Psychosocial Care of Adolescent and Young Adult Patients With Cancer and Survivors

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ABSTRACT

The delivery of quality care for adolescent and young adult (AYA) patients with cancer and survivors requires an understanding of the unique qualities of this group—the shared norms, attitudes, and beliefs that determine their behavior as well as the unique stresses they face on a day-to-day basis. All AYAs have typical concerns about being comfortable with who they are and who they want to become (identity development, including sexual identity), their bodies (body image), initiating intimate and emotional relationships, separating from parents, and making independent decisions about future goals such as career, higher education, and/or family (autonomy). Yet efforts of AYA patients with cancer and survivors to mature are often confounded by restrictions and limitations placed on them by their disease and treatment. This article promotes understanding of psychosocial challenges faced by AYAs when diagnosed with and treated for cancer. It reviews evidence-based psychosocial support interventions for AYAs with cancer and other life-threatening or chronic diseases, particularly the positive effects of peer support, technology-based interventions, and skill-based interventions. The article concludes with recommendations for clinical care that are intended to promote the ability of AYAs to cope with cancer.

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INTRODUCTION

Parent (confronting teenage child): “Why did you do that?”

Teenage child (shrugs shoulders): “I dunno.”

Parent: “What do you mean you don’t know?”

Teenage child: “I don’t know.”

Parents of teenage children, or physicians treating adolescent and young adult (AYA) patients, may have conversations like this when confronting them about behaviors (eg, staying out too late, not adhering to prescribed treatment regimens) that the adults find ill considered or irresponsible. The responses of the young person here typify the immature cognitive capabilities that often drive the actions of AYAs. Although rightfully trying to treat AYAs as independent and responsible decision makers, mature adults may sometimes have expectations of behavior that exceed the capabilities of AYAs. Goal-oriented behaviors, organization, planning, and impulse control skills may not be realized before 25 years of age, when the frontal cortex of the brain typically becomes fully developed.1 Yet AYAs are capable of caring for themselves and making responsible choices. A relational approach that acknowledges their fledging autonomy while positively reinforcing the importance of adhering to prescribed behaviors keeps AYAs closer to adult supports than do punitive approaches that may result in distancing them from authority figures and role models.

During the critical developmental transition from childhood to adulthood, AYAs have typical concerns about being comfortable with who they are and who they want to become (identity development, including sexual identity). They are acutely aware of their bodies (body image) and actively initiating intimate and emotional relationships, separating from parents, and making independent decisions about future goals such as career, higher education, and/or family (autonomy).2 When diagnosed with cancer, AYAs face additional challenges because of the intersection of the cancer experience with everyday aspects of their lives. 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.3-6

AYA patients and survivors are challenged to remain active and independent, cope with treatment-related adverse effects, manage stress, seek and understand information, manage emotional responses (of self and others), seek social support, and accept cancer and maintain a positive attitude.7 However, AYAs with cancer rarely have the life experience necessary to know how or
feel competent to cope effectively with these challenges. Accordingly, psychosocial interventions that promote coping and self-efficacy (ie, knowing what to do in the face of stress or trauma and feeling competent to perform these actions proficiently) may be a key construct when examining what AYAs need to manage the multiple and varied ways in which cancer disrupts their lives.

The delivery of quality care for AYA patients with cancer and survivors requires understanding the unique qualities of this group—the shared norms, attitudes, and beliefs that determine their behavior as well as the unique stresses they face on a day-to-day basis. This article serves to enhance understanding of psychosocial challenges faced by AYAs when diagnosed with and treated for cancer and to review psychosocial and supportive care interventions that address these challenges. Finally, recommendations for enhancing care are offered.

**Information Issues**

Information is one of the primary realms of need for AYA patients with cancer and survivors, particularly with regard to treatment and late effects, diet and nutrition, mental health counseling, peer support, fertility preservation, and age-appropriate Internet resources for information and support. Yet communicating information to AYAs can be challenging in terms of how much and what type of information each AYA needs, prefers, or can handle emotionally. Some prefer to be shielded from direct communication about their cancer; others may desire to assume a more prominent position in the information flow and management of their care. Parents often manage what and how their children are told about cancer. For some AYAs, information is distressing; for others, empowering. Asking AYAs directly about how much information they want and to whom it should be communicated (to themselves, to parents), and repeating this process throughout the continuum of care, will involve AYAs in their own care and thus promote autonomy.

**Practical Issues**

As AYAs undergo diagnostic procedures and treatments, they meet innumerable health care professionals and ancillary staff who will be involved in their cancer care. Diagnostic tests, treatment protocols, and treatment-related adverse effects often bring discomfort, pain, nausea, vomiting, fevers and infections, fatigue, changes in appetite, and sleep disturbances. Enduring these effects often requires major disruptions at school or work and further disrupts the social lives and usual activities of AYAs. AYAs may experience a renewed dependence on parents for physical care. End-of-life care presents special difficulty as physical functioning deteriorates, and pain management and palliation dominate the care regime.

Emerging research suggests that socioeconomic impacts of cancer on AYAs are substantial. Young adult survivors of childhood cancer have been reported to be six times more likely than healthy siblings to report health-related unemployment and almost twice as likely to be unemployed but seeking work. Compared with older adult cancer survivors, AYAs may be at the greatest risk of all when it comes to unemployment. Research indicates that two thirds of real lifetime wage growth typically occurs in the first 10 years of one’s career or involvement in the job market. Missing out on employment opportunities because of cancer and its treatment threatens the long-term career opportunities, financial status, and lifetime earnings of AYAs. Greater risks for unemployment among AYA patients and survivors also means potentially greater risk for lacking health insurance, which limits access to appropriate long-term follow-up care.

Indeed, within a large cohort of young adult cancer survivors, 20% reported not having had a general physical examination, cancer-related visit, or visit to a cancer center in the past 2 years.

**Emotional Issues**

Research studies inclusive of adults of all ages suggest that rates of psychologic distress are significantly greater among AYAs when compared with older adults. A life disrupted by cancer results in a range of emotional needs, with many AYAs grappling with issues such as anxiety and depression. More so than childhood cancer survivors, individuals diagnosed with cancer during adolescence or young adulthood have the cognitive capacity to understand the severity of their illness and frequently demonstrate persistent distress and anxiety over death, cancer recurrence, or late effects. Alterations in physical appearance, including weight changes, hair loss, amputations, placement of catheters to facilitate treatment administration, surgical scars, and alterations in skin coloration and texture not only make AYAs feel different from peers but also may represent frightening changes in the body and may adversely affect maturation processes (eg, formation of self-esteem, identity development).

Fear that the body will never return to its original appearance and fear of not being recognized by others or of being mistaken for an individual of the opposite sex often lead to shame, social isolation, and regressive behaviors.

Despite these deleterious effects, most AYAs actively seek to improve or adjust to their current physical, psychologic, and social status and view themselves as involved in a process of accepting their cancer and getting back to normal. AYAs also continue to be concerned about their physical health, the welfare of their immediate family, feeling cut off from the outside world, being different from peers, reintegrating into the school system, and returning to work. They express concerns about the future—access to life and health insurance, jobs and career options, genetic or hereditary risks of cancer passed on to offspring, and availability of appropriate survivorship care through a skilled and attentive medical system.

A special consideration related to self-image is the subject of sexual identity. During adolescence, individuals begin to realize that they are sexual beings, examine their sexual identity, and conceptualize their reproductive capacity. It is not surprising, then, that cancer and its associated treatments and adverse effects would have an impact on their burgeoning sexuality and sense of themselves as sexual beings as well as raise concerns about having sex.

**Interpersonal Issues**

Cancer often forces AYAs to move back home with, and become dependent on, parents and/or family members, usually after periods...
of time living independently. For AYAs who are married or in committed relationships when diagnosed, they are similarly forced into dependence on a spouse or partner in a way they never conceived imaginable. This untimely forced dependence is often a source of distress. Furthermore, as AYAs with cancer try to deal with or discuss their illness with their parents, spouses, or partners, they sometimes discover that they have quite different coping strategies. Parents, spouses, or partners may want or need to discuss issues with the AYA patient that he or she does not wish to discuss, or vice versa. Some young people with cancer desire to protect their family members. AYAs may try to shield family members from some of the things they themselves worry about, perhaps out of guilt for what their parents, spouses, or partners are going through, or perhaps just because they can see how upset family members are.

AYAs acknowledge family members as being the most important source of support. They also identify friends and other AYAs with cancer as important supports, in that peers and other AYA cancer survivors can acknowledge and understand them in ways that people who have not had cancer cannot. From the perspective of friends, a cancer diagnosis can be a source of emotional distress or discomfort for healthy young people, who may respond to ill friends by avoiding them. Isolation and alienation are thus commonly reported among AYA patients, particularly as AYAs miss out on life experiences being shared by their healthy peers. Some AYAs have problems connecting with their peers, whereas others report improvement in relationships but sometimes less satisfaction from them. As a result, these young people often form new friends, perhaps as a function of their own increased maturity and need to let go of less mature friends.

The issue of disclosing a cancer history with others, especially an intimate or potentially intimate partner, is particularly salient to the AYA population. Forming intimate emotional and sexual relationships is a highly meaningful aspect of human life that is initiated during adolescence and young adulthood. In the process of creating such relationships, individuals inevitably reveal themselves—personal histories, identities, emotions, thoughts, and bodies. For AYAs, such disclosures are complicated by the effects of cancer. For example, disclosure of a history of cancer to friends or others with whom potentially intimate relationships might be formed may mean risking alienation and rejection and often further compounds negative perceptions of the body and emerging sexuality. Cancer-related infertility also challenges intimate relationships, because AYAs fear that a partner or potential partner may reject them because of their inability to procreate biologically. For AYAs with cancer, the process of dating and disclosure becomes new and uncharted territory marked by uncertainty. Such issues may result in AYAs feeling deprived of fulfilling companionship and support and ultimately feeling alone.

Existential and Spiritual Issues

In the face of a life-and-death diagnosis that is rare and totally unexpected for people their age, AYAs experience a challenge to their sense of the normal order of things and the way they have assumed the world should work. Their faith in the continuity and predictability of life is threatened. As a result, AYAs often raise the question: “Why has this happened to me?” Answers come in the form of an accident, the result of parental misbehavior (smoking) or genetic/hereditary malformation, environmental assault (exposure to asbestos, chemical plant residue, electricity transmission lines), a twist of fate, punishment by God (for real or imagined sins committed by the patient or parents), or a test by God of personal or spiritual capacity and faith. Although this uncertainty can be a source of distress, it also can be a catalyst for personal growth, a deepened appreciation for life, greater awareness of life purpose, development of confidence and resilience, and optimism.
conventional support groups are manifesting as social networking opportunities, in which organizations formed by AYAs with cancer for AYAs with cancer offer age-relevant opportunities for AYAs to meet, be, and become who they want to be. Examples of support groups that appeal to AYA sensibilities include the I’m Too Young for This Annual OMG Stupid Cancer Summit, mAsskickers bonfires on the beach and paintball tournaments, Imerman Angels happy hours and golf tournaments, the Ulman Cancer Fund for Young Adults triathlons, First Descents outdoor adventures (kayaking, rock climbing, surfing), and the Children’s Brain Tumor Foundation Texas Hold’em Poker Night. These social networking events involve tens to hundreds of AYA patients, survivors, and family members at a time.

**Technology-Based Interventions**

As a technical- and electronics-savvy generation, AYAs are primed to benefit from age-appropriate information and support delivered through modern electronic applications. A large majority of AYAs demonstrate an expressed need and desire for information, particularly for information that is age appropriate, and for opportunities to interact with others via interactive Web sites and games. Satisfying AYA needs for information and support via electronic means (eg, video, telephone, Internet) has been demonstrated to be associated with increased self-efficacy and improvements in knowledge and treatment adherence. Furthermore, new media can facilitate AYA participation in their own care and may become new modes of delivering cost-effective and easy-to-disseminate psychosocial support. Emergent pilot studies testing the effects of telephone interventions and music video creation with AYA patients suggest high levels of participation and engagement with AYA patients suggest high levels of participation and satisfaction as well as improvement in symptom distress, self-efficacy and coping, and quality of life.

Social media and Internet-based forms of information delivery and communication encourage patients to actively participate in their own health-related decisions and improve confidence in communication with health care providers. The vast amount of information available on the Internet, however, and frequent encounters with conflicting information on cancer and treatment often leave AYAs confused. Furthermore, the ability of AYAs to evaluate information and distinguish truly helpful and relevant information from misinformation is limited. AYAs need guidance in how to seek, sift through, and understand the vast amount of information available to them.

**Skill-Based Interventions**

Problem-solving interventions and cognitive behavioral therapies (CBTs) are evidence-based approaches that teach new skills (behaviors) or induce new ways of thinking and subsequently acting on one’s conditions or circumstances. They are efforts to promote one’s ability to better cope with the stresses associated with disease. Few skill-based interventions have been developed for, and tested empirically in, the AYA population, but the theoretic underpinnings of CBTs may prove promising for AYA interventions. CBTs are based on the notion that it is not events, but people’s interpretations of events, that cause psychologic disturbance or influence behavior. Subjective perceptions and their influence on outcomes have been demonstrated as being better predictors of distress and well-being than objective health status measures, and evidence suggests that the perceptions of AYAs of how cancer has affected their lives are associated with distress levels and quality-of-life outcomes.

An examination of skill-based interventions implemented and tested in samples of AYAs with other serious or life-threatening diseases may be instructive. Project ACCEPT (Adolescents Coping, Connecting, Empowering, and Protecting Together), a skill-based group intervention for AYAs newly diagnosed with HIV, aimed to enhance the ability of AYAs to accept and cope with their disease. Participants reported feeling less socially isolated as a result of connecting with other group participants. In a skill-based intervention involving

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### Table 1. Resources for Adolescent and Young Adult–Specific Information and Support

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<thead>
<tr>
<th>Category</th>
<th>Resource</th>
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<tbody>
<tr>
<td></td>
<td>American Society of Clinical Oncology: <a href="http://www.cancer.net/patient/Coping/Age-Specific+Information/">http://www.cancer.net/patient/Coping/Age-Specific+Information/</a></td>
</tr>
<tr>
<td></td>
<td>Cancer + in + Young+ Adults</td>
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<tr>
<td></td>
<td>Ulman Cancer Fund for Young Adults: <a href="http://www.ulmanfund.org/">http://www.ulmanfund.org/</a></td>
</tr>
<tr>
<td>Practical support and day-to-day living with cancer</td>
<td>My Lifeline.org Cancer Foundation: <a href="http://mylifeline.org/">http://mylifeline.org/</a></td>
</tr>
<tr>
<td>Fertility-related information and resources</td>
<td>Oncofertility Consortium at Northwestern University: <a href="http://myoncofertility.org/">http://myoncofertility.org/</a></td>
</tr>
<tr>
<td></td>
<td>Cancer Legal Resources: <a href="http://www.disabilityrightslegalcenter.org/about/cancerlegalresource.cfm">http://www.disabilityrightslegalcenter.org/about/cancerlegalresource.cfm</a></td>
</tr>
<tr>
<td></td>
<td>Contact your state’s vocational rehabilitation office</td>
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<tr>
<td>Social networking and peer support</td>
<td>I’m Too Young for This Cancer Foundation: <a href="http://stupidcancer.com/">http://stupidcancer.com/</a></td>
</tr>
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<td></td>
<td>Imerman’s Angels (one-on-one cancer support connecting patients, survivors, and caregivers): <a href="http://www.imermanangels.org/">http://www.imermanangels.org/</a></td>
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<td></td>
<td>mAsskickers: <a href="http://masskickers.org/">http://masskickers.org/</a></td>
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<td>CaringBridge: <a href="http://www.caringbridge.org/profile/mycaringbridge">http://www.caringbridge.org/profile/mycaringbridge</a></td>
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<tr>
<td>Camps, retreats, and adventure programs</td>
<td>Camp k-a-Dream: <a href="http://www.campdream.org/">http://www.campdream.org/</a></td>
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<tr>
<td></td>
<td>First Descents: <a href="http://firstdescents.org/">http://firstdescents.org/</a></td>
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parents, health care providers, and teens diagnosed with type 1 diabetes, teens and family members were trained to integrate diabetes management into their daily routines. The program succeeded in reducing conflict between teens and their parents around treatment adherence.61 Other structured interventions involving patients and family members have resulted in observed improvements in disease and symptom management as well.52-64 In an intervention to minimize obesity risk, adolescents experienced improved self-efficacy, personal goal attainment, competence, and autonomy as a result of participating in a series of educational lessons involving nutrition science and motivational activities.65 Applied to AYAs with cancer, these findings suggest that skill-building interventions involving family members, as well as those that emphasize educational content, may result in desired outcomes for AYAs with cancer such as treatment adherence, disease/symptom management, and the achievement of developmental tasks like establishing autonomy and personal responsibility.

The following recommendations are intended to promote the ability of AYAs to cope with cancer. Related resources are listed in Table 1 and easily found via Internet searches and Facebook. In addition, clinical practice guidelines for AYAs will be available through the National Comprehensive Cancer Network as of March 2012.

Information

- Consider referral of AYAs to medical and psychosocial specialists with expertise in treatment and care of cancer in this age group66-67
- Encourage AYA participation in the diagnostic conference and subsequent decision making about their illness and course of treatment
- Direct AYAs to age-relevant resources for information regarding treatment and late effects, diet and exercise, financial support services (eg, health insurance, disabilities benefits), fertility preservation, mental health services, Internet resources, and employment protections

Practical Support

- Implement programs that promote the ability of AYAs to keep up with schoolwork and maintain peer relationships with classmates; having classmates who welcome and support AYAs’ return can facilitate positive adaptation and school performance
- Ensure the availability of educational and vocational support programs that assist with re-entry into school or the work force, and ensure nondiscrimination in survivor access to advanced educational opportunities and employment

Emotional/Social Support

- Identify and refer AYAs to reputable peer support programs; inform them about the existence of age-appropriate camps, retreats, recreational programs, and social media resources
- Consider use of AYA survivors who have the temperament and talent as peer counselors and role models for younger patients
- Encourage AYAs and their families to engage in open discussion of their reactions to the diagnosis and treatment, their concerns, and their hopes and dreams for the future; at the same time, such conversations must be undertaken in ways that are consistent with the family’s cultural norms and traditions
- Develop and implement intervention efforts that promote positive adaptation and growth as well as prevent or alleviate distress and psychiatric symptoms

Policy and Institutional Changes

- Implement policies in clinics, communities, and hospitals to reduce stigma among patients, physicians, and the general public regarding the use of and need for psychologic or psychiatric services; the impact of this stigma has been identified as a major barrier to integrating psychosocial care into routine oncology care68; health professionals may unwittingly reinforce stigma through reluctance to diagnose depression or by conveying unease in discussing mental health issues, and patients themselves may feel reluctant to seek assistance with psychologic issues
- Advocate for comprehensive health insurance initiatives that ensure access to care for AYAs; young adults in the United States between the ages of 18 to 24 years are more likely to be uninsured than any other age group69

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Data analysis and interpretation: All authors
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