

# Adolescent and young adult cancer: principles of care

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## ABSTRACT

Adolescents and young adults (AYAs) with cancer in active treatment face a number of barriers to optimal care. In the present article, we focus on the 3 critical domains of care for AYAs—medical, psychosocial, and research—and how changes to the system could overcome barriers. We summarize the current literature, outline recommended principles of care, raise awareness of barriers to optimal care, and suggest specific changes to the system to overcome those barriers in the Canadian context. Many of the recommendations can nevertheless be applied universally. These recommendations are endorsed by the Canadian Task Force on Adolescents and Young Adults with Cancer and build on outcomes from two international workshops held by that group.

**Key Words** Adolescents, young adults

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## INTRODUCTION

Although the body of evidence about the barriers that adolescents and young adults (AYAs) with cancer face as survivors is growing, there is a paucity of evidence about barriers faced by AYAs receiving active cancer care, with most existing studies being qualitative. In the present article, we summarize the available current literature, outline recommended principles of care, raise awareness of barriers to optimal care, and suggest specific changes to the system to overcome those barriers in the Canadian context. The recommendations are endorsed by the Canadian Task Force on Adolescents and Young Adults with Cancer and build on outcomes from two international workshops held by that group in 2010<sup>1</sup> and 2012<sup>2</sup>.

Canada is a large country, with regionalized health care and urban, rural, and remote areas. The optimal ways to improve the system, and the resources to do so, will vary between the regions. Nevertheless, AYAs with cancer in Canada and abroad appear to have many needs in common. Critical domains of care for AYAs include the medical, psychosocial, and research domains. In Canada, the already existing regional action partnerships (RAPs) of the Canadian Task Force on Adolescents and Young Adults with Cancer are well placed to implement principles of care and to disseminate knowledge at a local level. The RAPs can also share their experiences and effective strategies with other provinces.

## METHODS

Existing guidance documents were identified and reviewed, including documents from the United Kingdom's Teenage Cancer Trust, Cancer Australia, the U.S. National Comprehensive Cancer Network, and the U.S. National Cancer Institute's Adolescent and Young Adult Oncology Progress Review Group. Four systematic searches—for topics in the medical, psychosocial, social, and system areas—were carried out in Ovid for English-language publications between 2009 and 2014. All four searches used the keywords “cancer,” “neoplasm,” “carcinoma,” “malignant,” “tumor,” “adolescent,” and “young adult,” together with between 9 and 16 additional keywords specific to each of the searches.

The searches yielded 3475 citations in total, whose abstracts were reviewed by the 8 group members. After a review of the 562 articles chosen based on their abstracts, the number of relevant articles selected from each search was, by topic area, 94 medical, 155 psychosocial, 22 social, and 124 system ( $n = 395$ ). Those articles were then reviewed to assign them to one of the 3 critical domains of AYA care and to possible system changes, forming the basis for the present guidance document (Figure 1).

<sup>a</sup> A complete list of Task Force members can be found at [http://www.cancerview.ca/cv/portal/Home/TreatmentAndSupport/TSPProfessionals/PersonCentredPerspective/AYAcancer\\_ca/AboutUs](http://www.cancerview.ca/cv/portal/Home/TreatmentAndSupport/TSPProfessionals/PersonCentredPerspective/AYAcancer_ca/AboutUs).

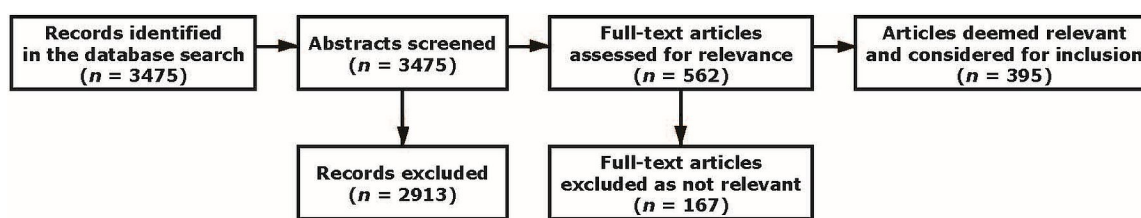


FIGURE 1 Flow diagram of the literature review.

## Medical Issues

Falling as they do between the well-established programs of pediatric and adult oncology, AYA cancer patients are inherently at risk of receiving suboptimal medical care. Cancer awareness in this age group is notably low<sup>3</sup>, and diagnosis can be delayed because of a low pre-test probability of cancer<sup>4</sup>. Referring physicians undoubtedly experience uncertainty about where best to send these patients, but that uncertainty is not well-documented in the literature.

In this age group, the diagnosed cancers span the spectrum from “pediatric” to “adult,” creating challenges for the treating oncologists specializing in one discipline or the other. The AYA patients treated in pediatric centres start treatment sooner and are more likely to enter a clinical trial<sup>5</sup>, but literature about whether AYA patients receive the best available therapy (however that might be defined) or experience different outcomes depending on the type of treatment centre is lacking. That such patients should have lifelong medical support is widely accepted, but how to implement that support remains a topic of debate<sup>6</sup>.

The fertility concerns of AYA cancer patients while on therapy and after therapy discontinuation have been documented to be one of the major causes for their anxiety<sup>7–11</sup>. Chemotherapy and radiotherapy can be gonadotoxic, resulting in impaired fertility<sup>12–14</sup>. Risk factors for impaired fertility correlate with site and dose of radiotherapy and the type and intensity of chemotherapy, with alkylating drugs and the disease being the most researched topics<sup>12–14</sup>. Impaired fertility requires discussion and consideration for fertility preservation referral, by the AYA health care professionals, at the time of the patient’s diagnosis, before the onset of therapy, and again later in the post-therapy period<sup>14</sup>. Reluctance on the part of health care professionals to discuss impaired fertility in AYAs is well documented<sup>7,8,11,12</sup>. The American Society of Clinical Oncology published specific practice guidelines in 2006 and updated them in 2013<sup>14</sup>. The guidelines were based on a review of 222 publications. A current approach to the assessment and discussion of fertility is presented in their Table 1.

In the Canadian context, most provinces and cancer health care facilities do not have a formulated guideline or policy<sup>15,16</sup>. Fertility preservation is undertaken chiefly in the private sector. Thus, there is the added concern of cost, and whether fertility preservation for cancer patients should be funded by the public system has been a subject of debate. The Canadian Task Force on Adolescents and Young Adults with Cancer has established a working group to develop evidence-based recommendations

relevant for Canada—that is, a report describing best practices for fertility preservation; identification of patients whose fertility could be at risk; fertility-preserving procedures; referral processes; and development and provision of education for patients and health care providers, including sources of funding. Within Canada, further information can be obtained from the Oncofertility Referral Network (<http://www.cancerkn.com/oncofertility-referral-network/>) and the Adolescent and Young Adult Oncology Program at the Princess Margaret Cancer Centre ([http://www.uhn.ca/PrincessMargaret/PatientsFamilies/Clinics\\_Tests/Adolescent\\_Young\\_Adult\\_Oncology/](http://www.uhn.ca/PrincessMargaret/PatientsFamilies/Clinics_Tests/Adolescent_Young_Adult_Oncology/)).

## Psychosocial Issues

Cancer has a significant effect on the psychological well-being of AYAs, and many of their psychosocial needs remain unmet<sup>17,18</sup>. Compared with their healthy peers, AYAs with cancer are at higher risk of experiencing poor psychological well-being and distress that can last for many years after treatment<sup>19</sup>. Distress often manifests as acute episodes of sadness, anxiety, and frustration in response to disease-related events. Compared with age-related norms of functionality, impaired physical functioning strongly correlates with the mental and emotional well-being of AYAs<sup>19</sup>. Other clinically relevant mood triggers to assess for AYAs during treatment include loss of autonomy and associated guilt stemming from conflicting dependency and autonomy needs. Ties to interrupted studies or a career and to boredom and isolation can also prompt or exacerbate mood episodes. Repeated assessments are necessary to capture mood fluctuations and to screen for distress<sup>20</sup>. An international effort that includes members of the Canadian Task Force on Adolescents and Young Adults with Cancer is underway to develop an AYA-cancer-specific distress screening tool.

Changes in physical health because of cancer treatment—including weight changes, hair loss, scarring, infertility, and amputation—not only make AYAs with cancer feel different from their peers, but also represent frightening changes that can have an adverse effect on self-esteem and relationships with others<sup>21,22</sup>. Recent research suggests that young women who have limb-sparing surgeries might be most at risk for difficulties with sexual functioning and self-worth and thus should be targeted for intervention<sup>23</sup>. Common fears among AYAs with cancer include fear that the body will never return to its original appearance, fear of not being recognized by others, and fear of being mistaken for an individual of the opposite sex<sup>21</sup>. Those fears

can result in loss of sex appeal or even a distorted body image, making it difficult for AYAs with cancer to reach important relationship milestones such as dating and marriage<sup>22</sup>. It is important to create opportunities for AYAs to have open and frank discussions about their emerging sexual identity and practices, including use of contraception, unintended pregnancies, and sexually transmitted infections<sup>22</sup>.

Finally, the social effects of cancer must be considered within AYA care. Establishing peer and intimate relationships is a key developmental task; however, AYAs report negative effects of cancer on those relationships<sup>24</sup>. Oncology peer support is identified as significant for AYAs, and a review of AYA peer-support interventions encourages their establishment within AYA environments<sup>25</sup>. Peer support is also a significant correlate for reintegration into school after cancer treatment. Although most AYA patients return to school and work after treatment, most report a continuing effect on education and work outcomes up to 35 months after diagnosis<sup>26</sup>. Therefore, AYAs need assistance to facilitate connection with peers, and support to prepare for a successful transition back to school or work.

### Research Issues

Overall cancer cure rates have continued to rise since the mid-1980s, but the AYA cohort (15–39 years) has not shared in that success. The reasons for the lack of progress in improving AYA cure rates have been reported to be multifactorial<sup>27</sup>. Compared with older and younger cohorts, AYAs diagnosed with cancer enrol into clinical trial at low rates, which is an important contributing factor, because improved cure rates correlate directly with improved rates of clinical trial enrolment<sup>28</sup>. In Canada, 30% of pediatric oncology patients are entered into clinical trials<sup>29</sup>; however, enrolment drops to 10% for patients 15–19 years of age, and declines to 1% for those 20–29<sup>30</sup>.

Several reasons—including both health care system factors and patient cohort factors—have been proposed for the observed decline in research participation within the AYA cohort. First, fewer clinical trials are available to the AYA cohort. The study age criterion might not include all of the AYA age range, and often, no studies are available for cancers diagnosed in the AYA cohort because of their relative rarity. Historically, cooperation between the pediatric clinical trial groups and the North American adult oncology intergroups has been lacking. Several Children's Oncology Group trials allow enrolment to 40 years of age, but because of regulatory issues, the challenges of opening such studies at adult centres are often limiting. Recently, adult centres in Canada have started accruing AYA patients to several Children's Oncology Group protocols, including those targeted to the AYA cohort. The establishment of an AYA program at one U.S. centre, with collaboration between the pediatric and adult oncology teams, increased clinical trial enrolment to 32% from 4%<sup>31</sup>.

Investigators have observed that patients in the AYA cohort often are ambivalent about clinical trial participation. The AYAs prefer to make choices about their therapy, which poses challenges to enrolment in randomized trials<sup>32,33</sup>. Members of the AYA cohort are progressing through challenging developmental stages, in which assertion of

independence is paramount. Participation in clinical trials could be perceived as a loss of control. The presentation and structure of clinical trials for the AYA cohort both have to consider the developmental needs of this age group.

In the AYA cohort, 5-year survival rates exceed 80%<sup>33</sup>. A better understanding of the survivorship experience in this age group informs transition-of-care models, medical and psychosocial patient support, and resource allocation. Survivorship research in the AYA cohort is challenging because of a high degree of residential mobility and because of lack of involvement with traditional primary care providers in their treatment and post-treatment journeys<sup>34</sup>. Two registries in Canada maintain survivorship information for the AYA cohort. The Childhood, Adolescent, Young Adult Cancer Survivorship population-based administrative database project is examining long-term outcomes in B.C. patients who were less than 25 years of age when they were diagnosed between the years 1970 and 2010<sup>35</sup>. The Pediatric Oncology Group of Ontario Networked Information System is a comprehensive database of children diagnosed with cancer in the province of Ontario, including information on clinical trial participation, but the data represent only individuals less than 18 years of age in Ontario who were treated in pediatric institutions (<http://www.pogo.ca/pogonis/>).

Several opportunities are available to increase clinical trial accrual in the AYA cohort in Canada:

- Greater collaboration between the NCIC and pediatric intergroups
- Recognition of clinical trial development in the AYA cohort as a strategic funding opportunity
- Development of AYA programs within provincial oncology treatment centres
- Improved linkage of national cancer data to allow for study of outcomes and survivorship in AYAs

The AYA cohort remains an underrepresented group in clinical research. To better define optimal management strategies for this group of patients, studies examining biology, optimal therapeutic approaches, and survivorship issues have to be further developed in Canada.

### Changes to the System to Facilitate AYA Oncology Care

Many of the barriers already discussed can be overcome with changes to the system. Some solutions, such as flexibility with appointment scheduling, likely require minimal or no additional cost, or could even save money in the long term. Other changes could require more planning and resources.

#### Age

Many Canadian pediatric institutions have a strict institutional age limit and will not treat newly diagnosed patients beyond that limit. Some pediatric institutions also transfer patients receiving active care to adult facilities once those patients reach the age limit. Institutions and governments should implement structural changes to ensure that care is provided at the institution that best meets the patient's needs regardless of age.

### **Geography**

Canada is a large country with a relatively sparse population and urban, rural, and remote areas. Quality of care should be equitable regardless of proximity to a specialized cancer centre. Possible solutions, such as satellite centres with easy access to experts in specialized centres and through telehealth consultations and Skype, could create more equitable care and reduce the number of trips that AYAs have to make to specialist centres.

### **Knowledge**

Care can be enhanced by improving communication, collaboration, and transfer of knowledge between pediatric and adult oncologists, oncologists and primary health care providers, oncologists and trainees, health care providers and patients (or parents), and between multidisciplinary team members. All health care providers have to be aware of the unique needs of AYA patients and should receive training that is adequate in helping to address those needs. Developing AYA oncology as a distinct subspecialist discipline within oncology will increase expertise in this area.

### **Research**

Poor accrual to clinical trials and insufficient access to AYA trials can be overcome by improving cooperation between pediatric and adult oncology clinical trial groups, expanding age eligibility criteria in clinical trials, and streamlining regulatory processes.

### **Physical Spaces**

Where possible, providing separate AYA space—either specific AYA units or designated space within other units—will allow for increased peer interaction and decreased isolation.

### **Finances**

Additional expenses such as medications, transport costs, and insurance coverage for AYAs are often less affordable. Governments would be well-advised to provide better health care benefits to this vulnerable group. After their illness, AYAs can find that insurance coverage is more difficult and expensive to obtain. They can also find it more difficult to gain employment or complete their education because of long-term sequelae from their cancer, side effects from its treatment, or concerns on the part of the employer or institution that health issues will interfere with productivity. The Successful Academic and Vocational Transition Initiative from the Pediatric Oncology Group of Ontario provides counsellors to assist AYAs in transitioning back to school, university, or employment. The counsellors provide career counselling, help with the job search, and facilitate communication with employers. Similar programs are needed throughout the country and have to be expanded to include young adults.

### **Community**

At a challenging developmental stage, AYAs with cancer face social isolation and changes in body image. Where possible, flexibility in the scheduling of appointments and treatments should be provided so that AYAs can attend important social events and continue with some school

activities, thus reducing their social isolation and potentially improving compliance. The use of technology such as Skype and social media to stay in touch with friends should be encouraged. Facilitating support groups so that AYAs with cancer can share their common experiences will help to provide peer support.

### **Psychology**

In AYAs battling cancer, levels of anxiety and depression increase<sup>36</sup>. The use of screening tools, with repeat assessments, will allow for earlier identification of, and intervention for, AYAs with those problems. Newer, easier-to-use screening tools specific for this population are in development.

### **Fertility**

Institutions should ensure that health care providers are aware of the latest fertility preservation options and that those options are offered to AYAs in a timely manner. Coordination between patients, the health care team, and fertility experts should be streamlined. All stakeholders should advocate for increased government funding for fertility preservation treatments so that such treatments are more accessible to all AYAs with cancer.

### **Communication or Information Delivery**

Communication should be age-appropriate so that AYAs can fully understand discussions.

### **Hospital**

Institutions should provide AYAs with hospital navigators to help them make their way through the hospital system. Whenever possible, home-based care should be facilitated, including in the palliative setting. Providing “one-stop shopping” by grouping services in a common area or at a common time will reduce the number of trips that AYAs must make to the hospital, which will improve compliance and appointment attendance.

### **Palliative Care**

Staff should be adequately trained to deal with the developmental needs and challenges in the AYA population. Providing separate spaces in palliative care units will allow AYAs to interact with their peers and reduce their sense of isolation.

## **CONCLUSIONS**

In Canada, provincial resources are variable. Each province should develop cost-effective strategies that are best suited to their population and should measure the effectiveness of the strategies implemented to ensure that the expected benefit is achieved. There may also be a role for federal leadership, with the federal minister of health guiding conversations about meeting the needs of the AYA cohort, using the RAP framework to define a national standard. Most of the evidence for the barriers faced by AYAs with cancer is at the level of expert opinion; very little quantitative evidence has been developed. As recommended changes are adopted, the current baseline has to be compared, using specific metrics, with the implemented change so as to demonstrate



the socioeconomic value of the change. Such research will ensure that finite resources are optimally used.

Key points highlighted here are that AYAS with cancer under active treatment face multiple barriers to optimal care. Increasing awareness about the types of barriers faced by this population is important. Changes to the system can ameliorate many of those barriers, and RAPS can facilitate change at a local level.

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#### CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare that we have none.

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