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# Adolescent and Young Adult Oncology: An Emerging Subspecialty

Kirstin A. Williams, MSN, RN, FNP-BC



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Adolescent and young adult (AYA) oncology is caught between the pediatric and adult oncology settings and, therefore, poorly defined. Unfortunately, progress in overall survival for this age cohort has been stagnant while children and older adults have seen significant improvements. Reasons for the lack of progress are multifactorial, with biologic and psychosocial explanations. The current article will detail the unique features of AYA patients with cancer in terms of outcomes, psychosocial issues, and recommendations. Literature pertaining to AYA patients with cancer from 2006–2012 was reviewed. Findings suggested that recognizing AYAs as a subspecialty that requires holistic, multidisciplinary care may improve outcomes. Nurses at all levels are adept at providing holistic care and are, therefore, excellent potential advocates for a specialized care delivery model that AYAs with cancer deserve.

Kirstin A. Williams, MSN, RN, FNP-BC, is an oncology nurse practitioner at Sanford Medical Center in Sioux Falls, SD. The author takes full responsibility for the content of the article. The author did not receive honoraria for this work. The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias. No financial relationships relevant to the content of this article have been disclosed by the author, planners, independent peer reviewers, or editorial staff. Williams can be reached at [kirstin.a.williams@sanfordhealth.org](mailto:kirstin.a.williams@sanfordhealth.org), with copy to editor at [CJONEditor@ons.org](mailto:CJONEditor@ons.org). (Submitted July 2012. Revision submitted September 2012. Accepted for publication October 1, 2012.)

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**A**dolescent and young adult (AYA) patients with cancer have received more attention since the mid-2000s. Traditionally, oncology services have been divided between the pediatric and the adult settings, with AYAs caught in the middle. The pediatric and adult cohorts experienced an improvement in overall cancer survival rates, while the AYAs lagged behind (Veal, Hartford, & Stewart, 2010; Wood & Lee, 2011). Emerging data describe the uniqueness of the AYA population, which support the notion that AYAs should be treated as a subspecialty. A subspecialty is defined as a narrow field of study within a specialty (Free Online Dictionary, n.d.), such as pediatric oncology. The purpose of the current article is to demonstrate the rationale for treating AYA patients with cancer as a separate entity.

## Methods

Pertinent articles were searched using the PubMed and CINAHL® databases. The following key words were used in each search: *adolescent and young adult, AYA, oncology, neoplasm, nursing, psychosocial, late effects, survivorship, and outcomes*. Articles published from 2006–2012 were included

in the review; no articles were found prior to that time period, which speaks to the relative newness of the topic. Other search criteria included English-language articles and content that centered on the AYA population. A standardized age range for AYAs does not exist in the literature; however, most experts define the population as patients aged from 15–39 years. Articles were not included if the population studied did not have a cancer diagnosis during the AYA years. The articles included in the review were grouped according to the following themes: outcomes, psychosocial issues, and recommendations.

## Outcomes

Improvements in overall survival for AYAs with cancer has been lacking relative to pediatric and adult populations (Burke, Albritton, & Marina, 2007; Fern & Whelan, 2010; Shaw et al., 2011; Wood & Lee, 2011). Reasons underlying the lack of progress are manifold. Several articles point to the biologic differences in the presenting disease, such as genetics and pathology (Gibbon & Diaz-Arrastia, 2009; Tricoli, Seibel, Blair, Albritton, & Hayes-Lattin, 2011). Wood and Lee (2011) detailed biologic differences found in the AYA group for hematologic malignancies.

For example, in acute lymphoblastic leukemia (ALL), the percentage of patients exhibiting a positive Philadelphia chromosome mutation increases with age and is associated with worse outcomes. Even in patients who are Philadelphia chromosome-negative, adverse cytogenetics that predict poorer outcomes were found more often in AYA patients with cancer (Tricoli et al., 2011). Wood and Lee (2011) also commented on the cytogenetic features of acute myelogenous leukemia, stating that favorable cytogenetics such as translocation 8;21 and inversion 16 are found more often in patients aged 13 years or younger. In solid tumors, such as breast and colon cancer, AYAs exhibit high-risk features associated with poorer outcomes (Tricoli et al., 2011). AYA patients diagnosed with breast cancer are more likely to have poorly differentiated and high-grade tumors, with an increased likelihood of developing the triple-negative subtype compared to older patients (Tricoli et al., 2011). Characteristics of colorectal cancer in AYAs include genetic features that predict poor prognosis and inherent disease resistance, as well as metastatic disease at diagnosis (Tricoli et al., 2011).

Additional research on biologic differences in the AYA population is needed. Cancer registries are valuable sources for research on tumor biology, possible etiologies, and survival information (Pollock & Birch, 2008). Unfortunately, a significant gap in AYA registry information exists. One reason for that gap is the use of different classification systems for pediatric and adult facilities (Pollock & Birch, 2008). In addition, certain pediatric registries limit patient cases to those aged 15 years and younger, missing a considerable number of AYA cases. Pollock and Birch (2008) determined goals to achieve by 2010 that would assist in collecting and tracking information about AYA cancers; however, no published updates have been found as of yet.

Enrolling AYAs for clinical trials is another challenge likely contributing to lack of progress and poorer outcomes (Burke et al., 2007; Downs-Canner & Shaw, 2009; Fern & Whelan, 2010; Wood & Lee, 2011). Only 2% of patients aged 20–29 years are estimated to have enrolled in research trials compared to 60% of patients aged 15 years or younger (Fern & Whelan, 2010). The under-representation of AYAs in clinical trials could be because of a lack of access. Young adults are more likely uninsured and lacking appropriate access to health care (Burke et al., 2007). Downs-Canner and Shaw (2009) performed a retrospective study on clinical trial enrollment rates for AYAs at affiliated pediatric and adult cancer centers. Of newly diagnosed AYA patients with cancer, 26% were put on clinical trials in the pediatric cancer center compared to 4% in the adult setting (Downs-Canner & Shaw, 2009). The authors concluded that a majority of AYAs were treated in adult settings, which contributed to the low clinical trial enrollment rates. Two years later, data were collected on clinical trial enrollment rates at the same institution after a joint pediatric and adult AYA oncology program was established (Shaw et al., 2011). The results showed a significant increase in enrollment for the AYA group, 33% in the adult setting and 23% in the pediatric setting.

Unique developmental issues arising during adolescence and young adulthood also are likely impacting their outcomes. Difficulty adhering to treatments can be a significant issue for this age group (Butow et al., 2010; Wood & Lee, 2011). Lack of adherence may be because of a variety of developmental factors such as asserting independence, financial difficulties, and juggling

other obligations. Noncompliance can decrease the efficacy of treatments and lead to poorer outcomes (Butow et al., 2010).

## Psychosocial Issues

AYAs with cancer experience a different journey compared to their younger and older counterparts. AYAs are faced with mastering developmental tasks, and the emotional turmoil of a cancer diagnosis often conflicts with those tasks. Concepts such as asserting autonomy, developing a set of values, and establishing relationships with peers, as well as intimate relationships, are essential even in the light of a cancer diagnosis (D'Agostino, Penney, & Zebrack, 2011). Lives are dramatically changed for AYAs with cancer; however, promoting a sense of normalcy is a key part in psychosocial care (D'Agostino et al., 2011; O'Callaghan, Barry, & Thompson, 2012).

The special life circumstances of AYAs prompted research aimed at identifying priority health and supportive care needs, as well as unmet needs in this population (Clinton-McHarg, Carey, Sanson-Fisher, D'Este, & Shakeshaft, 2012; Dyson, Thompson, Palmer, Thomas, & Schofield, 2012; Keegan et al., 2012; Zebrack, 2008; Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006; Zebrack, Mills, & Weitzman, 2007). A hallmark of the psychosocial needs of AYAs is the importance of peers, which has been demonstrated in the literature (Schiffman, Csongradi, & Suzuki, 2008; Zebrack et al., 2006, 2007). In a survey conducted by Zebrack et al. (2006), AYAs with cancer ranked opportunities to meet with other AYAs more important than the support from family and friends. Other surveys generally paired family and friends together, which was rated as being significant for supportive care needs (Evan & Zelter, 2006; Zebrack et al., 2007).

Unmet needs consistently were demonstrated in the literature. While conducting a study aimed at identifying predictors of distress, Dyson et al. (2012) found that unmet needs can lead to anxiety, depression, and distress. Main predictors of depression and anxiety in the group of AYAs surveyed by Dyson et al. (2012) were unmet physical and daily living needs as well as unmet health-system and information needs. Obtaining information about aspects of the disease process and treatment is a high priority for AYAs (Dyson et al., 2012; Keegan et al., 2012; Zebrack, 2008; Zebrack et al., 2006, 2007). Unfortunately, the data elucidated many gaps in informational needs. Zebrack (2008) found a high demand for information related to diet and nutrition, exercise, fertility options, and alternative therapies, but 50% of respondents reported those needs as unmet. Similarly, information needs regarding disease relapse and cancer treatments were unmet in more than half of AYAs included in a study conducted by Keegan et al. (2012). AYAs also rank information related to health insurance and financial aid for

### Exploration on the Go



A new resource, *Teenage Cancer Journey*, discusses cancer treatment and its effects from a teenager's perspective. To access, open a barcode scanner on your smartphone, take a photo of the code, and your phone will link automatically. Or, visit <http://resource.ons.org/productdetails.aspx?sku=INPUTEENCAJRNL>.

health services as a high priority (Keegan et al., 2012; Zebrack, 2008; Zebrack et al., 2006, 2007); however, multiple studies demonstrate that these needs are unmet (Clinton-McHarg et al., 2012; Keegan et al., 2012; Zebrack, 2008). Beyond information needs, unmet service needs were identified in the literature. Pain management, in-home nursing care, physical therapy, occupational therapy, and mental health needs were desired services that were not available to AYA patients with cancer (Keegan et al., 2012).

The literature clearly depicts disparities in the needs of AYAs, which likely occur because of the environment in which the AYAs are treated. At a pediatric-focused institution, the average patient age is 4–5 years, whereas the average patient age is 60 years at an adult institution (D'Agostino et al., 2011). The providers and support staff may be well versed in the needs of their average patient but unable to identify with the specialized needs of the AYAs. Identifying unmet needs is crucial so that appropriate interventions can follow. Clinton-McHarg et al. (2012) discussed a newly developed tool, the Cancer Needs Questionnaire–Young People (CNQ-YP), which measures unmet needs for AYAs in six factors: treatment environment and care, feelings and relationships, daily life, information and activities, education, and work. The CNQ-YP has demonstrated good internal consistency and reliability despite the small sample size. The CNQ-YP appears to be a promising tool for identifying specific needs that may be targets for supportive care services.

Addressing the circumstances exclusive to the AYA population is imperative. Support from peers and family is paramount; however, it also can serve as a source of conflict. Teenagers will rely heavily on their parents during a cancer diagnosis, which sets them apart from their peers who are exerting independence (D'Agostino et al., 2011). Zebrack, Hamilton, and Smith (2009) advocated the use of a self-efficacy model when treating AYA patients to foster their independence. Promoting self-efficacy may encourage AYAs to remain active, independent, in tune with healthcare information and decisions, and better able to physically and emotionally cope with treatment-related side effects. Establishing an open, flexible care environment is beneficial to AYA patients, particularly when the providers and staff are sensitive to age-appropriate needs. Creating a flexible environment for AYA patients could include delaying morning rounds until they are awake, adjust-

ing treatment schedules so they do not miss milestone events (e.g., graduation ceremonies, school dances), and talking about activities they can do versus cannot do (D'Agostino et al., 2011). Because the age of AYAs can range from teenager to young adult, specific concerns will relate to their phase in life. Teenagers may be more concerned with keeping up in school so they can graduate on time; however, young adults may be more concerned with the financial difficulties they may face if unable to work. AYAs may make choices during their treatment that appear to be irresponsible, but the fact that they are still cognitively maturing should be considered (D'Agostino et al., 2011). Maintaining an open and developmentally appropriate communication style that avoids condescension will help foster a therapeutic relationship between AYAs and treatment staff (D'Agostino et al., 2011).

Cancer survivors face physical and psychosocial difficulties even after completing treatment. Those survivorship difficulties often are called “late effects” and have become a subspecialty of their own. Mentioning late effects is beneficial because of the distressing qualities they can exert on AYA patients with cancer.

Concerns about fertility, risk of second malignancies, cardiotoxicity, hearing and/or vision loss, chronic fatigue, decreased sexual functioning, and amputation are examples of the physical difficulties they face (Nightingale et al., 2011; Soliman & Agresta, 2008; Thompson, Palmer, & Dyson, 2009). Fertility problems are a direct result of cancer treatments and can manifest as ovarian failure in women and azoospermia in men (Levine, Canada, & Stern, 2010). The American Society of Clinical Oncology (ASCO) recommends addressing reproductive issues with patients as part of the education provided prior to the initiation of therapy (Lee et al., 2006). Many AYAs, however, report unmet needs and dissatisfaction with the lack of information received about fertility issues (Thompson et al., 2009; Zebrack, 2008, 2009), or that it was discussed at diagnosis and then not addressed again (Thompson et al., 2009). The literature described AYAs frequently developing fear and anxiety about their cancer returning, as well as transitioning to a different care team (Thompson et al., 2009). Impaired body image also can be problematic for survivors (Nightingale et al., 2011; Soliman & Agresta, 2008), which can be particularly distressful for an already self-conscious population. Changes in weight, loss of hair, and presence of scars are examples of alterations in appearance that can affect survivors' self-esteem and ability to fit into social norms (Nightingale et al., 2011). Lack of self-esteem can equally affect challenges reassimilating into school or work (Thompson et al., 2009). Adjusting to the usual routine of school or work, fitting in with peers, and coping with cognitive and physical sequelae related to their treatment and disease are potentially problematic. Cognitive deficits can occur from modalities such as intrathecal chemotherapy or cranial radiation, and may require the AYA to seek extra support in the work or school setting (Soliman & Agresta, 2008; Thompson et al., 2009). Physical and emotional needs require consistent, long-term monitoring, which equates to the increased need for health care and, therefore, health insurance. Unfortunately, young adults are more likely uninsured while they are transitioning away from their parents' insurance and may have difficulties finding employment because of their disease (Soliman & Agresta, 2008).

#### Fertile Hope

- ▶ Provides reproductive information and support to people affected by cancer whose therapy presents the risk of infertility  
[www.fertilehope.org](http://www.fertilehope.org)

#### LIVESTRONG™ Foundation Young Adult Alliance

- ▶ List of resources addressing emotional, physical, practical, and treatment concerns  
[www.livestrong.org/Get-Help/Find-More-Resources](http://www.livestrong.org/Get-Help/Find-More-Resources)

#### National Cancer Institute

- ▶ List of organizations that support adolescents and young adults who have cancer  
[www.cancer.gov/cancertopics/aya/resources](http://www.cancer.gov/cancertopics/aya/resources)

FIGURE 1. Resources for Adolescents and Young Adults With Cancer

## Implications for Practice

- ▶ Because survival outcomes for adolescents and young adults (AYAs) with cancer have not improved since the 1990s, new strategies for care and prospective research are necessary.
- ▶ AYAs have distinct disease-related features as well as unique developmental and emotional challenges compared to their younger and older counterparts, which should be considered when caring for these individuals.
- ▶ Oncology nurses are adept at delivering the holistic, multidisciplinary care required for AYAs with cancer.

## Recommendations

Outcome improvements for this subspecialty will require a focus on the elements that make AYAs unique. Research will be key in identifying superior treatment options, discovering tumor and cancer genetics characteristics, and recognizing the differentiated care required (Hayes-Lattin, Mathews-Bradshaw, & Siegel, 2010; Ramphal, Meyer, Schacter, Rogers, & Pinkerton, 2011; Wood & Lee, 2011; Zebrack, Mathews-Bradshaw, & Siegel, 2010). Prospective clinical research trials are recommended because a majority of the research for AYAs is retrospective (Wood & Lee, 2011; Zebrack et al., 2010), and increased enrollment in clinical trials is necessary. Increased cooperation between adult and pediatric treatment centers would benefit AYAs by offering protocols that may not be available otherwise. For example, retrospective studies performed on AYAs with ALL demonstrate better outcomes when the patients are treated on a pediatric protocol versus an adult protocol (Wood & Lee, 2011). Adult facilities may not have access to the pediatric protocols or be accustomed to the complex design and, therefore, require partnership.

Perhaps the most important part of improving outcomes is the model of care delivered to AYAs. The Adolescent and Young Adult Oncology Progress Review Group formed a position statement on establishing standards of care for AYA patients with cancer (Zebrack et al., 2010), and provided a continuum of care model that describes the multidisciplinary approach for AYA care, particularly because their needs go beyond medical care. Examples of professionals involved in that model are oncology nurses, mental health specialists, peer supporters, nutritionists, reproductive health specialists, and pediatric and adult oncologists. All disciplines work together to treat the patient as a whole, and care is provided from initial diagnosis through survivorship (Zebrack et al., 2010).

A dedicated AYA program may be ideal, but is not feasible in every setting. Ramphal et al. (2011) suggested “virtual units” to optimize care by connecting patients to healthcare teams or connecting treatment facilities to AYA specialists. As awareness continues to increase, the hope is that oncology AYAs will be a subspecialty with specialized training programs (Ramphal et al., 2011). For resources available to AYAs with cancer, see Figure 1.

## Conclusion and Nursing Implications

AYA patients with cancer are a distinct population caught between the pediatric and adult worlds. Various factors likely

contribute to the lack of progress seen in cancer affecting AYAs; therefore, fundamental changes in care are necessary. Oncology nurses are well versed in providing holistic patient care, a requirement for AYAs. In addition, oncology nurses value and are very familiar with the multidisciplinary approach for oncologic care. Oncology nurses at all levels should reach out to each other to share knowledge and strategize on how to best provide age-appropriate services to the AYA. Nurses are adept at program development and should look for ways to increase awareness of AYA patients with cancer and advocate for a specialized delivery care model.

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