Oncologists should collaborate early with palliative care specialists to help care for AYA patients with cancer.

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# Palliative Care in Adolescents and Young Adults With Cancer

**Kristine A. Donovan, PhD, Dianne Knight, MD, and Gwendolyn P. Quinn, PhD**

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**Background:** Cancer survival rates for adolescents and young adults (AYA) have not improved over time relative to children or adults older than 39 years of age. Palliative care is specialized medical care focused on the control of symptoms and relief of suffering with the goal of improving quality of life for the patient and his or her family. To date, the integration of palliative care in AYA patients with cancer remains suboptimal.

**Methods:** We explore the role of palliative care in the continuum of clinical care for AYA patients with cancer. Clinical practice guidelines highlight the need for integrating palliative care for all patients with cancer, including the AYA population. Despite this, a paucity of evidence exists regarding the use of palliative care with AYA patients with cancer. Graduate clinical education represents an opportunity to promote the full inclusion and early integration of palliative care in the care of AYA patients with cancer. Advance care planning is one area where some agreement exists on the unique needs of AYA patients and their families.

**Conclusions:** In general, palliative care is seen as being synonymous with end-of-life care for patients with cancer. However, the emerging trend toward standardizing oncology care to meet the unique medical, psychosocial, and supportive care needs of AYA patients with cancer and their families represents an opportunity for health care professionals to collaborate early with palliative care specialists to control symptoms and relieve suffering in this vulnerable population.

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**Introduction**

Defined on the basis of age and cancer biology, cancer in adolescents and young adults (AYA) accounts for approximately 6% of all invasive cancers diagnosed on a yearly basis. Each year, nearly 70,000 AYA patients in the United States receive a cancer diagnosis. The incidence of specific cancers in the AYA population varies across the age span, which is typically defined as between 15 and 39 years. In the last 30 years, survival rates for AYA patients have not improved relative to younger and older age groups, and cancer is the leading cause of disease-related death in this population.

This lack of improvement in survival has been attributed to numerous factors, including the unique biology of AYA cancers, limited access to care, delays in diagnosis and treatment, lack of consistency in treatment approaches, patient nonadherence to treatment, and low rates of access to and participation in clinical trials, as well as the unique medical, psychosocial, and supportive care needs of this patient population.

Recent study results suggest that implementation of the Affordable Care Act will positively affect the AYA population; however, whether the applicable regulations will result in improved rates of cancer survival...
remains to be seen.11,12

Although the continuum of AYA development is different across its age span, many issues have been identified that distinguish AYA from pediatric and adult populations.13–16 Such issues include the transition away from parental dependence toward dependence on peers and social networks, concerns about future family and life plans, limited access to mental health services and social and peer support networks, and disruptions in school or work life with the associated financial challenges.13–15 Although the specific needs of individual AYA patients may vary, as a group, these patients have more in common than not.7

Cancer and its treatment confound the AYA patient's ability to establish autonomy and make independent decisions about education, employment, relationships, and starting a family.13 In a recent review of palliative care in AYA, Clark and Fasciano17 distinguish AYA patients as a vulnerable population and highlight the chasm between pediatric and adult oncology care where the AYA patient is often lost. This should be alarming to those who care for AYA patients, because research suggests that, as a group, AYA patients tend to experience more complex, more severe, and longer-lasting distress than children or adults with similar diagnoses.18–20

Palliative Care

Palliative care is specialized medical care for individuals with serious illnesses. It focuses on control of symptoms and relief of suffering with the goal of improving quality of life (QOL) for patients and their families. Palliative care in cancer is appropriate at any age and at any stage and can be provided along with curative treatment.21

Palliative medicine is a recognized medical specialty in the United States, and current models of palliative care suggest interdisciplinary approaches that include both the primary oncology team and a specialized palliative care team facilitate optimal patient and family care.22–25 In 2012, the American Society of Clinical Oncology issued a provisional clinical opinion calling for the integration of palliative care into standard oncology care for patients with metastatic cancer, high symptom burden, or both.21 This opinion derives from expert consensus and the results of several randomized controlled trials demonstrating the benefits of integrating palliative care into standard oncology care, including a trial of early palliative care in patients with cancer that found an increased survival benefit for those who received palliative care.21–24 Studies also have demonstrated a beneficial effect of early palliative care on QOL in patients with advanced cancer.25–26 By referencing the potentially practice-changing data from these studies, the opinion highlights the increasing relevance of palliative care for the care of all patients with cancer.21 Consistent with the opinion of the American Society of Clinical Oncology, many professional organizations now recommend that patients with cancer be screened for palliative care needs.21,25–27,28 For example, guidelines from the National Comprehensive Cancer Network recommend that all patients with cancer be routinely screened and rescreened at appropriate intervals for palliative care needs.23 The guidelines also recommend early collaboration with palliative medicine specialists to improve QOL.25

Cancer Treatment

Despite the focus on symptom control and QOL at any stage of disease or treatment, palliative care teams have historically been more often involved in the care of patients with cancer deemed challenging or at or near the end of life.7,29 The result is that, among oncology care providers, palliative care is generally synonymous with end-of-life care.29 Thus, integrating palliative care into standard oncology care for AYA, like that for pediatric and adult patients with cancer, remains suboptimal.30 To the best of our knowledge, no trial has integrated early palliative care into the care of AYA patients with cancer receiving treatment.

Data on symptom burden in AYA patients, especially at the end of life, are limited. Data on AYA patients with cancer are often contained within the adult and pediatric oncology literature, making it difficult to discern the potential effects of palliative care in the vulnerable AYA population.31–35 Nevertheless, data indicate most AYA patients with cancer experience multiple physical and psychological symptoms and often spend their last days of life within an acute care setting, with end-of-life discussions often occurring only when death is imminent.34–36

In one of the few studies to date of symptom burden in AYA patients with advanced cancer, Cohen-Gogo et al35 conducted a retrospective review of the medical records of 45 AYA patients with cancer treated in a specific AYA oncology unit who died as a result of progressive disease during a 2-year period. Diagnoses of sarcoma or a brain tumor predominated and accounted for 78% of diagnoses.35 A total of 40% of patients received palliative chemotherapy during the last month of life.35 The median time between the last cycle of chemotherapy and death was 30 days (range, 2–457 days).35 A total of 24% of patients received radiotherapy in the last month of life, mostly for pain and symptoms related to tumor volume.35 One-third of patients received artificial nutrition during the last week of life.35 The median number of physical symptoms was 4 (range, 1–7).35 Pain and dyspnea were the most common symptoms, particularly among patients with sarcoma, whereas patients with a brain tumor were more likely to experience paralysis, confusion, or coma.35 With respect to psychological symptoms, during the last month of life, all pa-
tients reported sadness, anxiety, fear of being alone, fear of death, fear of pain, and guilt. A total of 77% of patients met with the psychologist on staff at the AYA unit during their initial anticancer treatment; of these patients, 83% continued to receive care from the psychologist during the last month of life. In addition, most of the patients admitted to the unit spent more than 2 weeks in the hospital (median, 16 days; range, 0–30 days) during the last month of life.

Although this study provides only general baseline information about symptoms and patterns of end-of-life care of AYA patients treated in 1 specific AYA unit, it is noteworthy that in most of the patients, end-of-life care continued to be an active period of care. Many of the patients experienced substantial physical and psychological symptoms during the last week of life, a finding that supports the need for a well-trained, multidisciplinary palliative care team to collaboratively work with other members of the health care team.

Data on QOL among AYA patients with advanced cancer are also scarce, either from descriptive observational studies or randomized controlled trials of interventions aimed at enhancing QOL at any point along the disease trajectory. In a systematic review of the literature regarding QOL in AYA patients with cancer, Quinn et al identified 35 studies whose outcomes were any psychosocial factors affecting QOL in AYA patients. Most of the studies they reviewed focused on the post-treatment survivorship period and, broadly defined, the psychosocial supportive care needs of AYA cancer “survivors.” Only 1 study involved AYA patients with advanced cancer with an eye toward palliation of symptoms—in this case, at the end of life to improve QOL. In their review, Quinn et al note lack of sufficient QOL measurement tools and lack of evidence-based interventions to improve QOL in AYA at any point in the cancer care trajectory. They conclude by commenting on the unique needs of the AYA population and the emerging trend toward standardizing oncology care for this population (for additional commentary, see Thomas et al).

Palliative care has not been established in standard oncological care for AYA patients with cancer. However, clinical practice guidelines aimed at the care of AYA patients with cancer across the continuum of care—from diagnosis to survivorship, or end of life—have begun to reflect the need for integrated palliative care. For example, consistent with the recommendation that oncology care providers collaborate early with palliative medicine specialists to control symptoms and reduce suffering in all patients with cancer, guidelines from the National Comprehensive Cancer Network include several considerations for palliative care. The guidelines note that referral to palliative care is appropriate when patients are being treated with curative intent, that palliative care may be initiated at diagnosis (to provide the best possible care for patients), and that interdisciplinary members of the palliative care team should have expertise in understanding the psychosocial, emotional, and developmental issues unique to the AYA cancer population. The guidelines also specifically note the importance of creating an AYA team that includes palliative care as a means of improving early referrals, research, and patient-centered care.

**Clinical Education**

The creation of an AYA team that includes a palliative care clinician knowledgeable about the unique needs of AYA patients with cancer highlights a critical fact. As Wiener et al note in their review of factors that make the provision of palliative care particularly challenging in AYA, a dearth of clinicians exists, both in medicine and nursing, who have the requisite training and skills in palliative care needed to care for AYA with cancer. Formal palliative care training is limited in the average US medical school curriculum. Furthermore, training in adolescent medicine in the United States has been described by many graduates of subspecialty medical residency programs as inadequate for clinical practice. Some commentators, who are aware of the chasm that exists between pediatric and adult oncology care, have suggested that the key to appropriate symptom palliation among AYA patients with cancer is to transition the AYA patient to the adult oncology setting. Others have emphasized the need for specialized AYA multidisciplinary palliative care teams that can work in both pediatric and adult facilities. However, the most convincing commentators are those who seek to integrate palliative care into AYA oncological care by offering educational strategies for teaching clinicians about palliative care in the AYA population.

To this end, Wiener et al have proposed an educational and conceptual model for education aimed at palliative care in the AYA population that acknowledges existing contextual barriers, such as the limited exposure of clinicians-in-training to functional multidisciplinary teams. The model addresses key aspects of clinician development: knowledge (eg, of human development), skills (eg, symptom management, ability to work in teams), and attitudes (eg, about patient dignity). Weiner et al also advocate for the teaching of palliative care concepts via educational strategies and mentorship with the greatest potential to improve AYA outcomes. With respect to outcomes, their model highlights social outcomes, such as receiving respect, feeling understood, and trusting the system, and physical outcomes.

**Advance Care Planning**

In comprehensive palliative care, discussions about end-of-life care are paramount, and advance care plan-
ning documents are often used to facilitate these discussions. Several advance care planning guides are available for adults, including *Five Wishes* (Age With Dignity, Tallahassee, Florida; https://fivewishesonline.agingwithdignity.org), which is a document that appoints a legal health care decision-maker at the end of life and specifies an individual’s desired therapies for medical care (eg, palliative care). *Five Wishes* largely focuses on the expressed desire of adults to participate in medical decision-making regarding treatment at the end of life.

Researchers have begun to explore whether AYA patients with cancer are similarly motivated to participate in end-of-life discussions and whether they consider these discussions to be beneficial. Evidence does suggest that AYA patients with cancer are interested in having end-of-life discussions and that the patients, their families, and their health care professionals all benefit from such discussions. Although adult patients with cancer tend to focus on decision-making related to their end-of-life care, AYA patients with cancer appear to be more concerned with how they want to be treated and remembered than about decision-making.

Whether this finding is related to developmental differences (eg, many adolescent patients may depend on their parents to make treatment-related decisions for them) or to a limited understanding of life-support treatment options and the legal aspects of end-of-life care is unclear. Regardless, such findings suggest that advance care planning documents used to facilitate end-of-life discussions with AYA patients should include developmentally appropriate language and terminology and must also reflect AYA patient values and beliefs. Thus, advance care planning guides developed for adult patients are not suitable for AYA patients with cancer and their families.

Voicing My Choices (Aging With Dignity; www.agingwithdignity.org/voicing-my-choices.php) is an advance care planning guide designed for AYA patients to help them communicate their end-of-life preferences to family, caregivers, and friends. The guide was developed by investigators at the National Cancer Institute and National Institute of Mental Health via iterative formative research using *Five Wishes* in a population of patients with cancer and pediatric patients infected with HIV.

Similar to *Five Wishes*, Voicing My Choices is designed to facilitate communication between AYA and their families and health care professionals, including care providers from the fields of medicine, nursing, social work, chaplaincy, psychiatry, and psychology. It consists of an introduction followed by 9 sections, each one a separate module, that addresses topics such as how patients wish to be supported so they do not feel alone, who they would want to make their medi-cal care decisions if they cannot make them on their own, and what they wish their friends and family to know about them. *Five Wishes* is legally binding. By contrast, Voicing My Choices is designed to be a legacy document that is not legally binding but that fulfills the patient’s final wishes. The effectiveness of Voicing My Choices is predicated on the skills and attitude of the health care professional. The guide brings family members or a surrogate decision-maker into the discussion. However, it has not been systematically evaluated. Thus, although it is likely to enhance and facilitate discussion between the AYA patient and his or her health care professional, whether the guide serves to facilitate discussion between the AYA patient and his or her family is not yet known. These and other issues are currently being explored in a multi-institutional trial (NCT02108028), so more information about the utility of the guide should be forthcoming.

**Conclusions**

Cancer survival rates for adolescents and young adults (AYA) have not improved over time relative to younger and older age groups. Palliative care is specialized medical care that focuses on control of symptoms and relief of suffering with the goal of improving quality of life for the patient and his or her family. Palliative care is appropriate at any age and at any stage of cancer and can be provided along with curative treatment. To date, the integration of palliative care in AYA cancer care remains suboptimal. Existing clinical practice guidelines highlight the need for the integration of palliative care into the care of all patients with cancer, including the AYA population. Despite this, a paucity of evidence exists regarding the use of palliative care in AYA patients with cancer beyond care in the last few weeks or months of life. Graduate clinical education represents an opportunity to promote the full inclusion and early integration of palliative care in the care of AYA patients with cancer. Advance care planning is one area where some agreement exists on the unique needs of AYA patients and their families. Although palliative care is generally still synonymous with end-of-life care in cancer care, the emerging trend toward standardizing oncology care to meet the unique medical, psychosocial, and supportive care needs of AYA patients and their families represents an opportunity for health care professionals to collaborate early with palliative care specialists to control symptoms and reduce suffering in this vulnerable population.

**References**

