

## Adolescents and young adults (AYA) with cancer

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Adolescents and Young Adults (AYA) with cancer are distinct from the pediatric and the older adult cancer populations with respect to their spectrum of diseases, the biology of their cancers, their developmental status and their particular psychosocial needs. Moreover they are poorly served by the dichotomy of



the pediatric and adult oncology services. AYA may be survivors of childhood cancer or they may have experienced cancer as an adolescent or young adult. For this reason, the age range defining AYA varies depending on its application.

- For active therapy, an age range of approximately 15 to 24 is appropriate, with variations to fit local preferences or requirements;
- For epidemiology purposes, the age range of 15 to 29 years is consistent with data collection institutions such as the Surveillance, Epidemiology and End Results (SEER) Program in the United States, Eurocare and Statistics Canada;
- For long-term follow-up, the age range of 15 to 39 is consistent with the National Cancer Institute's Progress Review Group (NCI-PRG) in the United States. This allows for a minimum of 12 years of follow up (for example, acute lymphoblastic leukemia therapy in a 24 year old) and a maximum of almost 25 years (surgery only for a low grade glioma in a 15 year old).

The most common types of cancer seen in adolescents and young adults differ from those seen in adults. They are: lymphoma, germ cell tumours (including testicular cancer), melanoma, thyroid carcinoma, central nervous system tumours, and leukemias. AYA are much more likely to be diagnosed with carcinomas than children under the age of 15. Over the past 30 years, as reported in the United States, survival of AYA patients has changed little or not at all compared with the substantial improvements seen in children and older adult cancer patients.

In many parts of the world AYA with cancer and survivors of cancer in childhood, adolescence, and young adulthood face disparities of care affecting quality of life and other outcomes. In Canada, AYA with cancer experience these disparities in a healthcare system that is population-based (age) rather than patient-centric. Improving this situation will necessitate that AYA can benefit not only from the current state of knowledge regarding optimal cancer care, but also from research directed to the biology, treatment and specific needs of this population.

Establishing multidisciplinary clinical programs devoted to this age group and staffed by appropriately trained healthcare professionals who have an in-depth understanding of AYA needs has been found to achieve better results in countries such as Australia, Italy, the United States and the United Kingdom.

Care that includes a developmental approach for this age group will maximize survival rates and will have an even greater impact on the quality of life of survivors.

Survivors themselves have identified that enhanced counseling services and peer support would provide AYA cancer patients the opportunity to remain active and contribute to society while on treatment.

As system improvements are made, it is important to evaluate changes made so as to show the impact of those changes on survival and overall quality of life.

In Canada, the National Task Force on AYA Cancer, established in 2008, convened an international conference in 2010 to develop recommendations on how to improve the care of AYA with cancer and AYA survivors of cancer. The six broad recommendations highlight the need for age-appropriate, disease-specific expert medical care including psychosocial, survivorship, and palliative care. Research is required to redress the inequities in the care provided to this group relative to both younger and older cancer patients, and to support enhancements in care through systematic evaluation. Improved care for this group should enable individuals to reach their full potential as productive, functioning members of society, and will provide economic and other societal benefits.

The following six recommendations were developed by the Canadian Task Force on Adolescents and Young Adults with Cancer Workshop in March 2010 and published in the *Journal of Adolescent and Young Adult Oncology (JAYAO)*.

Additional recommendations for prevention and screening in AYA populations are being developed and will be incorporated into future versions of the Framework.



## 1. Active therapy and supportive care

Services must be provided to address the unique needs of AYA 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 met adequately within either care model. 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.

## 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.

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. 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.

## 3. Palliation and symptom management

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. This requires the services of an interdisciplinary palliative care team with training in the needs of AYA patients. 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. It is expected that if the patient and family are well supported, there will be less long-term comorbidity for the family and caregivers

## 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 treatment effects.

The five-year overall survival rate for AYA with cancer in Canada is over 80 per cent. However, approximately one-third of survivors will experience serious late- or long-term effects from their treatment. For this reason, cancer survivorship is a unique phase in the cancer trajectory that is as relevant for AYA 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.

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.

Moreover, AYA and childhood cancer survivors are unlikely to be sufficiently knowledgeable about their disease, treatment, or risks of late effects. 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 AYA because of their life stage and developmental maturity at the time of active cancer treatment.

## 5. Research and metrics

Research and the establishment of outcome metrics are required to investigate issues critical to AYA 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 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. 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. The full spectrum of AYA-specific oncologic healthcare should be measured from active care to either palliation or survivorship.

Evaluation should broadly cover tumor biology, translational research and clinical trials, genetic and familial predisposition, epidemiology, prevention and screening, access to care, patterns of healthcare utilization and transitions of care as each of these is essential in understanding the scope of the needs and points of potential intervention. Moreover, because the AYA population with cancer experiences a heterogeneous group of diseases and exhibits considerable variety in biological maturation, psychosocial needs, and educational achievement, 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.

## 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.

It is apparent that the needs of AYA 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 AYA is especially important. 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.

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.
- Psychosocial differences are associated with the

transition from pediatric to adult life.

- Behavioral and psychosocial differences are associated with passage through the developmental stages of adolescence and young adulthood.

In BC we are establishing a working group between BCCH and BCCA (regional action partnership) in order to explore the implementation of the recommendations of the national task force. It is the hope that in the future there will be combined dedicated multidisciplinary teams from BCCH and BCCA that will be available to consult on this complex cohort of patients. It is also a desire to develop a specific adolescent unit for oncology AYA patients in the new Children's Hospital and young adult unit in future developments at BCCA. These units will be involved in both active care and in survivorship care of AYA cancer patients.

## Upcoming conferences

Association of Pediatric Hematology Oncology Nurses  
APHON 37th Annual Conference, September 19-21, 2013  
Louisville, Kentucky  
[www.aphon.org/meetings/conference](http://www.aphon.org/meetings/conference)

Vancouver Island Oncology Conference  
Bridging the Gap, September 20-21, 2013  
Laurel Point Inn, Victoria, BC  
[www.eventcare.ca/clients/vionc/index.htm](http://www.eventcare.ca/clients/vionc/index.htm)

International Society of Pediatric Oncology (SIOP)  
45th Congress, September 25-28, 2013  
Hong Kong, China  
[www2.kenes.com/siop/pages/home.aspx](http://www2.kenes.com/siop/pages/home.aspx)

Canadian Association of Nurses in Oncology  
2013 CANO Conference, October 20-23, 2013  
Sheraton Vancouver Wall Centre, Vancouver, BC  
Inspiration Innovation Transformation  
[www.cano-acio.ca/annual-conference-2013](http://www.cano-acio.ca/annual-conference-2013)

BC Cancer Agency  
Annual Cancer Conference, October 31 – November 2, 2013  
Westin Bayshore Hotel, Vancouver, BC  
Cancer Care, Knowledge Translation and Research in BC,  
Legacies, Innovation, A Better Tomorrow  
[www.bccanceragencyconference.com](http://www.bccanceragencyconference.com)

Pediatric Oncology Group of Ontario (POGO)  
2013 Multi-Disciplinary Symposium on Childhood Cancer,  
November 22-23, 2013  
Westin Harbour Castle, Toronto, ON  
Innovation in Pediatric Oncology  
[www.pogo.ca/education/symposium](http://www.pogo.ca/education/symposium)

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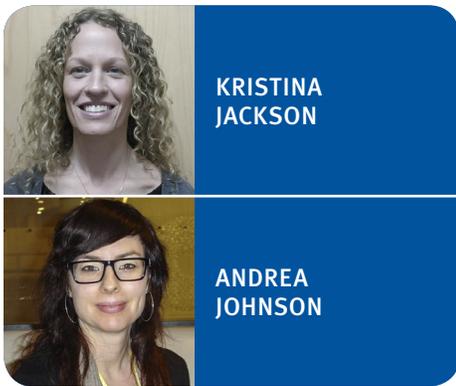
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# Finding our way with adolescents with cancer

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## Why adolescents?

Adolescents with cancer comprise a small percentage of the pediatric oncology population in BC. However, despite this small population size, these patients require significant attention and mindful care. Caring for this population can be complex and sometimes brings challenges for staff as adolescents with cancer have unique needs that differ from those of children and adults. Within the present dichotomy of pediatric and adult healthcare systems, the complete needs of adolescents are not consistently being met, and we have a lot to learn regarding best practice of care for this population. Within the Oncology/Hematology/Bone Marrow Transplant Program at BC Children's Hospital, we are striving to determine and define what constitutes best practice adolescent oncology care.



Caring for adolescents with cancer challenges us in different ways from caring for pediatric and adult oncology populations. Despite an international movement to highlight the unique experiences of adolescents with cancer, many of us struggle with how to work effectively with this population, how to communicate with them, and how best to support them. The psychosocial care needs of this population are significant and necessary, and there is no formula for their non-medical care. We believe that psychosocial care has an enormous impact on their wellbeing and their coping with cancer; yet knowing what this care looks like is often unclear. For many of us, the adolescent patient can also intimidate us – they demand an honesty



from us that challenges us and often we don't know what to say. However, as difficult as caring for adolescents may be at times, adolescents have the right to have their unique needs recognized and integrated within their healthcare.

## Developmental context of adolescence & cancer

Effective medical treatment and care of adolescents require an appreciation and understanding of their developmental life-stage. Their life-stage will influence nearly every aspect of their care as adolescents make sense of their diagnosis and treatment within the context of their lives, and we must recognize this. Cancer is difficult for this population not only because they have cancer but because having cancer prevents them from accomplishing developmental goals and living the lives they want to be living. To best treat adolescents, we must not forget that adolescents with cancer must be seen as adolescents first. At the same time of a cancer diagnosis and treatment, they are simultaneously grappling with complex normative developmental tasks that are difficult for any adolescent: independence, separation from family, establishment of interpersonal relationships, establishment of identity and self-esteem, sexual identity, future planning etc. Adolescents are not children but not adults and accommodating to cancer for this population can be a complex experience.

## Coping through peer to peer support

Adolescents with cancer have unique support needs. In efforts to meet these needs, the Oncology/Hematology/BMT program at BC Children's Hospital offers a monthly group for

adolescents with cancer. This group has been operating for six years, and we believe it to be one of the most potent sources of support for this population.

- **Rationale for a Teen Group**  
This group was developed as a response to our sense that adolescents diagnosed with cancer would benefit from peer support and normalization. Adolescents with cancer simply want to be 'normal' and engage in social interaction and activities that they would have done outside of their illness. We also had a sense that adolescents often felt isolated and alone as they were away from school and spending extended periods of time away from their peer network.
- **History of Teen Group**  
In March, 2007, we held a focus group with four adolescents with cancer. We discussed our interest in developing and implementing an oncology youth group, and the need for this type of group was communicated to us by the participating adolescents. Within this group, there was immediate relationships forming between the participants, and this validated our observation of the need for peer contact and connection.
- **Structure of Teen Group**  
This adolescent oncology group is for adolescents between the ages of 13-19 who have been recently diagnosed with cancer, or have experienced a recent progression of their disease within the past 12 months, or have been out of treatment for less than three years. This group meets monthly and is facilitated by oncology program social workers and

child life specialists. This group is an open group and we invite both new patients and adolescents familiar with this group to attend each session. Within each group, efforts are made by staff to promote connection and to engage each participant.

Adolescents who participate in this group have made a significant impact on our practice and have influenced how we provide care to this population. We have also learned that adolescents want to teach us how best to care for them, and we have begun actively using their voice to guide practice with this population. The following tips and narratives have come from adolescent patients in our program.

### Tips for communicating with adolescents

Communicating with adolescents can sometimes be complex and difficult. As above, thinking contextually about adolescents assists us in communicating with them. Adolescence is a life-stage that is already fraught with challenges. A medical diagnosis compounds this experience and we must take this into account when communicating with them. We must give thought to where they are at in their lives and what their concerns and worries might be outside of their diagnosis and treatment. We hear again and again... 'I just want to live my life...'

Creating relationships is essential with this population, and we believe they will cope best by developing genuine relationships with healthcare staff – relationships based on care and trust. The following communication guidelines are helpful in establishing trust and rapport with this population:

- Check in with yourself prior to meeting with the patient... How do I best deliver information to this specific patient?
- Introduce yourself & explain your role as soon as you meet with the adolescent – begin to create rapport
- Show empathy & understanding: acknowledging their fears & emotions, fostering empowerment through choices and decisions
- Respect what the adolescent is telling you
- Explain illness, treatment & procedures thoroughly
- Speak directly to the adolescent & make eye contact
- Ask open-ended questions

- Maintain patient privacy & confidentiality (we must be safe people for adolescents to share things that they may not be comfortable sharing with others)
- Provide opportunity for questions and come prepared to answer them
- Remember who your patient is
- Give time ... and be comfortable with silence
- And listen, listen, listen

Delivery of medical information has much meaning for this population, and healthcare staff must be sensitive to this. Adolescents need honest information but we must be mindful how we deliver it as information must be delivered different to this population than to children or to adults. The following questions are helpful with adolescents:

- We have a lot of medical information to share with you today - how do you want to/prefer to receive medical information?
- What kind of information do you want to receive?
- What do you know about this treatment/procedure you are receiving today?
- What are your concerns about this treatment/procedure?
- What is your understanding of what we have told you today?
- I'm wondering what your concerns & worries might be?
- What questions do you have for me? What are you curious about?
- Who would you like present when you receive information and we answer your questions?
- How can I support you right now?
- What would you like us to know about you to best care for you?

### What adolescents with cancer want you to know

These are the voices of adolescents with cancer telling us what they need and how to best care for them... we believe we have much to learn from them.

#### Truth telling and receiving bad news

- "You can't talk to teenagers like they are children, but you can't also treat us like we are just adults and feel like we can totally handle everything because it's obviously a very scary thing to go through."
- "Don't lie to us."

- "We need to receive all the information about our condition. It's not their choice to withhold information from us when it is about our bodies."

#### I am an individual, not my disease...

- "I want to be treated as an individual... not as someone with cancer..."
- "You think treatment is the best thing for us... and it is... but for us, we have hit a wall (cancer) and it has stopped everything that's important so you have to understand cancer in the context of our lives."
- "Don't compare our cancers – each of us is going through something significant."

#### We are a unique population... recognize we need different care...

- "Teens definitely need different care than kids... we're struggling severely with our identity already, you throw cancer in the mix... and that just messes it up even more."
- "Sometimes we want to cry... sometimes we want a toy put in front of our face and we want to get a hug because we are feeling everything a little kid is feeling... we're just not showing it ..."
- "Be prepared for some 'talk back'... I have a lot to say."

#### Be thoughtful in your communication and listening skills...

- "I don't want to be spoken to like a child, but I also need you to know that I don't always understand what you're trying to tell me when you use medical terms."
- "You know that gap/divide between patients and practitioners – we need to close that divide – we need to close that gap and make it smaller."
- "When we talk to you about our body, please listen to us... we really know our bodies... listen to the patient."

#### Moving forward

- "No one actually understands that recovery is the hardest part of having cancer."
- "Don't be so doctor straight-forward – this is what's going on... have a conversation with us."
- "Get to know me outside of cancer – learn about my life."
- "Don't assume you know what I want."
- "You have to realize our point of view and understand what's important to us."
- "Treat me with the kindness like you do with the younger kids and the respect you give adults."

## Minimal Residual Disease testing in children with leukemia at BC Children's Hospital

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Acute leukemia is the most common malignancy in children. B cell acute lymphoblastic leukemia (B-ALL) affects approximately 40 children per year in BC. T cell acute lymphoblastic leukemia (T-ALL) and acute myeloid leukemia (AML) also happen in children but at a much lower frequency.



The prognosis of acute leukemia depends on factors including age, involvement of the central nervous system, white blood cell count at diagnosis and cytogenetics. Patients with acute leukemia undergo chemotherapy to eradicate their blast cells: in the past, treatment response was measured morphologically in the bone marrow after treatment. Blast counts  $<5\%$  (i.e. fewer than 5 blasts per 100 nucleated cells in the marrow) were considered to represent morphological remission. Unfortunately this morphologic approach is relatively crude, so it is now being supplanted by newer methods.

Minimal Residual Disease (MRD) testing is designed to detect the presence of a very small number of leukemic cells during or after treatment, when the patient has no clinical symptoms (and no morphological evidence) of the disease. With the development of sophisticated techniques, the presence of MRD can now be measured by sensitive methods like Polymerase Chain Reaction and flow cytometry.

There is strong evidence that the presence of MRD ( $\geq 1/10,000$  cells or  $\geq 0.01\%$ ) in patients with B-ALL at day 29 of treatment is an independent prognostic factor and probably the single most important risk factor for relapse. The clinical significance of MRD in children with T-ALL and AML has not been as well established to date but research in this area is ongoing.

We introduced MRD testing by flow cytometry for patients with B-ALL in our clinical immunology laboratory in September 2011, both in bone marrow and peripheral blood samples. We first analyze bone marrow at diagnosis to determine the 'leukemia-associated' phenotype (LAP) of each new patient. The majority of B-ALL patients have an immunophenotype that falls outside the normal B cell maturation pattern in the bone marrow. As not every patient has the same LAP, it is important to establish this before we can look for a very small population of residual disease at day 29 of treatment. We also look for MRD in peripheral blood, and we do this at day 8 and at day 15. Peripheral blood MRD at day 8 and day 15 has replaced morphological analysis of bone marrow at day 8 and day 15, and bone marrow procedures are no longer performed at these time points. As immature B cells are very sensitive to chemotherapy, and normal immature B cells should not be seen in the blood at early time points of chemotherapy treatment, every immature B cell in blood at day 8 and day 15 is considered abnormal. MRD testing at these time-points gives us a good indication of sensitivity of the blast cells to chemotherapy.

We are also establishing protocols for MRD testing in T-ALL and AML, and as we include more and more markers in our panels we will be able to offer this as a clinical test in the near future.

### THE PROVINCIAL PEDIATRIC ONCOLOGY/HEMATOLOGY NETWORK

The Network is an interdisciplinary organization whose goal is to ensure appropriate diagnosis, management, follow-up, and end-of-life care for pediatric patients with malignancies and blood disorders.

The Network supports community hospitals and practitioners, and develops partnerships with other healthcare facilities to enable seamless and integrated care for patients and families on treatment and off treatment.

It will further develop and enhance the research programs of basic, translational, and clinical research to better childhood cancer control and improve outcomes for these patients and their families.

### FOR MORE INFORMATION

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Our mission is to improve the health and welfare of children in BC with cancer and blood disorders through research, education, and care.