

Adolescent and Young Adult Oncology Training for Health Professionals: A Position Statement

Brandon Hayes-Lattin, Beth Mathews-Bradshaw, and Stuart Siegel

ABSTRACT

We outline here the essential elements of training for health care professionals who work with adolescent and young adult (AYA) patients with cancer. Research is emerging that a number of cancers manifest themselves differently in the AYA population, both in terms of biology and treatment response. In addition, there are a number of issues uniquely experienced by the AYA population that are critical for health care professionals working within AYA oncology (AYAO) to understand. The LIVESTRONG Young Adult Alliance, a Lance Armstrong Foundation program and a result of the Adolescent and Young Adult Oncology Progress Review Group cosponsored by the Lance Armstrong Foundation and the National Cancer Institute, assembled a group of experts representing relevant medical, psychosocial, and advocacy disciplines to create a blueprint for the training and development of health care professionals caring for AYA patients with cancer. The Alliance recommends that all health care professionals working in AYAO receive training that provides expertise in the following three critical areas: AYA-specific medical knowledge; care delivery specific to AYAs relative to pediatric and older adult populations; and competency in application and delivery of AYA-specific practical knowledge. These three areas should form the foundation for curricula and programs designed to train health care professionals caring for AYAO patients.

J Clin Oncol 28:4858-4861. © 2010 by American Society of Clinical Oncology

INTRODUCTION

The discipline of adolescent and young adult (AYA) oncology (AYAO) is an evolving field that has begun to be defined only within the last decade. The increasing focus over the last 10 years on the outcomes, unique challenges of care, and distinct biology of young adult cancers is beginning to stimulate interest in the development of clinical programs specific to the care of AYAs. Many aspects of cancer as a disease among AYAs overlap with the common areas of expertise encountered in traditional pediatric and adult oncology training programs (including oncology specialties such as radiation and surgery). However, compounding factors such as differences in treatment response from those of other age groups, developmental and life stage differences, psychosocial effects, and fertility issues call for a comprehensive AYA-focused approach for the effective treatment of AYAs with cancer that is not included in existing training and education programs.

Research is beginning to delineate the many ways that cancer in AYAs is distinct from that in young children or older adults. For many cancers, including lymphoma, leukemia, sarcomas, melanoma, GI stromal tumor, breast cancer, and colon

cancer, the epidemiology and cancer biology differ in AYAs compared with younger children and older adults.¹⁻³ Furthermore, recent studies have found differences in outcomes for AYAs in certain cancers depending on whether they were treated on pediatric or adult protocols.^{1,2,4,5} Thus far, the clearest examples of this treatment outcome disparity are the recent retrospective analyses that found better outcomes for AYA patients with acute lymphoblastic leukemia treated on pediatric protocols compared with those reported for adult protocols.^{2,4,5}

In addition to knowledge of tumor biology, an understanding of the dynamic developmental period from adolescence through the reproductive adult years is a necessary component of the care of AYA patients with cancer. This age range is characterized by marked hormonal and physiologic changes, as well as significant psychological and sociocultural transitions such as attending college, starting a career or family, or caring for aging parents. These transitions bring additional considerations into cancer treatment decisions, such as lack of insurance, fertility preservation, and logistical challenges that can contribute to delays in diagnosis and lack of adherence to care plans, that are often not issues for older or younger patient populations.^{1,6,7} Generating and delivering treatment care

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Submitted May 17, 2010; accepted August 5, 2010; published online ahead of print at www.jco.org on September 7, 2010.

Supported by the LIVESTRONG Young Adult Alliance, a program of the Lance Armstrong Foundation, which provided funding and staff support for The Professional Development of Adolescent and Young Adult Oncology Providers Meeting and this resulting position paper. Financial support for meeting logistics was provided by a grant from Enzon Pharmaceuticals.

The ideas and opinions expressed herein are those of the authors and the LIVESTRONG Young Adult Alliance. Endorsement by the authors' or Alliance members' individual institutions is not intended and should not be inferred.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

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0732-183X/10/2832-4858/\$20.00

DOI: 10.1200/JCO.2010.30.5508

plans for the AYA population requires awareness of and sensitivity to these issues.

To address this, in 2005 to 2006, the National Cancer Institute and the Lance Armstrong Foundation jointly sponsored the Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG). The AYAO PRG identified five recommendations for advancing cancer care for this age-specific population.⁸ A strategic implementation plan was then developed by the LIVESTRONG Young Adult Alliance (hereafter referred to as the Alliance) to implement the AYAO PRG's recommendations.⁹ Oversight of the strategic plan is conducted through the Alliance with guidance from the Lance Armstrong Foundation and National Cancer Institute.

The second recommendation of the AYAO PRG is "to provide education, training, and communication to improve awareness, prevention, access, and quality of care for AYAs."⁸ In particular, the AYAO PRG recommendation relates poor recognition of AYAs' cancer risk and inadequate response on the part of providers to the lack of health care provider training programs. As a result, the AYAO PRG recommendation calls for core competency curricula and continuing education programs.⁸ The strategic plan developed a strategy for addressing this that includes "...preparing a position statement that lays the foundation for creating nationally accepted criteria and standards of care for practice, ultimately leading to the development of formal, certified training programs for AYAO healthcare practitioners."⁹ In accordance with its strategy to address the second AYAO PRG recommendation, the Alliance assembled a group of 15 experts representing relevant medical, psychosocial, and advocacy disciplines to develop a blueprint for the training and development of health care professionals caring for AYA patients with cancer. The following position statement is the result of that meeting and is put forth on behalf of the Alliance.

POSITION STATEMENT

It is the position of the LIVESTRONG Young Adult Alliance that a distinct discipline is needed to improve disease outcomes, survival, and health-related quality of life for AYA patients with cancer. The Alliance's goal for AYAO health care providers is to present curriculum recommendations for critical educational elements specific to AYAO that should be incorporated into existing training programs. These recommendations are intended to be incorporated into the teaching curriculum for medical students, primary care residents, specialty residents and fellows, nurse practitioners, physician assistants, nurses, psychosocial health care providers, and other health professionals. In addition to these training opportunities for all health care providers who interact with the AYA population, the creation of formal, certified programs, such as AYAO fellowships, is encouraged at sites with established AYAO programs.

RECOMMENDATIONS

AYA-Specific Medical Knowledge

Health care professionals caring for AYA patients with cancer should be familiar with the existing body of medical knowledge re-

garding this population, including common cancer histologies, physiologic responses, and developmental adaptations to cancer and cancer therapy.

- Epidemiology of cancer in the AYA population
- Biology and cancer genetics of common AYA malignancies (eg, sarcomas, lymphomas, leukemias, testicular cancer)
- Treatment regimens specific to AYAs for malignancies more common in AYAs
- Physiology and host biology across the AYA age range (eg, implications for chemotherapy dosing and toxicity and development of age-related comorbidities)
- Psychosocial and neurocognitive development across the AYA age range
- Biomedical consequences of cancer treatment (eg, acute adverse effects and late effects)
- Fertility preservation options
- Secondary and tertiary prevention applied to the AYA age range
- Knowledge of research (eg, basic, translational, and clinical research in AYAO)
- Knowledge of bioethical and legal issues particularly relevant to AYA patients (eg, consent or assent to research or therapy, sharing of health information with AYA minors and family members, consent for family members to share in health information for AYAs who are > 18 years old)

Care Delivery to the AYA Population

Many AYA patients with cancer fall through the cracks of the existing health care system, which classifies patients as either children or adults. AYA patients often straddle these two worlds, neither of which may be adequately equipped to recognize or respond to the unique complement of psychosocial and cultural forces that influence the diagnosis and treatment of cancer in this population. Optimally, caring for AYAs with cancer requires an appreciation of these factors as well as a commitment to building care teams and referral sources able to address these issues in appropriate ways.

- Factors impacting delays in diagnosis of AYA tumors (eg, physician and patient awareness, access to care, insurance status)
- Physical issues for AYA patients (eg, symptom management, body image, fertility, sexuality)
- Practical issues for AYA patients (eg, job or school, finances, insurance, transportation, housing)
- Emotional issues for AYA patients (eg, beliefs, values, attitudes, interpersonal relationships, independence or control, survival guilt)
- Substance use and abuse and interactions with treatment and outcomes
- Health disparities among the AYA population
- Engagement of AYA patients (eg, participation in care and adherence to treatment)
- AYA-tailored survivorship (eg, survivorship plan and transition of care)
- Recognition of the use of complementary and alternative medicines
- Palliative care and end-of-life issues within the AYA age range

Competency in Application and Delivery of AYA Knowledge

Effective application of medical knowledge requires professional skills and practical knowledge that are often neglected in existing training programs. These skills and knowledge are particularly critical for care of the underserved and understudied AYAO population and will enhance the ability of providers to deliver multidisciplinary care, perform research, and advocate for their patients.

- Understanding the need to develop and evaluate models of care for the AYA population
- Age- and culturally appropriate communication skills (eg, interfacing with patients, families, and caregivers, particularly through alternative methods such as social media, texting, and e-mail)
- Management skills to integrate multiple disciplines within an AYA cancer program or facilitation of referrals/access to other disciplines (eg, team building, fiscal management, and systems-based practice)
- Skills in developing effective relationships with AYA advocates

Methods of Incorporating Training

Incorporation of training in the field of AYAO may be facilitated by inclusion of these components into existing programs, as well as the creation of new AYA-focused training opportunities. Methods of providing this training could come from seminars at existing oncology meetings, adding AYA-specific courses to existing medical and other health professional schools' curricula, development of AYA-specific postgraduate training programs, and providing continuing medical education/continuing education units and other courses. In addition to these training opportunities for all health care providers who interact with the AYA population, the creation of formal, certified programs, such as AYAO fellowships, is encouraged at sites with established AYAO programs. At a minimum, sites sponsoring AYAO training programs must have adequate infrastructure,¹⁰ access to sufficient numbers of AYA patients with cancer, and dedicated mentoring.

The evolution of the field of AYAO from special forums, lectures, continuing medical education activities, and courses to integrated formal subspecialty training and certification may follow a path similar to that of the field of geriatric oncology.¹¹ Various models for AYAO fellowships are already being explored, including either as combined fellowship training in both pediatric and adult medical oncology or as additional training after completion of either fellowship alone. The market needs for these future AYA oncologists have yet to be determined, but at a minimum, these providers would be uniquely qualified to provide expert consultation to the tens of thousands of new AYA patients with cancer diagnosed each year in the United States.

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CONCLUSION

The current structure for cancer care has failed to meet the needs of AYA patients with cancer. Strategies developed for pediatric or older adult patients have not been effectively adapted to care for those who fall between these age groups. Immediate improvements in the quality of care for AYAO patients will occur if health care professionals become well versed in the existing body of knowledge about the basic biologic, genetic, epidemiologic, psychosocial, cultural, and economic factors that affect this age-specific population. However, continued progress will require deeper understanding of the diverse contributors to cancer incidence and outcomes and cancer-related quality of life in AYAs. Thus, a cadre of health care professionals capable of conducting high-quality basic, translational, clinical, and population-based research must be trained, and all AYAO providers should be instilled with an appreciation of the importance of research to ensure forward movement of the field.

The recommendations of the Alliance to provide exposure to the listed components of an AYAO curriculum are inclusive of all health care providers who interact with this population but also serve as the framework for existing and future efforts to create formal, certified, subspecialty training programs such as AYA fellowships.

It is the position of the Alliance that a distinct discipline is needed to develop, disseminate, and use the body of knowledge necessary to optimize disease outcomes, survival, and health-related quality of life for AYA patients with cancer. The elements described herein—AYA-specific medical knowledge, care delivery specific to AYAs as opposed to pediatric and older adult populations, and competency in application and delivery of AYA-specific practical knowledge—should form the foundation for curricula and programs designed to train health care professionals caring for AYAO patients.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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Final approval of manuscript: Brandon Hayes-Lattin, Beth Mathews-Bradshaw, Stuart Siegel

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