Adolescent and Young Adult (AYA) Cancer: Principles of Care
Rampal R1, Aubin S2, Czyzowski P3, De Pauw S4, Johnson A5, McKillop S5, Szwarcer D5, Wilkins K6, Rogers P5

BACKGROUND: CANADIAN TASK FORCE ON AYA WITH CANCER

- Adolescents and young adults (AYA) with cancer receiving active treatment face a number of age-specific barriers to optimal care.
- The Task Force was assembled in 2008 to address AYA cancer care in Canada, funded by the Canadian Partnership Against Cancer (CPAC).
- Regional Active Partnerships (RAPs) were assembled in 2012 to support and disseminate the work of the TF across Canada.
- As part of the Task Force, a Working Group was convened in 2013 to develop guidance on AYA active care issues.

OBJECTIVE: To summarize the current literature on active care of AYA with cancer, outline recommended principles of care, raise awareness of barriers to optimal care and suggest specific system changes to overcome these barriers in the Canadian context.

APPROACH

- Existing guidance documents from United Kingdom’s Teenage Cancer Trust, Cancer Australia, National Comprehensive Cancer Network, and the National institutes of Health Adolescent and Young Adult Oncology Progress Review were identified and reviewed.
- Four systematic searches were carried out in Ovid, for English-language publications between 2009 and 2014.
- Keywords in the searches included: cancer, neoplasm, carcinoma, malignant, tumor, adolescent, and young adult, along with additional keywords.

Figure 1: Literature Search Process Map

RESULTS

- Inadequate access to fertility preservation due to: lack of guidelines or policies about referral for assessment of fertility risk, discomfort or lack of knowledge inhibiting discussions by clinicians with patients, and concerns about cost.
- Low cancer awareness resulting in delayed diagnosis.
- Patients in the AYA cohort are often ambivalent about clinical trial participation. AYA prefer to make choices regarding their therapy, posing challenges to enrollment in randomized trials.
- Low rates of clinical trial enrollment among AYA diagnosed with cancer compared to older and younger cohorts.
- Survivorship research is challenging in the AYA cohort 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.
- Inadequate distress screening for age-specific issues such as emerging sexual identity, peer support, re-integration to school.
- Study age criteria may not include all of the AYA age range and studies are often not available for cancers diagnosed in the AYA cohort due to their relative rarity or regulatory issues.

DISCUSSION

System Changes to Facilitate AYA Cancer Care

- Age: Institutions and governments need to implement structural changes to ensure that the care best meets the patient’s needs irrespective of their age.
- Geography: Quality of care should be equitable irrespective of proximity to a specialized cancer centre. Possible solutions such as satellite centres with easy access to experts in specialized centres and consults through telehealth conferences and Skype could create more equitable care and reduce the number of trips AYA need to make to specialist centres.
- Knowledge: Improve communication, collaboration and transfer of knowledge within health team members and with the patient. Developing AYA oncology as a distinct subspecialist discipline within oncology will increase expertise, as will creation of multi-disciplinary care teams.
- Research: Poor accrual to clinical trials and insufficient access to AYA trials can be overcome by improved cooperation between pediatric and adult oncology clinical trial groups, expanding age eligibility criteria in clinical trials and streamlining regulatory processes.
- Physical: Providing separate AYA space where possible, either specific AYA units or designated space within other units.
- Palliative Care: Staff should be adequately trained to deal with the developmental needs and challenges in this population.

- Financial: Governments need to provide better health care benefits such as: affordable medication, and transportation and insurance coverage to this vulnerable group. In addition, programs that provide counsellors to assist AYA transition back to school, university or employment will be beneficial.
- Social: Providing flexibility in scheduling of appointments and treatments where possible will reduce their social isolation and may improve compliance.
- Psychological: The use of screening tools with repeat assessments will allow for earlier identification and intervention in AYA with these problems.
- Medical: Ensuring fertility considerations by clinicians with patients, and concerns about cost.
- Fertility: Institutions should ensure that healthcare providers are aware of the latest fertility-preservation options and that these are offered to AYA in a timely manner. Co-ordination between patients, the healthcare team and fertility experts should be streamlined. All stakeholders should advocate for increased government funding for fertility-preservation treatments in order to make them more accessible to all AYA cancer patients.
- Communication / Information Delivery: Communication should be age-appropriate so that AYA can fully understand discussions.
- Hospital: Institutions should provide AYA with hospital navigators to help them negotiate the hospital system.

CONCLUSION

Each province needs to develop cost-effective strategies best suited to their population and measure the effectiveness of strategies implemented to ensure that they are providing the expected benefit. There may also be a role for federal leadership with the federal Minister of Health guiding conversations to meet the needs of the AYA cohort, using the framework of RAPS to define a national standard. As recommended changes are adopted, there needs to be a comparison between the current baseline and the implemented change, using specific metrics, in order to demonstrate the socioeconomic value of the change. This will ensure that finite resources are used optimally.

Funding provided by the Canadian Partnership Against Cancer (CPAC)