A Process for Change in the Care of Adolescents and Young Adults with Cancer in Canada. “Moving to Action”: The Second Canadian International Workshop. International Perspectives on AYA, Part 1

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The Canadian National Adolescent and Young Adult Cancer Task Force (NTF) held its second international workshop in Toronto during March 2012. The workshop's theme, “Moving to Action,” focused on implementing the NTF's recommendations, published previously in the *Journal of Adolescent and Young Adult Oncology*. Here we provide a review of the NTF's process of engagement and actions in order to advocate for and implement a change process in the care of AYA patients in Canada. The highlights of the second international workshop and components of the resulting “Framework for Action” are reported.

Keywords: Canadian Task Force, international workshop, change process, implementation

ADOLESCENTS AND YOUNG ADULTS (AYAs) with cancer have been recognized internationally as a population whose needs are not being adequately met during and after therapy by the conventional pediatric and adult healthcare systems.^{1,2} Their overall survival in Canada is excellent and comparable to that in other developed countries,^{3,4} but the delivery of care to AYAs is suboptimal.⁵ Furthermore, research on the biology of cancers in this age group is limited,⁶ and enrollment of AYAs on clinical trials in Canada is dismal, anecdotally approximating 1–2%, equivalent to the rates reported from the United Kingdom (UK)⁷ and the United States (US).⁸

The recognition of these deficiencies prompted an initiative from the consortium of children's cancer centers in Canada, otherwise known as C17. In 2008, the C17 executive committee approached the newly formed Canadian Partnership Against Cancer (CPAC), a federally-funded organization tasked with implementing a pan-Canadian strategy for cancer control. CPAC agreed that the AYA population was poorly served and understudied, and that organizing a national task force (NTF) to address these issues fell within its mandate. The NTF was formed with representation from different regions

within Canada, from multiple healthcare disciplines, and from the community of survivors and their advocates.

The initial objectives of the NTF were:

- To document current cancer care for AYAs in Canada with respect to their referral, diagnosis, treatment, psychological support, and follow-up after therapy, and to compile an inventory of organizations interested in AYA oncology.
- To ascertain existing transition models for the long-term follow-up of survivors of cancer in childhood when they attain adulthood.
- To establish recommendations for the provision of healthcare to AYAs with cancer, and to survivors of cancer as children or AYAs, in order to improve their overall outcomes and quality of life.
- To determine that the recommendations put forward to improve health outcomes for AYAs are implementable and sustainable within the Canadian healthcare environment, and to develop mechanisms to ensure the sustainability of efforts to improve the care of AYAs with cancer.

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- To develop effective lines of communication between pediatric and adult healthcare providers and other influential parties to promote continuing improvement in the healthcare provided to AYAs with cancer and to AYA-aged survivors of cancer.
- To identify research priorities related to cancer in AYAs.
- To design educational programs for AYA cancer care.

Working groups were established to address these objectives. An early undertaking was a national survey of the status of AYA care. The results of that study, previously published in this journal,⁵ identified the inconsistencies and deficiencies of care across Canada. This and other findings stimulated the convening of an international workshop held in Toronto in March 2010, attended by an invited cross-section of 100 healthcare professionals, administrators, survivors, advocates, and international content experts. The proceedings of this workshop were published⁹ and laid the foundation for a set of recommendations pertinent to the Canadian context.¹⁰

These recommendations were:

- *Active therapy and supportive care:* Services must be provided to address the distinct needs of AYAs with cancer and survivors of cancer in childhood, adolescence, and young adulthood in order to redress inequities in care provided to this group compared to both younger and older cancer patients.
- *Psychosocial needs:* AYAs with cancer have particular psychosocial needs that must be met to enable each of them to reach their full potential as productive members of society.
- *Palliation and symptom management:* The challenge of providing palliative care to AYA patients who have special needs related to their developmental stage must be addressed.
- *Survivorship:* 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.
- *Research and metrics:* 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.
- *Awareness and advocacy:* Enhanced awareness of issues specific to AYAs with cancer must be achieved and advocacy for change must be nurtured.

These recommendations and related discussions were published in this journal.¹⁰ A communications strategy for the dissemination of these recommendations is currently active with numerous presentations at national and international conferences, meetings with key stakeholders and institutions, and further involvement of survivors.

This led to the organization of a second international workshop, held in Toronto during March 2012. The theme of this workshop was "Moving to Action." The overarching purpose of the workshop was to develop a comprehensive Framework for implementation of the recommendations derived from the preceding workshop in 2010. International experts in AYA oncology from Australia, Italy, the UK, and

the US were invited to present their experiences and models of care. Articles based on these presentations will be published as Parts 2–5 of the *International Perspectives on AYAO* series in this journal. Discussion was held on the components of their experiences that could be applicable to the Canadian context, especially as related to the vast geographical distances existing in this country. As with the first workshop, relevant stakeholders who had influence on decision making within regional jurisdictions and institutions across Canada were invited, along with strong representation from the survivor community.

A draft Framework was provided to delegates to use during discussion in the breakout groups, which were charged with making suggestions for implementation of each of the published recommendations. The subsequent plenary sessions elicited further discussion on priorities and what was feasible.

The following summarizes key components of these sessions:

1. Age range of "AYA"

The need for a definition of "AYA" by age was identified in order to be consistent in communication about a common cohort, but it was recognized that age range depended on its application.

- *Active therapy:* The age range of 15–24 is appropriate and in keeping with the teenage and young adult (TYA) model in the UK, with variations to fit local preferences or requirements in Canada.
- *Epidemiology:* The age range of 15–29 matches that of data collection undertaken by the US National Cancer Institute (NCI) Surveillance, Epidemiology and End Results (SEER) program,¹¹ by EUROcare (the EUROpean Cancer REgistry-based study on survival and CARE of cancer patients),¹² and by Statistics Canada.³
- *Long-term follow-up:* The age range of 15–39 is consistent with the position of the NCI's Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG).¹³ Long-term surveillance is required due to the considerable amount of treatment-related sequelae encountered in survivors of cancer in childhood, adolescence, and young adult life.¹⁴

2. New paradigm of cancer control for AYAs

It is assumed that AYA care combining a developmental approach and disease-specific expertise will produce the maximal survival benefits and have the greatest impact on survivors' quality of life.¹⁵ Establishing multidisciplinary clinical programs with appropriately trained healthcare professionals is required to achieve the best results. This has been the experience in other countries, such as Australia and the UK. A systems improvement approach across Canada is required, with ongoing engagement of all stakeholders and a process of evaluation.

3. Active therapy and supportive care

Services must be provided to address the special needs of AYAs with cancer and survivors of cancer in childhood, adolescence, and young adulthood in order to redress inequities

in current care provided to this group relative to both younger and older cancer patients.

Priority issues for implementation are:

- Given the disproportionately long delays to diagnosis and treatment,¹⁶ improved access to age- and disease-specific expertise and appropriate supportive care and monitoring is required.
- Interdisciplinary teams should be populated with medical and other experts able to communicate effectively and provide evidence-based care, including age-appropriate and developmentally-appropriate supportive and psychosocial care.
- Whenever possible, patients should be cared for in dedicated, purpose-designed, and appropriately resourced inpatient and outpatient environments to reduce patient isolation and encourage peer support.
- AYA cancer patients must be recognized as a special population at a critical developmental stage. 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.
- Opportunities for AYAs with cancer to participate in appropriate clinical trials must be increased, and such patients should be offered entry into any trials for which they are eligible.
- Patients not participating in clinical trials should be treated according to established evidence-based treatment protocols.
- Fertility risks and options for fertility preservation must be discussed with every patient.

4. Survivorship

Survivorship programs (including for AYAs who are survivors of cancers in childhood) do exist in Canada but are not consistent in their approach.⁵ Many patients are lost to follow-up in the transition from pediatric units to other institutions or primary care providers. A common set of evidence-based principles and guidelines is needed. Current guidelines, such as those from the Children's Oncology Group (COG),¹⁷ are too extensive and expensive for common application and lack evidence to support their use.

Priority issues for implementation are:

- The survivorship phase should begin during active treatment to prepare the patient and family for the transition; this must include discussion of potential long-term and late effects of treatment.
- Every AYA cancer survivor should be provided with a comprehensive health record to facilitate transition.
- This record should summarize information about the cancer and treatment given, screening and clinical surveillance-related issues that reinforce primary care practice and preventive healthcare, rehabilitation opportunities (educational, occupational, and financial) as individually required, and other relevant psychosocial concerns of the individual patient.
- The summary should be in a format and medium that allows it to be accessed by the survivor and the survivor's healthcare providers when needed (potentially

many years after treatment completion) and kept updated when new knowledge becomes available.

- 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 accessible by healthcare providers.

5. Psychosocial support

This is a fundamental component of AYA care that is specifically different from that for younger and older cancer patients.¹⁸ It must be recognized that AYAs are still undergoing a cognitive and emotional developmental process. Survivors have identified the need for peer support as critical.¹⁸ Existing online support opportunities should be made available to AYA patients. Due to the known multifactorial stress in AYA patients and survivors, a common distress tool should be developed or adapted from other established programs.

Priority issues for implementation are:

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

6. Terminal care and symptom management

The practical, emotional, and social needs of AYA patients with a terminal illness are typically quite complex and vary significantly depending on each patient's level of maturity and independence. This requires the services of a palliative care team with training in the needs of AYA patients.

Priority issues for implementation are:

- World Health Organization guidelines should be used to develop Canadian standards for palliative care in AYA patients.
- The palliative care team should be involved early to help manage clinically significant symptoms that may not be associated with imminent death.
- An AYA-specific screening tool should be developed to detect increased anxiety and new medical concerns, so as to help initiate discussions about death and dying, and palliative care.
- AYA-specific multidisciplinary 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.

- Physical facilities in hospices and hospitals should be developed to meet the particular needs of terminally ill AYA patients.

7. Research and metrics

There is an obvious lack of opportunity for AYAs to participate in clinical cancer trials in Canada, with less than 2% of this population accrued. Basic and translational research applicable to this cohort is also lacking.¹⁹ A research working group established to set priorities—the National Cancer Institute of Canada Clinical Trials Group (NCIC CTG)—has convened a meeting to discuss barriers to AYA patients' entry onto clinical trials. The intent is to form a committee to consider the development of AYA-specific trials and assist in enrollment for clinical trials that already exist within pediatric and adult cooperative groups. In addition, there is a need for the development of economic metrics to track whether the change process for AYA cancer care is beneficial and cost-effective.²⁰

Priority issues for implementation are:

- Develop an epidemiological assessment of prevalence and incidence trends.
- Establish prevention and screening programs on the incidence and outcomes of AYA-related cancers and cancer risk behaviors.
- Explore factors contributing to AYA cancer patients' lack of timely access to care.
- Design a formal evaluation of the impact of locus of care on outcomes, including determinants of current patterns of referral and practice.
- Investigate factors influencing AYA patients' access to clinical cancer trials, studies of tumor biology, and translational research.
- Advocate and foster oncofertility research, service provision and advances in fertility preservation, especially for young women.

8. Awareness and advocacy

Efforts to increase awareness and advocate for change must be nurtured. 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.
- Behavioral and psychosocial challenges are associated with the transition from pediatric to adult life.

9. Education

In order for AYA multidisciplinary teams or units to be formed, appropriate education and training will be required. A working group has developed and gained approval for a diploma program from the Royal College of Physicians and Surgeons of Canada. This will be a one-year program for physicians with entry after training in pediatric hematology/oncology, medical oncology, radiation oncology, or adult hematology. Other disciplines will require further training and educational opportunities, and the NTF should help facilitate their development. Online training and webinars are potential tools for education on AYA issues.

10. Prevention and screening

This was not originally a component of the published recommendations but has been recognized since as a deficiency. Specific issues that are relevant to the AYA population were suggested and require further discussion in order to implement. They are:

- Human papillomavirus (HPV) vaccination for both females and males.
- Sun protection and education.
- Lifestyle modification and education for the prevention of second cancers in survivors.
- Appropriate clinical surveillance for patients at risk and compliance with established screening programs for adult cancers (e.g., cancers of the breast and cervix).

The second day of the workshop involved breakout groups oriented to the regional jurisdictions (provinces and territories) across Canada. Their charge was to discuss how to set priorities for implementation, how to implement programs within their specific regions, and how the NTF should interact with Regional Action Partnerships (RAPs). All provinces have agreed to form RAPs.

The roles of the RAPs are to:

- Participate in the development of the Framework for Action.
- Modify the Framework to suit the healthcare system and needs of their particular regions.
- Communicate with the NTF on the modified Framework.
- Develop effective alliances with hospitals and subregions involved in the care of AYA patients.
- Establish models of care for AYA patients who require active care and for long-term follow-up of survivors appropriate to each region individually.
- Advocate for implementation of the NTF's recommendations according to the Framework and developing models of care within their region to improve the outcomes of AYAs with cancer.

Conclusion

A final document on implementation of the published recommendations—the Framework for Action—has been produced as a result of the 2012 workshop. It will be distributed to all attendees and other pertinent stakeholders relevant to AYA patients and survivors. RAPs are being formed, and a timeline for implementation has been set. It is realized that this will be an incremental process, and the different regions will proceed at different rates. A third workshop is planned for 2014 that will focus on building a community of survivors.

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