

PSYCHOSOCIAL ASSESSMENT FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER

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Abstract

Adolescents and young adults with cancer have unique medical and psychosocial needs. In addition to efforts aimed at improving survival, there is acknowledgement of the need to understand how social and emotional outcomes can also be improved for this group of young people. Psychosocial assessment firstly provides an important means of understanding how cancer, its treatment, late effects and its management affect the developmental concerns of young people. Secondly, psychosocial screening also helps identify preventable behaviours that add to the risk burden of young people with cancer and helps guide counselling and anticipatory guidance. Finally, the assessment helps effect a long-term management plan, taking into account complex socio-environmental factors that can affect adherence and transition to adult health care settings.

The field of adolescent and young adult oncology has grown over the last few decades, with greater recognition of the distinct medical and psychosocial needs of young people in this age group. The diagnosis of any severe disease in adolescence or early adult life can be challenging. At the same time almost 80% of children with cancer now survive into adolescence and adulthood due to advances in medical treatment.¹ This dramatic improvement in survival is accompanied by a significant burden of both acute and chronic 'late effects' from the long-term sequelae of chemotherapy and radiation therapy. For example, the Childhood Cancer Survivor Study found that 28% of survivors developed a severe or life threatening condition, while 62% had at least one chronic condition.²

The relative lack of improvement in survival in AYA cancer, relative to both younger children and older adults, provides a challenge to clinicians in ensuring the provision of best practice clinical care to this age group. This article will examine the psychosocial concerns of survivors and young people diagnosed with cancer, which provides a rationale for the importance of routine psychosocial assessment in this age group.

Impact of cancer on adolescent development

Adolescence can be a challenging time. The cancer experience directly impacts on every sphere of adolescent development, which risks making the passage through adolescence particularly challenging for survivors of childhood cancers and those diagnosed during adolescence and young adulthood. Young people with cancer not only face the same developmental challenges of adolescence that lead to profound maturation of the body physically, cognitively and psychosocially, but at the same time are having to negotiate the demands of cancer,

its management and the monitoring and management of late effects that may develop. As with any major illness, it is not uncommon for young people to regress and become more dependent on their family. While normative in the context of a cancer diagnosis, the challenges for young people and their families is that this is occurring at the very time that healthy young people are becoming more independent of their family. Frequent and prolonged periods of hospitalisation can interrupt school attendance and interfere with the maintenance of peer relationships, which are a critical socialising mechanism for young people. Educational and social isolation further restricts participation in age-appropriate activities, which are an important determinant of psychosocial maturation.³

Visible signs of cancer and its treatment risk further highlight the differences perceived by young people with cancer from their peers. Adolescent cancer survivors report lower self-esteem, more social anxiety and body image concerns compared to a healthy comparison group.⁴ Adolescence is also a time in which development of a sexual identity matures, as does a capacity to form intimate relationships. Lower self-esteem and social anxiety raise questions about how well AYA cancer survivors negotiate early intimate relationships, which commonly provide the background of confidence for embarking on more meaningful intimate relationships in adult life. How concerns about future fertility affect the way in which young cancer survivors approach intimate relationships is an important area of research with distinct implications for clinical practice.

Academic and psychosocial outcomes

Improved survival of children with cancer has resulted in detailed studies of cognitive and psychosocial outcomes of different types of cancers, using different scales that have assessed different outcome measures.⁵⁻⁷

Children and adolescents are at increased risk for neuro-cognitive deficits and learning difficulties as a result of the cancer itself, such as brain tumours, or its treatment, such as cranial irradiation or neurotoxic chemotherapy. Specific impairments of the auditory and visual pathways can further compound learning difficulties.⁸ The Childhood Cancer Survivor Study examined the behavioural and social outcomes of adolescent survivors. Although the majority of childhood cancer survivors were found to be psychologically healthy, more survivors were found to have somatic symptoms, depression and/or anxiety, attention deficit and antisocial behaviour compared to the sibling comparison group.⁵ Certain subgroups such as those with leukaemia, CNS tumours and neuroblastoma were at particular risk.⁶ However, as described previously, lack of participation in education can also result in poor educational outcomes and reduced vocational choices. The lack of social, educational and vocational opportunities that accompany poor physical health are additional factors that have also been shown to contribute to the psychological distress experienced by cancer survivors.⁷ As brain maturation continues well into young adulthood, ensuring that young people are engaged in social and educational activities as much as possible is an important aspect of early intervention efforts to improve psychosocial outcomes.

Impact of health risk behaviours on cancer outcomes

The developmental changes of adolescence can reciprocally affect cancer and its management. Exploration and experimentation with various behaviours and roles is common to all adolescents and is a core aspect of adolescent identity formation. In some instances however, experimentation results in risks to the physical and emotional wellbeing of the young person, as well as compromising their successful transition into adult life.⁹ Risk behaviours such as smoking, alcohol and other drug use or abuse, and poor eating habits, initiated in adolescence, commonly continue into adulthood, with the risk of long-term health effects.¹⁰⁻¹¹

Previously, it was commonly assumed that young people with chronic illness were less likely to participate in risk behaviours.¹² It is now known that this group is just as or more likely to do so.¹²⁻¹⁴ A large European study found that young people with chronic illness or disability were significantly more likely to smoke regularly, use cannabis and perform violent or anti-social acts compared to their healthy peers.¹⁴ Although it is debated how well cancer survivorship is consistent with more traditional models of chronic disease,¹⁵ it is known that adolescent and young adult survivors and those who have a cancer diagnosis in adolescence experience a significant disease burden, not unlike young people with chronic illness, which may well increase their likelihood of participating in risk behaviours.

To date, there is conflicting data about the risk behaviours of adolescents and young adults with cancer. Studies have shown that adolescent cancer survivors engaged in smoking and alcohol use and aggressive and antisocial behaviours at a rate consistent with that of age and gender-specific rates of the general population, but are

less likely to use marijuana.¹⁶⁻¹⁷ However, other studies have reported reduced involvement in most health-risk behaviours.¹⁸⁻¹⁹ Adolescents with cancer are less likely to report cigarette and alcohol use and binge drinking; they are more likely to engage in sedentary behaviour (television viewing) and less likely to be physically active compared to their healthy counterparts.¹⁸

Routine psychosocial assessment

Regardless of the prevalence of health risk behaviours in survivors and adolescents and young adults with cancer, a major concern is that AYA patients who engage in particular health risk behaviours may be even more vulnerable than healthy youth to develop adverse health outcomes as a result of the interactions between their behaviour, the cancer and ongoing late effects.²⁰ For example, the attributable risk of smoking will be much greater in cancer survivors who are already at increased risk of developing secondary cancers and cardiovascular disease. The rationale for efforts to ensure that young people with cancer or adolescent and young adult cancer survivors do not smoke could not be stronger, especially given the growing evidence that clinical approaches to risk reduction counselling in adolescents changes behaviours.²¹ This is the same rationale that underpins the value of psychosocial assessment and health risk screening, which can provide a conduit to developmentally appropriate preventive counselling and anticipatory guidance about various concerns, whether health risk behaviours such as tobacco use or unsafe sexual activity, or poor educational engagement.

A useful framework for psychosocial assessment is the HEADSS framework.²² HEADSS is the mnemonic for Home, Education and Employment, (Eating and Exercise), Activities and peers, Drugs, Sexuality, Suicide and depression and Safety (see table 1).

Adolescents and young adults with cancer, as well as cancer survivors, are a group that have frequent contact with the health care system. They generally have a close relationship with oncology staff who they respect as credible medical experts.²³ This context allows for more opportunities for health risk screening and preventive care than in healthy youth, which is appropriate given concerns of both the prevalence of risk behaviours and their attributable risk. In AYA cancer, it is unknown to what extent routine consultations have been utilised for wider screening. The wider chronic illness evidence suggests that health care providers infrequently discuss health risk behaviours or provide preventive counselling to young people with chronic illness.²⁴⁻²⁶ Just like adults, young people greatly value confidential health.²⁷ Those with chronic disease have voiced greater desire to discuss broader health concerns with their health care provider, including issues such as education and mental health.²⁸⁻²⁹

This is a particular challenge for paediatric settings where young people with chronic illness are often seen with their parent(s). Without explicit efforts to see young people alone for at least part of each consultation, this too commonly translates to few opportunities to discuss confidential or sensitive concerns.³⁰

Table 1: The HEADSS framework for psychosocial health assessment (adapted from Goldenring & Cohen)²²

Home	<p>Where do you live? Who do you live with? How do you get along with each member? Who could you go to if you needed help with a problem? Have there been any recent changes? Do you feel safe at home?</p>
Education and employment	<p>What do you like about school/work? What are you good/not good at? How do you get along with teachers/your employer and other students/colleagues? Have your grades changed recently? Many young people experience bullying at school/work, have you ever had to put up with this? What are your future plans?</p>
Eating	<p>Do you have meals with your family? Who cooks at home? What do you have? Is anyone worried about your weight? Are you happy with your weight? Do you worry about your weight?</p>
Exercise	<p>How do you get to school or work? Do you play a sport? How often do you do any form of physical activity?</p>
Activities and peers	<p>What do you like to do for fun? What sort of things do you do in your spare time out of school? Who do you hang out with? What sort of things do you like to do with friends? Tell me about parties... Do you belong to any clubs, groups etc? How much TV do you watch each night?</p>
Drugs	<p>Many young people at your age are starting to experiment with cigarettes or alcohol. Have any of your friends tried these or maybe other drugs like marijuana, IV drugs, amphetamines and ecstasy? How about you, have you tried any? If you have, how do you take the drug? What effects do drug-taking, smoking or alcohol have on them/you? Do they/you have any regrets about taking drugs? How much are you taking and how often, and has your use increased recently? How do you afford them?</p>
Sexuality	<p>Some young people are getting involved in sexual relationships; have you had a sexual experience with a guy or girl or both? Has anyone touched you in a way that has made you feel uncomfortable or forced you into a sexual relationship? How do you feel about relationships in general and about your own sexuality?</p>
Suicide and depression	<p>How do you feel in yourself at the moment on a scale of 1 to 10? What sort of things do you do if you are feeling sad/angry/hurt? Is there anyone you can talk to? Do you feel this way often? Some people who feel really down often feel like hurting themselves or even killing themselves. Have you ever felt this way? Have you ever tried to hurt yourself? What prevented you from doing so? Do you feel the same now? Do you have a plan?</p>
Safety	<p>Sometimes when young people are drunk or high, they do not think about what they are doing. Have you ever driven a car when you were drunk or high? Have you ever ridden in a car with a driver who was drunk or high? Have you ever felt that you needed to carry a knife or other weapon to protect yourself?</p>

Consent and adherence to treatment regimens

Specific aspects of adolescent development, such as progression from concrete to abstract thought patterns, a desire for autonomy and separation from parents and increased identification with the peer group, can clash with the demands of cancer treatment and adherence to treatment regimens. The most extreme example of this is outright refusal of treatment. Although most countries including Australia have a medico-legal framework that provides a context for decision-making about consent to treatment for legal minors, this issue remains complex and challenging for the young person, his or her parents and the health care providers involved. It could be argued that the more common developmental challenge for clinicians – of encouraging young people's emerging capacity for self-management while helping parents to take on a more supportive 'backseat' role – is a different manifestation of the same developmental and medico-legal set of issues.³¹

More practically, psychosocial assessment is highly useful as a tool to understand the context in which adherence to any treatment regimen exists (or doesn't). A particular focus should be about identifying 'adherence hooks', that is, reasons why the patient may benefit from particular health outcomes as seen from the young person's point of view. A focus on problem solving that addresses how the young person might develop treatment routines in the context of their day to day activities can be especially helpful.³¹ Active participation of the young person in negotiating treatment plans is an important aspect of ensuring that they develop a sense of ownership and control over the disorder and its management.

Transition to adult health care

Finally, the effective transition of health care from the paediatric setting, with its strong focus on family centred care, to the more patient centred aspect of adult health care is also important to consider. This can occur in two ways. One approach is at the time of stable health for adolescent cancer survivors. Their health care can be transferred to adult services in a planned and coordinated manner in order to facilitate developmentally appropriate, risk-based guidelines for surveillance of late effects, as well as providing a different context for ongoing psychosocial assessment.³² Close attention needs to be paid at this time to ensure that young people who have completed active treatment do not inadvertently use the opportunity of transfer from paediatric to adult services to drop out of care.³³ This highlights the importance of an active transition program. A second approach is a "crisis-oriented transition" that is more likely to occur at the time of a recently diagnosed primary or secondary or recurrent malignancy. In addition to age, type of malignancy and the upper age limit for admission to paediatric programs, psychosocial assessment can also help to identify developmental factors (such as maturity, autonomy, key supports) that may be important in considering whether treatment may be more appropriate in an adult or a paediatric setting.

While there are multiple models of transition, no single model is ideal. Rather, ensuring that each institution has a transition policy and ideally a transition program with close collaboration between paediatric and adult providers and active engagement of young people and their families, is integral to the success of transfer to adult health care.³⁴⁻³⁵

Conclusion

Adolescent and young adult cancer patients present challenges to health care professionals because of the impacts of cancer and its treatment on adolescent developmental tasks and reciprocally, the impact of adolescence on the disease itself. Improving health outcomes for adolescents and young adults with cancer is best achieved when the treatment is managed within a developmental understanding of the life of the young person and their family. The identification of preventable behaviours and mental health concerns through psychosocial screening is a necessary step towards preventive counselling and anticipatory guidance, with the aim of reducing morbidity and mortality from late effects, and improving psychosocial outcomes.

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