Implementing A Framework for Action from the Canadian Task Force on Adolescents and Young Adults (AYA) with Cancer: A New Paradigm for AYA Cancer Control

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Objective

• The overall objective of the national Task Force (NTF) is to mitigate the current disparities of care for AYA with cancer, including survivors, and survivors of cancer in childhood through advances in treatment and research, respecting the unique circumstances and needs of this population, across all health care jurisdictions in Canada.

• While cancer is relatively uncommon among AYA (ages 15 to 29 years) compared to older adults, its personal, societal, and socioeconomic impact is disproportionately greater.

• The needs of AYA with cancer are being met poorly by the conventional dichotomy of Canadian pediatric and adult health care systems, particularly their psychosocial needs.

• In 2008, the NTF was created by the Canadian Partnership Against Cancer and C17, the consortium of Canadian pediatric oncology centres.

Approach

• The NTF initially established working groups with respect to: the current state of AYA care, survivorship/transition issues, Canadian recommendations, communications, research and education.

• A survey regarding Canadian services available to AYA cancer patients, and for follow-up care of AYA survivors of cancer as children or AYA was carried out by the NTF in 2009.

• The survey identified that there is a wide diversity of care and service models across Canada for AYA patients and survivors.

• Two international workshops on AYA with cancer were held in March, 2009 and March, 2012; attendees included survivors and supporters, health care professionals, administrators, and international experts. The procedures of the first workshop have been published. (Cancer. 2011;117(Suppl 10):i–ii, 2239–2354)

Recommendations:

After the first workshop, 6 broad recommendations were developed highlighting the need for age-appropriate psychosocial, survivorship, palliative and medical care to redress inequities in the care provided to this group relative to younger and older cancer patients.

1. Active Therapy and Supportive Care

Services must be provided to address the unique needs of AYA with cancer and AYA 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. (Journal of Adolescent and Young Adult Oncology. 2011;1:53-59)

2. Psychosocial Needs

AYA 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.

3. Palliation and Symptom Management

The challenge of providing palliative care to AYA patients, with their unique needs related to their developmental stage, must be addressed.

4. 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 effects of treatment.

5. Research and Metrics

Research and the establishment of outcome metrics are required to investigate issues critical to AYA with cancer and AYA survivors of cancer in childhood, adolescence, and young adulthood in order to target interventions and healthcare policy to improve all phases of their cancer journey.

6. Awareness and Advocacy

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

Framework for Action:

Based on discussions at the second workshop, the NTF produced the Framework for Action on Recommendations for Care of AYA with Cancer. This road map will be used to develop strategies to implement the recommendations at the local, regional, provincial/territorial, and national levels.

The prioritization process identified two common areas of focus across all recommendations:

• Creation of AYA multi-disciplinary teams

• Development of tools specific to AYA needs

Also at the second workshop, representatives from all regions agreed to form Regional Action Partnerships (RAPs), to take the lead in implementing the Framework in their provinces and territories.

Results

Conclusions

• The NTF recommendations 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.

• A national Framework for Action on the NTF recommendations, including an evaluation component, has been created with input from all stakeholders.

• Action by the Regional Action Partnerships is beginning across Canada.

• Enhancing the care of AYA with cancer will require multi-disciplinary clinical programs staffed by appropriately trained health care professionals, a systems-improvement approach, continuous engagement of all stakeholders, and a process of ongoing evaluation.

• A third international workshop will be held in 2015 to discuss forming a Pan-Canadian alliance with existing stakeholders to ensure sustainability of the change process and the improvement of AYA cancer care.

Other initiatives:

• A proposal prepared by the NTF for a diploma program in AYA Oncology has been approved by the Royal College of Physicians and Surgeons. This will build on current pediatric and adult training programs in hematology and oncology.

• A program of collaborative research has produced 2 publications regarding AYA-specific fertility-preservation services in Canada.

• A communication and knowledge exchange plan to lead change and increase awareness was developed and is being implemented.

• Evaluation processes, including economic metrics, will be developed to build a case for investments in AYA services.

• As part of the NTF’s 2012-2017 strategic plan, standards and guidelines for active care of AYA with cancer, and for follow-up care of AYA-aged survivors are being developed.

• An NCIC-CTG sponsored meeting in April 2013 explored barriers to AYA patient accrual to clinical trials

• The NTF is participating in an international collaboration to develop an AYA-specific distress-screening tool

Find out more about the Canadian AYA Cancer Task Force at www.ayacancercanada.ca