
EMERGING ISSUES AMONG ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS

PANDORA PATTERSON, FIONA E. J. McDONALD, BRAD ZEBRACK, AND SHARON MEDLOW

OBJECTIVES: *To review the characteristics of cancer in the adolescence and young adult age group; the medical, psychosocial and behavioral late effects; survivorship care planning and transition; current research priorities; and practice implications.*

DATA SOURCE: *Published articles, research studies and position statements.*

CONCLUSION: *Survivors of cancers that occurred during adolescence and young adulthood (AYA) are confronted with the dual demands of managing their transition to independent adulthood, concurrently with their transition from cancer patient to cancer survivors, with an associated reduction in support from medical services. AYA survivors also face complex medical, psychosocial and behavioral late effects, including fertility and mental health issues.*

IMPLICATIONS FOR NURSING PRACTICE: *An understanding of the impact of cancer diagnoses among this age group, including survivors' abilities to reintegrate into 'normal' life and potential long term consequences, is necessary to provide the best support. This care and support can be enhanced through multidisciplinary teams who work together to address the medical and psychosocial needs of AYAs diagnosed with cancer.*

KEY WORDS: *Psychosocial, adolescent, young adult, survivor*

ADOLESCENCE and young adulthood are exciting yet challenging stages of life involving rapid physical, emotional, cognitive, and social maturation. While

generally a period of peak health, approximately 1 million new cases of cancer occur worldwide among 15 to 39 year olds.¹ After suicide, poisoning, and accidental death by injury, cancer

Pandora Patterson, PhD: General Manager, Research, Evaluation & Social Policy, *CanTeen Australia*, Sydney, New South Wales, Australia; Adjunct Assoc Professor, *Cancer Nursing Research Unit, The University of Sydney*, Sydney, New South Wales, Australia. Fiona E. J. McDonald, PhD: *CanTeen Australia*, Sydney, New South Wales, Australia. Brad Zebrack, PhD: Associate Professor, *University of Michigan School of Social Work, Ann Arbor, MI, USA*. Sharon Medlow, PhD: Senior

Research Officer, *CanTeen Australia*, New South Wales, Australia.

Address correspondence to Brad Zebrack, PhD, *University of Michigan School of Social Work, 1080 S. University, Ann Arbor, MI, 48109-1106, USA*. e-mail: zebrack@umich.edu

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is the leading cause of death for adolescents and young adults (AYAs).^{2,3} While most AYAs survive cancer, many experience significant life disruptions during treatment as well as for months or years after cessation of therapies. Emerging research and clinical care guidelines suggest that the medical and psychosocial needs of AYAs are distinct from those of younger children and older adults.^{4,5}

In this article, we define and distinguish the unique characteristics and needs of AYAs in treatment and survivorship, offer recommendations for clinical care, and conclude with an overview of research priorities for this unique age-defined population.

AYA DEFINED

Who are They?

Adolescent and young adult oncology is increasingly being recognized as a sub-specialty distinguishable from pediatric and adult oncology in terms of incidence,^{1,3,6} tumor types,⁷ psychosocial characteristics and health service needs.^{8,9} The age parameters are variously defined as extending from 15 years of age up to age 24,¹⁰ 29,¹¹ or 39-40 years.¹² These variations have implications for clinical care and the interpretation of AYA cancer research, particularly with regard to prevalence statistics and the diversity of tumor types across the AYA age-spectrum.¹³ For example, among 15 to 19 year olds, 82% of cancer cases are non-epithelial cancers (eg, central nervous system tumors, Hodgkin and non-Hodgkin lymphoma, leukemia, melanoma of the skin, testicular cancer), while among 45 to 49 year olds, 81% of cancer cases are epithelial cancers (eg, cervical, breast, thyroid, ovarian tumours).¹⁴ Cross-over from a predominance of non-epithelial to epithelial cancers occurs at approximately 30 years, but varies between the sexes, with females exhibiting a greater proportion of epithelial cancers approximately fifteen years earlier than males.¹⁴ Differing upper age limits between countries for AYAs therefore impacts which cancers are identified as being most prevalent.¹⁵ Recent global estimations indicate that new diagnoses of cancer occur at almost double the incidence rate among 30-39 year olds as compared with 15 to 29 year olds.¹

Evidence is growing that AYA cancers have unique biological characteristics differentiating them from cancers of the 'same' type occurring

in other age cohorts.^{6,16-19} For example, acute lymphoblastic leukemia and acute myelogenous leukemia diagnosed in AYAs exhibit "... either normal cytogenetics, yet-to-be-characterised (unknown) abnormalities, or other karyotypes that are rare in younger and older persons."^{17, p.5} Emerging findings about the biological differences between AYA cancers and those of other age groups have implications for AYA cancer research and therapeutic interventions.

Also critical for the characterization of AYAs with cancer is recognition of the life stage at which diagnosis occurs; a period of significant psychosocial development and maturation with regard to increasing autonomy and independence, identity development, greater responsibility for finances, peer relationships, emotional and sexual intimacy, education, careers, and self-sustaining employment.^{5,9,20} The cognitive and emotional capacities to express and explain themselves, make independent decisions, and comply with health recommendations are yet to be fully developed at this life stage.⁵ Coping with these typical developmental challenges complicates, and are complicated by, a cancer diagnosis and treatment in ways that differ from the experiences of younger children and older adults.^{4,8}

Distinguishing AYAs with Cancer and AYA Survivors of Childhood Cancer

Young people diagnosed with cancer as AYAs are distinguishable from young adult survivors of childhood cancer but are often combined in a single population group in clinical trials and observational studies, thus confounding analyses.^{21,22} Nonetheless, in a study of second primary malignancies, 57% occurred in survivors of AYA cancer, while 43% occurred in survivors of childhood cancers.²³ Additionally, AYA survivors of brain tumors have different concerns from AYA survivors of childhood brain tumors, including cognitive decline (versus failure to acquire cognitive skills) and a greater need to protect parents from worry.²⁴

MEDICAL, PSYCHOSOCIAL, AND BEHAVIORAL LATE EFFECTS

AYA survivors face a range of long-term medical and psychosocial late effects attributable to cancer type, treatment, and the effects of interrupted developmental processes upon cognitive and social outcomes. Well-known medical late effects

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