Principles and Recommendations for the Provision of Healthcare in Canada to Adolescent and Young Adult–Aged Cancer Patients and Survivors

Conrad Fernandez, MD,¹ Graeme A.M. Fraser, MD, MSc,² Carolyn Freeman, MBBS,³
Eva Grunfeld, MD, DPhil,⁴ Abha Gupta, MD, MSc,⁵ Leslie Stephen Mery, MSc,⁶
Sonja De Pauw, MSc,⁷ and Brent Schacter, MD,⁸ for the Canadian Task Force
on Adolescents and Young Adults with Cancer

Adolescents and young adults (AYA) with cancer and survivors of cancer in childhood, adolescence, and young adulthood are a constituency facing disparities of care affecting quality of life and other outcomes in many parts of the world. In Canada, this situation occurs in a nation with population-based cancer control programs and a government-funded healthcare system. The Canadian Task Force on Adolescents and Young Adults with Cancer was established in 2008 with a mission to ensure that AYA-aged Canadians with cancer and AYA survivors of cancer have prompt, equitable access to the best care, and to establish and support research to identify how their health outcomes and quality of life can be optimized. Following a survey of existing services, and in consultation with survivors, healthcare professionals, and policy makers, the Task Force identified principles of care, priority issues for research and the establishment of outcome metrics, and strategies for implementing change that are designed to improve the outcomes and quality of life of this specific cohort of patients and survivors with unique developmental needs. The six broad recommendations highlight the need for age-appropriate psychosocial, survivorship, palliative, and medical care as well as research to redress inequities in the care provided to this group relative to both younger and older cancer patients. Improved care for this group will enable individuals to reach their full potential as productive, functioning members of society, and will provide economic and other societal benefits.

Background

THE ADOLESCENT AND YOUNG ADULT (AYA) population has been recognized as an oncology group whose needs are not being adequately met by the conventional pediatric and adult healthcare systems.¹ This population, defined in this report as 15–29 years of age, has several distinct characteristics:

- AYA patients comprise a complex and diverse group with varying levels of developmental maturity, and consequentially unique and largely unmet clinical and psychosocial needs²
- While cancer is relatively uncommon among AYAs compared to older adults, its personal, societal, and socioeconomic impact is disproportionately greater^{3,4}
- Cancer in AYAs includes a broad spectrum of different tumor types from those occurring most frequently in children (i.e., non-epithelial) to those most frequent in adults (i.e., epithelial), requiring a correspondingly broad range of expertise for optimal management^{3,5}
- Over the past 30 years, survival of AYA patients has changed little or not at all compared with the substantial improvements seen in children and older adult cancer patients^{1,6}

¹Departments of Pediatrics and Bioethics, Dalhousie University and IWK Health Centre, Halifax, Nova Scotia, Canada.

²Department of Oncology, McMaster University, Juravinski Hospital and Cancer Centre, Hamilton, Ontario, Canada.

³Departments of Radiation Oncology and Pediatrics, McGill University Health Centre, Montreal, Québec, Canada.

⁴Ontario Institute for Cancer Research and Department of Family and Community Medicine, University of Toronto, Toronto, Ontario, Canada.

⁵Division of Hematology/Oncology, The Hospital for Sick Children, Toronto, Ontario, Canada.

⁶Chronic Disease Surveillance Division, Public Health Agency of Canada, Ottawa, Ontario, Canada.

⁷Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, Ontario, Canada.

⁸Department of Medical Oncology and Hematology, CancerCare Manitoba and University of Manitoba, Winnipeg, Manitoba, Canada.

- AYAs with cancer are largely understudied compared with both younger and older patients. Lack of opportunities for participation in clinical trials, studies examining late effects of therapy, and tissue banking for translational research have all impeded progress in this population⁷

The consequences of these unique features are outlined below and form the basis of this report and its recommendations, which consider both those diagnosed with cancer aged 15–29 and those aged 15–29 who are survivors of childhood cancers. The Task Force recognizes that these age limits vary in the AYA literature and that for purposes of implementing the recommendations broader age ranges may be considered.

Justification for change stems from the recognition that deficiencies in the care provided to AYAs with cancer result in long-term adverse health and social consequences, an increased burden on the healthcare system, and an overall loss of productivity. The economic burden to individuals, families, and society is considerable given the life expectancy of patients in this age group. Improvements in outcomes have the potential for profound societal benefit in terms of reduction in years-of-life lost and avoidance of morbidity that would interfere with full participation in society.

Although specific AYA cancer programs have been developed in many countries (most notably in the United Kingdom, the United States, and Australia), these have not been rigorously and systematically evaluated.⁸ Consequently, an optimal AYA model of care has not been defined and the evidence supporting recommendations for active therapy and supportive healthcare delivery specifically remain primarily at the level of expert opinion. However, there is near-global consensus with respect to recognition of current gaps in care, and of the basic components and guiding principles of care required for this population.^{1,8–10} Within the Canadian context, issues such as variability in local and provincial healthcare funding priorities and challenges associated with healthcare provision to urban versus rural populations render it unlikely that a single model of care would be broadly applicable across all jurisdictions. Individual cancer programs and healthcare providers must therefore instead apply guiding principles to develop appropriate local strategies to care for AYA cancer patients with the aim of improving health-related quality of life and survival. It is important to acknowledge that different models of AYA care will inevitably need to be adopted by different Canadian regions as appropriate for their context. It is also important that rigorous program evaluation is incorporated into the development of AYA cancer care initiatives. Moreover, AYA-specific care must be considered in the context of a broader healthcare system with finite resources and thus should be evaluated with respect to identifying positive outcomes for this population without detracting from other priorities.

To better understand these issues, the Canadian Task Force on Adolescents and Young Adults with Cancer was established in 2008. The Task Force is an initiative of C¹⁷ (comprised of the directors of pediatric oncology centers in Canada) and the Canadian Partnership Against Cancer, an entity at arm's length from but funded by the federal government. The Task Force has brought together a broad range of stakeholders and is focused on delivering a set of

comprehensive recommendations for implementing solutions to the issues identified.

In March 2010, a workshop was held to examine priorities. Six themes were identified as critical to advancing the care of AYAs with cancer: (1) active therapy and supportive care; (2) psychosocial needs; (3) palliation and symptom management; (4) survivorship; (5) research and metrics; and (6) awareness and advocacy. Discussions at the workshop, in addition to supporting material, have been used to formulate the recommendations included in this report. The proceedings of this event are in press.¹¹

Recommendations

1. Active therapy and supportive care

Recommendation: Services must be provided to address the unique needs of AYAs with cancer and survivors of cancer in childhood, adolescence, and young adulthood in order to redress inequities in the care provided to this group relative to both younger and older cancer patients.

In the context of active therapy and supportive healthcare delivery to Canadian cancer patients, a dichotomy currently exists: pediatric patients are treated at regional tertiary care centers according to a family-centered model, whereas adult patients are variably cared for within academic and community centers according to a disease-focused model of care. AYA cancer patients fall in the gap between these two organizational structures in the sense that they often share features of both pediatric and adult populations. Many of their care priorities and needs are unique and not adequately met within either care model.^{3,12} Furthermore, communication and collaboration between pediatric and adult healthcare providers is at best well-intentioned but far too limited, and at worst strained by competing interests, priorities, and resources. As a result, the care provided to AYA patients is often fragmented, poorly coordinated, and characterized by delays in diagnosis, poor accrual to appropriate clinical trials, and insufficient access to age-appropriate supportive care and psychosocial resources.^{1,3,8,12–16} Priority areas for intervention include:

- 1.1 Given the disproportionately long delays for AYA cancer diagnosis and treatment, improved access to age- and disease-specific expertise and appropriate supportive care and monitoring is required.
- 1.2 Age-appropriate care should be delivered and/or supported by interdisciplinary teams populated with age- and disease-specific medical and psychosocial experts able to effectively communicate and provide evidence-based care, including age-appropriate and developmentally appropriate supportive and psychosocial care.
- 1.3 Whenever possible, patients should be cared for in dedicated, purpose-designed, and appropriately resourced in-patient and out-patient environments to facilitate interdisciplinary care, reduce patient isolation, and encourage peer support; a variety of models have been used to achieve this aim.
- 1.4 AYA cancer patients must be recognized as a special population at a critical developmental stage between childhood dependency and adult independence. Systems should be in place to ensure interdisciplinary collaboration, coordination, and transition between

pediatric and adult healthcare providers, and to develop and promote linkages with relevant community-based resources.

- 1.5 Opportunities for AYAs with cancer to participate in appropriate clinical research trials must be increased and such patients should be offered entry into any appropriate clinical research trial for which they are eligible.
- 1.6 Patients not participating in clinical trials should be treated under the care of clinicians with age- and disease-specific expertise (hematologist, medical/radiation/surgical oncologist) according to established evidence-based treatment protocols.
- 1.7 Fertility risks and options for considering or not considering fertility preservation must be discussed with each patient.

2. Psychosocial needs

Recommendation: AYAs with cancer have unique psychosocial needs that must be met to enable each one to reach their full potential as productive, functioning members of society.

Providing optimal care for AYAs with cancer requires an appreciation for psychosocial elements in the dynamic developmental period from adolescence through young adulthood. The diagnosis and treatment of cancer in this age group may have a significant impact on quality of life, productivity, social and family relationships, cognitive functioning, and other aspects of development long after treatment completion.^{1,4,5,17} Developmental tasks of young adulthood—including establishing meaningful relationships, completing higher education, becoming financially independent, and developing an autonomous identity—can be disrupted or delayed. AYA patients experience distress, anxiety, and depression, and require psychosocial and supportive care expertise. Appropriate age-specific communication skills and tools are critical. Priority areas for intervention include:

- 2.1 Implementation of routine psychosocial screening of AYAs at diagnosis and intervals throughout the illness trajectory to provide opportunities for early or prophylactic intervention.
- 2.2 The interdisciplinary team should have access to experts in AYA psychosocial care and their services should be offered to all patients and their families.
- 2.3 Local and community resources—including live, Internet-based, and school-based support groups and social media containing age- and disease-specific information—should be identified, compiled, and made readily available to all AYA patients and survivors.
- 2.4 Clinical team meetings should be inclusive and interdisciplinary to ensure optimal care.

3. Palliation and symptom management

Recommendation: The challenge of providing palliative care to AYA patients who have unique needs related to their developmental stage must be addressed.

The practical, emotional, and social needs of AYA patients with a terminal illness are typically very complex, and vary

significantly depending on each patient's level of maturity and independence.¹⁸ This requires the services of an interdisciplinary palliative care team with training in the needs of AYA patients.^{19,20} Peer support is crucially important at this stage of life. Isolation from peers at school, at work, or in the community may be a major issue for AYA patients. Facilitating peer interaction is therefore an extremely important aspect of their care. Well-managed death should relieve physical and emotional suffering, allowing the patient to be comfortable and enjoy connections with family and friends to the end of life. Optimizing home-based care support will facilitate sustaining these relationships in a natural setting.²¹ It is expected that if the patient and family are well supported, there will be less long-term comorbidity for the family and caregivers. Priority areas for intervention include:

- 3.1 World Health Organization guidelines should be used to develop Canadian standards for palliative care in AYA patients.
- 3.2 The palliative care team should be involved early to help manage significant symptoms that may not be associated with imminent death.
- 3.3 An AYA-specific screening tool should be developed to detect increased anxiety and new medical concerns and to help initiate discussions about death and dying and palliative care.
- 3.4 AYA-specific interdisciplinary palliative care teams should be established throughout Canada; these teams should be flexible and able to work in both pediatric and adult facilities, as well as in a virtual environment to support patients being cared for in smaller communities or at home.
- 3.5 Physical facilities in hospices and hospitals should be developed to meet the unique needs of terminally ill AYA patients.
- 3.6 Out-of-hospital support for palliative and end-of-life care should be developed by changing legislation, such as that related to palliative and compassionate care benefits.

4. Survivorship

Recommendation: Implementation of life-long monitoring and follow-up of survivors of cancer in childhood, adolescence, and young adulthood will provide economic and other societal benefits and help mitigate late- or long-term treatment effects.

The 5-year overall survival rate for AYAs with cancer in Canada is over 80%.⁵ However, approximately one-third of survivors will experience serious late- or long-term effects from their treatment.²² For this reason, cancer survivorship is a unique phase in the cancer trajectory that is as relevant for AYAs with cancer as for survivors of childhood cancers. This survivorship phase warrants consideration of the clinical (side effects, late effects, and general medical and preventive healthcare), health system, and population health domains.^{23,24} The challenge of providing quality evidence-based care to AYA cancer survivors is made more acute by a number of factors, including their wide age range spanning important lifecycle changes during the survivorship period; the paucity of research specific to this population; the relatively small number of cases; and the lack of formal survivorship follow-up

guidelines for survivors of AYA cancer, including mechanisms to support compliance with follow-up care. Ironically, one of the challenges stems from the fact that AYA and childhood cancer survivors are typically asymptomatic at the time of transition from active treatment to survivorship and hence may not perceive a need for formal interaction with the healthcare system.²² Moreover, AYA and childhood cancer survivors are unlikely to be sufficiently knowledgeable about their disease, treatment, or risks of late effects.²⁵ The need for information about these factors may only become manifest years after completing primary cancer treatment, by which time the patient may have lost contact with their cancer care providers. While these factors are relevant to cancer survivors of all ages, each factor is far more likely to pertain to AYAs because of their life stage and developmental maturity at the time of active cancer treatment. Priority areas for intervention include:

- 4.1 Discussion and education about the survivorship phase should begin during active treatment to prepare the patient and family for the transition to survivorship; this must include discussion of potential long-term and late effects of treatment.
- 4.2 Every AYA cancer survivor should be provided with a record to facilitate transition.
 - 4.2.1 This record should summarize information about the tumor and the treatment given, surveillance-related issues (the risks of recurrence, possible long-term effects, late effects, and recommended follow-up visits and tests), general medical and preventive healthcare, rehabilitation opportunities (educational, occupational, and financial), and other relevant psychosocial factors.
 - 4.2.2 This record should be in a format and medium that allows it to be accessed by the survivor and the survivor's healthcare providers when needed (which may be many years after the end of treatment) and kept updated when new knowledge becomes available.
 - 4.2.3 As Internet-based formats are ideal mechanisms to store, update, and make accessible these transition records, healthcare institutions providing care to AYA cancer survivors should consider it part of their healthcare delivery responsibility to ensure the availability and maintenance of these Internet-based transition records (akin to their obligation to store and have accessible patient medical records).
- 4.3 Healthcare services and survivorship follow-up guidelines should be available to provide quality evidence-based long-term follow-up care for AYA cancer survivors; these healthcare services should be risk-stratified, considerate of patient needs and preferences, and easily integrated into the local healthcare delivery system.
- 4.4 Rehabilitation services should be available to provide quality evidence-based services meeting the range of AYA cancer survivors' rehabilitation needs (including physical, psychosocial, occupational, and educational).

5. Research and metrics

Recommendation: Research and the establishment of outcome metrics are required to investigate issues critical to

AYAs with cancer and survivors of cancer in childhood, adolescence, and young adulthood in order to target interventions and healthcare policy to improve all phases of the cancer journey.

The development of AYA oncology specialty care as a specific program of health requires ongoing research that will serve several purposes. Significant achievements to date have included an emerging understanding of the relative gap in outcome improvement for this population, baseline international comparisons of outcomes, and a preliminary description of the relative impact of pediatric versus adult protocols and locus of care.^{16,26–30}

Ongoing evaluative measures will need to be comprehensive yet flexible to measure process and outcomes in a manner that supports national comparisons demonstrating excellence and positive outcomes for the AYA population within the broader healthcare system. Research and metrics should support traditional clinical measures of outcome such as event-free survival and measures of quality of life and satisfaction. In addition, process and program assessments should compare resource utilization and service evaluation across the spectrum of AYA needs and against multiple other disease states within and beyond cancer care.^{13,31,32} The full spectrum of AYA-specific oncology healthcare should be measured from active care to either palliation or survivorship. Evaluation should address the priority research areas listed below as each of these is essential in understanding the full scope of AYA needs and points of potential intervention. Moreover, because the AYA population encompasses a heterogeneous group of diseases, biological maturation, psychosocial needs, and educational achievement,^{2,15,26,33–36} any research and metrics must allow for these differences while at the same time responding to multiple potential stakeholders (patients, survivors, families, healthcare providers, and government funders and planners). Synthesis of existing AYA research will be essential to establish a baseline upon which to conduct further study. Priority areas for AYA research include:

- 5.1 Epidemiological assessment of prevalence and incidence trends.
- 5.2 Assessment of prevention and screening programs on the incidence and outcomes of AYA-related cancers and cancer risk behaviors.
- 5.3 Investigation into factors contributing to the lack of timely access of AYA patients to care.
- 5.4 Formal evaluation of locus of care in supporting excellent outcomes, including determinants of current patterns of referral and practice, and by multifaceted assessments of quality of care.
- 5.5 Assessment of determinants of AYA patients' access to clinical trials, the study of tumor biology, and translational research.
- 5.6 Development of tools to identify AYA patients at high risk of, or experiencing, psychosocial distress from diagnosis to survivorship or palliative care.
- 5.7 Development of consensus for cross-program utilization of ideal patient-reported outcome instruments to measure health-related quality of life.
- 5.8 Measurement of the adequacy and effectiveness of AYA palliative care.
- 5.9 Systematic, validated evaluation of the sustainability of AYA programs.

- 5.10 Systematic evaluation of survivors of childhood and AYA cancer with respect to healthcare utilization, health-related quality of life, transitions of care, compliance with monitoring guidelines, reduction efforts in late morbidity and mortality, and enhanced implementation of survivor care plans.

6. Awareness and advocacy

Recommendation: Awareness of issues specific to AYAs with cancer must be improved and advocacy efforts to increase awareness and advocate for change must be nurtured.

It is apparent that the needs of AYAs with cancer have been largely unrecognized, and consequently there is a need to raise awareness and advocate for change. Increased awareness of the clinical and psychosocial needs that are particular and pertinent to AYAs is especially important.^{1,37} This work needs to be undertaken within and among the realms of all stakeholders, including the AYA cancer patient population, family and community support systems, health professionals, policy makers, the general population, and voluntary/non-profit and advocacy groups.³⁸

Building awareness requires taking several steps. The first is to clarify the message, the second is to identify the key stakeholders, and the third is to disseminate the information. Key messages that should be addressed in awareness campaigns include:

- Cancer does occur in this age group.
- There are biomedical and clinical differences associated with the spectrum of cancers in this age group.
- There are psychosocial differences associated with the transition from pediatric to adult life.
- There are psychosocial and behavioral differences associated with passage through the developmental stages of adolescence and young adulthood.

Engaging with stakeholder groups can stimulate those most responsible for advocating on behalf of AYAs and help assure transfer of knowledge into action. The advocacy movement for AYA cancer survivors has gained momentum internationally, and has become more organized both publicly and professionally. The best examples of this are the Teenage Cancer Trust, organized in the United Kingdom during the early 1990s;^{9,39} the LIVESTRONG Young Adult Alliance of the Lance Armstrong Foundation;⁴⁰ and the International Charter of Rights for Young People with Cancer.⁴¹ In Canada, groups such as Young Adult Cancer Canada are working in this area and need support.⁴² These models and others may inspire efforts to support solutions tailored to regions where needs exist. Priority areas for intervention include:

- 6.1 Develop awareness and advocacy strategies centered on implementing the recommendations made in this report.
- 6.2 Encourage collaboration among stakeholders to reinforce and effectively carry the message forward.
- 6.3 Awareness and advocacy should lead to sustainable policies and programs; the broader healthcare system has finite resources and efforts should focus on positive outcomes for this population without detracting from other priorities.

Conclusions

The recommendations—focusing on improvements to the provision of healthcare for AYA-aged cancer patients and survivors in Canada—reflect the consensus of evidence and expert opinion that was presented and discussed at the Canadian Task Force on Adolescents and Young Adults with Cancer Workshop in March 2010.¹¹ The deliberations at the workshop coalesced into six themes that were identified as being absolutely essential to address in order to improve and enhance AYA care. These are: active therapy and supportive care, psychosocial needs, palliation and symptom management, survivorship, research and metrics, and awareness and advocacy.

The recommendations made are intended to address the gaps and deficiencies in care that have stalled improvement in outcomes for this group of patients as compared with children or older adults. There is an urgent need to redress existing inequities, to relieve the burden on patients and families, and to reduce economic and social costs. While the AYA group is not large relative to the number of older adult cancer patients, improved care and enhanced survival is essential to enhance the quality of life of these individuals, resulting in fewer long-term and late complications and translating into large gains in years of life saved in the future. The recommendations made will enable Canadians to design programs and models of care that reflect and respect local needs and constraints, to build upon experience in other jurisdictions, and to allow for evaluation of the impact of changes made to existing systems. The systematic assessment of broad AYA oncology patient outcomes in a manner that will allow national comparisons and evaluations is essential to advancing excellence of care for these patients and should be situated in formal research of individual patients, provincial programs, and national AYA strategies.

The AYA Task Force strongly endorses the recommendations made and believes it is critically important to carefully review the recommendations and then plan and implement system changes and enhancements in order to improve cancer care and control for AYAs and, in the larger context, for cancer control as a whole.

Acknowledgments

Production of this report has been made possible through a financial contribution from Health Canada through the Canadian Partnership Against Cancer, and through the support of the C¹⁷Council, the national network of Canadian pediatric hematology/oncology programs. The Canadian Partnership Against Cancer is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. The authors acknowledge with thanks the important contributions Cynthia Ackland and all members of the Canadian Task Force on Adolescents and Young Adults with Cancer made to the production of this body of work, including this publication.

Disclaimer

The views expressed herein represent the views of the Canadian Task Force on Adolescents and Young Adults with Cancer. Dr. Grunfeld is supported by a clinician scientist award from the Ontario Institute for Cancer Research (OICR)

with funds from the Ontario Ministry of Research and Innovation. The research is independent and no endorsement by OICR is intended or should be inferred.

Disclosure Statement

No competing financial interests exist for any of the authors.

References

1. Adolescent and Young Adult Oncology Progress Review Group. Closing the gap: research and care imperatives for adolescents and young adults with cancer (NIH Publication No. 06-6067). Bethesda, MD: Department of Health and Human Services, National Institutes of Health, National Cancer Institute, and the LIVESTRONG Young Adult Alliance; 2006.
2. Bleyer A. Young adult oncology: the patients and their survival challenges. *CA Cancer J Clin*. 2007;57:242–255.
3. De P, Ellison LF, Barr RD, *et al*. Canadian adolescents and young adults with cancer: opportunity to improve coordination and level of care. *CMAJ*. 2011;183:E187–E194.
4. Eiser C, Kuperberg A. Psychological Support. In: *Cancer in Adolescents and Young Adults*. Bleyer WA, Barr RD (Eds); Heidelberg, Germany: Springer-Verlag; 2007; pp. 365–373.
5. Canadian Cancer Society. Canadian cancer statistics 2009. Toronto, Canada: Canadian Cancer Society; 2009.
6. Bleyer A, O'Leary M, Barr R, Ries LAG. Cancer epidemiology in older adolescents and young adults 15 to 29 years of age, including SEER incidence and survival: 1975–2000 (NIH Pub. No. 06-5767). Bethesda, MD: National Cancer Institute; 2006.
7. Bleyer A, Budd T, Montello M. Adolescents and young adults with cancer: the scope of the problem and criticality of clinical trials. *Cancer*. 2006;107:1645–1655.
8. Ferrari A, Thomas D, Franklin AR, *et al*. Starting an adolescent and young adult oncology program: some success stories and some obstacles to overcome. *J Clin Oncol*. 2010;28:4850–4857.
9. National Institute for Health and Clinical Excellence. Improving outcomes in children and young people with cancer. London, United Kingdom; August 2005. Accessed August 28, 2005 from: <http://guidance.nice.org.uk/CSGCYP/Guidance/pdf/English>
10. Zebrack B, Mathews-Bradshaw B, Siegel S. Quality cancer care for adolescents and young adults: a position statement. *J Clin Oncol*. 2010;28:4862–4867.
11. Barr RD, Rogers P, Schacter B (Eds). Supplement: adolescents and young adults with cancer: towards better outcomes in Canada. *Cancer*. 2011;117(Suppl 10):i–ii, 2239–2354.
12. Fernandez CV, Barr RD. Adolescents and young adults with cancer: an orphaned population. *Paediatr Child Health*. 2006;11:103–106.
13. Zebrack B, Bleyer A, Albritton K, *et al*. Assessing the health care needs of adolescent and young adult cancer patients and survivors. *Cancer*. 2006;107:2915–2923.
14. The Canadian Childhood Cancer Surveillance and Control Program. Diagnosis and initial treatment of cancer in Canadian adolescents 15 to 19 years of age, 1995–2000. Ottawa: Health Canada; 2004. Accessed January 15, 2011 from: www.phac-aspc.gc.ca/publicat/ditcca-dticca/pdf/ditcca-dticca-eng.pdf
15. Burke ME, Albritton K, Marina N. Challenges in the recruitment of adolescents and young adults to cancer clinical trials. *Cancer*. 2007;110:2385–2393.
16. Ferrari A, Montello M, Budd T, *et al*. The challenges of clinical trials for adolescents and young adults with cancer. *Pediatr Blood Cancer*. 2008;50:1101–1104.
17. Zebrack B, Chesler MA, Kaplan S. To foster healing among adolescents and young adults with cancer: what helps? What hurts? *Support Care Cancer*. 2010;18:131–135.
18. Edwards J. A model of palliative care for the adolescent with cancer. *Int J Palliat Nurs*. 2001;7:485–488.
19. Wein S, Pery S, Zer A. Role of palliative care in adolescent and young adult oncology. *J Clin Oncol*. 2010;28:4819–4824.
20. World Health Organization. WHO definition of palliative care. Accessed August 17, 2010 from: www.who.int/cancer/palliative/definition/en
21. Tang ST, McCorkle R. Determinants of place of death for terminal cancer patients. *Cancer Invest*. 2001;19:165–180.
22. Hudson MM, Oeffinger KC. Future Health of Survivors of Adolescent and Young Adult Cancer. In: *Cancer in Adolescents and Young Adults*. Bleyer WA, Barr RD (Eds). Heidelberg, Germany: Springer-Verlag; 2007; pp. 451–467.
23. Hewitt M, Greenfield S, Stovall E (Eds). From cancer patient to cancer survivor: lost in transition. Washington, DC: National Academies Press; 2006.
24. Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 3.0. Arcadia, CA: Children's Oncology Group; 2008.
25. Kadan-Lottick NS, Robison LL, Gurney JG, *et al*. Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood Cancer Survivor Study. *JAMA*. 2002;287:1832–1839.
26. Bleyer A, Barr R, Hayes-Lattin B, *et al*. The distinctive biology of cancer in adolescents and young adults. *Nat Rev Cancer*. 2008;8:288–298.
27. Martin S, Ulrich C, Munsell M, *et al*. Delays in cancer diagnosis in underinsured young adults and older adolescents. *Oncologist*. 2007;12:816–824.
28. Bleyer WA. Cancer in older adolescents and young adults: epidemiology, diagnosis, treatment, survival, and importance of clinical trials. *Med Pediatr Oncol*. 2002;38:1–10.
29. Nachman JB, La MK, Hunger SP, *et al*. Young adults with acute lymphoblastic leukemia have an excellent outcome with chemotherapy alone and benefit from intensive post-induction treatment: a report from the Children's Oncology Group. *J Clin Oncol*. 2009;27:5189–5194.
30. Nachman J, Sather HN, Buckley JD, *et al*. Young adults 16–21 years of age at diagnosis entered on Children's Cancer Group acute lymphoblastic leukemia and acute myeloblastic leukemia protocols: results of treatment. *Cancer*. 1993;71(10 Suppl):3377–3385.
31. Albritton KH, Wiggins CH, Nelson HE, *et al*. Site of oncologic specialty care for older adolescents in Utah. *J Clin Oncol*. 2007;25:4616–4621.
32. Thomas DM, Albritton KH, Ferrari A. Adolescent and young adult oncology: an emerging field. *J Clin Oncol*. 28: 4781–4782.
33. Scott JT, Harmsen M, Prictor MJ, *et al*. Interventions for improving communication with children and adolescents about their cancer. *Cochrane Database Syst Rev*. 2003: CD002969.
34. Ferrari A, Bleyer A. Participation of adolescents with cancer in clinical trials. *Cancer Treat Rev*. 2007;33:603–608.

35. Herzog CE. Overview of sarcomas in the adolescent and young adult population. *J Pediatr Hematol Oncol*. 2005; 27:215–218.
 36. Ferrari S, Palmerini E, Staals E, *et al*. Sex- and age-related chemotherapy toxicity in patients with non-metastatic osteosarcoma. *J Chemother*. 2009;21:205–210.
 37. McGoldrick D, Neal C, Whiteson M. Advocacy and adolescent/young adult cancer survivors. *Pediatr Blood Cancer*. 2008;50:1109–1111.
 38. Bleyer WA, Albritton K, Siegel S, *et al*. Challenges and Opportunities—The Way Forward. In: *Cancer in Adolescents and Young Adults (Pediatric Oncology)*. Bleyer A, Barr R (Eds); Heidelberg, Germany: Springer-Verlag; 2007; pp. 505–517.
 39. McGoldrick D, Gordon P, Whiteson M, *et al*. Awareness and advocacy for adolescents and young adults with cancer. *Cancer*. 2011;117:2311–2315.
 40. LIVESTRONG Young Adult Alliance. Lance Armstrong Foundation. Accessed January 3, 2011 from: www.livestrong.org/yaa
 41. International Charter of Rights for Young People. Accessed January 26, 2011 from: www.cancercharter.org/about.html
 42. Young Adult Cancer Canada. Accessed January 4, 2011 from: www.youngadultcancer.ca
- Address correspondence to:
Brent Schacter, MD
Department of Medical Oncology and Hematology
CancerCare Manitoba and University of Manitoba
2055—675 McDermot Avenue
Winnipeg, Manitoba R3E 0V9
Canada
E-mail: brent.schacter@cancercare.mb.ca