Context for Understanding Psychosocial Outcomes and Behavior Among Adolescents and Young Adults With Cancer

Brad Zebrack, PhD, MSW, MPH, and Melissa Butler, MS

Abstract

Across all age groups, cancer affects relationships with family and friends; challenges one's sense of independence; disrupts goals, aspirations, and achievements; alters one's body image and integrity; and poses existential challenges about the world and one's place in it. When diagnosed with cancer, adolescents and young adults (AYAs) in their 20s and 30s face unique challenges compared with younger children and older adults. Understanding how cancer-related challenges manifest needs and desires for psychological and social support services throughout a continuum of care may help clinicians improve cost-effective quality care and patient outcomes. This article provides a context for understanding the experiences of AYAs with cancer and highlights key domains of psychosocial need in this population. (*JNCCN* 2012;10:1151–1156)

Across all age groups, cancer affects relationships with family and friends; challenges one's sense of independence; disrupts goals, aspirations, and achievements; alters one's body image and integrity; and poses existential challenges about the world and one's place in it.¹ Although universal, these disruptions may be experienced differently according to the age and/or life stage at which cancer is diagnosed. When diagnosed with cancer, adolescents and young adults (AYAs) in their 20s and 30s face unique challenges compared with younger children and older adults. A cancer diagnosis may complicate or exacerbate the developmental struggles that are typical of AYAs, such as initiating intimate and emotional relationships, separating from parents,

and making independent decisions about employment, career, or starting a family.²

All patients with cancer deal with stresses related to information, practical day-to-day living, interpersonal relationships, and emotional struggles. AYAs' still-maturing cognitive and emotional capabilities and limited range of life experiences may restrict their ability to successfully cope with cancer. Developmental theories and emerging evidence suggest coping deficits occur among young people who experience threatening or traumatic conditions. AYAs' reactions to life-threatening illness can manifest as debilitating internalizing conditions (eg, anxiety, depression, posttraumatic stress symptoms) or externalizing behaviors (eg, substance abuse, suicide).³ These threatening or traumatic conditions that challenge coping may also motivate some young people to seek, initiate, and/or benefit from the use of age-appropriate psychosocial support services, or engage in developmentally unique coping behaviors. For example, a recent study of AYA patients with cancer found that engaging with music (listening, performing, rehearsing, practicing, composing, dancing, and imagery) resulted in adaptive outcomes, including the promotion of identity formation and a perceived sense of support and normalization of life.⁴

Understanding how cancer-related challenges manifest needs and desires for psychological and social support services throughout a continuum of care may help clinicians improve cost-effective quality care and patient outcomes. Managing expected disruptions via age-appropriate psychosocial support services and tailoring care to help AYAs achieve the developmental tasks of adolescence and young adulthood may curtail deleterious outcomes and improve the coping skills necessary to get AYAs through treatment and into survivorship. This article provides a context for understanding the experiences of AYAs with cancer and highlights key domains of psychosocial need in this population.

From the University of Michigan School of Social Work, Ann Arbor, Michigan.

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Correspondence: Brad Zebrack, PhD, MSW, MPH, University of Michigan School of Social Work, 1080 South University Avenue, Ann Arbor, MI 48109-1106. E-mail: zebrack@umich.edu.

Issues Affecting AYAs With Cancer

Psychosocial Support

AYAs may be inadequately or inappropriately served by existing cancer services. Unlike younger children and young adult survivors of childhood cancer, wide variability is present in the availability and accessibility of psychosocial support services across the varied oncology care settings in which AYAs are treated. With only a minority of AYAs being treated in tertiary care centers offering multidisciplinary teams of medical and psychosocial health professionals,⁵ a large proportion of AYAs do not have ready access to psychosocial support programs and services. Most AYAs are left to their own devices to identify and locate the support services they need or desire.

As part of a prospective, longitudinal investigation, 215 newly diagnosed AYA patients aged 14 to 39 years were identified and recruited to a study of psychosocial service use and needs at 3 pediatric cancer centers and 2 academic adult care institutions. Eligible patients were assessed 3 times to determine their needs for information, counseling services, and practical support services. Data were collected initially within the first 4 months of diagnosis, and again 6 and 12 months after baseline recruitment. Table 1 provides a summary description of the sample. Details related to recruitment, data collection, and measures are reported elsewhere.⁶ For each of 17 supportive care service items developed specifically for an AYA population,^{7,8} “need” for any of these services was indicated by a subject’s endorsement of any of the following response categories: 1) “Have used and would like to use more,” 2) “Have used and have no further need,” or 3) “Have NOT used but would like to.” A fourth response category, “Have NOT used and have no need,” suggested that a subject had no need or desire for that particular service. Finally, varying levels of developmental, cognitive, and emotional maturity across an age span ranging from 14 to 39 years suggest that needs may vary across subgroups; therefore, results were stratified across 3 age groupings (14–19, 20–29, and 30–39 years) to capture differences across developmental life stages based on theoretical models of human development.^{1,3}

Informational Issues

Results showed that 87% of adolescent patients with cancer, 92% of patients in their 20s, and 92%

Table 1 Sample Descriptives, Frequencies, and Percent

	n = 215 (%)
Age at Diagnosis	
14–19 y	103 (47.9)
20–29 y	48 (22.3)
30–39 y	64 (29.8)
Gender	
Male	114 (53)
Female	101 (47)
Race	
White/Caucasian	95 (44.6)
Hispanic/Latino	91 (42.7)
African American	11 (5.1)
Asian American	13 (6.1)
American Indian	3 (1.4)
Employment/School Status	
Employed/in school	127 (61.1)
Not employed/in school ^a	81 (39.0)
Relationship Status	
Married/partnered	81 (38.4)
Not married/partnered	130 (61.6)
Type of Cancer	
Hodgkin disease	23 (10.7)
Non-Hodgkin’s lymphoma	17 (7.9)
Melanoma	1 (0.5)
Testicular	14 (6.5)
Thyroid carcinoma	1 (0.5)
Female genital	8 (3.7)
Soft tissue sarcoma	21 (9.8)
Brain	14 (6.5)
Leukemia	50 (23.4)
Other carcinomas	19 (8.9)
Breast	19 (8.9)
Bone tumors	26 (12.1)
All other	1 (0.5)
Treatment Status	
Currently undergoing treatment	198 (92.1)
Not in treatment	17 (7.9)

Not all figures total 100% because of missing data.

^aIncludes temporary medical leave or disability, unemployed, permanently unable to work.

of patients in their 30s expressed need for information about cancer and its treatment within the first 4 months of diagnosis. In contrast, fewer AYAs—41% of adolescent patients, 73% of patients in their 20s and 69% of patients in their 30s—expressed a need for cancer information and support delivered specifi-

cally through the Internet. Information services may have to vary in content, focus, delivery mechanism, and language to best meet the varied but critical need for information. Existing patient education materials about cancer may not be useful, as AYAs have stated that these materials are geared toward older adults, not delivered in their “language,” and thus not perceived as relevant.⁹ Notably, a recent study identified unmet information needs as a significant predictor of distress.¹⁰

Communicating information to AYAs can be challenging, because levels of cognitive and emotional development are varied, labile, and maturing. However, optimal care requires that health care providers understand the nature of AYAs’ maturing cognitive and emotional capabilities. AYA patients have been found to prefer a democratic, respectful, and relaxed style of working with health care providers who understand their needs.¹¹ They generally prefer direct communication and want to take a prominent role in the management of their care⁵; however, some express ambivalence and need time to process information.¹² Furthermore, delays in cancer diagnosis and experiences with doctors who minimized precancer symptoms or told them they were “too young to have cancer” may contribute to AYAs’ mistrust of oncology care professionals. Discounting issues of importance to AYAs, such as hair loss or missing weekend activities with friends, may only reduce AYAs’ trust and faith in health care providers, and thus risk their adherence to therapy.

Effective communication with AYAs requires “cultural competence,” a recognition that AYAs have preferences, values, and ways of communicating that influence how they experience the world. Guiding and negotiating with AYAs on ways to integrate a cancer treatment regimen into their life in a way that preserves as much normal involvement in school and work and with friends can promote adherence to therapy. Involving AYAs in their oncology care also reinforces maturation in autonomy and ability to make independent and responsible decisions. Although capable of independent thought, AYAs still benefit from adult guidance that they perceive as being respectful of their values and preferences.

Practical Issues

Cancer and its often intensive and lengthy treatments put AYA patients at risk for disruptions of

their normal daily activities, which may have negative consequences for long-term career opportunities, financial status, lifetime earnings,¹³ and treatment adherence.¹⁴ Many AYAs stop work or school. Some decide to move back in with parents after living independently. Whether living with parents or a spouse/partner, many AYAs experience a regression of having to be dependent on others at a time when becoming independent and responsible for oneself is the norm. Rearrangement of existing household routines, transportation schedules, and child care options are required for AYAs to cope with cancer and adhere to treatment protocols. In some instances, AYAs are living alone or away from their parents’ home, making access to practical support difficult.

Treatment adherence is more problematic for AYAs than for older or younger patients.¹⁴ Factors hindering adherence include poor communication with health care providers, complex treatment regimens that disrupt everyday activities, and inadequate parental supervision or involvement.¹⁴ Lack of available transportation or child care may be barriers to treatment adherence, thus leading to AYAs’ expressions of need for support around these issues. Other factors influencing treatment adherence include patient health beliefs (eg, denial, sense of invincibility or invulnerability) and inadequate social support.^{14,15} Studies of other chronic diseases in AYAs suggest that barriers to treatment adherence may include an unwillingness to engage in treatment regimes in public, a lack of time, openness of communication within the family about the disease, and reactions of parents.¹⁶

Fortunately, many of the mechanisms and behaviors discussed here that impact treatment adherence are modifiable. Coping skills interventions may be particularly beneficial,¹⁷ because they can help reinforce the value and importance of therapy adherence, and decrease the likelihood the AYA will turn to deleterious risk-taking behaviors, such as alcohol or drug use, as a means to cope with the emotional fallout of having cancer. Some AYA patients with cancer may engage in risky behaviors (eg, tobacco, alcohol, or substance abuse) that impair their health. Although AYA patients may be aware of health risks associated with tobacco, alcohol, or substance abuse during their treatment, they may not avoid them throughout their treatment, because these habits can make them feel normal and part of their peer

group.¹⁸ Feeling like one is part of a peer group is a defining characteristic of adolescence and young adulthood,³ and thus a powerful influence in AYAs' experience with cancer. Having the opportunity to meet other young adult cancer survivors may offset negative peer influences or normalize new coping behaviors practiced by other young people who have "been there."

Some practical services may be of particular benefit to facilitate treatment adherence and minimize the impact of cancer on one's daily life. AYAs are less likely than older adults to be experienced in negotiating the medical system, and may need assistance understanding insurance coverage, medical billing, and other practical aspects of modern care. As the proportion of the US population most likely to be uninsured,¹⁹ AYAs may need assistance to not only understand their financial responsibilities but also learn about financial support services that may assist them in gaining access to treatment, or financial support because of job loss during treatment. More than 72% of AYAs between the ages of 20 and 39 indicated that they needed help understanding health insurance and other administrative aspects of cancer care.

Interpersonal Issues and the Importance of Peer Relationships

AYAs often have to endure lengthy hospital stays under the supervision of health care providers, resulting in significant isolation from their family members and peer group.¹⁸ Isolation and alienation are common among AYAs diagnosed with cancer because they often miss out on the life experiences shared by their non-ill peers. Reinforcing relationships with family, peers, and health professionals is an important aspect of life for AYAs with cancer.^{20,21} AYAs with young children of their own often express concern about how to talk to their children about cancer. At the time of diagnosis, 61% of young adults aged 30 to 39 years expressed a need for family counseling. Twelve months later, 50% of these patients continued to express this need.

Although some studies have identified family support and cohesiveness as important contributors to a survivor's psychosocial adjustment, others have identified the important role of same-aged peers (healthy peers and other AYA cancer survivors) in helping them cope with cancer and overcome feelings of loneliness.^{13,21} Adolescents report being dis-

satisfied with care in both pediatric and adult care facilities because of the lack of peer group interaction.^{9,22} Peer support programs help AYA patients and survivors build relationships, improve problem-solving and coping skills, and promote positive psychosocial adaptation.²³ They provide AYAs with an opportunity to address some of their concerns, such as coping with uncertainty about the future, establishing autonomy while being increasingly dependent on family and friends, sexual identity, and infertility, thereby reducing feelings of social isolation.²⁴ Within the first 4 months of diagnosis, 42% of adolescent patients, 44% of patients in their 20s, and 52% of patients in their 30s reported a need for peer support programs, such as camps or retreats that offer education and support specifically for AYAs. Twelve months later, 59% of adolescents and 50% of patients in their 30s still reported a need for this type of peer support. In contrast, however, only 22% of young adult patients in their 20s indicated a need for peer support programs, a decrease in this particular need over time. Further research is needed to understand these observed differences in age groups and identify when AYAs may most benefit from opportunities to meet other young adult cancer survivors.

Emotional Issues

In contrast to older adults with cancer with whom they come into contact, AYAs are significantly more likely than younger pediatric patients and older adults to report psychological distress.²⁵⁻³⁰ Investigations of cancer's impact on AYAs identify a distinct set of issues related to fertility and family planning, sexuality, relationships with spouses/partners and parents, and concerns for their young children that AYAs find distressing.^{20,31-38} Their increased risk for distress also may be attributable to a premature confrontation with mortality, disruptions in school or work, forced dependence on parents, loss of reproductive capacity, changes in physical appearance, and health-related concerns about the future.^{32,38-40} Within the first 4 months of their cancer diagnosis, 50% of adolescent patients, 40% of patients in their 20s, and 56% of patients in their 30s reported a need for counseling from a mental health professional. Throughout the first year after diagnosis and initiation of treatment, these proportions remained stable for all age groups: for adolescents, 53% at 6-month follow-up and 51% at 12-month follow-up; for young adults in their 20s, 36% at 6-month follow-up and 44% at 12-month

follow-up; and for young adults in their 30s, 58% at 6-month follow-up and 61% at 12-month follow-up.

Discussion

AYAs' needs for information, practical support, and counseling support are evident throughout the continuum of care. However, studies suggest that many of these supportive care needs are not being met.^{6-8,10,41} Unmet needs may be placing AYAs at an increased risk for distress¹⁰ and contributing to poor adherence to therapy.¹⁴ The variability of settings in which AYAs are treated—from pediatric oncology units to adult-oriented tertiary care facilities or small group oncology practices—may contribute to a lack of continuity of care. AYAs treated in pediatric facilities by multidisciplinary care teams may have greater availability of and accessibility to psychosocial support services.^{42,43}

The developmental tasks and life experiences across an age range from 15 to 39 years are different in content, scope, breadth, and depth. Many of the findings described here highlight age differences and indicate a need to provide age-related services that best help AYA patients achieve the best outcomes possible, but also to deliver cost-effective care. For example, the expressed need for cancer information, and specifically Internet-based information and support, was greater among young adults than adolescent patients. Perhaps surprisingly, the relatively low expressed need for Internet-based cancer information among adolescents in this study (41%) actually reflects national trends: although approximately 93% of US teens had access to the Internet in 2009, only 38% of teens aged 14 to 17 years (but 67% of young adults aged 18–29 years) tended to go online for health- or fitness-related topics.⁴⁴ These findings should be considered closely. Organizations and cancer agencies may not be making the best use of available resources if relying predominantly on Web-based forms of patient education, because other forms of information transmission may be more desirable or accessible. More research is needed on how best to deliver cancer-specific information and support to AYAs, particularly adolescents.

Conclusions

Developmental theories suggest that AYAs lack fully developed cognitive, emotional, and social capabilities

necessary for coping successfully with cancer's physical effects and life disruptions.^{1,45} Limited abilities to seek and understand medical information, manage side effects of treatment, maintain activity and independence, seek support, and manage emotions may contribute to risks for psychological distress, poor treatment outcomes, and diminished quality of life. An important barrier to progress in the field of AYA cancer care may involve the limited availability and types of informational, practical, and support services by age group. The implementation and use of specifically needed services may contribute to improved treatment outcomes. The data reported here on expressed need for supportive care services can guide interventionists and patient education and program developers to target and implement their services to those AYAs who want these services at the most important time points in their survival.

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