinsohn, Monroe, & Seeley, 2006). Specifically, youth with depression perform worse on various memory tasks measuring auditory working memory, verbal recall, and spatial memory (Günther, Holtkamp, Jolles, Herpertz-Dahlmann, & Konrad, 2004). Depression may also contribute to attention and concentration difficulties (Wilkinson & Goodyer, 2006), which can sometimes be misattributed to an attention disorder.

Social and familial impact. Social withdrawal is one of the most prevalent internalizing symptoms and is likely to occur with anxiety and depression. Aspects of internalizing disorders may make forming and maintaining peer relationships difficult. For example, youth with anxiety are often markedly concerned with how others view them and may excessively seek reassurance from others. This behavior may irritate others to the point that the child is ostracized by their peers (Scharfstein, Alfano, Beidel, & Wong, 2011). Youth with anxiety are often perceived as more socially withdrawn than non-anxious peers, which may further impair their ability to maintain healthy peer relationships (Coplan, Girardi, Findlay, & Frohlick, 2007). Children and adolescents with depression may be negatively evaluated by their peers due to their demeanor, resulting in rejection that further reinforces the withdrawal behavior (Rubin, Coplan, & Bowker, 2009). In addition to familial factors increasing the risk for internalizing symptoms in childhood, having a child with these symptoms can also negatively impact the family system. Both depression and anxiety in childhood are associated with increased family conflict and strained parental relationships (Crowe & Brinkley, 2015).

Physical Health Implications

There are limited empirical data regarding the co-occurrence of physical health and internalizing symptoms. Importantly, the diagnostic criteria for some internalizing disorders, such as anxiety or depression, include physical or somatic symptoms. For example, diagnostic criteria for depression includes sleep disturbances (e.g., insomnia/hypersomnia and fatigue), which could be related to a comorbid medical condition as opposed to signs of depression. Thus, it can be difficult to determine the underlying cause of these symptoms in patients with co-occurring medical conditions with similar symptoms. In these cases, it is critical to work collaboratively with the individual's care providers to ensure the patient as a whole is being considered, as opposed to symptoms in isolation. Furthermore, research has supported that youth with chronic medical conditions may be at higher risk for comorbid internalizing symptoms. In a systematic review of neurobiological and physical health symptoms in youth with either anxiety or depression, 19.4% of studies considered outcomes related to neuropsychological findings, 16% examined sleep-wake difficulties, 6.9% studied metabolic effects, and only 2.1% of articles included assessed general physical health complaints (Iorfino, Hickie, Lee, Lagopoulos, & Hermens, 2016). These results suggest that these domains are often overlooked when studying internalizing symptoms in children.

Sleep. Nearly 83% of children with clinical levels of anxiety experience at least one sleep-related problem, including difficulties initiating or maintaining sleep (Alfano, Beidel, Turner, & Lewin, 2006). Furthermore, sleep disturbances have also been found to be a risk factor for onset of depression or anxiety (Quach, Nguyen, Williams, & Sciberras, 2017). In a population-based study, adolescents who had higher levels of depressive symptoms were more likely to exhibit both insomnia and objectively measured insufficient total sleep time (Fernandez-Mendoza et al., 2016). Perfect and colleagues (Perfect, Levine-Donnerstein, Archbold, Goodwin, & Quan, 2014) found that a combination of sleep duration, sleep consistency, insomnia symptoms, daytime sleepiness, and sleep quality contributed to 17.4% and 20% of the variance in the Internalizing Composite on the parent and child versions of the Behavioral Assessment Scales for Children, Second Edition (BASC-2), with daytime sleepiness and concurrent insomnia symptoms uniquely contributing to the prediction. After controlling for demographics such as race/ethnicity, sex, and socioeconomic status, multiple sleep disturbances predicted parent-reported depressive symptoms and self-reported depressive and anxiety symptoms. Insomnia symptoms, sleep duration, and inconsistent sleep patterns between school and non-school nights were significantly related to depressive and anxiety symptoms. Although most studies examining sleep in relation to mental health outcomes have focused on inadequate sleep duration, a recent study found that both short sleep duration and sleep that exceeded the recommendations (well above 11 h for elementary age children) related to self-reported internalizing symptoms (James & Hale, 2017).

General health and medical conditions. In one study, physical health complaints were significantly related to self-reported anxiety and depressive symptoms in adolescents. Severity of these health concerns related to depressive symptoms as well (Guarneri-White, Jensen-Campbell, & Knack, 2015). A study of nearly 9000 older adolescents and adults (ages 16–85) found that internalizing disorders such as depression, anxiety, and PTSD were significantly related to the occurrence of a medical condition such as asthma, cardiac problems, stroke, and arthritis. Furthermore, the comorbidity of depression and pain has been well documented in the literature for adults (Koffel, Krebs, Arbisi, Erbes, & Polusny, 2016). Less information is available about this connection with school-age children; however, data support that youth who experience headaches have higher levels of internalizing symptoms (Arruda & Bigal, 2012).

Evaluation and Assessment of Internalizing Symptoms

As with all evaluations for children, it is considered best practice to utilize a multimethod, multi-informant, and multi-setting approach for the assessment of internalizing symptoms. This method is considered superior as it encompasses all aspects of the child and encourages the use of converging evidence to inform decision-making. The amount of error inherent to each measure is reduced, therefore, increasing the likelihood that the final conclusions are correct (Whitcomb & Merrell, 2013). However, comprehensive evaluations can be time consuming and may not be necessary in all cases. Screening has been shown to effectively identify individuals at high risk that may have been otherwise missed in a referral only model. Thus, practitioners in busy pediatric primary care settings or schools can utilize these procedures to reduce burden and cost. In addition to screening, internalizing symptoms can be further assessed using a variety of methods, such as single construct measures and omnibus rating scales. Table 12.2 presents common tools that can be utilized within multidisciplinary settings.

Screening measures. Screening instruments offer a brief, yet valid, option for assessing psychological impairment in children and adolescents, including internalizing symptoms. Questionnaires are generally short and can be administered by a variety of professionals across multiple settings with minimal training. Results of screening measures can be utilized to identify youth who are at-risk for or evidence impairment, determine individuals in need of further evaluation, and be used to monitor treatment outcomes. Measures that are commonly used as screeners in primary or clinical settings include the Screen for Child Anxiety Related Disorders (SCARED; Birmaher, Brent, Chiappetta, Bridge, Monga, & Baugher, 1999) or Patient Health Questionnaire (PHQ-9; Richardson et al., 2010) and are available for free. The BASC-3 Behavioral and Emotional Screening System (BASC-3 BESS) is frequently used in schools to assess for a variety of behavioral and emotional strengths and weaknesses.

Structured and semi-structured interviews. Comprehensive evaluations typically involve an interview component with both the child (if age appropriate) and their caregiver. These interviews can take multiple forms. Research has supported the use of structured or semi-structured interviews as a reliable tool for diagnosing psychopathology in children and adolescents (Leffler, Riebel, & Hughes, 2015). These instruments are unique from regular clinical interviews in that they have a set structure, involve a script, and are typically designed for a specific purpose, such as diagnosing a particular disorder (Whitcomb & Merrell, 2013). Several instruments have been validated for use in youth, such as the Diagnostic Interview Schedule for Children, Fourth Edition (DISC-IV; Shaffer, Fisher, Lucas, Dulcan, & SchwabStone, 2000).

Omnibus and single construct measures. Questionnaires offer a reliable way to collect information about symptomology from multiple sources. This method has the advantage of being able to compare responses to individuals of the same age and/or gender to determine symptoms severity. Omnibus questionnaires measure a broad range of symptoms (e.g., internalizing symptoms), whereas single construct measures typically focus on a single domain (e.g., depression). Typically, an omnibus measure is administered to examine functioning broadly. For example, the BASC-3 is a comprehensive rating scale for evaluating adaptive and problem behaviors in children and adolescents. If any areas of impairment are identified, a single con-

Table 12.2 Measures of internalizing symptoms

Measure	Description	Domain(s)	Informant(s)
Screeners			
Behavioral and Emotional Screening System (BESS)[a]	Identifies behavioral and emotional strengths and weaknesses from preschool through high school	Behavioral and emotional risk	Parent, teacher, self-report
Strengths and Difficulties Questionnaire (SDQ)[b]	Brief behavioral screening questionnaire for ages 3–16 years old	Emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, prosocial behavior subscales	Parent, teacher, self-report
Social, Academic, and Emotional Behavior Risk Screener (SAEBRS)[c]	Universal screening measure for behavioral and emotional risk in K-12	total behavior; academic, social, and emotional behavior subscales	Teacher and self-report
Pediatric Symptoms Checklist (PSQ)[d]	Brief screening measure designed to be used by physicians to assess psychosocial problems in children	Psychosocial impairment; internalizing, conduct, and attention problems subscales	Parent and self-report
Omnibus			
Behavior Assessment System for Children (BASC-3)[e]	Comprehensive rating scales for evaluating adaptive and problem behaviors in children and adolescents	Composite scales; clinical, content, and adaptive subscales	Parent, teacher, self-report
Beck Youth Inventories (BYI-2)[f]	Five inventories used to assess symptoms of emotional and social impairment in youth	Depression, anxiety, anger, disruptive behavior, and self-concept	Self-report
Single construct			
Screen for Child Anxiety Related Emotional Disorders (SCARED)[g]	Assess for symptoms of childhood anxiety disorders and school-related phobias	General anxiety disorder, separation anxiety disorder, panic disorder, and social phobia, school phobias	Parent and self-report
Revised Children's Manifest Anxiety Scale (RCMAS-2)[h]	Assesses the presence of anxiety symptoms	physiological anxiety, worry, and social anxiety subscales	Self-report
Multidimensional Anxiety Scale for Children (MASC-2)[i]	Assesses the presence of symptoms related to anxiety disorders in youth aged 8–19 years	Anxiety	Self-report
Patient Health Questionnaire (PHQ-9)[j]	Instrument for assessing the severity of depression validated for use in a primary care setting	Depression	Self-report
Children's Depression Inventory (CDI-2)[k]	Assesses key symptoms of depression	Depression	Self-report

[a] Kamphaus and Reynolds (2007)
[b] Goodman (2001)
[c] Kilgus, Chafouleas, Riley-Tillman, and Embse (2014)
[d] Jellinek et al. (1988)
[e] Reynolds, Kamphaus, and Vannest (2015)
[f] Beck, Beck, Jolly, and Steer (2001)
[g] Birmaher et al. (1997)
[h] Reynolds and Richmond (2008)
[i] March, Parker, Sullivan, Stallings, & Conners (1997)
[j] Kroenke, Spitzer, and Williams (2001)
[k] Kovac (2010)

struct measure can be administered to further examine the identified domain. For example, if a child's profile on the BASC-3 was elevated for anxiety, a clinician may want to administer the Multidimensional Anxiety Scale for Children (MASC-2), which is a single construct measure that specifically assesses the presence of symptoms related to anxiety disorders. Both omnibus and single construct measures can be used independently or in tandem within multiple setting by a variety of clinicians.

Risk assessment for suicidality. Mental health professionals and physicians should be aware of different psychological and psychiatric risk factors that contribute to suicide and how to assess for suicidality. One of the most widely used suicide assessment risk instruments is the Columbia-Suicide Severity Rating Scale (C-SSRS), a questionnaire that is available in over 100 languages that can be administered with minimal mental health training (Posner et al., 2011). The questionnaire assesses for the presence of suicidal ideation, intensity of ideation, and suicidal behaviors. Another suicide risk assessment is the Suicide Assessment Five-Step Evaluation and Triage (SAFE-T), which includes risk factors such as history of previous suicide attempts or self-injurious behavior, current and past psychiatric disorders, as well as risk factors for suicide (Jacobs, 2011). Furthermore, suicidal ideation is included in other single construct or omnibus rating scales of internalizing symptoms. The presence of suicidality should also always be assessed as part of any clinical interview, as well as history of attempts.

Preventing Internalizing Symptoms and Disorders

Prevention programs equip youth with behavioral skills and cognitive strategies in an effort to reduce the risk of internalizing symptoms. Given the negative impact on youth's functioning and long-lasting nature of symptoms, prevention is critically important. Many children and adolescents do not have access to treatment at the individual level. Thus, primary care and school-based interventions are advantageous in that they have access to the at-risk population and can provide treatment at a universal or targeted level. There is a body of literature indicating that prevention programs within these settings can be effective at preventing or reducing internalizing symptoms and potentially mitigate the long-term effects associated with these conditions. For example, the PENN Resiliency Program (PRP) for prevention of depression has been adopted by mental health professionals in the community, schools, and primary care facilities. The PRP is grounded in a positive psychology framework by which resiliency is promoted. Some components include coping skills, problem solving, decision-making, challenging faulty cognitions, assertiveness training, promoting optimistic versus pessimistic thinking, and connecting thoughts, feelings, and behaviors in a reflective way. PRP is considered both a universal (administered to all individuals) and targeted prevention program (directed towards individuals deemed at-risk), which has been studied in primary care settings as well as a school-based program (Gillham, Hamilton, Freres, Patton, & Gallop, 2006). Schools are an ideal setting for prevention, as it alleviates typical barriers to treatment such as lack of time, financial constraints, and it takes place where youth already spend a majority of their time. A meta-analytic review of school-based programs for internalizing symptoms found that a variety of programs exist, and many have been shown to prevent and/or reduce symptoms of anxiety and depression in school-aged youth who participate at either the universal or targeted level, both immediately and at a 12-month follow-up (Werner-Seidler et al., 2017). Most of the programs included in the meta-analysis utilized a manualized CBT approach, while others were focused on interpersonal psychotherapy (IPT), mindfulness, social skills training, psychoeducation, or a combination of approaches. In general, targeted approaches demonstrated stronger results when compared to universal approaches for depression, while both approaches were effective for anxiety. Interestingly, Stallard et al.

(2014) found that a universal program focused on anxiety prevention was most effective in reducing anxiety symptoms when delivered by trained mental health professions, rather than general classroom teachers. Thus, the training of the individuals delivering the intervention and the continued supervision or those interventionists may influence the efficacy of programs. In general, the evidence is generally positive on the use of prevention programs delivered across multiple settings and suggest that they can have promising effects on preventing or reducing internalizing symptoms in youth while reducing barriers to treatment.

Interventions for Internalizing Symptoms

Traditionally, internalizing symptoms have been addressed with psychotherapy, psychopharmacology, or a combination of the two (Compton, Burns, Egger, & Robertson, 2002).

Psychotherapy. Therapy interventions, such as CBT, have been shown to be an effective treatment for internalizing disorders, particularly in terms of anxiety and depression. Therapy generally involves weekly or bi-weekly sessions in individual or group format with a skilled clinician, which may limit accessibility for families. Thus, it is important to consider factors that serve as barriers to accessing therapy and work within the collaborative relationship to ensure continuity of care. CBT is considered the gold standard evidence-based treatment for internalizing disorders. In general, CBT promotes recognition of automatic thoughts and targets cognitive distortions through techniques such as Socratic questioning, examining the evidence, role playing, thought stopping, and challenging core beliefs. CBT for anxiety focuses on fears and worries, while CBT for depression targets symptoms such as hopeless and low self-worth. Numerous randomized controlled studies have shown CBT to be effective in treating various internalizing disorders in youth including anxiety (Wang et al., 2017) and depression (Zhou et al., 2015). Additionally, specific manualized versions of CBT have been classified as “well-established” treatments for childhood anxiety (Silverman, Pina, & Viswesvaran, 2008) and depression (David-Ferdon & Kaslow, 2008). A benefit of these evidence-based manuals, such as Coping Cat, is that they can be adapted for use in more time-limited settings such as schools and primary care (Kendall and Hedtke (2006). CBT-based interventions are generally provided in hour long sessions across 8–20 weeks. Research has supported the use of CBT over psychiatric medications, specifically selective serotonin reuptake inhibitors (SSRIs), as it has been shown to be more effective, cheaper, and have less side effects (Haby, Tonge, Littlefield, Carter, & Vos, 2004). Although CBT is recommended as first-line treatment in children and adolescents with internalizing disorders, it can be utilized in conjunction with psychopharmacology.

Acceptance and Commitment Therapy (ACT) and Dialectical Behavioral Therapy (DBT) are both offshoots of CBT that have also been shown to be effective in reducing some internalizing symptoms in adults, but limited information is available in children and adolescents. ACT uses mindfulness and promotes coping directly with feelings and situations, while DBT targets mindfulness, emotion regulation, and better communication within interpersonal relationships. One recent study found that ACT had similar effects as CBT in reducing anxiety in children and improved quality of life (Hancock et al., 2018). DBT has been used more to address suicidality and self-harm, but more recently has shown promising results in reducing depressive symptoms in adolescents (Cook & Gorraiz, 2016) Another modality of therapy that has been used to treat internalizing symptoms is IPT, which is a brief, non-cognitive based, empirically supported psychotherapeutic treatment centering on repairing relationships and reducing symptoms. Specifically, IPT for depressed adolescents (IPT-A) has been demonstrated to be effective in reducing depressive symptoms in children and adolescents based on multiple meta-analyses (Zhou et al., 2015).

Table 12.3 FDA-approved medication for the treatment of anxiety and depression in youth

Medication	Drug Class	FDA approval
Fluoxetine (Prozac)	SSRI	Approved for ages 8+ for MDD; 7+ for OCD; Off label for anxiety <18 years old
Sertraline (Zoloft)	SSRI	Approved for ages 6+ for OCD; Off label use for anxiety and depression <18 years old
Paroxetine (Paxil)	SSRI	Off label use for anxiety and depression <18 years old
Citalopram (Celexa)	SSRI	Off label use for anxiety and depression <18 years old
Escitalopram (Lexapro)	SSRI	Approved for depression 12+; Off label use for anxiety <18 years old
Fluvoxamine (Luvox)	SSRI	Approved for ages 8+ for OCD; Off label use for anxiety <18 years old
Diazepam (Valium)	Benzodiazepine	Off label use for anxiety <18 years old
Lorazepam (Ativan)	Benzodiazepine	Approved for ages 12+ for anxiety
Alprazolam (Xanax)	Benzodiazepine	Off label use for anxiety <18 years old
Clonazepam (Klonopin)	Benzodiazepine	Off label use for anxiety <18 years old
Buspirone (BuSpar)	5-ht1a receptor partial antagonist	Off label use for anxiety <18 years old

Note. *SSRI* selective serotonin reuptake inhibitor, *MDD* major depressive disorder, *OCD* obsessive compulsive disorder

Psychopharmacology. The use of psychopharmacologic treatment for internalizing disorders is supported by a body of research showing the effectiveness of medication, particularly SSRIs in reducing anxiety and depressive symptoms in children and adolescents (Walkup et al., 2008). Table 12.3 provides a list of commonly used medications for treating internalizing symptoms in youth. Some of the most common medication prescribed in youth are fluoxetine and sertraline for depression and anxiety. Although benzodiazepines are not generally FDA-approved or recommended for use in children and adolescents, they are still widely prescribed to that age range. Generally, medication is considered second-line treatment for internalizing problems, behind psychosocial interventions (Haby et al., 2004). In instances where symptoms are treatment resistant or more severe, medication is recommended in conjunction with therapy. Despite the positive outcomes associated with use of psychopharmacologic medication, there are also downsides to its use. Specifically, the use of any medication introduces the risk of adverse side effects. Also, parents may be resistant to initiating a medication trial for their children, particularly when symptoms are mild. Furthermore, psychopharmacologic interventions may require multiple medication trials to find the appropriate drug and dosage, and prolonged use to maintain improvements. Nevertheless, psychopharmacological interventions are widely used and have shown promising effects in reducing internalizing symptoms, particularly when combined with other forms of treatment. Appropriately trained behavioral health providers, such as school psychologists and pediatric psychologists, may be uniquely situated to assume collaborative roles with the prescribing primary care physician regarding medication management to improve the standard of prescribing such medications to youth (Shahidullah, Hostutler, & Stancin, 2018).

Case study

The following case study is presented to illustrate the process of evaluating and treating youth with internalizing symptoms from an integrated behavioral health perspective.

"Sarina" was a 15-year-old Latina female who was referred for treatment by her primary care physician due to ongoing symptoms of depression. Sarina was diagnosed with type 1 diabetes as a toddler and suffers from diabetes-related complications. Thus, she is regularly seen by both her primary care physician and endocrinologist. Culturally, Sarina came from a traditional Catholic family holding several values and beliefs reflective of Hispanic culture. Spanish was the dominant language spoken at home. The family did not have money to own any vehicles and relied on walking or public transportation. Socially, Sarina withdrew from peers and isolated herself. She reported thoughts such as "I will always be in pain," and "Nobody knows what it's like to deal with my illness all the time." She had a history of self-harm (cutting) and suicidal ideation that resulted in in-patient psychiatric hospitalization at the age of 12. While in-patient, she was treated for depression with medication prescribed by a psychiatrist and participated in cognitive-behavioral therapy with a licensed psychologist. She was released after 5 days with a prescription for medication and a referral for outpatient therapy. Given her lack of transportation and limited financial situation, she was unable to continue in therapy. She continued to experience depressive symptoms. During a routine appointment with her primary care physician, she completed a screener questionnaire where she endorsed symptoms of including persistent feelings of sadness, lack of motivation, sleep disturbance, and irritability. The social worker embedded in the clinic was alerted and spoke to Sarina and her mother about these concerns and the availability of services. The clinic was located within an academic medical center affiliated with the local university. Advanced doctoral level practicum students from the university rotated within the clinic provided psychotherapeutic services to patients and their families. The practicum students received supervision from a university faculty member, who was a licensed psychologist and certified school psychologist. Sarina and her mother agreed to services and therapy was initiated within the primary care clinic. Sarina was seen by a practicum student who conducted time-limited individual psychotherapy within a CBT framework. The practicum student consulted with both Sarina's primary care physician and endocrinologist regarding treatment goals. The focus of treatment was to reduce the helplessness that Sarina felt surrounding her medical condition, promote resiliency and self-efficacy in managing her diabetes, reframe her automatic thoughts, and replace negative cognitions regarding her self-worth. Goals included "Sarina will be able to more effectively regulate her emotions," and "Sarina will engage in diabetes self-care practices on a consistent basis in order to improve glucose control." Sarina's endocrinologist, primary care physician, and mental health providers (e.g., practicum student, faculty supervisor, and social worker) were all housed within the same hospital and, thus, were able to collaborate regarding Sarina's care and treatment progress. Additionally, the practicum student was able to coordinate contact with Sarina's school to ensure her medical and emotional needs were addressed to allow her to access the regular education curriculum. Her medical team and the school psychologist worked collaboratively to develop a medical safety plan and implement emotional check-ins with the school psychologist as needed.

Implications for Inter-Professional Collaboration

The case study provides an example of how integrated behavioral healthcare can benefit patients like Sarina, as well as the providers involved in her care. By having mental health providers embedded within the primary care setting, each of her providers were able to play a critical role in getting her access to services and structuring treatment to best fit her needs.

Although not all clinics have the embedded services like the ones Sarina engaged in, similar approaches can be implemented to provide integrated behavioral healthcare within primary care settings. A protocol proposed by Perfect and colleagues suggests universal screening, follow-up assessment for youth identified at-risk or symptoms in the clinical range during the screening process, direct service delivery within the primary care or specialty clinic, and follow-up as needed (Perfect, Levine-Donnerstein, Swartz, Wheeler, & Amaya, 2011). With regard to screening, the primary care clinics can adopt a brief measure of general symptoms (e.g., Pediatric Symptoms Checklist) or targeted (e.g., SCARED). The screening measure could be administered annually or biannually. Assessment tools that could be used as part of a further evaluation include a more detailed omnibus (e.g., BASC-3) or single construct measure (e.g., CDI-2). Treatment using evidence-based practices should conducted within the clinic or in close coordination to address the treatment goals. In order to be most effective, clinical care staff need to have clearly defined roles (who does what) working collaboratively to master functional and disease-related goals as part of a treatment plan (Zuckerbrot, Cheung, Jensen, Stein, Laraque, & GLAD-PC STEERING GROUP, 2018). It is essential that primary care physicians develop a safety plan for youth with evidence of suicidal ideation, such as removal of methods (pills, knives, firearms) that may be used for a child to engage in self-harm (Zuckerbrot et al., 2018). Based on a study on adolescents' preferences for addressing depression with healthcare professionals, some potential strategies include normalizing feelings of stress, being upfront about limits of confidentiality, discussing any emotional issues without the presence of a parent, reflecting on what the adolescent says, providing resources directly to the adolescent, asking about beliefs about medications, and involving them in any decisions related to treatment and care (Wisdom, Clarke, & Green, 2006). When collaborating with schools, medical and mental health professionals involved in the patient's care can provide school personnel with crucial information regarding how the student's performance may be impacted by their medical or psychiatric diagnoses, or conversely, they may obtain information regarding the child's functioning at school that may influence treatment.

Conclusions and Directions for Future Research

In conclusion, the presentation of internalizing symptoms can vary across individuals and may be associated with an underlying internalizing disorder. The challenge for clinicians is to identify symptoms as early as possible through comprehensive evaluation and connect youth with appropriate services to mitigate negative consequences. The Guidelines for Adolescent Depression in Primary Care emphasize the need for practitioners who will implement screening to be fully trained on appropriate tools and suicidal risk assessment (Zuckerbrot et al., 2018).

Integrated behavioral healthcare, whereby a trained mental health professional is housed in the clinic, offers an ideal arrangement for ease of access and a collaborative treatment approach. Frequent and clear communication between families, schools, and physical and mental health providers is essential to ensure continuity of care. Future research should examine different protocols for addressing suicidality in primary care, training requirements, feasibility, and acceptability of mental health professionals to work within primary care settings, and patient outcomes of those who are served through integrated behavioral healthcare.

References

Alfano, C. A., Beidel, D. C., Turner, S. M., & Lewin, D. S. (2006). Preliminary evidence for sleep complaints among children referred for anxiety. *Sleep Medicine, 7*, 467–473.

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.

Arruda, M. A., & Bigal, M. E. (2012). Migraine and migraine subtypes in preadolescent children: Association with school performance. *Neurology, 79*, 1881–1888.

Birmaher, B., Brent, D. A., Chiappetta, L., Bridge, J., Monga, S., & Baugher, M. (1999). Psychometric properties of the Screen for Child Anxiety Related Emotional Disorders (SCARED): a replication study. *Journal of the American Academy of Child & Adolescent Psychiatry, 38*, 1230–1236.

Beck, J. S., Beck, A. T., Jolly, J. B., & Steer, R. (2001). *Beck Youth Inventories for Children and Adolescents*. San Antonio, TX: Pearson.

Beesdo, K., Knappe, S., & Pine, D. S. (2009). Anxiety and anxiety disorders in children and adolescents: Developmental issues and implications for DSM-V. *The Psychiatric Clinics of North America, 32*, 483–524.

Birmaher, B., Khetarpal, S., Brent, D., Cully, M., Balach, L., Kaufman, J., & Neer, S. M. (1997). The screen for child anxiety related emotional disorders (SCARED): Scale construction and psychometric characteristics. *Journal of the American Academy of Child & Adolescent Psychiatry, 36*, 545–553.

Bittner, A., Egger, H. L., Erkanli, A., Costello, J. E., Foley, D. L., & Angold, A. (2007). What do childhood anxiety disorders predict? *Journal of Child Psychology and Psychiatry, 48*, 1174–1183.

Burstein, M., He, J.-P., Kattan, G., Albano, A. M., Avenevoli, S., & Merikangas, K. R. (2011). Social phobia and subtypes in the national comorbidity survey-adolescent supplement: Prevalence, correlates, and comorbidity. *Journal of the American Academy of Child and Adolescent Psychiatry, 50*, 870–880.

Compton, S. N., Burns, B. J., Egger, H. L., & Robertson, E. (2002). Review of the evidence base for treatment of childhood psychopathology: Internalizing disorders. *Journal of Consulting and Clinical Psychology, 70*,1240.

Cook, N. E., & Gorraiz, M. (2016). Dialectical behavior therapy for non-suicidal self-injury and depression among adolescents: Preliminary meta-analytic evidence. *Child and Adolescent Mental Health, 21*, 81–89.

Coplan, R. J., Girardi, A., Findlay, L. C., & Frohlick, S. L. (2007). Understanding solitude: Young children's attitudes and responses towards hypothetically socially withdrawn peers. *Social Development, 16*, 390–409.

Crick, N. R., & Zahn–Waxler, C. (2003). The development of psychopathology in females and males: Current progress and future challenges. *Development and Psychopathology, 15*, 719–742.

Crowe, A., & Brinkley, J. (2015). Distress in caregivers of a family member with serious mental illness. *The Family Journal, 23*, 286–294.

David-Ferdon, C., & Kaslow, N. J. (2008). Evidence-based psychosocial treatments for child and adolescent depression. *Journal of Clinical Child & Adolescent Psychology, 37*, 62–104.

Donnelly, C., & Amaya-Jackson, L. (2002). Post-traumatic stress disorder in children and adolescents: Epidemiology, diagnosis and treatment options. *Pediatric Drugs, 4*, 159–170.

Eklund, K., Tanner, N., Stoll, K., & Anway, L. (2015). Identifying emotional and behavioral risk among gifted and nongifted children: A multi-gate, multi-informant approach. *School Psychology Quarterly, 30*, 197.

Fernandez-Mendoza, J., Calhoun, S. L., Vgontzas, A. N., Li, Y., Gaines, J., Liao, D., & Bixler, E. O. (2016). Insomnia phenotypes based on objective sleep duration in adolescents: Depression risk and differential behavioral profiles. *Brain Sciences, 6*, 59.

Georgiades, K., Lewinsohn, P. M., Monroe, S. M., & Seeley, J. R. (2006). Major depressive disorder in adolescence: The role of subthreshold symptoms. *Journal of the American Academy of Child & Adolescent Psychiatry, 45*, 936–944.

Gillham, J. E., Hamilton, J., Freres, D. R., Patton, K., & Gallop, R. (2006). Preventing depression among early adolescents in the primary care setting: A randomized controlled study of the Penn Resiliency Program. *Journal of Abnormal Child Psychology, 34*, 195–211.

Goodman, R. (2001). Psychometric properties of the strengths and difficulties questionnaire. *Journal of the American Academy of Child & Adolescent Psychiatry, 40*, 1337–1345.

Grover, R. L., Ginsburg, G. S., & Ialongo, N. (2007). Psychosocial outcomes of anxious first graders: A seven-year follow-up. *Depression and Anxiety, 24*, 410–420.

Guarneri-White, M. E., Jensen-Campbell, L. A., & Knack, J. M. (2015). Is co-ruminating with friends related to health problems in victimized adolescents? *Journal of Adolescence, 39*, 15–26.

Günther, T., Holtkamp, K., Jolles, J., Herpertz-Dahlmann, B., & Konrad, K. (2004). Verbal memory and aspects of attentional control in children and adolescents with anxiety disorders or depressive disorders. *Journal of Affective Disorders, 82*, 265–269.

Haby, M. M., Tonge, B., Littlefield, L., Carter, R., & Vos, T. (2004). Cost-effectiveness of cognitive behavioural therapy and selective serotonin reuptake inhibitors for major depression in children and adolescents. *Australian and New Zealand Journal of Psychiatry, 38*, 579–591.

Hancock, K. M., Swain, J., Hainsworth, C. J., Dixon, A. L., Koo, S., & Munro, K. (2018). Acceptance and commitment therapy versus cognitive behavior therapy for children with anxiety: Outcomes of a randomized controlled trial. *Journal of Clinical Child & Adolescent Psychology, 47*(2), 296–311.

Hankin, B. L., Fraley, R. C., Lahey, B. B., & Waldman, I. D. (2005). Is depression best viewed as a continuum or discrete category? A taxometric analysis of childhood and adolescent depression in a population-based sample. *Journal of Abnormal Psychology, 114*, 96.

Iorfino, F., Hickie, I. B., Lee, R. S., Lagopoulos, J., & Hermens, D. F. (2016). The underlying neurobiology of key functional domains in young people with mood and anxiety disorders: A systematic review. *BMC Psychiatry, 16*, 156.

Jacobs, D. G. (2011). Suicide assessment five-step evaluation and triage. In *Best Practices Registry (BPR) for suicide prevention* (pp. 83–88). SPRC (Suicide Prevention Resource Center).

James, S., & Hale, L. (2017). Sleep duration and child well-being: A nonlinear association. *Journal of Clinical Child & Adolescent Psychology, 46*, 258–268.

Jellinek, M. S., Murphy, J. M., Robinson, J., Feins, A., Lamb, S., & Fenton, T. (1988). Pediatric Symptom Checklist: Screening school-age children for psychosocial dysfunction. *The Journal of Pediatrics, 112*, 201–209.

Kamphaus, R. W., & Reynolds, C. R. (2007). *BASC-2 behavioral and emotional screening system manual*. Circle Pines, MN: Pearson.

Kendall, P. C., & Hedtke, K. A. (2006). *Cognitive-behavioral therapy for anxious children: Therapist manual*. Ardmore, PA: Workbook Publishing.

Kilgus, S. P., Chafouleas, S. M., Riley-Tillman, T. C., & von der Embse, N. P. (2014). *Social, academic, and emotional behavior risk screener (SAEBRS)*. Minneapolis, MN: Theodore J. Christ & Colleagues.

Koffel, E., Krebs, E. E., Arbisi, P. A., Erbes, C. R., & Polusny, M. A. (2016). The unhappy triad: Pain, sleep complaints, and internalizing symptoms. *Clinical Psychological Science, 4*, 96–106.

Kovacs, M. (2010). *Children's Depression Inventory, second edition (CDI-2)*. North Tonawanda, NY: Multi-Health Systems, Inc.

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9. *Journal of General Internal Medicine, 16*, 606–613.

Leffler, J. M., Riebel, J., & Hughes, H. M. (2015). A review of child and adolescent diagnostic interviews for clinical practitioners. *Assessment, 22*, 690–703.

Lewinsohn, P. M., Solomon, A., Seeley, J. R., & Zeiss, A. (2000). Clinical implications of "subthreshold" depressive symptoms. *Journal of Abnormal Psychology, 109*, 345.

March, J. S., Parker, J. D., Sullivan, K., Stallings, P., & Conners, C. K. (1997). The Multidimensional Anxiety Scale for Children (MASC): factor structure, reliability, and validity. *Journal of the American Academy of Child & Adolescent Psychiatry, 36*, 554–565.

Martin, J. A., Kung, H. C., Mathews, T. J., Hoyert, D. L., Strobino, D. M., Guyer, B., & Sutton, S. R. (2008). Suicidal behavior in children and adolescents: Epidemiology and risk factors. *Pediatrics, 121*, 788.

Mattejat, F., & Remschmidt, H. (2008). The children of mentally ill parents. *Deutsches Ärzteblatt International, 105*, 413.

McLoone, J., Hudson, J. L., & Rapee, R. M. (2006). Treating anxiety disorders in a school setting. *Education and Treatment of Children, 29*, 219–242.

Merikangas, K. R., Nakamura, E. F., & Kessler, R. C. (2009). Epidemiology of mental disorders in children and adolescents. *Dialogues in Clinical Neuroscience, 11*, 7–20.

Perfect, M. M., Levine-Donnerstein, D., Archbold, K., Goodwin, J. L., & Quan, S. F. (2014). The contribution of sleep problems to academic and psychosocial functioning. *Psychology in the Schools, 51*, 273–295.

Perfect, M. M., Levine-Donnerstein, D., Swartz, N. E., Wheeler, L., & Amaya, G. (2011). Parents' and diabetic adolescents' perceptions of mental health screening, assessment, and feedback. *Administration and Policy in Mental Health and Mental Health Services Research, 38*, 181–192.

Posner, K., Brown, G. K., Stanley, B., Brent, D. A., Yershova, K. V., Oquendo, M. A., … Mann, J. J. (2011). The Columbia-Suicide Severity Rating Scale: Initial validity and internal consistency findings from three multisite studies with adolescents and adults. *American Journal of Psychiatry, 168*, 1266–1277.

Quach, J. L., Nguyen, C. D., Williams, K. E., & Sciberras, E. (2017). Bidirectional associations between child sleep problems and internalizing and externalizing difficulties from preschool to early adolescence. *JAMA Pediatrics, 172*(2), e174363.

Reynolds, C. R., Kamphaus, R. W., & Vannest, K. J. (2015). *BASC-3: Behavior Assessment System for Children*. San Antonio, TX: Pearson.

Reynolds, C. R., & Richmond, B. O. (2008). *The Revised Children's Manifest Anxiety Scale, second edition (RCMAS-2)*. Los Angeles, CA: Western Psychological Services.

Richardson, L. P., McCauley, E., Grossman, D. C., McCarty, C. A., Richards, J., Russo, J. E., … Katon, W. (2010). Evaluation of the Patient Health Questionnaire (PHQ-9) for detecting major depression among adolescents. *Pediatrics, 126*, 1117–1123.

Rubin, K. H., Coplan, R. J., & Bowker, J. C. (2009). Social withdrawal in childhood. *Annual Review of Psychology, 60*, 141–171.

Scharfstein, L., Alfano, C., Beidel, D., & Wong, N. (2011). Children with generalized anxiety disorder do not have peer problems, just fewer friends. *Child Psychiatry & Human Development, 42*, 712–723.

Shaffer, D., Fisher, P., Lucas, C. P., Dulcan, M. K., & SchwabStone, M. E. (2000). NIMH Diagnostic Interview Schedule for Children Version IV (NIMH DISC-IV): Description, differences from previous versions, and reliability of some common diagnoses. *Journal of the American Academy of Child & Adolescent Psychiatry, 39*, 28–38.

Shahidullah, J. D., Hostutler, C. A., & Stancin, T. (2018). Collaborative medication-related roles for pediatric primary care psychologists. *Clinical Practice in Pediatric Psychology, 6*, 61.

Silverman, W. K., Pina, A. A., & Viswesvaran, C. (2008). Evidence-based psychosocial treatments for phobic and anxiety disorders in children and adolescents. *Journal of Clinical Child & Adolescent Psychology, 37*, 105–130.

Stallard, P., Skryabina, E., Taylor, G., Phillips, R., Daniels, H., Anderson, R., & Simpson, N. (2014). Classroom-based cognitive behaviour therapy (FRIENDS): A cluster randomized controlled trial to Prevent Anxiety in Children through Education in Schools (PACES). *The Lancet Psychiatry, 1*, 185–192.

Van Ameringen, M., Mancini, C., & Farvolden, P. (2003). The impact of anxiety disorders on educational achievement. *Journal of Anxiety Disorders, 17*, 561–571.

Walkup, J. T., Albano, A. M., Piacentini, J., Birmaher, B., Compton, S. N., Sherrill, J. T., … Iyengar, S. (2008). Cognitive behavioral therapy, sertraline, or a combination in childhood anxiety. *New England Journal of Medicine, 359*, 2753–2766.

Wang, Z., Whiteside, S. P., Sim, L., Farah, W., Morrow, A. S., Alsawas, M., … Daraz, L. (2017). Comparative effectiveness and safety of cognitive behavioral therapy and pharmacotherapy for childhood anxiety disorders: A systematic review and meta-analysis. *JAMA Pediatrics, 171*, 1049–1056.

Werner-Seidler, A., Perry, Y., Calear, A. L., Newby, J. M., & Christensen, H. (2017). School-based depression and anxiety prevention programs for young people: A systematic review and meta-analysis.*Clinical Psychology Review, 51*, 30-47.

Whitcomb, S., & Merrell, K. W. (2013). *Behavioral, social, and emotional assessment of children and adolescents*. Abingdon, UK: Routledge.

Wilkinson, P. O., & Goodyer, I. M. (2006). Attention difficulties and mood-related ruminative response style in adolescents with unipolar depression. *Journal of Child Psychology and Psychiatry, 47*, 1284–1291.

Wisdom, J. P., Clarke, G. N., & Green, C. A. (2006). What teens want: Barriers to seeking care for depression. *Administration and Policy in Mental Health, 33*, 133–145.

Woodruff-Borden, J., Morrow, C., Bourland, S., & Cambron, S. (2002). The behavior of anxious parents: Examining mechanisms of transmission of anxiety from parent to child. *Journal of Clinical Child and Adolescent Psychology, 31*, 364–374.

Zhou, X., Hetrick, S. E., Cuijpers, P., Qin, B., Barth, J., Whittington, C. J., … Zhang, Y. (2015). Comparative efficacy and acceptability of psychotherapies for depression in children and adolescents: A systematic review and network meta-analysis. *World Psychiatry, 14*, 207–222.

Zuckerbrot, R. A., Cheung, A., Jensen, P. S., Stein, R. E., Laraque, D., & GLAD-PC STEERING GROUP. (2018). Guidelines for adolescent depression in primary care (GLAD-PC): Part I. Practice preparation, identification, assessment, and initial management. *Pediatrics*. https://doi.org/10.1542/peds.2017-4081. e20174081.

13

Attention-Deficit/Hyperactivity Disorder

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Abstract

Psychological service delivery systems of care (i.e., schools, hospitals, community-based mental health centers) have shifted to recognize the complex treatment needs associated with mental health conditions like attention deficit hyperactivity disorder (ADHD). School-based multi-tiered systems of support (MTSS) and integrated behavioral healthcare (IBH) are designed to address the diverse needs of children and adolescents. The purpose of this chapter is to review health risk conditions (i.e., substance use, gambling, criminality, self-harm, accidental injury, pregnancy/sexually transmitted infections, obesity, hypertension, diabetes) associated with ADHD and implications these have on prevention and intervention. Given that biological interventions (e.g., psychostimulant medication) are commonly used to treat ADHD, health implications associated with those treatments and the importance of medication treatment progress monitoring across settings are also discussed.

Introduction

Psychological service delivery systems of care (i.e., schools, hospitals, community-based mental health centers) have shifted to recognize the complex treatment needs associated with mental health conditions like attention deficit hyperactivity disorder (ADHD). School-based multi-tiered systems of support (MTSS) and integrated behavioral healthcare (IBH) are designed to address the diverse needs of children and adolescents. This chapter will review health risk conditions (i.e., substance use, gambling, criminality, self-harm, unintentional injury, pregnancy/sexually transmitted infections, obesity, hypertension, diabetes) associated with ADHD and implications these have on prevention and intervention. Given that biological interventions (e.g., psychostimulant medication) are commonly used to treat ADHD, health implications associated with those treatments and the importance of medication treatment progress monitoring across settings are also discussed.

Three of the top five causes of death in school-aged children within the United States have strong connections to behavioral health (National Center for Health Statistics, 2016). Death due to unintentional injury, suicide, and homicide warrant considerable attention and further investigation within the field of child psychopathology. For example, behavioral symptoms associated with impulsivity/risk taking, depression, and

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conduct problems in children and adolescents are associated with accidents, harming oneself, or harming others. A close examination of the link between mental health disorders and related health risk is needed to decrease mortality rates associated with behavioral health in youth.

This chapter will review a range of potentially harmful health risk conditions (i.e., substance use, gambling, criminality, self-harm, unintentional injury, pregnancy/sexually transmitted infections, obesity, hypertension, diabetes) in youth with ADHD. These health risks are associated with higher mortality rates in children and adults with ADHD largely due to unintentional death, especially when comorbid conditions of oppositional defiant disorder (ODD), conduct disorder (CD), and substance use disorder (SUD) are present (Dalsgaard, Ostergaard, Leckman, Mortensen, & Pedersen, 2015). Attending to both mental and physical health issues in ADHD requires complex approaches to prevention, early intervention, and management. This complexity of care required creates an essential need to integrate multiple stakeholders. Integrated care can best address the unique symptom management needs of children diagnosed with ADHD with special attention on keeping them safe and out of harm's way.

Background

ADHD is a neurodevelopmental disorder. The Diagnostic Statistical Manual of Mental Disorders (DSM-5: American Psychiatric Association [APA], 2013) defines ADHD as behaviors of inattention and/or hyperactivity-impulsivity that affects an individual's daily functioning. For children under the age of 17, inattention and/or hyperactive-impulsive behaviors must occur for 6 months or longer. In addition, ADHD symptoms must be present in more than one setting (e.g., school, home, work).

There are three presentations of ADHD, which include predominantly inattentive, predominantly hyperactive-impulsive, and a combined inattentive-hyperactive-impulsive presentation. Each is conceptually and empirically linked to neurocognitive deficits associated with problems of self-regulation and executive function (Schoenfelder & Kollins, 2016). According to the DSM-5, six or more symptoms must be present for at least 6 months in each presentation to meet criteria for an ADHD diagnosis. Onset of symptoms must present prior to age 12. The symptoms for inattentive presentation include: (1) failing to pay attention to details, (2) difficulty sustaining attention, (3) difficulty listening when spoken to, (4) not following through on instructions and not completing schoolwork or workplace duties, (5) difficulty organizing tasks and activities, (6) avoiding or disliking tasks that require sustained focus, (7) losing things necessary for tasks or activities, (8) easily distracted by extraneous stimuli, and (9) being forgetful in daily activities. The symptoms for hyperactive-impulsive presentation include: (1) fidgeting with or taps hands and feet, or squirms in seat, (2) difficulty staying in seat when remaining seated is expected, (3) running/climbing in situations where it is inappropriate, (4) difficulty participating in activities quietly, (5) often "on the go," acting as if driven by a motor (6) talking excessively, (7) blurting out answers before a question has been completed, (8) difficulty with waiting their turn, and (9) interrupting or intruding on others. Youth who are diagnosed with the combined type of ADHD will meet symptom criterion counts of both inattentive and hyperactive-impulsive presentations.

ADHD is believed to be caused by a combination of genetic and environmental factors (Sciberras, Mulraney, Silva, & Coghill, 2017). An estimated 10–40% of the variance related to this disorder is due to environmental factors and an estimated 70% of the variance is due to genetics (Barkley, 2015; Burt, 2009). There are specific prenatal risk factors that are related to the diagnosis of ADHD including maternal substance use, low birth weight, stress during pregnancy, and complications during delivery. Additionally, mothers smoking during pregnancy and maternal alcohol use may put children at greater risk for developing ADHD.

The prevalence of ADHD appears to be steadily increasing across time. Recent reports have found that ADHD is diagnosed in 7–9% of the population (Visser et al., 2014; Wolraich et al., 2014). DSM-5 indicates that ADHD occurs in 5% of children and is more prevalent in males. Hyperactivity is typically manifested when children begin preschool, however youth in elementary school to high school exhibit greater symptoms of inattention (APA, 2013).

Associated Features

ADHD symptoms (e.g., high energy, distractibility, impulsivity) resulting from executive functioning deficits (e.g., poor decision-making, self-regulation challenges) appear to lead to considerable environmental adversity furthering the risk for behavioral and physical health difficulties (Schoenfelder & Kollins, 2016). ADHD symptoms create interactional challenges within an individual's physical, social, educational, and occupational environments. These external difficulties too can further exacerbate one's lack of self-efficacy.

Motor coordination/development. Motor deficits (e.g., balance, coordination, manual dexterity) are one of the associated features of children diagnosed with ADHD. Studies reveal that motor deficits are present in approximately 50% of children with ADHD (Barkley, 2015). Moreover, children with ADHD are also more likely to have Developmental Coordination Disorder (DCD; Chambers, Sugden, & Sinani, 2005). Children with comorbid ADHD and DCD have motor difficulties that hinder their academic achievement or performing everyday tasks, such as tying their shoes or writing their name. They are also more likely to have delays in meeting motor milestones, such as walking or sitting. These motor deficits may lead to clumsiness and accidents, especially when combined with high levels of distractibility and impulsivity.

Social impairment/functioning. Children with ADHD have difficulties with social relationships and may struggle with interpersonal conflict (APA, 2013). Symptoms of ADHD such as interrupting others, talking excessively, and difficulty waiting their turn could make establishing friendships with other peers and attending to social cues difficult (McQuade & Hoza, 2015). Peer and family difficulties can lead to isolation, withdrawal, and emergence of symptoms of anxiety or depression.

Parent–child conflict. Research has found greater parental stress and parent–child conflicts in families of children who are diagnosed with ADHD (Deault, 2010; Theule, Wiener, Tannock, & Jenkins, 2013). Children with ADHD exhibit high levels of impulsivity and difficulty with self-regulation (Barkley, 2015). Parents with children who are diagnosed with ADHD may be more controlling and have an authoritarian parenting style. Pelham and Lang (1999) found that parents had an increase in stress, depression, and hostility when children exhibited ADHD symptoms. Thus, parent–child conflict emerges through a coercive interaction between poor parenting practices and ADHD symptoms exhibited by children. Parent–child interaction challenges can lead to withdrawal from the family unit and seeking social support from one's peers.

Poor self-esteem. Poor self-esteem is another associated feature of children who are diagnosed with ADHD. Because children with ADHD have difficulty with social relationships, they have a higher likelihood of experiencing peer rejection and victimization (Gardner & Gerdes, 2015). For example, studies have found that between 29 and 43% of children with ADHD have experienced peer victimization (Timmermanis & Wiener, 2011; Twyman et al., 2010). Peer victimization has been related to higher rates of internalizing symptoms (e.g., depression, anxiety) and lower self-esteem (Becker, Mehari, Langberg, & Evans, 2017).

School/occupational challenges. Children with ADHD are likely to have reduced school performance, which include lower attendance and not meeting grade expectations (Barkley, 2015). After high school, children with ADHD are less likely to attend college than children who are not diagnosed with ADHD (Kuriyan et al., 2013). Adults with ADHD symptoms are rated as performing significantly worse (e.g., reduced productivity, absenteeism, risk of injury, behavioral problems) by their employer than adults who did not exhibit symptoms (Klein et al., 2012).

Behavioral and Physical Health Implications

The core symptoms (inattention, hyperactivity, impulsivity) and associated features (poor self-esteem, motor coordination deficits, peer and family difficulties) of ADHD may uniquely put individuals at-risk for physical injury, self-harm, or problems with the law. Children, adolescents, and adults with ADHD have double the risk of death, primarily due to unnatural causes such as unintentional injuries, when compared to individuals without ADHD (Dalsgaard et al., 2015). Several comprehensive reviews of the literature have highlighted the negative physical health outcomes associated with ADHD, some of which may be fatal (Fladhammer, Lyde, Meyers, Clark, & Landau, 2016; Nigg, 2013; Schoenfelder & Kollins, 2016; Sciberras et al., 2016). This chapter further updates those risks (see Table 13.1) while addressing the physical health and behavioral aspects of ADHD within an integrated care context.

Table 13.1 ADHD-related health risks

Substance use	More likely to use nicotine, alcohol, cannabis, and cocaine
Gambling	More likely to engage in gambling behaviors which can lead to problem gambling
Criminality	Increased rates of adult arrests, convictions, and incarceration
Self-harm	Increased risk for internalizing disorders, which when combined with impulsivity can be a lethal combination for those who harm themselves
Unintentional injury	Increased risk for unintentional poisoning and car accidents
Pregnancy/sexually transmitted infections	More likely to engage in sex before the age of 18, become pregnant before the age of 18, and have unprotected sex
Obesity	Increased rates due to suspected abnormal eating patterns, lack of physical activity, comorbid conduct disorder, neurobiological underpinnings, and genetics
Hypertension	Possible increased risk when taking psychostimulants
Diabetes	More likely to have type 2 diabetes

Age and gender differences. Age and gender are important to consider when examining the link between ADHD and health risk. While individuals diagnosed with ADHD present higher mortality rates compared to non-ADHD populations, it is important to recognize those diagnosed with ADHD in adulthood have higher mortality rates when compared to individuals diagnosed with ADHD in childhood (Dalsgaard et al., 2015). Furthermore, this study's findings indicated that women with ADHD (without comorbid ODD, CD, and SUD) are at higher risk for death when compared to a similar population of men, likely due to the persistence and severity of unmanaged ADHD symptoms and resulting impairment. Recent research also highlights that young children (under 6 years) with ADHD have similar levels of health-related impairments compared to peers. Though when comorbid internalizing and externalizing problems are present, an increased health risk exists (i.e., sleep problems, body mass index; Sciberras et al., 2016).

Substance use (smoking/alcohol/other drugs). The link between ADHD and SUD is well established. Youth with ADHD are almost two to three times more likely to use nicotine, alcohol, cannabis, and cocaine when compared to youth without ADHD (e.g., Lee, Humphreys, Flory, Liu, & Glass, 2011). Being female, the presence of conduct disorder, and later initiation of stimulant treatment all appear to increase the risk for later SUD and alcohol abuse in those with ADHD (Dalsgaard, Mortensen, Frydenberg, & Thomsen, 2014). The link between ADHD and risk for smoking has been noted as particularly strong (Nigg, 2013). The implications of self-medicating one's symptoms of inattention, hyperactivity, and impulsivity by nicotine and the resulting negative health implications are especially important to consider within ADHD treatment planning. The potential protective nature of early psychostimulant treatment for ADHD warrants considerable attention within treatment decision-making. When the presence of SUD and ADHD are present at the time of diagnosis, special treatment considerations around the possible use of alternative medications (i.e., nonstimulant v. extended-release psychostimulant) must be undertaken due to abuse potential (Wilens, 2015).

Gambling. ADHD appears to put individuals at-risk for a few addictive behaviors, including problem gambling. About one in four treatment-seeking problem gamblers report ADHD with particularly high levels of impulsivity and co-occurring antisocial behaviors (Waluk, Youssef, & Dowling, 2016). Youth with ADHD are more likely to engage in gambling behaviors which in turn can lead to problem gambling. Gambling addiction can create considerable interpersonal, occupational/financial challenges, and associated health risks (i.e., poor physical health, substance use). Faulty cognition/attributions, impulsivity/risk taking, and sensation seeking in ADHD youth may account for this greater engagement in gambling behavior (Romer, 2010).

Criminality. ADHD, itself, may not lead to increased difficulties in conforming to societal norms. Instead many believe the comorbid conditions associated with ODD, CD, substance use/abuse, and parent–child conflict can put a child on a pathway toward criminal behavior (e.g., Nigg, 2013). However, a recent meta-analytic review indicates that a childhood ADHD diagnosis without comorbidity is associated with twofold rates of adolescent and adult arrests, convictions, and incarceration (Mohr-Jensen & Steinhausen, 2016). Early antisocial behavioral risk and more frequent criminal offenses are further associated with youth diagnosed with ADHD who also present with comorbid conduct problems and a history of maltreatment. Trouble with the law, behaving outside societal norms, and other antisocial behaviors can lead to a few health risk behaviors and public health issues, more generally (e.g., theft, violence, homicide).

Self–harm/suicide. Teenage suicide has recently surpassed homicides as the second leading cause of death in teenagers within the United States (National Center for Health Statistics, 2016). Children and adolescents diagnosed with ADHD are at increased risk for a variety of internalizing disorders including anxiety and depression. Female teens with ADHD (hyperactivity, impulsivity, distractibility) and comorbid depression appear to be particularly at-risk for self-injury and completed suicide as recently reviewed by Fladhammer et al. (2016). A combination of hopelessness, helplessness, suicidal ideation, and impulsivity appear to be particularly lethal combinations in those who harm themselves. Monitoring of both externalizing and internalizing behaviors warrants close attention within the management of ADHD youth. When suicidal ideation is present, close consideration of symptoms of impulsivity and access to means of self-harm must be undertaken.

Risk for unintentional injury. Acting impulsively and without consideration of consequences appears to lead to considerable physical health implications. Recent research by Merrill, Thygerson, and Palmer (2016) suggests that ADHD (i.e., impulse inhibition difficulties, poor decision-making, motor coordination challenges) is associated with an increased risk for unintentional injury. Unintentional injury is primarily the cause of higher mortality in those with ADHD (Dalsgaard et al., 2015). Furthermore, this association is stronger when the individual has ADHD comorbid with another mental illness but made better when the individual with ADHD is taking psychostimulants (Merrill et al., 2016). Specific examples of ADHD risk can be seen within the unintentional poisoning and motor vehicle accident literatures. In young children, risk of injury or death due to unintentional poisoning (e.g., exploratory ingestion) is greater in those who show early symptoms of ADHD (Silva, Colvin, Hagemann, Stanley, & Bower, 2014). In adolescents and adults, risk for significant injury due to car accidents appears to be about 1.5 times greater in those diagnosed with ADHD (Vaa, 2014). It is noteworthy that use of psychostimulant medication treatment may cut that risk in half for men with ADHD, but not women (Chang, Lichtenstein, D'Onofrio, Sjölander, & Larsson, 2014).

Pregnancy/STIs. Individuals with ADHD may be more likely than their peers to engage in risky sexual behavior, in which unplanned pregnancy or contraction of sexually transmitted infections (STIs) may be a result. Hechtman et al. (2016) found that individuals with ADHD initiated sex for the first time at a younger age and engaged in sexual intercourse with more sexual partners. Huggins, Rooney, and Chronis-Tuscano (2015) reported that female undergraduate college students with ADHD were less likely to use condoms than male students (with and without ADHD) and female students without ADHD. In addition, they reported students with ADHD as having nearly five times (10 vs. 2) more unfamiliar sexual partners than students without ADHD. Additionally, a study of at-risk youth from the juvenile justice system showed an association between ADHD diagnosis and risky sexual behavior in adolescents with comorbid conduct problems, mediated by frequency of marijuana use (Sarver, McCart, Sheidow, & Letourneau, 2014). Recent research by Meinzer et al. (2017) suggested individuals with ADHD had nearly twice the rate of pregnancy before the age of 18 than a comparison group (9.3 vs. 4.6%). Delinquency and substance use, together, was a significant mediator between ADHD diagnosis and early pregnancy in this study.

Obesity/body mass index/physical fitness. Findings related to increased rates of obesity in individuals with ADHD appear mixed. In a recent meta-analysis of 17 articles in the last 4 years by Cortese and Tessari (2017), findings were inconclusive about the prevalence of obesity in individuals with ADHD and the possible preventive impact of psychostimulant treatment on obesity. Conversely, Nigg (2013) reported a significant relation between ADHD and obesity in their meta-analysis, including a higher association between obesity and ADHD in adults. Proposed reasons for these differences include abnormal eating patterns (i.e., binge/impulsive eating), lack of physical activity, comorbid conduct disorder, neurobiological underpinnings, and genetics (Cortese & Tessari, 2017).

Hypertension. Evidence suggests a link between hypertension and adults with ADHD (Nigg, 2013). Young children with ADHD may be at risk for hypertension, especially if they are taking psychostimulants. According to a case study by Luebbert and Gidding (2016), a 14-year-old boy with ADHD was experiencing increased blood pressure. Though there was no family history of hypertension, the boy's blood pressure had increased from 124/72 to 132/74 mmHg after 6 years of taking psychostimulants to manage his ADHD. These challenges within the cost-benefit analysis of psychostimulant treatment for this youth resulted in close attention to both weight management and school performance as a part of treatment refinement.

Diabetes. There is evidence to suggest an association between an ADHD diagnosis and diabetes. In a population-based study, individuals with ADHD were more likely to have type 2 diabetes than individuals without ADHD (Chen, Lee, Yeh, & Lin, 2013). These individuals had a higher proportion of preexisting type 1 diabetes mellitus though the association was non-significant. Alternatively, children with ADHD and type 1 diabetes mellitus have recently been reported as having worse metabolic control when compared to a comparison group without ADHD (Hilgard et al., 2017). Kappellen and colleagues (2016) found children with diabetes were more likely to have an ADHD diagnosis, possibly due to more frequent health service utilization for ADHD symptoms. Lindblad, Engström, Nylander, and Fernell (2017) found that diabetes management may be challenging for children and adolescents with ADHD due to difficulties in creating, adhering to, and maintaining routines. Additionally, they found diabetes management was especially challenging for young people with ADHD faced with stress, such as busy schedules interfering with treatment schedules and parent criticism about improper diabetes management.

Other physical health risks. Individuals with ADHD also present with higher rates of other health conditions. In a recent investigation (Stickley et al., 2017) examining the prevalence of 20 physical diseases in over 7000 adults, those who screened positively for ADHD had significantly higher rates in more than half of the diseases when compared to those without ADHD. These 11 health issues included asthma, bladder problems/incontinence, bone/back/joint or muscle problems, bowel/colon problems, bronchitis/emphysema, epilepsy/fits, infectious disease, liver problems, migraine/frequent headaches, skin problems, and stomach ulcer/digestive problems. Study findings indicated that stressful life events, eating disorders, and internalizing symptoms (i.e., anxiety, depression) mediated the relationship between ADHD and physical multimorbidity.

Health risks Associated with Psychostimulant Treatment

The core symptoms and associated features of ADHD are important to address to mitigate health risk conditions. Current medications used to treat ADHD within a combined (biopsychosocial) treatment approach include stimulants (i.e., methylphenidate, amphetamines) and nonstimulants (i.e., atomoxetine, clonidine, guanfacine). These effective treatments for ADHD may present with adverse effects, most of which are considered mild and transient (Clavenna & Bonati, 2017). For example, stimulants are associated with increased irritability, emotional lability, insomnolence, headaches, tics, and decreased appetite (weight loss). Atomoxetine treatment is associated with somnolence, fatigue, headaches, and stomach ache. Guanfacine and clonidine treatment, often prescribed to counter the insomnolence effects of stimulants, are linked to adverse effects of somnolence and fatigue. Three uncommon but serious adverse effects to be monitored closely in youth prescribed ADHD medications include cardiovascular problems (increased blood pressure, tachycardia, arrhythmia, palpitation), psychosis, and suicidal ideation (Clavenna & Bonati, 2017).

Growth suppression. One adverse effect of ADHD medicines that has received considerable attention is growth (height and weight) suppression in youth. A review of studies appears to indicate that both psychostimulants and atomoxetine lead to small reductions in height (2.5 cm) and weight (3 kg) during the first 3 years of treatment with subsequent recovery (Clavenna & Bonati, 2017). Only psychostimulants appear to impact body mass index (BMI) scores in childhood with a relative increase in BMI appearing in later adolescence.

Disturbed sleep. Children diagnosed with ADHD may present with sleep problems (Nigg, 2013). It is important to rule out sleep problems prior to a diagnosis of ADHD given the role that a lack of sleep can play on inattention. Sleep problems (i.e., later sleep onset) associated with medications such as extended-release psychostimulants may result in a prescription for a sleep aid such as melatonin or an alpha2-agonist (i.e., clonidine; Clavenna & Bonati, 2017).

Screening and Assessment/ Evaluation

Population-level. Population screening in primary care and school settings may increase the likelihood of early identification of children at-risk for ADHD. Early identification and treatment of ADHD may reduce the negative academic and social outcomes that individuals with ADHD experience (Barry et al., 2016). Screening can occur through electronic survey completed by teachers or parents, for example. An example of an electronic-based or paper-pen screener is the Vanderbilt ADHD Diagnostic Rating Scale (VADRS; Wolraich et al., 2003), which includes teacher and parent forms. The Strengths and Difficulties Questionnaire (SDQ; Goodman, 2001) is a brief behavioral screener commonly used to measure the emotional and behavioral functioning of children as young as three (Barry et al., 2016). Screening results may identify children at-risk for ADHD, and thus, promote the subsequent coordination of preventative services between the child's parents, school, and primary care provider.

Individual-level. A comprehensive individual assessment will involve multiple stakeholders (child, parents, pediatrician, school personnel) across settings and contexts. Communication between stakeholders is essential during the assessment process (Barry et al., 2016). A review of family and school history, interviews, broadband and narrowband rating scales from multiple informants, and observations across settings are necessary to make an informed decision about a diagnosis of ADHD. As there tend to be genetic links to ADHD, a review of family history is conducted to identify relatives with an ADHD diagnosis. Also, parent interviews may reveal parental ADHD-related symptoms, as parental ADHD is often undiagnosed until child diagnosis (Waite & Ramsay, 2010). Additionally, a review of academic history is conducted to understand the child's functioning in school (e.g., grades, absences, teacher report of behavior).

Interviews, broadband rating scales, narrowband rating scales, and observations are important to the assessment of ADHD, as well. The purpose of structured and semi-structured interviews with parents, teachers, and the child are to probe at behaviors related to ADHD criteria, rule out other diagnoses, and understand child functioning at school and with family and peers (Pelham, Fabiano, & Massetti, 2005; Tobin, Schneider, & Landau, 2014). Unstructured interviews with similar interview objectives are a more feasible, time-efficient option in the school setting (Tobin et al., 2014). The Achenbach System of Empirically Based Assessment (ASEBA; Achenbach, 2009) and Behavior Assessment System of Children-Third Edition (BASC-3; Reynolds & Kamphaus, 2015) are two commonly used broadband measures for ADHD, and they both include parent, teacher, and child forms. Examples of narrowband measures include the ADHD Rating Scale- 5 (DuPaul, Power, Anastopoulos, & Reid, 2016), Attention Deficit Disorder Evaluation Scale-Fourth Edition (ADDES-4; McCarney & Arthaud, 2013), VADRS (Wolraich et al., 2003), and Conners-Third Edition (Conners-3; Conners, 2008). Direct observations provide supplemental data to interviews and rating scales when conducted across contexts and during the interviews (Tobin et al., 2014).

Prevention and Intervention of Health Risk Behaviors

Evidence-based prevention programs. Schoolwide positive behavior interventions and support (SWPBIS) and the Incredible Years (IY) are evidence-based prevention programs for problem behaviors and children with ADHD-related symptoms (see Table 13.2; McKevitt & Fynaardt, 2014). SWPBIS intervention and classroom strategies encourage appropriate behavior from all students and subsequent praise for behaviors aligned with expectations. Key features of SWPBIS include defined expectations across school contexts (e.g., classroom, hallway), direct instruction of expectations, reinforcement/acknowledgement system, consequence system, and a data system to evaluate effectiveness and identify strategies to best address student behavior. The critical components of promoting explicitly taught positive behavior and systematic consideration of data to identify students who

Table 13.2 Service delivery approaches for children with ADHD

Prevention programs	
School-wide positive behavior interventions and support	Consistent expectations in school settings, direct instruction, and school/classroom reinforcement systems
Incredible years	Parent, teacher, and child series are available to promote positive behaviors in children with ADHD (e.g., social skills training, attention strategies)
Intervention programs	
Behavioral interventions	Token economy programs, positive reinforcement, time-out/time away, response cost (e.g., Daily Report Card)
Parent training	Parents create a daily routine, minimize distractions, give specific directions, and rewards for positive behaviors
Parent and child education	Psychoeducation about symptoms and treatment of ADHD for parents and children
Educational support	Preferential seating, reducing classwork requirement, reducing distractions in the classroom
Medication	Incorporating psychostimulants along with behavioral interventions have been found to be effective in decreasing symptoms of ADHD

may need more support make SWPBIS a preventative program (McKevitt & Fynaardt, 2014). Within the prevention framework are opportunities for early identification of students with behavioral problems. For students at-risk for ADHD, SWPBIS teaches them appropriate behavior in school. In the case that they have difficulty complying with expectations (e.g., office referrals), then systematic data evaluation may be used to identify the student and provide them with extra behavioral support and intervention.

There is research support to suggest that IY is an evidence-based prevention program for ADHD. IY includes parents, teacher, and children series and aims to improve behavioral outcomes, specifically conduct. Curriculum content includes a variety of age-appropriate activities aimed at improving competence, regulation, and academic functioning (McKevitt & Fynaardt, 2014). IY promotes active practice and self-monitoring toward identified goals through behavioral parent training learning strategies like videotape modeling, role-play, and a collaborative approach (Lessard, Normandeau, & Robaey, 2016). There are IY aspects that align with prevention of ADHD, including child-focused skill practice of play, social skills, and improved attention and frustration-management strategies. Parent and teacher-focused IY encourages promotion of social-emotional development, reinforcement, and ignoring strategies (McKevitt & Fynaardt, 2014). In a research synthesis by Murray, Lawrence, and LaForett (2017), parents who participated in IY reported positive effects on ADHD outcomes in their children, including improved conduct and social skills.

Evidence-based intervention programs. Multimodal intervention is recommended for children with ADHD, including behavioral interventions, parent training, parent and child education, appropriate educational support, and medication when indicated or preferred by parents. Behavioral interventions may include positive reinforcement, time-out/time away, response cost, and token economy programs. These are strategies implemented in common intervention, such as Daily Report Cards (e.g., Fabiano et al., 2010; Moore, Whittaker, & Ford, 2016). Additionally, psychoeducation of ADHD may be useful for parents and the child to understand the diagnosis. Educational supports such as reducing work requirements, preferential seating, reducing distraction, and partner work may provide needed supports for children with ADHD. Additionally, medication is an intervention important to consider within a comprehensive treatment approach for ADHD, though as a second-line treatment. Individuals with ADHD who started behavioral intervention before medication violated classroom rules significantly less and scored more desirably on ratings of oppositional behaviors than individuals who started medication intervention before behavioral (Pelham et al., 2016). Such psychosocial approaches are also substantially less costly over the long-term than beginning with a low dose psychostimulant ($961 v. $1669; Page et al., 2016).

Implications for Interprofessional Care

Multiple types of professional expertise are needed to appropriately treat ADHD and its associated health risks. The etiological complexities of ADHD require coordinated care from those professionals with expertise in behavioral and physical health. Typically, that would include coordinated services from primary care physicians, psychologists, clinical social workers, family members, and school personnel (e.g., school psychologists) to help address a range of potential challenges. That collaboration would wrap around the unique needs and values of the child and their family. Such a team of professionals would also be focused on monitoring any health-related conditions. Targets of intervention would likely initially address the need to reduce the core symptoms of ADHD (impulsivity, hyperactivity, inattention). Associated impairments across home, school, and community contexts would be identified. Additional stakeholders (e.g., case/care workers, juvenile justice personnel, social workers, dieticians, addiction specialists) would be included in the treatment team to prevent further emotional, behavioral, or physical health dysfunction. Six models of integrated care in a range of service sectors (i.e., primary care, psychiatry, nursing) have recently been reviewed as having evidence of the effectiveness of coordinated services in meeting the behavioral health treatment needs of youth with ADHD, including Enhanced Collaborative Care, Partnering to Achieve School Success, Doctor Office Collaborative Care, Targeted Child Psychiatric Services, Protocol for On-Site, Nurse-Administered Intervention, and Collaborative Psychiatry Liaison (Shahidullah, Carlson, Haggerty, & Lancaster, 2018). Further development and research on school health models of ADHD care are needed.

A school-based MTSS approach to services should be in place for those who show ADHD symptoms. Effective classroom management techniques targeting all children are essential. Targeted behavioral interventions may be implemented with those who fail to respond to classroom-wide approaches. Finally, for those who fail to respond to group and individually based interventions, more intensive supports such as special education supports and/or referral to the family's physician for a medication consult may be necessary. When medications are prescribed, best practices in medication evaluation for ADHD in schools/home are essential to promote positive outcomes and reduce risk of health concerns, accidents, and death within youth with ADHD. Specific behavioral targets (i.e., intended effects, side effects) should be identified and monitored across time. Parent and teacher rating scales, direct behavior ratings, home-school notes are especially important to implement repeatedly across time to determine if treatment goals are met or need refinement. Collaboration, coordination, and communication are essential for efficient and effective service delivery across contexts. School personnel such as school psychologists can serve in these case management roles and work closely with providers outside of the school setting to promote effective services.

Case Study

"Josh," a 10-year-old male, has symptoms of ADHD-combined type. He experiences symptoms of fidgeting, excessive movement, interrupting others, and not listening when being directly talked to by others. These symptoms have been occurring at home and school according to his parents and teacher. There is a familial history of ADHD and substance abuse. His father and 17-year-old brother have a history of substance abuse and ADHD-combined type. Josh has a long history of injuries resulting in emergency healthcare (i.e., broken bones, stitches). Josh also has a diagnosis of DCD, which relates to his history of school difficulties (e.g., handwriting, organization). In school, Josh has difficulty completing his school work, staying in his seat when instructed by his teacher, and with peer relationships. At home, Josh does not comply with directives from his parents and does not complete chores when asked. Additionally, his parents notice that he struggles to remain seated in one area for extended durations (e.g., eating dinner, doing homework). The school psychologist coordinates services across home, school, and Josh's physician's office. These coordination efforts result in a prescription of atomoxetine (due to family history of substance abuse) with combined parent/teacher management training. The combined parent/teacher management training consists of psychoeducation about ADHD, utilizing positive reinforcement, and token economy programs at home and school. Academic treatment goals include improved school performance as evidenced by increased homework completion and increased rate of on-task behavior. Monitoring of academic treatment goals is conducted by the school psychologist through daily report cards, where Josh's teacher signs off on whether he met classroom and behavioral expectations for each day. Josh's parents are assigned to provide reinforcement at home (i.e., access to rewards) contingent on whether he meets his target goals at school. Additional treatment goals include improved peer and family relationships and a reduction in unintentional injury. These goals are monitored through weekly parent interviews. In addition, the school psychologist collects data on parent and teacher reports of Josh's behaviors by using the BASC-3 (Reynolds & Kamphaus, 2015). Close monitoring of side/treatment effects along with use of emergency services is undertaken. The school psychologist shares data collected from Josh's parents and teacher with Josh's physician through an internet-based program called myADHDportal, where parents, teachers, and Josh's physician can view, and input prescription or behavioral information collected (e.g., BASC-3 parent/teacher reports; Epstein et al., 2011). After 2 months of combined treatment, data indicate that Josh made behavioral and academic improvements in both home and school contexts. Difficulties with sleep onset result in an additional prescription for clonidine and specific side effects for that medication are monitored.

Conclusions and Future Directions

School-based MTSS and IBH are designed to address the diverse needs of children and adolescents and their families. Behavioral health service delivery systems (i.e., schools, hospitals, community-based mental health centers) have recognized the complex treatment needs associated with mental health conditions like ADHD. Interdisciplinary collaborative approaches are necessary to meet the complexity of behavioral and physical health risks that arise in those with ADHD. Biopsychosocial treatments are essential to prevent risk for more serious conditions. Future research for ADHD physical health risks may include the investigation of risks by race, clarification of obesity rates in individuals with ADHD, and the expansion of research regarding risks of hypertension and diabetes in individuals with ADHD.

References

Achenbach, T. M. (2009). *The Achenbach System of Empirically Based Assessment (ASEBA): Development, findings, theory, and applications*. Burlington, VT: University of Vermont Research Center for Children, Youth, & Families.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed.). Arlington, VA: Author.

Barkley, R. A. (2015). *Attention-deficit hyperactivity disorder: A handbook for diagnosis and treatment* (4th ed.). New York, NY: Guilford Press.

Barry, T. D., Sturner, R., Seymour, K., Howard, B., McGoron, L., Bergmann, P., … Werle, H. (2016). School-based screening to identify children at risk for attention-deficit/hyperactivity disorder: Barriers and implications. *Children's Health Care, 45*, 241–265.

Becker, S. P., Mehari, K. R., Langberg, J. M., & Evans, S. W. (2017). Rates of peer victimization in young adolescents with ADHD and associations with internalizing symptoms and self-esteem. *European Child & Adolescent Psychiatry, 26*, 201–214.

Burt, S. A. (2009). Rethinking environmental contributions to child and adolescent psychopathology: A meta-analysis of shared environmental influences. *Psychological Bulletin, 135*, 608–637.

Chambers, M. E., Sugden, D. A., & Sinani, C. (2005). The nature of children with developmental coordination disorder. In D. A. Sugden & M. E. Chambers (Eds.), *Children with developmental coordination disorder* (pp. 1–18). London, UK: Whurr Publishers Ltd.

Chang, Z., Lichtenstein, P., D'Onofrio, B. M., Sjölander, A., & Larsson, H. (2014). Serious transport accidents in adults with Attention-Deficit/Hyperactivity Disorder and the effect of medication: A population-based study. *Journal of the American Medical Association Psychiatry, 71*, 319–325.

Chen, H., Lee, Y., Yeh, G. C., & Lin, H. (2013). Association of attention-deficit/hyperactivity disorder with diabetes: A population-based study. *Pediatric Research, 73*, 492–496.

Clavenna, A., & Bonati, M. (2017). Pediatric pharmacoepidemiology - safety and effectiveness of medicines for ADHD. *Expert Opinion on Drug Safety, 16*, 1335–1345.

Conners, C. K. (2008). *Conners Comprehensive Behavior Rating Scale manual*. Toronto, ON, Canada: Multi-Health Systems.

Cortese, S., & Tessari, L. (2017). Attention-Deficit/Hyperactivity disorder (ADHD) and obesity: Update 2016. *Current Psychiatry Reports, 19*, 1–15.

Dalsgaard, S., Mortensen, P. B., Frydenberg, M., & Thomsen, P. H. (2014). ADHD, stimulant treatment in childhood and subsequent substance abuse in adulthood-A naturalistic long-term follow-up study. *Addictive Behaviors, 39*, 325–328.

Dalsgaard, S., Ostergaard, S. D., Leckman, J. F., Mortensen, P. B., & Pedersen, M. G. (2015). Mortality in children, adolescents, and adults with attention deficit hyperactivity disorder: A nationwide cohort study. *Lancet, 385*, 2190–2196.

Deault, L. C. (2010). A systematic review of parenting in relation to the development of comorbidities and functional impairments in children with attention-deficit/hyperactivity disorder (ADHD). *Child Psychiatry and Human Development, 41*, 168–192.

DuPaul, G. J., Power, T. J., Anastopoulos, A. D., & Reid, R. (2016). *ADHD Rating Scale- 5 for Children and Adolescents: Checklists, norms, and clinical interpretation*. New York, NY: Guilford Press.

Epstein, J., Langberg, J., Lichtenstein, P., Kolb, R., Altaye, M., & Simon, J. (2011). Use of an internet portal to improve community-based pediatric ADHD care: A cluster randomized trial. *Pediatrics, 128*, 1201–1208.

Fabiano, G. A., Vujnovic, R. K., Pelham, W. E., Waschbusch, D. A., Massetti, G. M., Pariseau, M. E., … Volker, M. (2010). Enhancing the effectiveness of special education programming for children with attention deficit hyperactivity disorder using a daily report card. *School Psychology Review, 39*, 219–239.

Fladhammer, A. B., Lyde, A. R., Meyers, A. B., Clark, J. K., & Landau, S. (2016). Health concerns regarding children and adolescents with attention-deficit/hyperactivity disorder. In *Health Promotion for Children and Adolescents* (pp. 145–165). New York, NY: Springer Publishing Co.

Gardner, D. M., & Gerdes, A. C. (2015). A review of peer relationships and friendships in youth with ADHD. *Journal of Attention Disorders, 19*, 844–855.

Goodman, R. (2001). Psychometric properties of the Strengths and Difficulties Questionnaire. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*, 1337–1345.

Hechtman, L., Swanson, J. M., Sibley, M. H., Stehli, A., Owens, E. B., Mitchell, J. T., Arnold, L. E. for the MTA Cooperative Group. (2016). Functional adult outcomes 16 years after childhood diagnosis of attention-deficit/hyperactivity disorder: MTA results. Journal of the American Academy of Child & Adolescent Psychiatry*,* 55, 945–952.

Hilgard, D., Konrad, K., Meusers, M., Bartus, B., Otto, K., Lepler, R., … Hall, R. W. (2017). Comorbidity of attention deficit hyperactivity disorder and type 1 diabetes in children and adolescents: Analysis based on the multicentre DPV registry. *Pediatric Diabetes, 18*, 706–713.

Huggins, S. P., Rooney, M. E., & Chronis-Tuscano, A. (2015). Risky sexual behavior among college students with ADHD: Is the mother–child relationship protective? *Journal of Attention Disorders, 19*, 240–250.

Kapellen, T. M., Reimann, R., Kiess, W., & Kostev, K. (2016). Prevalence of medically treated children with ADHD and type 1 diabetes in Germany – analysis of two representative databases. *Journal of Pediatric Endocrinology and Metabolism, 29*, 1293–1297.

Klein, R. G., Mannuzza, S., Olazagasti, M. A. R., Roizen, E., Hutchison, J. A., Lashua, E. C., & Castellanos, F. X. (2012). Clinical and functional outcome of childhood attention-deficit/hyperactivity disorder 33 years later. *Journal of the American Medical Association: Psychiatry, 69*, 1295–1303.

Kuriyan, A. B., Pelham, W. E., Jr., Molina, B. S. G., Waschbusch, D. A., Gnagy, E. M., Sibley, M. H., … Kent, K. M. (2013). Young adult educational and vocational outcomes of children diagnosed with ADHD. *Journal of Abnormal Child Psychology, 41*, 27–41.

Lee, S. S., Humphreys, K. L., Flory, K., Liu, R., & Glass, K. (2011). Prospective association of childhood attention-deficit hyperactivity disorder (ADHD) and substance use and abuse/dependence: A meta-analytic review. *Clinical Psychology Review, 31*, 328–341.

Lessard, J., Normandeau, S., & Robaey, P. (2016). Effects of the incredible years program in families of children with ADHD. *Journal of Child and Family Studies, 25*, 3716–3727.

Lindblad, I., Engström, A., Nylander, C., & Fernell, E. (2017). Adolescents with type 1 diabetes mellitus and attention-deficit/hyperactivity disorder require specific support from healthcare professionals. *Acta Paediatrica, 106*, 1994–1997.

Luebbert, J., & Gidding, S. S. (2016). A patient with attention deficit hyperactivity disorder and hypertension. *The Journal of Pediatrics, 173*, 254–257.

McCarney, S. B., & Arthaud, T. J. (2013). *Attention Deficit Disorder Evaluation Scale Fourth Edition: School version technical manual*. Columbia, MO: Hawthorne.

McKevitt, B. C., & Fynaardt, A. B. (2014). Best practices in developing a positive behavior support system at the school level. In P. L. Harrison & A. Thomas (Eds.), *Best practices in school psychology: System-*

level services (pp. 165–179). Baltimore, MD: NASP Publications.

McQuade, J. D., & Hoza, B. (2015). Peer relationships of children with ADHD. In R. A. Barkley (Ed.), *Attention-deficit hyperactivity disorder: A handbook for diagnosis and treatment* (pp. 210–222). New York, NY: Guilford Press.

Meinzer, M. C., LeMoine, K. A., Howard, A. L., Stehli, A., Arnold, E., Hechtman, L., … Chronis-Tuscano, A. (2017). Childhood ADHD and involvement in early pregnancy: Mechanisms of risk. *Journal of Attention Disorders, 21*, 1–11.

Merrill, R. M., Thygerson, S. M., & Palmer, C. A. (2016). Risk of injury according to attention deficit hyperactivity disorder, comorbid mental illness, and medication therapy. *Pharmacopsychiatry, 49*, 45–50.

Mohr-Jensen, C., & Steinhausen, H. C. (2016). A meta-analysis and systematic review of the risks associated with childhood attention-deficit hyperactivity disorder on long-term outcome of arrests, convictions, and incarcerations. *Clinical Psychology Review, 48*, 32–42.

Moore, D. A., Whittaker, S., & Ford, T. J. (2016). Daily report cards as a school-based intervention for children with attention-deficit/hyperactivity disorder. *Support for Learning, 31*, 71–83.

Murray, D. W., Lawrence, J. R., & LaForett, D. R. (2017). The Incredible Years® Programs for ADHD in young children: A critical review of the evidence. *Journal of Emotional and Behavioral Disorders.* Advance online publication. https://doi.org/10.1177/1063426617717740

National Center for Health Statistics. (2016). *Health, United States, 2015: With special feature on racial and ethnic health disparities*. MD: Hyattsville.

Nigg, J. T. (2013). Attention-deficit/hyperactivity disorder and adverse health outcomes. *Clinical Psychology Review, 33*, 215–228.

Nolan, E. E., Gadow, K. D., & Sprafkin, J. (2001). Teacher reports of DSM-IV ADHD, ODD, and CD symptoms in school children. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*, 241–249.

Page, T. F., Pelham, W. E., III, Fabiano, G. A., Greiner, A. R., Gnagy, E. M., Hart, K. C., … Pelham, W. E., Jr. (2016). Comparative cost analysis of sequential, adaptive, behavioral, pharmacological, and combined treatments for childhood ADHD. *Journal of Clinical Child & Adolescent Psychology, 45*, 416–427.

Pelham, W. E., Fabiano, G. A., & Massetti, G. M. (2005). Evidence-based assessment of attention deficit hyperactivity disorder in children and adolescents. *Journal of Clinical Child & Adolescent Psychology, 34*, 449–476.

Pelham, W. E., Jr., Fabiano, G. A., Waxmonsky, J. G., Greiner, A. R., Gnagy, E. M., Pelham, W. E., III, … Karch, K. (2016). Treatment sequencing for childhood ADHD: A multiple-randomization study of adaptive medication and behavioral interventions. *Journal of Clinical Child & Adolescent Psychology, 45*, 396–415.

Pelham, W. E., & Lang, A. R. (1999). Can your children drive you to drink?: Stress and parenting in adults interacting with children with ADHD. *Alcohol Research and Health, 23*, 292–298.

Reynolds, C. R., & Kamphaus, R. W. (2015). *Behavior Assessment System for Children – third edition (BASC-3)*. Bloomington, MN: Pearson.

Romer, D. (2010). Adolescent risk taking, impulsivity, and brain development: Implications for prevention. *Developmental Psychobiology, 52*, 263–276.

Sarver, D. E., McCart, M. R., Sheidow, A. J., & Letourneau, E. J. (2014). ADHD and risky sexual behavior in adolescents: Conduct problems and substance use as mediators of risk. *Journal of Child Psychology and Psychiatry, 55*, 1345–1353.

Schoenfelder, E. N., & Kollins, S. H. (2016). Topical review: ADHD and health risk behaviors: Toward prevention and health promotion. *Journal of Pediatric Psychology, 41*, 735–740.

Sciberras, E., Bisset, M., Hazell, P., Nicholson, J. M., Anderson, V., Lycett, K., … Efron, D. (2016). Health-related impairments in young children with ADHD: A community-based study. *Child: Care, Health and Development, 42*, 709–717.

Sciberras, E., Mulraney, M., Silva, D., & Coghill, D. (2017). Prenatal risk factors and the etiology of ADHD—review of existing evidence. *Current Psychiatry Reports, 19*, 1–8.

Shahidullah, J. D., Carlson, J. S., Haggerty, D., & Lancaster, B. M. (2018). Integrated care models for ADHD in children and adolescents: A systematic review. *Families, Systems, and Health, 36*, 233–247.

Silva, D., Colvin, L., Hagemann, E., Stanley, F., & Bower, C. (2014). Children diagnosed with attention deficit disorder and their hospitalisations: Population data linkage study. *European Child and Adolescent Psychiatry, 23*, 1043–1050.

Stickley, A., Koyanagi, A., Takahashi, H., Ruchkin, V., Inoue, Y., & Kamio, Y. (2017). Attention-deficit/hyperactivity disorder and physical multimorbidity: A population-based study. *European Psychiatry, 45*, 227–234.

Theule, J., Wiener, J., Tannock, R., & Jenkins, J. M. (2013). Parenting stress in families of children with ADHD: A meta-analysis. *Journal of Emotional and Behavioral Disorders, 21*, 3–17.

Timmermanis, V., & Wiener, J. (2011). Social correlates of bullying in adolescents with Attention-Deficit/Hyperactivity disorder. *Canadian Journal of School Psychology, 26*, 301–318.

Tobin, R. M., Schneider, W. J., & Landau, S. (2014). Best practices in the assessment of youth with attention deficit hyperactivity disorder within a multitiered services framework. In P. L. Harrison & A. Thomas (Eds.), *Best practices in school psychology: Data-based and collaborative decision making* (pp. 391–404). Baltimore, MD: NASP Publications.

Twyman, K. A., Saylor, C. F., Saia, D., Macias, M. M., Taylor, L. A., & Spratt, E. (2010). Bullying and ostracism experiences in children with special health care needs. *Journal of Developmental and Behavioral Pediatrics, 31*, 1–8.

Vaa, T. (2014). ADHD and relative risk of accidents in road traffic: A meta-analysis. *Accident Analysis and Prevention, 62*, 415–425.

Visser, S. N., Danielson, M. L., Bitsko, R. H., Holbrook, J. R., Kogan, M. D., Ghandour, R. M., … Blumberg, S. J. (2014). Trends in the parent-report of health care provider-diagnosed and medicated attention-deficit/hyperactivity disorder: United States, 2003-2011. *Journal of the American Academy of Child and Adolescent Psychiatry, 53*, 34–46.

Waite, R., & Ramsay, J. R. (2010). Adults with ADHD: Who are we missing? *Issues in Mental Health Nursing, 31*, 670–678.

Waluk, O. R., Youssef, G. J., & Dowling, N. A. (2016). The relationship between problem gambling and Attention Deficit Hyperactivity Disorder. *Journal of Gambling Studies, 32*, 591–604.

Wilens, T. (2015). Attention-deficit hyperactivity disorder and the substance use disorders in ADHD. In L. Adler, T. Spencer, & T. Wilens (Eds.), *Attention-deficit hyperactivity disorder in adults and children* (pp. 111–122). Cambridge, UK: Cambridge University Press.

Wolraich, M. L., Lambert, W., Doffing, M. A., Bickman, L., Simmons, T., & Worley, K. (2003). Psychometric properties of the Vanderbilt ADHD Diagnostic Parent Rating Scale in a referred population. *Journal of Pediatric Psychology, 28*, 559–568.

Wolraich, M. L., McKeown, R. E., Visser, S. N., Bard, D., Cuffe, S., Neas, B., … Danielson, M. (2014). The prevalence of ADHD: Its diagnosis and treatment in four school districts across two states. *Journal of Attention Disorders, 18*, 563–575.

Autism Spectrum Disorder

14

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Abstract

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder that is characterized by deficits in communication and social interaction and the presence of restricted and repetitive behavior. This chapter will provide an overview of ASD including screening and evaluation process, physical health implications, and current knowledge of interventions. The chapter will also focus on interprofessional issues associated with providing treatment to individuals with ASD including increased presence of behavioral and medical disorders, number of practitioners providing service across different settings, and the importance of and methods to facilitate coordination of services.

Definition

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by persistent deficits in social communication and social interaction and is accompanied by restricted, repetitive patterns of behavior, interests, or activities. The signs of ASD are usually evident in early childhood prior to age 3. Some studies have shown that it is possible to diagnose ASD in toddlers as young as 12–24 months (Kim & Lord, 2012).

Prevalence and Etiology

In 2014, the Centers for Disease Control and Prevention reported that the prevalence of ASD had risen to 1 in every 68 births in the United States (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). ASD is four to five times more likely to affect boys than girls and can be found in all racial, ethnic, and social groups. The surveillance study found that the incidence of ASD was 1 in 42 in males and 1 in 189 in females. There is no known single cause for ASD. However, the research literature suggests that there is a large genetic component to the disorder. Strong evidence for the genetic etiology can be found in twin studies (e.g., Frazier et al., 2014). For example, Frazier and colleagues found that in monozygotic twin pairs, if one twin is diagnosed

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with ASD, the other twin has a 76% chance of also being diagnosed. In fraternal twin pairs, if one twin has a diagnosis of ASD, the other twin has a 34% likelihood of being diagnosed with ASD.

Diagnosis of Autism Spectrum Disorder

The diagnostic criteria for ASD encompass two broad areas. The extent to which these deficits are present may vary significantly (mild to severe), allowing for a wide spectrum of symptom presentation.

Persistent deficits in social communication and social interaction across multiple contexts. These deficits can be characterized by a lack of social-emotional reciprocity (e.g., failure of normal back-and-forth social exchange), a lack of nonverbal communicative behavior during social interaction (e.g., a lack of eye contact or facial expressions), and deficits in developing, maintaining, and understanding social relationships.

Restricted, repetitive patterns of behavior, interests, or activities. The repetitive patterns of behavior may manifest in several ways. They may include stereotyped or repetitive motor movements or speech (e.g., repeated motor movements, echolalia). There may also be an insistence on sameness and/or inflexible adherence to specific routines or rituals. Individuals with ASD will also often present with highly restricted, fixated interests that are abnormal in intensity or focus. People with ASD may also present with hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment.

Screening and assessment/evaluation. The identification of a child with ASD may first begin with parents who notice differences in the way their child learns or behaves as compared to other children, or with a friend or relative who expresses concerns about the child's development to the parent. As the child enters school settings with peers, teachers may share ways in which the child differs from other children his or her age, such as tending to play by him or herself, expressing frustration with changes in the environment, or limits in communication skills. The concerns of the parent, family member, friend, or teacher may eventually spur the parent to seek out a professional opinion.

Often, parents may first turn to their child's pediatrician. As per the American Academy of Pediatrics (AAP), pediatricians should conduct a developmental screening at preventative care visits for children aged 9, 18, and 24 months. Early signs of ASD, such as lack of eye contact, may appear in a 9-month screening. The AAP recommends an autism-specific screening in addition to the developmental screening at the ages of 18 and 24 months (AAP, 2006). To accomplish this screening, pediatricians who follow the recommendations often make use of a screening questionnaire such as the Modified Checklist for Autism in Toddlers - Revised (M-CHAT-R; Robins, Fein, & Barton, 2009). The M-CHAT-R is a 23-item questionnaire comprising questions regarding symptoms of ASD that may be noticed by parents, such as the child's infrequent use of eye contact or lack of responsiveness to his or her name. If a pediatrician finds that a child screens positive for ASD using the M-CHAT-R, he or she should complete the M-CHAT-R follow-up, which guides the practitioner through a structured interview regarding the child's symptoms. If the child again screens positive on the follow-up interview, the pediatricians should provide a referral to a diagnostician and early intervention.

Commonly, diagnoses of ASD are provided by a developmental pediatrician, pediatric neurologist, or psychiatrist. Parents of children under the age of 3 may also seek assessment through their state's early intervention program, while parents of those over the age of 3 years may also seek an evaluation from their school district's evaluation team. This team must be multidisciplinary and include a teacher or specialist with expertise in the area of ASD evaluation and treatment. The team must also use multiple methods of assessment, such as those described below.

Parents who seek out a diagnosis for their child can expect a two-component evaluation process. First, the professional will conduct an interview with the parent regarding the symptoms of ASD to identify whether the child demonstrates common markers of the disorder, such as difficulties with social-communication skills or the presence of repetitive or restricted interests. While pediatric experts may employ their own interview techniques, structured interview tools are available for diagnostic purposes. As an example, the Autism Diagnostic Interview - Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) is an evaluation tool that may be used to conduct this interview. The ADI-R protocol guides the professional through a set of 93 interview items that focus specifically on the presence of abnormalities in social reciprocal interaction, communication, and restricted and repetitive interests or behaviors. Parent responses to these interview questions, scored using an algorithm to generate a summary score, help inform the diagnosis of ASD.

While structured interviews are a valuable tool in evaluating a child for the possibility of an ASD diagnosis, the professional cannot rely solely on the report of the caregiver for diagnosis. Parents may under-report or over-report their child's symptoms, or justify them in ways that may challenge the diagnostician. A comprehensive evaluation of the child must also rely on observation and interaction with the child with ASD so that the diagnostician can determine whether and how the symptoms of autism manifest. The use of a semi-structured observation provides the clinician with a standard method of assessment that will highlight specific symptoms of ASD if they are present.

The gold standard for observational assessment is the Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2; Lord et al., 2012), which is supported by substantial research.

In the ADOS-2, a series of activities is presented that pull for communication and social interaction and that may also set the occasion for any rigid or repetitive behavior. The examiner does not prompt communication or social interaction during the activities, but merely sets the occasion for them to occur and observes to see how the child responds. Following the ADOS-2 observation, the examiner provides ratings for the individual with ASD in the areas of communication, reciprocal social interaction, imagination and creativity, and stereotyped behavior and restricted interests. A summary score that provides a classification of ASD based on the findings of the ADOS-2 is provided, which can subsequently be used to inform a clinical diagnosis. As with the interview process, the ADOS-2 is not meant to stand alone in the evaluation, but should be used in tandem with other components of diagnostic evaluations, such as the interview, to provide a full picture of the child and his or her symptoms.

Some clinicians may also make use of questionnaires, such as the Social Communication Questionnaire (Rutter, Bailey, & Lord, 2003), to assess overall symptomatology and to help differentially diagnose children with ASD from other developmental disabilities, such as a language delay. These measures can also be administered to other individuals who know the child well, such as a teacher, to provide another source of information regarding the child's behavior in settings other than home. While these measures can be informative, they should not be used in isolation as a method of diagnosis.

Although some of the assessment tools described here can be used with children as young as 12 months, the median age of diagnosis for children with ASD is between the ages of 4 and 5 years of age (Christensen et al., 2016). Notably, the age of diagnosis for children of color, including African-American, Hispanic, and Asian children is later than that of White children. As an example, Black children are diagnosed, on average, 1.5 years later than White children and are more likely to receive another diagnosis such as attention-deficit-hyperactivity disorder or conduct disorder prior to a diagnosis of ASD (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). Given the significant benefit of early intervention for children with ASD, the delay in diagnosis is highly contraindicated and continued outreach efforts to provide early and accurate diagnosis for all children, and especially so for children of color, is warranted.

Outcomes

ASD is a lifelong condition. Research suggests that individuals who are diagnosed in childhood retain the diagnosis in adolescence and adulthood (e.g., Billstedt, Gillberg, & Gillberg, 2005). Due to the heterogeneity of the condition, outcomes can vary significantly across individuals. Individuals who present with less severe symptoms in early childhood are more likely to improve rapidly over time (Fountain, Winter, & Bearman, 2012). Early identification and subsequent intervention are also thought to improve long-term outcomes for this population (e.g., Sallows & Graupner, 2005). However, individuals with ASD and intellectual disabilities require continued support into adulthood and very few are able to live independently (Billstedt et al., 2005).

Physical Health Implications

The diagnosis of ASD interacts with a number of physical health issues that have a significant impact on the long-term quality of life. In fact, the mortality rate for individuals with ASD is estimated to be three to ten times higher than that of the general population (e.g., Hirvikoski et al., 2016). This disparity in the mortality rate is largely the result of medical comorbidities that interact with the diagnosis of ASD and contribute to poor health outcomes. As an example of how the diagnosis of ASD can complicate and exacerbate a medical diagnosis, many individuals with ASD are unable to effectively convey the nature of the physical symptoms they experience (e.g., telling someone they have a headache or pain in their chest) and may exhibit a variety of different behaviors while in pain that are erroneously attributed to the ASD diagnosis itself (e.g., aggression, self-injury, irritability, impulsivity, sleep disturbances). Thus, the inability to report physical discomfort has the potential to lead to larger, more costly health issues in the future. Similarly, the restricted, repetitive patterns of behavior associated with ASD can also interact with these health comorbidities. Certain types of repetitive behavior, for example, can produce tissue damage (e.g., hand wringing), and food selectivity, a type of restricted behavior, has the potential to produce gastrointestinal problems or cause significant weight gain. Medical conditions commonly associated with ASD follow.

Intellectual disabilities (ID). ASD is commonly associated with intellectual disabilities. Given the difficulties in measuring intelligence in people with ASD, the ranges of ID vary widely across studies. It has been reported that the incidence of ID in individuals with ASD ranges from 25% to 70% (Chakrabarti & Fombonne, 2001; Mash & Barkley, 2014). While the presence of intellectual disabilities does not necessarily *directly* contribute to poor health outcomes, they represent a contributing factor that may exacerbate health issues. For instance, individuals presenting with ID may make more impulsive, less health-conscious decisions regarding healthy life choices.

Severe maladaptive behavior. Individuals with ASD often present with behavioral challenges which have a negative impact on their quality of life. These behaviors include, but are not limited to, self-injurious behavior, aggression, pica, property destruction/disruption, socially offensive behavior, and noncompliance. While estimates of the prevalence of maladaptive behavior in individuals with ASD tend to vary widely depending on how they are defined, more than half of the population is reported to exhibit abnormal levels of challenging behavior (e.g., Woodman, Smith, Greenberg, & Mailick, 2015). Studies have found that the prevalence of maladaptive behavior is higher in individuals diagnosed with ASD relative to neurotypical peers or people with intellectual disability alone (e.g., Matson & Rivet, 2008). The presence of maladaptive behavior can be particularly problematic as the damage produced by the behavior itself can lead to health complications (e.g., injuries sustained from aggressive or self-injurious episodes).

Epilepsy. Epilepsy is another commonly diagnosed comorbid health issue for individuals with ASD. It is estimated that approximately one in four individuals diagnosed with ASD develops epilepsy in early childhood or adolescence (Canitano, 2007). Epileptic episodes are caused by abnormal electrical activity in the brain and can produce a temporary loss of consciousness, body convulsions, unusual movements, or staring spells. The comorbid diagnosis of epilepsy can have both direct (e.g., injury from falls, neurological problems) and indirect (e.g., disruptions to social/community integration) negative outcomes for people on the autism spectrum.

Sleep disorders. Sleep disorders are another common health issue for individuals diagnosed with ASD. Sleep disturbances are reported in approximately 53–78% of individuals diagnosed with ASD (Malow et al., 2012), and they may be characterized by late sleep onset, early morning awakening, and poor sleep maintenance (Reynolds & Malow, 2011).

Gastrointestinal difficulties. Gastrointestinal (GI) difficulties are among the most common medical conditions associated with ASD. The prevalence of reported GI symptoms in this population ranges anywhere from 23% to 70% (Gorrindo et al., 2012; Molloy & Manning-Countney, 2003). Among the most commonly reported GI problems are chronic constipation, frequent diarrhea, irritable and inflammatory bowel conditions, and gastroesophageal reflux. Several studies have shown that children with ASD are much more likely than age-matched typically developing peers to suffer GI discomfort, chronic diarrhea, or constipation (Chaidez, Hansen, & Hertz-Picciotto, 2014).

Obesity. Another commonly reported health issue in individuals diagnosed with ASD is obesity. Estimates suggest that 30.4% of people with ASD are obese as compared to 23.6% for their neurotypical counterparts (Curtin, Anderson, Must, & Bandini, 2010). Obesity is a pervasive problem in this population and has been linked to a number of serious health problems, such as heart disease, type 2 diabetes, orthopedic problems, sleep apnea, and certain cancers (He & Baker*,* 2004*)*.

While several studies have documented the high rate of comorbid health issues in individuals with ASD, relatively few viable solutions address these concerns. This is problematic on at least two fronts. Although the human cost of these poor outcomes is readily apparent, there are significant financial costs to both the individual family and society as well (Cidav, Marcus, & Mandell, 2012; Knapp, Romeo, & Beecham, 2009). These comorbid health issues are all problematic in their own right; however, their interaction with the symptoms of ASD creates a significant barrier to the identification and treatment of health problems in this at-risk population.

Intervention

Although there are more studies aimed at investigating treatments for ASD than ever before, what constitutes effective intervention continues to be disputed (McGrew, Ruble, & Smith, 2016). Much of the intervention research has relied on single subject experimental designs. These designs allow for the demonstration of effectiveness of strategies for specific target behaviors on an individual level but do not allow for the demonstration of efficacy for the larger clinical population. Randomized control trials (RCTs) are considered the gold standard to determine intervention efficacy and evaluate potential treatment moderators but relatively few have been conducted. In addition, inclusion and exclusion criteria for research studies limit the focus on intervention effectiveness to a specific portion of the ASD population in highly controlled settings. Thus, the extent to which effects generalize to the wide variety of individuals with ASD and across contexts is unknown.

Behavioral intervention. Despite the limitations in current empirical knowledge, a number of behavioral and educational treatment strategies have been shown to be effective at alleviating symptoms of ASD. Treatment location may vary based upon the age of the individual but it is not uncommon for school-aged children with ASD to receive behavioral and education treatment services at home, school, and/or in specialty clinics. The most well-established interventions for ASD are based upon the principles of behavior analysis and are known as applied behavior analysis (ABA; Smith & Iadarola, 2015; Wong et al., 2015). Behavior analytic interventions incorporate measurement of behavior targets to evaluate the effectiveness of treatment procedures. Individualized assessments are conducted to identify specific skill deficits and effective teaching strategies. Additionally, variables responsible for behavioral excesses are evaluated so that the environment can be arranged to promote appropriate communication and reduce problem behavior.

Treatments using ABA strategies typically involve highly structured, one-to-one instruction to promote pre-academic, academic, communication, and social skills. Each skill is broken down into basic components and is taught through systematic prompting and reinforcement. Teaching strategies may include adult-led discrete trial teaching (DTT) or child-led naturalistic teaching strategies. For example, using DTT, a therapist may target the skill of responding to one's name by simultaneously providing the instruction (i.e., stating the learner's name while he is distracted) and a prompt (e.g., gesture to look at the therapist) before providing reinforcement for compliance. This process would be repeated across numerous learning trials. Using naturalistic teaching strategies, the teaching may take place in the context of turn-taking during a preferred board game. Before the learner takes a turn, the therapist could state the child's name and provide a prompt to respond. The student's appropriate response would result in natural reinforcement of resuming the game and taking a turn. In both cases, additional prompts could be systematically faded over trials until the learner is independently responding to his or her name.

Early intensive behavioral intervention (EIBI) is type of ABA treatment that aims to provide as many learning opportunities as possible throughout a young child's day and includes instruction in naturalistic settings and high levels of parent involvement (Lovaas & Smith, 2003). Research has shown some positive gains for most children who receive EIBI with greater treatment gains correlated with a younger age (prior to the age of 5 years) of treatment onset, greater intensity and duration of treatment, and higher developmental level of the individual (Harris & Handleman, 2000; Makrygianni & Reed, 2010). The most well-established model of EIBI was described by Lovaas and colleagues in their work with young children with autism at UCLA. In the seminal experiment, Lovaas (1987) compared an experimental group of young children with autism who received 40 h per week of intensive behavioral treatment for up to 3 years to a control group. This study found that children in the experimental group showed gains in educational and intellectual functioning, with 47% achieving normal-range IQ scores. This finding stood in contrast to 2% of the control group who achieved normal functioning levels. Numerous replications of the Lovaas model have been conducted and have shown similar treatment gains with a slightly lower dose of treatment and in community settings (e.g., Eldevik, Hastings, Jahr, & Hughes, 2012).

Additional comprehensive intensive behavioral and educational treatment models utilizing behavioral principles have been developed and shown to be effective including Pivotal Response Training (Koegel, O'Dell, & Koegel, 1987), the Early Start Denver Model (Dawson et al., 2010), Learning Experiences and Alternative Program for Preschoolers (LEAP; Strain & Bovey, 2011), and Treatment and Education of Autism and

Related Communication-Handicapped Children (TEACCH; Marcus, Schopler, & Lord, 2001).

Behavioral treatment of core ASD symptoms and challenging behavior. Many behavioral treatments target specific symptoms of ASD including communication and social skills deficits. Although approximately a third of individuals with ASD do not develop fluent vocal language (Norrelgen et al., 2015), a number of alternative and augmentative communication strategies including Picture Exchange Communication System (Bondy & Frost, 1994), sign language, and speech generating devices may be used to repair language deficits as well as increase social skills and reduce challenging behavior. Once basic forms of communication are established, treatments may focus on increasing the frequency and quality of social interactions as well as help the individual navigate various social situations. Established strategies to increase social skills include prompting, video modeling, self-monitoring, and social scripts (Bellini & Peters, 2008).

Numerous studies on the assessment and treatment of restricted and repetitive behavior exist in the behavioral literature and primarily focus on the assessment and treatment of stereotypy. Behavior analytic approaches to decreasing stereotypy assume that stereotypic behavior is maintained by environmental variables. Stereotypy often persists in the absence of social consequences and is thought to be maintained by the sensory consequences the behavior itself produces (Rapp & Vollmer, 2005). Several strategies that have been shown to be effective include providing the individual with leisure items with which to engage, interrupting stereotypy and redirecting the individual to engage in a more socially appropriate activity, and teaching the individual appropriate times or places to engage in stereotypy.

While behavioral treatment has been effective at addressing core symptoms of ASD, it can also be helpful for decreasing other prevalent challenging behavior and behavioral issues. A behavioral approach to treatment of challenging behavior presumes that each behavior serves a purpose for the individual and may be used as a form of communication. For example, an individual may engage in aggressive and self-injurious behavior to escape demands because he or she has no means to appropriately ask for a break. Best practices include conducting a functional analysis (Iwata, Dorsey, Slifer, Bauman, and Richman, 1982/1994) to identify maintaining environmental variables. Once variables are identified, function-based treatments such as functional communication training can be implemented to teach the individual appropriate ways of requesting wants and needs. In addition, caregiver training can be conducted to teach caregivers to minimize access to reinforcers (i.e., stimuli whose contingent delivery or removal increases behavior) when problem behavior occurs.

Psychopharmacological interventions. It is estimated that over half of children with ASD are prescribed at least one psychotropic medication (Mandell et al., 2008). A number of psychotropic medications have been prescribed including antipsychotics, ADHD medications, and antidepressants. However, evidence for effectiveness of these medications is extremely limited. Siegel and Beaulieu (2012) conducted a review of psychotropic medication use for children and categorized the level of evidence for each pharmacological agent. Only three antipsychotic drugs showed established evidence (highest level) in the treatment of some target symptoms. Aripiprazole was found to be effective in treatment of irritability, hyperactivity, and stereotypy, haloperidol was found to be effective for treating behavioral symptoms and risperidone was found to be effective for irritability and hyperactivity. In addition, methylphenidate, naltrexone, and atomoxetine showed preliminary evidence of effectiveness in the treatment of hyperactivity. Even less is known about the effectiveness of psychotropic medications for adolescents and young adults with ASD. For example, Dove et al. (2012) found insufficient evidence for all medications for this population.

Sensory integration therapy. Sensory integration therapy (SIT) involves presenting items and activities that offer different sensory inputs to individuals to address underlining "sensory processing" issues (Ayres, 1979). The American Academy of Pediatrics policy statement on sensory integration therapy (2012) raises several concerns with the practice including no standard diagnostic criteria for sensory processing disorder. In addition, there is a lack of empirical evidence for the clinical usefulness of SIT.

Complementary and alternative medicine. Although there is little to no evidence of their effectiveness, complementary and alternative medicine (CAM) interventions are frequently used for individuals with ASD (Höfer, Hoffmann, & Bachmann, 2017). The most frequently used CAM interventions are special diets or various dietary supplements, which may be viewed as relatively innocuous. However, therapies such as chelation have also been used in treatment, and deaths from inappropriate administration of chelation therapy have been reported (Brown, Willis, Omalu, & Leiker, 2006).

Implications for Interprofessional Care

Due to the complexity of symptoms that often accompany an ASD diagnosis, individuals with ASD and their families rely on a network of professionals for care. These professionals may span educational and medical settings, and include public or private school teachers and personnel, psychologists, behavior analysts, speech therapists, occupational and physical therapists, primary care physicians, neurologists, and other medical specialists such as gastroenterologists. While each professional may work to address the same symptoms of ASD, these professionals often operate independently with little collaboration or coordination with one another. To best provide comprehensive services to individuals with ASD, communication between these professionals and the family of the individual with ASD is monumentally important.

One reason why coordination care is critical among individuals with ASD is that individual treatment approaches may affect a child's health or behavior in a way that other professionals should be aware. For example, the administration of some medications may have side effects that significantly alter the individual's behavior; he or she may become more agitated, or lethargic, or hungry, or exhibit unexpected behaviors such as tics or seizures. Awareness of these possible side effects will help other professionals be prepared for and account for these changes.

Additionally, the efforts of each professional to improve the health and progress of the individual with ASD may also impact the treatment provided by other providers, or the ability to accurately evaluate the outcome of such treatment. For instance, if a child with ASD exhibits significant aggression at home and at school, one might expect that it would be a primary focus of treatment for a number of professionals. A psychiatrist might address the problem by providing medication, such as risperidone, to reduce agitation. Simultaneously, a behavior analyst may suggest that the child's special education teacher address aggression by teaching the individual to request for preferred activities while simultaneously reducing access to those activities when the problem behavior occurs. However, if changes are made in both educational and medical settings at the same time, neither of the professionals will be able to clearly attribute the changes to the treatment they have provided. Ideally, one change will be made at a time and the changes on behavior will be assessed separately. A process such as this will allow for a careful analysis of the effects of each treatment on behavior and reduces the likelihood that progress will be misattributed to an ineffective treatment.

Additionally, professionals can often work together to provide the best opportunities for evaluation of treatment by pooling the data they have available for the expected outcome of the treatment. For example, occupational therapists may make recommendations to incorporate sensory activities into the school day of a child with

ASD. The child's teachers and behavior analysts can help evaluate a treatment such as this by taking data on the child's behavior both before and after the implementation of the treatment. If an effect is observed, brief removal of the treatment is conducted to assess if behavior returns to pretreatment levels. The treatment can then be re-implemented to confirm its effectiveness.

The use of data and the coordination between professionals is especially important when the treatment is medical in nature; while the implementation and removal of sensory activities have no expected impact on the child's health, the manipulation of medication regimens is not so straightforward. Medication can have tremendous impact—both therapeutic and detrimental—on the child's behavior and progress in home and school settings. However, only the prescribing doctor can determine how medication changes should be made to evaluate their impact on behavior, and so coordination between the doctor and educational staff is necessary. By working directly with private or public schools, a medical doctor can clearly convey the changes that are made and teachers or other professionals within the school system can carefully monitor, using data, the behaviors of interest.

Currently, the coordination of child care commonly falls to the parents of the child with ASD. However, this burden of acting as liaison may be alleviated by the efforts of care providers to coordinate their services. A "medical home" can be rooted in virtually any setting, including hospitals, pediatrician's offices, and school clinics, but in all cases the setting is a regular source of care and the treatment of the child is managed by well-trained physicians (Medical Home Initiatives for Children with Special Needs Project Advisory Committee & AAP, 2002). The guidelines provided by the AAP recommend that medical treatment of children within a medical home be accessible, continuous, comprehensive, family-centered, compassionate, culturally effective, and, of importance here, coordinated. To coordinate care, the AAP recommends that primary and pediatric medical subspecialties collaborate as a team by taking steps such as sharing treatment plans across professionals and with the family and clearly delineating the roles each will play in the child's treatment. Further, the AAP recommends that medical homes communicate with educational programs or other care providers to ensure that the needs of the child with ASD are met. Finally, a central record should be maintained that can be accessed by all clinicians in the medical home (AAP, 2002).

Research indicates that children with ASD who receive services through a medical home are four times more likely to have no unmet medical needs than children who do not, with the effects of the model driven largely by the positive impact of family-centered care and coordination of services provided (Cheak-Zamora & Farmer, 2015). However, the receipt of services consistent with a medical home model for children with ASD lags behind that of other childhood medical conditions, with less than 25% of children with ASD receiving services through a medical home (Farmer et al., 2013). Parents specifically cite lack of comprehensive services, family-centered care, and coordination in their child's medical care. Physicians point to a lack of resources, time, and training as primary barriers for the development of medical homes for children with ASD (Carbone, Behl, Azor, & Murphy, 2010), while the insurance coverage and family income can also impact the extent to which a family's needs are met. These findings indicate that physician training on the healthcare needs specific to individuals with ASD, beyond just diagnosis, is greatly needed. Further, medical systems that support coordinated care through the use of technology and other communication systems, and that provide the necessary insurance coverage for the care provided are necessary for the coordination of effective treatment of individuals with ASD.

Case Study

Harold is a 12-year-old Hispanic male with ASD. Harold has an IQ of 42 as measured by the Stanford-Binet and limited vocal language. He was diagnosed with ASD at age 2 after failure to meet expected milestones in language and social development. Because Harold has significant intellectual impairments and engages in severe problem behavior, he was placed at an out-of-school district placement at a university-based school specializing in applied behavior analysis. In addition to his school placement, Harold also receives in-home services to address behavioral issues and deficits in daily living skills and is under the care of a neurologist who prescribes medication for severe problem behavior. Harold's case will be used to illustrate the importance of treatment coordination across care providers.

Medication evaluation. Harold engages in severe aggression (hitting, kicking, scratching, biting others) and self-injurious behavior (head banging and hitting, hand biting) at home and school. Harold received clearance from medical professionals that his behavior was not caused by medical issues. After obtaining consent to assess, the board certified behavior analyst (BCBA) who oversees Harold's classroom began the assessment process, including operationally defining and collecting data on target behaviors. A functional analysis (Iwata et al., 1982/1994) was conducted and showed that Harold engaged in high rates of target problem behavior when he was asked to complete tasks and would stop engaging in target problem behavior when contingent breaks were provided. A treatment was implemented which included teaching Harold to appropriately ask for breaks from demands and granting those requests frequently, providing motivation for compliance, and redirecting Harold to complete tasks when he engaged in challenging behavior (i.e., escape extinction). The treatment resulted in substantial decreases in problem behavior at school. However, although these decreases in challenging behavior were an improvement from the level measured prior to the start of treatment, Harold continued to engage in severe episodes of behavior that occurred every 2–3 weeks. Escalations were observed at both home and school and Harold's behavior was often so dangerous that crisis management strategies (e.g., physical restraint) were implemented as a safety precaution.

Due to the severity and cyclical nature of Harold's behavior, his parents brought him to see a neurologist for medical treatment. Harold's parents informed the school program staff when medications were begun so that they could note the change on his behavior graphs. School staff also ensured that behavioral treatment procedures were kept constant across the school day so the particular effects of the medications could be isolated and evaluated. Behavioral data collected at school were shared with Harold's doctor to assist in the medication evaluation.

Figure 14.1 presents summary data from the medication evaluation and includes levels of problem behavior (aggression and self-injury) and compliance with instructions (percentage of time that Harold initiated a task within 5 s of an instruction). Data from 10 days prior to medication implementation were summarized as a baseline measure. During baseline, Harold engaged in problem behavior in 25% of 1-min intervals. Compliance with demands occurred during 80% of opportunities. Harold was initially prescribed Clonidine for hyperactivity. However, following increases in frequency and intensity of problem behavior (to 50% of 1-min intervals on average) as well as increases in other disruptive behavior and decreased compliance, clonidine was discontinued and Harold was prescribed risperidone. An initial dose (risperidone A) was administered for 2 weeks before being increased. An immediate decrease in target behavior was observed during the initial dose (problem behavior decreased to 15% of 1-min intervals). Problem behavior was further reduced to zero levels during when the medication dosage was doubled (risperidone B). However, additional side effects were observed. Harold became lethargic and showed decreased responsiveness to instructional demands and bids for communication. These side effects are evident in the low levels of compliance observed during risperidone B. When medication dosage was reduced slightly (risperidone C), problem behavior increased slightly but was still greatly reduced in frequency and intensity. In addition, compliance returned to baseline levels.

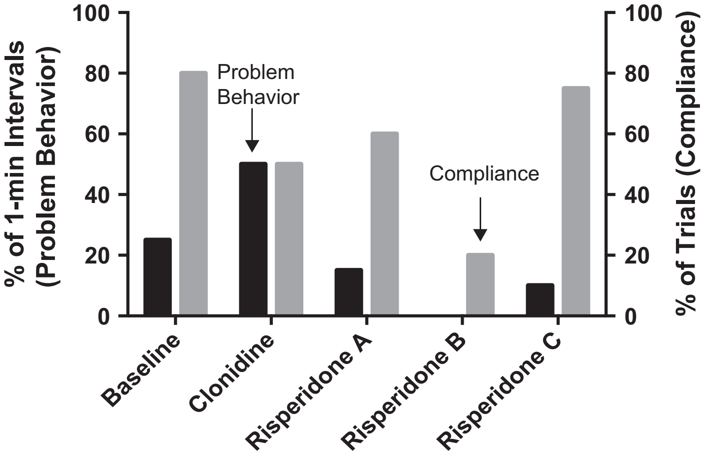

Fig. 14.1 The graph displays the results for the medication evaluation for Harold. Conditions are plotted on the x-axis. Percentage of 1-min intervals with severe problem behavior are represented by the black bars and are plotted on the left y-axis. Percentage of learning trials with compliance are represented by the gray bars and are plotted on the right y-axis

Harold's parents and physician are pleased with his progress and have no plans to make modifications to his medication regimen. The school program will continue to collect and evaluate behavior data as well as share information on any perceived side effects. The coordination between Harold's parents, neurologist, and school program staff ensured that the medication evaluation was conducted in a timely matter and that Harold was not placed on a medication dose that prevented him from engaging in habilitative and preferred activities.

Summary

ASD is a neurological disorder characterized by deficits in social communication and interaction and restricted and repetitive behavior. It is considered to be a lifelong disorder and most individuals with ASD will require continued support throughout their lifetime. Individuals with ASD are at a greater risk of having intellectual disabilities, severe behavior disorders, seizures, sleep and feeding disorders, and obesity than their neurotypical peers. Interventions based on the principles of applied behavior analysis are one of the only established treatments for ASD. Additional research is needed to compare behavioral treatments to identify effective components as well as individual factors that may predict treatment effectiveness. Because of the complexity of ASD, individuals may seek out and receive treatment from a variety of treatment providers and across different contexts. Coordination between providers is paramount because implementation of one treatment may inadvertently affect treatment in another context. The medical home model provides a method to coordinate services across professionals and alleviate the need for family members having to fill a coordinator role. However, this approach is currently lacking for families of individuals with ASD. Therefore, additional research on overcoming barriers to implementing a medical model as well as training for physicians is necessary.

References

American Academy of Pediatrics, Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics, Bright Futures Steering Committee, & Medical Home Initiatives for Children With Special Needs Project Advisory Committee. (2006). Identifying infants and young children with developmental disorders in the medical home: An algorithm for developmental surveillance and screening. *Pediatrics, 118*, 405–420.

Ayres, A. J. (1979). *Sensory integration and the child*. Los Angeles, CA: Western Psychological Services.

Bellini, S., & Peters, J. K. (2008). Social skills training for youth with autism spectrum disorders. *Child Adolesc Psychiatr Clin N Am, 17*, 857–873.

Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: Population-based 13-to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders, 35*, 351–360.

Bondy, A. S., & Frost, L. A. (1994). The picture exchange communication system. *Focus on Autistic Behavior, 9*, 1–19.

Brown, M. J., Willis, T., Omalu, B., & Leiker, R. (2006). Deaths resulting from hypocalcemia after administration of edetate disodium: 2003-2005. *Pediatrics, 118*(2), e534–e536.

Canitano, R. (2007). Epilepsy in autism spectrum disorders. *European Child & Adolescent Psychiatry, 16*, 61–66.

Carbone, P. S., Behl, D. D., Azor, V., & Murphy, N. A. (2010). The medical home for children with autism spectrum disorders: Parent and pediatrician perspectives. *Journal of Autism and Developmental Disorders, 40*, 317–324.

Chaidez, V., Hansen, R. L., & Hertz-Picciotto, I. (2014). Gastrointestinal problems in children with autism, developmental delays or typical development. *Journal of Autism and Developmental Disorders, 44*, 1117–1127.

Chakrabarti, S., & Fombonne, E. (2001). Pervasive developmental disorders in preschool children. *Journal of the American Medical Association, 285*, 3093–3099.

Cheak-Zamora, N. C., & Farmer, J. E. (2015). The impact of the medical home on access to care for children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 45*, 636–644.

Christensen, D. L., Baio, J., Braun, K. V., Bilder, D., Charles, J., Constantino, J. N., … Yeargin-Allsopp, M. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8. *Morbidity and Mortality Weekly Report, Surveillance Summary, 65*, 1–23.

Cidav, Z., Marcus, S. C., & Mandell, D. S. (2012). Implications of childhood autism for parental employment and earnings. *Pediatrics, 129*, 617–623.

Curtin, C., Anderson, S. E., Must, A., & Bandini, L. (2010). The prevalence of obesity in children with autism: A secondary data analysis using nationally representative data from the National Survey of Children's health. *BMC Pediatrics, 10*, 11.

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., … Varley, J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: The early start Denver model. *Pediatrics, 125*, e17–e23.

Dove, D., Warren, Z., McPheeters, M. L., Taylor, J. L., Sathe, N. A., & Veenstra-VanderWeele, J. (2012). Medications for adolescents and young adults with autism spectrum disorders: A systematic review. *Pediatrics, 130*(4), 717–726.

Eldevik, S., Hastings, R. P., Jahr, E., & Hughes, J. C. (2012). Outcomes of behavioral intervention for children with autism in mainstream pre-school settings. *Journal of Autism and Developmental Disorders, 42*, 210–220.

Farmer, J. E., Clark, M. J., Mayfield, W. A., Cheak-Zamora, N., Marvin, A. R., Law, J. K., & Law, P. A. (2013). The relationship between the medical home and unmet needs for children with autism spectrum disorders. *Maternal and Child Health Journal, 18*, 672–680.

Fountain, C., Winter, A. S., & Bearman, P. S. (2012). Six developmental trajectories characterize individuals with autism. *Pediatrics, 129*, 1112–1120.

Frazier, T. W., Thompson, L., Youngstrom, E. A., Law, P., Hardan, A. Y., Eng, C., & Morris, N. (2014). A twin study of heritable and shared environmental contributions to autism. *Journal of Autism and Developmental Disorders, 44*, 2013–2025.

Gorrindo, P., Williams, K. C., Lee, E. B., Walker, L. S., McGrew, S. G., & Levitt, P. (2012). Gastrointestinal dysfunction in autism: Parental report, clinical evaluation, and associated factors. *Autism Research, 5*, 101–108.

Harris, S. L., & Handleman, J. S. (2000). Age and IQ at intake as predictors of placement for young children with autism: A four-to six-year follow-up. *Journal of Autism and Developmental Disorders, 30*, 137–142.

He, X. Z., & Baker, D. W. (2004). Body mass index, physical activity, and the risk of decline in overall health and physical functioning in late middle age. *American Journal of Public Health, 94*, 1567–1573.

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry, 208*, 232–238.

Höfer, J., Hoffmann, F., & Bachmann, C. (2017). Use of complementary and alternative medicine in children and adolescents with autism spectrum disorder: A systematic review. *Autism, 21*, 387–402.

Iwata, B. A., Dorsey, M. E., Slifer, K. J., Bauman, K. E., & Richman, G. S. (1994). Toward a functional analysis of self-injury. *Journal of Applied Behavior Analysis, 27*, 197–209. (Reprinted from Analysis and Intervention in Developmental Disabilities, 2, 3–20, 1982).

Kim, S. H., & Lord, C. (2012). New autism diagnostic interview-revised algorithms for toddlers and young preschoolers from 12 to 47 months of age. *Journal of Autism and Developmental Disorders, 42*, 82–93.

Knapp, M., Romeo, R., & Beecham, J. (2009). Economic cost of autism in the UK. *Autism, 13*, 317–336.

Koegel, R. L., O'Dell, M. C., & Koegel, L. K. (1987). A natural language teaching paradigm for nonverbal autistic children. *Journal of Autism and Developmental Disorders, 17*, 187–200.

Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., & Bishop, S. (2012). *Autism diagnostic observation schedule: ADOS-2*. Los Angeles, CA: Western Psychological Services.

Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism diagnostic interview-revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disabilities, 24*, 659–685.

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology, 55*, 3–9.

Lovaas, O. I., & Smith, T. (2003). Early and intensive behavioral intervention in autism. In A. E. Kazdin & J. R. Weisz (Eds.), *Evidence-based psychotherapies for children and adolescents* (pp. 325–340). New York, NY: Guilford Press.

Makrygianni, M. K., & Reed, P. (2010). A meta-analytic review of the effectiveness of behavioural early intervention programs for children with autistic spectrum disorders. *Research in Autism Spectrum Disorders, 4*, 577–593.

Malow, B. A., Byars, K., Johnson, K., Weiss, S., Bernal, P., Goldman, S. E., … Glaze, D. G. (2012). A practice pathway for the identification, evaluation, and management of insomnia in children and adolescents with autism spectrum disorders. *Pediatrics, 130*, S106–S124.

Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2007). Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. *Journal of Autism and Developmental Disorders, 37*, 1795–1802.

Mandell, D. S., Morales, K. H., Marcus, S. C., Stahmer, A. C., Doshi, J., & Polsky, D. E. (2008). Psychotropic medication use among Medicaid-enrolled children with autism spectrum disorders. *Pediatrics, 121*, e441–e448.

Marcus, L., Schopler, E., & Lord, C. (2001). TEACCH services for preschool children. In J. S. Handleman & S. L. Harris (Eds.), *Preschool education programs for children with autism* (2nd ed., pp. 215–232). Austin: PRO-ED.

Mash, E. J., & Barkley, R. A. (Eds.). (2014). *Child psychopathology*. New York, NY: Guilford Publications.

Matson, J. L., & Rivet, T. T. (2008). Characteristics of challenging behaviours in adults with autistic disorder, PDD-NOS, and intellectual disability. *Journal of Intellectual and Developmental Disability, 33*, 323–329.

McGrew, J. H., Ruble, L. A., & Smith, I. M. (2016). Autism spectrum disorder and evidence-based practice in psychology. *Clinical Psychology: Science and Practice, 23*, 239–255.

Medical Home Initiatives for Children with Special Needs Project Advisory Committee, & American Academy of Pediatrics. (2002). The medical home. *Pediatrics, 110*(1 Pt 1), 184.

Molloy, C. A., & Manning-Countney, P. (2003). Prevalence of chronic gastrointestinal symptoms in children with autism and autistic spectrum disorders. *Autism, 7*, 165–171.

Norrelgen, F., Fernell, E., Eriksson, M., Hedvall, Å., Persson, C., Sjölin, M., … Kjellmer, L. (2015). Children with autism spectrum disorders who do not develop phrase speech in the preschool years. *Autism, 19*, 934–943.

Rapp, J. T., & Vollmer, T. R. (2005). Stereotypy I: A review of behavioral assessment and treatment. *Research in Developmental Disabilities, 26*, 527–547.

Reynolds, A. M., & Malow, B. A. (2011). Sleep and autism spectrum disorders. *Pediatric Clinics of North America, 58*, 685–698.

Robins, D. L., Fein, D., & Barton, M. (2009). *Modified Checklist for Autism in Toddlers, Revised, with Follow-up* (M-CHAT-R/F). Author.

Rutter, M., Bailey, A., & Lord, C. (2003). *The social communication questionnaire (SCQ) manual*. Los Angeles, CA: Western Psychological Services.

Sallows, G. O., & Graupner, T. D. (2005). Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Journal on Mental Retardation, 110*, 417–438.

Siegel, M., & Beaulieu, A. A. (2012). Psychotropic medications in children with autism spectrum disorders: A systematic review and synthesis for evidence-based practice. *Journal of Autism and Developmental Disorders, 42*, 1592–1605.

Smith, T., & Iadarola, S. (2015). Evidence base update for autism spectrum disorder. *Journal of Clinical Child & Adolescent Psychology, 44*, 897–922.

Strain, P. S., & Bovey, E. H. (2011). Randomized, controlled trial of the LEAP model of early intervention for young children with autism spectrum disorders. *Topics in Early Childhood Special Education, 31*, 133–154.

Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, S., … Schultz, T. R. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of Autism and Developmental Disorders, 45*, 1951–1966.

Woodman, A. C., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2015). Change in autism symptoms and maladaptive behaviors in adolescence and adulthood: The role of positive family processes. *Journal of Autism and Developmental Disorders, 45*, 111–126.

Zablotsky, B., Black, L.I., Maenner, M.J., Schieve, L.A., Blumberg, S. J. (2015). Estimated prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 National Health Interview Survey. National Health Statistics Reports, 87. Hyattsville, MD: National Center for Health Statistics. 1–20.

15

Learning Disabilities

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Abstract

Learning disabilities are prevalent and have significant health implications. Healthcare and school systems must work collaboratively with families to promote academic health. This chapter proposes best practices in preventing, identifying, and treating learning disabilities with a focus on interprofessional care. Barriers to collaboration across systems are many, including: definitional, conceptual, and linguistic differences across settings; administrative and fiscal pressures; varying beliefs and attitudes related to responsibility of assessing and treating learning disabilities; absence of built mechanisms to coordinate care; and differences in communication preferences. This chapter outlines a shared conceptual and definitional understanding of learning disabilities; delineates roles of healthcare and school settings in the prevention, identification, and treatment of learning disabilities; and synthesizes conceptual and empirical work into an actionable plan for interprofessional care. A case study is included to elucidate what this interprofessional collaboration may look like in practice.

Introduction

Learning disabilities are prevalent and have significant health implications. Healthcare and school systems must work collaboratively with families to promote academic health. This chapter proposes best practices in preventing, identifying, and treating learning disabilities with a focus on interprofessional care. Barriers to collaboration across systems are many, including: definitional, conceptual, and linguistic differences across settings; administrative and fiscal pressures; varying beliefs and attitudes related to responsibility of assessing and treating learning disabilities; absence of built mechanisms to coordinate care; and differences in communication preferences. This chapter outlines a shared conceptual and definitional understanding of learning disabilities; delineates roles of healthcare and school settings in the prevention, identification, and treatment of learning disabilities;

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and synthesizes conceptual and empirical work into an actionable plan for interprofessional care. A case study is included to elucidate what this interprofessional collaboration may look like in practice.

Background

Definition

Broadly speaking, the term learning disability (LD) refers to impairment in the ability to learn a specific academic skill as quickly and readily as expected given an individual's age, adequate educational opportunity, and overall cognitive ability. More precise definition of the term is complicated by differing names and definitions used across different organizations. For example, the terms LD, specific learning disability, learning disorder, developmental disorder of scholastic skills, reading disability, and dyslexia may all be used to refer to the same condition. Some professionals differentiate between some of these terms; others do not. Additionally, some of these terms mean very different things in different countries. For example, in the United Kingdom the term "learning disability" is used to refer to the condition known as "intellectual disability" in the United States.

In addition, different authorities currently support definitions that differ in meaningful ways. The International Classification of Diseases (ICD-10), for example, emphasizes that academic difficulty associated with developmental disorders of scholastic skills "is not simply a consequence of a lack of opportunity to learn, it is not solely a result of mental retardation, and it is not due to any form of acquired brain trauma or disease" (World Health Organization, 2016), also adding that specific learning problems are not the result of poor visual acuity or inadequate schooling. The Diagnostic and Statistical Manual, Fifth Edition (DSM-5) of the American Psychiatric Association (2013) further characterizes specific learning disorders as academic difficulties that are present from an early age, persist despite the provision of targeted interventions, and result in skills that are substantially and quantifiably lower than age-based expectations. The DSM-5 additionally requires that learning difficulties are not the result of mental disorders, neurological disorders, psychosocial adversity, or language proficiency. The Individuals with Disabilities Education Act (IDEA) adds more specificity yet, defining a specific LD as "a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations" (IDEA, 2004) and adds that the disability is not the result of emotional disturbance or environmental, cultural, or economic disadvantage.

In addition to variability *between* these organizations, definitions also vary *within* organizational entities. For example, the IDEA allows for at least three different ways to identify learning disabilities, each of which has implications for the understanding of LD. These differences are further discussed in the diagnosis and assessment sections.

Discussion of variability is not intended to confuse the reader; rather it is introduced to highlight the fact that many discussions about LD are often confusing. It is important to note that the same term may mean something different to a health care provider, a parent, a school psychologist, and a teacher. Understanding this variability and communicating precisely can help families avoid frustrating confusion.

Etiology

Not surprisingly, research has indicated that both genetic and environmental factors play a role in the development of LD (Petril, 2013). For example, twin studies have indicated that about one-third to two-thirds of variation in math achievement is attributable to genetics (Kovas, Haworth, Dale, & Plomin, 2007). Specific genes related to LD have remained elusive, leading to the hypothesis that learning disabilities are related to multiple genes that occur infrequently or have a small effect size (Petril, 2013).

Specific etiological pathways to learning disorders may vary as a function of the definition adopted. If simple lack of achievement is the most salient criteria, environmental disadvantage or lack of educational opportunity may have a large impact on learning difficulty. When more strict definitions are employed, such as those typically used by schools, it is more likely that unexpected difficulty in a basic cognitive or academic process has played a part in the development of LD. For example, research has indicated that reading disabilities are often linked to deficits in phonological processing, rapid automatized naming, and working memory. Math disabilities are often linked to difficulty in number sense, learning arithmetic procedures, memorizing math facts, and working memory (Swanson, Harris, & Graham, 2013).

Diagnosis

A considerable difference in definitions of learning disabilities has led to differing diagnostic criteria, both within and between professional settings. Overall, diagnostic criteria can be categorized within the following categories:

Very Low Achievement Academic achievement is "quantifiably below" the level expected for the individual's chronological age. This is the least stringent definition and can be obtained through "clinical synthesis" of school data or low performance on standardized academic achievement tests (e.g., scoring below the fifth percentile). If a child has a diagnosis of LD established by a primary care provider or psychiatrist, they almost always have used the "very low achievement" definition based solely on parent report. It may be helpful to inform parents that these definitions are rarely accepted by schools to determine special education eligibility.

Ability-Achievement Discrepancy Academic achievement is significantly below the level predicted by intelligence. For example, a child's reading performance is two standard deviations lower than her full scale IQ score.

Response to Instruction and Intervention The student has failed to show progress in a specific area despite targeted and intensive evidence-based instruction and intervention. For example, despite individual interventions, regular progress monitoring data show that a student shows no or limited progress in oral reading fluency.

Processing Strengths and Weaknesses The student has an identifiable weakness in a cognitive skill that can be related to a specific academic deficit. For example, a student with an average IQ has deficits in basic word reading skills and in phonological processing ability.

Regardless of the definition, the most stringent and precise diagnoses are typically provided by school, clinical, or neuropsychologists. In schools, diagnosis is often made by a team including psychologists, teachers, interventionists, and parents. In clinical practice, diagnosis should be based on information from these multiple informants and from multiple methods of assessment including the results of standardized cognitive assessments, standardized and classroom-based academic assessments, developmental and academic history, and an assessment of behavioral and emotional functioning. Given the time, materials, and training necessary to gather and consider all of these data, it is not generally recommended that pediatricians diagnose LD. Rather, pediatricians can and should refer patients to their school for appropriate testing when medically indicated. Schools provide evaluations free of charge to children suspected of having learning disabilities and requiring special education. Allowing the school to provide evaluation also ensures that definition and methods used for identification will be accepted by the school for special education purposes.

Prevalence

The National Center for Learning Disabilities estimates that about 5% of students in American public schools, or 2.4 million students, are identified with learning disabilities for the purposes of receiving special education (NCLD, 2014). About two-thirds of students identified with learning disabilities are male, and black and Hispanic students are overrepresented in many states (NCLD, 2014). The DSM-5 (APA, 2013) suggests that the prevalence of learning disabilities may be broader, noting that 5–15% of children across different languages and cultures demonstrate characteristics of an LD in reading, writing, or math.

Outcomes

Learning disabilities have been associated with a range of negative academic, occupational, and economic outcomes. Students with learning disabilities are two to three times more likely than non-disabled peers to drop out of school (Gregg, 2013). Though rates of college attendance among students with learning disabilities continue to increase over time, they still lag behind non-disabled peers, with only 21.2% of learning disabled students attending 4-year college (Gregg, 2013; Newman et al., 2011). Little research has documented the employment outcomes of individuals with learning disabilities, and the extant research lacks rigor. However, research does suggest that individuals with learning disabilities are more likely to work semi-skilled, part-time jobs and that the wage gap between learning disabled and non-disabled peers is growing over time (Gregg, 2013).

Longitudinal research has indicated that academic achievement is the greatest predictor of occupational outcomes among students with learning disabilities (Rojewski & Kim, 2003). Given this finding, effective, evidence-based instruction is essential in maximizing the potential of students with learning disabilities. Additionally, helping students develop known protective factors, including positive relationships with caring adults, self-regulation skills, positive self-concept, and motivation, can help make positive outcomes more likely.

Physical Health Implications

A paucity of research has addressed physical health implications specific to LD. Only two studies were identified that directly reported the physical health implications for this population. Cook, Li, and Heinrich (2015) reported that children with LD were 33% *less* likely to meet the daily recommended levels of physical activity and 40% *more* likely to be sedentary relative to typically developing peers after controlling for demographic variables; however, there were no differences in obesity rates after controlling for demographic variables. Additionally, Fuller-Thomson, Carrol, and Yang (2018) reported that the prevalence of suicide attempts was significantly higher among those with LD (11.1%) relative to those without LD (2.7%). Further, even after controlling for adverse childhood events (e.g., witnessing chronic domestic violence), comorbid mental illness, substance abuse, and demographic information (e.g., income), adults with LD were 46% more likely to have attempted suicide relative to adults without an LD. Additional adverse health outcomes of LD can be inferred by considering the health outcomes associated with poorer educational attainment including the development of chronic illness (Friedman, Montez, Sheehan, Guenewald, & Seeman, 2015), decreased life expectancy and quality adjusted years of life (Kaplan, 2014), and the development of unhealthy behaviors (Cutler & Lleras-Muney, 2010).

Screening and Assessment/Evaluation

This section provides a brief overview of the evidence-based screening and assessment of LDs, with particular emphasis on interprofessional collaboration. Although the primary activities in the screening and assessment of LDs (e.g., academic and ability testing) are generally completed by the schools, the American Academy of Pediatrics' (AAP) (2009) Joint Technical Report on LDs, Dyslexia, and Vision outlines a number of vital roles health care professionals fill during this process (Handler & Fierson, 2011).

Screening in Medical Settings

Though the IDEA requires schools to identify children with disabilities from the time children are born, schools' limited access to children before kindergarten makes compliance with this requirement difficult. Consequently, health care workers have frequent interactions with young children and their families and can play a vital role screening for developmental disabilities, including LD.

The American Academy of Pediatrics' Bright Future's Steering Committee (2006) recommends that all infants and young children be screened for developmental delays at every well-child visit, including formal, standardized screening tools at selected age intervals (9, 18, and 24 or 30 months) and whenever developmental concerns are raised by the parent or provider. Further, health care professionals should screen patients who have a genetic, medical, or neurological concern that is associated with LDs (e.g., ADHD). Following the introduction of formal, standardized screening tools, detection of existing developmental delay, and mental health problems increased from 20 to 30% detection to 70–90% detection (Palfrey, Singer, Walker, & Butler, 1987; Squires, Nickel, & Eisert, 1996).

Referring a child to their school for LD assessment is a qualitatively different process relative to referring a child to a medical specialist (e.g., pulmonologist). Whenever possible, requests for assessment should come from the family and be supplemented with relevant medical information (i.e., health care data indicating the student is at risk for LD). To request a formal evaluation, parents need only submit their dated request to the school in writing. A letter and/or a prescription from a health care professional is not sufficient to initiate an evaluation or an individualized education plan (IEP).

Medical Assessment and Evaluation

The medical assessment for a child with learning concerns centers around the exclusion of an organic diagnosis for the presenting symptoms (e.g., poor visual acuity, hearing, sleep disorder, anemia). Biopsychosocial history and physical exam (e.g., abnormal facies, reflexes, body habitus) are broadly explored to identify and/or treat an organic medical cause for learning difficulty (e.g., genetic disorder) or mitigating diagnosis (e.g., obstructive sleep apnea, diabetes) that could impact learning. Once a medical diagnosis has been excluded or treated, the LD is more fully explored typically with referral to schools or specialist for testing and individualized educational planning. Health care professionals should provide the school-based multidisciplinary team information regarding the presence or absence of relevant genetic, neurological, and medical conditions that may explain the child's difficulties (Committee on Children with Disabilities, 1999).

Screening in Schools

Within the school setting, especially in elementary schools, screening for LD is an ongoing process. Schools rely on a student's performance on classwork, state standardized test scores, report card grades, and commercially available curriculum-based measures to continually screen for LD. This allows for an efficient and psychometrically valid (e.g., January, Ardoin, Christ, Eckert, & White, 2016) process for schools to identify students at risk for LD. Universal screening can provide schools the data necessary to individualize academic interventions to the student's instructional level to improve overall academic performance. Across all assessment frameworks, universal screening data can aid school personnel in determining if a comprehensive psychoeducational evaluation is warranted.

School-Based Assessment Evaluation

Federal education laws allow schools to evaluate for LDs using three overall methods: ability-achievement discrepancy; RTII; and alternative research-based methods (e.g., cognitive processing strengths and weaknesses). Although a full discussion is beyond the scope of this chapter, it is worth mentioning that debate continues regarding the most accurate, helpful, and efficient LD evaluation method (Hale, Wycoff, & Fiorello, 2010; Scanlon, 2013). This section will focus on ability-achievement and RTII as these are common and the most defined within the law.

Ability-Achievement This method of LD determination primarily consists of the administration of an IQ test and an academic achievement assessment. The primary purpose of this method is to identify the presence or absence of a "severe discrepancy" between achievement (i.e., estimate of how much a child has learned) and the student's intellectual ability. This method has been criticized as a "wait-to-fail" approach in which school professionals must wait until achievement is low enough for a student to meet predetermined criteria for special education services (Hudson & McKenzie, 2016). Additionally, research has noted concerns about this method's reliability and validity (Fletcher, Francis, Morris, & Lyon, 2005) and limited sensitivity and specificity (Stuebing, Fletcher, Branum-Martin, & Francis, 2012).

Response to Instruction and Intervention (RTII) This method of LD determination is based upon the child's unresponsiveness to both the core curriculum and increasingly intensive interventions (Hudson & McKenzie, 2016). Response to intervention refers to a 3-tiered system of instructional supports (VanDerHeyden & Burns, 2010). Tier one consists of an evidence-based *general education curriculum and instruction methods* for all students as well as universal screening. Students who are identified as at-risk based upon universal screening data or poor classroom performance are moved to tier two where they are provided with evidence-based *interventions* with more frequent monitoring of progress. Students are grouped according to their academic level and interventions are delivered in small group settings. In theoretical conceptualizations of RTII, tier two should represent no more than 15% of the student population. The third tier of RTII is reserved for the approximately 5% of students who do not respond to the evidence-based interventions at tier 2. At this level, intensive and individualized interventions are developed for each student to meet their unique educational needs and are delivered in a one-on-one setting or utilizing small groups (i.e., 2–3 students) and students' progress is monitored very frequently to ensure they are making progress and/or to make modifications to the intervention.

When students fail to respond to the intensive individualized intervention in tier 3, the majority of children can be identified as having an LD without an IQ test being administered (Bradley, Danielson, & Doolittle, 2005). However, this method of diagnosing LD has been also been criticized for waiting to give special education services until a student fails multiple interventions and not fully considering the underlying neurocognitive profile of individuals when making a diagnosis (Hale et al., 2010). Thus, in some school districts, lack of progress in tier 3 initiates the traditional assessment method described above.

Prevention and Intervention

Prevention

The AAP Council on Early Childhood recommends regular literacy promotion in primary care starting during infancy and continuing until school entry, particularly for vulnerable populations (High et al., 2014). The ratio of books to children in low-income neighborhoods has been estimated at 1 book for every 300 children compared to 13 books per child in middle-income neighborhoods (Dickinson & Neuman, 2007). Children in low-income households are estimated to hear 30 million less words by 3 years of age (Hart & Risley, 1995), which is associated with reduced ability to process language and lower vocabulary (Fernald, Marchman, & Weisleder, 2013). Early literacy programs in primary care can provide families with developmentally and culturally appropriate books, emphasize the importance of reading, and model reading to the child at each well-child visit between 6 months and 5 years of age. One such program, Reach Out and Read, has been implemented widely and has been associated with increased reading frequency, improved attitudes towards reading, and increased language development in at-risk children (e.g., Zuckerman & Augustyn, 2011).

Equally important, but largely unstudied, is the development of numeracy skills in children. Although no specific published programs have been developed at this time, several activities in early childhood can facilitate successful development of math skills. Pediatricians can encourage families to engage in imaginative play from a young age; as such child-centered play can contribute to cognitive development (Ginsburg, 2006). Pediatricians can also advocate for activities that involve building or playing with blocks. Such activities can help children develop spatial reasoning skills and have been associated with later math achievement (Casey et al., 2008). Additionally, key skills and activities related to early numeracy include counting, number naming, estimating quantity, and making size comparisons. Health care providers can encourage and track the use of these activities in the home and can model and coach families to engage in these activities from an early age.

Intervention

Interventions for LD generally follow a similar protocol: (1) assess and identify specific skills deficits; (2) provide opportunities to systematically practice identified and requisite skills; (3) frequently monitor progress in attaining targeted skills; (4) adjust interventions as indicated (i.e., frequency, intensity, account for interfering comorbidities such as ADHD). Table 15.1 provides a breakdown of the fundamental areas of intervention for reading, mathematics, and writing.

What does not work? It is worth noting that there are several controversial interventions for LD. Below is a list of interventions that have either been directly found to be ineffective, or lack sufficient credible evidence: Optometric training (e.g., AAP, 2009), Pharmacotherapy for vestibular dysfunction (e.g., Handler & Fierson, 2011), Chiropractic manipulation (Shaywitz & Shaywitz, 2003), Dietary supplementation (e.g., Tan, Ho, & Teh, 2012), and Music education (Cogo-Moreira et al., 2012). “Irlen syndrome” is a controversial proposed perceptual disorder that purportedly causes distortions that interfere with reading and purportedly is treated with colored lenses or overlays; however, research does not support the use of these interventions (e.g., Galuschka, Ise, Krick, & Schulte-Körne, 2014).

Accommodations and modifications In addition to interventions that focus on teaching specific skills, schools may also provide accommodations or modifications. *Accommodations* are physical or environmental alterations in the *way* tasks are presented that allow children with a disability to complete the same assignments or tasks as other children. *Modifications* are changes in the *actual* course of study, standards, test preparation, location, expectations, or student response which fundamentally alters or lowers the expectation for a student. Some common accommodations and modifications are extra time for reading and test-taking; recording classroom lectures; use of note-takers or a note services; access to syllabi and lecture notes; having someone read the text or question out-loud or use of audiobooks; use of a word processor and spell-checker; opportunity to take tests in alternate formats (orally, short essays); careful consideration of requirements of learning a second language; and being allowed to type.

Implications for Interprofessional Care

Professionals across all settings and disciplines should communicate a message that promotes collaboration. It is important to set expectations for the family including a clear definition of the roles and responsibilities of medical, school, and family partners. As a professional, team members should work to minimize negative comments and model constructive behaviors and respect. This

Table 15.1 Overview of interventions for learning disabilities

Area of intervention	Description of skill	Interventions
Reading		
Phonemic awareness	The ability to hear, identify, and manipulate the smallest units of sound that can differentiate meaning	Direct instruction in: • Isolation—initial sounds • Categorization—which sound does not belong • Blending—what word does /c/ /a/ /t/ make • Segmentation—how many and what sounds make up a word • Deletion—what is “band” without the/b/ sound
Phonics	Understanding relationship between sounds (i.e., phonemic awareness) and symbols (e.g., letters)	Planned, sequential instruction in the relationship between sounds and written symbols (e.g., letters)
Fluency	Ability to read out loud with accuracy, appropriate speed, and expression	• Reading same text repeatedly • Paired or shared reading • Reading together with a group, tape • Reading silently or independently is not generally effective
Vocabulary	Knowing what words mean	• Reading, listening to others read, tell stories, talk • Repeated exposure to words inside and outside of the classroom • Previewing vocabulary in a story before reading • Drilling (e.g., flashcards)
Comprehension	Understanding what is read. If children are struggling over each word, it is difficult to access and improve higher order thinking, organizing, and tracking of ideas. Thus, mastery of other reading skills is integral to improving comprehension.	• Dialogic reading • Comprehension monitoring • Cooperative learning • Graphic and semantic organizers • Explicit instruction on story structure • Question generation and answering • Summarizing
Writing		
Transcription	Writing symbols (e.g., letters, numbers)	• Direct or explicit instruction through drilling/practice
Spelling	Writing or naming the letters/symbols of a word	• Teaching phonics • Repeated practice • Cover copy compare • Folding in
Writing fluency	Writing accurately and legibly with reasonable pace	• Repeated writing • Writing familiar text
Proof reading	Identifying and correct errors in writing	• Read words/sentences aloud • Have peer read word/sentence • Read text backward • Use dictionary/spell check program • Peer review
Composition	Creating a written product (e.g., paragraph, story, poem)	• Sequential teaching of sentence, paragraph, and composition structure • Brainstorming • Story diagramming • Making outlines • Sentence combining • Reverse outlining (making outline from what is written) • Receiving and conducting peer reviews

(continued)

Table 15.1 (continued)

Area of intervention	Description of skill	Interventions
Mathematics		
Number sense	Understanding and mental/symbolic representations of quantity	• Estimating quantity • Teaching 1:1 correspondence • Serial ordering—numbers are always counted in the same order • Counting on—identifying changes in quantity by adding up from a smaller quantity to create a larger quantity • Establishing link between addition and subtraction using objects • Making visual comparisons of size, quantity, volume
Math facts/ calculation	Learning rules for math computation	• Direct instruction • Cover copy compare • Folding in • Incremental rehearsal • Peer assisted learning
Counting strategy	Understanding numbers as sequential set of symbols representing quantity and being able to develop effective strategies for comparing, combining, and subtracting quantities	• Repeated rehearsal of counting • Counting starting at different numbers (e.g., count up from 5) • Counting by intervals other than one (e.g., count by 3's)
Math fluency	Automatic, accurate retrieval of answers to math facts/computations	• Incremental rehearsal • Folding in • Timed drills
Math vocabulary	Understanding computational and symbolic ("+" means add) language of math	• Direct instruction • Incremental rehearsal • Folding in
Word problems	Mathematical problems presented in words rather than mathematical notation	• Conjoint reading interventions • Identifying relevant and irrelevant information • Translating words into visual representation
Visual spatial skills	Ability to understand, reason, organize, and remember spatial relations among objects or space. In math, can manifest as misaligning numbers, left-right disorientation of numbers, misplacing digits in multidigit numbers, skipping rows or columns during calculations, failing to carry numbers, starting a calculation in the wrong place, poor organization	• Use of graph paper • Direct instruction of operational order • Self-monitoring

approach sets the tone for how you want the family to interact with the other partners and ultimately with you. Most often, the family will act as a conduit of information between providers; thus, when synthesizing information from patients, it is important to consider the family's level of understanding, frustration, and goals. If the information communicated is worrisome, unclear, or in opposition to your recommendations, consider speaking directly with the involved party to clarify information prior to making recommendations.

Although building effective family–school–health care partnerships is typically valued by all parties and has a positive impact on the outcome of the student and the family (e.g., Power, DuPaul, Shapiro, & Kazak, 2003), there are several barriers to interprofessional practice. Fortunately, these barriers can be lessened by using a collaborative, proactive, and standardized approach.

This section will identify common barriers and provide recommendations for interprofessional practice.

Differing conceptualizations of LD have led to different methods of assessment and diagnostic criteria, both within and across professional settings. Each method of LD identification can be subject to criticism. Ability-achievement discrepancy and RTII approaches have both been referred to as "wait-to-fail" approaches for different reasons. Models depending on discrepancy or processing strengths and weaknesses place an emphasis on broad or narrow cognitive abilities that often have little impact on educational planning and may lead to under-identification of children with significant needs. Each school chooses criteria based on a range of theoretical and practical factors. Given the importance of a strong family–school partnership, health care providers can best serve families by helping them identify the approach being used by their school, understanding the pros and cons of that approach, and explaining that each approach typically allows schools to identify and serve children in need.

Fiscal, temporal, and privacy barriers can often be attenuated by developing a standardized, proactive approach (Shaw, Glaser, & Ouimet, 2011). For example, using templated documents (e.g., letters, releases of information, "smartphrases" in electronic health record systems) can reduce time spent and can be created to be consistent with privacy laws. This strategy would be further enhanced if these documents are sent to the intended recipient for review and feedback (e.g., sending templated letters created in the medical center to local schools for them to review for clarity, comprehensiveness, and accuracy). Identifying a designated contact person in each setting is also likely to make communication more efficient and effective (e.g., school psychologist, social worker, nurse, office manager). Finally, outlining specific roles for existing team members in each setting may help distribute the workload. For example, in an interdisciplinary primary care team: a *social worker* may send and receive important information from schools; a *primary care psychologist* may read, interpret, and summarize the findings of psychoeducational report from the school in the patients chart and outline any additional tasks that need to be accomplished; and a *medical provider* completes the medical evaluation and reviews the psychoeducational summary-report documented by the psychologist; and a brief curbside consultation is conducted once everyone has had time to review documents to create a treatment plan to propose to the family and school.

When possible, connecting professionals with similar training in each setting (e.g., nurses, psychologists, social workers) can help reduce problems related to differences in language used and communication preferences. However, this is not always an option, as not every school or health care team may have multiple professionals to support coordination of care. In these situations, it is important to consider the time and preferences of the professional receiving the information. For example, research has found that pediatricians prefer brief phone calls or timely, concise reports (i.e.,1–3 paragraphs) that provide a brief summary of findings, diagnostic conclusions, and a recommended plan (HaileMariam, Bradley-Johnson, & Johnson, 2002).

Case Study

Ella is a 7-year-old African American natal female with a medical history positive for anemia due to lead exposure who presents for a well-child visit. Her caregivers express frustration that the school is "dragging their feet" helping their child and request that the primary care physician (PCP) write a medication prescription for Ella to be evaluated for an IEP.

Working as a partner with the family and school, the PCP acknowledges parental frustration, validates the family's expressed value of education, and explains that a prescription is unlikely to be helpful. The PCP explains that the first step to addressing this problem is to start a conversation with everyone on the team—the child, caregivers, school, and the PCP. The PCP offers to write a letter that explains the family's concerns with learning, that the family is motivated to obtain help, and a summary of the relevant medical information including passed hearing/vision screenings, previous developmental screening results, and treatment of prior anemia that has since resolved. Parents are instructed to create and provide the school with a dated letter requesting a meeting to discuss their concerns and their desire to obtain psychoeducational testing at school. The parents then sign a release of information form allowing the PCP office to discuss relevant information with the school, particularly Ella's teacher.

The PCP also screens for environmental stressors (e.g., food insecurity, parent–child dynamics) that may impact school performance. This screening reveals stress around homework completion. The PCP consults with a psychologist who is integrated within their medical practice to enhance coping strategies and implement behavior modifications to reduce parent–child conflict and support homework completion.

Ella's school returns a letter to the family and PCP thanking them for the information provided and explaining that Ella is currently receiving intensive intervention within the RTII process. Ella made initial progress; however, progress has slowed to a rate over the past few weeks that make it unlikely that she will "catch-up." The family and school agreed that if lack of improvement continues over the next month, psychoeducational testing will be conducted. Ella was tested and qualified for an LD in Math Calculation. Her school documents this diagnosis, briefly states the relevant results and intervention plan for home and school so that the PCP and primary care psychologist can follow-up and support home-based learning strategies.

At age 15, Ella is diagnosed with Type 1 Diabetes Mellitus (T1DM) and with the knowledge of LD in math, the PCP requests that the primary care psychologist meet with Ella and her caregivers to adjust to life with T1DM, identify strategies to manage carb counting, correction formulas, and set appropriate developmental expectations for Ella's responsibility in managing T1DM. The PCP also writes a letter to the school documenting diagnosis and recommendations for management within school setting.

Conclusion and Future Directions

Despite the many barriers that exist, steps can be taken to build strong family–school–medical partnerships to support children and families through the process of preventing, diagnosing, and treating learning disabilities. With a well-informed team, the family will receive a uniform message and a comprehensive, contextualized treatment plan where team members work towards shared goals. Continued work is needed to continue building mechanisms for communication (e.g., electronic communication portals), reimbursement models for collaboration and care coordination, and continued interprofessional training.

References

American Academy of Pediatrics. (2009). Joint statement Learning Disabilities, Dyslexia, and Vision. *Pediatrics, 124*, 837–844.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Press.

Bradley, R., Danielson, L., & Doolittle, J. (2005). Response to intervention. *Journal of Learning Disabilities, 38*, 485–486.

Bright Futures Steering Committee, & Medical Home Initiatives for Children with Special Needs Project Advisory Committee. (2006). Identifying infants and young children with developmental disorders in the medical home: An algorithm for developmental surveillance and screening. *Pediatrics, 118*, 405–420.

Casey, B. M., Andrews, N., Schindler, H., Kersh, J. E., Samper, A., & Copley, J. (2008). The development of spatial skills through interventions involving block building activities. *Cognition and Instruction, 26*, 269–309.

Cogo-Moreira, H., Andriolo, R. B., Yazigi, L., Ploubidis, G. B., Brandão, D. Á. C., & Mari, J. J. (2012). Music education for improving reading skills in children and adolescents with dyslexia. *The Cochrane Database of Systematic Reviews*, (8), CD009133.

Committee on Children with Disabilities. (1999). The pediatrician's role in development and implementation of an individual education plan (IEP) and/or an individual family service plan (IFSP). *Pediatrics, 104*, 124–127.

Cook, B. G., Li, D., & Heinrich, K. M. (2015). Obesity, physical activity, and sedentary behavior of youth with learning disabilities and ADHD. *Journal of Learning Disabilities, 48*, 563–576.

Cutler, D. M., & Lleras-Muney, A. (2010). Understanding differences in health behaviors by education. *Journal of Health Economics, 29*, 1–28.

Dickinson, D. K., & Neuman, S. B. (Eds.). (2007). *Handbook of early literacy research* (Vol. 2). New York, NY: Guilford Press.

Fernald, A., Marchman, V. A., & Weisleder, A. (2013). SES differences in language processing skill and vocabulary are evident at 18 months. *Developmental Science, 16*, 234–248.

Fletcher, J. M., Francis, D. J., Morris, R. D., & Lyon, G. R. (2005). Evidence-based assessment of learning disabilities in children and adolescents. *Journal of Clinical Child and Adolescent Psychology, 34*, 506–522.

Friedman, E. M., Montez, J. K., Sheehan, C. M., Guenewald, T. L., & Seeman, T. E. (2015). Childhood adversities and adult cardiometabolic health: Does the quantity, timing, and type of adversity matter? *Journal of Aging and Health, 27*, 1311–1338.

Fuller-Thomson, E., Carrol, S. Z., & Yang, W. (2018). Suicide attempts among individuals with specific learning disorders: An under-recognized issue. *Journal of Learning Disabilities, 51*(3), 283–292.

Galuschka, K., Ise, E., Krick, K., & Schulte-Körne, G. (2014). Effectiveness of treatment approaches for children and adolescents with reading disabilities: A meta-analysis of randomized controlled trials. *PLoS One, 9*, e89900.

Ginsburg, K. R. (2006). The importance of play in promoting healthy child development and maintaining strong parent-child bonds. *Pediatrics, 119*, 182–191.

Gregg, N. (2013). Adults with learning disabilities: Factors contributing to persistence. In H. L. Swanson, K. R. Harris, & S. Graham (Eds.), *Handbook of learning disabilities* (2nd ed., pp. 85–103). New York: Guilford.

Hale, J. B., Wycoff, K. L., & Fiorello, C. A. (2010). RTI and cognitive hypothesis testing for specific learning disabilities identification and intervention: The best of both worlds. In D. Flanagan & V. Alfonso (Eds.), *Essentials of specific learning disability identification*. Hoboken, NJ: Wiley.

HaileMariam, A., Bradley-Johnson, S., & Johnson, C. M. (2002). Pediatricians' preferences for ADHD information from schools. *School Psychology Review, 31*, 94–106.

Handler, S. M., & Fierson, W. M. (2011). Learning disabilities, dyslexia, and vision. *Pediatrics, 127*, 818–856.

Hart, B., & Risley, T. R. (1995). *Meaningful differences in the everyday experience of young American children*. Baltimore, MD: Brookes Publishing.

High, P. C., Klass, P., Donoghue, E., Glassy, D., DelConte, B., Earls, M., … Schulte, E. E. (2014). Literacy promotion: An essential component of primary care pediatric practice. *Pediatrics, 134*, 404–409.

Hudson, T. M., & McKenzie, R. G. (2016). Evaluating the use of RTI to identify LD: A survey of state policy, procedures, data collection, and administrator perceptions. *Contemporary School Psychology, 20*, 31–45.

Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004).

January, S. A. A., Ardoin, S. P., Christ, T. J., Eckert, T. L., & White, M. J. (2016). Evaluating the interpretations and use of curriculum-based measurement in reading and word lists for universal screening in first and second grade. *School Psychology Review, 45*, 310–326.

Kaplan, R. M. (2014). Behavior change and reducing health disparities. *Preventive Medicine, 68*, 5–10.

Kovas, Y., Haworth, C. M. C., Dale, P. S., & Plomin, R. (2007). The genetic and environmental origins of learning abilities and disabilities in the early school years. *Monographs of the Society for Research in Child Development, 72*(3), 1–144.

National Center for Learning Disabilities. (2014). *The state of learning disabilities: Facts, trends and emerging issues* (3rd ed.). New York: New York.

Newman, L., Wagner, M., Knockey, A., Marder, C., Nagle, K., Shaver, D., & Wei, X. (2011). *The post-high school outcomes of young adults with disabilities up to 8 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2)*. Menlo Park, CA: SRI International.

Palfrey, J. S., Singer, J. D., Walker, D. K., & Butler, J. A. (1987). Early identification of children's special needs: A study in five metropolitan communities. *The Journal of Pediatrics, 111*, 651–659.

Petril, S. A. (2013). Behavioral genetics, learning abilities, and disabilities. In H. L. Swanson, K. R. Harris, & S. Graham (Eds.), *Handbook of learning disabilities* (2nd ed., pp. 293–306). New York: Guilford.

Power, T. J., DuPaul, G. J., Shapiro, E. S., & Kazak, A. E. (2003). *Promoting children's health: Integrating school, family, and community*. New York, NY: Guilford Press.

Rojewski, J. W., & Kim, H. (2003). Career choice patterns and behavior of work-bound youth during early adolescence. *Journal of Career Development, 30*, 89–108.

Scanlon, D. (2013). Specific learning disability and its newest definition: which is comprehensive? And which is insufficient? *Journal of Learning Disabilities, 46*, 26–33.

Shaw, S. R., Glaser, S. E., & Ouimet, T. (2011). Developing the medical liaison role in school settings. *Journal of Educational and Psychological Consultation, 21*, 106–117.

Shaywitz, S. E., & Shaywitz, B. A. (2003). Dyslexia (specific reading disability). *Pediatrics in Review, 24*, 147–153.

Squires, J., Nickel, R. E., & Eisert, D. (1996). Early detection of developmental problems: Strategies for monitoring young children in the practice setting. *Journal of Developmental & Behavioral Pediatrics, 17*, 420–427.

Stuebing, K. K., Fletcher, J. M., Branum-Martin, L., & Francis, D. J. (2012). Evaluation of the technical adequacy of three methods for identifying specific learning disabilities based on cognitive discrepancies. *School Psychology Review, 41*, 3–22.

Swanson, H. L., Harris, K. R., & Graham, S. (2013). Overview of foundations, causes, instruction, and methodology in the field of learning disabilities. In H. L. Swanson, K. R. Harris, & S. Graham (Eds.), *Handbook of learning disabilities* (2nd ed., pp. 3–14). New York: Guilford Press.

Tan, M. L., Ho, J. J., & Teh, K. H. (2012). Polyunsaturated fatty acids (PUFAs) for children with specific learning disorders. *Cochrane Database of Systematic Reviews*, (9), CD009398. Retrieved from the http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009398.pub2/full

VanDerHeyden, A. M., & Burns, M. K. (2010). *Essentials of response to intervention* (Vol. 79). Hoboken, NJ: Wiley.

World Health Organization. (2016). *International statistical classification of diseases and related health problems, 10th revision (ICD-10)*. Geneva: World Health Organization.

Zuckerman, B., & Augustyn, M. (2011). Books and reading: Evidence-based standard of care whose time has come. *Academic Pediatrics, 11*, 11–17.

Substance Abuse

16

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Abstract

Substance use, misuse, and dependence are among the most prevalent causes of adolescent morbidity and mortality in the United States. The onset of the opioid epidemic, changes in state laws pertaining to marijuana use, and the emergence of vaping products have added more uncertainty to the landscape of adolescent substance abuse. This chapter provides an overview of an interdisciplinary and collaborative approach to prevention, evaluation, and management of substance abuse. A case study is provided and future directions for research and practice are also discussed.

Introduction

Substance use, misuse, and dependence are among the most prevalent causes of adolescent morbidity and mortality in the United States (e.g., linked to accidents, overdoses, and violent events; Brannigan, Schackman, Falco, & Millman, 2004; Johnston, O'Malley, Miech, Bachman, & Schulenberg, 2017; Newcomb & Bentler, 1988; National Institute on Drug Abuse, 2017; Sussman, Dent, & Galaif, 1997). In 2016, the proportions of 8th, 10th, and 12th graders who reported illicit drug use in the prior 12 months were 12%, 27%, and 38%, respectively (Johnston et al., 2017). Thirty-day prevalence rates for any illicit drug use have fluctuated only slightly for teens over the past decade although annual prevalence rates for specific drugs have changed more dramatically (see Table 16.1; Johnston et al., 2017; e.g., decrease in alcohol use and cigarette smoking; advent of e-cigarettes). The onset of the opioid epidemic, changes in state laws pertaining to marijuana use, and the emergence of vaping products have added more uncertainty to the landscape of adolescent substance abuse.

Risk Factors and Consequences

Various risk factors that both incite and sustain substance abuse in adolescents include biological (e.g., genetics, neurotransmission, maturational

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Table 16.1 30-day prevalence: adolescent substance use

	2006	2016
Any illicit drug	14.9	15.5
Marijuana/Hashish	12.5	13.7
Inhalants	2.7	1.2
Hallucinogens	1.3	1.0
LSD	0.6	0.7
Hallucinogens other than LSD	1.1	0.5
Ecstasy/MDMA	1.0	0.6
Cocaine	1.6	0.5
Crack	0.7	0.3
Heroin	0.4	0.2
Amphetamines	3.0	2.5
Tranquilizers	2.1	1.4
Alcohol	31.0	19.8
Cigarettes	14.4	5.9
Smokeless tobacco	5.1	4.1
E-Vaporizers		9.9
Large cigars		3.3
Flavored little cigars		5.6
Regular little cigars		3.6
Steroids	0.7	0.4

Adolescents includes combined reports from 8th, 10th, and 12th grade students

factors), cognitive (e.g., beliefs, executive cognitive function), microsocial (e.g., family and peer relations), and large physical and social environmental factors (e.g., the mass media, accessibility to substances) (Newcomb, Maddahian, & Bentler, 1986; Sussman, 2017). Risk factors that incite substance abuse in adolescents can also coexist as consequences of substance abuse. Specifically, adolescents may struggle with other compulsive behaviors (e.g., internet addiction), issues of self-control, conduct disorder, anxiety, and PTSD due to their substance abuse, as well as leading to it (Griswold, Aronoff, Kernan, & Kahn, 2008). Adolescent substance abuse is also associated with an increased risk of motor vehicle accidents (e.g., alcohol use is associated with up to 50% of all car accidents), emergency department admissions, and suicide attempts (Griswold et al., 2008). Adolescents engaging in multiple risk behaviors, including substance abuse, exhibit an increased risk of poor educational attainment, future morbidity, and premature mortality (Kipping, Campbell, MacArthur, Gunnell, & Hickman, 2012).

A key consequence of early initiation into drug use includes increased risk for lifelong addiction (Andersen & Teicher, 2009). Because maturational events serve as an inciting factor to initiation of substance use and increases likelihood of addiction (Andersen & Teicher, 2009), transition from initiation to regular use in adolescence often occurs within 3 years, often resulting in dependence on alcohol, marijuana, or other drugs prior to graduating from high school (King & Chassin, 2007). Impact on executive cognitive function can injure planning behavior and facilitate enduring use (e.g., see US Department of Health and Human Services, 2016).

Addiction and Dependence Substance dependence was previously defined by the *Diagnostic and Statistical Manual of Mental Disorders-4-TR* as a severe disorder, consisting of a maladaptive pattern of substance use leading to clinically significant impairment or distress as manifested in a 12-month period by three or more of seven criteria (American Psychiatric Association, 2013). These seven criteria are listed in Table 16.2. In addition, four other criteria are in Table 16.2: craving and social, physical danger, and role consequences. This separate substance dependence category is no longer used in the DSM-5. Rather, the seven dependence items were merged with a “substance abuse” disorder category (that had consisted of social, physical danger, role and legal consequences). In addition, the legal consequences criterion was removed from consideration all together and was replaced by craving.

A total of 11 criteria for “substance use disorder” now might be applied to any of the following ten drug categories: (1) alcohol, (2) caffeine, (3) cannabis, (4) hallucinogens (which subsumes phencyclidine and “other hallucinogens”), (5) inhalants, (6) opioids, (7) sedatives/hypnotics/anxiolytics, (8) stimulants (including amphetamine-type substances, cocaine, and other or unspecified stimulants), (9) tobacco, and (10) “other” or “unknown” (e.g., anabolic steroids, antihistamines, betel nut). Again, the criteria for substance use disorder are outlined in Table 16.2 below. These criteria intend to reflect

Table 16.2 DSM-5 criteria for substance use disorder

Tolerance	With repeated use, a person will no longer achieve the same degree of pleasurable effect experienced in the past and the person must use increasing amounts of the substance to get the same pleasurable effect
Withdrawal	When physically dependent on a substance, individuals will develop withdrawal symptoms, which cause distress or impairment when use stops, or the amount is cut down; the person will continue to use the substance to avoid the withdrawal symptoms
Using larger amounts of substance	The substance is taken in larger amounts or over a longer period than intended
Repeated attempts to quit/control use	The person experiences a persistent desire or unsuccessful efforts to cut down or control substance use
Majority of time is spent using/withdrawal	A great deal of time is spent on activities necessary to obtain the substance, use it, or recover from its effects
Normal activities are given up	Important social, occupational, or recreational activities are given up or reduced because of use
Physical/psychological problems caused by use	Substance use is continued despite knowledge of having a persistent physical or psychological problem that is likely to have been caused or exacerbated by the substance. While these criteria also were created primarily for an adult population, one may speculate that dependence symptoms encompass people at any developmental period
Failure to fulfill obligations	Failure to fulfill major role obligations at work, school, or home due to substance misuse
Problems in social life	Continued use despite related social problems
Hazardous use	Involved in behaviors associated with substance use that are physically dangerous
Cravings	Constant craving for substance of choice

impaired behavioral control or social judgment, risky use, or pharmacologic effects (e.g., physiological dependence). Since only two criteria are now required to be present per DSM-5 (APA, 2013), it is possible that there will be a measurement artifact, suggesting an increase in the prevalence of diagnoses (Wakefield & Schmitz, 2014).

Many of society's macro-level social issues are linked to young people becoming addicted to drugs. Crimes such as stealing, vandalism, and violence are associated with "heavy drug use" in adolescence. Such crimes may be due not just to the pharmacologic effects of drugs but also economic and systemic factors related to procuring and distributing substances (Sussman & Ames, 2008). Other adverse immediate consequences can also occur (e.g., overdoses, accidents, acute psychosis). In fact, the incidence of drinking and driving among older adolescents and emerging adults is double that of the general population (Bennett et al., 1993). Substance-using youths are more likely to develop disorganized thinking and unusual beliefs that may interfere with problem-solving skills and emotional functioning which in turn may lead to greater social isolation and depression (Sussman & Ames, 2001, 2008). Substance dependent adolescents also endure additional consequences, such as drug tolerance effects, withdrawal symptoms, and preoccupation with using a drug to the exclusion of other activities.

Assessment

The first step in the process of evaluating whether an adolescent has a substance abuse problem is to use a *screening instrument* such as the CRAFFT questionnaire, a validated "screener" outlined later in this chapter. A *mental status exam*, to screen general functioning, also may be completed, also described briefly below. Given that substance use disorder is a possibility, and that concurrent difficulties may need to be addressed (e.g., need for shelter, mental health issues, legal problems), comprehensive *assessments of drug use history and consequences* can then be utilized to explore the extent and nature of drug involvement as well as treatment needs. These assessments provide vital information for developing a treatment plan (setting, interventions, intensity, frequency) and treatment goals (Winters & Kaminer, 2008).

Of primary importance *clinical interviews* are used to clarify a presenting medical or social-psychological problem that may be caused or made worse by an addiction and assist with differential diagnosis (Sussman, 2017). A formal diagnosis is completed through the use of the structured clinical interview from the DSM-5, which accompanies the American Psychological Association (APA) diagnostic criteria and permits clarification of symptomatology (APA, 2013). *Biochemical testing* for the presence of drug use (e.g., through immunoassay screening followed by gas chromotography/mass spectrometry involving blood or urine) is typically used to assess whether the youth is under the influence during the time of assessment or has recently used. A positive result is not diagnostic of substance use disorder and gives little information about drug use history as the time window for detecting substances is highly variable (Winters & Kaminer, 2008). Toxicology testing is not recommended for diagnosis but might be important during and after treatment (Griswold et al., 2008).

Mental Status Exam and the CRAFFT Screener A mental status examination includes the assessment of appearance, attitude and behavior, speech, affect, thought and language, perceptions, and cognitive functioning (such as insight and judgment). This process can help behavioral healthcare providers identify other assessments required to determine whether a formal psychiatric diagnosis of a comorbid condition is appropriate for the youth's circumstances.

The CRAFFT is a brief six-item screener that has demonstrated good convergent validity and acceptable internal consistency (Grigsby, Sussman, Chou, & Ames, 2017). That is, items are: C-Have you ever ridden in a CAR driven by someone (including yourself) who was "high" or had been using alcohol or drugs? R-Do you ever use alcohol or drugs to RELAX, feel better about yourself, or fit in? A-Do you ever use alcohol/drugs while you are by yourself, ALONE? F-Do you ever FORGET things you did while using alcohol or drugs? F-Do your family or FRIENDS ever tell you that you should cut down on your drinking or drug use? T-Have you gotten into TROUBLE while you were using alcohol or drugs? The items on this assessment, often administered as a brief interview (though they are also administered as a self-report), represent neurobiologically based (drinking or using to relax), cognitively based (poor decision-making, such as riding in the car of someone who is under the influence, or forgetting things while drinking or using), and non-socially based (drinking or using alone) drug use motivations, as well as interpersonal-based consequences of use (family or friends telling one to cut down; getting into trouble while under the influence). Furthermore, the CRAFFT questionnaire is capable of detecting problems related to alcohol and other drug use whereas most similar measures only capture alcohol use (Knight, Sherritt, Shrier, Harris, & Chang, 2002; Sussman, 2017).

Self-Report Assessments There are several self-report assessments available and useful for diagnosing addictions. These assessments generally have cut-off scores, with minimum scores indicating the "true" presence of addiction. They permit the clinician and patient to gauge the dimensions and severity of an addiction. Self-report assessment tools for specific substance use problems include: the *Cigarette Dependence Scale*, (CDS) (Courvoisier & Etter, 2010), the *Michigan Alcohol Screening Test* (MAST) (Selzer, Vinokur, & Rooijen, 1975), and the *Drug Use Screening Inventory* (DUSI) (Kirisci, Mezzich, & Tarter, 1995).

Comprehensive assessments specific to adolescent populations include the *Problem Oriented Screening Instrument for Teenagers* (POSIT), which is a 139-item self-administered yes/no questionnaire that was developed by NIDA as part of their Adolescent Assessment/Referral System (Rahdert, 1991). The POSIT contains ten scales—substance use/abuse, physical health status, mental health status, peer relations, family relations, educational status, vocational status, social skills, leisure and recreation, and aggressive behavior/delinquency—and takes 20 min to complete (Grigsby et al., 2017). The *Personal Experience Inventory* (PEI; Winters & Henly, 1993; Winters, Stinchfield, & Fulkerson, 1993) is a multidimensional questionnaire used for detection of problem consequences and potential risk factors associated with diagnostic classification of substance use disorders in adolescent populations (Guthmann & Brenna, 1990). This 267-item questionnaire quantifies the level of involvement with a variety of drugs and the severity of problems in personal, family, and psychosocial domains. The scale also inquires about cognitive, social, and immediate environmental impacts of drug use in addition to items concerning social reinforcement to maintain drug use (Grigsby et al., 2017). The advantage of employing an exhaustive inventory assessment in a behavioral healthcare setting is that the comprehensive nature of the measures allows providers to assess co-occurring substance use problems for young patients and develop an integrated treatment plan for the youth and family members. (see www.knowmo.ca/Capacity/AddictionMeasures.aspx/ for a list of self-report assessments; see Grigsby et al., 2017 for a description of relevant assessments).

Etiology-Anchored Prevention

Counteraction of acquisition-oriented factors (i.e., blocking the causal chain from antecedent variables that facilitate the problematic behavior) has long been highlighted as a key direction for utilization of prevention strategies (Chassin, Presson, & Sherman, 1985). There are several acquisition-oriented factors that may help prevent addictive behaviors. These operate at different levels; the intrapersonal (impacting on neurobiological and cognitive factors), and the extrapersonal (impacting on micro-level factors such as influence from small groups, peers, family, or large physical and social environments such as one's socioeconomic status and stimuli from mass media). Intrapersonal- and extrapersonal-level prevention strategies are presented below. Some may simultaneously serve as cessation treatments for certain youth. Additional cessation approaches will be addressed later in this chapter. Also, it should be mentioned that several programs being described involve intrapersonal and extrapersonal components; they are grouped within the general category where their main emphasis appears to be.

Intrapersonal Prevention Here, the focus is on strategies that alter or attempt to alter something about the person, as opposed to the environment the person is in. *Neurobiological-level strategies* include use of pharmacotherapy and vigilance (monitoring) and instruction in social-emotional competence. Education programs might include instruction on emotional regulation as an adjunct to an early intervention. For example, an intervention could focus on being able to recognize emotions in one's self and others (e.g., facial expressions), being respectful of others' emotions, understanding meanings of emotions, and learning self-control. Early instruction for young children in these areas may improve social and emotional competence, which could, in turn, minimize a sense of relative imbalance for some youth, and possibly help in normalizing one's neurobiological wiring if exposure to these lessons occurs during critical periods in neural development, preventing subsequent addictive behaviors (Sussman, 2017).

Cognitive strategies attempt to alter the way in which a person thinks and consist of (a) correction of cognitive-information errors, (b) maximizing executive processing, (c) focusing on belief-behavior discrepancies, and (d) decreasing situational distortions. This includes use of elaborative processing to link thinking to situational-behavioral events, strengthening executive processing capacity, and using implementation intentions to control how one might act in high-risk situations. In addition, one might make use of cognitive exercises to make one's own equivocations explicit in working memory (e.g., that one views oneself as a "moderate person" but also uses lots of drugs). One may then attempt to reduce such discrepancies by not engaging in the addictive behavior (Sussman, 2017).

As another example, as operationalized in a curriculum by Sussman and colleagues (Project Towards No Drug Abuse [TND]; Sussman, 2017), a program could initially provide a discussion about the "kernel of truth" in any given addictive behavior "myth" and then discuss why the myth is, in fact, a myth. A prevention lesson might discuss the myth that individuals use drugs as a means of being emotionally protected from life stresses. The *kernel of truth* in this myth is that one might initially feel that their drug use is protective, at least temporarily, from negative life stressors; that is, they experience some temporary relief or pleasure from drug use that distracts them from real-life events. The *myth*, however, is a myth because the individual thinks less clearly under the influence and the individual may be more likely to become increasingly uninhibited and become victimized (e.g., get robbed or mugged) and, hence, incur greater stress over time (Sussman & Ames, 2008). The key is to engage in elaborative processing of information such that truths later on are not recalled as myths, or myths as truths.

Extrapersonal Prevention In comparison to intrapersonal-level prevention programming, extrapersonal-level prevention programming has been conceptualized and evaluated to a much greater extent. There are several advantages of extrapersonal approaches to prevention, including the opportunity for youth to work in a group setting to practice newly learned behaviors and skills, with corrective input from educators and feedback from peers during simulations of real-world situations (Sussman, 2015). Additionally, structural changes to the youth's environment and adoption of policies at the organizational and societal level can work in concert with substance use prevention programming.

The most effective and widely used microsocial-based substance abuse prevention approach for young teens involves *comprehensive social influences/life skills prevention programming*. Schools and other community-based settings (e.g., youth clubs, afterschool programs) are the ideal site for this type of prevention programming. Examples of this approach include Project TNT, Life Skills Training, Project ALERT, and All Stars (Sussman, 2013). The comprehensive social influences/life skills approach generally addresses 11 substantive components: listening and communication skills, refusal assertion, information on short- and long-term physical consequences, peer group unacceptability regarding using the substance, correction of risk behavior prevalence overestimation, awareness of adult influences, media influences, activism, self-confidence building, decision-making, and making a commitment to not use the substance (Sussman & Ames, 2008; Tobler et al., 2000).

In addition to youth-focused *school-based* prevention efforts, *family-focused programming* has been developed to address tobacco, alcohol, and other drug use among young people. Family involvement with relaying prevention messaging outside of school and other community-based settings can lead to a modest incremental substance use prevention effect if families are willing to comply with a program (Bröning et al., 2012; Sussman et al., 2013). Examples of evidence-based family drug use prevention programming include Strengthening Families and Family Matters (Bauman et al., 2000, 2001, 2002; Kumpfer & DeMarsh, 1985). Such programming teaches participants communication skills and the appropriate behaviors based on the role of parent or child. One caveat relating to family-based efforts is that many youth who are at greatest risk for substance use are relatively unlikely to be in families who will engage in prevention programming or serve as support persons.

The *mass media* is an important macro-level sociocultural influence affecting individuals' engagement in substance use behaviors. The use of different forms of media, because of its reach to a large audience, may prompt prevention effects and can be a useful supplementary tool to a variety of substance use prevention efforts. There are six stochastic steps that have been identified as needed for media-based programming to impart behavioral effects on individuals. These are (1) exposure to the communication, (2) awareness of the key messages, (3) knowledge change, (4) belief change, (5) behavior change, and (6) maintenance of belief and behavior change (Flay, 1981). Mass media prevention has varied from use of public service announcements (PSAs) to extensive multi-media campaigns. Public service announcements may be defined to include any media announcement, for which there is no charge, which educates and increases awareness about the consequences of substance use. Mass media campaigns tend to involve multiple PSAs and other media channels (e.g., internet, flyers, radio, TV). Although the effectiveness of PSAs is yet to be fully determined, some *anti-drug misuse* public health messages have been found to be effective. Utilizing media channels at prime viewing times, repeating an ad, arousing personal involvement, entertaining the viewer, involving discussion, and providing opportunities for the viewers to act are important for influencing the target audience. These prevention campaigns may attract their attention and reinforce their intentions to quit using drugs (Flay, d'Avernas, Best, Kersell, & Ryan, 1983; Sussman, 2017).

Policy-based efforts might also be employed as prevention strategies. When considering the prevention of tobacco, alcohol, and other drugs among minors, the legal regulation of substance use can be accomplished through three sometimes complementary strategies. First, the use of a *prohibitory scheme* can be implemented through limiting the production and/or distribution of the substance via tactics such as zoning and age restrictions. For example, some city and state jurisdictions have recently passed stricter laws restricting the sale of tobacco products to anyone under the age of 21 years old (New York City, Chicago, and California). Second, a *regulatory scheme* can be used to set conditions for use, requires the sharing of information about use of the substance (e.g., warning labels), or implements sanctions, including taxation and legal limits (e.g., alcohol and tobacco taxes, driving under the influence statutes). Finally, *interdiction* or the delaying, disruption, or forbidding of drug use or distribution by authorities has been the primary policy approach used regarding illicit drug use (Pentz, Bonnie, & Shopland, 1996; Sussman & Ames, 2008).

Consideration of Human Development and Prevention Approaches Behavioral healthcare providers in a variety of settings and disciplines working with youth substance abusers should consider a lifespan developmental-stage approach to tobacco, alcohol, and other drug abuse prevention. For young children, issues around parental bonding and emotional development play an important role with downstream behaviors putting youth at risk for substance use problems as they mature. Elementary-aged children also require attention to emotional development and can benefit from learning basic facts about substance use (e.g., tobacco use leads to lung disease). As children enter early adolescence or middle school, the importance of recognizing social influences related to substance use become the focus of prevention programming (e.g., Project TNT), as youth tend to spend time in small same-sex peer groups. Once youth enter their high school years, a time spent in heterosexual crowds and dyads, and a period in which a general sense of self is formed, prevention efforts should address motivations for substance use, development of life skills to avoid substance use, and decision-making processes pertaining to substance use (Sussman, 2013).

Cessation Approaches for Youth Substance Use

While prevention attempts to anticipate and stop future behavior from developing or escalating, cessation attempts to stop present (heavy) use behavior from reoccurring, arrest consequences of the behavior, and help those affected live with any enduring consequences. There are several ways youth may be able to address their substance use problems. Some may self-initiate their own natural recovery or participate in a cessation program (Sussman, 2017). Others may "grow out" of the substance use disorder as they reach adulthood (Wakefield & Schmitz, 2014). Some young people quit after experiencing a physical complication associated with the substance use, or are able to stop through support of friends, family, or informal counselors (Sussman, 2017). Still others may require treatment with a counselor or attend group therapy in an outpatient setting. Finally, a small percentage may require initial care for their addiction in an inpatient setting. We highlight examples from interpersonal-level and extrapersonal-level approaches to treatment/cessation among youth below.

Intrapersonal Cessation For youth who have become physiologically addicted to a substance, an initial period of detoxification will often necessitate participation in an inpatient detoxification program that will manage withdrawal symptoms (e.g., to avoid cholinergic shock coming down from alcohol use). In these cases, pharmacotherapy might not only help with the withdrawal symptoms (e.g., seizures) but also with the associated features of drug addiction, including anxiety, depression, and cravings.

Motivational interviewing involves a series of steps therapists can use to help young patients set goals aimed at behavior change and ensure they follow through with them. Motivational interviewing involves eight strategies to motivate behavior change: (1) giving advice to elicit and reinforce change goals, (2) removing impediments to change through use of problem-solving and other techniques, (3) providing positive choice options as elicited by the patient (youth), (4) decreasing desirability of not changing, (5) showing empathy, (6) providing accurate feedback on patients' behavior, (7) clarifying goals by confronting the patient with discrepancies between future goals and the current situation, and (8) supporting the development of self-efficacy through active helping (Miller & Rollnick, 2013).

Extrapersonal Cessation Extrapersonal-level treatments approach change the individual through microsocial (group) and macrosocial (cultural, physical environmental) contexts. There are many cessation-related strategies that involve social processes. Mobilizing a person into treatment often involves social forces, which may include suggestions from family, friends, and teachers, or orders from a physician.

A "*motivational intervention*" is implemented to confront the addict with how his or her actions result in detrimental effects on others, particularly family and close friends (Johnson, 1980). The Johnson Institute-style motivational intervention is a confrontational method used to encourage addicts to acknowledge the negative impact of his or her problem on self and others and to be motivated to change through confrontation with family and significant others. This intervention involves five steps: (1) inquiry, (2) assessment, (3) preparation, (4) intervention, and (5) follow-up/case management (Storti, 2001). During an inquiry, concerned individuals gather information and screen whether an individual requires an intervention. The assessment process generally involves family or friends who will participate in the intervention. Preparation involves rehearsal of what others will say when confronting the addict. During the actual confrontation (the intervention), others express their emotions, their specific current concerns, and their worries about the future. During the follow-up/case management phase, the addict enters treatment. While there are often difficulties recruiting families to use the intervention approach, those who do use it are highly successful in getting the targeted addict into treatment (Miller, Meyers, & Tonigan, 1999).

Once recognition of the problem behavior is understood or perhaps debated among the addict and significant others, formal or informal treatment providers (e.g., a therapist, 12-step sponsor or group) may be selected either by the addict or by external agents. Next, therapeutic relationships are attempted. If a solid *therapeutic alliance* is created (i.e., a trusting and mutually respectful relationship is developed), progress towards solutions to problematic addictive behavior may be achieved. Indeed, establishment of trust with a therapist, pathfinder, or support person is one major key to successful resolution of addictive behavior.

The person in recovery may attempt to learn alternative social behaviors. *Social skills training* may be needed for some individuals to attempt reintegration into a relatively addiction-free social world (Grenard, Ames, Pentz, & Sussman, 2006; Sussman & Ames, 2008). Social skills training may include the teaching or reinforcing of self-control skills (showing restraint under simulated high-risk conditions in social interactions; urge control), shaping of good listening or conversational skills (e.g., through direction instruction, role-play instruction, or by example), instruction of anger or other affect management (e.g., learning how to cope with negative emotions through role-playing), and learning stimulus-response control approaches (learning how to remove oneself from addiction-related cues such as escape from drug-using peers gracefully). Because a lack of social skills may influence drug use or other addictions, such as the inability to refuse drug offers from friends, social skills training often involves assertiveness training (how to tactfully stand up for oneself, e.g., often involving "other," "self," and "action-alternative" statements).

While *12-step programming* involves both intrapersonal and extrapersonal features, the small group social level is possibly most fundamental to this approach. Twelve-step programs such as Alcoholics Anonymous (AA) and Narcotics Anonymous (NA) provide the basic philosophy of change for many inpatient and outpatient addictions treatment facilities in the United States (over 2/3 s) and have worldwide impact (Sussman, 2010). More importantly, these programs may be the main sources of peer social support for the maintenance of habit change. Twelve-step programs are abstinence-oriented, multidimensional, nonprofit, humanistic, voluntary, socially supportive, self-help fellowships for individuals for whom an addiction has become problematic (Galaif & Sussman, 1995; Sussman, 2010; Sussman & Ames, 2008). Treatment and maintenance of change relies on 12 steps of recovery, often guided by a pathfinder (sponsor). Essentially, the participant learns to acknowledge loss of control over the addiction and obtains hope for change, attempts to understand and acknowledge personal assets and liabilities and wrongs done through the addiction, and attempts to make amends to others and practice prosocial living (Alcoholics Anonymous, 1976). One unfortunate consideration is the relative paucity of community-based 12-step programming aimed at adolescents' needs though such programming is now extending more widely to youth (Sussman, 2010).

Family therapy tends to view the addiction as a family (systems) problem and focuses on changing one part of the system (e.g., the addict's behavior), which may effectively change other parts of the system (Horigian et al., 2015). Among addicts, family relationships are viewed as potentially problematic and boundaries within the family are viewed as possibly distorted (e.g., enmeshed, disengaged). In family therapy for an addiction, the family's strengths and resources are utilized to assist in developing means for family members and the addict to cohabitate without the problematic addiction and to minimize the negative impact or consequences of the addict's behavior on the familial system. That is, the goal is to help the system integrate the recovering addict and heal. Family therapy provides neutral space for family members to express their emotions and concerns and work towards improving communication among family members. Family and group therapies for addictions work relatively well when the addict is an adolescent.

Modifications of the larger environment through *civil engineering or policy solutions*, and the introduction of social services, may also provide means to arrest youth substance abuse problems. Many of the same environmental and policy-focused prevention efforts also apply to cessation strategies (e.g., legal remedies such as drug courts [not much empirical evidence to support their value though]; mass media programming). Local and state policies that limit substance use in public spaces (e.g., no smoking laws, drug-free school zones) prohibit the sale of marijuana or other vaping products within close proximity to schools, and no-host ordinances that crack down on parents providing a place for teenagers to engage in illegal substance use can all help create a more optimal environment for complementary cessation strategies to be effective.

Considerations for Providing Culturally Tailored Cessation and Treatment Despite the variety of cessation approaches available to treat youth with substance use disorders, disparities persist in the outcomes and effectiveness of substance use treatment for different populations (Davis & Ancis, 2012; Guerrero et al., 2013). Therefore, treatment interventions must be individually tailored and include culturally competent and linguistically appropriate providers for specific subpopulation groups of youth (Longshore & Grills, 2000). For example, a substance use disorder treatment program called *Alcohol Treatment Targeting Adolescents in Need* (ATTAIN) was designed to target Latino and African American youth. Cultural factors experienced by these racial/ethnic subgroups were incorporated into the curriculum and addressed issues ranging from discrimination and acculturation to ethnic pride and cultural mistrust (Gil, Wagner, & Tubman, 2004). Lesbian, gay, bisexual, and transgender youth are at increased risk for developing a substance use disorder (McCabe, West, Hughes, & Boyd, 2013). Cessation programs aimed at this population should address issues such as homophobia and transphobia, violence, and social isolation (Lombardi & van Servellen, 2000).

Implications for Interprofessional Care

If one explores programming for youth substance use disorders through the lens of the Substance Use Care Continuum—primary prevention, early intervention, treatment, and recovery support (USDHHS, 2016), it becomes apparent that a wide array of providers, organizations, and community settings might work together to ensure youth suffering from substance use disorders receive the necessary care to succeed in their cessation efforts.

Primary Prevention Primary prevention of substance use disorders for youth must address both the individual and environmental risk factors for substance use through evidence-based programs, policies, and strategies. Given that youth spend a majority of their time in school-based settings, prevention programming has often been incorporated into health education in middle and high schools (e.g., Project TND). Substance use prevention programs fit well with common core strategies aimed at building and developing life, social, and emotional skills among the student body. Such programming may be led by teachers, counselors, or school nurses. Community-based organizations, such as the Boys and Girls Club, and other afterschool programs, also may offer substance use prevention programming to at-risk youth (e.g., Project CHOICE; e.g., D'Amico & Edelen, 2007), or interface with school-based programming to bolster maintenance of effectiveness. School administrators, teachers, counselors, and coaches also work closely with students and may be the first to identify signs of substance use and can offer referrals to students and their families into early intervention programming.

Early Intervention Early intervention aims to address substance misuse problems and mild disorders and to prevent more severe substance use disorders. For example, adolescents who engage in binge drinking are at risk for future substance use disorders because of their young age (Center for Behavioral Health Statistics and Quality, 2015). Schools, churches, and other community-based organizations that have regular contact with youth may be in the best position to identify and refer youth for early intervention services. Children whose parents are in the social welfare system, children in the social welfare system themselves, and youth in the juvenile justice system are all at increased risk for developing an enduring substance use disorder (Fettes, Aarons, & Green, 2013; CBHSQ, 2015). Therefore, social workers, judges, and probation and parole officers should be adequately trained to identify early signs of substance misuse and refer youth to qualified healthcare providers for screening and assessment. Approaches include brief interventions which inform adolescents on risks of substance misuse, strategies to control or quit use, and may involve motivational interviewing-related counseling (see https://addiction.surgeongeneral.gov/chapter-4-treatment.pdf).

Treatment The "treatment gap" for individuals with substance use disorders in the United States is most concerning. On average only one in 10 affected individuals receive treatment (CBHSQ, 2015). This fact highlights the importance of early intervention and the identification of youth at risk for developing a substance use disorder in community-based settings. For youth who have a regular source of medical care, behavioral healthcare providers are urged to follow the American Academy of Pediatricians' recommendations for inquiring about substance use among youth, including asking them if they have smoked a cigarette, consumed alcohol, and used illicit drugs (Levy & Kokotailo, 2011). Unlike adults dealing with substance use disorders, health insurance coverage for youth in substance use treatment is more generous and widespread across public and private payers (Substance Abuse and Mental Health Services Administration, 2013). The passage of the Affordable Care Act and its essential health benefits package, which includes substance use treatment, has expanded coverage for previously uninsured children. In addition, benefits for children enrolled in state Medicaid or Children's Health Insurance Program (CHIP) plans are eligible for substance use disorder treatment under the medical necessity requirements (Buck, 2011). Treatment may involve inpatient services, including cognitive behavioral approaches (e.g., self-management and assertiveness training), group therapy, 12-steps, and family therapy (Sussman, Skara, & Ames, 2008).

Recovery Support SAMHSA established the Recovery Support Strategic Initiative to promote partnering with people in recovery from mental and substance use disorders and their family members. The effort aims to guide the behavioral health system and promote individual, programmatic, and system-level approaches that foster health and resilience (including helping individuals with behavioral health needs to be well, manage symptoms, and achieve and maintain abstinence); increase housing to support recovery; reduce barriers to employment, education, and other life goals; and secure necessary social supports in their chosen community (see https://www.samhsa.gov/recovery).

Recovery support services help people enter into and navigate systems of care, remove barriers to recovery, stay engaged in the recovery process, and live full lives in communities of their choice. These services should incorporate a full range of social, legal, and other options that facilitate recovery, wellness, and linkage to and coordination among service providers, and other supports shown to improve quality of life for people in and seeking recovery and their families. Assimilation back into the education system is important for adolescent youth recovering from substance use disorders. Recovery support services also include access to employment and housing, assertive community treatment, illness management, and peer-operated services.

Emerging Treatment Technologies Technological advancements in the provision of health care have the potential to improve treatment of substance use disorders among children and adolescents. Greater numbers of substance use disorder treatment programs have adopted *electronic health record* (EHR) systems, which allow providers to more readily access and share treatment records, thus improving coordination of care. In turn, the use of EHRs can improve care quality, reduce the "treatment gap," and increase costs savings to health systems (USDHHS, 2016). The further dissemination and use of EHRs also supports the formation of Accountable Care Organizations (ACOs) that are designed to more effectively and efficiently deliver care across provider settings (D'Aunno, Friedmann, Chen, & Wilson, 2015). Outcomes for substance use disorder treatment include improved coordination of care from early intervention to treatment to recovery across care settings, including behavioral healthcare physicians and therapist offices, inpatient treatment and recovery centers, and pharmacies.

Electronic-based modalities may enhance cessation efforts. For example, *internet-based adolescent substance abuse relapse prevention modules* show promise as a supplement to treatment

(Trudeau, Black, Kamon, & Sussman, 2017). Inclusion of modules that provide instruction on relapse triggers (e.g., irrational thinking, negative affect, social pressures), coping with cravings, and planning, can favorably impact drug use outcomes beyond other treatment provided.

Telemedicine, or two-way, real-time interactive communication between a patient and healthcare provider, represents a rapidly expanding, but still relatively untapped resource to engage children, adolescents, and their family members in treatment-based interventions. Currently, technology-assisted care within substance use disorder treatment utilizes three main approaches: (1) telemedicine as an add-on to enhance standard care; (2) telemedicine as a substitute for an aspect of standard care; or (3) telemedicine as a replacement for standard care (Kiluk & Carroll, 2013; Rosa, Campbell, Miele, Brunner, & Winstanely, 2015). The promise of technology-based interventions may increase access to care for those in underserved areas of the country, provide alternative care options for those hesitant to seek in-person care, increase fidelity to evidence-based intervention components, and reduce costs (USDHHS, 2014).

Case Study: Project TND-The Talk Show

Project Towards No Drug Abuse, or Project TND, is an evidence-based drug abuse prevention program aimed at high school-age youth (14–18 years old). The 12 sessions are held in a classroom setting by a trained instructor and integrate both intrapersonal and extrapersonal approaches to change, involving a motivation enhancement–social and life skills–decision-making (MSD) model of change (Sussman, 2015).

Scripted and non-scripted interaction as depicted in the Talk Show provides students with an empathetic understanding of the negative consequences of drug abuse. In the talk show setting, various panelists report their experiences. Scripts are provided to all participants in the group who volunteer to take on various roles, and they can work off the scripts, either as panelists or audience members. After one talk show session some years ago, a youth commented “Both of my parents are alcoholics; maybe I shouldn’t drink.” During another talk show session, one youth commented that they only used “meth” on weekends so that wasn’t drug misuse. Another youth said to that same student, “No, that is drug abuse.” In other words, it is likely that spontaneous and heartfelt “*corrective*” statements made by youth about their own behavior, or a classmate’s behavior, elicited by the classroom process demands, leads to favorable program effects. The talk show format is an activity highly preferred by older teens. Use of psychodramas in the format of “talk shows” can assist in prompting responsibility, spreading information on consequences of use, and achieving healthy lifestyle changes (Sussman, 2015).

Conclusion and Future Directions

Many adolescents begin misusing substances merely due to curiosity. For those who achieve a reliable appetitive effect, use regularly, become preoccupied with substance use, and lose control over the when, where, how much, and consequences of use, a negative consequential addiction is developing, which upsets self and others, and may result in a variety of legal, financial, medical, and psychosocial outcomes. The material in this chapter may be useful to a range of behavioral healthcare providers. It may also provide background material for the potential to identify and implement telemedicine strategies (e.g., video therapy) to increase access and address current treatment gaps among pediatric substance users. However, it is also important to note that vulnerable persons, lured by easy access to addictive objects and pushed on by desires to cope with the demands of modern life, may suffer from any number of addictive behaviors (e.g., gambling, shopping, food, work, sex, internet, exercise) that serve similar appetitive motivation functions (Sussman, 2017). Also, while there are many similarities among addictive behaviors, including across the spectrum of substance use disorders, there are unique aspects of each addiction that require specification through screening and further assessment. For example, a gambling addict may try to "chase losses," which is not associated with substance misuse (APA, 2013; Sussman, 2017). Much research is needed to not only prevent use from developing or stop engagement in a substance use disorder, but also to prevent or arrest a generalized addictive process if it might become negatively consequential (Sussman, 2017), as well as be attentive to unique parameters of multiple addictions a youth may experience.

References

Alcoholics Anonymous. (1976). *Alcoholics Anonymous*. New York, NY: Alcoholics Anonymous World Services.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Andersen, S. L., & Teicher, M. H. (2009). Desperately driven and no brakes: Developmental stress exposure and subsequent risk for substance abuse. *Neuroscience and Biobehavioral Reviews, 33*, 516–524.

Bauman, K. E., Ennett, S. T., Foshee, V. A., Pemberton, M., King, T. S., & Koch, G. G. (2002). Influence of a family program on adolescent smoking and drinking prevalence. *Prevention Science, 3*, 35–42.

Bauman, K. E., Ennett, S. T., Foshee, V. A., Pemberton, M., King, T. S., & Koch, G. G. (2000). Influence of a family-directed program on adolescent cigarette and alcohol cessation. *Prevention Science, 1*, 227–237.

Bauman, K. E., Foshee, V. A., Ennett, S. T., Pemberton, M., Hicks, K. A., King, T. S., … Koch, G. G. (2001). The influence of a family program on adolescent tobacco and alcohol use. *American Journal of Public Health, 91*, 604–610.

Bennett, M. E., McCrady, B. S., Frankenstein, W., Laitman, L. A., Van Horn, D. H., & Keller, D. S. (1993). Identifying young adult substance abusers: The Rutgers Collegiate Substance Abuse Screening Test. *Journal of Studies on Alcohol, 54*, 522–527.

Brannigan, R., Schackman, B. R., Falco, M., & Millman, R. B. (2004). The quality of highly regarded adolescent substance abuse treatment programs: Results of an in-depth national survey. *Archives of Pediatrics & Adolescent Medicine, 158*, 904–909.

Bröning, S., Kumpfer, K., Kruse, K., Sack, P. M., Schaunig-Busch, I., Ruths, S., & Thomasius, R. (2012). Selective prevention programs for children from substance-affected families: A comprehensive systematic review. *Substance Abuse Treatment, Prevention, and Policy, 7*, 1–17.

Buck, J. A. (2011). The looming expansion and transformation of public substance abuse treatment under the Affordable Care Act. *Health Affairs, 30*, 1402–1410.

Center for Behavioral Health Statistics and Quality. (2015). *Behavioral health trends in the United States: Results from the 2014 National Survey on Drug Use and Health* (HHS Publication No. SMA 15-4927, NSDUH Series H-50). Retrieved from http://www.samhsa.gov/data

Chassin, L. A., Presson, C. C., & Sherman, S. J. (1985). Stepping backward in order to step forward: An acquisition-oriented approach to primary prevention. *Journal of Consulting and Clinical Psychology, 53*, 612–622.

Courvoisier, D. S., & Etter, J. E. (2010). Comparing the predictive validity of five cigarette dependence questionnaires. *Drug and Alcohol Dependence, 107*, 128–133.

D'Amico, E. J., & Edelen, M. O. (2007). Pilot test of Project CHOICE: A voluntary afterschool intervention for middle school youth. *Psychology of Addictive Behaviors, 21*(4), 592–598. https://doi.org/10.1037/0893-164X.21.4.592

D'Aunno, T., Friedmann, P. D., Chen, Q., & Wilson, D. M. (2015). Integration of substance abuse treatment organizations into accountable care organizations: Results from a national survey. *Journal of Health Politics, Policy, and Law, 40*, 797–819.

Davis, R. A., & Ancis, J. (2012). Look to the relationship: A review of African American women substance users' poor treatment retention and working alliance development. *Substance Use & Misuse, 47*, 662–672.

Fettes, D. L., Aarons, G. A., & Green, A. E. (2013). Higher rates of adolescent substance use in child welfare versus community populations in the United States. *Journal of Studies on Alcohol and Drugs, 74*, 825–834.

Flay, B. R. (1981). On improving the chances of mass media health promotion programs causing meaningful changes in behavior. In M. Meyer (Ed.), *Health education by television and radio* (pp. 56–91). Munich, Germany: Saur.

Flay, B. R., d'Avernas, J. R., Best, J. A., Kersell, M. W., & Ryan, K. B. (1983). Cigarette smoking: Why young people do it and ways of preventing it. In P. McGrath & P. Firestone (Eds.), *Pediatric and adolescent behavioral medicine* (pp. 132–183). New York: Springer-Verlag.

Galaif, E., & Sussman, S. (1995). For whom does Alcoholics Anonymous work? *International Journal of the Addictions, 30*, 161–184.

Gil, A. G., Wagner, E. F., & Tubman, J. G. (2004). Culturally sensitive substance abuse intervention for Hispanic and African American adolescents: Empirical examples from the Alcohol Treatment Targeting Adolescents in Need (ATTAIN) project. *Addiction, 99*, 140–150.

Grenard, J. L., Ames, S. L., Pentz, M. A., & Sussman, S. (2006). Motivational interviewing with adolescents and young adults for drug-related problems. *International Journal of Adolescent Medical Health, 18*, 53–67.

Grigsby, T. J., Sussman, S., Chou, C.-P., & Ames, S. L. (2017). Chapter 11: Assessment of substance misuse. In J. B. VanGeest, T. P. Johnson, & S. A. Alemagno (Eds.), *Research methods in the study of substance abuse* (pp. 197–234). Cham, Switzerland: Springer.

Griswold, K., Aronoff, H., Kernan, J., & Kahn, L. (2008). Adolescent substance use and abuse: Recognition and management. *American Family Physician Journal, 77*, 331–336.

Guerrero, E. G., Marsh, J. C., Duan, O. L., Oh, C., Perron, B., & Lee, B. (2013). Disparities in completion of substance abuse treatment between and within racial and ethnic groups. *Health Services Research, 48*, 1450–1467.

Guthmann, D. R., & Brenna, D. C. (1990). The personal experience inventory: An assessment of the instrument's validity among a delinquent population in Washington state. *Journal of Child & Adolescent Substance Abuse, 1*, 15–24.

Horigian, V. E., Feaster, D. J., Brincks, A., Robbins, M. S., Perez, M. A., & Szapocznik, J. (2015). The effects of Brief Strategic Family Therapy (BSFT) on parent substance use and the association between parent and adolescent substance use. *Addictive Behaviors, 42*, 44–50.

Johnson, V. E. (1980). I'll quit tomorrow: A practical guide to alcoholism treatment. San Francisco, CA: Harper & Row.

Johnston, L. D., O'Malley, P. M., Miech, R. A., Bachman, J. G., & Schulenberg, J. E. (2017). *Monitoring the Future national survey results on drug use, 1975–2016: Overview, key findings on adolescent drug use* (pp. 1–120). Ann Arbor: Institute for Social Research, The University of Michigan.

Kiluk, B. D., & Carroll, K. M. (2013). Bew developments in behavioral treatments for substance use disorders. *Current Psychiatry Reports, 15*, 1–14.

Kipping, R. R., Campbell, R. M., MacArthur, D. J., Gunnell, D. J., & Hickman, M. (2012). Multiple risk behavior in adolescence. *Journal of Public Health, 34*, i1–i2.

King, K., & Chassin, L. (2007). A prospective study of the effects of age of initiation of alcohol and drug use on youth substance dependence. *Journal of Studies on Alcohol and Drugs, 68*, 256–265.

Kirisci, L., Mezzich, A., & Tarter, R. (1995). Norms and sensitivity of the adolescent version of the Drug Use Screening Inventory. *Addictive Behaviors, 20*, 149–157.

Knight, J. R., Sherritt, L., Shrier, L. A., Harris, S. K., & Chang, G. (2002). Validity of the CRAFFT substance abuse screening test among adolescent clinic patients. *Archives of Pediatrics & Adolescent Medicine, 156*, 607–614.

Kumpfer, K. L., & DeMarsh, J. P. (1985). Prevention of chemical dependency in children of alcohol and drug abusers. *NIDA Notes, 5*, 2–3.

Levy, S. J., Kokotailo, P. K., & Committee on Substance Abuse. (2011). Substance use screening, brief intervention, and referral to treatment for pediatricians. *Pediatrics, 128*, 1330–1340.

Longshore, D., & Grills, C. (2000). Motivating illegal drug use recovery: Evidence from culturally congruent intervention. *Journal of Black Psychology, 26*, 288–301.

Lombardi, E. L., & van Servellen, G. (2000). Building culturally sensitive substance use prevention and treatment programs for transgendered populations. *Journal of Substance Abuse Treatment, 19*, 291–296.

McCabe, S. E., West, B. T., Hughes, T. L., & Boyd, C. J. (2013). Sexual orientation and substance abuse treatment utilization in the United States: Results from a national survey. *Journal of Substance Abuse Treatment, 44*, 4–12.

Miller, W. R., Meyers, R. J., & Tonigan, J. S. (1999). Engaging the unmotivated in treatment for alcohol problems: A comparison of three strategies for intervention through family members. *Journal of Consulting and Clinical Psychology, 67*, 688–697.

Miller, W. R., & Rollnick, S. (2013). *Motivational interviewing: Helping people change* (3rd ed.). New York, NY: The Guilford Press.

National Institute on Drug Abuse, National Institutes of Health, & U.S. Department of Health and Human Services. (2017).

Newcomb, M. D., & Bentler, P. M. (1988). *Consequences of adolescent drug use*. Newbury Park: Sage.

Newcomb, M. D., Maddahian, E., & Bentler, P. M. (1986). Risk factors for drug use among adolescents: Concurrent and longitudinal analysis. *American Journal of Public Health, 76*, 525–531.

Pentz, M. A., Bonnie, R. J., & Shopland, D. R. (1996). Integrating supply and demand reduction strategies for drug abuse prevention. *American Behavioral Scientist, 39*, 897–910.

Rahdert, E. (1991). *Adolescent assessment/referral system manual* (Publication No. (ADM) 91-1735). Rockville, MD: U.S. Department of Health and Human Services.

Rosa, C., Campbell, A. N. C., Miele, G. M., Brunner, M., & Winstanely, E. L. (2015). Using e-technologies in clinical trials. *Contemporary Clinical Trials, 45*, 41–54.

Selzer, M. L., Vinokur, A., & Rooijen, L. V. (1975). A self-administered short Michigan alcoholism screening test (SMAST). *Journal of Studies on Alcohol and Drugs, 36*, 117–128.

Storti, E. (2001). Motivational intervention: The only failure is the failure to act. In R. H. Coombs (Ed.), *Addiction recovery tools: A practical handbook* (pp. 3–16). Thousand Oaks, CA: Sage.

Substance Abuse and Mental Health Services Administration. (2013). *Behavioral Health, United States, 2012* (HHS Publication No. (SMA) 13-4797).

Rockville, MD: Substance Abuse and Mental Health Administration.

Sussman, S. (2010). A review of Alcoholics Anonymous/Narcotics Anonymous programs for teens. *Evaluation & the Health Professions, 33*, 26–55.

Sussman, S. (2013). A lifespan developmental-stage approach to tobacco and other drug abuse prevention. *ISRN-Addiction, 2013*, 1–19.

Sussman, S. (2015). Evaluating the efficacy of Project TND: Evidence from seven research trials. In L. M. Scheier (Ed.), *Handbook of adolescent drug use prevention: Research, intervention strategies, and practice*. Washington, DC: American Psychological Association.

Sussman, S. (2017). *Substance and behavioral addictions: Concepts, causes, and cures*. New York, NY: Cambridge University Press.

Sussman, S., & Ames, S. L. (2001). *The social psychology of drug abuse*. Buckingham, UK: Open University Press.

Sussman, S., & Ames, S. L. (2008). *Drug abuse: Concepts, prevention, and cessation*. Cambridge, GB: Cambridge University Press.

Sussman, S., Dent, C. W., & Galaif, E. R. (1997). The correlates of substance abuse and dependence among adolescents at high risk for drug abuse. *Journal of Substance Abuse Treatment, 9*, 241–255.

Sussman, S., Levy, D., Hassmiller, K., Cena, D. W., Kim, M., Rohrbach, L. A., & Chaloupka, F. (2013). A speculation on modalities of tobacco use prevention. *Tobacco Induced Diseases, 11*, 1–14.

Sussman, S., Skara, S., & Ames, S. L. (2008). Substance abuse among adolescents. *Substance Use & Misuse, 43*, 1802–1828.

Tobler, N. S., Roona, M. R., Ochshorn, P., Marshall, D. G., Streke, A. V., & Stackpole, K. M. (2000). School-based adolescent drug prevention programs: 1998 meta-analysis. *The Journal of Primary Prevention, 20*, 275–336.

Trudeau, K. J., Black, R. A., Kamon, J. L., & Sussman, S. (2017). A randomized controlled trial of an online relapse prevention program for adolescents in substance abuse treatment. *Child & Youth Care Forum, 46*, 437–454.

U.S. Department of Health and Human Services. (2014). *The health consequences of smoking-50 years of progress: A report of the surgeon general*. Atlanta, GA: U.S. DHHS, CDC, NCCDPHP, OSH.

U.S. Department of Health and Human Services. (2016, November). *Facing addiction in America: The surgeon general's report on alcohol, drugs, and health*. Washington, DC: HHS.

Wakefield, J. C., & Schmitz, M. F. (2014). How many people have alcohol use disorders? Using the harmful dysfunction analysis to reconcile prevalence estimates in two community surveys. *Frontiers in Psychiatry, 5*, 22. (Corrigendum: 5, Article 144, 3 pages).

Winters, K. C., & Henly, G. A. (1993). *Adolescent diagnostic interview schedule and manual*. Los Angeles: Western Psychological Services.

Winters, D., & Kaminer, Y. (2008). Screening and assessing adolescent substance use disorders in clinical populations. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*, 740–744.

Winters, K. C., Stinchfield, R., & Fulkerson, J. (1993). Patterns and characteristics of adolescent gambling. *Journal of Gambling Studies, 9*, 371–386.

17 Eating Disorders

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Abstract

Eating disorders (EDs) and feeding disorders are characterized by maladaptive eating behaviors resulting in psychosocial, physical, or nutritional impairment. In this chapter, we review the most common EDs among children and adolescents, including anorexia nervosa, bulimia nervosa, binge eating disorder, avoidant/restrictive food intake disorder, and other specified eating and feeding disorder. While all the disorders we discuss can appear across the lifespan, our focus in this work will be on youth. This chapter will further review the physical health implications of EDs, case identification methods in pediatric settings, and the relevant prevention and intervention literature. We will conclude with a discussion of implications for interprofessional care, a case study, and future directions for the field.

Background

Eating disorders (EDs) and feeding disorders are a cluster of psychiatric diagnoses collectively characterized by maladaptive eating behavior resulting in psychosocial, physical, or nutritional impairment (American Psychiatric Association, 2013). These disorders range in their prevalence rates, presentations, and outcomes. In this chapter, we review the most common EDs among children and adolescents. While all the disorders we discuss can appear across the lifespan, our focus in this work will be on youth. EDs have significantly elevated mortality rates among mental disorders (Arcelus, Mitchell, Wales, & Nielsen, 2011; Crow et al., 2009); however, children and adolescents appear to have better outcomes, especially with intervention (Watson & Bulik, 2013). EDs' medical, functional, and psychological complications necessitate interdisciplinary collaboration, from prevention efforts to early identification and treatment. This chapter will conclude with a case study and future directions for the field.

Diagnostic Categories

Anorexia Nervosa (AN)

AN is marked by restrictive eating that leads to a significantly low weight in relation to an individual's age, sex, physical health, and devel-

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opmental trajectory. Individuals with AN place an undue amount of attention on their shape or weight, which influences their self-evaluation and may contribute to a lack of awareness of the serious negative consequences associated with their low weight (American Psychiatric Association, 2013). AN is further categorized by the types of behavior a patient engages in to maintain a low weight. In the restricting subtype of AN, individual's severely limit the quantity, quality, and frequency of their food intake, and/or engage in excessive exercise (American Psychiatric Association, 2013), while individuals with binge-eating/purging subtype also binge eat on subjectively or objectively large amounts of food and/or purge (vomit or misuse laxatives or diuretics). Across subtypes, individuals with AN experience an intense fear of weight gain that has a catastrophic quality and paradoxically does not subside, or can even intensify, with further weight loss (Steinglass & Walsh, 2006). Eating rigidity as well as ritualistic behaviors to avoid food consumption or obscure restriction are common (Bravender et al., 2010; Steinglass et al., 2010). Children in particular may express fear of weight gain through behavioral resistance and avoidance rather than by verbally articulating their affective state (Bravender et al., 2010). They may also fail to make expected weight gain milestones rather than losing drastic amounts of weight, an insidious process that can be missed until the patient's next annual well-child visit.

The prevalence of AN is 0.3% in adolescents (13–18 years) and 0.1% in younger children (8–15 years) (Merikangas et al., 2010; Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011) and there have been cases documented in children as young as 5 years (Hudson, Nicholls, Lynn, & Viner, 2012). In clinical samples, the age of onset for AN is seemingly decreasing as the incidence of AN in younger children has been increasing (Favaro, Caregaro, Tenconi, Bosello, & Santonastaso, 2009). A younger age of onset has additional medical and psychological ramifications; younger children may demonstrate more sudden and extreme weight loss and may fail to reach their genetic height potential (Lantzouni, Frank, Golden, & Shenker, 2002). AN is historically and currently found to be more prevalent in girls (Hoek, 2006; Striegel-Moore et al., 2009; Striegel-Moore & Bulik, 2007). Few studies have studied the population-based prevalence or incidence of AN in boys as it was previously thought that AN was rare in this gender and age group. One study reported an incidence rate for early-onset AN (5–12 years) in boys to be between 0.4 and 1.2% (Pinhas, Morris, Crosby, & Katzman, 2011).

The naturalistic illness course and outcomes for individuals with AN can vary considerably with onset, severity, age, sex, and other idiosyncratic variables, with prognosis seemingly more positive in youth (Watson & Bulik, 2013). Generally, AN can have significant medical, psychiatric, and even fatal consequences. While trends appear to be showing improvement over time, possibly secondary to the dissemination of efficacious interventions, the data are also variable, likely as a function of discrepant definitions of remission and recovery (Keel & Brown, 2010; Smink, van Hoeken, Oldehinkel, & Hoek, 2014; Wentz, Gillberg, Anckarsäter, Gillberg, & Råstam, 2009).

Bulimia Nervosa (BN)

The essential features of BN include recurrent eating binges, consequent inappropriate compensatory behaviors to avoid weight gain, and an undue influence of shape and weight on one's self-concept and evaluation (American Psychiatric Association, 2013). Binge eating in the context of BN is defined as the consumption of objectively large quantities of food within a discrete amount of time, along with attributed feelings of a loss of control. The compensatory behaviors seen in BN can involve purging or nonpurging mechanisms such as fasting and compulsive exercise. Bulimic behaviors often occur in secret and can remain undetected by parents for some time.

The prevalence and incidence rates of BN will likely change in accordance with the more inclusive behavior frequency requirements in DSM-5; one study found that with the lowered criteria threshold, BN rates increased by 1% (Stice, Marti, & Rohde, 2013). BN is more common in adolescents than in children (Merikangas et al., 2010), with the overall prevalence being 0.1% (Swanson et al., 2011). BN is less common than AN and Binge Eating Disorder (BED) in adolescents (Smink et al., 2014). Similar to AN, the age of BN onset seems to be decreasing over time (Favaro et al., 2009), and BN is more prevalent among females (Hoek, 2006). Males with BN have been found to be heavier and to present with a less distorted body experience and more realistic goal weights (Nagl et al., 2016). A study on the naturalistic outcomes of adolescent women with BN and subthreshold BN found that within a year, 100% of the sample showed remission. However, reemergence of BN and subthreshold BN in subsequent years was 33% (Stice, Marti, & Rohde, 2013).

Binge Eating Disorder (BED)

BED is characterized by recurrent binge eating in the absence of inappropriate compensatory behavior. Binge eating episodes are associated with markers of affective and/or behavioral loss of control, as well as distress or impairment. The mean age of onset is 12.6 years old (Swanson et al., 2011) and prevalence estimates are between 1 and 1.6% among adolescents (Merikangas et al., 2010). BED, like the other EDs, is more common among female than male adolescents with the prevalence for females at 2.3% and 0.8% for males (Swanson et al., 2011). Few studies have examined the onset or course of BED among the adolescent population, but research suggests that loss-of-control eating behavior in youth may predict BED in adulthood (Tanofsky-Kraff et al., 2013).

Avoidant/Restrictive Food Intake Disorder (ARFID)

ARFID is a newly recognized disorder in the psychiatric diagnostic system although its collection of features is not a new clinical phenomenon. Children and adolescents with ARFID engage in restrictive eating behaviors that result in malnourishment, low body weight, or psychosocial impairment; however, they do not present with the body image symptoms evident in AN (American Psychiatric Association, 2013). Children and adolescents may present with disinterest in eating and may avoid foods based on disgust or sensory concerns (Wildes, Zucker, & Marcus, 2012). Some may be reluctant to eat for fear of negative consequence like choking, vomiting, or developing stomach pain (Norris et al., 2014). Given its recent addition to the DSM, there is little research on the prevalence, incidence, or outcomes of ARFID. Estimates are that 12–22.5% of children and adolescents meet criteria for the disorder (Ornstein et al., 2013; Wallin & Råstam, 2016). Studies suggest that while ARFID typically onsets in early childhood, it may begin as early as infancy, and persist longer than other EDs (Fitzpatrick, Forsberg, & Colborn, 2015; Stice, Marti, Shaw, & Jaconis, 2009; Wallin & Råstam, 2016).

Other Specified Feeding or Eating Disorder (OSFED)

OSFED evolved from Eating Disorder not Otherwise Specified (EDNOS), which was the most common DSM-IV-TR (American Psychiatric Association, 2000) ED diagnosis in clinical and community samples (Smink, van Hoeken, & Hoek, 2013). Individuals who have a functionally interfering feeding or ED that does not meet criteria for any other category are assigned this diagnosis. Previous studies have found that 64.4% of adolescents with an ED fell in the EDNOS category (Keel, Brown, Holm-Denoma, & Bodell, 2011). However, with expanded criteria in the DSM-5 for AN, BN, and BED, the rates of this residual diagnosis will likely decrease. Though there are few studies to evaluate the prevalence and incidence of OSFED in the context of this and other ED changes in DSM-5, a community-based study estimated the prevalence of OSFED at 15.5%. They further found that at a diagnostic interview follow-up, 57.1% of adolescents with OSFED were fully recovered (Smink et al., 2014).

Etiology

The exact etiology of EDs is largely unknown though there are suggestions of a correlation between genetic predispositions, sociocultural and economic influences, and other psychological traits that may contribute to the development of an ED (Campbell & Peebles, 2014). EDs are historically more prevalent in societies that value thinness (often post-industrialized, high-income countries), and among professions that encourage thinness such as modeling, dancing, and elite athletics (Makino, Tsuboi, & Dennerstein, 2004). Twin studies have suggested an increased risk of AN with a heritability for AN between 33 and 84% and for BN between 28 and 83% (Trace, Baker, Penas-Llecio, & Bulik, 2013).

Physical Health Implications

EDs are associated with many significant negative health concerns, most of which are secondary to starvation and low weight (Society for Adolescent Health and Medicine (SAHM), 2015). Notably, in children and adolescents, the medical sequelae often carry implications for growth and development. The consequential impact of EDs on a child or adolescents overall health, emphasizes the need for interprofessional collaboration to ensure the safety of patients.

AN affects every system of the body (Academy for Eating Disorders (AED), 2016), conferring both acute, life-threatening risk, and longer term sequelae if left untreated. Many of these complications may be reversed with successful treatment (e.g., cardiac complications) and others may persist for many years following recovery (e.g., skeletal complications or stunted growth) (Meczekalski, Podfigurna-Stopa, & Katulski, 2013). Initially, the body responds adaptively to malnutrition and low weight to protect itself in the short-term, but long-term weight loss and restriction can render these adaptive processes life-threatening. Like in AN, ARFID, which is also typically characterized by low weight, can lead to low heart rate, stunted growth, nutritional deficiencies, and low bone density (Nicholls & Bryant-Waugh, 2009).

Overall, the acute medical consequences in children and adolescents are similar to those in adults. There are, however, major differences in their response to weight loss (Campbell & Peebles, 2014). Children can become ill more rapidly even with small amounts of weight loss given their unique nutritional needs to support ongoing normal growth and development. Smaller amounts of weight loss in children represent much larger percentages of total body weight than in adults. Such weight loss can have long-term and potentially permanent effects on children's health, particularly on ongoing bone maturation, pubertal development, and ultimate adult height (Campbell & Peebles, 2014; Rome & Ammerman, 2003). Individuals with restrictive EDs are also at risk for developing refeeding syndrome at the onset of treatment for their malnourished state (SAHM, 2014). This syndrome can lead to potentially fatal hormonal and metabolic changes (Mehanna, Moledina, & Travis, 2008). At-risk patients need to be closely monitored in a higher level of care during the renourishment process (Loeb & Sanders, 2016; SAHM, 2014).

BN has similar negative health consequences as AN, impacting many organ systems (Mehler, 2011). Bone development in children and adolescents with BN may also be negatively affected in the context of suppressed weight or menstrual disturbance secondary to dietary restriction (Rosen, 2010). Vomiting and laxative misuse can result in life-threatening changes in electrolytes, which affect heart function. Damage to the gastrointestinal tract includes esophagitis, esophageal tears, or the development of gastroesophageal reflux. Other complications include renal dysfunction, swollen parotid glands, and dental issues (Trent, Moreira, Colwell, & Mehler, 2013).

Binge eating and BED are associated with weight gain that may contribute to rates of pediatric obesity (Mitchell, 2016; Ogden, Carroll, Kit, & Flegal, 2012). This correlation between binge eating and obesity leads adolescents with BED to be at a higher risk for complications associated with a high weight, including cardiac issues, type 2 diabetes, and sleep apnea (Mitchell, 2016). Notably, there is an increasing body of literature suggesting that BED may contribute to the development of metabolic syndrome, distinct from the health impacts of obesity (Barnes et al., 2011; Hudson et al., 2010; Roehrig, Masheb, White, & Grilo, 2009).

Screening, Assessment, and Evaluation

Screening in primary care settings is imperative for early identification and treatment for children and adolescents with EDs. Screening requires casting a wide net over a large group based on an identified demographic, such as age or gender, in an effort to avoid missing "caseness" (i.e., the presence of the disorder in an individual). AN and BN are insidious disorders which, if left undetected, can become chronic, life-impairing, and lethal. Thus, it is better to risk obtaining a false positive (and putting an individual through a second step of assessment/evaluation) than a false negative (and overlooking someone in need of treatment) (Hautala et al., 2009). While screening is the first phase of identifying those in need of treatment, assessment and evaluation comprises the second tier of the process. In this second level, a comprehensive medical evaluation as well as diagnostic and psychological assessment are necessary, with the latter components designed to evaluate specific psychopathology, severity of illness, comorbidities, and risk of self-harm (SAHM, 2015). Elements of the medical evaluation are part standard and part individualized based on diagnosis and presentation and reflect the range of potential medical sequelae from EDs. The medical evaluation will also determine the level of care to which the patient is initially referred (AED, 2016).

While ED patients are significantly more likely than healthy controls to go to their primary care physician or the emergency room in the 5 years prior to diagnosis with a variety of symptoms, such as gastrointestinal or genitourinary complaints (Dooley-Hash, Lipson, Walton, & Cunningham, 2013), many physicians report that they are not routinely screening for EDs or including other informants in the process (Robinson, Boachie, & Lafrance, 2012). Most visits to the pediatrician are less than 10 min in duration, so it is unrealistic to conduct a lengthy interview to screen for EDs within this setting (Halfon, Stevens, Larson, & Olson, 2011). Therefore, it is suggested that the introduction of short screener questions regarding body and shape concerns can elicit enough information to determine if a follow-up session with a specialist should be recommended (Waller, Micali, & James, 2014). Available brief measures for use in primary care settings include the Sick, Control, One, Fat, Food (SCOFF; Morgan, Reid, & Lacey, 1999; Mond et al., 2008), and the Eating Disorder Screen for Primary Care (ESP; Cotton, Ball, & Robinson, 2003). While these measures have been validated only with adults in primary care settings, they can still provide a useful framework for screening EDs in youth (Rosen, 2010).

A multiple informant approach is recommended for screening, assessment, and evaluation, as it is likely that these different perspectives will yield complementary, additive, or even valuably discrepant information regarding symptoms, diagnosis, and, by extension, treatment recommendations. While generally recommended in the evaluation for youth psychopathology (Dirks, Reyes, Briggs-Gowan, Cella, & Wakschlag, 2012), multiple informant methods are particularly useful for ego syntonic (i.e., feelings and behaviors experienced as concordant with one's identity and self-concept), treatment-resistant disorders like AN (Mariano, Watson, Leach, McCormack, & Forbes, 2013; Swanson et al., 2014). This approach allows clinicians to include, in their diagnostic impressions, objective readings of the youth's behaviors with valuable observations and input from others, as patients with EDs have a tendency to deny, minimize, excuse, or conceal their symptoms (Bravender et al., 2010; Loeb, Brown, & Goldstein, 2011). The current diagnostic system presents challenges when assessing children and adolescents as they may not report some of the same cognitive characteristics as adults (Becker, Eddy, & Perloe, 2009; Micali & House, 2011). The psychological components of some of the AN criteria, including fear of weight gain (Criterion B) and the impact of one's body image on self-evaluation (Criterion C), requires the patient to go beyond identifying their emotion to recognize the more abstract motivation for the behavior as well, which is a barrier when working with youth who are still cognitively developing in this regard (Becker et al., 2009; Bravender et al., 2010; Loeb, Brown et al., 2011; Loeb et al., 2011).

Prevention and Intervention

Prevention

Given the low prevalence of EDs, primary prevention efforts within the field have primarily focused on selective and indicated interventions, which are aimed at groups of people who are at increased risk for developing pathology (Gordon, 1987). There are three such well-researched programs that target adolescent females experiencing high levels of thin-ideal internalization, shape/weight concerns, or dieting behaviors as well as other risk factors (Le, Barendregt, Hay, & Mihalopoulos, 2017; Stice, Becker, & Yokum, 2013; Watson et al., 2016); these programs measure both reduction of risk factors and ED incidence as metrics of utility.

The Body Project is a cognitive dissonance-based, selective ED prevention program targeting thin-ideal internalization (Stice, Rohde, & Shaw, 2013); it has the most robust evidence base and greatest amount of independent replication within the prevention literature (Le et al., 2017; Stice et al., 2013; Watson et al., 2016). The Healthy Weight intervention uses behavior modification to encourage positive, healthy weight management through cognitive-behavioral and motivational interviewing techniques (Stice, Rohde, Shaw, & Marti, 2013). Finally, Student Bodies is the most thoroughly researched computer-based ED prevention program, which delivers cognitive-behavioral techniques in an interactive format (Beintner, Jacobi, & Taylor, 2012; Le et al., 2017; Loucas et al., 2014; Watson et al., 2016).

Comparatively less research has focused on the development of successful universal prevention programs (Le et al., 2017; Watson et al., 2016), and there is a need for continued research in this area such that primary prevention can better address the needs of younger children and boys (Ciao, Loth, & Neumark-Sztainer, 2015). The most promising universal prevention programs are those emphasizing media literacy, such as Media Smart, which enable participants to challenge stereotypical mass media messages concerning shape and weight (Le et al., 2017; Wade, Wilksch, Paxton, Byrne, & Austin, 2017; Watson et al., 2016; Wilksch et al., 2015). Public health professionals should play a larger role in ED prevention, striving to merge universal ED prevention with other efforts (e.g., obesity or depression prevention) as working in tandem could more powerfully address broader, shared environmental factors (Austin, 2012; Becker, Plasencia, Kilpela, Briggs, & Stewart, 2014; Ciao et al., 2015). Appeals have also been made within the ED field to distill the concepts of efficacious prevention in a way that has improved translational capacity to physician–patient interactions in a pediatric care context (Golden, Schneider, & Wood, 2016).

Intervention

There are several forms of evidence-based treatment for pediatric EDs. Family-based treatment (FBT) for AN is a three-phased, theoretically agnostic outpatient intervention for medically stable adolescents, in which the family is tasked with restoring weight and encouraging normal adolescent development (Lock & Le Grange, 2013). In Phase 1 of FBT, parents are supported in temporarily taking charge of their child's eating and weight restoration. The therapist works with the family to absolve parents of blame for causing the illness, while enhancing their sense of efficacy in their ability to restore their child's weight. In addition, the ED is conceptually externalized as an illness beyond the patient's control. During Phase 2, the therapist supports the parents in returning control over eating to the adolescent, as is developmentally appropriate. Finally, in Phase 3 the family learns to address psychosocial issues of adolescent development in the absence of the ED. Although other interventions have approached the efficacy of FBT it remains the treatment of choice as it is the most efficient and economical, largely because it most effectively reduces the need for hospitalization (Agras et al., 2014; Couturier, Kimber, & Szatmari, 2013; Lock, 2015; Lock, Agras, et al., 2016; Lock et al., 2010; NICE, 2017).

Other psychological treatments include enhanced cognitive-behavioral therapy, a transdiagnostic treatment for EDs (Fairburn, 2008), which has recently demonstrated potential in the treatment of adolescent BN and BED (Dalle Grave, Calugi, Sartirana, & Fairburn, 2015) and AN (Dalle Grave, Calugi, Doll, & Fairburn, 2013; Dalle Grave, Calugi, El Ghoch, Conti, & Fairburn, 2014). Adolescent-focused therapy is a psychodynamically informed and developmentally oriented individual psychotherapy for adolescents with AN (Fitzpatrick, Moye, Hoste, Lock, & Le Grange, 2010; Lock et al., 2010). Finally, systemic family therapy is a distinct family therapy, in which treatment focuses on patterns of beliefs and behaviors within the family system without particular emphasis on food or weight (Agras et al., 2014).

Psychopharmacological interventions have demonstrated limited utility in the treatment of adolescent EDs (Mitchell, Roerig, & Steffen, 2013) although they are frequently prescribed. Specifically, atypical antipsychotics have shown limited efficacy in the treatment of adolescent AN (Balestrieri, Oriani, Simoncini, & Bellantuono, 2013; Lebow, Sim, Erwin, & Murad, 2013; McKnight & Park, 2010). Fluoxetine, which is efficacious in the treatment of adults with BN, has less established evidence to support its use in adolescents (Couturier & Lock, 2007; Golden & Attia, 2011; Kotler, Devlin, Davies, & Walsh, 2003). Hormone therapies are sometimes prescribed for adolescents with amenorrhea to prevent low bone mineral density; however, it has been demonstrated that such medications do not protect against the development of osteopenia or osteoporosis (Bergström et al., 2013; Golden, 2007). Indeed, use of hormone therapies may discourage earnest renourishment efforts and weight restoration, as the induced menses will give the false impression of restored health despite ongoing low body weight and malnutrition.

Implications for Interprofessional Care

Early identification and treatment should include collaboration with physicians, school personnel, and other child-serving agencies. Because school personnel observe children throughout the school day, they represent an essential component of detecting the possibility of an ED and making referrals for further assessment (Cook-Cottone, Tribole, & Tylka, 2013; Early & Drew, 2013; Johnson et al., 2017). During the course of treatment, the patient's social and academic functioning should be assessed and monitored, and teachers' perspectives can uniquely highlight these areas (Rosen, 2010). School-based health and mental health clinics are extremely valuable in this process.

In light of the medical risks, psychological treatment for pediatric EDs cannot be conducted without medical clearance, monitoring, and intervention. Therefore, early establishment of an interdisciplinary treatment team is a clinical and even ethical mandate, not just within higher levels of care but perhaps even more importantly, with outpatient approaches such as FBT (Loeb & Sanders, 2016). A pediatrician, ideally one knowledgeable in the identification and management of EDs, will assess the patient's level of physical safety for initial and continued appropriateness of participation within this level of care (Katzman, Peebles, Sawyer, Lock, & Le Grange, 2013). As such, pediatric care in EDs is both proactive and reactive. In addition, the medical professional has the role of communicating important information to the family regarding the patient's diagnosis, relevant clinical data and observations, and treatment recommendations. While physicians are not involved in the direct implementation of psychological interventions, they can help the family to identify and understand the benefits of such treatment and make an informed decision about participation (Katzman et al., 2013).

Although the therapist and physician will carry different roles in the treatment process, outcomes are best achieved with a unified front and continuous communication on behalf of all professionals on the treatment team (Loeb & Sanders, 2016). It is imperative for all professionals involved to send the same message to the patient. For instance, AN is a disorder in which any target weight that is uttered is experienced by the patient as the permanent top end of an acceptable range. Rather, estimated expected weight ranges corresponding to premorbid, healthy individual growth curve trajectories are adjusted throughout treatment as the patient develops (Katzman et al., 2013; Loeb & Sanders, 2016). Therefore, a specific "goal weight" should not be articulated by any member of the collaborative team, at any time. An additional implication of this issue is that the weight-based diagnostic criterion for AN should be made by comparing a child's current weight status to their own personalized body mass index (BMI)-for-age percentile baseline; absolute BMI or percentile may be misleading and yield false negatives (Bravender et al., 2010; Cole, Flegal, Nicholls, & Jackson, 2007). Other medical indicators of a compromised weight, such as amenorrhea, should be considered as well in diagnosis even if weight is not dramatically low (Bravender et al., 2010; Loeb, Brown, & Goldstein, 2011).

Case Illustration

"Rachel" was an 18-year-old high school senior with a 5-year history of AN. She had previously been hospitalized twice on specialty ED units, each followed by step-down courses of partial hospitalization and intensive outpatient programs. The summer following her second course of treatment, Rachel's family moved to a different state, where they initiated care with a new general pediatrician. Rachel also saw a psychodynamic therapist and registered dietician weekly, who proceeded with outpatient care based on medical clearance from the new physician, who also cleared Rachel to resume her participation in competitive soccer. The doctor interpreted her low-normal heart rate as indicative of athletic fitness, and ordered routine labs, results of which were unremarkable as they often are in patients with restrictive EDs.

Two months into the school year, Rachel's parents received a call from the school nurse informing them that Rachel had become dizzy during gym class. The nurse reported that Rachel's friends and teacher mentioned that she had consumed no food, only diet soda, at lunch. The school nurse also observed Rachel's thin state, prompting her to obtain an updated weight and compare it to Rachel's health record. This review showed that Rachel had lost 9 lbs since her physical in August. While there was no mention of an ED in Rachel's record, the nurse expressed concern that such an issue was at play. Rachel's parents readily discussed her history and current treatment. The nurse referred the family to a local adolescent medicine specialist with experience in EDs. The parents made an appointment immediately.

The adolescent medicine specialist evaluated Rachel the following week, expressed concern about her low heart rate, low blood pressure, and light periods, revoked clearance for exercise, and ordered additional labs, which showed a low T3 level reflective of her inadequate intake compared to her energy expenditure, as well as low estradiol (Warren, 2011). The pediatrician noted that the estradiol was so low it was unlikely that Rachel was even having periods. Rachel then admitted she was not having her period but told her mother she was to avoid concern about her clinical status. This physician elicited a 24-h dietary recall, which revealed minimal intake. Based on her low heart rate, Rachel was admitted to a medical unit for monitoring as well as to begin the process of renourishment with adequate medical supervision. She referred the parents to a therapist certified in FBT in anticipation of a rapid discharge.

Rachel's family engaged well with FBT, but became frustrated with the absence of an exact target weight to which they could direct their efforts and measure their degree of progress. The therapist explained that expected weight is a moving target in adolescence, even at age 18 and especially during recovery from an ED, and that they would collaboratively use functional markers of improvement (medical, psychosocial, symptomatic) as their guide. When the patient reached the "goal weight" previously set by the prior therapist, they asked the adolescent medicine specialist to order new labs, even though those from 1 month earlier still showed abnormalities. When the new labs revealed a persistently low T3 level and an only-moderately-improved estrogen level, the parents inquired whether staying at this weight for longer would yield better results. The physician expressed doubt that this would occur and said she would consult with the FBT therapist and get back to the parents with recommendations.

The physician and FBT therapist collaboratively decided to continue to send a message that further weight gain was necessary and to help the family tolerate the uncertainty regarding when recovery would occur. The parents accepted this position, although the patient rejected it and temporarily exhibited a renewed resistance to her parents' renourishment strategies and expressed increased fear of fat. Eventually, as Rachel gained more weight, she began to express increased interest in socializing and in non-sports activities. Her scores on a depression measure decreased, and her labs normalized. She was able to increasingly eat independently and met criteria for remission 10 months after beginning FBT. When asked during the final phase of FBT how she experienced her body (which at that point was 20 lbs higher than baseline) Rachel stated that "being thin just isn't the most important thing in my life anymore."

Conclusions

In summary, EDs are among the most severe and life-threatening psychiatric disorders that develop in childhood and adolescence. EDs specifically necessitate the collaboration of a multidisciplinary team due to their complicated and multifaceted presentations that includes serious health complications, educational impacts, and emotional and family turmoil. Consistency of messages to families across team members is essential to mobilize parental efforts, reduce reduction of treatment task demands in the face of illness resistance, and prevent confusion. Currently, there are select evidence-based treatments targeting EDs in children and adolescents, but as these do not provide a cure for all, more intervention research, including further study of moderators, is key. More research is also needed within the new diagnosis of ARFID, in particular its longitudinal and etiological relationship to both AN and developmentally typical selective eating, as well as targeted treatments.

References

Academy for Eating Disorders' (AED) Medical Care Standards Committee. (2016). *Eating disorders: A guide to medical care*, 3rd ed. AED Report.

Agras, W. S., Lock, J., Brandt, H., Bryson, S. W., Dodge, E., Halmi, K. A., … Woodside, B. (2014). Comparison of 2 family therapies for adolescent anorexia nervosa: A randomized parallel trial. *JAMA Psychiatry, 71*, 1279–1286.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental Disorders (DSM-IV-TR)*. Arlington, VA: Author.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5)*. Arlington, VA: Author.

Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders. *Archives of General Psychiatry, 68*, 724–731.

Austin, S. B. (2012). A public health approach to eating disorders prevention: It's time for public health professionals to take a seat at the table. *BMC Public Health, 12*, 854.

Balestrieri, M., Oriani, M. G., Simoncini, A., & Bellantuono, C. (2013). Psychotropic drug treatment in anorexia nervosa. Search for differences in efficacy/tolerability between adolescent and mixed-age population. *European Eating Disorders Review, 21*, 361–373.

Barnes, R. D., Boeka, A. G., McKenzie, K. C., Genao, I., Garcia, R. L., Ellman, M. S., … Grilo, C. M. (2011). Metabolic syndrome in obese patients with binge-eating disorder in primary care clinics: A cross-sectional study. *The Primary Care Companion for CNS Disorders, 13*, 1–10.

Becker, A. E., Eddy, K. T., & Perloe, A. (2009). Clarifying criteria for cognitive signs and symptoms for eating disorders in DSM-V. *International Journal of Eating Disorders, 42*, 611–619.

Becker, C. B., Plasencia, M., Kilpela, L. S., Briggs, M., & Stewart, T. (2014). Changing the course of comorbid eating disorders and depression: What is the role of public health interventions in targeting shared risk factors? *Journal of Eating Disorders, 2*, 15.

Beintner, I., Jacobi, C., & Taylor, C. B. (2012). Effects of an internet-based prevention programme for eating disorders in the USA and Germany—A meta-analytic review. *European Eating Disorders Review, 20*, 1–8.

Bergström, I., Crisby, M., Engström, A. M., Hölcke, M., Fored, M., Jakobsson Kruse, P., & Sandberg, A. M. (2013). Women with anorexia nervosa should not be treated with estrogen or birth control pills in a bone-sparing effect. *Acta Obstetricia et Gynecologica Scandinavica, 92*, 877–880.

Bravender, T., Bryant-Waugh, R., Herzog, D., Katzman, D., Kriepe, R. D., Lask, B. E., … Zucker, N. (2010). Classification of eating disturbance in children and adolescents: Proposed changes for the DSM-V. *European Eating Disorders Review, 18*, 79–89.

Campbell, K., & Peebles, R. (2014). Eating disorders in children and adolescents: State of the art review. *Pediatrics, 134*, 582–592.

Ciao, A. C., Loth, K., & Neumark-Sztainer, D. (2015). Preventing eating disorder pathology: Common and unique features of successful eating disorders prevention programs. *Current Psychiatry Reports, 16*, 453.

Cole, T. J., Flegal, K. M., Nicholls, D., & Jackson, A. A. (2007). Body mass index cut offs to define thinness in children and adolescents: International survey. *BMJ, 335*, 194.

Cook-Cottone, C. P., Tribole, E., & Tylka, T. L. (2013). Screening, assessing, and supporting students with eating and body image problems. In *Healthy eating in schools: Evidence-based interventions to help kids thrive* (pp. 185–199). Washington, DC: American Psychological Association.

Cotton, M., Ball, C., & Robinson, P. (2003). Four simple questions can help screen for eating disorders. *Journal of General Internal Medicine, 18*, 53–56.

Couturier, J., & Lock, J. (2007). A review of medication use for children and adolescents with eating disorders. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 16*, 173–176.

Couturier, J., Kimber, M., & Szatmari, P. (2013). Efficacy of family-based treatment for adolescents with eating disorders: A systematic review and meta-analysis. *International Journal of Eating Disorders, 46*, 3–11.

Crow, S. J., Peterson, C. B., Swanson, S. A., Raymond, N. C., Specker, S., Eckert, E. D., & Mitchell, J. E. (2009). Increased mortality in bulimia nervosa and other eating disorders. *American Journal of Psychiatry, 166*, 1342–1346.

Dalle Grave, R., Calugi, S., Doll, H. A., & Fairburn, C. G. (2013). Enhanced cognitive behaviour therapy for adolescents with anorexia nervosa: An alternative to family therapy? *Behaviour Research and Therapy, 51*, R9–R12.

Dalle Grave, R., Calugi, S., El Ghoch, M., Conti, M., & Fairburn, C. G. (2014). Inpatient cognitive behavior therapy for adolescents with anorexia nervosa: Immediate and longer-term effects. *Frontiers in Psychiatry, 5*, 14.

Dalle Grave, R., Calugi, S., Sartirana, M., & Fairburn, C. G. (2015). Transdiagnostic cognitive behaviour therapy for adolescents with an eating disorder who are not underweight. *Behaviour Research and Therapy, 73*, 79–82.

Dirks, M. A., Reyes, A. D. L., Briggs-Gowan, M., Cella, D., & Wakschlag, L. S. (2012). Embracing not erasing contextual variability in children's behavior: Theory and utility in the selection and use of methods and informants in developmental psychopathology. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 53*, 558–574.

Dooley-Hash, S., Lipson, S. K., Walton, M. A., & Cunningham, R. M. (2013). Increased emergency department use by adolescents and young adults with eating disorders. *International Journal of Eating Disorders, 46*, 308–315.

Early, T. J., & Drew, H. (2013). Effective interventions for students with eating disorders. In C. Franklin, M. B. Harris, P. Allen-Meares, C. Franklin, M. B. Harris, & P. Allen-Meares (Eds.), *The school services sourcebook: A guide for school-based professionals* (pp. 179–189). New York, NY: Oxford University Press.

Fairburn, C. G. (2008). *Cognitive behavior therapy and eating disorders*. New York, NY: Guilford Press.

Favaro, A., Caregaro, L., Tenconi, E., Bosello, R., & Santonastaso, P. (2009). Time trends in age at onset of anorexia nervosa and bulimia nervosa. *The Journal of Clinical Psychiatry, 70*, 1–478.

Fitzpatrick, K. K., Moye, A., Hoste, R., Lock, J., & Le Grange, D. (2010). Adolescent focused psychotherapy for adolescents with anorexia nervosa. *Journal of Contemporary Psychotherapy, 40*(1), 31–39.

Fitzpatrick, K. K., Forsberg, S. E., & Colborn, D. (2015). Family-based therapy for avoidant restrictive food intake disorder: Families facing food neophobias. In K. L. Loeb, D. le Grange, & J. Lock (Eds.), *Family therapy for adolescent eating and weight disorders: New applications* (pp. 256–276). New York: Routledge.

Golden, N. H. (2007). Eating disorders in adolescence: What is the role of hormone replacement therapy? *Current Opinion in Obstetrics & Gynecology, 5*, 434–439.

Golden, N. H., & Attia, E. (2011). Psychopharmacology of eating disorders in children and adolescents. *Pediatric Clinics of North America, 58*, 121–138.

Golden, N. H., Schneider, M., & Wood, C. (2016). Preventing obesity and eating disorders in adolescents. *Pediatrics, 138*, e20161649.

Gordon, R. (1987). An operational classification of disease prevention. In J. A. Steinberg & M. M. Silverman (Eds.), *Preventing mental disorders: A research perspective*. Rockville, MD: US Department of Health and Human Services, National Institute of Mental Health.

Halfon, N., Stevens, G. D., Larson, K., & Olson, L. M. (2011). Duration of a well-child visit: Association with content, family-centeredness, and satisfaction. *Pediatrics, 128*, 657–664.

Hautala, L., Junnila, J., Alin, J., Grönroos, M., Maunula, A., Karukivi, M., … Saarijärvi, S. (2009). Uncovering hidden eating disorders using the SCOFF questionnaire: Cross-sectional survey of adolescents and comparison with nurse assessments. *International Journal of Nursing Studies, 46*, 1439–1447.

Hoek, H. W. (2006). Incidence, prevalence and mortality of anorexia nervosa and other eating disorders. *Current Opinion in Psychiatry, 19*, 389–394.

Hudson, J. I., Lalonde, J. K., Coit, C. E., Tsuang, M. T., McElroy, S. L., Crow, S. J., … Pope, H. G. (2010). Longitudinal study of the diagnosis of components of the metabolic syndrome in individuals with binge-eating disorder. *The American Journal of Clinical Nutrition, 91*, 1568–1573.

Hudson, L. D., Nicholls, D. E., Lynn, R. M., & Viner, R. M. (2012). Medical instability and growth of children and adolescents with early onset eating disorders. *Archives of Disease in Childhood, 97*, 779–784.

Johnson, C., Weiner, K., Marx, R., O'Melia, A. M., Mehler, P. S., & Pikus, C. (2017). The role of the multidisciplinary team and levels of care in the treatment of eating disorders. In P. S. Mehler & A. E. Andersen (Eds.), *Eating disorders: A guide to medical care and complications* (3rd ed.). Baltimore, MD: Johns Hopkins University Press.

Katzman, D. K., Peebles, R., Sawyer, S. M., Lock, J., & Le Grange, D. (2013). The role of the pediatrician in family-based treatment for adolescent eating disorders: Opportunities and challenges. *Journal of Adolescent Health, 53*, 433–440.

Keel, P. K., & Brown, T. A. (2010). Update on course and outcome in eating disorders. *International Journal of Eating Disorders, 43*, 194–204.

Keel, P. K., Brown, T. A., Holm-Denoma, J., & Bodell, L. P. (2011). Comparison of DSM-IV versus proposed DSM-5 diagnostic criteria for eating disorders: Reduction of eating disorder not otherwise specified and validity. *International Journal of Eating Disorders, 44*, 553–560.

Kotler, L. A., Devlin, M. J., Davies, M., & Walsh, B. T. (2003). An open trial of fluoxetine for adolescents with bulimia nervosa. *Journal of Child and Adolescent Psychopharmacology, 13*, 329–335.

Lantzouni, E., Frank, G. R., Golden, N. H., & Shenker, R. I. (2002). Reversibility of growth stunting in early onset anorexia nervosa: A prospective study. *Journal of Adolescent Health, 31*, 162–165.

Le, L. K., Barendregt, J. J., Hay, P., & Mihalopoulos, C. (2017). Prevention of eating disorders: A systematic review and meta-analysis. *Clinical Psychology Review, 53*, 46–58.

Lebow, J., Sim, L. A., Erwin, P. J., & Murad, M. H. (2013). The effect of atypical antipsychotic medications in individuals with anorexia nervosa: A systematic review and meta-analysis. *International Journal of Eating Disorders, 46*, 332–339.

Lock, J., Agras, W. S., Bryson, S. W., Brandt, H., Halmi, K. A., Kaye, W., … Jo, B. (2016). Does family-based treatment reduce the need for hospitalization in adolescent anorexia nervosa? *International Journal of Eating Disorders, 49*, 891–894.

Lock, J. (2015). An update on evidence-based psychosocial treatments for eating disorders in children and adolescents. *Journal of Clinical Child & Adolescent Psychology, 44*, 707–721.

Lock, J., & Le Grange, D. (2013). *Treatment manual for anorexia nervosa: A family-based approach* (2nd ed.). New York, NY: Guilford Press.

Lock, J., Le Grange, D., Agras, W. S., Moye, A., Bryson, S. W., & Jo, B. (2010). Randomized clinical trial comparing family-based treatment with adolescent-focused individual therapy for adolescents with anorexia nervosa. *Archives of General Psychiatry, 67*, 1025–1032.

Loeb, K. L., Brown, M., & Goldstein, M. M. (2011). Assessment of eating disorders in children and adolescents. In D. Le Grange & J. Lock (Eds.), *Eating disorders in children and adolescents: A clinical handbook* (pp. 156–198). New York, NY: Guilford Press.

Loeb, K. L., Le Grange, D., Hildebrandt, T., Greif, R., Lock, J., & Alfano, L. (2011). Eating disorders in youth: Diagnostic variability and predictive validity. *International Journal of Eating Disorders, 44*, 692–702.

Loeb, K. L., & Sanders, L. (2016). Physician-therapist collaboration in family-based treatment for anorexia nervosa: What each provider wants the other to know. In S. Murray, L. Anderson, & L. Cohn (Eds.), *Innovations in family therapy for eating disorders: Novel treatment developments, patient insights, and the role of carers* (pp. 81–96). New York, NY: Routledge.

Loucas, C. E., Fairburn, C. G., Whittington, C., Pennant, M. E., Stockton, S., & Kendall, T. (2014). E-therapy in the treatment and prevention of eating disorders: A systematic review and meta-analysis. *Behaviour Research and Therapy, 63*, 122–131.

Makino, M., Tsuboi, K., & Dennerstein, L. (2004). Prevalence of eating disorders: A comparison of Western and non-Western countries. *Medscape General Medicine, 6*, 49.

Mariano, P., Watson, H. J., Leach, D. J., McCormack, J., & Forbes, D. A. (2013). Parent–child concordance in reporting of child eating disorder pathology as assessed by the eating disorder examination. *International Journal of Eating Disorders, 46*, 617–625.

McKnight, R., & Park, R. (2010). Atypical antipsychotics and anorexia nervosa: A review. *European Eating Disorders Review, 18*, 10–21.

Meczekalski, B., Podfigurna-Stopa, A., & Katulski, K. (2013). Long-term consequences of anorexia nervosa. *Maturitas, 75*, 215–220.

Mehanna, H. M., Moledina, J., & Travis, J. (2008). Refeeding syndrome: what it is, and how to prevent and treat it. *BMJ, 336*, 1495–1498.

Mehler, P. S. (2011). Medical complications of bulimia nervosa and their treatments. *International Journal of Eating Disorders, 44*, 95–104.

Merikangas, K. R., He, J. P., Brody, D., Fisher, P. W., Bourdon, K., & Koretz, D. S. (2010). Prevalence and treatment of mental disorders among US children in the 2001–2004 NHANES. *Pediatrics, 125*, 75–81.

Micali, N., & House, J. (2011). Assessment measures for child and adolescent eating disorders: A review. *Child and Adolescent Mental Health, 16*, 122–127.

Mitchell, J. E., Roerig, J., & Steffen, K. (2013). Biological therapies for eating disorders. *International Journal of Eating Disorders, 46*, 470–477.

Mitchell, J. E. (2016). Medical comorbidity and medical complications associated with binge-eating disorder. *International Journal of Eating Disorders, 49*, 319–323.

Mond, J. M., Myers, T. C., Crosby, R. D., Hay, P. J., Rodgers, B., Morgan, J. F., … Mitchell, J. E. (2008). Screening for eating disorders in primary care: EDE-Q versus SCOFF. *Behaviour Research and Therapy, 46*, 612–622.

Morgan, J. F., Reid, F., & Lacey, J. H. (1999). The SCOFF questionnaire: Assessment of a new screening tool for eating disorders. *BMJ, 319*, 1467–1468.

Nagl, M., Jacobi, C., Paul, M., Beesdo-Baum, K., Hofler, M., Lieb, R., & Wittchen, H.-U. (2016). Prevalence, incidence, and natural course of anorexia and bulimia nervosa among adolescents and young adults. *European Child & Adolescent Psychiatry, 25*, 903–918.

National Institute for Health and Care Excellence (NICE). (2017). *Eating disorders: Recognition and Treatment* (NICE guideline NH69).

Nicholls, D., & Bryant-Waugh, R. (2009). Eating disorders of infancy and childhood: Definition, symptomatology, epidemiology, and comorbidity. *Child and Adolescent Psychiatric Clinics of North America, 18*, 17–30.

Norris, M. L., Robinson, A., Obeid, N., Harrison, M., Spettigue, W., & Henderson, K. (2014). Exploring avoidant/restrictive food intake disorder in eating disordered patients: A descriptive study. *International Journal of Eating Disorders, 47*, 495–499.

Ogden, C. L., Carroll, M. D., Kit, B. K., & Flegal, K. M. (2012). Prevalence of obesity and trends in body mass index among US children and adolescents, 1999-2010. *JAMA, 307*, 483–490.

Ornstein, R. M., Rosen, D. S., Mammel, K. A., Callahan, S. T., Forman, S., Jay, M. S., … Walsh, B. T. (2013). Distribution of eating disorders in children and adolescents using the proposed DSM-5 criteria for feeding and eating disorders. *Journal of Adolescent Health, 53*, 303–305.

Pinhas, L., Morris, A., Crosby, R. D., & Katzman, D. K. (2011). Incidence and age-specific presentation of restrictive eating disorders in children. *Archives of Pediatrics and Adolescent Medicine, 165*, 1–5.

Robinson, A. L., Boachie, A., & Lafrance, G. A. (2012). Assessment and treatment of pediatric eating disorders: A survey of physicians and psychologists. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 21*, 45.

Roehrig, M., Masheb, R. M., White, M. A., & Grilo, C. M. (2009). The metabolic syndrome and behavioral correlates in obese patients with binge eating disorder. *Obesity, 17*(3), 481–486.

Rome, E. S., & Ammerman, S. (2003). Medical complications of eating disorders: An update. *Journal of Adolescent Health, 33*, 418–426.

Rosen, D. S. (2010). Identification and management of eating disorders in children and adolescents. *Pediatrics, 126*, 1240–1253.

Smink, F. R. E., van Hoeken, D., & Hoek, H. W. (2013). Epidemiology, course, and outcome of eating disorders. *Current Opinion in Psychiatry, 26*, 543–548.

Smink, F. R. E., van Hoeken, D., Oldehinkel, A. J., & Hoek, H. W. (2014). Prevalence and severity of DSM-5 eating disorders in a community cohort of adolescents. *International Journal of Eating Disorders, 47*, 610–619.

Society for Adolescent Health and Medicine (SAHM). (2014). Refeeding hypophosphatemia in hospitalized adolescents with anorexia nervosa: A position statement of the Society for Adolescent Health and Medicine. *Journal of Adolescent Health, 55*, 455–457.

Society for Adolescent Health and Medicine (SAHM). (2015). Position paper of the Society for Adolescent Health and Medicine: Medical management of restrictive eating disorders in adolescents and young adults. *Journal of Adolescent Health, 56*, 121–125.

Steinglass, J. E., Sysko, R., Mayer, L., Berner, L. A., Schebendach, J., Wang, Y., … Walsh, B. T. (2010). Pre-meal anxiety and food intake in anorexia nervosa. *Appetite, 55*, 214–218.

Steinglass, J., & Walsh, B. T. (2006). Habit learning and anorexia nervosa: A cognitive neuroscience hypothesis. *International Journal of Eating Disorders, 39*, 267–275.

Stice, E., Becker, C. B., & Yokum, S. (2013). Eating disorder prevention: Current evidence-base and future directions. *International Journal of Eating Disorders, 46*, 478–485.

Stice, E., Marti, C. N., Shaw, H., & Jaconis, M. (2009). An 8-year longitudinal study of the natural history of threshold, subthreshold, and partial eating disorders from a community sample of adolescents. *Journal of Abnormal Psychology, 118*, 587.

Stice, E., Marti, C. N., & Rohde, P. (2013). Prevalence, incidence, impairment, and course of the proposed DSM-5 eating disorder diagnoses in an 8-year prospective community study of young women. *Journal of Abnormal Psychology, 122*, 445–457.

Stice, E., Rohde, P., & Shaw, H. (2013). *The body project: A dissonance-based eating disorder prevention intervention. Facilitator guide* (Updated ed.). New York: Oxford University Press.

Stice, E., Rohde, P., Shaw, H., & Marti, C. N. (2013). Efficacy trial of a selective prevention program targeting both eating disorders and obesity among female college students: 1- and 2-year follow-up effects.

Journal of Consulting and Clinical Psychology, 81(1), 183–189.

Striegel-Moore, R. H., & Bulik, C. M. (2007). Risk factors for eating disorders. *American Psychologist, 62*, 181–198.

Striegel-Moore, R. H., Rosselli, F., Perrin, N., DeBar, L., Wilson, G. T., May, A., & Kraemer, H. C. (2009). Gender difference in the prevalence of eating disorder symptoms. *International Journal of Eating Disorders, 42*, 471–474.

Swanson, S. A., Aloisio, K. M., Horton, N. J., Sonneville, K. R., Crosby, R. D., Eddy, K. T., … Micali, N. (2014). Assessing eating disorder symptoms in adolescence: Is there a role for multiple informants? *International Journal of Eating Disorders, 47*, 475–482.

Swanson, S. A., Crow, S. J., Le Grange, D., Swendsen, J., & Merikangas, K. R. (2011). Prevalence and correlates of eating disorders in adolescents: Results from the national comorbidity survey replication adolescent supplement. *Archives of General Psychiatry, 68*, 714–723.

Tanofsky-Kraff, M., Bulik, C. M., Marcus, M. D., Striegel, R. H., Wilfley, D. E., Wonderlich, S. A., & Hudson, J. I. (2013). Binge eating disorder: The next generation of research. *International Journal of Eating Disorders, 46*, 193–207.

Trace, S. E., Baker, J. H., Penas-Llecio, E., & Bulik, C. M. (2013). The genetics of eating disorders. *Annual Review of Clinical Psychology, 9*, 589–620.

Trent, S. A., Moreira, M. E., Colwell, C. B., & Mehler, P. S. (2013). ED management of patients with eating disorders. *The American Journal of Emergency Medicine, 31*, 859–865.

Wade, T. D., Wilksch, S. M., Paxton, S. J., Byrne, S. M., & Austin, S. B. (2017). Do universal media literacy programs have an effect on weight and shape concern by influencing mediation internalization? *International Journal of Eating Disorders, 50*, 731–738.

Waller, G., Micali, N., & James, A. (2014). Debate: General practitioners are poor at identifying the eating disorders. *Advances in Eating Disorders: Theory, Research, and Practice, 2*, 1–12.

Wallin, U., & Råstam, M. (2016). Childhood anorexia nervosa compared with low weight food intake disorder without weight and shape-related psychopathology: A retrospective study of 102 patients. *European Eating Disorders Review, 24*, 329–333.

Warren, M. P. (2011). Endocrine manifestations of eating disorders. *Journal of Clinical Endocrinology & Metabolism, 96*, 333–343.

Watson, H. J., & Bulik, C. M. (2013). Update on the treatment of anorexia nervosa: Review of clinical trials, practice guidelines and emerging interventions. *Psychological Medicine, 43*, 2477–2500.

Watson, H. J., Joyce, T., French, E., Willan, V., Kane, R. T., Tanner-Smith, E. E., … Egan, S. J. (2016). Prevention of eating disorders: A systematic review of randomized, controlled trials. *International Journal of Eating Disorders, 49*, 833–862.

Wentz, E., Gillberg, I. C., Anckarsäter, H., Gillberg, C., & Råstam, M. (2009). Adolescent-onset anorexia nervosa: 18-year outcome. *The British Journal of Psychiatry, 194*, 168–174.

Wildes, J. E., Zucker, N. L., & Marcus, M. D. (2012). Picky eating in adults: Results of a web-based survey. *International Journal of Eating Disorders, 45*, 575–582.

Wilksch, S. M., Paxton, S. J., Byrne, S. M., Austin, S. B., McLean, S. A., Thompson, K. M., … Wade, T. D. (2015). Prevention across the spectrum: A randomized-controlled trial of three programs to reduce risk factors for both eating disorders and obesity. *Psychological Medicine, 45*, 1811–1823.

Sleep Disorders

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Abstract

Sleep is an essential task of human development with meaningful implications for children and adolescents. Adequate sleep duration varies by age and is connected to enhanced cognitive development, emotional control, attention, behavioral regulation, learning, memory, diet, and quality of life. Poor sleep in children and adolescents may result from several factors: obstructive sleep apnea, restless legs syndrome, periodic limb movement disorder, frequent night wakings, bedtime problems, deficient sleep, delayed sleep phase disorder, parasomnias, and poor sleep hygiene. Adequate sleep duration has been associated with a number of positive health outcomes while inadequate total sleep has been correlated with several health risks. Conditions that have a bidirectional relationship with poor sleep include obesity, concussions, asthma, pain, unintentional injuries, and attention-deficit/hyperactivity disorder. Sleep assessment provides meaningful information to inform intervention and service delivery for medical and behavioral health providers. To assess sleep difficulties among youth, a multidimensional approach is commonly used. Further, due to the multifaceted aspect of sleep, simultaneously assessing multiple domains can be time-saving and reduce the likelihood of misdiagnosis. A brief review of multi-dimensional questionnaires and sleep diaries is provided in the chapter. This chapter also provides an overview of common behavioral sleep interventions to improve sleep practices of children and adolescents.

Background

Sleep is an essential task of human development with meaningful implications for children and adolescents. Adequate sleep duration varies by age (see Table 18.1 for sleep guidelines) and is connected to enhanced cognitive development, emotional control, attention, behavioral regulation, learning, memory, diet, and quality of life for children and adolescents (Baum et al., 2014; Beebe, 2011; Beebe et al., 2013; Garetz et al., 2015). Negative secondary effects have also been noted for maternal and family well-being when children do not obtain adequate sleep (McDowall, Galland, Campbell, & Elder, 2017). Sleep duration and quality has been shown to vary significantly among

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Table 18.1 Childhood sleep guidelines (Paruthi et al., 2016)

Age	Sleep recommendations per 24 h period
0–3 months	14–17 h (including naps)
4–12 months	12–16 h (including naps)
1–2 years	11–14 h (including naps)
3–5 years	10–13 h (including naps)
6–12 years	9–12 h
13–18 years	8–10 h
18–25 years	7–9 h

healthy children and those with medical or developmental conditions (Crabtree et al., 2016; Quach, Mensah, & Hiscock, 2016).

Poor sleep in children and adolescents may result from several factors. Sleep disorders include medically based conditions such as obstructive sleep apnea (OSA), restless legs syndrome (RLS), and periodic limb movement disorder (PLMD). Sleep problems include sleep difficulties with psychological and behavioral contributors such as frequent night wakings, bedtime problems, deficient sleep, and poor sleep hygiene. It is estimated that up to 40% of children experience a sleep problem between infancy and adolescence, whereas sleep disorder diagnoses are less common and thought to occur in close to 5% of children and adolescents (Meltzer, Johnson, Crosette, Ramos, & Mindell, 2010). Common sleep disorders and problems experienced by children and adolescents are briefly described below.

Childhood Sleep Disorders

Obstructive Sleep Apnea (OSA) OSA is characterized by upper airway obstruction, despite respiratory effort, that disrupts normal sleep patterns and ventilation (American Academy of Sleep Medicine, 2005). Pediatric OSA is often associated with enlarged tonsils and adenoids, unusual sleep positions, and nighttime enuresis (American Academy of Sleep Medicine, 2005; Marcus et al., 2012). Onset is typically between 2 and 8 years of age with prevalence estimated to be between 1 and 5% (Marcus et al., 2012). Snoring and apneas that can be associated with OSA are thought to affect males and females equally. Adenotonsillectomy is the first-line treatment for OSA in children.

Sleep-Related Movement Disorders Sleep movement disorders include RLS and PLMD. RLS is defined by an urge to move the legs with associated discomfort often beginning in the evening. Additional symptoms include difficulty falling asleep, bedtime resistance, and increased motor movement (Carter, Hathaway, & Lettieri, 2014). Symptoms can be exacerbated by rest or inadequate physical activity, caffeine or nicotine use, and use of antihistamines or tricyclic antidepressants (Gamaldo & Earley, 2006). PLMD includes brief movements or "jerks" during sleep that can last up to 5 s, occur in 20–40 s intervals, and are more common in lower extremities. Children are usually unaware of these movements. Information surrounding the prevalence of sleep movement disorders is limited but available studies suggest a prevalence of around 2% (Picchietti et al., 2007). Higher incidence has been shown among those with attention-deficit/hyperactivity disorder (ADHD) and a family history of RLS. Treatment includes implementing strict routines for bedtime and wake up time, reducing environmental stimulation prior to bedtime (e.g., limiting television or video games), iron supplementation due to low ferritin levels, and encouraging daily exercise.

Childhood Sleep Problems

Behavioral Insomnia Behavioral insomnia of childhood is characterized by a learned difficulty with sleep initiation, duration, consolidation, or quality that occur despite age-appropriate bedtime and opportunity for sleep (Carter et al., 2014). Behavioral insomnia often presents as bedtime refusal or resistance, delayed sleep onset, or prolonged nighttime waking that requires parental intervention. The condition is divided into sleep-onset association type, limit-setting type, and combined type. Sleep-onset association type is characterized by a child's inability or unwillingness to fall asleep or return to sleep in the absence of sleep-specific conditions (e.g., parent's presence, bottle feeding, watching television; Moturi & Avis, 2010). Limit-setting type occurs when parents do not set appropriate boundaries for sleep, such as allowing a child to sleep in their bed, which result in bedtime delay. Prevalence is estimated to be between 10 and 30% with males and females equally affected. Prevention is the best treatment including education on typical sleep patterns, sleep hygiene, setting boundaries, implementing regular and consistent feedings, nap times, bedtime routines, and consistent sleep-wake times.

Delayed Sleep Phase Disorder In children with delayed sleep phase disorder, habitual sleep-wake times are delayed by at least 2 h compared to socially acceptable times. This disorder is most common during adolescence when the circadian rhythm is thought to lengthen and the child becomes more social. Up to 16% of adolescents have been diagnosed with delayed sleep phase disorder with 40% having a family history of the condition (Carter et al., 2014). Concerns usually focus on late bedtimes (i.e., 2:00 am or later), sleeping in, difficulty awakening, daytime sleepiness, and school tardiness. Treatment aligns the circadian rhythm with desired sleep-wake times, maintaining a regular sleep-wake cycle, and practicing good sleep hygiene.

Parasomnias Sleepwalking, sleep talking, sleep terrors, and nightmares affect up to 50% of children and most often occur between 8 and 12 years (Carter et al., 2014). Parasomnias are defined as undesirable events that accompany sleep and typically occur during sleep-wake transitions. During these events, children appear to exhibit purposeful movements although interactions within their environment is not purposeful. Additional symptoms include confusion, difficulty awakening, amnesia, and rapid return to sleep after the event. Factors that can influence the presence of parasomnias include insufficient sleep, disorders causing partial awakenings from sleep, OSA, PLMD, forced awakenings, gastroesophageal reflux disease, and specific medications (Guilleminault, Palombini, Pelayo, & Chervin, 2003). Parasomnias often resolve spontaneously by adolescence; however, 4% will have recurring events (Carter et al., 2014). Treatment focuses on providing reassurance, reducing triggers, and increasing sleep duration (Carter et al., 2014).

Poor Sleep Hygiene Sleep hygiene are behaviors that facilitate good sleep quality and duration while limiting or avoiding behaviors that interfere with sleep (Riedel, 2000). Good sleep hygiene includes having a consistent bedtime routine, falling asleep and waking near the same time daily, limiting use of electronics or caffeine prior to bedtime, getting regular exercise, eliminating bedroom activities not associated with sleep, keeping the bedroom quiet and dark, and engaging in relaxing activities prior to bedtime. Signs of poor sleep hygiene include frequent sleep disturbances, daytime sleepiness, and difficulty falling asleep (National Sleep Foundation, 2018). Behavioral strategies that modify sleep routines and habits have been shown to be effective in promoting sleep onset and duration.

Physical Health Implications

Adequate sleep duration has been associated with several positive health outcomes while inadequate total sleep has been shown to lead to several health risks.

Obesity The relationship between sleep and obesity has been well studied in pediatric populations. Children with short sleep duration tend to have more adiposity and larger waist circumference (Wang et al., 2016). Furthermore, obese children with short sleep duration have a greater number of metabolic risk factors and poorer physical activity index (Navarro-Solera et al., 2015). Short sleep duration has also been linked to insulin sensitivity in obese individuals (Kong et al., 2011; Koren et al., 2011). In a study of 3–12-year-olds, more hours asleep, earlier bedtimes, and later wake times were associated with lower BMI and lower likelihood of being overweight 5 years later (Snell, Adam, & Duncan, 2007). Preschoolers with bedtimes before 8 pm were half as likely as children with bedtimes after 9 pm to be obese as adolescents (Anderson, Andridge, & Whitaker, 2016). For school-aged children, each additional hour of sleep predicted a 1-unit lower BMI at age 32 and a 30% reduction in obesity risk (Landhuis, Poulton, Welch, & Hancox, 2008). A meta-analysis demonstrated a consistent increased risk of obesity in children who do not receive the recommended amount of sleep (Cappuccio et al., 2008). For males ages 12–18, shorter sleep duration is related to higher BMI (Ames, Holfeld, & Leadbeater, 2016). Similarly, shorter sleep duration is associated with longitudinal increases in BMI for females 16–18 years (Ames et al., 2016).

Concussion Approximately 10–38% of teens experience sleep disturbance following a concussion (Beebe et al., 2007; Bramley et al., 2017). Furthermore, concussion symptoms such as headache, fatigue, anxiety, and depression exacerbate sleep disturbances (Castriotta et al., 2007). Unfortunately, sleep disturbance following concussion is associated with a three- to fourfold increase in recovery time (Bramley et al., 2017) and is a predictor of poorer functional outcomes (Tham et al., 2012). Interestingly, non-sport-related concussions are more likely to result in sleep disturbance than sport-related concussions (Bramley et al., 2017).

Asthma Asthma is the most common chronic illness of childhood, and these children experience a significantly higher risk for developing sleep disordered breathing and disturbed sleep than healthy peers (Brockmann, Betrand, & Castro-Rodriguez, 2014; Stores, Ellis, Wiggs, Crawford, & Thomson, 1998; Strachan, Anderzon, Limb, O'Neill, & Wells, 1994). One study found that 34% of children with asthma wake at least once a week due to breathing difficulties (Action Asthma, 1993). Youth with asthma and obesity exhibit greater week to weekend variability in sleep and get less sleep during the week than youth with obesity who do not have asthma (Krietsch, Lawless, Fedele, McCrae, & Janicke, 2017).

Pain Pain can interfere with quality and quantity of sleep due to frequent night awakenings and prolonged sleep-onset duration (Logan et al., 2015; Valrie, Bromberg, Palermo, & Schanberg, 2013). Conversely, sleep disturbances impact pain by interfering with the ability to implement coping skills for pain management and compromised emotional, cognitive, and behavioral functioning (Lewin & Dahl, 1999; Valrie et al., 2013). Improvements in sleep habits are related to improvements in functional disability, mood, greater sleep duration, less sleep-onset delay, and fewer night wakings (Logan et al., 2015).

Unintentional Injuries Children with frequent injuries or parent-reported injury prone behaviors tend to have significantly more sleep problems overall than children with low injury rates (Owens & Dalzell, 2005). Conversely, preschool boys with less than 10 h of sleep the night before were found to have an increased risk of injury (Valent, Brusaferro, & Barbone, 2001). In addition, temperament-related "irregular sleep patterns" in young children may play a role in increasing injury risk (Irwin, Cataldo, Matheny, & Peterson, 1992). The relationship between sleep and unintentional injuries has also been demonstrated in teens. Severity of teen-reported sleep problems and daytime sleepiness is positively correlated with accidental injuries (Giannotti & Cortesi, 2003). Poor sleep quality is also associated with crash risk in teen drivers (Pizza et al., 2010) and risk-taking behaviors in adolescents (O'Brien & Mindell, 2005).

ADHD Inadequate sleep has been linked to difficulties with attention, impulse control, and behavior regulation (Paavonen, Porka-Heiskanen, & Lahikainen, 2009; Sadeh, Gruber, & Raviv, 2002). Behavioral sleep difficulties affect up to 70% of children with ADHD (Owens, Spirito, McGuinn, & Nobile, 2000). Children with ADHD present with elevated levels of sleep problems, significantly longer duration awakenings, poorer sleep efficiency, and changes in sleep architecture (Vigliano et al., 2016; Williams & Sciberras, 2016). Furthermore, sleep problems in children with ADHD tend to be more persistent than children not diagnosed with ADHD (Lycett, Sciberras, Hiscock, & Mensah, 2016). To complicate the relationship between ADHD and sleep, as high as 30% of OSA-hypopnea syndrome (repetitive episodes of airflow reduction or cessation due to upper airway collapse during sleep) have ADHD (Wu et al., 2017). Treatment with stimulant medications for 6 months did not significantly change sleep parameters (Lycett et al., 2016). One study found a general association between increased methylphenidate dose and increased sleep problems in children with ADHD particularly for children of lower weight and BMI (Becker, Froehlich, & Epstein, 2016). However, children with preexisting sleep problems no longer had sleep difficulties once on the highest methylphenidate dose (Becker et al., 2016).

Screening and Assessment

Clinical assessments of sleep need to accurately describe various dimensions of sleep and identify appropriate intervention strategies (Lewandowski, Toliver-Sokol, & Palermo, 2011). Without accurate assessment, clinicians may reach misleading conclusions about the causal factors of a child's presentation. Fortunately, there is great variety in available methods to assess sleep. For instance, biophysiological assessment of sleep includes polysomnography and actigraphy. Polysomnography records changes in brain function, heart rate, eye movement, and muscle activation and is used primarily to diagnose OSA (Mindell & Owens, 2015). Actigraphy uses sensors to record motor movement and provide an objective estimate of sleep patterns. While biophysiological measures are useful, they do not account for environmental, psychological, or behavioral factors that contribute to sleep difficulties or the dimensions of sleep that are amenable to intervention. These factors are best captured using questionnaires.

Questionnaires can be used alone or in combination with biophysiological measures to provide a comprehensive assessment of sleep. Questionnaires are typically retrospective and measure typical sleep patterns, disturbances, or behaviors (Lewandowski et al., 2011). To be considered useful to clinicians, questionnaires must be valid, brief, easy to administer and score, cost-efficient, and easy to read (Sheldrick & Perrin, 2009).

Most pediatric sleep measures assess multiple dimensions of sleep. Due to the multifaceted aspect of sleep, simultaneously assessing multiple domains can be time-saving and reduce the likelihood of misdiagnosis. For example, a child may have prolonged sleep-onset latency, which could support a diagnosis of insomnia. However, if sleep-onset difficulties are caused by leg discomfort, RLS may be a more accurate diagnosis and target for treatment. A brief review of multidimensional questionnaires is provided below.

The *Children's Sleep Habits Questionnaire (CSHQ)* is a 45-item parent-completed questionnaire designed to assess symptoms of common pediatric sleep disorders. (Seifer, Sameroff, Dickstein, & Hayden, 1996). Initially designed for ages 4–12, a revised version of the CSHQ has been adapted for use with preschoolers (Sneddon, Peacock, & Crowley, 2013). Each version takes approximately 10–15 min to complete. Parents rate statements about their child's sleep using a 3-point scale (*Usually, Sometimes, Rarely*) and indicate if each statement constitutes a problem. The Overall Total Sleep Disturbances score ranges from 33 to 99, with higher scores indicating greater disturbances. There are eight subscales: Bedtime Resistance, Sleep-Onset Delay, Sleep Duration, Sleep Anxiety, Night Wakings, Parasomnias, Sleep Disordered Breathing, and Daytime Sleepiness. Psychometrics are acceptable for use in community settings (Owens et al., 2000).

The *Sleep Disturbances Scale for Children (SDSC)* is a 27-item standardized parent-completed measure of sleep disturbance (Bruni et al., 1996). Initially developed for use with children ages 6–15, the SDSC has been adopted for use with preschoolers (Romeo et al., 2013). The SDSC generates a total *T* score and six subscale scores: Disorders of initiating and maintaining sleep, sleep breathing, disorders of arousal, sleep-wake transition disorders, disorders of excessive somnolence, and sleep hyperhidrosis. The SDSC has strong internal consistency and test-retest reliability (Bruni et al., 1996). The SDSC is considered "well-established" due to acceptable psychometrics and use by multiple researchers (Lewandowski et al., 2011).

The *Children's Report of Sleep Patterns (CRSP)* is a 60-item self-report measure for children ages 8–12 (Meltzer et al., 2013). Three modules assess sleep patterns, sleep hygiene, and sleep disturbance, as well as a brief sleepiness scale. Validation for children ages 13–18 has occurred on the sleep hygiene and sleep disturbance modules (Meltzer et al., 2014). The Sleep Disturbance Indices had acceptable internal consistency except for the Parasomnia Scale. Test-retest reliability was good for all scales except for the Restless Legs Scale.

Another essential sleep assessment tool is the sleep diary as it prospectively records sleep on a night-by-night basis (Bootzin & Engle-Friedman, 1981). While there is generally no standard form, most clinicians agree that sleep diaries should capture several relevant metrics such as sleep-onset latency, wakefulness after initial sleep onset, total sleep time, total time spent in bed, sleep efficiency, and sleep quality or satisfaction (Carney et al., 2012). As such, multiple lab-specific sleep diaries have emerged, with response formats including numerical sleep-wake estimates, Likert ratings, and visual analogue scales. Despite the lack of a standardized format, the sleep diary has been regarded as a "gold standard." Sleep diaries are considered more accurate than sleep questionnaires due to the influence of memory, experiences, vague and often inaccurate, and recall bias (Werner, Molinari, Guyer, & Jenni, 2008). While several studies have not found sufficient agreement for actual sleep time and nocturnal wake time between actigraphy and sleep diaries (Sadeh, 1995; Sadeh, Sharkey, & Carskadon, 1994), Werner et al. (2008) have asserted that actigraphy and sleep diary are interchangeable regarding sleep start, sleep end, and assumed sleep.

Prevention and Intervention

As noted earlier, it is important for children to have sufficient sleep quality and quantity. If a child is extremely difficult to wake in the morning (i.e., takes longer than 15 min to get out of bed), is sleeping two or more additional hours on weekends or school vacations when compared to school nights, is falling asleep at school or other inappropriate times, or exhibiting noticeable changes in mood or behavior following nights of increased sleep, intervention is recommended (American Sleep Association, 2018). The following strategies are common behavioral sleep interventions to improve sleep.

Prevention Strategies Techniques that focus on teaching children to fall asleep independently put themselves back to sleep following awakenings, healthy and consistent bedtime routines, and promoting restful sleep environments are first-line approaches to improve sleep. For infants and young children, strategies that prevent sleep difficulties may include putting children to sleep when drowsy but not yet asleep and having a consistent bedtime routine. As children get older, engaging in relaxation exercises before bed, discussing worries outside of bedtime, and making bedrooms electronic free promote sleep onset. In adolescents, encouraging bedrooms to be used solely for sleep and limiting caffeine intake are additional strategies that promote good sleep habits. Additional guidance from medical, behavioral health, and school providers to prevent sleep problems before they occur are presented in Table 18.2.

Table 18.2 Interdisciplinary sleep anticipatory guidance recommendations

Medical provider	Behavioral health provider	Daycare/school-based provider
Infants and toddlers		
– Encourage parents to get plenty of sleep and sleep when infant is sleeping – Help baby wake for feedings by light patting, diaper change, or undressing – Continue to offer feeds during the night every 3 h	– Provide coping skill recommendations to caregivers to help with transition of having a newborn at home and impact on parental sleep and stress level	– Maintain regular sleep schedule and feeding schedule – Maintain safety recommendations – Put baby to sleep when drowsy but awake
– Put infant to sleep on their back. Choose cribs with slats 2 3/8″ apart. Don't use loose, soft bedding and infant should sleep in crib in caregiver's room – Pay attention to infants' cues for sleep	– Help families set a consistent schedule and routine for sleep – Provide psycho-education on sleep-onset associations	– Implement consistent routine for sleep – Help provide feedback to caregivers on daytime sleep habits
– Put baby to sleep when drowsy but awake – Develop a schedule for naps and nighttime sleep – Infant should sleep in crib in caregiver's room (starting at 2 months) – Do not put baby in crib with a bottle – Choose mesh playpen with weave less than ¼″	– Discuss routine for feeds – Help family gradually fade nighttime feeds – Psycho-education on daytime disruptive behavior management (i.e., differential attention)	– Support independent sleep-onset and fade feedings during naps – Provide families feedback on helpful behavioral strategies and positive discipline techniques used at daycare
– Discuss changing sleep pattern – Discuss limit setting and positive discipline – Nighttime feeds not necessary (starting at 9 months to 1 year) – One nap per day (starting at about 1-year old) – Encourage quiet time such as reading, singing, and a favorite toy before bed – Discuss night awakenings, parents should reassure briefly, give a preferred object (blanket or stuffed animal), and put back to bed. No bottle in bed – Do not put TV, computer, or digital device in bedroom. Use other methods to improve calming behavior	– Discuss nap schedule as to not disrupt nighttime sleep – Discuss use of transitional object for sleep – Discuss limit setting around electronics and digital media for sleep	– Monitor sleepiness outside of daily sleep schedule – Monitor developmental performance (i.e., cognitive, oral, and motor development). Assess sleep concerns if developmental delays arise – Maintain consistent naptime earlier in the afternoon to avoid impact on nighttime sleep – Use transitional object at naptime
School age children		
– Create and maintain a calm bedtime routine – Limit TV to no more than 1 h a day, no TV in bedroom – Monitor school performance and consider impact of poor sleep on tardiness, daytime behavior – Consider implementation of family media plan to balance needs of physical activity, sleep, school, and quiet time without media (www.healthychildren.org/mediauseplan)	– Help families establish a consistent bedtime routine that is not too long (i.e., bath, brush teeth, PJs, story, lights out) – Encourage daytime exercise and limit electronics use. Eliminate TV and other screens at least 1 h before bed	– Monitor drowsiness in school, report episodes of sleep during school day to caregivers – Monitor academic and behavioral performance. Assess sleep difficulties when evaluating concerns – Introduce psycho-education on sleep during class time and to parents during PTO/PTA meetings and back-to-school night

(continued)

Table 18.2 (continued)

Medical provider	Behavioral health provider	Daycare/school-based provider
– Do not operate machinery, especially motor vehicles, when drowsy – Discuss maintaining a sleep routine in light of other activities, work, school, exercise, extracurricular activities, free time. Keep routine consistent on weekends and vacations	– Provide psycho-education around proper use of Melatonin if used – Introduce CBT strategies for older children to help calm bedtime fears, anxiety, and mood concerns – Help families implement behavioral strategies for bedtime refusal, night awakenings, and parasomnia's – Discuss daily schedule to maintain balance between school, friends, homework, and work – Discuss limit setting around driving a vehicle if sleep deprived	– Monitor tardiness, school attendance, and changes in mood or anxiety levels – Encourage regular exercise (i.e., PE classes) – Consider changing school start times – Provide psycho-education on the impact of poor sleep on driving behavior and safety – Manage school schedules so extracurricular activities do not occur too early in the morning or too late at night

Sleep Hygiene Strategies that address bedtime routines, sleep habits, and nighttime interactions are essential to allow other sleep interventions to be successful (Johnson, Giannotti, & Cortesi, 2009). As such, improving sleep habits is often recommended as a first-line treatment to improve sleep (Jan et al., 2008). Keeping consistent wake and sleep times across weekday and weekends is recommended. Further, eliminating naps can help build sleep debt and improve sleep onset at bedtime. Sleep should occur when sleepy and time in bed should be minimized to ensure a child is in bed only for sleep. This includes eliminating "sleeping in" and engaging in play, homework, or social media use while in bed. To help maintain regular sleep schedules and decrease sleep-onset latency, children should avoid caffeine, especially in evening hours, and eliminate access to stimulating activities before bed (i.e., use of electronics/screen use and rigorous exercise) at least 1 h before sleep. This includes eliminating access to TV in the bedroom and eliminating TV use as part of the bedtime routine. Other modifications to the sleep environment include keeping a bedroom temperature between 60 and 75° Fahrenheit, eliminating internal and external light within the bedroom, and making the bedroom a place only for sleep. Engaging in brief nighttime rituals and routines can also improve sleep hygiene. This can include taking a bath or shower, putting on pajamas, engaging in a quiet activity like reading independently or with a caregiver, and prayer at a consistent time each night, including weekends (Tierney & Wang, n.d.). Completion of the nighttime routine should not exceed 30 min.

Extinction Typical extinction procedures involve parents ignoring all bedtime disruptions and not interacting with a child until the next morning. Extinction may involve a temporary increase in negative behaviors prior to sleep habits improving. There are three types of extinction procedures a caregiver may implement to decrease crying or disruptive behavior concerns at bedtime. The first is the unmodified extinction or "cry it out" method. This requires caregivers to endure crying and other disruptive behaviors and ignore these behaviors until the next morning. Caregivers may only attend to disruptive behavior if concerns about the child being ill or safety issue arises (Etherton, Blunden, & Hauck, 2016). The second type of extinction is graduated extinction. With this method, caregivers respond to crying after a set amount of time on a fixed or incremental schedule. This strategy is different than the unmodified approach as it can be tailored to a child's age and developmental level and caregiver's comfort in how long they can ignore before responding to crying and other disruptive behaviors (Mindell, Kuhn, Lewin, Meltzer, & Sadeh, 2006). The third type of extinction approach is extinction with caregiver presence wherein a caregiver stays in the room with the child but ignores crying behaviors (Etherton et al., 2016). Common pitfalls include misconceptions about the amount of time it may take for this intervention to reach success, difficulty allowing disruptive behaviors to continue if they are affecting family members' or neighbors' sleep, and caregiver frustration (Etherton et al., 2016).

Scheduled Awakenings If a child exhibits a chronic (>3 episodes per month) and severe (almost nightly, or at least multiple times per week) pattern of NREM parasomnia (abnormal movements, behaviors, emotions, perceptions, or dreams that occur while falling asleep, sleeping, or waking up) episodes which is significantly disruptive to the child or family, scheduled awakenings may be indicated (Byars, 2011; Sadeh, 2005). Scheduled awakenings have been reported to work with full resolution at 1-year follow-up (Lask, 1988). The mechanism by which scheduled awakenings works is not fully understood and may involve disruption of sleep cycling into slow wave sleep (Owens & Mohan, 2016). Scheduled awakenings consist of parents keeping a diary of the timing of the parasomnia over several nights and then wake the child 15 min before the event typically occurs, making sure the child was fully awake for at least 5 min. Scheduled awakenings have been shown to eliminate sleepwalking in more than 80% of children and results were shown to be maintained for 3 and 6 months (Frank, Spirito, Stark, & Owens-Stively, 1997).

Stimulus Fading Stimulus fading often targets co-sleeping and involves gradually removing the presence of a parent from the child's room (Vriend, Corkum, Moon, & Smith, 2011). To target parental presence at bedtime, on the first night a parent may sleep on a mattress beside the child's bed as opposed to directly in bed with them. On subsequent nights, the parent continues to distance themselves from their child until they are completely out of the child's room. Stimulus fading has been shown to be effective at decreasing sleep onset and reducing night wakings and co-sleeping (Howlin, 1984).

Multi-component Intervention Intervention packages involving more than one approach to improve sleep (e.g., extinction, graduated extinction, stimulus fading, sleep hygiene, reward plans) have been shown to decrease sleep-onset latency, night wakings, bedtime disturbances, and improve daytime behavior (Montgomery, Stores, & Wiggs, 2004; Reed et al., 2009). Though it can be difficult to evaluate the efficacy of intervention packages, a combination of intervention strategies is often more feasible and practical for families to implement rather than individual intervention techniques.

Cognitive Therapy Cognitive strategies can help manage age-appropriate bedtime fears and comorbid anxiety concerns. It can be helpful for a child to identify maladaptive thinking patterns, and automatic thoughts around sleep and engaging children in basic cognitive restructuring techniques (Gradisar et al., 2011). Additionally, other cognitive behavioral therapy (CBT) strategies for sleep include self-control training, systematic desensitization, relaxation strategies, use of positive self-statements, and positive reinforcement (Tikotzky & Sadeh, 2010). Incorporating cognitive strategies to challenge bedtime fears or worry around not obtaining enough sleep, for example, can help decrease the further likelihood that catastrophic thoughts will lead to further sleep problems. For children, employing cognitive strategies during the day, such as "worry time" before starting the bedtime routine be helpful.

Exposures/Imagery Rehearsal Approximately 5–8% of the general population experience nightmares (i.e., unpleasant dreams that awaken the sleeper; Zadra & Donderi, 2000). Imagery rehearsal therapy (IRT) has received the most empirical support as an intervention (Krakow & Zadra, 2006). Imagery rehearsal therapy is a CBT intervention consisting of cognitive restructuring of thoughts around the unpleasant dream and a specific set of imagery steps to decrease the frequency and intensity of nightmares. Those who received IRT experienced reduced frequency of nightmares compared to those on a waiting-list and results were maintained over a 9-month follow-up (St-Onge, Mercier, & DeKoninck, 2009). IRT has also been found helpful in treating PTSD-related forms of nightmares (Kellner, Neidhardt, & Krakow, 1992). One study investigated the effectiveness of IRT for nightmares of 6- to 11-year-old children. Keeping a prospective dream log was associated with decreases in unpleasant dream frequency, nightmare distress, and manifest anxiety. Results also suggested that drawing modified versions of nightmares was associated with reductions in distress and anxiety (Simard & Nielsen, 2009).

Implications for Interprofessional Care

Youth live and function within multiple systems. Various professionals within these systems contribute to the health and well-being of each child throughout the lifespan. For instance, medical providers monitor a child's health and well-being starting at the mother's prenatal visit and continuing over the life of the child during well-child visits. Childcare and educational professionals also impact a child's growth and development by informing caregivers of child behavior while they are out of the home. Given significant implications of sleep on behavior and learning, it is appropriate and necessary that these professionals provide interprofessional care of sleep.

Anticipatory guidance is a process which medical providers discuss issues with families in anticipation of their emergence (Hagan, Shaw, & Duncan, 2017). Early discussions on sleep can start before a baby is born and continue at each well-child visit. Expectations for variability in infant sleep patterns, as well as, safe sleep practices, night time feedings, development of self-soothing skills, consistent sleep location, and strategies to decrease likelihood of an inappropriate sleep-onset association should be discussed (Hagan et al., 2017; Mindell & Owens, 2015). During toddler years, discussions among medical and daycare providers are focused around use of transitional objects at sleep, developmental fears at sleep onset, transition from a crib to toddler bed, behavioral limit-setting strategies, and use of electronics at bedtime (Hagan et al., 2017; Meltzer & Mindell, 2006; Mindell & Owens, 2015; Stein, Mendelsohn, Obermeyer, Amromin, & Benca, 2001). As children reach school age, focus shifts to maintaining a regular sleep routine, sleeping an adequate amount of time, screening for sleep disordered breathing, and functional impact of poor sleep on learning, school engagement, and social-emotional development (Dewald, Meijer, Oort, Kerkhof, & Bögels, 2010; Meltzer & Mindell, 2006; National Sleep Foundation, 2015; Sadeh et al., 2002). School personnel should not only monitor these factors, but assess for sleep difficulties before completing psycho-educational assessments for academic and behavioral concerns (Taras & Potts-Datema, 2005). During teenage years, focus should be centered on implications of poor sleep on academic performance, school truancy, and disruptive behavior and increased internalizing symptoms common to anxiety and depression, memory and attention issues, and safety (Dahl, 2008). Table 18.2 summarizes how sleep can be addressed inter-professionally along childhood development.

Daycare providers, teachers, nurses, social workers, and school psychologists can also provide anticipatory guidance of sleep. Schools and daycares can incorporate psycho-education into curricula. Youth spend a majority of their day in school allowing for ongoing monitoring of daytime sleepiness and the evaluation and impact of poor sleep on behavior, emotional regulation, and academic performance. For instance, Wilson, Miller, Bonuck, Lumeng, and Chervin (2014) evaluated the impact of a preschool-based sleep education program consisting of a presentation to parents and teachers and 2 weeks of lessons on sleep. Results demonstrated an increase in parent knowledge, attitudes, self-efficacy, and beliefs around sleep. In addition, participants increased weeknight sleep by 30 min compared to a control group. Another study of first-grade students found improved sleep habits over a 12-month period after families received brief school-based consultation around sleep issues (Quach, Hiscock, Ukoumunne, & Wake, 2011). Two studies of 11th-grade students examined the efficacy of providing sleep education within the school setting. Results of one study indicated a decrease in the discrepancy between time out of bed from weekday to weekend (Moseley & Gradisar, 2009) while the other study demonstrated significant improvement of knowledge with a large proportion of students attempting to change sleep behaviors (Cain, Gradisar, & Moseley, 2011).

Beyond providing educational intervention to students and caregivers within the school setting, delaying start times is another strategy schools can employ to improve sleep. Changing school start time by 1 h later has been found to increase sleep duration, decrease sleeping later on weekends to make up for lost sleep, and a decrease in motor vehicle accidents (Danner & Philips, 2008). In a study of high school boarding students, a delay in school start time by 30 min resulted in an increase of sleep duration and a decrease in daytime sleepiness (Owens, Belon, & Moss, 2010). A large longitudinal study demonstrated that daytime sleepiness and nighttime sleep duration improved following a delay of school start times by 30 and 60 min (Li et al., 2013).

Case Study

"Ben" is a Caucasian male seen by his primary care provider (PCP) for his 5-year well-child visit. During the visit, Ben's mother reported concerns regarding inattention and hyperactivity at home and school, as well as difficulty meeting Kindergarten academic benchmarks. During a parent–teacher conference, school staff suggested that Ben be evaluated for ADHD. Ben's mother reported that she does not want Ben to fall behind academically and would like an evaluation to address these concerns. Ben's PCP agreed to discuss the possibility of an ADHD evaluation after considering other factors such as sleep. Ben's mom shares that while bedtime is 8:30 pm, he often does not fall asleep until 11:00 pm or later. He no longer naps at home but falls to sleep in school a couple times each week. He is sometimes permitted to sleep in the nurse's office. Ben's mother noted that he is often awake during the night, two to three times, for at least 30 min each awakening. She awakens him at 6:00 am on school mornings so he may catch the bus at 6:30 am. Ben has the TV on at night and uses a timer to shut it off at 2:00 am. Ben turns on his TV with each night awakening. The PCP discusses the importance of setting limits on TV and electronics use to less than 1 h per day and to eliminate use at least 1 h before bedtime. The PCP also provides suggestions to improve the bedtime routine. Ben's mother was resistant to remove the TV from Ben's bedroom due to concerns that this may increase tantrums and lead to difficulties falling asleep. The PCP consulted with the pediatric primary care psychologist to discuss techniques for gradually fading the TV out of the bedroom. The psychologist explained that a sleep-onset association has developed around TV use. The psychologist, Ben, and his mother engaged in a 15-min discussion around electronics use and sleep and steps for gradually fading out the use of TV at bedtime. The psychologist also provided the family with a 2-week sleep diary and the preschool version of the CSHQ for the parents to complete. The family expressed interest in implementing these strategies and scheduled a visit with the psychologist for short-term solution focused treatment for insomnia. The psychologist further explained how poor sleep can result in decreased attention thereby impacting academic performance. Ben's mother agreed to defer evaluation of ADHD until sleep interventions are implemented. Ben's mother provided permission for the psychologist to discuss sleep concerns with Ben's school counselor. Furthermore, the psychologist recommended that school staff do not allow Ben to sleep at school. The psychologist also suggested use of a Daily Report Card to help Ben and his parents monitor his level of school engagement that can be tied to privilege-based rewards at home if he meets his daily behavior goals at school.

Conclusions and Future Directions

Addressing youth sleep issues requires a multi-systems level approach. Medical providers discuss implications of poor sleep, preventative strategies, and basic intervention techniques during well-child visits. However, moving recommendations into action can be difficult for caregivers at times. Assistance from behavioral health providers (i.e., pediatric psychologists) and school personnel can be helpful as these professionals are uniquely qualified and have resources (e.g., time and increased contact with youth) to further assess and treat sleep problems. Despite growing literature indicating the benefit of assistance from each of these groups on improving sleep problems, more research is needed to demonstrate the efficacy of a collaborative multi-system level approach to inform assessment and intervention.

References

Action Asthma. (1993). *The young asthmatics survey: Summary of results*. London: Action Asthma.

American Sleep Association. (2018). *Sleep deprivation: Symptoms, causes, dangers and treatment*. Retrieved from https://www.sleepassociation.org/sleep/sleep-deprivation

American Academy of Sleep Medicine. (2005). *International classification of sleep disorders: Diagnostic and coding manual* (2nd ed.). Westchester, IL.

Ames, M. E., Holfeld, B., & Leadbeater, B. J. (2016). Sex and age group differences in the associations between sleep duration and BMI from adolescence to young adulthood. *Psychology & Health, 31*, 976–992.

Anderson, S., Andridge, R., & Whitaker, R. C. (2016). Bedtime in preschool-aged children and risk for adolescent obesity. *Journal of Pediatrics, 176*, 17–22.

Baum, K. T., Desai, A., Field, J., Miller, L. E., Rausch, J., & Beebe, D. W. (2014). Sleep restriction worsens mood and emotional regulation in adolescents. *Journal of Child Psychology and Psychiatry, 55*, 180–190.

Becker, S. P., Froehlich, T. E., & Epstein, J. N. (2016). Effects of methylphenidate on sleep functioning in children with Attention-Deficit/Hyperactivity Disorder. *Journal of Developmental and Behavioral Pediatrics, 37*, 395–404.

Beebe, D. W. (2011). Cognitive, behavioral, and functional consequences of inadequate sleep in children and adolescents. *Pediatric Clinics of North America, 58*, 649–665.

Beebe, D. W., Krivitzky, L., Wells, C. T., Wade, S. L., Taylor, H. G., & Yeates, K. O. (2007). Brief report: Parental report of sleep behaviors following moderate or severe pediatric traumatic brain injury. *Journal of Pediatric Psychology, 32*(7), 845–850.

Beebe, D. W., Simon, S., Summer, S., Hemmer, S., Strotman, D., & Dolan, L. M. (2013). Dietary intake following experimentally restricted sleep in adolescents. *Sleep, 36*, 827–834.

Bootzin, R. R.,& Engle-Friedman, M. (1981). The assessment of insomnia. *BehavioralAssessment, 3*, 107–126.

Bramley, H., Henson, A., Lewis, M. M., Kong, L., Stetter, C., & Silvis, M. (2017). Sleep disturbance following concussion is a risk factor for a prolonged recovery. *Clinical Pediatrics, 56*(14), 1280–1285.

Brockmann, P. E., Betrand, P., & Castro-Rodriguez, J. A. (2014). Influence of asthma on sleep disordered breathing in children: A systemic review. *Sleep Medicine Reviews, 18*(5), 393–397.

Bruni, O., Ottaviano, S., Guidetti, V., Romoli, M., Innocenzi, M., Cortesi, F., & Giannotti, F. (1996). The Sleep Disturbance Scale for Children (SDSC) Construct ion and validation of an instrument to evaluate sleep disturbances in childhood and adolescence. *Journal of Sleep Research, 5*, 251–261.

Byars, K. (2011). Scheduled awakenings: A behavioral protocol for treating sleepwalking and sleep terrors in children. In M. L. Perlis, M. Aloia, & B. R. Kuhn (Eds.), *Behavioral treatments for sleep disorders: A comprehensive primer of behavioral sleep medicine treatment protocols*. London: Elsevier.

Cain, N., Gradisar, M., & Moseley, L. (2011). A motivational school-based intervention for adolescent sleep problems. *Sleep Medicine, 12*, 246–251.

Cappuccio, F. P., Taggart, F. M., Kandala, N. B., Currie, A., Peile, E., Stranges, S., & Miller, M. A. (2008). Meta-analysis of short sleep duration and obesity in children and adults. *Sleep, 31*(5), 619–626.

Carney, C. E., Buysse, D. J., Ancoli-Israel, S., Edinger, J. D., Krystal, A. D., Lichstein, K. L., & Morin, C. M. (2012). The consensus sleep diary: Standardizing prospective sleep self-monitoring. *Sleep, 35*(2), 287–302.

Carter, K. A., Hathaway, N. E., & Lettieri, C. F. (2014). Common sleep disorders in children. *American Family Physician, 89*, 368–377.

Castriotta RJ, Wilde MC, Lai JM, Atanasov S, Masel BE, Kuna ST. (2007) Prevalence and consequences of sleep disorders in traumatic brain injury. *J Clin Sleep Med. 3*, (4):349–56.

Crabtree, V., Graef, D., Phipps, S., Parris, K., Martin-Elbahesh, K., Huang, L., & Zhang, H. (2016). Sleepiness, fatigue, behavioral functioning, and quality of life in survivors of childhood hematopoietic stem cell transplant. *Journal of Pediatric Psychology, 41*, 588–599.

Dahl, R. E. (2008). Biological, developmental, and neurobehavioral factors relevant to adolescent driving risks. *American Journal of Preventive Medicine, 35*(3S), S278–S284.

Danner, F., & Philips, B. (2008). Adolescent sleep, school start times, and teen motor vehicle crashes. *Journal of Clinical Sleep Medicine, 4*(6), 533–535.

Dewald, J. F., Meijer, A. M., Oort, F. J., Kerkhof, G. A., & Bögels, S. M. (2010). The influence of sleep quality, sleep duration and sleepiness on school performance in children and adolescents: A meta-analytic review. *Sleep Medicine Reviews, 14*, 179–189.

Etherton, H., Blunden, S., & Hauck, Y. (2016). Discussion of extinction-based behavioral sleep interventions for young children and reasons why parents may find them difficult. *Journal of Clinical Sleep Medicine, 12*(11), 1535–1543.

Frank, N. C., Spirito, A., Stark, L., & Owens-Stively, J. (1997). The use of scheduled awakenings to eliminate childhood sleepwalking. *Journal of Pediatric Psychology, 22*(3), 345–353.

Gamaldo, C. E., & Earley, C. J. (2006). Restless legs syndrome: A clinical update. *Chest, 130*, 1596–1604.

Garetz, S. L., Mitchell, R. B., Parker, P. D., Moore, R. H., Rosen, C. L., Giordani, B., … Redline, S. (2015). Quality of life and obstructive sleep apnea symptoms after pediatric adenotonsillectomy. *Pediatrics, 135*, e477–e486.

Giannotti, F., & Cortesi, F. (2003). Sleep patterns and daytime functions in adolescents: An epidemiological survey of Italian high-school student population. In M. A. Carskadon (Ed.), *Adolescent sleep patterns: Biological, social, and psychological influences* (pp. 132–147). New York: Cambridge University Press.

Gradisar, M., Dohnt, H., Gardner, G., Paine, S., Starkey, K., Menne, A., … Trenowden, S. (2011). A randomized controlled trial of cognitive-behavioral therapy plus bright light therapy for adolescent delayed sleep phase disorder. *Sleep, 34*(2), 1671–1680.

Guilleminault, C., Palombini, L., Pelayo, R., & Chervin, R. D. (2003). Sleepwalking and sleep terrors in prepubertal children: What triggers them? *Pediatrics, 111*, e17–e25.

Hagan, J. F., Shaw, J. S., & Duncan, P. M. (Eds.). (2017). *Bright futures: Guidelines for health supervision of infants, children, and adolescents* (4th ed.). Elk Grove Village, IL: American Academy of Pediatrics.

Howlin, P. (1984). A brief report on the elimination of long term sleeping problems in a 6-yr-old autistic boy. *Behavioural Psychotherapy, 12*, 257–260.

Irwin, C. E., Cataldo, M. F., Matheny, A. P., & Peterson, L. (1992). Health consequences of behaviors: Injury as a model. *Pediatrics, 90*, 798–807.

Jan, J. E., Owens, J. A., Weiss, M. D., Johnson, K. P., Wasdell, M. B., Freeman, R. D., & Ipsiroglu, O. S. (2008). Sleep hygiene for children with neurodevelopmental disabilities. *Pediatrics, 122*, 1343–1350.

Johnson, K. P., Giannotti, F., & Cortesi, F. (2009). Sleep patterns in autism spectrum disorders. *Child and Adolescent Psychiatric Clinics of North America, 18*, 917–928.

Kellner, R., Neidhardt, J., & Krakow, B. (1992). Changes in chronic nightmares after one session of desensitization or rehearsal instructions. *American Journal of Psychiatry, 149*(5), 659–663.

Krakow, B., & Zadra, A. (2006). Clinical management of chronic nightmares: Imagery rehearsal therapy. *Behavioral Sleep Medicine, 4*(1), 45–70.

Krietsch, K. N., Lawless, C., Fedele, D. A., McCrae, C. S., & Janicke, D. M. (2017). Influence of asthma status on sleep variability in overweight/obese youth. *Journal of Asthma, 54*(4), 383–391.

Kong, A. P., Wing, Y. K., Choi, K. C., Li, A. M., Ko, G. T., Ma, R. C., … Chan, J. C. (2011). Associations of sleep duration with obesity and serum liquid profile in children and adolescents. *Sleep Medicine, 12*, 659–665.

Koren, D., Levitt Katz, L. E., Brar, P. C., Gallagher, P. R., Berkowitz, R. I., & Brooks, L. J. (2011). Sleep architecture and glucose and insulin homeostasis in obese adolescents. *Diabetes Care, 34*, 2442–2447.

Landhuis, C. E., Poulton, R., Welch, D., & Hancox, R. J. (2008). Childhood sleep time and long- term risk for obesity: A 32-year prospective birth cohort study. *Pediatrics, 122*, 955–960.

Lask, B. (1988). Novel and non-toxic treatment for night terrors. *British Medical Journal, 297*(6648), 592.

Lewandowski, A. S., Toliver-Sokol, M., & Palermo, T. M. (2011). Evidence-based review of subjective pediatric sleep measures. *Journal of Pediatric Psychology, 36*, 780–793.

Lewin, D. S., & Dahl, R. E. (1999). Importance of sleep in the management of pediatric pain. *Journal of Developmental and Behavioral Pediatrics, 20*(4), 244–252.

Li, S., Arguelles, L., Jiang, F., Chen, W., Jin, X., Yan, C., … Shen, X. (2013). Sleep, school performance, and a school-based intervention among school-aged children: A sleep series study in China. *PLoS One, 8*(7), e67928.

Logan, D. E., Sieberg, C. B., Conroy, C., Smith, K., Odell, S., & Sethna, N. (2015). Changes in sleep habits in adolescents during intensive interdisciplinary pediatric pain rehabilitation. *Journal of Youth and Adolescence, 44*, 543.

Lycett, K., Sciberras, E., Hiscock, H., & Mensah, F. K. (2016). Sleep problem trajectories and well-being in children with Attention-Deficit Hyperactivity Disorder: A prospective cohort study. *Journal of Developmental and Behavioral Pediatrics, 37*, 405–414.

Marcus, C. L., Brooks, L. J., Draper, K. A., Gozal, D., Halbower, A. C., Jones, J., … Shiffman, R. N. (2012). Diagnosis and management of childhood obstructive sleep apnea syndrome. *Pediatrics, 130*, 576–584.

McDowall, P. S., Galland, B. C., Campbell, A. J., & Elder, D. E. (2017). Parent knowledge of children's sleep: A systematic review. *Sleep Medicine Review, 31*, 39–47.

Meltzer, L. J., Avis, K. T., Biggs, S., Reynolds, A. C., Crabtree, V. M., & Bevans, K. B. (2013). The Children's Report of Sleep Patterns (CRSP): A self-report measure of sleep for school-aged children. *Journal of Clinical Sleep Medicine, 9*(3), 235–245.

Meltzer, L. J., Brimeyer, C., Russell, K., Avis, K. T., Biggs, S., Reynolds, A. C., & Crabtree, V. M. (2014). The children's report of sleep patterns: Validity and reliability of the sleep hygiene index and sleep disturbance scale in adolescents. *Sleep Medicine, 15*(12), 1500–1507.

Meltzer, L. J., Johnson, C., Crosette, J., Ramos, M., & Mindell, J. A. (2010). Prevalence of diagnosed sleep disorders in pediatric primary care practices. *Pediatrics, 125*, 1410–1418.

Meltzer, L. J., & Mindell, J. A. (2006). Sleep and sleep disorders in children and adolescents. *Psychiatric Clinics of North America, 29*, 1059–1076.

Mindell, J. A., Kuhn, B., Lewin, D. S., Meltzer, L. J., & Sadeh, A. (2006). Behavioral treatment of bedtime problems and night wakings in infants and young children. *Sleep, 29*(10), 1263–1276.

Mindell, J. A., & Owens, J. A. (2015). *A clinical guide to pediatric sleep: Diagnosis and management of sleep problems*. Philadelphia, PA: Lippincott Williams & Wilkins/Wolters Kluwer.

Montgomery, P., Stores, G., & Wiggs, L. (2004). The relative efficacy of two brief treatments for sleep problems in young learning disabled (mentally retarded) children: A randomized controlled trial. *Archives of Disease in Childhood, 89*, 125–130.

Moseley, L., & Gradisar, M. (2009). Evaluation of a school-based intervention for adolescent sleep problems. *Sleep, 32*(3), 334–341.

Moturi, S., & Avis, K. (2010). Assessment and treatment of common pediatric sleep disorders. *Psychiatry, 7*, 24–37.

National Sleep Foundation. (2015). *National sleep foundation recommends new sleep times*. Retrieved from https://sleepfoundation.org/press-release/national-sleep-foundation-recommends-new-sleep-times

National Sleep Foundation. (2018). *Sleep hygiene: What is sleep hygiene?* Retrieved from https://sleepfoundation.org/sleep-topics/sleep-hygiene

Navarro-Solera, M., Carasco-Luna, J., Pin-Arboledas, G., Gonzalez-Carrascosa, R., Soriano, J. M., & Cadoner-Franch, P. (2015). Short sleep duration is related to emerging cardiovascular risk factors in obese children. *Journal of Pediatric Gastroenterology and Nutrition, 61*, 571–576.

O'Brien, M., & Mindell, J. (2005). Sleep and risk-taking behavior in adolescents. *Behavioral Sleep Medicine, 3*, 113–133.

Owens, J. A., Belon, K., & Moss, P. (2010). Impact of delaying school start time on adolescent sleep, mood, and behavior. *Archives of Pediatrics and Adolescent Medicine, 164*(7), 608–614.

Owens, J. A., & Dalzell, V. (2005). Use of the 'BEARS' sleep screening tool in a pediatric residents' continuity clinic: A pilot study. *Sleep Medicine, 6*, 63–69.

Owens, J., & Mohan, M. (2016). Behavioral interventions for parasomnias. *Current Sleep Medicine Reports, 2*, 81.

Owens, J. A., Spirito, A., McGuinn, M., & Nobile, C. (2000). Sleep habits and sleep disturbance in elementary school-aged children. *Journal of Developmental and Behavioral Pediatrics, 21*(1), 27–36.

Paavonen, E. J., Porka-Heiskanen, T., & Lahikainen, A. R. (2009). Sleep quality, duration, and behavioral symptoms of 5-6-year-old children. *European Child Adolescent Psychiatry, 123*, 747–754.

Paruthi, et al. (2016). Recommended amount of sleep for pediatric populations: A consensus statement of the American Academy of Sleep Medicine. *Journal of Clinical Sleep Medicine, 12*(6), 786.

Picchietti, D., Allen, R. P., Walters, A. S., Davidson, J. E., Myers, A., & Ferini-Strambi, L. (2007). Restless legs syndrome: Prevalence and impact in children and adolescents-the Peds REST study. *Pediatrics, 120*, 253–266.

Pizza, F., Contardi, S., Antognini, A. B., Zagoraiou, M., Borrotti, M., … Cirignotta, F. (2010). Sleep quality and motor vehicle crashes in adolescents. *Journal of Clinical Sleep Medicine, 6*(1), 41–45.

Reed, H. E., McGrew, S. G., Artibee, K., Surdkya, K., Goldman, S. E., Frank, K., … Malow, B. A. (2009). Parent-based sleep education workshops in autism. *Journal of Child Neurology, 24*, 936–945.

Quach, J., Hiscock, H., Ukoumunne, O. C., & Wake, M. (2011). A brief sleep intervention improves outcomes in the school entry year: A randomized controlled trial. *Pediatrics, 128*(4), 692–701.

Quach, J., Mensah, F., & Hiscock, H. (2016). Differential outcomes of sleep problems in children with and without special health care needs: Australian population study. *Journal of Developmental and Behavioral Pediatrics, 37*(5), 415–423.

Riedel, B. W. (2000). Sleep hygiene. In K. L. Lichstein & C. M. Morin (Eds.), *Treatment of late-life insomnia* (pp. 125–146). Thousand Oaks, CA: Sage.

Romeo, D. M., Bruni, O., Brogna, C., Ferri, R., Galluccio, C., De Clemente, V., … Mercuri, E. (2013). Application of the Sleep Disturbance Scale for Children (SDSC) in preschool age. *European Journal of Paediatric Neurology, 17*(4), 374–382.

Sadeh, A. (1995). Activity-based measures of sleep. In M. A. Carskadon (Ed.), *Encyclopedia of sleep and dreaming* (pp. 4–6). New York: Macmillan.

Sadeh, A. (2005). Cognitive-behavioral treatment for childhood sleep disorders. *Clinical Psychology Review, 25*(5), 612–628.

Sadeh, A., Gruber, R., & Raviv, A. (2002). Sleep, neurobehavioral functioning, and sleep problems in school-age children. *Child Development, 73*(2), 405–417.

Sadeh, A., Sharkey, K. M., & Carskadon, M. A. (1994). Activity based sleep–wake identification: An empirical test of methodological issues. *Sleep, 17*, 201–207.

Seifer, R., Sameroff, A. J., Dickstein, S., & Hayden, L. C. (1996). Parental psychopathology and sleep variation in children. *Child and Adolescent Psychiatric Clinics of North America, 5*(3), 715–728.

Sheldrick, R. C., & Perrin, E. C. (2009). Surveillance of children's behavior and development: Practical solutions for primary care. *Journal of Developmental & Behavioral Pediatrics, 30*(2), 151–153.

Simard, V., & Nielsen, T. (2009). Adaptation of imagery rehearsal therapy for nightmares in children: A brief report. *Psychotherapy, 46*, 492–497.

Sneddon, P., Peacock, G. G., & Crowley, S. L. (2013). Assessment of sleep problems in preschool aged children: An adaptation of the children's sleep habits questionnaire. *Behavioral Sleep Medicine, 11*(4), 283–296.

Snell, E. K., Adam, E. K., & Duncan, G. J. (2007). Sleep and body mass index and overweight status of children and adolescents. *Child Development, 78*, 309–323.

Stein, M. A., Mendelsohn, J., Obermeyer, W. H., Amromin, J., & Benca, R. (2001). Sleep and behavior problems in school-aged children. *Pediatrics, 107*(4), 1–9.

St-Onge, M., Mercier, P., & DeKoninck, J. (2009). Imagery rehearsal therapy for frequent nightmares in children. *Behavioral Sleep Medicine, 7*(2), 81–98.

Stores, G., Ellis, A. J., Wiggs, L., Crawford, C., & Thomson, A. (1998). Sleep and psychological disturbance in nocturnal asthma. *Archives of Disease in Childhood, 78*, 413–419.

Strachan, D. P., Anderzon, H. R., Limb, E. S., O'Neill, A., & Wells, N. (1994). A national survey of asthma prevalence, severity, and treatment in Great Britain. *Archives of Disease in Childhood, 70*, 174–178.

Taras, H., & Potts-Datema, W. (2005). Sleep and student performance at school. *Journal of School Health, 75*(7), 248–254.

Tham, S. W., Palermo, T. M., Vavilala, M. S., Wang, J., Jaffe, K. M., … Rivara, F. P. (2012). The longitudinal course, risk factors, and impact of sleep disturbances in children with traumatic brain injury. *Journal of Neurotrauma, 29*(1), 154–161.

Tierney, C., & Wang, G. (n.d.). *Sleep Apnea in Children vs. Poor Sleep Hygiene*. Retrieved from https://www.sleepassociation.org/patients-general-public/children-and-sleep/sleep-apnea-children-vs-poor-sleep-hygiene/

Tikotzky, L., & Sadeh, A. (2010). The role of cognitive-behavioral therapy in behavioral childhood insomnia. *Sleep Medicine, 11*, 686–691.

Valent, F., Brusaferro, S., & Barbone, F. (2001). A case-crossover study of sleep and childhood injury. *Pediatrics, 107*, E23.

Valrie, C. R., Bromberg, M. H., Palermo, T., & Schanberg, L. E. (2013). A systemic review of sleep in pediatric pain populations. *Journal of Developmental and Behavioral Pediatrics, 34*, 120–128.

Vigliano, P., Galloni, G. B., Bagnasco, I., Delia, G., Moletto, A., … Cortese, S. (2016). Sleep in children with attention-deficit/hyperactivity disorder before and after 6-month treatment with methylphenidate: A pilot study. *European Journal of Pediatrics, 175*(5), 695–704.

Vriend, J. L., Corkum, P. V., Moon, E. C., & Smith, I. M. (2011). Behavioral intervention for sleep problems in children with autism spectrum disorders: Current findings and future directions. *Journal of Pediatric Psychology, 36*, 1017–1029.

Wang, J., Adab, P., Liu, W., Chen, Y., Li, B., … Pallan, M. (2016). Prevalence of adiposity and its association with sleep duration, quality, and timing among 9–12-year-old children in Guangzhou, China. *Journal of Epidemiology, 27*(11), 531–537.

Werner, H., Molinari, L., Guyer, C., & Jenni, O. G. (2008). Agreement rates between actigraphy, diary, and questionnaire for children's sleep patterns. *Archives of Pediatrics and Adolescent Medicine, 162*, 350–358.

Williams, K. E., & Sciberras, E. (2016). Sleep and self-regulation from birth to 7 years: A retrospective study of children with and without Attention-deficit hyperactivity disorder at 8 to 9 years. *Journal of Developmental and Behavioral Pediatrics, 37*, 385–394.

Wilson, K. E., Miller, A. L., Bonuck, K., Lumeng, J. C., & Chervin, R. D. (2014). Evaluation of a sleep education program for low-income preschool children and their families. *Sleep, 37*(6), 1117–1125.

Wu, J., Meizhen, G., Chen, S., Chen, W., Ni, K., Xu, H., & Li, X. (2017). Factors related to pediatric obstructive sleep apnea-hypopnea syndrome in children with attention deficit hyperactivity disorder in different age groups. *Medicine, 96*(42), 1–6.

Zadra, A., & Donderi, D. C. (2000). Nightmares and bad dreams: Their prevalence and relationship to well-being. *Journal of Abnormal Psychology, 109*, 273–281.

Part IV

Cross-Cutting Issues

19

Coping with Chronic Illness and Medical Stress

Cynthia A. Riccio, Cheryl Maykel, Meiko Howell, and Melissa A. Bray

Abstract

Many children experience a myriad of chronic medical issues that affect not only their physical, but psychological functioning as well. Internalizing disorders, such as depression, anxiety, and stress, in addition to coping and quality of life have been implicated in the initiation and exacerbation of many health outcomes. Poor social functioning with peers and family also may occur. Furthermore, the negative effects on academic achievement that are due to a variety of associated problems such as cognitive impact and resulting poor attendance also need to be addressed for these children. Research supports interaction of disease factors, child and family factors, and both medical and mental health outcome. A coordinated approach to care would include medical treatment as well as mental health support for the affected child and their family with consideration to the school context. Both primary and secondary coping strategies have been found to be helpful and may be delivered through a cognitive behavioral approach. Additional research is called for in the areas of assessment of coping ability as well as intervening to promote coping capabilities among children with chronic illness and the systems in which they function.

Many children experience medical issues that are chronic and have the potential to affect their functioning. Chronic illness can be defined conservatively as a condition that is persistent and results in a substantial and major impairment in daily activities (National Center for Health Statistics [NCHS], 2006) or a condition that is prolonged, does not resolve spontaneously, and is rarely cured (Centers for Disease Control [CDC], 2009). A commonly accepted definition of a chronic illness or condition includes the presence of a health or medical problem that lasts at least 3 months, requires ongoing medical care at some point, affects normal activities, and is associated with functional impairment (van der Lee, Mokkink, Groutenhuis, Heymans, & Offinga, 2007). How chronic illness or a chronic condition is defined varies with some definitions including that the condition or its

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sequelae last for a considerable period of time (i.e., more than 3 months in a year) or necessitates continuous hospitalizations for more than a month (Thompson Jr. & Gustafson, 1996). Examples of common chronic illness include asthma, cancer, epilepsy, and sickle cell disease. Although some include other chronic conditions (e.g., autism spectrum disorder, attention-deficit/hyperactivity disorder) on this list, for the purpose of this chapter, the focus will be on chronic illnesses that warrant medical involvement for physical considerations as well as mental health concerns.

The overall prevalence of chronic illness is estimated to have increased, or at least the identification and tracking of chronic illness has risen over the last few decades (Halfon & Newachuck, 2010; Perrin, Bloom, & Gortmaker, 2007; van der Lee et al., 2007). Estimates of affected children and adolescents range from 10 to 35%, depending on the method used to collect data and how chronic illness was defined (Martinez & Ercikan, 2009; Nabors, Little, Akin-Little, & Iobst, 2008; NCHS, 2012; Van Cleave, Gortmaker, & Perrin, 2010; van der Lee et al., 2007). Based on a national survey, 14% of children under 18 years of age had a health problem that was being treated with medication within the previous 3 months of the survey, most often asthma (NCHS, 2012). Across illnesses, Van Cleave et al. (2010) estimated that 27% of children experience a chronic condition that may or may not continue through their lifetime. Moreover, for approximately 6.5–7% of children, the illness is severe enough to interfere with their normal school or life activities (American Academy of Pediatrics, Council on Children with Disabilities, 2005; NCHS, 2006). With advances in medicine, the survival rate for children with chronic illnesses has been significantly increased. At the same time, research suggests that as these survivors progress in development, the disease process and consequences of treatment can have negative effects on brain development and associated function (Armstrong, 2006; Compas, Jaser, Reeslund, Patel, & Yarboi, 2017; Rosoff, 2006).

Associated Medical Stress

Many factors are associated with the effect of chronic illness on children and youth, but will vary as a function of the illness. Research has begun to focus on the disease-specific and treatment-specific mechanisms that contribute to poorer outcomes. An assumption is that children with chronic illness, unless compounded by another neurodevelopmental disorder, experience typical brain development until the disease takes effect (Armstrong, 2006). Depending on the illness, there may be acute effects from the illness itself, for example, acute hypoxia associated with anemia or illnesses associated with lung capacity and function (Henderson et al., 2003). In some cases, the effects are short term and resolve following treatment (Santoro et al., 2005); in others, the acute event (e.g., stroke) may result in permanent damage, loss of previous functions, and disruption of typical brain development (e.g., Schwartz & Major, 2006). The long-term effects of the illness itself are hard to discern as long-term follow-up occurs after treatment(s).

Some of the effects of the illness or treatment are not immediately evident, but emerge over time, as with "cognitive late effects" associated with cancer treatment (Armstrong, 2006, p. 170). For example, with chemotherapy a side effect is the suppressed ability to fight infection, fatigue, hair loss, and pain (Vance & Eiser, 2001), as well as impairment in the ability to learn and remember new academic information (Wade, Dang, Nelson, & Wasserberger, 2010). Children with chronic illnesses may be distracted from learning and unable to participate in physical activities due to pain (Compas et al., 2006; Madan-Swain, Katz, & LaGory, 2004). Further, children with sickle cell disease, for example, may suffer from frequent pain episodes that affect sleep, activity level, and overall functioning (Jacob et al., 2006). With insulin-dependent diabetes, children and youth may experience hypo- or hyperglycemia, which can affect their attention, memory, and processing speed (Desrocher & Rovet, 2004). In addition to the fatigue associated with seizures, anticonvulsant medications also commonly have effects on distractibility, memory, and information processing (Charlton, 1997). Similarly, medications for asthma and allergies can lead to irritability, restlessness, and problems maintaining focus (Favreau, Bacon, Joseph, & Labrecque, 2012; Saricoban et al., 2011).

Chronic illness also may result in sporadic school attendance, along with associated academic difficulties and difficulty in peer relations (Boonen & Petry, 2011; Newacheck & Halfon, 2000). Children and adolescents with chronic illness are absent from school an average of 16 days each year, in comparison to children without chronic illness, who miss an average of only 3 days (McDougall et al., 2004). The average days absent varies significantly based on the disorder, the severity, and course of the illness, and how the child and their family cope with the disease. As a result, children with chronic illnesses may be eligible for Section 504 or special education services (Shaw & McCabe, 2008) with an emphasis on meeting their educational needs. Educational needs are not the only school-related issues for children and adolescents with chronic illness. The majority of children with chronic illness demonstrate lower academic motivation, more disruptive behaviors, and/or lower achievement (Forrest, Bevans, Riley, Crespo, & Louis, 2011). The most obvious effects may be due to the disease itself or the treatments that are employed to address the disease, as well as any subsequent restrictions to activities (Boonen & Petry, 2011; Newacheck & Halfon, 2000).

Research has examined factors that contribute to the risk of long-term negative outcomes (see Armstrong & Briery, 2004 for review; Armstrong & Horn, 1995 for model). These include disease characteristics, child characteristics, family characteristics, and available resources and services. A major consideration is the extent to which the disease is progressing, whether effects are cumulative, and whether the disease is controlled through treatment. A second factor is the age of onset, with more difficulties exhibited in the neurocognitive areas that have not yet developed and a lesser residual effect on those domains that already have developed. Remaining factors include the course and progression of the disease, treatment approach, and the extent to which treatment is effective. Armstrong and Horn's model (1995) suggests that the interaction of all these factors leads to the outcome of the survivors over time. Further, the effects may be exacerbated by environmental risk factors including poverty, which also have effects on structural changes to the cortex (Hanson et al., 2012). With increased research, it is evident that many children with chronic illness experience disruption of neural development and the associated neurocognitive functions well into adulthood (Compas et al., 2017). These neurocognitive deficits are predictive of the struggles in academic areas, occupational attainment, social emotional learning, and overall quality of life (e.g., Robinson et al., 2015).

Quality of Life Quality of life (QoL) refers to "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organization, 1993, p. 2). QoL often is conceptualized as a multidimensional construct that incorporates the physical, psychological, and social impact that a disease has on the daily existence of the individual (Sawyer et al., 2001). A sub-category within this multidimensional construct addresses QoL specifically associated with medical concerns and how physical health impacts one's quality of life. This is referred to as health-related quality of life (HRQoL).

The role of health-related quality of life (HRQoL) in patient-reported outcomes is also important to the behavioral health of children with chronic illness, though HRQoL measures for pediatric use are limited. Furthermore, the use of a generic measurement without domain-specific constructs could potentially end up compromising the validity of results. Therefore, current research generally supports a need for illness-specific measurements. For instance, Cella et al. (2011) proposed that HRQoL measures for neurologic conditions (e.g., stroke, multiple sclerosis, Parkinson's disease, epilepsy, muscular dystrophies, TBI, migraine headache, cerebral palsy) focus on patient-reported outcomes associated with rehabilitation medicine.

Coping with Chronic Illness

The construct of coping has been conceptualized in many ways; however, the general consensus includes those behaviors the individual uses to regulate aspects of self and their environment under stress (Compas, Jaser, Dunn, & Rodriguez, 2012; Eisenberg, Fabes, & Guthrie, 1997; Skinner & Edge, 1998). Skinner and Wellborn (1994) described coping as the ways that individuals "mobilize, guide, manage, energize, and direct behavior, emotion, and orientation, or how they fail to do so" when under stress (p. 113). Many of the conceptualizations of coping reflect the bidirectional link between coping and regulation of psychological and physiological processes as well (Compas, Connor-Smith, Saltzman, Thompson, & Wadsworth, 2001).

Coping behaviors can be categorized in a variety of ways with some identifying up to 400 subtypes of coping in the research literature (Skinner, Edge, Altman, & Sherwood, 2003); however, few have been developed, tested, and applied with children and adolescents coping with chronic illness (e.g., Ayers, Sandler, West, & Roosa, 1996; Connor-Smith, Compas, Wadsworth, Harding Thompson, & Saltzman, 2000; Walker, Smith, Garber, & Van Slyke, 1997). Some make a distinction between automatic or involuntary processes and active, controlled processes (Compas et al., 2001; Compas, Connor, Osowiecki, & Welch, 1997; Eisenberg et al., 1997). Automatic responses include the physiological responses of increased heart rate and so on, which potentially can influence physical health of the individual (i.e., exacerbate illness presentation), as well as automatic thoughts and behaviors. These are more involuntary and reactive, possibly conditioned responses to stress, while voluntary responses include active attempts to cope with stressors (Connor-Smith et al., 2000). Others differentiate between active and passive coping in response to stress. Common components of these frameworks are presented in Table 19.1.

Table 19.1 Common components of coping in chronic illness

General category	Definition	Focus
Active/ primary	Efforts to directly alter or change the source of the stress or one's own response to the stress	Problem-focused strategies
Active/ secondary	Efforts to adapt to the stress through positive thinking, reframing, acceptance, or distraction	Emotion-focused strategies Social support-focused
Passive/ avoidant	No effort to alter or control the stress, disengagement	Avoidant-focused

Within active or voluntary coping, primary control strategies are those that attempt to directly alter the source of the stress (problem-focused). Problem-focused coping targets what can be done to change or manage the situation, whereas secondary control strategies are typically those aimed at adapting to the stressor (emotion-focused) or seeking social support to buffer the stressor (social support-focused). A third possible response is referred to as relinquished control, or the absence of any attempt to cope with the stressor (Rudolph, Dennig, & Weisz, 1995). Avoidance may be a common reaction, though as one might expect, it will not likely yield the most successful outcomes (Dempster, Howell, & McCorry, 2015).

These frameworks in some form have been applied and researched with child and adolescents coping in chronic illness with mixed findings (see Compas et al., 2012 for review). For example, research has found support for a relation between metabolic control and active/passive coping (e.g., Jaser & White, 2011). Active primary coping was found to result in improved metabolic control (Jaser & White, 2011); however, secondary forms of coping were not found to be effective and reliance on passive/avoidant coping resulted in poor treatment adherence and decreased metabolic control (Jaser & White, 2011). For chronic pain, secondary approaches have been found to lead to lower levels of somatic complaints (e.g., Compas et al., 2006; Hocking et al., 2011).

Coping approaches also can impact overall mental health and adjustment. For example, active coping mechanisms were found to be associated with better self- and parent-reported social competence and QoL in adolescents with diabetes (e.g., Jaser & White, 2011). Use of secondary approaches was found to be associated with greater positive well-being for those with diabetes (Edgar & Skinner, 2003), fewer symptoms of anxiety, and depression in children and youth with chronic abdominal pain (Hocking et al., 2011). In contrast, for those with chronic abdominal pain, disengagement and avoidant behavior were associated with poorer adjustment (e.g., Shirkey, Smith, & Walker, 2011), and higher levels of anxiety and depression (e.g., Compas et al., 2006). Similar studies and results have emerged for children with cancer and coping. As expected, the use of avoidance strategies was associated with, and predictive of, children's depressive and anxiety symptoms, as well as lower levels of social competence (Frank, Blount, & Brown, 1997).

Overall, there is considerable research to support the importance of active (primary and secondary) coping mechanisms in relation to improved outcome for children with chronic illness (Compas et al., 2012). Further, effective coping mechanisms are necessary for resilience in children and youth with chronic illness (e.g., Hilliard, McQuaid, Nabors, & Hood, 2015; Wallander, Thompson, & Alriksson-Schmidt, 2003). Use of appropriate coping mechanisms can be considered as protective processes or behaviors children engage in to deal with medical stressors and the potential lack of control they may feel with regard to chronic illness. It is important to consider the disease process and fluctuations that may render some coping mechanisms more effective for some than others and effectiveness may vary over time (Compas et al., 2012).

Implications for Integrated Behavioral Care

Clinical care for children with chronic illness involves a number of professionals from multiple disciplines (e.g., psychologists, dietitians, doctors, nurses, pharmacists, therapists, social workers, teachers). A collaborative treatment approach should be orchestrated in a way that brings about the most optimal outcomes for the children and is consistent with the integration of mental health services into a primary care setting promulgated by integrated behavioral health models (Collins, Hewson, Munger, & Wade, 2015). It is also consistent with the Disability-Stress-Coping Model (DSC; Wallander & Varni, 1992; Wallander et al., 2003).

The DSC initially organized various factors associated with adjustment of children with chronic illness into a risk and resiliency framework. It was later revised utilizing a non-categorical approach in lieu of the previous risk-resiliency categorization (Wallander et al., 2003). The revised model identified several factors that influence child adjustment to chronic illness including condition parameters (e.g., diagnosis, severity), functional independence, psychosocial stress, social-ecological factors (e.g., parental adjustment, family environment), intrapersonal factors (e.g., competencies, temperament), and stress processing. In this way, it is similar to the neurodevelopmental model (Armstrong & Horn, 1995), with increased emphasis on adjustment. With the DSC model, adjustment is observed in the three domains of mental health, physical health, and social functioning; resilience is retained in the inclusion of family environment and coping (Wallander & Varni, 1992).

Given the interaction of physical health, mental health, and social functioning, the probability of positive adjustment increases when the healthcare planning process includes the understanding of how the particular child's family environment and coping affect the child's functioning in these three domains. This is best accomplished by coordination of care for physical and mental health (Collins et al., 2015), which, for children and adolescents, needs to consider the school context.

Assessment for Integrated Care

Children's coping is often reflected in their behavioral health. Children's coping may be best measured by their attitude toward changing and managing an emotionally and physically taxing situation (Blount et al., 2008). Measurements and monitoring tools that are used with children who have chronic illnesses should be developmentally sensitive and appropriate, as the physical, cognitive, and emotional functioning of children are constantly changing as they develop and as the impact of their illness also changes over time. In order to make psychometrically sound and clinically relevant decisions and recommendations, an initial evaluation of children with chronic illnesses would ideally include coping measures and subjective well-being measures (Blount et al., 2008; Zanon et al., 2017).

There are multiple measures that examine coping mechanisms in relation to chronic illness. Some of these are more specific to coping with medical procedures, while others are more specific to everyday coping activities. Blount et al. (2008) provides a review of evidence-based measures of coping with chronic illness in childhood and adolescence. Two measures are consistent with the categories of coping presented in Table 19.1. The Response to Stress Questionnaire (RSQ; Connor-Smith et al., 2000) was developed for use with adolescents and has been empirically supported for use among chronically ill youth (see Compas et al., 2012 for a review). The RSQ includes an adolescent self-report as well as a form for parents to fill out with regard to their adolescents' responses. Promising research with the RSQ includes convergent validity of child and parent reports (Connor-Smith et al., 2000), as well as between specific factors (i.e., disengagement) and physiological response (i.e., heart rate; Dufton, Dunn, Slosky, & Compas, 2011). The Pain Response Inventory (PRI; Walker et al., 1997) is another self-report measure that is specific to chronic pain and has been validated for use with children as young as 8 years old to young adults. While the PRI is specific to pain, there is strong convergence between the factor structures of the RSQ and PRI (Connor-Smith et al., 2000; Walker et al., 1997). Unfortunately, most of the coping measures rely on self-report with minimal to no convergent validity data available (Blount et al., 2008; Compas et al., 2012).

The assessment of HRQoL should be designed in a way that would clinically evaluate children's physical, psychological, and social functioning in relation to their specific chronic illness. An assessment that measures quality of life in children with asthma is the Pediatric and Adult Asthma Quality of Life Questionnaire (Juniper, 1996). It was designed to measure numerous factors related to the overall quality of life in individuals with asthma. Similarly, Varni, Limbers, and Burwinkle (2007) discussed the use of HRQoL components of the PedsQL for a variety of disease categories and severity. Related to HRQoL and overall adjustment for children with chronic illness is the individual's ability to cope with the lack of predictability, changes that occur in the progression of the disease, and the related medical stressors.

One outcome measure that is specific to children with chronic illness is the Patient-Reported Outcomes Measurement Information System (PROMIS), Pediatric Measures. Similar to other measures of HRQoL, the PROMIS is a web-based patient-reported outcome measurement system developed by the National Institute of Health to measure the patient's perception of their own physical, mental, and social health (Cella et al., 2007; NIH, 2017). The pediatric measures are available in two forms: the self-report form is designed for ages 8–17, and the parent proxy report form is for ages 5–17. PROMIS is being used in many clinical trials nationally.

Comorbid Conditions In addition to the assessment of coping mechanisms and HRQoL, it is important to evaluate and monitor internalizing behaviors in children with chronic illness, such as depression, stress, and anxiety. Anxiety and chronic stress in particular have been on the rise in youth with medical conditions (Smith, Richardson, Hoffman, & Pilkington, 2005). They have been associated with the initiation and/or exacerbation of a myriad of health issues including, asthma (Bray, Kehle, Grigerick, Loftus, & Nicholson, 2008), cancer (Middleton, 2014), diabetes (Jacob et al., 2013), and cardiovascular disease (Steca et al., 2013). Stress in particular is expressed biologically by neuroendocrine markers including hormones and immune system markers. Therefore, assessment including those such as the Spielberger State—Trait Anxiety Scale (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983), the Beck Depression Inventory (Beck, Steer, & Brown, 1996), and the Perceived Stress Scale (Cohen & Williamson, 1988) are particularly useful for those with chronic medical conditions.

It is no surprise that coping, positive affect, and subjective well-being are interrelated. Lyubomirsky, King, and Diener (2005) reviewed experimental studies on the relationship between positive affect and subjective well-being and reported that the relationship is causal. They further illustrated a positive association between active goal involvement and happiness. Interestingly, McCabe, Bray, Kehle, Theodore, and Gelbar (2011) found gratitude to be one of the core elements of happiness. One can easily imagine how challenging it would be for children with chronic illness to experience gratitude and positive affect and to maintain a positive outlook without adequate coping mechanisms.

Prevention/Intervention

Historically, with chronic illness, medical professionals have focused on the physiological condition. The impetus behind integrated behavioral health is the recognition that all aspects of functioning are interrelated and thus, all aspects need to be addressed (Collins et al., 2015). As such, education for children, family, school personnel, and medical professionals is an essential component of preventions and interventions designed to improve and optimize behavioral health in children with chronic illnesses. Oftentimes, limited negotiation around treatment-related decisions compromises the collaborative nature of interdisciplinary effort, highlighting the crucial role that parents play in improving the physical, psychological, and social well-being of the child. Swallow et al. (2013) proposed three patterns of parent-educative activity that help professionals and parents negotiate clinical caring: engagement of parents in shared practice, exchange of knowledge and role negotiation, and promotion of common ground.

Systematic reviews have been performed on an effectiveness of various intervention options with children and adolescents. Current research generally supports the effectiveness of cognitive behavior therapy (CBT). For example, one of the recent meta-analyses concluded that skill-based interventions delivered over multiple sessions may be the most effective for children dealing with chronic illness (Sansom-Daly, Peate, Wakefield, Bryant, & Cohn, 2012). Skill-based programs involve "explicit and often practical training in adaptive coping strategies, to deal with current or future stressors" (p. 382). Components of CBT often include (a) goal-setting; (b) role-playing; (c) family/parent involvement; (d) cognitive restructuring or reframing the issue in a different way; (e) problem-solving; and (f) psychoeducation. The problem-solving and psychoeducational component of CBT may be one of the reasons for the overall effectiveness of CBT with this particular population. Illness uncertainty may have a significant influence on psychological functioning, distress, and coping associated with pediatric chronic illness (Szulczewski, Mullins, Bidwell, Eddington, & Pai, 2017). Through increased levels of education for children and parents, illness uncertainty would likely be reduced, leading to much more favorable outcomes for their psychological functioning. One of the considerations related to prevention and intervention is pain management. Emotional pain/stress heightens physical pain and vice versa. Emotional pain/stress with chronic illness can become even more debilitating due to uncertainty, limited knowledge of the medical condition, poor coping skills, and perhaps also due to having a limited opportunity to engage in self-directed and goal-oriented behaviors associated with the experience of gratitude and positive affect. Acceptance and Commitment Therapy (ACT) is another example of CBT-based treatment that has been used with pediatric chronic illness (Ernst & Mellon, 2016). With ACT, components of CBT are combined with mindfulness approaches to address goals or direction, as well as acceptance and commitment to change and an emphasis on psychological flexibility and self-awareness (McCracken & Vowles, 2014).

Undoubtedly, there is a family factor that impacts the outcomes of treatments designed to improve children's well-being. Children's coping and parents' coping interact with each other in a complex manner, as the family system plays an integral and instrumental part in the efficacy of psychotherapeutic treatments. Eccleston, Fisher, Law, Bartlett, and Palermo (2015) found that CBT-based treatments improved the children's medical symptoms and reduced distress in parents. Thus, the ability of parents to provide support can be supported directly through allowing the parents agency (Swallow et al., 2013) and indirectly through the provision of CBT to the children (Eccleston et al., 2015).

Mindfulness approaches also have been found useful with children and adolescents dealing with chronic illness (e.g., Bray, Root, Gelbar, Bruder, & Menzies, 2017; Kohut, Stinson, Davies-Chalmers, Ruskin, & van Wyk, 2017; Riccio, Pliego, & Rae, 2016). As with CBT, mindfulness involves the specific training of attention directed and regulated to the present moment. The individual is taught to be aware of where their attention is, to prioritize it, and maintain its direction. This technique has been successfully used with youth with asthma as well as other chronic health conditions. The use of visualization techniques used in mindfulness have also been implemented within standard relaxation and guided imagery protocols (RGI). The use of mental imagery, as a part of RGI, specific to human anatomy and physiology has more recently been documented showing successful outcomes in hormone regulation, glucose levels, lung functioning, along with positive mental and physical effects in the parents of children with various illnesses (Bray et al., 2017).

Case Study

A middle school student, Kathy (female, age 12, seventh grade), was diagnosed with asthma at 2 years old. She had chronic asthma that was debilitating at times where psychological triggers were implicated in the occurrence of the symptomology. Kathy used relaxation and guided imagery (RGI) to treat her asthmatic symptoms and related anxiety. RGI was an excellent choice for her condition as it addresses the frequency of the attacks by decreasing the anxiety surrounding the episodes. RGI lends itself well to the facilitation of effective coping mechanisms when asthmatic episodes are increasingly severe and difficult to resolve.

At baseline, she had large airway (FEV1) values at 80% predicted, meaning there was no obstruction; however, she had substantially diminished small airway (FEF25–75) values. She reported that triggers to her asthma included stress, anxiety, anger, exercise, respiratory infections, cold air, and ragweed. Further, she experienced interrupted sleep due to coughing at night, resulting in absences from school. In terms of medication, a long-acting beta2-agonist inhaler was used.

The RGI protocol she followed was designed for children. It emphasized process imagery, which involved visualizing end-state imagery of goals in the final state of success. In particular, this script included relaxation exercises aimed at the entire body, guided imagery where Kathy listened to lung healing mechanisms in the bronchial tubes, the visualization of her taking part in activities with no breathing issues, and guided imagery where she visualized breathing in a special green-colored air that completely cleared up the airways and improved her lung function. She engaged in these activities approximately two to three times per week. At the end of the 1 month intervention, Kathy's lung functioning had improved. Her anxiety also was reduced and she reported an improved quality of life. She was able to sleep better at night, attend school consistently, and she experienced little to no anxiety surrounding her breathing (Peck, Bray, & Kehle, 2003).

Conclusion

It is clear that many youth, their families, and their communities are negatively impacted by chronic child illnesses. With rates of identified childhood chronic illness on the rise, professionals tasked with addressing the needs of children and families faced with a broad variety of chronic illnesses requires a collaborative, integrated approach from case conceptualization to treatment. With chronic illness, functioning is affected by the disease process and characteristics certainly, but also the long-term effects of the illness on physical and emotional well-being. As noted with the DSC model (Wallander et al., 2003), factors such as the changes in the expression of the illness, potential side-effects of treatments, the child's daily and long-term sense of well-being and the ability to function in school and among peers, the family's ability to cope emotionally and financially while attempting to continuously meet the child's varying needs, are just some of the important considerations for all professionals to keep in mind while working with the child and their family. The DSC model, therefore, highlights where multiple different professionals might be involved in caring for the child and family, as well as the potential for maximizing the benefits of care through a coordinated approach.

To effectively provide integrated care requires acquisition of information relative to all aspects of function. The focus of this chapter is coping, with the interaction between coping and physiological processes, as well as coping and HRQoL. Unfortunately, few measures of child coping and HRQoL have been developed specifically for use with children with limited information on validity and reliability (Blount et al., 2008; Compas et al., 2012). Although the information garnered from these assessments can be useful in evaluating how the child manages their emotional reactions and their outlook for the future, the best match of coping mechanisms based on characteristics and illness process has not been established. This suggests that measures be specifically adapted for each type of illness (Cella et al., 2011; Varni et al., 2006), which further complicates the availability of the most useful measures. With most of the measures relying on self-report, the question arises as to the validity of the results (Compas et al., 2012).

As part of integrated care, treatment decisions need to address not only medical concerns, but also mental health and coping. Cognitive-behavioral approaches that emphasize education and training in various coping strategies may be the most helpful approach for families confronted with a child's illness (Sansom-Daly et al., 2012). As indicated in the case study included above, RGI and other non-traditional approaches may also be helpful in coping with, and potentially even managing the symptoms of some chronic illnesses. While the challenge of encouraging gratitude and a positive, future-focused outlook may be great, these are likely to be important goals in therapy. Much as parents need to be involved in medical treatment decisions (Swallow et al., 2013), it is important for parents to be involved in the support and scaffolding of their child's efforts to cope with illness (Cameaux & Jaser, 2010).

Directions for Future Research

Given the increasing rates of childhood chronic illnesses, coupled with the wide range of disorders and disabilities that result from these conditions, it is clear that more attention and research in these areas as a whole is needed. Research needs to take more of a developmental approach, as well as disease-specific approach, as there is a real deficit in our understanding of how children, and particularly very young children, perceive their experiences and cope, or do not cope, with their illnesses, and how this changes over time. To accomplish this, additional multi-source assessment of coping and HRQoL using developmentally appropriate measures and consideration of disease characteristics are required. Additional research also is needed to identify and fine-tune intervention approaches, particularly those that could be implemented in a school setting. Both CBT and mindfulness approaches are promising but require additional research support to better inform which specific approach may be most effective.

References

American Academy of Pediatrics, Council on Children with Disabilities. (2005). Care coordination in the medical home: Integrating health and related systems of care for children with special health care needs. *Pediatrics, 116*, 1238–1244.

Armstrong, F. D. (2006). Neurodevelopment and chronic illness: Mechanisms of disease and treatment. *Mental Retardation and Developmental Disabilities Research Reviews, 12*, 168–173.

Armstrong, F. D., & Briery, B. G. (2004). Childhood cancer and the school. In R. T. Brown (Ed.), *The handbook of pediatric psychology in school settings* (pp. 263–281). New York: Lawrence Erlbaum.

Armstrong, F. D., & Horn, M. (1995). Educational issues in childhood cancer. *School Psychology Quarterly, 10*, 292–304.

Ayers, T. S., Sandler, I. N., West, S. G., & Roosa, M. W. (1996). A dispositional and situational assessment of children's coping: Testing alternative models of coping. *Journal of Personality, 64*, 923–958.

Beck, A., Steer, R., & Brown, G. (1996). *Beck depression inventory manual* (2nd ed.). San Antonio, TX: The Psychological Corporation.

Blount, R. I., Simons, L. E., Devine, K. A., Jaaniste, T., Cohen, L. L., … Hayutin, L. G. (2008). Evidence-based assessment of coping and stress in pediatric psychology. *Journal of Pediatric Psychology, 33*, 1021–1045.

Boonen, H., & Petry, K. (2011). How do children with a chronic or long-term illness perceive their school re-entry after a period of homebound instruction? *Child: Care, Health, and Development, 38*, 490–496.

Bray, M. A., Kehle, T. J., Grigerick, S. E., Loftus, S., & Nicholson, H. (2008). Children with asthma: Assessment and treatment in school settings. *Psychology in the Schools, 45*, 63–73.

Bray, M., Root, M., Gelbar, N., Bruder, M. B., & Menzies, V. (2017). Relaxation and guided imagery for parents of offspring with developmental disabilities. *Journal of Psychological Abnormalities, 6*, 155. https://doi.org/10.4172/2471-9900.1000155

Cameaux, S. J., & Jaser, S. S. (2010). Autonomy and insulin in adolescents with type 1 diabetes. *Pediatric Diabetes, 11*, 498–504.

Cella, D., Nowinski, C., Peterman, A., Victorson, D., Miller, D., Lai, J., & Moy, C. (2011). The neurology quality-of-life measurement initiative. *Archives of Physical Medicine and Rehabilitation, 92*(10 Suppement), S28–S36.

Cella, D., Yount, S., Rothrock, N., Gershon, R., Cook, K., Reeve, B., … PROMIS Cooperative Group. (2007). The Patient-Reported Outcomes Measurement Information System (PROMIS): Progress of an NIH Roadmap cooperative group during its first two years. *Medical Care, 45*(5 Suppl 1), S3–S11.

Centers for Disease Control. (2009). *The power to prevent, the call to control*. Retrieved from http://www.cdc.gov/chronicdisease/resources/publications/AAG/chronic.htm

Charlton, C. (1997). Learning with epilepsy: In the classroom. *Australian Journal of Learning Disabilities, 2*, 30–33.

Cohen, C. S., & Williamson, G. (1988). Perceived stress in a probability sample of the United States. In S. Spacapan & S. Oskamp (Eds.), *The social psychology of health* (pp. 31–67). Newbury Park, CA: Sage.

Collins, C., Hewson, D. L., Munger, R., & Wade, T. (2015). *Evolving models of behavioral health integration in primary care*. New York: Milbank Memorial Fund. Retrieved from https://www.milbank.org/wp-content/uploads/2016/04/EvolvingCare.pdf

Compas, B. E., Boyer, M. C., Stanger, C., Colletti, R. B., Thomsen, A. H., Dufton, L. M., & Cole, D. A. (2006). Latent variable analysis of coping, anxiety/depression, and somatic symptoms in adolescents with chronic pain. *Journal of Consulting and Clinical Psychology, 74*, 1132–1142.

Compas, B. E., Connor, J., Osowiecki, D., & Welch, A. (1997). Effortful and involuntary responses to stress: Implications for coping with chronic stress. In B. H. Gottlieb (Ed.), *Coping with chronic stress* (pp. 105–130). New York: Plenum.

Compas, B. E., Connor-Smith, J. K., Saltzman, H., Thompson, A. H., & Wadsworth, M. (2001). Coping with stress during childhood and adolescence: Progress, problems, and potential. *Psychological Bulletin, 127*, 87–127.

Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology, 8*, 455–480.

Compas, B. E., Jaser, S. S., Reeslund, K., Patel, N., & Yarboi, J. (2017). Neurocognitive effects in children with chronic health conditions. *American Psychologist, 72*, 326–338.

Connor-Smith, J. K., Compas, B. E., Wadsworth, M. E., Harding Thompson, A., & Saltzman, H. (2000). Responses to stress in adolescence: Measurement of coping and involuntary stress responses. *Journal of Consulting and Clinical Psychology, 68*, 976–992.

Dempster, M., Howell, D., & McCorry, N. K. (2015). Illness perceptions and coping physical health conditions: A meta-analysis. *Journal of Psychosomatic Research, 79*, 506–513.

Desrocher, M., & Rovet, J. (2004). Neurocognitive correlates of type 1 diabetes mellitus in childhood. *Child Neuropsychology, 10*, 36–52.

Dufton, L. M., Dunn, M. J., Slosky, L. S., & Compas, B. E. (2011). Self-reported and laboratory-based responses to stress in children with pain and anxiety. *Journal of Pediatric Psychology, 36*, 95–105.

Eccleston, C., Fisher, E., Law, E., Bartlett, J., & Palermo, T. M. (2015). Psychological interventions for parents of children and adolescents with chronic illness. *Cochrane Database of Systematic Review*, (4), CD009660.

Edgar, K. A., & Skinner, T. C. (2003). Illness representations and coping as predictors of emotional wellbeing in adolescents with type 1 diabetes. *Journal of Pediatric Psychology, 28*, 485–493.

Eisenberg, N., Fabes, R. A., & Guthrie, I. K. (1997). Coping with stress: The roles of regulation and development. In S. A. Wolchik & I. N. Sandler (Eds.), *Handbook of children's coping: Linking theory and intervention* (pp. 41–70). New York: Plenum.

Ernst, M. M., & Mellon, M. W. (2016). Acceptance and commitment therapy (ACT) to foster resilience in pediatric chronic illness. In C. DeMichelis & M. Ferrari (Eds.), *Child and adolescent resilience within medical contexts: Integrating research and practice* (pp. 193–207). New York: Springer International.

Favreau, H., Bacon, S. L., Joseph, M., & Labrecque, M. (2012). Association between asthma medications and suicidal ideation in adult asthmatics. *Respiratory Medicine, 106*, 933–941.

Forrest, C. B., Bevans, K. B., Riley, A. W., Crespo, R., & Louis, T. A. (2011). School outcomes of children with special health care needs. *Pediatrics, 128*, 303–312.

Frank, N. C., Blount, R. L., & Brown, R. T. (1997). Attributions, coping, and adjustment in children with cancer. *Journal of Pediatric Psychology, 22*, 563–576.

Halfon, N., & Newachuck, P. W. (2010). Evolving notions of childhood chronic illness. *JAMA: Journal of the American Medical Association, 303*, 665–666.

Hanson, C. L., Cigrang, J. A., Harris, M. A., Carle, D. L., Relyea, G., & Brughen, G. A. (2012). Coping styles in youth with insulin-dependent diabetes mellitus. *Journal of Consulting and Clinical Psychology, 57*, 644–651.

Henderson, J. N., Noetzel, M. J., McKinstry, R. C., White, D. A., Armstrong, M., & DeBaun, M. R. (2003). Reversible posterior leukoencephalopathy syndrome and silent cerebral infarcts are associated with severe acute chest syndrome in children with sickle cell disease. *Blood, 101*, 415–419.

Hilliard, M. E., McQuaid, E. L., Nabors, L., & Hood, K. K. (2015). Resilience in youth and families living with pediatric health and developmental conditions: Introduction to the special issue on resilience. *Journal of Pediatric Psychology, 40*, 835–839.

Hocking, M. C., Hobbie, W. L., Deatrick, J. A., Lucas, M. S., Szabo, M. M., Volpe, E. M., & Barakat, L. P. (2011). Neurocognitive and family functioning and quality of life among adult survivors of childhood brain tumors. *Clinical Neuropsychology, 25*, 942–962.

Jacob, E., Miaskowski, C., Savedra, M., Beyer, J. E., Treadwell, M., & Styles, L. (2006).Changes in sleep, eating, and activity levels in children with sickle cell disease. *Journal of Pediatric Nursing, 21*, 23–34.

Jacob, M. M., Gonzales, K. L., Calhoun, D., Beals, J., Jacobsen Muller, C., Goldberg, J., & Howard, B. V. (2013). Psychological trauma symptoms and type 2 diabetes prevalence, glucose control, and treatment modality among American Indians in the strong heart family study. *Journal of Diabetes and Its Complications, 27*, 553–557.

Jaser, S. S., & White, L. E. (2011). Coping and resilience in adolescents with type 1 diabetes. *Child: Care, Health, and Development, 37*, 736–746.

Juniper, E. (1996). *Asthma quality of life questionnaire*. Hamilton, ON, Canada: McMaster University Medical Center.

Kohut, S. A., Stinson, J., Davies-Chalmers, C., Ruskin, D., & van Wyk, M. (2017). Mindfulness-based interventions in clinical samples of adolescents with chronic illness: A systematic review. *The Journal of Alternative and Complementary Medicine, 23*, 581–589.

Lyubomirsky, S., King, L., & Diener, E. (2005). The benefits of frequent positive affect: Does happiness lead to success? *Psychological Bulletin, 131*, 803–855.

Madan-Swain, A., Katz, E. R., & LaGory, J. (2004). School and social reintegration after a serious illness or injury. In R. T. Brown (Ed.), *Handbook of pediatric psychology in school settings* (pp. 637–654). Mahwah, NJ: Erlbaum.

Martinez, Y. J., & Ercikan, K. (2009). Chronic illnesses in Canadian children: What is the effect of illness on academic achievement, and anxiety, and emotional disorder? *Child: Care, Health, and Development, 35*, 391–401.

McCabe, K., Bray, M. A., Kehle, T. J., Theodore, L. A., & Gelbar, N. W. (2011). Promoting happiness and life satisfaction. *Canadian Journal of School Psychology, 26*(3), 177–192.

McCracken, L. M., & Vowles, K. E. (2014). Acceptance and commitment therapy and mindfulness for chronic pain. *American Psychologist, 69*, 178–187.

McDougall, J., King, G., deWit, D. J., Miller, L. T., Hong, S., Offord, D. R., … Meyer, K. (2004). Chronic physical health conditions and disability among Canadian school-aged children: A national profile. *Disability and Rehabilitation, 26*, 35–45.

Middleton, R. J. (2014). Meeting the psychological care needs of patients with cancer. *Nursing Standard, 28*(21), 39–45.

Nabors, L. A., Little, S. G., Akin-Little, A., & Iobst, E. A. (2008). Teacher knowledge of and confidence in meeting the needs of children with chronic medical conditions: Pediatric psychology's contribution to education. *Psychology in the Schools, 45*, 217–226.

National Center for Health Statistics. (2012). *Summary health statistics for U.S. children: National health interview survey, 2011*. Vital and Health Statistics, Series 10, Number 254. Retrieved January 30, 2013, from http://www.cdc.gov/nchs/data/series/sr_10/sr10_254.pdf

National Center for Health Statistics. (2006). *Health United States 2006*. Retrieved from https://www.cdc.gov/nchs/data/hus/hus06.pdf

National Institute of Health. (2017). *Patient Reported Outcomes Measurement Information System (PROMIS)*. Retrieved from https://commonfund.nih.gov/promis/index

Newacheck, P. W., & Halfon, N. (2000). Prevalence, impact, and trends in childhood disability due to asthma. *Archives of Pediatrics and Adolescent Medicine, 154*, 287–293.

Peck, H. L., Bray, M. A., & Kehle, T. J. (2003). Relaxation and guided imagery: A school-based intervention for children with asthma. *Psychology in the Schools, 40*, 657–675. https://doi.org/10.1002/pits.10127

Perrin, J. M., Bloom, S. R., & Gortmaker, S. L. (2007). The increase of childhood chronic conditions in the United States. *JAMA: Journal of the American Medical Association, 297*, 2755–2759. https://doi.org/10.1001/jama.297.24.2755

Riccio, C. A., Pliego, J., & Rae, W. A. (2016). Mind-body approaches and chronic illness: Status of research. *International Journal of School and Educational Psychology, 4*, 16–24.

Robinson, K. E., Pearson, M. M., Cannistracti, C. J., Anderson, A. W., Kuttesch, J. F., Jr., Wymer, K., … Compas, B. E. (2015). Functional neuroimaging of working memory in survivors of childhood brain tumors and health children: Associations with coping and psychosocial outcomes. *Child Neuropsychology, 21*, 779–802. https://doi.org/10.1080/09297049.2014.924492

Rosoff, P. M. (2006). The two-edged sword of curing childhood cancer. *New England Journal of Medicine, 355*, 1522–1523.

Rudolph, K. D., Dennig, M. D., & Weisz, J. R. (1995). Determinants and consequences of children's coping in the medical setting: Conceptualization, review and critique. *Psychological Bulletin, 118*, 328–357.

Sansom-Daly, U. M., Peate, M., Wakefield, C. E., Bryant, R. A., & Cohn, R. J. (2012). A systematic review of psychological interventions for adolescents and young adults living with chronic illness. *Health Psychology, 31*, 380–393. https://doi.org/10.1037/a0025977

Santoro, N., Giordano, P., Del Vecchio, G. C., Guido, G., Rizzari, C., Varotto, S., … De Mattia, D. (2005). Ischemic stroke in children treated for acute lymphoblastic leukemia: A retrospective study. *Journal of Pediatric Hematology and Oncology, 27*, 153–177.

Saricoban, H. E., Ozen, A., Harmanci, K., Razi, C., Zahmacioglu, O., & Cengizlier, M. R. (2011). Common behavioral problems among children with asthma: Is there a role in asthma treatment? *Annals of Allergy, Asthma & Immunology, 106*, 200–204.

Sawyer, M. G., Spurrier, N., Whaites, L., Kennedy, D., Martin, A. J., & Baghurst, P. (2001). The relationship between asthma severity, family functioning and health-related quality of life of children with asthma. *Quality of Life Research, 9*, 1105–1115.

Schwartz, L., & Major, E. O. (2006). Neural progenitors and HIV-1 associated CNS disease in adults and children. *Current HIV Research, 4*, 319–327.

Shaw, S. R., & McCabe, P. C. (2008). Hospital-to-school transition for children with chronic illness: Meeting the new challenges of an evolving health care system. *Psychology in the Schools, 45*, 74–87.

Shirkey, K. C., Smith, C. A., & Walker, L. S. (2011). Dispositional versus episode-specific assessment of children's coping with pain. *Journal of Pediatric Psychology, 36*, 74–83.

Skinner, E., & Edge, K. (1998). Reflections on coping and development across the lifespan. *International Journal of Behavioral Development, 22*, 357–366.

Skinner, E., Edge, K., Altman, J., & Sherwood, H. (2003). Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. *Psychological Bulletin, 129*, 216–269.

Skinner, E. A., & Wellborn, J. G. (1994). Coping during childhood and adolescence: A motivational perspective. In D. Featherman, R. Lerner, & M. Perlmutter (Eds.), *Life-span development and behavior* (Vol. 12, pp. 91–133). Hillsdale, NJ: Erlbaum.

Smith, J., Richardson, J., Hoffman, C., & Pilkington, K. (2005). Mindfulness-based stress reduction as supportive therapy in cancer care: Systematic review. *Journal of Advanced Nursing, 52*, 315–332.

Spielberger, C. D., Gorsuch, R. L., Lushene, R., Vagg, P. R., & Jacobs, G. A. (1983). *Manual for the state-trait anxiety inventory*. Palo Alto, CA: Consulting Psychologists Press.

Steca, P., Greco, A., Monzani, D., Politi, A., Gestra, R., Ferrari, G., … Parati, G. (2013). How does illness severity influence depression, health satisfaction and life satisfaction in patients with cardiovascular disease? The mediating role of illness perception and self-efficacy beliefs. *Psychology & Health, 28*, 765–783.

Swallow, V. M., Nightingale, R., Williams, J., Lambert, H., Webb, N. J. A., Smith, T., … Allen, D. (2013). Multidisciplinary teams, and parents, negotiating common ground in shared-care of children with long-term conditions: A mixed methods study. *BMC Health Services Research, 13*(264), 1–17.

Szulczewski, L., Mullins, L. L., Bidwell, S. L., Eddington, A. R., & Pai, A. L. H. (2017). Meta-analysis: Caregiver and youth uncertainty in pediatric chronic illness. *Journal of Pediatric Psychology, 42*(4), 395–421.

Thompson, R. J., Jr., & Gustafson, K. E. (1996). *Adaptation to chronic childhood illness*. Washington, DC: American Psychological Association.

Van Cleave, J., Gortmaker, S. L., & Perrin, J. M. (2010). Dynamics of obesity and chronic health conditions among children and youth. *JAMA: Journal of the American Medical Association, 303*, 623–630.

van der Lee, J. H., Mokkink, L. B., Groutenhuis, M. A., Heymans, H. S. A., & Offinga, M. (2007). Definitions and measurement of chronic health conditions in childhood. *JAMA: Journal of the American Medical Association, 297*, 2741–2751.

Vance, Y. H., & Eiser, C. (2001). The school experience of the child with cancer. *Child: Care, Health and Development, 28*, 5–19.

Varni, J. W., Lane, M. W., Burwinkle, T. M., Fontaine, E. N., Youssef, N. N., Scwimmer, J. B., … Easley, D. J. (2006). Health-related quality of life in pediatric patients with irritable bowel syndrome: A comparative analysis. *Journal of Developmental and Behavioral Pediatrics, 27*, 451–458.

Varni, J. W., Limbers, C. A., & Burwinkle, T. M. (2007). Impaired health-related quality of life in children and adolescents with chronic conditions: A comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the PedsQL 4.0 Generic Core Scales. *Health and Quality of Life Outcomes, 16*, 43.

Wade, J. F., Dang, C. V., Nelson, L., & Wasserberger, J. (2010). Emergent complications of the newer anticonvulsants. *The Journal of Emergency Medicine, 38*, 231–237.

Walker, L. S., Smith, C. A., Garber, J., & Van Slyke, D. A. (1997). Development and validation of the pain response inventory for children. *Psychological Assessment, 9*, 392–405.

Wallander, J. L., & Varni, J. W. (1992). Adjustment in children with chronic physical disorders: Programmatic research on a disability-stress-coping model. In A. M. LaGreca, L. J. Siegel, J. L. Wallender, & C. E. Walker (Eds.), *Stress and coping in child health* (pp. 279–298). New York: Guilford.

Wallander, J. L., Thompson, R. J., & Alriksson-Schmidt, A. (2003). Psychosocial adjustment of children with chronic illness. In M. C. Roberts (Ed.), *Handbook of pediatric psychology* (3rd ed., pp. 141–158). New York: Guilford.

World Health Organization (WHO). (1993). *Measurement of QOL in children*. Geneva, Switzerland: World Health Organization, Division of Mental Health.

Zanon, R. B., Da Silva, M. A., De Mendonça Filho, E. J., Bandeira, D. R., Dos Santos, M. A., Halpern, R., & Bosa, C. A. (2017). Brazilian study of adaptation and psychometric properties of the Coping Health Inventory for Parents. *Psicologia: Reflexão E Crítica, 30*, 65–69.

Treatment Adherence

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Kathleen L. Lemanek and Heather L. Yardley

Abstract

Patient adherence to medical provider's recommendations is considered the main mediator between health care practice and patient outcomes. Implications to patients, families, and society of nonadherence include inadequate disease management or treatment outcome, increased morbidity and mortality, and escalating health care costs. This chapter will summarize the literature in pediatric adherence with attention to defining adherence, providing prevalence estimates, describing factors affecting adherence and models of adherence, and outlining assessment measures and intervention strategies. The chapter will also offer a case example that incorporates aspects of these topics. Finally, the chapter concludes with suggestions for clinical practice and research to promote adherence.

Patient adherence to medical provider's recommendations is considered the main mediator between health care practice and patient outcomes (Kravitz & Melnikow, 2004). Implications to patients, families, and society of nonadherence include inadequate disease management or treatment outcome, increased morbidity and mortality, and escalating health care costs (DiMatteo, 2004b; Rapoff, 2010). This chapter will summarize the literature in pediatric adherence with attention to defining adherence, providing prevalence estimates, describing factors affecting adherence and models of adherence, and outlining assessment measures and intervention strategies. The chapter will also offer a case example that incorporates aspects of these topics. Finally, the chapter concludes with suggestions for clinical practice and research to promote adherence.

Definition of Compliance/Adherence

The definition and meaning of medical compliance/adherence have changed over the past decades with an increased focus on a collaborative relationship between patients, families, and medical providers. One of the original definitions of medical compliance was proposed by Haynes (1979), "the extent to which a person's behavior (in terms of medications, following diets, or executing lifestyle changes) coincides with medical or health advice" (pp. 1–2). This definition focuses on patients readily following instructions and recommendations of medical providers, with minimal input or questions from the patients and

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families. The term adherence replaced compliance as models of health care began to highlight disease management and shared decision-making (Bauman, 2000). Murphy and Coster (1997) proposed the following definition of adherence: "the willingness and ability of a person to follow health instructions, to take medications as prescribed, to attend scheduled clinic appointments, and to complete recommended investigations" (p. 797). This definition emphasizes the partnership between patients and medical providers, with mutual and ongoing interactions. A recent distinction has been made between adherence and self-management, where management is considered a broader construct that includes both behaviors and processes families follow to manage a medical condition (Modi et al., 2012).

Prevalence of Nonadherence

Adherence to medical recommendations is estimated across pediatric populations to be at or less than 50% (Rapoff, 2010) although there have been estimates putting nonadherence between 75 and 88% (Hommel, Davis, & Baldassano, 2009; Logan, Zelikovsky, Labay, & Spergel, 2003).

Classification categories of nonadherence have been proposed that expand the meaning of medical adherence. Categories of nonadherence usually pertain to medication management but may extend to other regimen components, such as doing daily chest physiotherapy or taking blood glucose readings. Unintentional nonadherence has been characterized as forgetfulness or being careless about medications (Gadkari & McHorney, 2012). Chronic nonadherence refers to a patient refraining from taking medications or following recommendations on a consistent basis, while acute nonadherence may reflect episodic or periodic nonadherence with recommendations. Finally, cost-related nonadherence (CRN) is a more recent category and includes delaying refills, taking medications sporadically or splitting pills to reduce medication costs (Gibson, Ozminkowski, & Goetzel, 2005).

Approximately 125,000 deaths per year are attributed to nonadherence and about 33–69% of hospital admissions related to medications are due to nonadherence (Benjamin, 2012). Indirectly, nonadherence leads to incorrect prescribing of medication and excessive health care utilization (Lemanek, Kamps, & Chung, 2001; Quittner, Espelage, Ievers-Landis, & Drotar, 2002).

Factors Affecting Adherence

Numerous factors have been associated with promoting or impeding adherence depending on the correlational nature of the relationship. Predictive studies have been scant in the literature due, in part, to the complex interrelationship between these factors. However, studies support an association between greater number of risk factors and poorer adherence (Logan et al., 2003). These factors have been grouped into one of four board categories: (1) patient/family factors, (2) disease factors, (3) regimen factors, and (4) health system-related factors (Goh, Tan, Thirumoorthy, & Kwan, 2017; Rapoff, 2010).

Patient factors highlight demographic variables, knowledge, and psychological functioning. Adolescents, patients with deficits in executive functioning skills, and patients/families from minority or lower socioeconomic status show less adherence (e.g., Dew et al., 2009; McQuaid, Everhart, Seifer, et al., 2012; Perez, Patel, Lord, et al., 2017). Patients' and parents' knowledge of the disease and regimen components have been consistently related to adherence (e.g., Carbone, Zebrack, Plegue, Joshi, & Shellhaas, 2013). Rapoff (2010) has distinguished between patients and parents "knowing that" (having knowledge) and "knowing how" (having specific skills to implement the regimen). La Greca and Bearman (2003) extended this conceptualization of knowledge to decision-making about executing regimen components in daily situations, which may, in fact, be related to executive functioning skills. Adherence is more problematic in those patients with behavioral and psychiatric problems that were present before or following a medical condition. Internalizing problems, such as anxiety and depression, (e.g., Gray, Denson, Baldassano, & Hommel, 2012), externalizing problems, such as conduct problems and hyperactivity, (e.g., Malee et al., 2011) and general distress (e.g., Dew et al., 2009) are associated with poorer adherence.

Parental distress, family conflict and disorganization, parent over- or under-involvement, and poor communication between patient, family, and medical providers are associated with poor adherence (e.g., Dew et al., 2009; DiMatteo, 2004a; Landers, Friedrich, Jawad, & Miller, 2016). The differential influence of these factors within families of diverse cultural and ethnic backgrounds has not been extensively examined. One study, though, found greater adherence in families who recently immigrated to the USA (Hsin, La Greca, Valenzuela, Moine, & Delamater, 2010).

The second category of factors pertains to the nature of the medical condition. Adherence declines over time, especially with earlier age of onset (e.g., Hilliard, Mann, Peugh, & Hood, 2013). Patients who are not experiencing symptoms or a reduction in the frequency or severity of symptoms show poorer adherence (e.g., Adams, Dreyer, Dinakar, & Portnoy, 2004). Finally, patient and family beliefs about benefits of the regimen promote adherence, while beliefs about severity and susceptibility of the disease, and barriers to care hinder adherence (e.g., Riekert & Drotar, 2002).

The third category is factors associated with the regimen. Poor adherence is related to complex and/or lengthy regimens (e.g., Chandwani et al., 2010), regimens that interfere with activities (e.g., Modi & Quittner, 2006), and regimens that involve frequent and/or aversive hospital-based procedures (Goh et al., 2017). Finally, physical and cosmetic side effects and ingestion issues (e.g., taste of medication) are associated with poor adherence (e.g., Simons, McCormick, Devine, & Blount, 2010).

Health system-related factors reflect perceptions of patients/families' communication with medical providers and hospital experiences, and barriers to medical providers' adherence to clinical guidelines (Goh et al., 2017). In general, positive communication between patients/families and health care providers about the medical condition and its treatment (e.g., DiMatteo, 2004a), and perception of support (e.g., Cohen & Wamboldt, 2000) are correlated with adherence. Medical providers' adherence to clinical guidelines may impact medical outcomes for patients, which may then indirectly affect patient adherence. Barriers to medical providers' adherence include lack of knowledge or awareness of current treatments, and flexibility in implementing guidelines or applying them correctly (Cabana, Rand, Becher, & Rubin, 2001). Other factors associated with nonadherence include insufficient health insurance, availability of medications, and financial and transportation problems (Goh et al., 2017).

Models of Adherence

Several models of adherence have been proposed, each providing a slightly different approach to understanding and encouraging adherence behaviors. One of the most known models is the Health Belief Model (HBM), which proposes the perceived susceptibility (beliefs about the risk of an illness), severity (consequences of an illness or treatment), benefits (benefits of taking a health action), barriers (perceived or actual barriers to care), and cues (internal or external cues that prompt action) combine to influence adherence. The HBM has been shown to significantly account for a large portion of the variance in adherence behaviors (Jones et al., 2014; Soliday, 2000). Health beliefs have been shown to influence adherence behaviors in parents (Conn, Halterman, Lynch, & Cabana, 2007) and in adolescents (Bond, Aiken, & Somerville, 1992).

Clinically, interventions to improve adherence would depend on the most prominent aspect of the HBM (e.g., addressing barriers) area. For example, helping the individual have a realistic understanding of susceptibility would entail having patients monitor symptoms closely and reviewing potential benefits to adhering to their regimen. In terms of barriers, it is important to help patients identify and then problem-solve identified barriers to adhering to their regimen.

Cues can be more difficult to help patients identify. For example, if patients are asymptomatic when nonadherence they may need external cuing to regimen activities, when symptoms do not provide cues.

Social cognitive theory emphasizes the interaction between behavior, internal personal factors, and the external environment when considering engaging in health behaviors (Bandura, 2004). In this model, the mechanism by which health behaviors happen is based on self-efficacy, which includes having the skills and confidence to use skills effectively. Self-efficacy is influenced by several factors, including learning through experience, vicarious learning, verbal persuasion, physiological states, and affective states.

In terms of improving adherence through this model, the provider will want to emphasize skills building so the patient is aware of and comfortable with the tasks required. Second, providers should be assessing self-efficacy and working to bolster this belief through the use of examples, videos, or in vivo practice; as well as encouraging patients to attribute success to their hard work. Finally, assessing and helping patients manage outcome expectations (e.g., adherence leads to positive benefits) would be part of this intervention.

The theory of planned behavior (TPB; Ajzen, 1991) is an extension of the theory of reasoned action. Reasoned action theory suggests that attitude (evaluation of a behavior), subjective norm (someone else would like this to happen), and motivation (higher intention) combine to impact the likelihood of completing a behavior. Adding the idea that behavior can be planned (i.e., planned behavior) adds perceived behavioral control to the model. Perceived behavioral control involves the evaluation of self-efficacy to complete the behavior and the controllability of a behavior and has been shown to be related to adherence (Downs & Hausenblas, 2005).

Interventions to improve adherence under this model are similar to those for the social cognitive theory. For example, providers should assess the patient's motivation and perception of being able to control the behaviors and whether he/she believes there can be a positive outcome. Once this perception is established, helping patients to understand the positives around engaging in appropriate adherence behaviors and increasing their self-efficacy is key to encouraging adherence.

Prochaska and DiClemente (1983) and Prochaska (2013) described the transtheoretical or stages of change model. The stages include pre-contemplation (no intent to take action), contemplation (evaluating pros and cons of changing behavior), preparation (preparing to take action in the immediate future), action (taking specific actions to change behavior), and maintenance (sustained changes and relapse prevention). Each stage represents a relatively discrete period in the evolution of the health behaviors and involves both overt and covert behaviors, decisional balance, and self-efficacy. Presence in different stages can both impact adherence (Guite et al., 2014) and appropriate intervention to improve adherence. Providers or school personnel should work to "stage" a patient or child and base intervention or encouragement on where the child falls. For example, in the pre-contemplation/contemplation stage, providing more personalized education and opportunities for discussion would be appropriate, while in the preparation stage, assisting in setting specific and achievable goals would be optimal. In the action stage, providing behavioral skills training and self-management strategies (i.e., rewards) may be helpful. Finally, in the maintenance stage, providers should help to anticipate and strategize how to manage obstacles/barriers.

Applied behavior analytic theory suggests that behavior is shaped through environmental contingencies including: positive reinforcement, positive punishment, negative reinforcement, and extinction (negative punishment; Baer, Wolf, & Risley, 1968; DeLuca & Holborn, 1992). Thus, we maintain or stop a behavior based on the learned consequences of that behavior and, as such, all behavior is assumed to be rule governed. The amount of adherence to following "rules" is based on the history of reinforcement for following rules, immediate local consequences for not following rules and contact with contingencies in the rules (e.g., having familiarity with the consequence before receiving it again). When applied to adherence behaviors, many of the contingencies may be far removed from the behavior and thus, do not lend themselves to quick learning in this model. For example, many of the long-term consequences of nonadherence to diabetes regimen manifest weeks to years later and thus might not translate to immediate learning.

To help improve adherence under this model, providers should perform a functional analysis by which they operationally define adherence, identify the antecedents that predict adherence, generate consequences (e.g., rewards for completing behaviors, negative consequences for missing tasks) to maintain behavior and collect data on performance. In addition, it is helpful to assist patients and families in looking for cues to adherence behaviors when the individual is asymptomatic (i.e., preventative adherence) and discussing ways to reduce negative consequences.

Adherence Measures

Adherence measures can be classified along a continuum of directness to indirectness (Rapoff, 2010) or objective to subjective (Duncan, Mentrikowski, Wu, & Fredericks, 2014). Treatment outcomes, such as clinical symptoms and quality of life, have been assessed along with adherence. Each measure has distinct advantages and disadvantages that affect clinical and research reliability, validity, and utility. Overall, objective measures reflect lower rates of adherence but are more reliable and valid measures (DiMatteo, 2004b). Objective measures may be more readily available to administer by medical providers and pediatric psychologists, while subjective measures can be initiated by others with knowledge of and experience with them, such as school personnel and parents. The following summary of information on adherence measures is based on literature reviews by Duncan et al. (2014), Quittner, Modi, Lemanek, Ievers-Landis, and Rapoff (2008), and Rapoff (2010).

Bioassays directly measure drug levels, metabolic products of drugs, or markers (inert substances) in bodily fluids, such as blood, urine, and saliva. The rate of absorption depends on the dose administered and the route of administration, such as orally through the mouth or injected into the skin. Data from assays are quantifiable, which allows providers to adjust doses. However, assays are not available for all medications, they are costly, and are less reliable due to pharmacokinetic variations based on drug metabolism factors and individuals' absorption rates.

Automated measures pertain to electronic monitoring of different regimen components where the date and time ("timestamping") of tablet or liquid medication removal from standard vials, removal of pills from blister packages, actuation of metered-dose inhalers, blood glucose test results, and completion of chest physiotherapy are recorded and stored. Electronic monitors, such as the Medication Management System (MEMS) bottle caps and the Metered Dose Inhaler (MDI), are often considered the "gold standard" when assessing adherence because they provide continuous and specific dosing data in real-time. Unfortunately, these automated systems often experience mechanical failures, are costly, and do not measure actual consumption of medications or performance of other adherent behaviors. The cost disadvantage may be offset by reduction in unnecessary clinic visits and hospitalizations, laboratory tests, and medication changes (Urquhart, 1997).

Pharmacy refill data, pill counts, and canister weights (e.g., inhaled medications) are objective measures of adherence though counts and weights are indirect. Refill records can be used to arrive at a medication possession ratio (MPR) to determine the percentage of time a patient has medication available. This ratio is calculated by dividing the sum of days of a medication for all fills during a specific period of time by the number of days during that time. Pharmacy refill data are inexpensive, if fees are not charged by pharmacies, and seem to be accurate, but obtaining such data can be difficult if several pharmacies are used or not possible if medications are filled through automatic medication programs. Pill counts and canister weights are also inexpensive and easy to collect, but again actual consumption of medication is not measured.

Subjective reports from patients and parents are the most common methods used and include structured interviews, questionnaires, and diaries or self-monitoring of adherence. Most questionnaires and interviews are disease specific to such pediatric populations as diabetes (e.g., Adherence in Diabetes Questionnaire; Kristensen, Thastum, Mose & Birkebaek, 2012) and asthma (e.g., Family Asthma Management System Scale; McQuaid, Walders, Kopel, Fritz, & Klinnert, 2005). Diary data on adherence can be obtained from written logs, hand-held computers (PDAs), or phone interviews. The 24-h recall is a well-known phone-based diary that is completed at least three times (2 weekdays and 1 weekend) with attention to patient's day activities, including adherence (Johnson et al., 1992). Unstructured interviews can be administered during clinic but questions should focus on discrete behaviors and within a brief time frame (e.g., day or week before visit). Likert-type rating scales, if added to the interview, should be more specific than, for example, 0 = not adherent to 10 = very adherent. Including behavior anchors along this continuum and a time frame would improve specificity, such as did not complete any chest physiotherapy for cystic fibrosis the past week to completed one therapy a day to completed two therapies a day as prescribed. Advantages of these methods include they are inexpensive, available for multiple informants, and provide information about adherence to regimen components and factors influencing adherence. Disadvantages involve concern that self-reports are subject to recall bias and social desirability factors that, then, result in overestimates of adherence.

Provider estimates involve global ratings of adherence to regimen components by medical providers. Ratings can be dichotomous (Yes/No) for overall adherence or for each regimen component, or according to a Likert-type scale, ranging from, for example, 4 (almost always adherent) to 0 (rarely adherent). Provider estimates are cost-effective and feasible, but adherence can be overestimated, perhaps due to ratings being unreliable as they are based on perceptions of individual providers.

Treatment outcomes are not direct measures of adherence but are associated with adherence as they are indicators of health status. Health status indicators include clinical signs usually obtained through instrumentation, such as blood pressure or limited joint range of motion, and symptoms more often based on patient- or parent-report, such as pain or fatigue. Another measurement of treatment outcome is the subjective perception of quality of life across domains of physical, emotional, social, and academic/work functioning. Measures can be general or specific, depending on the degree to which the impact of illness, injury, or medical treatment on daily functioning is referenced. While treatment outcome measurement can be one aspect of routine clinical health care as a means of tracking treatment goals, it is not a measure of adherence.

A consistent recommendation from the literature reviews on adherence measures is that at least two measures of adherence from multiple informants should be used to account for the advantages and disadvantages of each measure (DiMatteo, 2004b; Duncan et al., 2014; Quittner et al., 2008). Electronic monitoring and diaries have been identified as the two most accurate measures of adherence in terms of convergence of data. Self-report questionnaires and interviews may provide more qualitative information about barriers to adherence. Treatment outcome measurement should be incorporated into clinical practice and research when assessing adherence, along with the impact of nonadherence on health care costs to families and to society (Rapoff, 2010). Finally, it is recommended that assessment of adherence occur at each clinic visit and be time-efficient to facilitate communication about the nature of adherence and barriers (Decivita & Dobkin, 2005; Hommel et al., 2009; Wu et al., 2013).

Adherence Improvement Strategies

Several types of specific adherence improvement strategies have been studied. Educational strategies involve providing information in verbal or written form to educate the family or individual about the necessary tasks of adherence and consequences of nonadherence. Educational interventions have been found initially helpful but are often not enough in isolation to maintain adherence (Dean, Walters, & Hall, 2010). Organizational strategies include addressing the way that care is delivered and increasing access, or simplifying regimens (DiMatteo, 2004a). Improving communication and maintaining a positive provider–patient relationship has been shown to be effective in maintaining adherence (DiMatteo, 2004a).

Cognitive behavioral therapy (CBT) is one theoretical model that underpins many adherence interventions. CBT seeks to help individuals to "reframe" maladaptive thoughts into more positive/realistic ones (i.e., "I'll never be adherent" to "I can improve my adherence if I choose.") through cognitive restructuring. CBT also works to modify behavior in pursuit of identified goals.

Incorporating behavioral strategies into adherence promotion efforts has been shown to increase the effectiveness of intervention (Dean et al., 2010). Assessing and addressing barriers to adherence may involve using behavioral interventions (i.e., self-monitoring, activity planning, or incentives) and use of technology (apps, reminders). Multicomponent strategies are often the most effective (Kahana, Drotar, & Frazier, 2008) although they have only a medium effect size. Multicomponent interventions often combine education, behavioral components, and family intervention. Specifically, family support and communication have been examined (DiMatteo, 2004a). For providers or school personnel, monitoring and managing frustration with adherence, providing advice without "bossing," and building rapport with the individual are important in helping him/her maintain adherence for the long term (Gould & Mitty, 2010).

Case Example

Chris (a pseudonym) was an 18-year-old male with a 3-year history of type 1 diabetes (T1D). He was currently in high school, involved in sports, and reportedly had several friends. Chris was referred to psychology for nonadherence, worries about his diabetes management, and no longer attending school regularly. This behavior increased over the 2 months before the referral. His specific worries about diabetes management included having long-term consequences, having an "episode" at school and not being able to obtain help, not being able to pursue a medical career, and dying early. As a result of these concerns, he was no longer caring for his diabetes stating that he can "tell" when his blood sugar is out of range and did not want to see the evidence on his meter. Chris was also no longer attending school as he did not "see the point" if he could not become a physician.

Chris was seen by a pediatric psychologist specializing in nonadherence, particularly related to T1D. He was seen for 15 sessions of cognitive behavioral therapy that included several components related to adherence promotion. Initially, education regarding T1D and its management was provided to assure Chris that taking care of his diabetes could prevent any long-term sequelae and early death. Cognitive restructuring was taught to help Chris combat some of his anxiety regarding his treatment, particularly concerns about accessing health care at school. He was encouraged to review safety procedures in place to help him (i.e., nurse being available, peers to take him to nurse). In addition, Chris was asked to educate friends about his health concerns (at a level with which he was comfortable) so that he could have additional social support. In terms of behavioral strategies, Chris set a goal of increasing blood glucose checks and was able to find an app that prompted him and recorded this information. The results of his checks could then be sent to his physician, who was coached to provide Chris with additional praise and constructive feedback regarding his progress. Positive reinforcement was used to encourage reentry into school. Chris was provided with additional privileges from his parents when he was able to attend school for the whole day; Chris identified these privileges before the contingency plan was put into place.

Over the course of treatment, Chris returned to school and increased his blood glucose checking.

He also reported being better able to accept his illness and reduce his fears. Chris's case demonstrates the need to design and implement a multi-component approach to treatment as his nonadherence was multi-factored. Using only an educational approach would not have addressed his worries and maladaptive thoughts around his diabetes management. However, not including education would have left him without the needed information to improve his care and better understand his illness. Coordinating care between the patient, the family, school personnel, and medical providers also was essential to ensure consistency in setting and implementing intervention goals and strategies.

Conclusions and Future Directions

In rethinking adherence, Steiner (2012) identified three common assumptions or misconceptions about adherence: (a) adherence is a single behavior rather than a cluster of behaviors, (b) sociodemographic or clinical characteristics can predict whether an individual will adhere, and (c) clinicians/medical providers can successfully improve adherence on their own regardless of time, interest, or training in adherence counseling. The conceptualization of adherence as a single or cluster of behavior(s) will affect multiple aspects of adherence, such as prevalence rates and the impact of adherence on health outcomes, based on the definition used and assessment methods administered (Quittner et al., 2008). With respect to strengthening the reliability and validity of assessment measures, the literature reflects an increased attention to electronic methods of measurement and technology in general. Recommendations to expand this focus include the development of brief, patient-reported adherence measures that can be incorporated into electronic health records, linkage of computerized prescription orders with pharmacy dispensing records, and inexpensive electronic measures (Steiner, 2012).

Multiple risk factors correlate with adherence/nonadherence but the predictive ability of these sociodemographic or clinical characteristics is minimal. The sensitivity and specificity of assessment measures should be examined to identify individual differences in beliefs and behaviors within racial, ethnic, and cultural and economic factors that influence adherence (Quittner et al., 2008; Steiner, 2012). Health literacy is an overlooked sociodemographic characteristic that has been positively associated with adherence and found to be a predictor of health outcome (Miller, 2016). Health literacy is defined as the ability to read, understand and act on health information (Healthy People, 2010). Clinical practice guidelines will require consideration of any individual differences to promote optimal adherence. Verbal and written communication between patients, families and medical providers using terminology understood by patients and families is one recommended education tool (Miller, 2016). Electronic medical records can be used to provide patients and families with written comprehensive treatment plans (Quittner et al., 2008) or "dashboards" to monitor specific intervention steps (Steiner, 2012). Miscommunication about aspects of the medical condition and its treatment may be decreased by referring to these written plans during medical appointments (Quittner et al., 2008). These treatment plans can also be given to school personnel to assist in monitoring symptom management and regimen adherence, and facilitate communication with patients, families, and medical providers.

Evidence-based practice requires an integration of research findings and clinical practice (Rapoff, 2010). Duncan et al. (2014) have noted that the literature on translating research findings into clinical practice is limited and have, therefore, offered the following recommendations: (a) research efforts need to be directed at developing adherence assessment and interventions that are time-efficient and applicable in clinical settings, (b) education and training of clinicians need to occur for translation of findings, (c) a quality improvement approach in practice should be applied to help demonstrate effectiveness of adherence assessment and intervention strategies, and (d) effective strategies for collaborating with multidisciplinary teams need to be developed. Duncan et al. (2014) also indicate how educating health care providers can occur when working within multidisciplinary teams through formal workshops or training, grand rounds presentations, and/or informally through clinical rounds and team meetings.

Multicomponent adherence intervention strategies should be emphasized in future clinical and research efforts (Rapoff, 2010; Wu et al., 2013). Rapoff (2010) has recommended targeting patients: (a) whose adherence drops below some acceptable level (80%) and (b) who experience compromised health care outcomes. Clinicians will then need to decide which assessment/intervention strategy to use, how these strategies are tailored to individual differences of patients and families, what treatment materials to implement, how assessment and intervention are carried out within multidisciplinary teams, and how interventions are evaluated in real-world practices (Duncan et al., 2014; Wu et al., 2013).

A Distillation and Matching Model has been proposed by Duncan et al. (2014) to employ in future research to identify aspects of effective and tailored adherence promotion strategies across pediatric populations. This model posits that it is possible to identify the core effective elements in evidence-based practice (distillation) and apply them based on how they fit with client/patient characteristics (i.e., matching; Chorpita, Daleiden, & Weisz, 2005). Another critical element of practice implementation is treatment integrity. Treatment integrity refers to the degree to which individuals conducting interventions, such as parents and school personnel, adhere to specific intervention protocol in a consistent manner (Rapoff, 2010). Adherence research in terms of designing and implementing intervention strategies may be enhanced using this outcome within both quality improvement projects and clinical trials.

The commentary by Kravitz and Melnikow (2004) on the comprehensive review by DiMatteo (2004b) seems relevant for both future research and clinical practice. They highlight five conclusions from the review: (a) nonadherence will always be with us, (b) the method of assessment matters, (c) mean adherence is higher for some conditions than others, (d) correlations between adherence and sociodemographic factors, while statistically significant, are quite modest in magnitude, and (e) the field of adherence research is ready for a multi-trait multi-method approach (i.e., different regimen components measured by at least two assessment methods). Kravitz and Melnikow (2004) add that reliable and valid assessment measures will be based on clinically grounded adherence models. Self-management models are becoming more prevalent in the literature (Modi et al., 2012) and support the development of measures grounded in theory, as well as effective and individually tailored interventions. Within these models the question, as posed by Kravitz and Melnikow (2004), is not whether a patient does what the medical providers prescribes but whether the patient performs behaviors that maximize personal self-management and result in improved health outcomes.

Continual assessment and intervention will be required to achieve optimal adherence due to the waxing and waning nature of adherence. The adherence of all patients should be screened at set intervals, such as at the beginning of or change in medical regimen, to determine their level or risk status of nonadherence (e.g., low, medium, high). Based on this risk assessment, a tiered approach to intervention can then be implemented, with ongoing examination of effectiveness. Education about their medical condition and regimen, and periodic supervision or monitoring by medical providers, parents, and other key individuals, such as school personnel, benefits all patients. Organizational and behavioral interventions can then be added in a systematic manner to address individual needs of patients in the medium and high risk groups. Such a systematic approach to adherence in pediatric practice can optimize the health status and quality of life of children and adolescents with medical conditions.

References

Adams, C. D., Dreyer, M. L., Dinakar, C., & Portnoy, J. M. (2004). Pediatric asthma: A look at adherence from the patient and family perspective. *Current Allergy and Asthma Report, 4*, 425–432.

Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes, 50*, 179–211.

Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis, 1*, 91–97.

Bandura, A. (2004). Health promotion by social cognitive means. *Health Education and Behavior, 31*, 143–164.

Bauman, I. J. (2000). A patient-centered approach to adherence: Risks for nonadherence. In D. Drotar (Ed.), *Promoting adherence to medical treatments in chronic childhood illnesses. Concepts, methods, and interventions* (pp. 71–94). Mahwah, NJ: Erlbaum.

Benjamin, R. M. (2012). Medication adherence: Helping patients take their medicines as directed. *Public Health Reports, 127*, 2–3.

Bond, G. G., Aiken, L. S., & Somerville, S. C. (1992). The health belief model and adolescents with insulin-dependent diabetes mellitus. *Health Psychology, 11*, 190–198.

Cabana, M. D., Rand, C. S., Becher, O. J., & Rubin, H. R. (2001). Reasons for pediatrician nonadherence to asthma guidelines. *Archives in Pediatric Adolescent Medicine, 155*, 1057–1062.

Carbone, L., Zebrack, B., Plegue, M., Joshi, S., & Shellhaas, R. (2013). Treatment adherence among adolescents with epilepsy: What really matters? *Epilepsy and Behavior, 27*, 59–63.

Chandwani, S., Koenig, L. J., Sill, A. M., Abramowitz, S., Conner, L. C., & D'Angelo, S. (2010). Predictors of antiretroviral medication adherence among a diverse cohort of adolescents with HIV. *Journal of Adolescent Health, 51*, 242–251.

Chorpita, B. F., Daleiden, E. L., & Weisz, J. R. (2005). Identifying and selecting the common elements of evidence based interventions: A distillation and matching model. *Mental Health Services Research, 7*, 5–20.

Cohen, S. Y., & Wamboldt, F. S. (2000). The parent-physician relationship in pediatric asthma care. *Journal of Pediatric Psychology, 25*, 69–77.

Conn, K. M., Halterman, J. S., Lynch, K., & Cabana, M. D. (2007). The impact of parents' medication beliefs on asthma management. *Pediatrics, 120*, e521–e526.

Dean, A. J., Walters, J., & Hall, A. (2010). A systematic review of interventions to enhance medication adherence in children and adolescents with chronic illness. *Archives of Disease in Childhood, 95*, 717–723.

DeCivita, M., & Dobkin, P. L. (2005). Pediatric adherence: Conceptual and methodological considerations. *Children's Health Care, 34*, 19–34.

DeLuca, R. V., & Holborn, S. W. (1992). Effects of a variable-ration reinforcement schedule with changing criteria on exercise in obese and non-obese boys. *Journal of Applied Behavior Analysis, 25*, 671–679.

Dennis, D. (2009). Physician behavior in the care of pediatric chronic illness: Association with health outcomes and treatment adherence. *Journal of Developmental & Behavioral Pediatrics, 30*, 246–254.

Dew, M. A., Dabbs, A. D., Myaskovsky, L., Shyu, S., Shellmer, D. A., AF, D. M., … Greenhouse, J. B. (2009). Meta-analysis of medical regimen adherence outcomes in pediatric solid organ transplantation. *Transplantation, 88*, 736–746.

Department of Health and Human Services. (2000, November). *Healthy People 2010* (2nd ed.). Washington, DC: U.S. Government Printing Office.

DiMatteo, M. R. (2004a). The role of effective communication with children and their families in fostering adherence to pediatric regimens. *Patient Education and Counseling, 55*, 339–344.

DiMatteo, M. R. (2004b). Variation in patients' adherence to medical recommendations: A quantitative review of 50 years of research. *Medical Care, 42*, 200–209.

Downs, D. S., & Hausenblas, H. A. (2005). The theories of reasoned action and planned behavior applied to exercise: A meta-analytic update. *Journal of Physical Activity and Health, 2*, 76–97.

Duncan, C. L., Mentrikowski, J. M., Wu, Y. P., & Fredericks, E. M. (2014). Practice-based approach to assessing and treating nonadherence in pediatrics regimens. *Clinical Practice in Pediatric Psychology, 2*, 322–336.

Gadkari, A. S., & McHorney, C. (2012). Unintentional non-adherence to chronic prescription medications: How unintentional is it really? *Health Services Research, 12*, 98.

Gibson, T. B., Ozminkowski, R. J., & Goetzel, R. Z. (2005). The effects of prescription drug cost sharing: A review of the evidence. *American Journal of Managed Care, 11*, 730–740.

Goh, X. T., Tan, Y. B., Thirumoorthy, T., & Kwan, Y. H. (2017). A systematic review of factors that influence treatment adherence in paediatric oncology patients. *Journal of Clinical Pharmacy and Therapeutics, 42*, 1–7.

Gould, E., & Mitty, E. (2010). Medication adherence is a partnership, medication compliance is not. *Geriatric Nursing, 31*, 290–298.

Gray, W. N., Denson, L. A., Baldassano, R. N., & Hommel, K. A. (2012). Treatment adherence in adolescents with inflammatory bowel disease: The collective impact of barriers to adherence and anxiety/depressive symptoms. *Journal of Pediatric Psychology, 37*, 282–291.

Guite, J. W., Kim, S., Chen, C., Sherker, J. L., Sherry, D. D., Rose, J. B., & Hwant, W. (2014). Pain beliefs and readiness to change among adolescents with chronic musculoskeletal pain and their parents before an initial pain clinic evaluation. *Clinical Journal of Pain, 30*, 27–35.

Haynes, R. B. (1979). Introduction. In R. B. Haynes, D. W. Taylor, & D. L. Sackett (Eds.), *Compliance in health care* (pp. 1–7). Baltimore, MD: Johns Hopkins University Press.

Hilliard, M. E., Mann, K. A., Peugh, J. L., & Hood, K. K. (2013). How poorer quality of life in adolescence predicts subsequent type 1 diabetes management and control. *Patient Education and Counseling, 91*, 120–125.

Hommel, K. A., Davis, C. M., & Baldassano, R. N. (2009). Objective versus subjective assessment of oral medication adherence in pediatric inflammatory bowel disease. *Inflammatory Bowel Disease, 15*, 589–593.

Hsin, O., La Greca, A. M., Valenzuela, J., Moine, C. T., & Delamater, A. (2010). Adherence and glycemic control among Hispanic youth with type 1 diabetes: Role of family involvement and acculturation. *Journal of Pediatric Psychology, 35*, 156–166.

Johnson, S. B., Kelly, M., Henretta, J. C., Cunningham, W., Tomer, A., & Silverstein, J. (1992). A longitudinal analysis of adherence and health status in childhood diabetes. *Journal of Pediatric Psychology, 17*, 537–553.

Jones, C. J., Smith, H. E., Frew, A. J., Du Toit, G., Mukhopadhyay, S., & Llewellyn, C. D. (2014). Explaining adherence to self-care behaviours amongst adolescents with food allergy: A comparison of the health belief model and the common sense self-regulation model. *British Journal of Health Psychology, 19*, 65–82.

Kahana, S., Drotar, D., & Frazier, T. (2008). Meta-analysis of psychological interventions to promote adherence to treatment in pediatric chronic health conditions. *Journal of Pediatric Psychology, 33*, 590–611.

Kravitz, R. L., & Melnikow, J. (2004). Medical adherence research. Time for a change in direction? *Medical Care, 42*, 197–199.

Kristensen, L. J., Thastum, M., Mose, A. H., & Birkebaek, N. H. (2012). Psychometric properties of the Adherence in Diabetes Questionnaire. *Diabetes Care, 35*, 2161–2166.

La Greca, A. M., & Bearman, K. J. (2003). Adherence to pediatric treatment regimens. In M. C. Roberts (Ed.), *Handbook of pediatric psychology* (3rd ed., pp. 119–140). New York: Guildford Press.

Landers, S. E., Friedrich, E. A., Jawad, A. F., & Miller, V. A. (2016). Examining the interaction of parental involvement and parenting style in predicting adherence in youth with type 1 diabetes. *Families, Systems, & Health, 34*, 41–50.

Lemanek, K. L., Kamps, J., & Chung, N. B. (2001). Empirically supported treatments in pediatric psychology: Regimen adherence. *Journal of Pediatric Psychology, 26*, 253–275.

Logan, D., Zelikovsky, N., Labay, L., & Spergel, J. (2003). The Illness Management Survey: Identifying adolescents' perceptions of barriers to adherence. *Journal of Pediatric Psychology, 28*, 383–392.

Malee, K., Williams, P., Montepiedra, G., McCabe, M., Nichols, S., Sirois, P. A., … PACTG 219C Team. (2011). Medication adherence in children and adolescents with HIV infection: Associations with behavioral impairment. *AIDS Patient Care and STDs, 25*, 191–200.

McQuaid, E. L., Everhart, R. S., Seifer, R., et al. (2012). Medication adherence among Latino and non-Latino white children with asthma. *Pediatrics, 129*, e1404–e1410.

McQuaid, E. L., Walders, N., Kopel, S. J., Fritz, G. K., & Klinnert, M. D. (2005). Pediatric asthma management in the family context: The family asthma management system scale. *Journal of Pediatric Psychology, 30*, 492–502.

Miller, T. A. (2016). Health literacy and adherence to medical treatment in chronic and acute illness: A meta-analysis. *Patient Education and Counseling, 99*, 1079–1086.

Modi, A. C., Pai, A. L., Hommel, K. A., Hood, K. K., Cortina, S., Hilliard, M. E., … Drotar, D. (2012). Pediatric self-management: A framework for research, practice, and policy. *Pediatrics, 129*, e473–e485.

Modi, A. C., & Quittner, A. L. (2006). Barriers to treatment adherence for children with cystic fibrosis and asthma: What gets in the way? *Journal of Pediatric Psychology, 31*, 846–858.

Murphy, J., & Coster, G. (1997). Issues in patient compliance. *Drugs, 54*, 797–800.

Perez, K. M., Patel, N. J., Lord, J. H., et al. (2017). Executive function in adolescents with type 1 diabetes: Relationship to adherence, glycemic control, and psychosocial outcomes. *Journal of Pediatric Psychology, 42*, 636–646.

Prochaska, J. O. (2013). Transtheoretical model of behavior change. In M. D. Gellman & J. R. Turner (Eds.), *Encyclopedia of behavioral medicine*. New York: Springer.

Prochaska, J. O., & DiClemente, C. C. (1983). Stages and processes of self? Change of smoking: Toward an integrative model of change. *Journal of Consulting and Clinical Psychology, 51*, 390–395.

Quittner, A. L., Espelage, D. L., Ievers-Landis, C., & Drotar, D. (2002). Measuring adherence to medical treatment in childhood chronic illness: Considering multiple methods and sources of information. *Journal of Clinical Psychology in Medical Settings, 7*, 41–54.

Quittner, A. L., Modi, A. C., Lemanek, K. L., Ievers-Landis, C. E., & Rapoff, M. A. (2008). Evidenced-based assessment of adherence to medical treatments in pediatric psychology. *Journal of Pediatric Psychology, 33*, 916–936.

Rapoff, M. A. (2010). *Adherence to pediatric medical regimens* (2nd ed.). New York: Springer.

Riekert, K. A., & Drotar, D. (2002). The beliefs about medication scale: Development, reliability, and validity. *Journal of Clinical Psychology in Medical Settings, 9*, 177–184.

Simons, L. E., McCormick, M. L., Devine, K., & Blount, R. L. (2010). Medication barriers predict adolescent transplant recipients' adherence and clinical outcomes at 18-month follow-up. *Journal of Pediatric Psychology, 35*, 1038–1048.

Soliday, E. (2000). Health beliefs and pediatric emergency department after-care adherence. *Annals of Behavioral Medicine, 22*, 299–306.

Steiner, J. F. (2012). Rethinking adherence. *Annals of Internal Medicine, 157*, 580–585.

Urquhart, J. (1997). The electronic medication event monitor. Lessons for pharmacotherapy. *Clinical Pharmacokinetics, 32*, 345–356.

Wu, Y. P., Rohan, J. M., Martin, S., Hommel, K., Greenley, R. N., Loiselle, K., … Fredericks, E. M. (2013). Pediatric psychologist use of adherence assessments and interventions. *Journal of Pediatric Psychology, 38*, 595–604.

School Reintegration After Illness

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Abstract

Chronic physical illnesses affect a significant proportion of the US child and adolescent population. Approximately 20% of children with chronic medical conditions may be removed from school for an extended amount of time or for repeated brief time periods due to medical issues (e.g., hospitalizations, medical appointments), parent concerns about school's ability to meet medical needs (e.g., monitor symptoms, handle emergencies), or children's concerns regarding peer reactions. Due to medical advances (e.g., treatment of pediatric cancer) that have significantly reduced mortality rates, increasingly more students are returning to school settings following diagnosis and/or periods of intense treatment. The purpose of this chapter is to provide best practices and guidelines to interdisciplinary practitioners who work with community stakeholders to assist children in re-entering school after illness- and/or treatment-related absences. We draw on the current literature in this area of research as well as interdisciplinary and related sources to recommend methods for implementing, assessing, monitoring, and evaluating reintegration programs, as well as provide recommendations for interdisciplinary collaboration. A case study is described to illustrate application of recommended implementation and evaluation methods. The chapter concludes by identifying important directions for future research in school reintegration.

Rationale for School Reintegration

Chronic physical illnesses affect a significant proportion of the US child and adolescent population. The definition of chronic illness has evolved over the years from a sole focus on duration of symptoms to a broader consideration of both duration and extent of functional limitations. For example, Perrin and colleagues (1993) define a physical condition as chronic if symptoms last more than 3 months and the level of impairment or medical need exceeds expectations for a child's given age. Given the variability in definitions, prevalence estimates have ranged from 3 to 35%, with a generally accepted rate around 15–18% (Roberts & Steele, 2017). Further, incidence of some

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chronic conditions (e.g., asthma, obesity) has increased over the past several decades (e.g., Ogden et al., 2016).

Approximately 20% of children with chronic medical conditions may be removed from school for an extended amount of time or for repeated brief time periods due to medical issues (e.g., hospitalizations, medical appointments), parent concerns about school's ability to meet medical needs (e.g., monitor symptoms, handle emergencies), or children's concerns regarding peer reactions (Alderfer & Rourke, 2014). Due to medical advances (e.g., treatment of pediatric cancer) that have significantly reduced mortality rates, increasingly more students are returning to school settings following diagnosis and/or periods of intense treatment (Thompson et al., 2015). Because school experiences are critical for normative academic, social, and psychological functioning, it is important for students with chronic illnesses to return to schools with as little adjustment issues as possible. Stated differently, children need to partake in essential school experiences as quickly and fully as possible following illness-related absences. Thus, educators, healthcare providers, and families share a collective responsibility to assist students in making a smooth transition back to school after recovering from or being treated for a chronic illness.

The purpose of this chapter is to provide best practices and guidelines to interdisciplinary practitioners who work with community stakeholders (e.g., parents, school personnel, healthcare providers) to assist children in re-entering school after illness- and/or treatment-related absences. We draw on the current literature in this area of research as well as interdisciplinary and related sources to recommend methods for implementing, assessing, monitoring, and evaluating reintegration programs, as well as provide recommendations for interdisciplinary collaboration. A case study is described to illustrate application of recommended implementation and evaluation methods. The chapter concludes by identifying important directions for future research in school reintegration.

Implementation of School Reintegration Programs

For children with chronic illness, making a transition back to school is associated with more positive outcomes (e.g., Bessel, 2001; Helms et al., 2016; Houlahan, 1991; Kagen-Goodheart, 1977; Prevatt, Heffer, & Lowe, 2000; Thompson et al., 2015). For example, school reintegration programs have been demonstrated to increase social competencies, self-esteem, and school adjustment for the affected child as well as decrease externalizing and internalizing problems (Katz, Rubinstein, Hubert, & Blew, 1988; Rynard, Chambers, Klinck, & Gray, 1998; Varni, Katz, Colegrove, & Dolgin, 1993). Moreover, there is general agreement among researchers and practitioners that returning to school can facilitate a child's sense of normalcy, improve health-related quality of life, and promote positive adjustment, academic progress, and socialization (Prevatt et al., 2000; Suzuki & Kato, 2003). Despite such findings, an evidence-based standard of care has yet to be established. Instead, there are promising trends across studies regarding what steps should be taken to best support students as they return to school after illness.

Comprehensive school reintegration programs should include the following components: (a) family support to maintain strong parent–child relationships and prepare the family for school reintegration, (b) education of school staff regarding the child's illness and effective school-based approaches to intervention, (c) peer education and support programs, and (d) sustained follow-up to monitor progress and adjust the educational plan as needed (Madan-Swain, Katz, & LaGory, 2004). For example, Power, DuPaul, Shapiro, and Kazak (2003) proposed a staged model that includes interventions to prepare systems for integration and to guide participants through an extended integration process. The first step focuses on efforts to strengthen the family (e.g., strengthen and sustain parent partnership, support family in collaborating with healthcare system); the second step involves preparing the family to partner with the school; the third step emphasizes preparing school professionals to partner with the family and health system; and the final step focuses on engaging the family, school, and health system in a conjoint process of planning and implementation as per the principles of conjoint behavioral consultation (Sheridan & Kratochwill, 2008). In this context, the process of school reintegration is viewed as an ongoing, recursive process involving intervention design, implementation, progress monitoring, intervention modification, and continuing monitoring and fine-tuning of the intervention. Ideally, school reintegration would identify and build upon child strengths and system resources, anticipate and address challenges, and solve problems when they arise.

To achieve successful school reintegration, it is critical for an individual to serve as a liaison who coordinates the school reentry process. Thompson et al. (2015) recommend that a well-trained hospital team member (e.g., physician, social worker, nurse clinician, child life work, or psychologist) can lead school reentry support by coordinating communication among the child, family, school, and healthcare team. Similarly, Shaw, Glaser, and Ouimet (2011) advocate for a hospital–school liaison who has knowledge in both education and medical systems to help bridge the gap in communication and increase collaboration across systems and stakeholders. Despite this call for hospital personnel involvement in school reentry planning and programming, precipitous advancements in medical services, limited hospital-based resources, and a greater shift to outpatient care for children with medical issues (e.g., Blank & Burau; Landrigan, Conway, Edwards, & Srivastava, 2006; Newacheck, Park, Brindis, Biehl, & Irwin, 2004; Wazeka, Valacer, Cooper, Caplan, & DiMaio, 2001) have placed the burden of care largely on parents, schools, and outpatient clinics, rather than on hospitals. Recognizing this change, recommendations have been made for school personnel who already have the requisite knowledge and skills to coordinate school reintegration programs. For example, the National Association of School Nurses (2013) asserts that school nurses are not only prepared to serve the role of hospital–school liaison, but can also attend to the medical needs of children with chronic illness and assist with medical equipment and treatment (Fauteux, 2010; Merianos, Vidourek, King, & Nabors, 2015). Because the student-to-nurse ratio is currently too low to meet the needs of all students (National Association of School Nurses, 2013), school psychologists have also been recognized as well suited to coordinate school reintegration efforts. Specifically, school psychologists are armed with training and expertise to act as liaisons among schools, parents, and medical personnel as well as have the skills to evaluate children for possible special education services, consult with teachers on medical and treatment aspects of the disease, provide counseling to students, and work with classroom peers (Harris, 2009; Kaffenberger, 2006; Merianos et al., 2015; Prevatt et al., 2000).

Once a school-based or medical-team coordinator of services has been identified, this person should oversee the first stage of the transition process by conducting individual interviews and assessments with the child and family. These interviews should address whether children would like to disclose their illness to their classmates or teachers, and if so, how much information should be divulged. Some children want as much contact as possible with teachers and peers (e.g., cards, phone calls, text messages, visits, videotapes of the class, and social media); while others, especially adolescents, may prefer to limit contact with the school and to receive support from close friends and only a few teachers (Kaffernberger, 2006; Sexson & Madan-Swain, 1993). It is important to respect these individual differences and support children based on their preferences. During these initial interviews, it also is imperative to gauge children's understanding of their own illness, children's interests (e.g., extracurricular activities), and any illness-related concerns that children may have (Prevatt et al., 2000). This information is vital for preparing for the child's return to school. For example, educators can use children's illness-related concerns to help facilitate the child's return to the classroom (e.g., provide child breaks at pre-designated times; incorporate child's interests into lessons and assignments) or school guidance counselors can use this to inform their care for the child (e.g., individual counseling sessions aimed at ameliorating child's fears and/or promoting child's strengths). In addition, schools should be assessing children regarding the need for special education or Section 504 services. Assessing the need for support services is crucial considering how federal legislation, Public Law 94-142, and the Individuals with Disabilities Education Improvement Act (2004) guarantees an appropriate education for all people, including students with chronic illness.

After learning about the child's diagnosis, the family should be contacted by the school liaison[1]as soon as possible. Ideally, the school liaison should offer to meet with the family in person. During the initial crisis period (i.e., when the family first learns of the child's diagnosis and/or when the family first informs the school of the child's diagnosis), the family may not know what they need or how to proceed. Thus, during the meeting with the family, one of the first steps should be a needs assessment through which the family can identify their needs in the areas of medical concerns, academics, child's social relationships, and/or financial functioning. Prevatt et al. (2000) describe several additional activities that can provide reassurance to families, including identification of needs and goals; preparation of a calendar for appointments, schedules, and treatment regimens; a list of names and phone numbers of school and medical personnel; and a specific plan for subsequent actions (e.g., meeting, conferences). If the student will be absent from school for extended periods of time, homebound services should be requested and plans for school reentry should begin. How the illness will be discussed with other school personnel and students should also be discussed with the family (Kaffenberger, 2006).

After meeting with the family, a conference should be held with relevant school personnel (e.g., school liaison, teachers, principals, counselors, school psychologist, school nurse, and special education representatives). During this meeting, school personnel can discuss current understandings of the child's condition, prognosis, and treatment; confidence working with the child; the child's past and current academic achievement and whether they suspect any deficits due to the illness; the child's academic strengths and weaknesses; whether psychoeducational testing and/or modifications are needed; the child's peer relationships and whether social interventions are necessary; and methods to communicate with healthcare personnel (Prevatt et al., 2000). In addition, plans for educating school staff about the child's illness and school reintegration needs should be initiated.

Because school personnel often feel unprepared to meet the educational and interpersonal needs of children with chronic illness, school personnel workshops should be provided through which individuals receive information about the illness and its treatment, discuss attitudes towards working with ill children, the emotional impact of working with a child, and develop strategies for communicating with family and medical personnel (Baskin, Saylor, Furey, Finch, & Carek, 1983; Canter & Roberts, 2012; Dubowy et al., 2006; Pallmayer et al., 1986; Prevatt et al., 2000; Ross, 1984). In addition to educating schoolwide staff about chronic health conditions, many intervention programs have also focused explicitly on increasing teacher knowledge and confidence in supporting children academically and socioemotionally (e.g., Georgiadi & Kourkoutas, 2010; Thies & McAllister, 2001). The identified school liaison can lead these workshops or collaborate with medical personnel to help lead these efforts.

Peer education programs have similar goals to those of school personnel workshops; however, their focus is on instructing peers in an age-appropriate manner (Canter & Roberts, 2012). For elementary school students, peer education programs are typically delivered to the child's class, whereas for middle school and high school students, peer education programs are usually delivered directly to peers that the child designates

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[1] The term "liaison" is used here to refer to the individual who is responsible for coordinating the child's school reintegration with the parents, school, and medical team. Depending on the type of care the child receives, as well as the services the hospital or school has resources to provide, this individual can be a social worker, a child life specialist, a school psychologist, or another individual who has training in coordination of interdisciplinary child needs. This individual may be school or hospital-based.

as friends and classmates. Regardless of age, it is important to consult children regarding their preferred target audience for peer education programs. The key feature to peer education programs are brief workshops or presentations (e.g., 30–60 min) that aim to increase classmates' knowledge of the illness, its treatment, side-effects, and potential psychosocial outcomes (Helms et al., 2016). In addition, education programs can help facilitate supportive peer interactions towards classmates with chronic illnesses (Goodell, 1984; Houlahan, 1991). Results across studies have generally demonstrated that classmates' knowledge of childhood cancer and willingness to interact with the sick child increased significantly following peer education (Benner & Marlow, 1991; Prevatt et al., 2000; Thompson et al., 2015; Treiber, Schramm, & Mabe, 1986). Delong (1999) also found that increased levels of peer knowledge was associated with reduced fears about sick classmates' well-being and prospects for survival. Additional benefits of peer education programs include being cost-effective and the ability to reach a large number of individuals in a short period of time (Prevatt et al., 2000).

Although medical team members may not be able to serve in the role of a liaison, they should be involved in school reintegration efforts. With parent permission, the school-based liaison can contact a member of the child's medical team to receive information regarding the diagnosis, treatment, post-treatment, and recovery period (Kaffenberger, 2006). Additionally, the school liaison can consult the medical team regarding anticipated illness-related complications that may affect schoolwork (Prevatt et al., 2000). Because the medical team is not in school to observe the cumulative effects of treatment and medications, it is imperative that the school-based liaison observe the child's academic functioning and report back to the medical team (Shaw & McCabe, 2008). Ultimately, children benefit greatly when there is strong collaboration and established communication channels among schools, families, and medical team personnel (Katz & Varni, 1993; Prevatt et al., 2000; Sexson & Madan-Swain, 1993).

There are several model school reintegration programs that include most, if not all, of the four aforementioned features (i.e., strengthen the family, prepare family to partner with school, prepare school professionals to partner with family and healthcare system, and engage in conjoint planning and implementation) (e.g., Henning & Fritz, 1983; Katz et al., 1988; Katz, Kellerman, Rigler, Williams, & Siegel, 1977; McCormick, 1986; Power et al., 2003; Sachs, 1980; Varni et al., 1993). For example, the comprehensive programs described by Sachs (1980), McCormick (1986), and Henning and Fritz (1983) include intensive assessment of needs and goals, individualized plans, and liaison work among parents, teachers, and medical personnel. Specific activities across these programs included tutoring, visiting the child's school to assess architectural barriers and arrange transportation, role-play of peer question-and-answer sessions, and educational programs for classmates, teachers, and staff. Unfortunately, most of studies of these programs were conducted 15 or more years ago and were led by hospital personnel. Thus, it is unlikely that these studies reflect the current programming typically available for students with chronic illnesses. Given the recent trends in healthcare service delivery that have shifted the burden of care from hospitals to schools and parents, there is a clear need to further investigate school reintegration programs led by school personnel.

Other reintegration programs can be led by the school program within the child's hospital. These programs, typically called hospital schools, are set up within many major hospitals in the USA to provide education and reintegration services for children with medical issues that prevent them from attending typical schools during treatment. These schools often serve short-term educational needs while the child is undergoing treatment, and they have not been widely studied in the recent literature (Calloway, 2008).

Building and Classroom Accommodations/Modifications

Once the child has returned to school, there are many accommodations and modifications that can be made within the building and classroom to best support the child's success. Sexson and

Madan-Swain (1993) advocate that teachers initially avoid teaching at frustration level (i.e., level that requires moderate or extensive assistance from instructor, as opposed to instructional or independent level in which child needs little to no help), as would be the case for all children but particularly important for students returning to classroom instruction. Rather they should teach at a level that is easy but nevertheless challenges the child. For example, some academic curricula may build upon previously taught concepts and become more complex as the school year progresses. If a student leaves school at the beginning of the year, but returns later in the year when the class has moved onto more complex topics, it would be reasonable for the teacher to acknowledge how behind the student may be. Alternatively, it would be unreasonable for the teacher to regress to such a point in the math curriculum that the student had mastered before he or she left school for treatment. Sexson and Madan-Swain also suggest that teachers remain firm and not allow children to escape tasks they are capable of doing. Chunking activities, such as breaking down assignments into smaller more manageable steps, and movement breaks are also recommended.

Shaw and McCabe (2008) outline several structural and material adaptations that may be necessary to install to support children with chronic illnesses, including physical therapy equipment, assistive mobility and communication devices, improved building accessibility for individuals with disabilities, and life support equipment. Although the latter may be costly, cheaper and easier methods to implement physical supports are available to supplement or replace typical adaptations, including providing additional quiet space to complete work, making a cot available for brief naps to overcome fatigue of a long school day, using partitions to reduce distractions and potentially embarrassing situations from classmates, reducing activity in physical education classes, and having medications delivered to the classroom (or just outside the door) to minimize lost class time (Shaw & McCabe).

Flexible school days are another important component of the transition back to school (American Academy of Pediatrics [AAP] Committee on School Health, 1993). For example, half days are commonly used for children with chronic illness at least during initial stages of school reintegration (Frieman & Settel, 1994). However, when determining the modified length of the school day for children, the reintegration team should evaluate for school refusal behavior, as attending a shorter length of the school day may reinforce some children's behaviors of resisting school reentry. Children returning to school may be anxious about resuming school life and as such, they may attempt to avoid it. Additionally, their parents may support the child's hesitance to re-enter school by suggesting home school. Although this may be an appropriate option for some children, parents, and teachers will still need to collaborate extensively to ensure the child is meeting educational standards in the removed educational setting (Shaw & McCabe, 2008). Telephone consultation, instant-messaging, text-messaging, and delivery of assignments via email can also enhance instructional flexibility (Shaw & McCabe, 2008). It is important to note that these recommendations, while conceptually appealing, have little in the way of controlled empirical support.

School Reintegration Program Outcomes

Generally, the empirical support for school reintegration programs has lagged behind theoretical and conceptual models. Canter and Roberts (2012) conducted a comprehensive, quantitative review of the school reintegration literature and identified only 12 empirical studies published between 1983 and 2007. Selected studies were focused on interventions specific to ill or injured children's return to school that targeted school personnel, healthy classmates, and/or the ill or injured child. Large effect sizes were found for positive attitude change for teachers as well as increases in teacher knowledge. Increases in peer knowledge and positive attitude change were in the medium range. School reintegration programs were associated with small effects on children's self-worth and self-esteem. Unfortunately, the small number of studies limits conclusions based on this meta-analytic review.

Assessing and Monitoring the Effectiveness of School Reintegration

Little research details how to assess and monitor the progress of school reintegration programs. Indeed, controlled investigations assessing outcomes of school reintegration programs may be difficult to do in a systematic way given the individual nature of reentry programs to address specific needs of children returning to schools, as well as the nature of the chronic illness associated with reintegration (Prevatt et al., 2000). Because of the specific information on assessment of school reintegration for children with chronic illnesses, practitioners should consider adopting evidence-based assessment and progress monitoring procedures based on children's primary concerns. Specifically, practitioners are encouraged to take several steps when assessing and monitoring reintegration programs including setting specific goals, systematically monitoring progress towards goals, and making adjustments to program goals and/or methods based on obtained data.

Goal Setting

When the interdisciplinary team initially convenes to discuss school reintegration, one member (e.g., school psychologist) should lead the group to outline clear goals regarding adequate adjustment to school. It is important for the goals to be observable, specific, and incremental. For example, complete re-adjustment to the school setting may take time for a child to accomplish. As such, there should be short- and long-term goals, similar to the implementation of a goal for an Individualized Education Program (IEP). Along this line of thought, goal setting is tied with the timeline of school adjustment. Specifically, the time of the school year in which the child re-enters the school should be taken into consideration. For example, if children with a chronic illness re-enter school towards the end of the school year, the goals set for them must be realistically accomplishable within the remaining school year. Educators, families, and health professionals must work together to create goals that can be met between the time the child returns to school and the time the child will again either leave school due to a known medical procedure or hospital stay, or the time of a natural break in the school year (e.g., winter break, summer vacation). If children are enrolled in a hospital school program that has a reintegration component, the reintegration team there should coordinate with the school and family to extend or expand upon the goals established in the hospital school to the original school setting once children exit the hospital school program and re-enter their main school.

Goals may vary depending on the case and may go beyond ill or injured children re-entering school, but also involve desired outcomes for the school staff or the student's classmates. Goals may target academic, behavioral, socioemotional, and medical functioning, or combinations of each. Academic goals typically focus on ensuring that the child catches up on content missed during absence or has remained on target with current academic skills despite an absence. Behavioral and socioemotional goals focus on the child's or the class's observable adjustment back into the classroom. Goals may include ensuring that children are welcomed back to the class appropriately, that children can follow daily routines and remain attentive during the class day, or that children's classmates are appropriately interacting with them during the day. Medical goals typically focus on the physiological abilities of the child—if weakness, mobility, or any other physiological action remains challenging upon school reentry, goals can relate to ensuring the child can function as independently as possible.

Monitoring Progress Towards Goals

Once goals for school reintegration have been set, the team should decide how to make sure that the goals are being met by collecting data on relevant outcomes. As noted before, the goals should be observable, and as such, data should be available to provide objective evidence of whether or not the goal is being met. Because it is likely there will be multiple goals for school reintegration, the liaison should work with the team to determine who will monitor the progress of each goal for the child. Ideally, assessment activities would be delegated across team members, such that one person is not responsible for monitoring all the goals. Tools for measuring progress should be identified for each goal, preferably involving multiple informants and methods. Ideally, data are collected before, during, and throughout the program. Some data may be collected daily (e.g., attendance, completion of assignments), while other data could be obtained on a weekly (e.g., curriculum-based measurement probes of academic skills) or monthly (e.g., teacher ratings of child behavior) basis.

To monitor *academic goals*, although it may be appropriate in some cases to implement an IEP or a Section 504 plan to modify academic placement, in many other cases simple monitoring of academic progress may ensure that children maintain appropriate progress once they return from a health-related absence. Curriculum-Based Measurement (CBM) probes can be used to assess children's current academic skills and monitor progress across time (Shinn, 2002). CBM is a standardized assessment tool used to determine a child's grade level within skillsets of core academic subjects (e.g., reading, writing, math) (Hosp, Hosp, & Howell, 2016). Similar but much abridged when compared to achievement testing, brief probes are administered to the student at a specific grade level, and they are scored systematically and uniformly. Not only are children's scores compared to their grade-level normative data, but scores are also categorized into either mastery, instructional, or frustrational level within the grade. If children's scores fall into the range of scores in the mastery level, this means that children are performing above peers in their grade, and the material may not be challenging enough for them. If children perform in the instructional level, this means that they are performing within the average range of peers in their grade on the academic skill. Children whose scores fall into the frustrational level range of scores on a measure may be experiencing difficulties in learning the topics assessed, which should indicate to the school staff that additional academic intervention in the skills assessed may be warranted.

To monitor *behavioral and social-emotional goals* for students returning to school, school personnel or the reintegration team liaison should ideally monitor these goals in vivo (i.e., in the situation where goals have been set). For example, systematic direct observation of behavior (Hintze, Volpe, & Shapiro, 2002) can be used by the school psychologist or counselor to monitor the target child or classroom. For example, the Behavior Observation of Students in Schools (BOSS; Shapiro, 2003) can be used to assess engagement in the classroom or other school settings. Using partial interval recording as well as momentary time sampling, the observer notes whether target students are actively engaged or passively engaged in the ongoing task, as well as if they are exhibiting off-task behaviors (e.g., verbal, motor, or passive) within the time period. The observer can also monitor these behaviors in a randomly selected classmate to compare the child's adjustment to the classroom setting to that of a peer. This way, the child's behaviors can be examined in relation to how the rest of the class is behaving.

Other ways to assess behavioral and socio-emotional goals include periodically implementing Check In Check Out procedures between the student, classroom, or teacher and the team liaison (Campbell & Anderson, 2011). At its core, the intervention involves checking in with the child before school to review behavioral or socio-emotional goals for the day, and check out at the end of the day to determine if the goals have been met. The Behavior Assessment System for Children (BASC-3; Reynolds & Kamphaus, 2015) can also be used to assess the child's behavioral and socioemotional functioning across settings; however, because this measure is relatively time consuming to score, this may be better used as a one-time assessment tool, rather than a regularly implemented progress monitoring tool (Thompson et al., 2015). The BASC-3 includes parent, teacher, and child input, so data can be quite informative regarding multiple perspectives of current levels of functioning.

School archival data also can be collected as well to monitor reintegration goals. Specifically, attendance, tardiness, discipline referrals, report card grades, and standardized testing results are important to monitor when evaluating the success of the child's reintegration program. Ongoing monitoring can identify sudden changes in attendance, academic performance, or social adjustment that should be addressed quickly.

To monitor the progress of the child's *medical goals* upon reintegration, the team should also conduct periodic physiological evaluations to ensure that their medical needs are being met in the school and to troubleshoot any barriers to these issues. These evaluations are completed by the school nurse, the child's primary care provider, or any of the child's specialty healthcare team, depending on the needs of child and who is best trained to monitor the child's specific health condition(s). Shaw and McCabe (2008) recommend that regular check-ups should be conducted with students to identify any new health-related sources of academic difficulty or social isolation. These can be conducted by whomever the team deems appropriate based on the child's medical conditions. Although a school nurse may be able to monitor the child's vital signs and basic physiological functioning, depending on the child's condition, a more in-depth check-up may be needed at least periodically.

Barriers to Implementation of School Reintegration Programs

The most significant organizational barriers to implementation of successful and comprehensive school reintegration programs are costs for programming and personnel. Thompson et al. (2015) highlight how institutional resources often limit the availability of hospital personnel who can be dedicated to school support, as programming is non-revenue generating and thus may be perceived as cost-prohibitive. Similarly, school personnel often are already overwhelmed by other duties, making them less prepared to best serve children with chronic illnesses. It also is unclear how comprehensive school programs can be self-sustaining without outside grants (Prevatt et al., 2000).

Another barrier to implementation is the lack of supporting research data about the effectiveness of school reintegration programs (Kaffenberger, 2006). Many of the comprehensive studies available for review are dated and more recent studies are limited due to a small number of patients, lack of control groups, and diversity among interventions used in previous studies (Canter & Roberts, 2012). Consequently, there is a critical need for controlled investigations of intervention programs that explore how to best support individuals' reintegration into the education system and their peer groups (Helms et al., 2016). With a stronger literature base, funding options may become more attainable and available.

Implications for Interprofessional Care

Collaboration and communication between stakeholders (i.e., parents, health professionals, and school personnel) are essential for successful reintegration after chronic illness. In particular, effective communication between school and health practitioners is critical in facilitating a smooth transition back to the school environment (Shaw, Clayton, Dodd, & Rigby, 2004). Several components of communication are key to promoting a strong continuum of care including regular, ongoing contact between systems; clear articulation of value and respect for each team member's knowledge and expertise; competent facilitation of group meetings and interactions (e.g., provide an agenda and stick to agree upon meeting time schedule); and use of open-ended questions to solicit input from all participants to encourage joint problem-solving (Eagle & Dowd-Eagle, 2014). If necessary, conjoint behavioral consultation principles and methods (Sheridan & Kratochwill, 2008) can be used to address particularly challenging problems that may arise during school reintegration. This would involve collaborative problem identification, needs analysis, plan implementation, and plan evaluation on a more formalized basis.

Legal implications for communication and collaboration across health and education systems must be considered. The medical and school-based confidentiality requirements must be mediated appropriately, such that the reintegration team can know enough information about children's conditions to make their transition back to school successful, while also ensuring that unnecessary confidential information is not shared. Parents typically are the only team members who will have immediate access to children's medical and school records. According to the Family Educational Rights and Privacy Act (FERPA; 1974), parents or eligible students have the right to inspect and review the student's educational records (U.S. Department of Education, 2015). Schools need written permission from the parent or the eligible student to release personally identifiable information in educational records to another party, with the exception of several cases, including cases of health or physical emergencies. In the case of school reintegration and collaboration with the healthcare team, written permission from parents needs to be provided for educational information to be shared with healthcare team members (e.g., social workers, nurse, physicians).

In similar fashion, according to regulations stated in the Health Insurance Portability and Accountability Act (HIPAA; 2007), healthcare providers cannot disclose protected health information unless the individual who the information is about or the representatives of the individual (i.e., parents/guardians) provide written consent (U.S. Department of Health and Human Services, 2004, 2017). Timely yet confidential communication between the medical and school team can be a daunting task, especially when sensitive information is involved. It is recommended that no informal conversations take place because of legal ramifications of privacy breaches. Everything should be either discussed in a meeting (with notes) or via letters/email if appropriate. Important conversations about children's reintegration should ideally not be held over the phone or without written notes.

Should children's chronic illnesses require them to receive services from the school in the form of an IEP or a Section 504 Plan, parents should attend to several issues. First, children with chronic illnesses may be eligible for educational services under IDEA if their chronic illness adversely affects their educational performance; typically classified as other health impairment (OHI). Children may be eligible for Section 504 protection and planning if their medical condition affects one or more major life activities in school (e.g., learning). The Children's Hospital of Philadelphia (2013) suggests that children's physicians write a letter to the school with suggestions and basic information regarding how to address the child's health condition(s) within the school setting. They also suggest that the parent facilitate any reentry and/or special education meetings to ensure that children receive the federal funding or support that may be entitled to them.

Case Study

"Maria," an 8-year-old third grader from Hispanic background, was diagnosed with leukemia early in the school year. As she completed treatment, a reintegration plan was formulated to facilitate her return to the classroom midway through the school year. Although her teacher described her as an average student in terms of academic performance and behavior prior to her cancer diagnosis, she experienced some minor difficulties with reading comprehension and math word problems. Prior to her illness, Maria's family had minimal contact with the school, only sporadically attending parent–teacher conferences.

Following her diagnosis and during the early stages of her treatment, a member of Maria's treatment team (i.e., nurse from the pediatric oncology unit) received permission from Maria's parents to initiate contact with the school. Initial contacts were made with the school nurse to explain Maria's diagnosis and provide information regarding the content and course of her treatment. Subsequently, a school reintegration planning team was formed led by the school psychologist that included the school nurse and Maria's classroom teacher. The school team initiated contact with Maria's parents and medical team to collaboratively set goals for school reintegration, plan steps for the reintegration process, and identify a tentative timeline for implementation.

The school reintegration plan included many of the components described previously including (a) working with Maria's parents to identify ways that the school could support her family during the reintegration process, (b) setting up periodic online opportunities for Maria to communicate with her teacher and classmates throughout the treatment process, (c) providing education about Maria's condition and treatment to her classroom teacher and classmates, (d) identifying school accommodations she would need based on her compromised physical functioning, and (e) planning for progress monitoring of reading and math skills prior to, during, and for several months following school reintegration. In addition, the school psychologist would conduct a cognitive assessment prior to Maria's return to school as well as about a year following her return given evidence of possible delayed deleterious effects of cancer treatment on some areas of neurocognitive functioning (Compas, Jaser, Reeslund, Patel, & Yarboi, 2017).

Progress monitoring data indicated that during her absence Maria fell behind her classmates in growth of reading and math skills. Thus, a paraprofessional provided daily 30-min tutoring sessions for the first 2 months of her return. By midway through the fourth grade, Maria's skills were on par with grade-level expectations. Further, she did not experience any significant social, emotional, or behavioral difficulties during or following reintegration. One positive outcome associated with Maria's illness and subsequent reintegration is that her parents became more involved in her schooling and developed a strong relationship with school personnel.

Conclusions and Directions for Future Research

A structured, cross-systems, collaborative approach to school reintegration appears critical to successful classroom reentry of children with chronic medical conditions. Several reintegration models have been recommended that typically include forming an interdisciplinary team comprised of parents, health professionals, and school personnel; providing education about the child's illness to the classroom teacher and classmates; identifying specific academic, behavioral, social-emotional, and medical goals for the target child, teacher, and peers in the context of reintegration; engaging in collaborative problem-solving and ongoing communication to implement necessary support strategies; periodically collecting data to monitor reintegration process; and using data to inform decisions regarding modifications to reintegration programming. Unfortunately, minimal empirical research has been conducted to evaluate recommended procedures and strategies for school reintegration.

Given the minimal research in this area, there are many important directions for future investigations, most notably the need for systematic evaluations of school reintegration programs that include appropriate control conditions, multiple assessment methods and respondents, and analysis of both short- and long-term outcomes. Further, it is necessary to ascertain whether school reintegration methods and processes may need to vary as a function of children's illness, gender, age, or race/ethnicity. For example, it is possible that specific cognitive assessment and academic support strategies may differ based on whether the target child has cancer or sickle-cell disease. It is particularly important for future studies to examine the impact of school reintegration programs on educational outcomes (i.e., academic functioning) and consider the possibility of iatrogenic effects (e.g., increased likelihood for children with chronic health conditions to be bullied) (Canter & Roberts, 2012). Research in this area also may benefit from including mixed quantitative and qualitative methods so that findings may inform practice in terms of desired outcomes as well as the lived experiences of school reintegration teams.

According to Canter and Robert's (2012) meta-analysis, previous research suggests that older children are significantly more accepting of peers with chronic health conditions than younger children (e.g., Kister & Patterson, 1980; Royal & Roberts, 1987). Future research endeavors should explore intervention techniques to promote acceptance and understanding among younger peers while simultaneously eradicating their misconceptions of illness and disease. Relatedly, in Treiber et al. (1986) study, more than 40% of parents of healthy classmates refused to let their child participate in a workshop on childhood cancer, citing fear that it may harm their child. Helms et al. (2016) recommend that parents of healthy classmates should be invited to participate in the intervention, for they too can benefit from learning more about cancer, its treatment, and its effects. Future research endeavors should explore the possibility of including parents of healthy classmates in peer education programs.

As is the case for healthy children (Tsitsika et al., 2014), studies indicate that pediatric cancer patients spend an average of more than 2 h per day online (Nisselle, Hanns, Green, & Jones, 2012; Schiffman, Csongradi, & Suzuki, 2008). This finding reflects the feasibility and importance of providing access to educational and socializing technologies for youth with chronic illness, including cancer. Recognizing the potential in videoconferencing, Ellis et al. (2013) examined "The Connectivity Project," a pilot program led by a clinical nurse consultant in the pediatric oncology department at Sydney Children's Hospital in Australia. This program was established to enable patients to dial-in to their classrooms from the hospital or their homes. The goal of the program was to keep children better connected to their home school and peers during treatment and rehabilitation and to assist with school reintegration. This program increased the family's sense of normalcy and connection to the outside world, boosted patients' mood, strengthened relationships with classmates and teachers, and improved peer acceptance and school reintegration. Future research should further examine the role that telehealth can play in connecting children undergoing treatment to their classmates and classroom.

References

Alderfer, M. A., & Rourke, M. T. (2014). School reintegration: Providing consultation to schools and families. In M. C. Roberts, B. S. Aylward, & Y. P. Wu (Eds.), *Clinical practice of pediatric psychology* (pp. 109–125). New York: Guilford.

American Academy of Pediatrics, & Committee on School Health. (1993). Children with chronic illness. In P. R. Nader (Ed.), *School health: Policy and practice* (pp. 188–195). Elk Grove, IL: Author.

Baskin, C. H., Saylor, C. F., Furey, W. M., Finch, A. J., & Carek, D. J. (1983). Helping teachers help children with cancer: A workshop for school personnel. *Children's Health Care, 12*, 76–83.

Benner, A. E., & Marlow, L. S. (1991). The effect of a workshop on childhood cancer on students' knowledge, concerns, and desire to interact with a classmate with cancer. *Children's Health Care, 20*, 101–107.

Bessel, A. G. (2001). Children surviving cancer: Psychosocial adjustment, quality of life, and school experiences. *The Council of Exceptional Children, 6*, 345–359.

Calloway, V. (2008, November 27). *Hospital school provides routine, relief for sick children*. WRAL. Retrieved from https://www.wral.com/news/local/story/4035320/.

Campbell, A., & Anderson, C. M. (2011). Check in/check out: A systematic evaluation and component analysis. *Journal of Applied Behavior Analysis, 44*, 315–326.

Canter, K. S., & Roberts, M. C. (2012). A systematic and quantitative review of interventions to facilitate school reentry for children with chronic health conditions. *Journal of Pediatric Psychology, 37*, 1065–1075.

Children's Hospital of Philadelphia. (2013). *Facilitating your child's school reentry. Psychosocial Services: A parent's guide* (pp. 2–17). Retrieved from http://media.chop.edu/data/files/pdfs/oncology-oncology-parent-guide-school-reentry.pdf.

Compas, B. E., Jaser, S. S., Reeslund, K., Patel, N., & Yarboi, J. (2017). Neurocognitive deficits in children with chronic health conditions. *American Psychologist, 72*, 326–338.

DeLong, M. D. (1999). *Knowledge and attitudes toward a classmate with cancer: An evaluation of a school reintregration program*. Doctoral dissertation. Retrieved from Proquest Dissertation and Theses. (UMI No. 9975585).

Dubowy, R. L., Rieger, B. P., Songer, N. S., Kleinmann, A. E., Lewandowski, L. J., Rogers, C. L., & Silber, J. M. (2006). Teaching teachers about childhood cancer: The effects of a web-based training program. *Journal of Pediatric Hematology and Oncology, 28*, 729–733.

Eagle, J. W., & Dowd-Eagle, S. E. (2014). Best practices in school-community partnerships. In P. L. Harrison & A. Thomas (Eds.), *Best practices in school psychology: System-level services* (pp. 197–210). Bethesda, MD: National Association of School Psychologists.

Ellis, S. J., Drew, D., Wakefield, C. E., Saikal, S. L., Punch, D., & Cohn, R. J. (2013). Results of a nurse-led intervention: Connecting pediatric cancer patients from the hospital to the school using videoconferencing technologies. *Journal of Pediatric Oncology Nursing, 30*, 333–341.

Fauteux, N. (2010). Unlocking the potential of school nursing: Keeping children healthy in school and ready to learn. *Charting Nursing's Future*, 14. Retrieved from http://www.rwjf.org/content/dam/farm/reports/issue_briefs/2010/rwjf64263

Family Educational Rights and Privacy Act of 1974, 20 U.S.C. § 1232g (1974).

Frieman, B. B., & Settel, J. (1994). What the classroom teacher needs to know about children with chronic medical problems. *Childhood Education, 70*, 196–205.

Georgiadi, M., & Kourkoutas, E. E. (2010). Supporting pupils with cancer on their return to school: A case study report of a reintegration program. *Procedia-Social and Behavioral Sciences, 5*, 1278–1282.

Goodell, A. (1984). Peer education in schools for children with cancer. *Issues in Comprehensive Pediatric Nursing, 7*, 101–106.

Harris, M. S. (2009). School reintegration for children and adolescents with cancer: The role of school psychologists. *Psychology in the Schools, 46*, 579–592.

Health Insurance Portability and Accountability Act, 45 C.F.R. § 164 (2007).

Helms, A. S., Schmiegelow, K., Brok, J., Johansen, C., Thorsteinsson, T., Simovska, V., & Larsen, H. B. (2016). Facilitation of school re-entry and peer acceptance of children with cancer: A review and meta-analysis of intervention studies. *European Journal of Cancer Care, 25*(1), 170–179.

Henning, J., & Fritz, G. K. (1983). School reentry in childhood cancer. *Psychosomatics, 24*, 261–269.

Hintze, J. M., Volpe, R. J., & Shapiro, E. S. (2002). Best practices in the systematic direct observation of student behavior. In A. Thomas & J. Grimes (Eds.), *Best practices in school psychology* (4th ed., pp. 993–1006). Bethesda, MD: National Association of School Psychologists.

Hosp, M. K., Hosp, J. L., & Howell, K. W. (2016). *The ABCs of CBM: A practical guide to curriculum-based assessment* (2nd ed.). New York: Guilford.

Houlahan, K. E. (1991). School reentry program. In *Association of pediatric oncology nurses conference proceedings* (pp. 70–71). Boston: Children's Hospital.

Individuals With Disabilities Education Improvement Act of 2004, 20 U.S.C. §1400 et seq. (2004) (reauthorization of the Individuals With Disabilities Education Act of 1990).

Kaffenberger, C. (2006). School reentry for students with chronic illness: A role for professional counselors. *Professional School Counseling, 9*, 223–230.

Katz, E. R., Kellerman, J., Rigler, D., Williams, K. O., & Siegel, S. E. (1977). School intervention with pediatric cancer patients. *Journal of Pediatric Psychology, 2*, 72–76.

Katz, E. R., Rubinstein, C. L., Hubert, N. C., & Blew, A. (1988). School and social reintegration of children with cancer. *Journal of Psychosocial Oncology, 6*, 123–140.

Katz, E. R., & Varni, J. W. (1993). Social support and social cognitive problem-solving in children newly diagnosed with cancer. *Cancer, 71*, 3314–3319.

Kagen-Goodheart, L. (1977). Reentry: Living with childhood cancer. *American Journal of Orthopsychiatry, 47*, 651–658.

Kister, M., & Patterson, C. (1980). Children's conceptions of the causes of illness: Understanding of contagion and use of immanent justice. *Child Development, 51*(3), 839–846.

Landrigan, C. P., Conway, P. H., Edwards, S., & Srivastava, R. (2006). Pediatric hospitalists: A systematic review of the literature. *Pediatrics, 117*, 1736–1744.

Madan-Swain, A., Katz, E. R., & LaGory, J. (2004). School and social reintegration after a serious illness or injury. In R. T. Brown (Ed.), *Handbook of pediatric psychology in school settings* (pp. 637–655). Mahwah, NJ: LEA.

McCormick, D. (1986). School reentry program for oncology patients. *Journal of the Association of Pediatric Oncology Nurses, 3*, 13–25.

Merianos, A. L., Vidourek, R. A., King, K. A., & Nabors, L. A. (2015). Hospital, school, and community-based strategies to enhance the quality of life of youth with chronic illnesses. *Applied Research in Quality of Life, 10*, 329–342.

National Association of School Nurses. (2013). http://www.nasn.org/PolicyAdvocacy/PositionPapersandReports/NASNPositionStatementsFullView/tabid/462/ArticleId/644/Transition-Planning-for-Students-with-Chronic-Health-Conditions-Adopted-January-2014.

Newacheck, P. W., Park, M. J., Brindis, C. D., Biehl, C. D., & Irwin, C. E. (2004). Trends in private and public health insurance for adolescents. *Journal of the American Medical Association, 291*, 1231–1237.

Nisselle, A., Hanns, S., Green, J., & Jones, T. (2012). Accessing flexible learning opportunities: Children's and young people's use of laptops in a paediatric hospital. *Technology, Pedagogy and Education, 21*, 3–20.

Ogden, C. L., Carroll, M. D., Lawman, H. G., Fryar, C. D., Kruszon-Moran, D., Kit, B. K., & Flegal, K. M. (2016). Trends in obesity prevalence among children and adolescents in the United States, 1988-1994 through 2013-2014. *Journal of the American Medical Association, 315*, 2292–2299.

Pallmayer, T. P., Saylor, C. F., Treiber, F. A., Eason, L. J., Finch, A. J., & Carek, D. J. (1986). Helping school personnel understand the student with cancer: Workshop evaluation. *Child Psychiatry and Human Development, 18*, 250–254.

Perrin, E. C., Newacheck, P., Pless, I. B., Drotar, D., Gortmaker, S. L., Leventhal, J., … Weitzman, M. (1993). Issues involved in the definition and classification of chronic health conditions. *Pediatrics, 91*(4), 787–793.

Power, T. J., DuPaul, G. J., Shapiro, E. S., & Kazak, A. E. (2003). *Promoting children's health: Integrating school, family, and community*. New York: Guilford.

Prevatt, F. F., Heffer, R. W., & Lowe, P. A. (2000). A review of school reintegration programs for children with cancer. *Journal of School Psychology, 38*, 447–467.

Reynolds, C. R., & Kamphaus, R. W. (2015). *Behavior assessment system for children* (3rd ed.). Pearson.

Roberts, M. C., & Steele, R. G. (Eds.). (2017). *Handbook of pediatric psychology* (5th ed.). New York: Guilford.

Ross, J. W. (1984). Resolving non-medical obstacles to successful school reentry for children with cancer. *Journal of School Health, 54*, 84–86.

Royal, G. P., & Roberts, M. C. (1987). Students' perceptions of and attitudes toward disabilities: A comparison of twenty conditions. *Journal of Clinical Child Psychology, 16*(2), 122–132.

Rynard, D. W., Chambers, A., Klinck, A. M., & Gray, J. D. (1998). School support programs for chronically Ill children: evaluating the adjustment of children with cancer at school. *Children's Health Care, 27*, 31–46.

Sachs, M. B. (1980). Helping the child with cancer go back to school. *Journal of School Health, 66*, 328–331.

Schiffman, J. D., Csongradi, E., & Suzuki, L. K. (2008). Internet use among adolescent and young adults (AYA) with cancer. *Pediatric Blood & Cancer, 51*, 410–415.

Sexson, S. B., & Madan-Swain, A. (1993). School reentry for the child with chronic illness. *Journal of Learning Disabilities, 26*, 115–137.

Shapiro, E. S. (2003). Behavioral Observation of Students in Schools-BOSS [Computer Software]. San Antonio, TX: Pearson.

Shaw, S. R., Clayton, M. C., Dodd, J. L., & Rigby, B. T. (2004). Collaborating with physicians: A guide for school leaders. *Principal Leadership Magazine*, 5. Retrieved from http://www.naspcetner.org/principals/nasp_collab.html.

Shaw, S. R., Glaser, E. E., & Ouimet, T. (2011). Developing the medical liaison role in school settings. *Journal of Educational Psychology Consultation, 21*, 106–117.

Shaw, S. R., & McCabe, P. C. (2008). Hospital-to-school transition for children with chronic illness: Meeting the new challenges of an evolving health care system. *Psychology in the Schools, 45*, 74–87.

Sheridan, S. M., & Kratochwill, T. R. (2008). *Conjoint behavioral consultation: Promoting family-school connections and interventions* (2nd ed.). New York, NY: Springer.

Shinn, M. R. (2002). Best practices in using curriculum-based measurement in a problem-solving model. In A. Thomas & J. Grimes (Eds.), *Best practices in school psychology* (4th ed., pp. 671–697). Bethesda, MD: National Association of School Psychologists.

Suzuki, L. K., & Kato, P. M. (2003). Psychosocial support for patients in pediatric oncology: The influences of parents, schools, peers, and technology. *Journal of Pediatric Oncology Nursing, 20*, 159–174.

Thies, K. M., & McAllister, J. W. (2001). The health and education leadership project: A school initiative for children and adolescents with chronic health conditions. *Journal of School Health, 71*, 167–172.

Thompson, A. L., Christiansen, H. L., Elam, M., Hoag, J., Irwin, M. K., Voll, M., … Kelly, K. P. (2015). Academic continuity and school reentry support as a standard of care in pediatric oncology. *Pediatric Blood & Cancer, 62*, S805–S817.

Treiber, F. A., Schramm, L., & Mabe, P. A. (1986). Children's knowledge and concerns towards a peer with cancer: A workshop intervention approach. *Child Psychiatry and Human Development, 16*, 249–260.

Tsitsika, A. K., Tzavela, E. C., Janikian, M., Ólafsson, K., Iordache, A., Schoenmakers, T. M., … Richardson, C. (2014). Online social networking in adolescence: Patterns of use in six European countries and links with psychosocial functioning. *Journal of Adolescent Health, 55*(1), 141–147.

U.S. Department of Education. (2015). *Family Educational Rights and Privacy Act (FERPA)*. Retrieved from https://www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html.

U.S. Department of Health and Human Services. (2004). *Your rights under Section 504 of the Rehabilitation Act*. Washington, DC: Author.

U.S. Department of Health and Human Services. (2017). *Your rights under HIPAA*. Retrieved from https://www.hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index.html.

Varni J. W., Katz E. R., Colegrove R., Jr & Dolgin, M. (1993) The impact of social skills training on the adjustment of children with newly diagnosed cancer. Journal of Pediatric Psychology, 18, 751–767.

Wazeka, A., Valacer, D. J., Cooper, M., Caplan, D. W., & DiMaio, M. (2001). Impact of a pediatric asthma clinical pathway on hospital cost and length of stay. *Pediatric Pulmonology, 32*, 211–216.

22

Future Directions for Integrated Pediatric Behavioral Healthcare

Susan G. Forman and Jeffrey D. Shahidullah

Abstract

This chapter synthesizes the evidence for use of interdisciplinary, collaborative care in pediatric behavioral health. In addition, the importance of multi-tiered integrated healthcare service delivery is addressed, as well as current barriers to this approach. The chapter calls for further development of models of professional training and professional functioning in integrated care, as well as the organizational structures and processes, and implementation strategies that will support these. Several areas for further development are emphasized as a means of increasing the uptake of integrated pediatric behavioral healthcare. These include increasing cross-systems understanding, common factors training, collaboration with parents and families, cross-system progress monitoring, eHealth/mHealth approaches, and financial issues. In addition, actions that can be taken at a number of levels that represent the systems that affect pediatric behavioral health service delivery are addressed. These levels include graduate and professional education, the individual practitioner, service delivery setting management/administration, researchers, professional organizations, and the state and federal level.

Interdisciplinary, Collaborative Care: The Imperative

The chapters in this volume establish the many ways in which pediatric behavioral and physical health conditions are intertwined. These chapters also establish the need for increased communication and collaboration between physical and behavioral healthcare providers, with the objective of increasing integration of physical and behavioral healthcare services. Achieving this objective promises to improve outcomes for individual clients, improve the health of populations, and thus ultimately reduce healthcare costs.

At first glance, the relationship between physical and behavioral health is supported by the existence and development of co-occurring conditions. As indicated in the chapters on externalizing disorders, internalizing disorders, ADHD, autism spectrum disorder, learning disabilities,

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substance abuse, eating disorders, and sleep disorders, many pediatric behavioral health conditions have physical health concomitants and consequences. In addition, physical illness during childhood can affect school attendance, academic achievement, and relationships with peers, teachers, and family members, as established in the chapters on obesity, diabetes, asthma, epilepsy, traumatic brain injury, cancer, chronic pain, and chronic illness and medical stress.

Beyond and partially because of the existence of many co-occurring conditions, several other issues related to pediatric behavioral and physical health support the need for care which is interdisciplinary and collaborative, and thus integrated. First, because of the fact that chronic pediatric physical health conditions frequently have behavioral health concomitants, assessment of psychosocial functioning is important in the provision of high quality physical healthcare. In addition, as indicated in the previous chapters, psychosocial interventions are frequently necessary for management of chronic physical health conditions and for medical treatment adherence.

Current information on the efficacy of treatment for many conditions also indicates the importance of interdisciplinary collaboration and integration. For many behavioral health problems, both medication and psychosocial interventions are effective, and sometimes most effective when combined. In addition, one type of treatment may influence another, underscoring the importance of treatment coordination.

Monitoring effectiveness is essential for high quality treatment and can best be supported through collaborative, integrated care. In order to be effective, a treatment must be utilized. Adherence in pediatric populations is related to the child’s functioning in multiple settings, including school and home. Thus, assessment of adherence, which is part of assessing treatment effectiveness, typically requires observations by multiple professionals and parents in the settings in which children function in their daily lives. Progress monitoring toward physical/medical, social-emotional, and academic goals may need to be conducted by a variety of professionals, with the information gained from progress monitoring provided back to the treatment team.

Issues related to access to care also support the need for collaboration and integration. Pediatricians and other primary care physicians (PCPs) such as family physicians typically have access to very young children that schools do not have and therefore may have the potential to identify a problem very early. For some conditions, such as autism spectrum disorder, risk factors or symptoms are most likely to be identified by the PCP, but prevention and intervention can most easily take place in schools. For some problems, such as eating disorders, the problem may first be noticed in school and because of the physical health consequences should be treated in part by a physician.

Multi-tiered Integrated Service: Importance and Barriers

The biopsychosocial and ecobiodevelopmental models for understanding wellness and illness provide explanatory frameworks that include the importance of biological, psychological, and social factors interacting and affecting the individual across the lifespan, emphasizing the effect that early experiences and development can have on later functioning. These models and research related to them support the importance of prevention, early identification through screening, and early, integrated treatment. Thus, a multi-tiered service approach is called for in which education is provided and screening is conducted for populations, prevention programs are provided for high-risk individuals and groups, and integrated treatment with ongoing progress monitoring is provided for those with chronic conditions. Each of the three tiers in this multi-tiered service approach presents challenges in terms of collaboration and integration in the provision of care. Just as the biopsychosocial and ecobiodevelopmental models explain human functioning using a systems lens, in order to address these challenges, it will be important to use a systems approach to understand the manner in which healthcare providers work, the barriers to collaborative, integrated care, and how effective action can be taken to increase collaboration and integration.

Several chapters in this book discuss the importance of prevention and screening, tier 1 universal programs and services, as a means of reducing the occurrence of many behavioral and physical health problems in individuals and populations, and of identifying the need for early treatment which can reduce the impact of some conditions on functioning. However, screening in pediatric primary care is not ubiquitous despite professional association standards that encourage it. Pediatricians have reported lack of time, staff, and reimbursement as barriers to screening (Schonwald, Horan, & Huntington, 2009). Schools also report lack of time, staff, and finances as barriers. In addition, reluctance to implement screening programs in schools at times relates to reluctance to identify problems and therefore be required to provide services to address them, or reluctance to upset parents with feedback about potential problems of their children. For some problem areas, such as suicide, some stakeholder groups feel that asking about it may cause incidence to increase (Baum, Green, & Weitzman, 2018). Prevention programs for very young children involve extensive interaction with parents. For pediatric practices, this can be problematic in terms of time, reimbursement, and staff knowledge of evidence-based programs; and schools frequently do not have contact with children until age 5.

Tier 2 selective programs and services, which target children at risk, can address risk factors and prevent the progression from risk to illness and pathology. This can include targeted screening with subsequent referral to intensive assessment and treatment. Family engagement and early intervention are key to service delivery in this tier. Barriers to service delivery for both the pediatric primary care provider and school include difficulty in working intensively and extensively with families, availability of staff, time, financial resources, skill in provision of evidence-based programs, comprehensive knowledge of services available across child-serving systems in the community, and the ability to communicate and collaborate across those systems.

Tier 3 targeted programs and services are focused on providing evidence-based care for children with identified problems and illnesses. For children with chronic conditions, such care is frequently complex and best carried out by multiple professionals from different disciplines. Barriers to collaborative, integrated behavioral health service provision in this tier for both the pediatric primary care provider and the school include staff knowledge of evidence-based treatments, treatment cost, and time and finances to support collaboration across the different organizations that may be providing treatment in order to develop and implement a high quality treatment plan and monitor treatment outcomes.

Facilitating Uptake

In the face of barriers at all service delivery tiers, there is a need for increased interprofessional collaboration in the provision of behavioral health services and development of models of professional training, professional functioning, and organizational structures and processes that support this. In the process of developing these models, additional research is needed on the outcomes and potential added value of interprofessional, integrated care and evidence-based implementation strategies that promote it. The current knowledge base indicates that action in the following areas is warranted.

Increasing Cross-systems Understanding

Across service delivery tiers, lack of knowledge about existing services and professional practices in a community will hinder effective integrated care. A basic activity that must be engaged in on the part of professionals across child-serving systems, both medical, psychosocial, and educational, is learning about prevention and treatment service availability and eligibility requirements. In addition, some basic knowledge of how the various professions that provide pediatric physical and behavioral health services function is a prerequisite for collaboration and integration. For some chronic conditions (e.g., learning disabilities), different professional organizations define conditions in different ways. An understanding of how various chronic conditions are defined by different professions is necessary for the development of meaningful, comprehensive assessment and treatment. Other areas that professionals need knowledge of in order to increase the potential for cross-systems collaboration include the varying privacy laws across child-serving systems (i.e., HIPPA, FERPA), and the typical skill sets of professionals that deal with behavioral health issues (e.g., PCP, school psychologist, social worker, nurse), as well as the skill sets of those professionals in the community and the basic procedures they follow in dealing with patients/clients. This type of information will provide some basic prerequisites for behavioral healthcare team functioning.

Common Factors Training

A sizeable percentage of children seen in pediatric primary care practices present with behavioral health problems (Polaha, Dalton, & Allen, 2011). Yet, training of pediatric primary care professionals in basic strategies to address behavioral health issues has been suboptimal (Shahidullah et al., 2018). Pediatric primary care providers have reported that they lack the skills and knowledge to deal with behavioral health problems (Olson et al., 2001). When families are referred in primary care to specialty providers only 40% follow through (Rushton, Bruckman, & Kelleher, 2002) and in many locations referral sources are limited. These conditions speak to the need for training for pediatric primary care professionals in the identification and basic treatment of children who are likely to present in their practices with common behavioral health issues.

"Common factors" training is an approach that has the potential to address this issue. It is based on the idea that there are elements across treatments and diagnoses that have a positive impact on patient outcomes, and that providers can be trained to build skills that promote the patient–provider relationship and influence behavior change. Common factors include a core set of skills and interventions applicable to all behavioral health problems. In addition, common factors training includes practice elements that have been identified across evidence-based treatments for more specific behavioral health conditions. Much of the work in common factors training emanates from the review of psychotherapy research conducted by Grencavage and Norcross (1990) which found that therapeutic common factors included development of a therapeutic alliance, the opportunity for catharsis, the acquisition and practice of new behaviors, clients' positive expectancies, beneficial therapist qualities, and the provision of a rationale for the change process.

For example, the American Academy of Pediatrics Task Force on Mental Health (2010) recommended that primary care clinicians employ common factors represented by the acronym HELP to address childrens' mental health problems. H—*Hope* focuses on increasing a family's hopefulness by discussing realistic expectations for improvement and emphasizing child and family strengths and assets. E—*Empathy* focuses on listening attentively. L—*Language and Loyalty* includes using the child's or family's language to reflect the clinician's understanding of the problem, and communicating support and commitment to help. P—*Permission, Partnership, and Plan* includes asking the family's permission to ask in-depth questions and make recommendations; partnering with the child and family to identify barriers and resistance, find strategies to address barriers, and agree on achievable steps; and establishing a plan for action, monitoring progress, and following up with the clinician.

Research on common factors training in pediatric behavioral health is in its infancy. Wissow et al. (2008) provided brief training for pediatric primary care providers in communication skills targeting eliciting parent and child concerns, partnering with families, and increasing expectations that treatment would be helpful. Minority children cared for by trained providers showed a greater reduction in mental health impairment than those cared for by control providers. Parents of children cared for by trained providers had a greater reduction in mental health symptoms than those cared for by control providers. In a subsequent study of this training Wissow et al. (2011) found that trained clinicians showed increased patient-centeredness toward standardized patient parents, but not adolescents, and that increased patient-centeredness toward parents predicted improvement in parent ratings of child/youth symptoms and functioning, and improvement in youth-rated symptoms. Brown et al. (2013) provided brief training for paraprofessional medical assistants in pediatric primary care in skills aimed at enhancing their ability to have therapeutic interactions with Latino families with mental health concerns. The communication skills targeted included: using patient names and appropriate body language; explaining the role of the medical assistant and next steps in visit; asking open-ended questions to obtain information about physical and behavioral health problems; helping patients prioritize their concerns; probing patient body language; acknowledging concern; empathizing with the patient; getting agreement on the agenda for the visit; and prompting the patient to discuss physical and mental health concerns with the PCP. The paraprofessionals were able to master most of the skills and parents were more willing to discuss mental health concerns with them after the training compared to before the training.

Motivational interviewing is another approach to improving health providers' communication skills and patient outcomes that has been viewed as part of common factors training. Motivational interviewing focuses on increasing motivation to change by resolving ambivalence. It can be applied to a range of child health issues including substance use, asthma, diabetes, obesity and diet change, HIV/AIDS, sleep, accident/injury prevention, and dental care. A recent meta-analysis indicted that motivational interviewing is an effective method to use for pediatric health behavior change (Gayes & Steele, 2014). This study also found that it can be used effectively by professional and nonprofessional practitioners, and that nonprofessionals have demonstrated greater effectiveness. In addition, it was found to be most effective when conducted with both parent and child together. This analysis indicates that this approach seems to have great potential because it is a brief intervention that can be delivered to families by well-trained nonprofessional health workers, thus reducing costs.

A study of training pediatric healthcare providers in adherence promotion provides an example of another approach to improving patient outcomes by training physicians and nurse practitioners in principles of behavioral interventions (Rohan et al., 2013). In this study, providers working with pediatric asthma patients were trained to promote adherence by using graphed feedback to patients and their parents about their adherence pattern, and problem solving concerning barriers to adherence. Problem solving included development of solutions to adherence barriers, evaluating the potential effectiveness of the solutions, considering relevant barriers to the solution, and developing a plan for adherence promotion. Positive reinforcement was given if the family implemented the plan and problem solving was used to modify the plan if adherence continued to be a problem. Providers were given brief individual training on these procedures followed by individual coaching. Adherence promotion sessions during routine medical visits were found to be associated with increased medication adherence. This type of training has the potential for useful outcomes with a variety of pediatric conditions as treatment regimen adherence is important for a positive outcome.

Collaboration with Parents and Families

The need for increasing collaboration with families is especially important in efforts to provide high quality pediatric behavioral healthcare. As indicated by the biopsychosocial and ecobiodevelopmental models, child functioning is affected by family system functioning. Parent and family member emotions and behavior may be contributors to the nature of a child behavioral health problem and may impact access to and adherence to treatment. In addition, the identified patient impacts the entire family system, and family members, including parents and siblings, may be in need of behavioral health services as well as the identified patient. Efforts to increase collaboration with parents and families around behavioral health issues have generally taken three forms:

improving clinician skills in interacting with families around behavioral health issues; increasing family abilities to participate actively in medical care; and prevention and intervention programs aimed at increasing family strength and skills.

Although a large percentage of children with behavioral health problems access healthcare through a pediatric primary care practice, these providers frequently do not detect such problems (Wissow et al., 2008). More than half of parents with behavioral health concerns about their child do not discuss them with their pediatrician (Horwitz, Leaf, & Leventhal, 1998). Common factors theory described above indicates that providers need to build relationships with and attend to the behavioral needs of both the child and the parents, and the strategies included in the common factors approach include actions aimed at increasing family engagement.

Efforts focusing on increasing family abilities to participate in care include attempts at fostering family communication skills in medical encounters. “Ask Me 3” is one such program developed by the National Patient Safety Foundation (Ahmann & Dokken, 2012, www.npsf.org/askme3). Through this approach, family members are encouraged to be active participants in care by asking three questions during each healthcare encounter: (1) What is my (or my child’s) main problem? (2) What do we need to do? and (3) Why is it important for me (us) to do this? The impact of use of Ask Me 3 specifically on behavioral healthcare has not been examined. Prevention and intervention programs aimed at increasing family strength and skills, such as the Nurse Family Partnership (Eckenrode et al., 2017), the Incredible Years (Webster-Stratton & McCoy, 2015), and Triple P (Fawley-King, Trask, Calderón, Aarons, & Garland, 2014) have developed evidence-bases indicating their effectiveness, but widespread uptake of these programs has not occurred.

Kuo et al. (2012) delineate three barriers to family-centered care in pediatric healthcare. The first is a lack of understanding of what family-centered care is, and what this means in terms of specific actions by the provider, the patient, and the family member, as well as a lack of understanding that racial/ethnic and language differences can provide additional barriers to provider–patient communication. In addition, inadequate financial support, including insurance coverage, hinders collaboration with families, as collaboration requires considerable time, effort, and repeated visits. Finally, there is a need for additional high quality research to guide practice and policy, including development of validated measures of family collaboration and studies of outcomes of family collaboration.

Cross-system Progress Monitoring

Several of the chapters in this volume mention the importance of progress monitoring of patients. This becomes especially complex when behavioral health is at issue and multiple professionals in different service delivery systems may be working with patients. In addition, in many cases treatment may occur in one setting, such as the pediatric practice, while patient symptoms and behavior may best be monitored in another setting, such as the school or home. Monitoring patient progress across systems requires cross-system commitment to the importance of progress monitoring, agreement about treatment goals, agreement about measurement methods, and commitment on the part of multiple stakeholders (i.e., professionals and parents) to use them. In order to maintain the motivation of the behavioral health treatment team, creation and maintenance of a team feedback loop, through which feedback is regularly provided to all team members (and other stakeholders) is important. In order to accomplish this, identification of a treatment team member who will coordinate patient progress monitoring and feedback to relevant stakeholders is essential.

eHealth/mHealth Approaches

The rapid development and uptake of technological innovations presents opportunities to address issues pertaining to cross-system collaboration, such as the need for treatment monitoring and adjustment. "eHealth" applications include the use of digital technologies to address a healthcare gap or need that may be difficult to address using traditional approaches. Examples may include intervention, data collection, or communication amongst stakeholders. eHealth (or sometimes referred to as mHealth when considering the use of mobile technologies such as smartphones with text messaging and apps) approaches can be used to allow the patient and their family to take a more active role in their treatment regimen outside the confines of their healthcare providers' office. Given the importance of patient self-monitoring for many health conditions (obesity/weight management, diabetes), these tools more easily allow real-time tracking of progress, with built-in reminders of action steps (blood glucose testing). These approaches hold a great deal of potential for increasing the effectiveness of established interventions although more research in this area is needed.

Financial Issues

A major barrier that is frequently cited as hindering interprofessional, integrated care is finances. Several of the activities that have been identified as important aspects of integrated behavioral healthcare are either not eligible for reimbursement in medical practices through health insurance, or in the case of schools, do not receive funding because of programs that are perceived as of greater importance, such as those directly related to academics. These activities include screening, interprofessional/interorganizational collaboration/meeting time, behavioral health education/prevention programs, and case management services. In medical practices, behavioral health conditions without a specific diagnosis are not reimbursed, thus hindering the use of universal and selective (for at-risk patients) prevention. Financial support for the activities essential to interprofessional, integrated care needs to be established in order for widespread uptake to occur. In order for this to occur, payers and policy makers must partner with pediatric healthcare delivery systems and professionals to develop innovative funding approaches. The move toward value-based payment reform presents an innovative funding shift toward providing payments to support care that achieves improved health and wellness, which may lead to lowered long-term costs.

Moving Forward

The value of integrated pediatric behavioral healthcare has been illustrated and examples of the process and procedures used in this type of care abound. However, in practice, integrated pediatric behavioral healthcare is not widespread. Physical and behavioral health professionals continue to work in relative isolation, failing to fully link their services with others within their work settings and across service delivery settings. The previous section in this chapter described issues that are important to address to increase and speed the uptake of integrated care. In order to address these issues, action at a number of levels that represent the systems that affect pediatric behavioral health service delivery will be important.

Graduate and Professional Education

To keep up with the integrated care workforce demands, health profession training programs and other graduate training programs must continue to develop new and innovative ways to prepare graduates to assume roles in the rapidly changing healthcare landscape. Jobs in this healthcare landscape require practitioners to work as part of teams, adapt to oftentimes fast paced clinical environments, and function in a new culture of medicine. Training in the mental health professions in particular have traditionally not prepared a workforce to have the necessary attitudes, knowledge, and skills to immediately integrate into the healthcare setting and function effectively. More commonly, behavioral health providers may have been trained in traditional models of specialty mental health practice (e.g., 60-min appointment model; little to no collaboration with the patients' medical providers due to separate locations and patient records systems). They then must adapt those skills to fit and function effectively within an integrated healthcare setting; a process that takes time/flexibility and comes with some initial difficulty in adapting. There is a need to prepare the future workforce to practice in these healthcare settings from an earlier stage in their training so that they possess necessary core competencies for interprofessional collaboration and practice. For example, the Interprofessional Education Collaborative (IPEC, 2016) has developed a set of core competencies for interprofessional collaborative practice. These core competencies are assumed to cut across all educational curricula within health professions and help facilitate interprofessional collaborative practice. Another approach to training a future interdisciplinary healthcare workforce to integrate care around both physical and behavioral health conditions is training in common factors, as described earlier in this chapter.

The Individual Practitioner

While health professional training programs and other graduate training programs are slowly adapting to prepare the future healthcare workforce in evidence-based practices around interprofessional collaboration and integrated care, current practitioners may often be overlooked. While most professional disciplines have continuing education requirements for licensure renewal, the format of traditional continuing education modalities (e.g., brief workshops) are largely ineffective (Herschell, Kolko, Baumann, & Davis, 2010). Workshops may produce small increases in treatment knowledge, but are less effective in changing clinician behaviors or skills. Instead, innovative approaches such as peer learning collaboratives or peer supervision groups which can be facilitated by an expert moderator appear to foster increased skill use (Chu, Carpenter, Wyszynski, Conklin, & Comer, 2017) improved process and therapeutic flexibility (Bennett-Levy, Lee, Travers, Pohlman, & Hamernik, 2003) and engagement in professional development (Miller, Duron, Bosk, Finno-Velasquez, & Abner, 2016). Professional healthcare organizations or university training programs can lead efforts to initiate and facilitate peer learning collaboratives and practitioners will need to participate in opportunities to engage in these types of activities.

Service Delivery Setting Management/Administration

To meet the Quadruple Aims of healthcare reform (Bodenheimer & Sinsky, 2014), health systems management and administrators will undoubtedly be tasked with transforming their practice models to encompass integrated care. This transformation must center around improving patient access, satisfaction, quality treatment, cost-effectiveness, and collaboration amongst an interdisciplinary team. Transformation components may include the need to initiate a shared electronic medical record (EMR) system, shared space and office/scheduling staff, and developing opportunities for clinicians from multiple disciplines and office staff/administrators to participate in meetings together. Part of the ongoing development for practice settings will be for all stakeholders to continually strive to work together as teams through communication, collaboration, and using a shared language. The shared EMR system is designed to facilitate these practices and also a range of other critical support functions including scheduling, billing, and finance management. The EMR system can also be used as a tool to drive continuous quality improvement through the use of metrics such as office workflows and referral tracking, patient outcomes, and reimbursement outcomes from billable services.

Researchers

As indicated previously, continued research is needed to demonstrate the added value of interprofessional, integrated care. In addition, several areas related to improving uptake will be especially important in terms of increasing current research findings. Common factors training presents a promising approach to improving the reach and quality of behavioral healthcare for children and adolescents. However, substantial additional research is needed in order to define the content and process of effective common factors training. Issues that need answers include which skills to teach as part of common factors training and which professionals or other healthcare personnel to teach them to, and what patient characteristics impact outcomes. Related to common factors training is the area of collaboration with families. Additional research is needed to determine what good collaboration with families consists of; effective, culturally sensitive methods of engaging and collaborating with families; and how collaboration with families can impact patient outcomes.

Professional Organizations

Changes in policy at the state and federal level, such as those that will be required in order to address the financial barriers to high quality, collaborative, integrated pediatric behavioral healthcare, may best be addressed by action from multiple professional associations working together to make systems level changes. One area in which a coordinated advocacy effort is needed is in financial reimbursement for behavioral health services (e.g., reimbursement specifically for Health and Behavior Codes). Professional organizations can also play a major role in improving the standard of integrated care through workforce development, research and practice symposia, and development of cost-effective service delivery models. One example of a professional organization that leverages its membership base of a wide range of professional disciplines to unify around the promotion of cost-effective models of integrated care is the Collaborative Family Healthcare Association (see www.cfha.net). This organization offers a number of symposia as well as continuing education offerings for a variety of disciplines around integrated care topics.

State and Federal Level

State and federal agencies and organizations can contribute to the effort to expand the uptake of integrated pediatric behavioral healthcare through funding of research, training, and dissemination activities; policy initiatives; and development of certifications and standards. For example, a number of government agencies, such as the Health Resources and Services Administration (HRSA) and the Substance Abuse and Mental Health Services Administration (SAMHSA), provide grant funding for training and development activities, as well as guidance regarding standards that can provide the initial support for uptake. Especially important in HRSA's efforts as part of its goal to strengthen the health workforce is their intention to "Expand the number and type of training and technical assistance opportunities that educate students and providers to work in interprofessional teams and participate in practice transformations" (HRSA, 2017) and the grant and scholarship programs that support this. Another example of federal level support that can help build the capacity for integrated pediatric behavioral healthcare is the SAMHSA-HRSA Center for Integrated Health Solutions, which promotes the development of integrated primary and behavioral health services through information, training, and technical assistance to health, primary care, and behavioral health organizations. The Agency for Healthcare Research and Quality's work to promote evidence-based practices, develop patient care outcome measures, and develop methods of training professionals for interprofessional teamwork is and will continue to be of major importance in efforts to scale-up integrated behavioral healthcare service delivery.

In addition, at the federal and state level, agencies that set curriculum standards for graduate and professional education program accreditation and agencies that determine professional licensing requirements can work to build the competencies necessary for effective professional functioning in integrated care into requirements for program accreditation and licensing of individual practitioners. For example, the Accreditation Council for Graduate Medical Education has required exposure to developmental-behavioral pediatrics in pediatric residency programs. The American Psychological Association has required programs to demonstrate how they develop student competence in a number of aspects of professional functioning related to integrated care.

Reimbursement has been cited as one of the most common barriers to provision of integrated pediatric behavioral healthcare. Both government and private health insurance payers will need to more broadly pay for mental healthcare without a specific diagnosis and for consultation between primary care and behavioral health professionals if the goal of increasing use of an integrated behavioral health approach is to be achieved. Without substantial reform to our system of payment for healthcare, these specific issues need to be addressed in order for integrated behavioral healthcare services to spread.

Conclusion

Provision of both behavioral and physical pediatric healthcare through an interdisciplinary, collaborative, and therefore, integrated approach makes sense in terms of potential improved outcomes for individual patients as well as populations. The interconnectedness of physical and behavioral health conditions in terms of high quality assessment, diagnosis, treatment planning, treatment monitoring, and treatment effects establishes the imperative for integrated care. In addition, access to care issues, especially for high need, vulnerable, underserved populations, add to the rationale for providing healthcare in this manner. In order to increase implementation of integrated behavioral healthcare, all levels of the healthcare workforce pipeline and healthcare delivery systems will need to take action to address identified systemic barriers. Through concerted attention to and use of evidence-informed strategies to address implementation barriers, the potential of integrated pediatric behavioral healthcare can be realized.

References

Ahmann, E., & Dokken, D. (2012). Strategies for encouraging patient/family member partnerships with the health care team. *Pediatric Nursing, 38*, 232–235.

American Academy of Pediatrics Task Force on Mental Health. (2010). Enhancing pediatric mental health care: Algorithms for primary care. *Pediatrics, 125*, S109–S125.

Baum, R., Green, C., & Weitzman, C. (2018, May). *How can you care for children who present with symptoms of ADHD and Depression in your office?* Workshop presented at the meeting of the Pediatric Academic Societies, Toronto, Canada.

Bennett-Levy, J., Lee, N., Travers, K., Pohlman, S., & Hamernik, E. (2003). Cognitive therapy from the inside: Enhancing therapist skills through practising what we preach. *Behavioural and Cognitive Psychotherapy, 31*, 143–158.

Bodenheimer, T., & Sinsky, C. (2014). From triple to quadruple aim: Care of the patient requires care of the provider. *Annals of Family Medicine, 12*, 573–576.

Brown, J. D., Wissow, L. S., Cook, B. L., Longway, S., Caffery, E., & Pefaure, C. (2013). Mental health communications skills training for medical assistants in pediatric primary care. *Journal of Behavioral Health Services & Research, 40*, 20–35.

Chu, B. C., Carpenter, A. L., Wyszynski, C. M., Conklin, P. H., & Comer, J. S. (2017). Scalable options for extended skill building following didactic training in cognitive-behavioral therapy for anxious youth: A pilot randomized trial. *Journal of Clinical Child & Adolescent Psychology, 46*, 401–410.

Eckenrode, J., Campa, M. I., Morris, P. A., Henderson, C. R., Jr., Bolger, K. E., Kitzman, H., & Olds, D. L. (2017). The prevention of child maltreatment through the Nurse Family Partnership Program: Mediating effects in a long-term follow-up study. *Child Maltreatment, 22*, 92–99.

Fawley-King, K., Trask, E., Calderón, N. E., Aarons, G. A., & Garland, A. F. (2014). Implementation of an evidence-based parenting programme with a Latina population: Feasibility and preliminary outcomes. *Journal of Children's Services, 9*, 295–306.

Gayes, L. A., & Steele, R. G. (2014). A meta-analysis of motivational interviewing interventions for pediatric health behavior change. *Journal of Consulting and Clinical Psychology, 82*, 521–535.

Grencavage, L. M., & Norcross, J. C. (1990). Where are the commonalities among the therapeutic common factors? *Professional Psychology: Research and Practice, 21*, 372–378.

Health Resources and Services Administration. (2017). *Strategic plan FY 2016–2018*. Retrieved from https://www.hrsa.gov/about/strategic-plan/index.html.

Herschell, A. D., Kolko, D. J., Baumann, B. L., & Davis, A. C. (2010). The role of therapist training in the implementation of psychosocial treatments: A review and critique with recommendations. *Clinical Psychology Review, 30*, 448–466.

Horwitz, S. M., Leaf, P. J., & Leventhal, J. M. (1998). Identification of psychosocial problems in pediatric primary care: Do family attitudes make a difference? *Archives of Pediatric and Adolescent Medicine, 152*, 367–371.

Interprofessional Education Collaborative. (2016). *Core competencies for interprofessional practice: 2016 update*. Washington, DC: Interprofessional Education Collaborative. Retrieved from https://nebula.wsimg.

com/2f68a39520b03336b41038c370497473?AccessKeyId=DC06780E69ED19E2B3A5&disposition=0&alloworigin=1.

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: Current applications and future directions in pediatric health care. *Maternal and Child Health Journal, 16*, 297–305.

Miller, J. J., Duron, J. F., Bosk, E. A., Finno-Velasquez, M., & Abner, K. S. (2016). Peer-learning networks in social work doctoral education: An interdisciplinary model. *Journal of Social Work Education, 52*, 360–371.

Olson, A. L., Kelleher, K. J., Kemper, K. J., Zuckerman, B. S., Hammond, C. S., & Dietrich, A. J. (2001). Primary care pediatricians' roles and perceived responsibilities in the identification and management of depressions in children and adolescents. *Ambulatory Pediatrics, 1*, 91–98.

Polaha, J., Dalton, W. T., III, & Allen, S. (2011). The prevalence of psychosocial concerns in pediatric primary care serving rural children. *Jounal of Pediatric Psychology, 36*, 652–660.

Rohan, J. M., Drotar, D., Perry, A. R., McDowell, K., Malkin, J., & Kercsmar, C. (2013). Training healthcare providers to conduct adherence promotion in pediatric settings: An example with pediatric asthma. *Clinical Practice in Pediatric Psychology, 1*, 314–325.

Rushton, J., Bruckman, D., & Kelleher, K. (2002). Primary care referral of children with psychosocial problems. *Archives of Pediatrics and Adolescent Medicine, 156*, 592–598.

Schonwald, A., Horan, K., & Huntington, N. (2009). Developmental screening: Is there enough time? *Clinical Pediatrics, 48*, 648–655.

Shahidullah, J. D., Kettlewell, P. W., Palejwala, M. H., Forman, S. G., Billups, A., Anismatta, S. L., & Madsen, B. (2018). Behavioral health training in pediatric residency programs: A national survey of training directors. *Journal of Developmental and Behavioral Pediatrics, 39*, 292–302.

Webster-Stratton, C., & McCoy, K. P. (2015). Bringing The Incredible Years® programs to scale. *New Directions in Child and Adolescent Development, 149*, 81–95.

Wissow, L., Anthony, B., Brown, J., DosReis, S., Gadomski, A., Ginsburg, G., & Riddle, M. (2008). A common factors approach to improving the mental health capacity of pediatric primary care. *Admistration and Policy in Mental Health and Mental Health Services Research, 35*, 305–318.

Wissow, L., Gadomski, A., Roter, D., Larson, S., Lewis, B., & Brown, J. D. (2011). Aspects of mental health communication skills training that predict child and parent outcomes in pediatric primary care. *Patient Education and Counseling, 82*, 226–232.

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