

# Adolescents and Young Adults with Cancer: A Biopsychosocial Approach

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Rapid and significant human development characterizes adolescence and young adulthood. New social demands and ongoing cognitive and emotional maturation coincide with neuroendocrine changes and sexual development making this a

stressful yet exciting phase of life. Adolescence and young adulthood are also times when developmental and health trajectories can be derailed by significant challenges to physical, psychological, and social well-being. These challenges are experienced quite differently by older adolescents and young adults (AYAs) in their 20s and 30s and have distinct behavioral implications, when compared to children and older adults.

Cancer is one example. It is the leading cause of death from disease for young people aged 15–29 years in the United States (Bleyer et al. 2006). Only accidents, homicide, and suicide claim more young lives than cancer. Cancer incidence peaks during the first 5 years of life with a second peak occurring during adolescence and early adulthood, most prominently in males. About five times as many people are diagnosed with cancer during the second 20 years of life as they are during the first two decades of life (National Cancer Institute 2015).

The types and prevalence of malignancies that occur in AYAs differ from those occurring in pediatric and older adult populations and vary as age increases from 15 to 39 years. The most prevalent cancers among the AYA population include leukemias, lymphomas, germ cell tumors (including testicular cancer), sarcomas, central nervous system tumors, melanoma, and colorectal, liver, cervical, breast, and thyroid cancer (<http://www.cancer.gov/cancertopics/aya/types>). Among 25- to 39-year-olds, the prevalence of breast cancer

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and melanoma increases (Bleyer et al. 2006). These early breast cancers tend to be aggressive, with an excess rate of death for AYAs, and particularly African American women, compared to older women (Johnson et al. 2013). Less than 5 % of cancers in 15- to 29-year-olds have been attributed to a family cancer syndrome (Bhatia and Sklar 2002), and environmental factors appear to affect AYAs differentially.

In general, a biopsychosocial approach to care acknowledges that biological, psychological (i.e., emotions, cognitions), social (i.e., environment, economics, culture), and behavioral processes are interrelated in shaping human responses to disease (Engel 1977). For example, disparities in survival outcomes for AYAs with cancer may be a function of some or all of the following factors: differential biologic tumor response, delays in diagnosis and initiation of treatment, environmental exposures, genetic susceptibility, access to clinical trials, and health insurance (Bleyer 2011). Young peoples' brains and related neuroendocrine functions are still "under construction" and not fully developed until they are well into their twenties. The regulation of impulse control, which is controlled by the frontal lobes, develops last with the greatest changes occurring between puberty and adulthood. AYAs are physiologically underdeveloped in the areas that control impulses, foresee consequences, and temper emotional responses to environmental stressors. The amygdala, which develops before the frontal lobes, is responsible for impulsive and aggressive behavior, and its dominance makes AYAs less likely than mature adults to give due consideration to their behavior and its consequences. The brain is most vulnerable when young people are most likely to experiment with drugs or alcohol. Furthermore, when confronted with chronic health conditions, AYAs are often likely to resist adherence to medical recommendations (Patton et al. 2012). However, since the AYA brain is plastic and amenable to change, intervening with AYAs has great potential to shape cognition function and lifelong health behaviors.

AYAs engage in a myriad of developmental tasks associated with physiological, psycholog-

ical, and social maturation, such as establishing autonomy from parents; developing a personal set of values and identity; establishing and reinforcing peer relationships, particularly intimate and sexual relationships; and obtaining adequate preparation to join the workforce. Prevalence of mental health disorders is highest during young adulthood, with 15 % of 18- to 29-year-olds having reported a history of major depressive disorder, 21 % reporting a mood disorder, and 30 % reporting any anxiety disorder (National Institute of Mental Health 2005; Kessler and Wang 2008). Coupled with risks for mood and other mental disorders, adolescents and young adults are primed to experience profound emotional distress, including anxiety and depression, when faced with a life-threatening event such as cancer. Anxiety and depression can have negative implications on the quality of life and even survival outcomes of AYAs with cancer including an increase in physical pain, potential for nonadherence with treatment, and higher disease morbidity (Lauer 2015). Post-traumatic stress symptoms and post-traumatic stress disorder have been associated with young adult survivors of childhood cancer (Rourke et al. 2007). In comparison to older adult cancer patients, adolescents and young adults lack the range of coping tools and life experiences, and this makes them particularly vulnerable to emotional distress (Lauer 2015; Trevino et al. 2012). Mental health professionals should provide routine screening of emotional distress and psychosocial adjustment to cancer for every newly diagnosed AYA patient, early in the cancer diagnosis. After accidents and homicide, suicide is the 3rd leading cause of death for young people aged 15–24 years (Lizardi et al. 2010).

Other complicating social and environmental factors may be history of substance use, child abuse, and poverty. Substance use is one of the largest contributors to morbidity and mortality among AYAs. Fifty-five percent of adolescents report having been drunk by 12th grade, and 28 % of 18- to 24-year-olds report binge drinking (5+ drinks in the last 2 weeks) (Centers for Disease Control and Prevention 2012). Prevalence

rates are high for alcohol abuse (14 %), drug abuse (11 %), and any substance abuse disorder (17 %) among 18- to 29-year-olds (Kessler and Wang 2008).

Overall, 3–18 % of children in the United States have been sexually abused before the age of 12 (United States Department of Health and Human Services 2013). Around the world, 20 % of females and 8 % of males have suffered some form of sexual abuse before age 18 years (Pereda et al. 2009). The emotional and behavioral responses to sexual abuse and other traumatic experiences can exacerbate during adolescence or young adulthood and be expressed as unsafe sexual behavior, drug/alcohol abuse, psychiatric symptoms, and low levels of self-esteem (Lalor and McElvaney 2010). These risk factors can complicate disease management and adherence to therapy for AYAs diagnosed with cancer.

Twenty-one percent of children age 18 years and younger in the United States live in poverty (Felner and DeVries 2013). AYAs who grow up in poverty will likely continue to experience adverse events that can increase the likelihood of comorbid medical and psychosocial problems. Once these problems develop, AYAs who are impoverished can experience limited and disparate access to health care and other resources that address the constellation of biopsychosocial challenges. On the other hand, AYAs who have experience negotiating early life stressors can be resilient to adverse effects of later life stressors.

### **Case Vignette Substance Abuse**

After meeting with a 16-year-old male with a premorbid history of opioid addiction and new diagnosis of acute lymphoblastic leukemia, the oncology team collaborated with the hospital's adolescent medicine service to develop a structured pain medication plan and behavioral regimen for the patient. A primary goal of the patient's pain plan was to provide clinically appropriate pain relief with the least amount of opiates. In order to maintain close monitoring of the patient's pain medication use, the oncology team

became the sole prescribers of pain medication for this patient. Opioid medication was introduced only during potentially more painful points of treatment including surgical procedures such as a bone marrow biopsy and for debilitating side effects of treatment such as mucositis. The oncology team engaged the patient and his mother in the development and execution of a written behavioral contract signed by the patient and his mother. Some of the core stipulations of the contract included the following:

The patient would actively engage in his health care by continuing to participate in cancer treatment and outpatient substance treatment.

The oncology team would be the only health-care providers to prescribe pain medication to the patient.

The patient's mother would dispense his pain medication and monitor his use outside of the hospital setting.

His mental health-care needs were met by ensuring that he continued to work with the outpatient substance abuse counselors as well as the oncology social worker to address the risk of substance abuse relapse during the course of his illness and strategies for coping with stress. Effective psychosocial models utilized with this patient included cognitive behavioral therapy and motivational interviewing. Complementary modalities of managing pain such as meditation, deep breathing exercises, and yoga were also used. Throughout his treatment, the oncology team assessed the patient's pain with a focus on any potential drug-seeking behaviors.

## **Experiencing Cancer as an AYA**

Understanding the biological, psychological, and social contexts of AYAs' lives and the interface between adolescent and young adult devel-

opment and cancer is critical for the delivery of optimal care for this age-defined population. Cancer-related issues such as premature confrontation with mortality, changes in physical appearance, increased dependence on parents, disruptions of social life and school/employment because of treatment, and loss of reproductive capacity become particularly distressing (Zebrack and Isaacson 2012) and have the potential to exacerbate or complicate self-management of cancer-related symptoms, treatment side effects, and adherence to medical recommendations including medications, health-care appointments, and lifestyle modifications (Butow et al. 2010). While healthy peers are experiencing typical adolescence and young adulthood, AYAs are hospitalized or become homebound, often under the watchful eyes of hypervigilant parents and clinicians. They lack privacy and may become isolated from their peer group. Ultimately, most are unable to experience a “normal” adolescent life (Jones 2008). Confronting the adversities of cancer also has the potential to promote AYA maturation and psychosocial development. It exposes them to ideas, people, and opportunities for renewed esteem and confidence, identity transformation, and enriched knowledge about their body, empathy for others, and interest in health-related career paths (Lehmann et al. 2014; Phillips and Jones 2014).

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## Caring for AYAs with Cancer

Optimal assessment, care planning, and treatment across a continuum of care must occur with the understanding that maturation and development is co-occurring and that life disruptions can put AYAs at risk for lasting psychological, emotional, and social complications. To enhance care for AYAs, health-care professionals must cultivate their own clinical skills to help AYAs successfully cope with the challenges of cancer and the extent to which cancer influences their social worlds, particularly with regard to substance use/abuse, fertility, sex and sexuality, dying, and death. Quality cancer care for AYAs is dependent

upon their needs being addressed by providers particularly trained to do so and should include mental health providers (e.g., social workers, psychologists, and psychiatrists, psychiatric mental health nurse practitioners), fertility specialists, nutritionists, music and art therapists, physical therapists, sexual health counselors, and palliative care teams.

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## Key Components of AYA Care

There exists an essential and unique set of medical and psychosocial aspects of care for AYAs for which age-appropriate clinical approaches and interventions are essential.

### Family-Centered Care

Family-centered care provides an important model for how to best support adolescents and young adults with cancer, and particularly in the area of medical decision-making. A core component of family-centered care is an acknowledgment of various levels of engagement of families within the patient’s medical care (Institute for Patient- and Family-Centered Care 2010). This is an especially relevant concept in the care of AYAs who, while flexing a sense of independence and autonomy, also seek input and support from others in the navigation of their medical care.

### AYAs and Family of Origin

Many AYA patients remain or return to the family home during treatment and rely on their parents for tangible assistance and emotional support to an extent that can be inconsistent with previously held personal expectations and developmental norms. Thus, being mindful of the developmental challenges that AYA cancer can pose for parents and AYA siblings is critical. Family support and cohesiveness can be important contributors to positive adjustment. Family functioning has been identified as the single best predictor of distress, with poorer family functioning predictive of greater distress and subop-

timal treatment adherence (Kondryn et al. 2011; Zebrack 2011).

Given the strong influence of family functioning, the provision of family-focused care is essential in the form of providing psychosocial support information and needs assessments where possible. In cases where poor family functioning is identified, additional support and assessment should be provided along with referrals to psychosocial care providers (e.g., oncology social workers) where appropriate. Health professionals should identify potential risk and protective factors in terms of family functioning

as well as family-related concerns so that appropriate levels of support can be provided (see Table 12.1).

### AYAs as Parents

Some AYA patients will already be parents when they are diagnosed with cancer. Pressing concerns include when, how, and how much to tell their children about the cancer diagnosis as well as changes in the parent's appearance and family routines. Parents, especially single parents with cancer, will also worry about who can help care for their children during treatment or

**Table 12.1** Family risk factors and the promotion of protective factors

Family risk factors	Promoting protective factors
<i>Closed communication</i> , e.g., family members are not kept informed and there are limited opportunities for involvement and discussion in decision-making	Encourage <i>open communication</i> among family members; keeping each other informed provide opportunities for negotiation and open decision-making
<i>Avoidance of sharing of feelings</i> , e.g., there is an overemphasis on positive thinking or fear that sharing feelings may upset or worry others	Teach family members to <i>express feelings</i> and feel comfortable doing so
<i>Unbalanced cohesion</i> , e.g., families may be enmeshed and may be dependent and reactive to each other, relying heavily on each other for support	Work with the family to achieve <i>healthy boundaries</i> ; remaining close to each other, but also maintaining their own independence
<i>Low levels of adaptability</i> , e.g., difficulty accepting or adapting to change	Increase <i>psychological flexibility</i> among family members allowing them to respond and reorganize themselves well in times of change/stress
<i>Loss of familiarity</i> , e.g., disruptions to family life over an extended period of time can bring instability and lack of familial support	Work with the family to <i>restore</i> previous family activities and priorities. Also allow for the possibility to develop <i>new ways of being</i> as a family
<i>Lack of a social support network</i> , e.g., families who are socially isolated are likely to rely heavily/exclusively on immediate family members for emotional and practical support	Promote the <i>development of, and access to, a social support network</i> to provide adequate emotional and practical support outside of the immediate family
<i>Parental distress</i> , e.g., parents experiencing elevated levels of psychological distress, finding it difficult to adjust and cope with the difficulties a cancer diagnosis brings	Foster <i>effective parental adjustment</i> by assisting parents to be aware of their levels of distress and to seek psychological assistance where needed; provide coping strategies and increase psychological flexibility to allow acceptance of their situation
<i>Financial instability</i> (existing or as a result of the cancer diagnosis), e.g., due to medical costs, time out of work, travel	Link family with <i>financial services</i> to assist in ameliorating the financial impact associated with the cancer diagnosis
<i>Poor parenting skills</i> , e.g., focus on negative behaviors with little acknowledgment of positive behaviors, inconsistent discipline techniques, and expectations placed on each young person	Encourage <i>parenting competence</i> by teaching effective and consistent disciplining and monitoring of AYAs, good conflict resolution skills, and reinforcement of positive behaviors
<i>Preexisting stressors</i> , e.g., mental health issues, domestic violence, drug and alcohol issues, or care duties of other family members	Address stressors to nurture a <i>stable family environment</i> where additional stressors are well managed. This may involve referring to other services as appropriate

Source: Supporting adolescent and young adult siblings of cancer patients: the family context. Retrieved from [https://www.canteen.org.au/media/63525/RTPIssue1\\_Paper.pdf](https://www.canteen.org.au/media/63525/RTPIssue1_Paper.pdf). Permission obtained to adapt material (CanTeen Australia 2011b)

if they do not survive their cancer. AYA patients who are parents can benefit from specific guidance about how to talk with their children about cancer and what to watch for in terms of signs of child distress (Maynard et al. 2013). More information about addressing AYA parent's concerns about their children can be found at [www.mghpact.org](http://www.mghpact.org).

### **Managing and Comprehending Information**

Health-care providers should ask AYAs directly about how they would prefer to receive this information, be it verbal, written, and audiovisual instruction. Doing so becomes one way to restore a sense of control to AYAs, for whom lost control and autonomy are major challenges. The main topics AYA patients want information about are their cancer and its treatment, the decision-making process, the health-care system, and survivorship issues such as what can be done to manage persistent, worsening, or late adverse effects (Palmer et al. 2007; Zebrack 2008). Many AYAs also want information about healthy diet, exercise, infertility, complementary and alternative approaches, and insurance. Addressing AYAs' information needs requires health professionals to (1) use a caring manner and understandable language, (2) allow time for AYAs to process information, (3) not assume AYAs are confident to ask questions, and (4) expect AYA and parent concerns to differ (Palmer et al. 2007). Many AYAs independently access cancer-related information and support online. With online usage prevalent in this age group, the development of evidence-based, developmentally appropriate Web-based information for AYA patients is essential. For example, the website [www.nowwhat.org.au](http://www.nowwhat.org.au) supports young people affected by cancer, whether they are dealing with their own or an immediate family member's cancer. This website sets an international benchmark, combining access to professional counselors and youth-specific information and providing interactive, personalized online peer support community (Patterson et al. 2014).

### **Patient-Provider Relationships and Communication**

The quality of the patient-provider relationship and therapeutic bond, specifically between the oncologist and AYA patient, has been shown to demonstrate a great impact on the psychosocial well-being of the patient, which, in turn, can have implications on treatment adherence and quality of life (Trevino et al. 2013). Special consideration of how information is communicated is essential to AYA patients who will engage most effectively with providers who present information in a direct yet genuine, non-authoritative manner (Trevino et al. 2013). Clinicians should demonstrate a sense of self-awareness and exhibit a clear sense of professional boundaries when working with AYAs, who might be inclined to question authority. Flexibility and patience on the part of the clinician are critical to the development of a trusting patient-provider relationship.

AYA health communications and collaborative decision-making can be sensitive issues. Some AYAs prefer to be shielded from discussions about their cancer, treatment options, and potential late effects and/or to assume a dependent position with regard to decision-making. Others want a prominent or fully independent role. Respecting AYAs' preferences for autonomy can be agonizing for their parents. AYAs over age 18 years are legal adults in the United States and are expected to provide informed consent for both their medical treatment and participation in biomedical research. Their parents are deemed to have no rights to their health information without specific patient agreement, which could be a blanket agreement or vary by the nature and complexity of the decision being made.

AYAs under age 18 years should be engaged in health communications and decision-making and asked to provide assent. Although most AYAs lack experience to guide communications and decisions about cancer treatment and rely heavily on parental advice about how to proceed, others prefer to function independently of their parents. Parents, however, can feel responsible to protect and advocate for their children and thus struggle with their child and their child's clinician over access to health



information and control of decisions and other aspects of care.

Clinicians must determine, as early as feasible, the extent to which the AYA patient wishes to involve parents in health communications and treatment decision-making and then acknowledge that these wishes may change over time. Health-care providers must be mindful of the potential conflict and tension that might arise between AYAs and their families in decisions concerning medical care (Grinyer 2009). Should a patient wish for an individual(s), such as a parent or spouse/partner, to have access to her medical information, the treating health-care provider should implement procedures (Health Insurance Portability and Accountability Act (HIPAA) release form in the United States) and establish specific parameters for doing so. One approach is for the clinician to give information to the patient first and then, with patient permission and to the extent specified, to parents or other designated individuals with the patient together (Grinyer 2003). This approach also provides AYAs with opportunities to hear complex and significant information repeated and to learn from parent questions. However, it is also important to note that there may be a history of problems between a parent and child that will complicate the AYA's cancer experience. Assessment is required to determine the best approach for integrating parents and other individuals into AYA care. This approach can also promote development of an open, trusting health-care relationship between AYAs, their social network members, and their oncology care providers.

### **Case Vignette : Patient-Provider Communication and Shared Decision-Making**

A 22-year-old woman received chemotherapy and radiation for a brain tumor. During the course of her treatment, she took a medical leave from college and moved home to live with her mother, who served as her primary caregiver. The patient's parents were divorced. The patient included her mother in the initial discussions with the patient's primary medical

team in order to review her diagnosis and proposed treatment plan. From the outset, it was evident that the patient displayed a full range of capacity to make medical decisions. Following the consultation, the social worker met with the patient individually to perform a psychosocial assessment. The primary goal of the interview was to educate the patient about her legal rights to make medical decisions and the confidential and protected nature of her health information. Moreover, the social worker aimed to glean an understanding of the patient's communication style and preferences. The following questions were posed to the patient:

How do you learn best (i.e., verbal, written, and audiovisual formats)?

How much information would you like to know about your medical condition?

With whom have you engaged in the past when making important decisions, such as those concerning your health?

Are there others with whom you wish to have access to your medical information?

The patient stated that while she would be in charge of her health care, she wanted her mother to be engaged in all levels of her care from daily medical rounds to meetings with the medical team about changes in her medical condition and treatment planning. Moreover, the young woman was emphatic that she did not wish for her father, from whom she was estranged, to have access to her medical information or be involved in any aspect of her care. To formalize the patient's wishes about who could be granted access to her health information, the social worker facilitated the implementation of a HIPAA release form, which established that her mother could have access to her health information. A copy of this document was included in the patient's medical records so that health-care providers were properly informed of her wishes.

## Clinical Trials

Pediatric and adult settings can each lack opportunities for AYA enrollment in clinical trials, particularly trials that consider the unique biology and behavior of some AYA cancers. Much of the improvement that has been made in survival rates for children with cancer has been attributed to their high rates of enrollment in national collaborative or institutional clinical trials. More than 60 % of pediatric cancer patients in the United States (most under the age of 15 years) are treated on research protocols (<http://www.childrensoncologygroup.org/index.php/what-is-a-clinical-trial>; accessed 13 Feb 2015). In contrast, 10–15 % of 15- to 19-year-olds and about 2 % of 20- to 29-year-olds with cancer are enrolled in such trials in the United States (Bleyer et al. 2006), with similar low figures observed in other Western countries (Fern and Whelan 2010; Ferrari et al. 2008). While disparities in clinical trial participation for 20- to 29-year-olds are similar across racial and ethnic groups, gender disparity with lower male participation stands out (Fern and Whelan 2010).

Some psychosocial barriers to AYA enrollment in clinical trials include intense emotional responses to the cancer diagnosis; lack of experience making important decisions, especially medical decisions; concerns about further loss of control and quality of life due to clinical trial requirements; lack of information about available clinical trials or complexity of the information; beliefs that community providers can offer the same level of care, monitoring, and services as what they would receive through clinical trial participation; misconceptions about clinical trials and fears of being “treated as a guinea pig”; and the costs that can be associated with being treated outside the local community (Buchanan et al. 2014). AYAs, however, report that they participate in clinical trials for both the therapeutic benefits that they hope to accrue for themselves and as a means to help other people like them (Miller et al. 2013). AYAs might need assistance identifying clinical trial options, comprehending trial requirements and implications and, for those who want to participate in a trial, ongoing emotional

and practical support for accessing the trial and adhering to its requirements. Without improving AYA access and participation in clinical trials, improving medical outcomes for AYA cancer patients will continue to be limited.

## Psychosocial Screening, Assessment, and Care Planning

A biopsychosocial approach requires the use of developmentally appropriate assessment tools to identify AYAs at risk for psychosocial distress or other conditions that may disrupt their care or compromise survival and quality of life. Given the dearth of instruments available (Wakefield et al. 2013), an *AYA Oncology Psychosocial Care Manual* (CanTeen Australia 2011a) was developed which includes an AYA-modified version of the National Comprehensive Cancer Network (NCCN) Distress Thermometer and Psychosocial Problem Checklist (areas related to practical, family, emotional, social, physical information) and a comprehensive assessment of cancer experience inclusive of physical systems review, family, education, employment, social activities, substance use (e.g., alcohol, drugs, tobacco), sexuality and sexual relationships, religious and spiritual beliefs, mental health, current stressors, strengths, and support. These instruments screen, assess, and assist in identifying patients at risk for psychosocial challenges managing their cancer (Evan and Zeltzer 2006; Hedstrom et al. 2006). Consideration should be given to acute stress symptoms along with risk factors including lower socioeconomic status, prior exposure to trauma, history of childhood adversity such as parental death, family psychiatric history, and protective factors such as social support and resilience that can affect AYAs’ emotional responses to cancer and its treatment.

The screening tool, care plan, and assessment measure were developed to be administered at key time points along the AYA psychosocial care pathway, aiming to support the young person throughout their treatment by addressing current support needs and taking into consideration needs that may be most significant posttreatment



for healthy survivorship. In addition to the screening and assessment tools, the *AYA Oncology Psychosocial Care Manual* includes a care plan *pro forma* to provide a means for clinicians to collate relevant screening and assessment information and develop a strategy to manage issues raised. It enables treating teams to identify patients at risk, monitor the progressive coping of the patient, identify areas of need requiring additional care and support, and guide counseling so that AYAs receive the support they need, even as their needs change (CanTeen Australia 2011a; Palmer et al. 2014). Table 12.2 outlines how the patient moves through the

pathway as described in the *AYA Oncology Psychosocial Care Manual* (pp. 5–6) (CanTeen Australia 2011b).

The initial psychosocial assessment should also include attention to substance abuse risk factors including personal, family or peer group history of substance abuse (e.g., illicit drugs, prescription drugs, alcohol), and personal or family history of psychological problems especially depression. This is especially important since most AYA patients will be prescribed opioid therapy for cancer-related pain. Abuse risk factors are dynamic and must be carefully monitored over the cancer trajectory (Pergolizzi et al. 2012).

**Table 12.2** The AYA psychosocial care pathway

Elements	Process
Initial Psychosocial Screen	Every young person should receive a psychosocial screen, ideally within 2 weeks of diagnosis and/or first treatment cycle. It identifies the level of distress currently experienced by the patient and the nature of such distress. Information should also be provided about clinical trials, support organizations, entertainment, home comforts, websites, alcohol and drug use, fertility preservation, communication tools, sexual health, educational support, and the lead clinician
Development of Care Plan	Within 2 weeks following the administration of the screening tool, a care plan based on the outcomes of the screening tool should be developed by the treating team in collaboration with the patient. It focuses on addressing the current needs of the patient through referral, information provision, further assessment, and/or standard patient management
Second Screen and Psychosocial Assessment	This is conducted once treatment is established. Approximately 8 weeks post diagnosis and/or treatment commencement is a significant period for the patient. Given it is often a time of changing and/or increasing need, a second screen is conducted. Resources permitting, it is beneficial for patients to also receive a full psychosocial assessment during this stage of their cancer journey to further inform care planning and the provision of psychosocial support
Development of Working Care Plan	While the template for the Working Care Plan is the same as that used for the initial care plan, the information documented differs due to the clinician's increased knowledge of the patient, their family, and environment. Developed within 2 weeks of the Second Screen and Psychosocial Assessment, the Working Care Plan should have further depth of detail than the initial care plan and incorporate patient-specific strategies to manage adherence, identify risks, and plan for survivorship
Progress Screen	A Progress Screen is conducted approximately 6 months post diagnosis and/or treatment commencement to address any changes in the patient's experience, illness trajectory, family, or environment throughout the cancer journey
Revision of Working Care Plan	Any changes in need identified by the Progress Screen should be incorporated into a revised care plan to allow continued patient support in a relevant and effective manner
Further Screening and Care Planning	Any further screening and care planning should take place at the clinician's discretion or the patient's request. At a minimum, this should occur at remission, recurrence, or progression. Additional time points to consider include changes in treatment, changes in treatment goals, treatment completion, and during significant times in the young person's life (e.g., moving into a new school year, relationship breakups, family breakdown)

Overall, AYAs are more likely to abuse opioids than adults (Pergolizzi et al. 2012), and opioid abuse can develop through experimentation or legitimate opioid use. AYAs who use more than one opioid concurrently seem to merit particularly close monitoring for abuse (Ehrentraut et al. 2013).

## Treatment Adherence

Whether or not an AYA patient is eligible for or opts to enroll in a clinical trial, treatment adherence is a significant issue. Less than 90 % adherence to oral therapy has been associated with 3.9-fold higher risk of relapse among children and adolescents with acute lymphoblastic leukemia (Bhatia et al. 2012). Adolescents are among the groups at highest risk for suboptimal adherence to oral cancer therapy. One small study found that adolescents took less than 75 % of prescribed doses and had perfect adherence to their oral regimen post-stem cell transplant on fewer than 4 days per week (McGrady et al. 2014). Adolescent difficulties with adherence to oral therapy tend to become more pronounced over time (McGrady et al. 2014; Rohan et al. 2015). Adolescent adherence can be adversely affected by factors that include wanting to be like their peers, cognitive decline, and lower parental involvement (Buchanan et al. 2014; Malbasa et al. 2007). Factors associated with perfect adherence include having future-oriented goals, family support, and a second “overprotective” parent caregiver (Hullman et al. 2015).

Clinicians should expect that AYAs will have difficulties with adherence and that adherence will deteriorate over time (Bhatia et al. 2012). Means of assessing adherence include self-report, pharmacy records, pill counts, and laboratory tests such as leukocyte counts and drug metabolite assays. Self-report tends to overestimate adherence for reasons that include social desirability and recall bias. Clinicians can elicit more reliable self-reports by using nonjudgmental, understanding, and optimistic approaches that normalize less than perfect adherence and include

questions about doses missed during specific time frames and the circumstances. Clinicians can also explore strategies to improve adherence and reinforce good adherence. Parents might help by obtaining and organizing medications and establishing reminder systems to maximize adherence (Malbasa et al. 2007). However, given their drive for independence, AYAs can be irritated by parental involvement. Also, parents with high demands on their time and low levels of social support might prematurely delegate sole responsibility for medication adherence to the AYA (Bhatia et al. 2012). Clinicians can coach AYAs in explicating what they need from their parents with regard to supporting positive health behaviors such as helping AYAs stay organized with medications and fostering engagement in decisions about medical care.

At diagnosis, health literacies and reading abilities in English and the AYA family’s primary language also should be assessed. AYAs, and when applicable their parents and partners, should be encouraged to discuss their understandings of the disease and its prognosis, treatment goals, and beliefs about treatment efficacy and to define their roles and responsibilities in adherence considering AYA development and routines (Williams 2001). AYAs routinely should be provided with precise verbal and written information, in both English and their primary language, about the treatment that has been prescribed and copies of treatment calendars.

Information is not sufficient to promote optimal adherence. Regular reminders via mobile devices using Internet applications such as “Pillbox” and “MedCoach” could help promote AYA adherence by using the normative means that AYAs use to communicate and manage their lives (Santacroce and Crandell 2013). Reminders can be sent by short message service (SMS) or text messaging, or personal devices can be set to alarm or display an image at predetermined times when medication is due. Other possibilities include medication adherence-oriented applications that AYAs can download to their smartphones (e.g., MyMedSchedule) and provide means for recording doses and side effects (Dayer et al. 2013).

Technology and social media should not be overlooked as effective tools for addressing adherence in the adolescent and young adult population. For example, the videogame “Re-Mission,” which conceptualizes chemotherapy as battling cancer, has been shown to improve adolescents’ understanding of and engagement in cancer treatment (Kato et al. 2008). The facilitation of social media such as Facebook and Twitter, when utilized in a safe and HIPAA-compliant manner, also may serve as effective platforms of engagement with AYAs in medication adherence and other important aspects of cancer care.

### Case Vignette : Medication Adherence

A 17-year-old female patient with acute lymphoblastic leukemia who was in the middle of her treatment regimen reported to her primary oncologist that she was no longer taking her oral chemotherapy medication as prescribed. The social worker met with her to explore the patient’s attitudes and behaviors as they might relate to non-adherence. The patient talked about increased stress related to her returning to school and her mother working longer hours. With the transition back to school, the patient indicated a heightened sense of wanting to feel “normal” again and a desire to spend more time with friends. She endorsed the belief that continuing to take chemotherapy meant that she was still sick, an identity that she wanted desperately to break away from in an attempt to return to “normal.” She also talked about “forgetting” to take her medication and about not being reminded to do so by her mom. After the meeting, the social worker met with the patient’s mother to gain a better understanding of the family system. The patient’s mother reported that her job had become more demanding and as a result, she was less focused on her daughter’s medication adherence. Based on these separate encounters, the team decided to meet with the

patient and her mother to address how to better support the patient’s efforts toward improved medication adherence. Psychoeducation about the critical importance of medication adherence to overall survival was provided verbally and with educational pamphlets. In addition, medication organizational systems were suggested including a weekly pillbox and electronic medication calendars. Moreover, the social worker began to provide counseling to the patient on a regular basis to address her beliefs about her identity as a cancer patient and connected her with programs to meet other teens living with cancer, including the Ulman Cancer Fund for Young Adults and the Leukemia & Lymphoma Society.

### Sex and Sexuality

The adolescent and early adult years represent a critical time in sexual development. A cancer diagnosis can seriously threaten onset of puberty, normative exploration of sexual practices and behaviors, and formation of gender identity and sexual orientation. Early menopause, infertility, fatigue, osteoporosis, and changes in cognition represent treatment-related side effects that can adversely impact AYAs’ sexual function and practices as well as overall sense of self (Bolte and Zebrack 2008). Physical alterations to the body as a result of treatment such as scarring, weight loss/gain, and hair loss can adversely impact body image. In addition, self-esteem may be compromised by poor body image, lack of sufficient sexual knowledge, and increased difficulties relating to family, peers, and intimate partners (Evan et al. 2006). In turn, a positive identity and healthy social relationships can suffer and lead to a heightened sense of isolation and alienation (Bolte and Zebrack 2008). Moreover, impaired sexual development can increase emotional and psychological distress that, if left untreated, can have implications on overall quality of life (Canada et al. 2006).

The topic of sexual health should be included as part of the medical and psychosocial assessment early in the diagnosis. Of note, adolescents and young adults aged 15–24 comprise half of all new cases of sexually transmitted disease (STDs) (Centers for Disease Control and Prevention, 2014, 2012 Sexually Transmitted Diseases Surveillance, <http://www.cdc.gov/std/stats12/adol.htm>). Medical providers should be especially diligent about engaging AYA patients in a conversation about sexual history and safe sexual practices (Centers for Disease Control and Prevention 2011, 2014, [www.cdc.gov/std/treatment/2010/clinical.htm](http://www.cdc.gov/std/treatment/2010/clinical.htm)).

Some AYAs interpret information about the risk for impaired fertility as meaning they will be unable to become pregnant or get someone pregnant. Furthermore, AYA patients and survivors may engage in risky sexual behavior to feel “normal,” because they feel lonely, or to address worries about poor body image, sexual performance, and other aspects of sexuality as well as a sense of invincibility. These responses to AYA cancer can lead to unintended or high-risk pregnancy (Murphy et al. 2013). Therefore, AYAs also need information about how to protect their sexual health and prevent pregnancy until they are prepared to be a parent. Sexual health and safe sexual practices should also be presented within the context of infection control and potential for bleeding, as well as other potential health risks associated with engaging in sexual behaviors during certain points of cancer treatment (Lauer 2015). Males should be counseled to protect themselves from sexually transmitted diseases while neutropenic, to use condoms, and to not engage in oral sex. They should also use condoms for 2 weeks post chemotherapy to prevent exposing partners to chemotherapy. Female condoms and dental dams may also serve as protective barriers from protecting against chemotherapy exposure (Kelvin et al. 2014). Menstrual cycles during chemotherapy can pause or become irregular, and females should be made aware that this does not mean they are unable to get pregnant. Females should be counseled to use a reliable form of birth control throughout the treatment phase and to limit their risk of sexually transmit-

ted infections that can further impair fertility by assuring that their male sexual partners wear condoms. AYA females should have a pregnancy test before therapy is initiated. Since pregnancy symptoms (e.g., nausea, vomiting, fatigue, cessation of menses) can also be caused by cancer therapy, pregnancy testing at the start of each treatment cycle can identify unrecognized pregnancy and limit the possibility of fetal exposures to chemotherapy.

In efforts to provide comprehensive oncology care to the AYA population, health-care professionals must acknowledge the normative and healthy sexual development of AYAs with cancer. The responsibility to address sexual health rests with the health-care providers, not the patient (Bolte and Zebrack 2008). However, research indicates that health-care providers do not routinely address the topic of sexual health with cancer patients as a result of a lack of knowledge about normative sexual development and behaviors and lack of comfort in communicating about this topic (Katz 2005).

The PLISSIT Model (Permission, Limited Information, Specific Suggestions, Intensive Therapy) is an effective tool that can be implemented to effectively assess, educate, and provide intervention in the sexual well-being of AYA cancer patients (Bolte and Zebrack 2008) as described below:

**Permission** Health-care providers should encourage patients to discuss their sexuality, a topic that many AYAs may lack proper knowledge about and feel reluctant or uncomfortable to bring up on their own. Health-care providers should be sensitive to patient confidentiality and privacy when engaging in a dialogue about sensitive information, such as sexual health. There should be the opportunity for the patient to meet alone with the provider unless the patient specifically indicates a desire for his loved ones to be present during a conversation about the patient’s sexual health (Kelvin et al. 2014). When addressing sexual health, providers should use language that is empathic and accessible as a means to promote comprehension of medical concepts (Centers for Disease Control and Prevention 2011). Open-ended versus closed-

ended questions can allow for patients to feel more comfortable to engage openly and honestly in a dialogue about sexual health. For example, in addressing current sexual activity, a provider might say, “How do you protect yourself when you have sex?” rather than, “You’re using protection, right?”

**Limited Information** When addressing sexual matters with the AYA population, health-care providers should provide information and resources that educate patients about the implications of a cancer diagnosis on their sexual health. For the AYA cancer population in particular, safe sex practices should always be encouraged, for both protections against STIs and STDs as well as pregnancy. As mentioned in the Fertility section, some AYAs may recover from impaired fertility; thus, safe sexual practices should always be practiced during and following treatment.

### Specific Suggestions

If indicated, health-care providers should offer specific suggestions on strategies to enhance sexual well-being and guide patients and their partners in a renewed set of expectations around sexuality and sexual behavior. For example, if an AYA female patient is struggling with body image issues related to hair loss, normalizing this experience for the patient by educating her that it is a common challenge for many other patients and also offering a specific suggestion as to how to address the issue, such as “Many patients find that wearing a wig, hat, or scarf can help make them feel more comfortable about their body and hanging out with friends,” might serve as an effective approach.

**Intensive Therapy** For patients who have experienced physical side effects of treatment impacting sexual function, oncology providers should enlist the support of a gynecologist, urologist, physical therapist, endocrinologist, and other specialists who may be able to appropriately address sexual side effects of cancer treatment. In addition, as sexual changes can fuel emotional distress, it is important to consider the support of a mental health provider or sex therapist to guide

the psychosocial adjustment and impact of a cancer diagnosis on sexuality. Psychoeducational interventions focused on sexual development and reproductive health issues have shown to be meaningful in the reduction of psychosocial distress in AYAs with cancer (Canada et al. 2006). Some helpful resources for patients and providers to consider include American Association of Sexuality Educators, Counselors, and Therapists ([www.aoc.org/patients](http://www.aoc.org/patients)), American Congress of Obstetricians and Gynecologists Information ([www.acog.org/patients](http://www.acog.org/patients)), Sexuality Information and Education Council of the United States ([www.siecus.org](http://www.siecus.org)), and American Cancer Society’s *Sexuality for the Woman with Cancer* (<http://bit.ly/1rTICty>) and *Sexuality for the Man with Cancer* (<http://bit.ly/1m5Houb>).

### Case Vignette : Sexuality and Fertility

A 24-year-old woman receiving treatment for Ewing sarcoma expressed a deep-seated desire to become pregnant during her cancer journey. She had preexisting mental health disorders, including borderline personality disorder and bipolar disorder, which made her more vulnerable to impulsive, risky behavior. Prior to the initiation of treatment, the patient was educated about the potential risk for infertility and was provided a listing of educational and supportive resources. The patient decided against cryopreservation due to conflict with religious beliefs. Throughout the course of treatment, the patient continued to manifest a strong desire to become pregnant and engaged in unsafe sexual practices. The medical team was proactive about regularly assessing the patient for unsafe sexual practices and provided her with education and information about the risks associated with such behavior including high-risk pregnancy, STIs/STDs, and increased risk of infection during periods when her neutrophil count was low from chemotherapy, as well as risk to the fetus



related to chemotherapy. It became apparent that sexuality and fertility, specifically, were so highly connected to the patient's core fears about facing mortality. Getting diagnosed with a life-threatening illness during this particular stage of the patient's life, and facing mortality as a young adult, may have contributed to a desire to expedite life goals such as getting married and starting a family. The social worker addressed with the patient other life goals including returning to college and work and connected the patient to a psychologist and psychiatrist in the community to manage the ongoing mental health needs of the patient, which were magnified by the cancer. Shortly following completion of treatment, the patient's oncologist referred the patient to a gynecologist to address the patient's sexual health and reproductive capacity. About a year following completion of treatment, the patient became pregnant. Around this time, she also relapsed with cancer. The case highlights that safe sexual practices should be employed not only during the treatment phase but also during the period of time following treatment when the risk of relapse remains high.

## Fertility

Having received information from clinicians about their cancer diagnosis and proposed treatment regimen, AYAs can experience great psychological urgency to start treatment (Keim-Malpass et al. 2013). For AYAs who will undergo therapies that can impair fertility, this urgency can be a barrier to consultation with a fertility specialist and fertility preservation. Other barriers to consultation and preservation include gatekeeping by clinicians and parents who underestimate the importance of fertility to AYAs or the risk of impaired fertility, not knowing what can be done to preserve fertility or feeling awkward addressing these sensitive issues.

When fertility is at risk, providers should discuss the risk and options for fertility preservation with the patient or parents as appropriate before treatment starts, answer questions about whether fertility preservation could adversely affect treatment outcomes, initiate referral to a reproductive specialist for those who are interested, document these discussions (Loren et al. 2013), and provide access to resources that can help address potential financial barriers to fertility preservation. An additional role for psychosocial experts is to help AYAs and their family members address distress related to risk for infertility (Loren et al. 2013).

Psychosocial providers play a critical role in fertility preservation. Effective psychosocial services for both sexes should include using a proactive approach to ensure that all AYA patients and, as applicable, their parents and partners receive information about the potential impact of cancer therapy on fertility through face-to-face discussion and educational materials (Crawshaw 2013). Clinicians' areas of expertise include, but are not limited to, the following: referrals to fertility specialists, counseling and guiding patients and families in the decision-making process in regard to fertility preservation, providing information and resources designed to help address potential financial barriers to fertility preservation, and fostering relationships within the community, specifically with fertility centers and long-term storage facilities of sperm, oocyte (egg), embryo, ovarian, and testicular tissue specimens.

Reliable sources of information about fertility preservation include *LIVESTRONG* (<http://www.livestrong.org/we-can-help/fertility-services/>), the Oncofertility Consortium, and National Comprehensive Cancer Network Guidelines for Patients: Caring for Adolescents and Young Adults. For health-care professionals, the following are recommended guidelines and resources: National Comprehensive Cancer Network Guidelines: Adolescent and Young Adult (AYA) Oncology, Fertility Preservation for Patients with Cancer: American Society of Clinical Oncology Guideline Update, and the Clinical Oncology Society of Australia ([http://wiki.cancer.org.au/australia/COSA:AYA\\_cancer\\_fertility\\_preservation](http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation)).

## End of Life

AYAs living with a potentially life-limiting disease such as cancer have beliefs, values, and medical preferences about end-of-life care and wish to communicate this information with loved ones and health-care providers (Wiener et al. 2012). It is critical that health-care providers bring up the topic of end-of-life care preferences as early as is medically appropriate and continue this discussion through the course of treatment. Allowing AYAs the opportunity to engage in end-of-life care preferences can help to reestablish a sense of control and independence over their health care (Wiener et al. 2012). Moreover, guiding AYA patients as much as possible in a meaningful dialogue with their family members about advance care planning preferences can be beneficial to the overall psychosocial adjustment of a family coping with impending death (Lyon et al. 2013).

AYAs with advanced or terminal cancer have distinctive medical and psychosocial needs that are not adequately provided by either pediatric or adult palliative care services (Pritchard et al. 2011). A discussion group, as part of a larger workshop on AYAs with cancer, was held during 2010 in Toronto. Recommendations included the development of a specific AYA screening tool designed to detect increased anxiety or new symptoms and to initiate discussion about palliative or symptom care; set standards for palliative care in AYA patients and include in hospital accreditation; involve the palliative/symptom care team early in the disease trajectory to help manage clinically important symptoms that may not be associated with imminent death; establish specific AYA multidisciplinary palliative care teams that are flexible and can work in both pediatric and adult facilities, as well as a “virtual” environment to support AYAs being cared for at home; improve physical facilities in hospices and hospitals to meet the distinctive needs of AYAs who are terminally ill; and enhance support for palliative care at home by changing legislation to improve care benefits and developing “virtual, palliative care support teams” (Fernandez et al. 2011). Adequate provision of AYA palliative care and symptom management services will likely

confer notable benefits to AYA and their families. The outcome of research exploring the written preferences for end of life is a tool, “Voicing My CHOICES,” which allows AYAs living with serious illnesses to plan their end-of-life care (Wiener et al. 2012). The tool, which is not a legally binding document, provides AYAs an opportunity to express and share their preferences for how they wish to be cared for as they approach the end of life and be remembered after their death. Guidance is provided on how to incorporate the tool into AYA care (Zadeh et al. 2015).

In addition to Voicing My CHOICES, patients over the age of 18 years should also be encouraged to execute advance directives, which are legal documents that allow patients to elect a medical power of attorney and complete a living will. An advance directive aims to ensure that medical preferences and wishes be honored at end of life should a patient become unable to make decisions about their medical care. It is critical that end-of-life care preferences for clinical care, including pain management, spiritual support, and advanced directives, be documented in the electronic medical record.

## Age-Appropriate Resources and Social Support

To minimize the disruption caused by the cancer experience and promote healthy development, young people with cancer need opportunities to participate in typical activities with peers as much as possible. To achieve this, the health-care environment must be flexible, for example, with scheduling treatments and clinical evaluations to minimize school and work disruptions, overnight visitation by romantic partners and friends during hospitalization, and use of technology to deliver cancer therapy, symptom management, and peer support in community settings.

Identifying and recognizing AYA strengths and support networks provides an important base to build upon and promote healthy growth and development. Taking this approach with young people can empower them to improve in areas in which they already feel confident and

encourage them to tackle more difficult issues as their confidence builds. AYAs may need assistance in identifying their strengths, so explaining this concept and giving them examples can be helpful. Further, young people often have a support network of other people (including family members, friends, teachers, other services) in their lives. Encouraging AYAs to identify and seek assistance from supportive others is critical.

Quality of life in AYA patients has been shown to be largely a function of social support. Improving social support can be used as a strategy to mitigate the adverse influence of the cancer experience on body image, identity formation, emotions, coping skills, and occupational goals (Roberts et al. 1997). While parents are usually identified as a primary source of support, peers who have experienced cancer can also play important roles. Interventions that aim to enhance peer support can offer safety and encouragement not usually available to AYAs and promote their psychological adjustment.

Peer support provides AYA patients with opportunities to address mutual concerns and can also decrease feelings of social isolation, depression, and anxiety (Roberts et al. 1997). Participation in usual activities with friends and new cancer-related experiences can promote successful achievement of AYAs' developmental tasks. The positive effects of peer support and technology- and skill-based interventions, along with minimizing disruption to important social roles, cannot be underestimated, thereby helping AYAs overcome potential adverse effects of cancer on development by strengthening their internal and external coping resources (Zebrack and Isaacson 2012). Clinicians can enhance care to AYAs by being knowledgeable about, and referring AYA patients to, reputable organizations and online peer support programs. See Chap. 25 for specific resources.

### Conclusion

Adolescent and young adult (AYA) patients often fall through a schism between pediatric oncology (mainly family focused and holistic)

and adult oncology (mainly individual and disease focused) and, as a result of the disjuncture between these two worlds, bear the brunt of limited access to clinical trials and decreased quality of care (Ferrari et al. 2010). Neither the pediatric nor the adult models of care are ideally suited to the complex psychosocial needs of AYA patients. A comprehensive, multipronged effort is required to bridge the gap in the psychosocial care of AYA patients, to provide AYAs with the attention they require, and ultimately to eliminate the observed disparities in outcomes and supportive care services.

### Clinical Pearls

- Adolescents and young adults with cancer face an intense, complex psychosocial experience that, if not properly addressed, can lead to diminished quality of life and potentially low survival outcomes. As such, psychosocial care is critical in the overall treatment plan in AYAs with cancer.
- The delivery of care and overall health-care environment for AYAs with cancer should honor the unique life stage of this patient population and promote opportunities for developmental milestones to be reached.
- Clinicians should aim to promote a sense of self-efficacy and control in AYAs and their families, which, in turn, may lead to a more positive engagement in cancer treatment.
- In order to effectively and appropriately engage AYA cancer patients in their health care, health-care providers need to be knowledgeable about adolescent and young adult development and normative behaviors. Moreover, providers should display comfort and an aptitude in communication about potentially uncomfortable topics such as sex and sexuality, fertility, substance use and abuse, and death and dying.

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