Caring for Young People with Cancer: Practical implications of qualitative engagement with cancer survivors and members of the multidisciplinary team


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Journal: Australian Journal of Cancer Nursing

Word Limit: 4,000

Words: 2,750 (including abstract and references)
Abstract
Many adolescent and young adult (AYA) cancer survivors live with ongoing adverse consequences of their cancer experience. While an increasing number of these young Australians have direct access to care in the specialised Youth Cancer Service, many continue to receive care in diverse, non-specialised settings. It is important that health professionals in specialised and non-specialised settings are aware of the continuing diverse consequences of cancer, including the challenges created for negotiating family, peer and intimate relationships. This paper draws together insights derived from qualitative studies into the experiences of AYA who have survived cancer, with a focus on our recent Australian study of young people diagnosed during adolescence and young adulthood. We describe how members of multidisciplinary teams (MDT) can help young cancer survivors maintain their social relationships.
Introducing

Approximately 1,700 young Australians aged between 15 and 29 years, are diagnosed with cancer every year\(^1\). Due to recent advances in treatment, a greater proportion survive their illness and treatment than ever before. Indeed, members of this patient population have a 95% chance of surviving for one year after diagnosis while 88% will be alive at 5 years across all diagnoses\(^1\).

Survival however is not always easy. Young people who survive cancer often live with a range of issues including the adverse social effects of illness and treatment; disrupted life plans\(^2\), loss of independence\(^3,4\), stigma\(^3\), and exclusion from the experiences of daily life commonly enjoyed by people of their age\(^5,6\). These difficulties are further complicated by a number of barriers which include health professional training and development needs in survivorship, lack of role clarity in the follow-up of cancer survivors, and a lack of research to inform practice, education and policy\(^7,8\). Health professionals also need skills, expertise, and resources to help young survivors manage the social effects of cancer in their daily lives and relationships.

The Growing Up with Cancer study

To gain insight into the longer term experiences of people diagnosed with cancer in adolescence or young adulthood, we conducted an innovative qualitative study of young people, the Growing Up With Cancer project\(^9,10\). This study included 48 in-depth interviews with 27 young people aged between 16 and 29 years who had been diagnosed with cancer in adolescence or young adulthood (the youngest was diagnosed at age 11 and the oldest at age 22).

Young people who participated in this study provided many insights into how health professionals could assist survivors of cancer. Some participants described how the
guidance they received from health professionals during treatment helped them negotiate their diagnosis and treatment, and helped them develop expectations for their life following treatment. Others described how they benefited from the diverse skills provided by a multidisciplinary team (MDT) to help them return to school and other activities, while others spoke of how cancer support groups, social workers, and/or psychologists smoothed their transition from cancer patient to cancer survivor.

All the young people in our study spoke about the ongoing effects their cancer experience had on their relationships with parents and peers, and on their capacity and willingness to establish new intimate or sexual relationships. In this way, the Growing Up With Cancer study provides important insights into how nurses— and other healthcare professionals— can support young cancer survivors to maintain relationships with their parents and peers and to form new relationships.

**Supporting young people’s independence**

Adolescents and young adults enjoy a degree of independence usually unavailable to younger children, and this can be significantly compromised by cancer and its treatment. For example, some of our participants lived in their own accommodation before diagnosis but returned to the family home for parental care during treatment and recovery. This is a common experience (as it is for many young people facing serious illnesses) and requires them to negotiate the loss of independence and then re-establish their independence as they recover. While many young people and their parents successfully manage this process, not all families will have the emotional resources or the communicative skills to do so and compromised independence can last for years after treatment has finished.
Families with compromised resources or skills might benefit from the guidance of health professionals experienced in facilitating strong family relationships.\(^{13}\)

Members of the MDT can provide guidance for families during the period of illness and treatment that helps to prepare the family to re-negotiate a young person’s independence when they are well enough to care for themselves. This would include helping young people and parents to understand and empathise with the other’s perspective; the experience and frustration of lost independence\(^{10}\); and the desire to (over)protect vulnerable offspring. One practical strategy is to engage in activities designed to “scaffold” the young person as they develop – or redevelop – their independence during recovery.\(^{10}\) At the same time, members of the MDT need to support parents in a process of stepping back.

**Supporting friendships**

Young people are typically separated from their peers during illness and treatment.\(^{5,6}\) This is problematic as peers form a critical support network for adolescents and young adults whether sick or well, hospitalised or at home. In the Growing Up With Cancer study, young people diagnosed when they were school students spoke at length about the process of returning to school and of renegotiating their place within the peer group.\(^{10}\) While there were few accounts of explicit bullying, many spoke of feeling misunderstood by friends, or of friends unsure of how to talk about cancer.

A number of strategies can support young people re-entering their social worlds. In general terms, when re-entering their peer group after treatment, it is important that young cancer survivors are honest when discussing their health, and patient with friends who might not understand the extent of the ongoing effects of cancer treatment.\(^{10,12}\) For most young people in our study, talking about their cancer
experience at the ‘right’ time and in the ‘right’ place was beneficial for them and their friendships. What constitutes the right time or place will, of course, vary from person to person and situation to situation. Health professionals can encourage young survivors to think in advance about how they might approach disclosure. For example, how much do they want to talk about their experiences, and with whom? How can they let friends know who they in turn can tell so young survivors retain a sense of control over their experiences?

Young cancer survivors were generally receptive to questions about the experience of illness or treatment and to hearing about the experience of those events from the perspectives of their friends. Again, AYAs with cancer can be encouraged to think about how to let friends know that talking about cancer, and how they felt about their friend having cancer, are both okay.

Friends who are uncertain about a young cancer survivor’s physical capabilities after treatment can be encouraged to choose social activities that are mutually enjoyable. One young woman in the Growing Up With Cancer study described how she enjoyed dancing with her friends but was sometimes restricted in her physical activity by ongoing fatigue. At these times, she said, her friends were happy to stay home and watch movies with her.

Several electronic and printed resources have been developed in Australia to help guide young people’s re-negotiation of relationships with their peers. CanTeen’s freely available resources offer valuable guidance to help friends and partners during this often challenging time. Resources such as A guide to supporting your friend when they have cancer are a simple and effective way for young people to address issues that arise when they return to their usual social worlds. And programs such as Recapture Life - AYA are also useful for members of the MDT to
be aware of and direct young people to where appropriate. Further, CanTeen’s e-mental health platform\textsuperscript{17, 18} provides a primary site where young people living with cancer can find information, connect with others going through a similar experience, express their feelings, utilise tools for support and access professional psychosocial support services that will meet their individual needs.\textsuperscript{1} Health professionals may find these resources useful for their own practice and understanding.

Health professionals can do an enormous amount to facilitate the maintenance of social relationships during treatment periods, thus supporting young cancer survivors’ social reintegration into their peer group. Strategies including facilitating attendance at important social events from which they would normally be absent because of their illness, or facilitating involvement in the event some other way.\textsuperscript{10} For example, one parent told us that her daughter’s friends held a fashion parade in the hospital ward to show off their end of school formal dresses as a way of including her in the event.

Health professionals can also provide information or educational materials to the young person’s school or even attend their school in order to educate school students and teachers about the range of issues faced by young cancer survivors.\textsuperscript{19} For example, Ronald McDonald House Charities has a freely available printed resource known as \textit{EdMed} that provides teachers with information and educational strategies they can apply to children with a diverse range of illnesses.\textsuperscript{20} Ronald McDonald House Charities can also provide teachers with a one hour \textit{EdMed} professional development session.\textsuperscript{20} And if a young cancer survivor agrees, health professionals can invite peers into the clinic in order to de-mystify the medical

\textsuperscript{1} Recapture Life – AYA is an online group-based cognitive-behavioural therapy program for adolescents and young adults who have completed cancer treatment. It is currently available to Australian residents, with plans for international implementation in progress.
aspects of cancer and provide a shared familiarity of the clinical setting for young people and their peers. Each of these suggestions must, of course, be undertaken in collaboration with young cancer survivors themselves, be ‘offered’ rather than ‘prescribed’ and be done with the support of the institution.

**Supporting new relationships**

As well as affecting existing relationships, the ongoing effects of cancer often intrude on the formation and conduct of new relationships. Ongoing medical surveillance can be time consuming and anxiety-provoking. The physical effects of treatment can leave young people feeling unattractive and unworthy, even when their physical appearance has been “restored”. Lingering scars, the need for medication, and constraints on activity can be difficult to talk about with new friends, and particularly with new sexual partners. For many young cancer survivors, a cancer history can be experienced as stigmatising.

Members of the MDT can talk to young cancer survivors about how the ongoing physical and psychological effects of cancer might shape their experience of everyday life. They can provide young cancer survivors with specific techniques for communicating with others about their cancer history and its effects – introducing the mundane daily scenarios that may create challenges for young people, and exploring possible responses to them. This would give young people the chance to consider how they might disclose their cancer experience to new acquaintances in the future, minimising the anxiety or distress that may result when they find themselves, as one of our participants, said “in an awkward situation”. One practical approach here is for ‘experienced’ cancer survivors to share their experiences and strategies with ‘inexperienced’ survivors; cancer support groups play a vital role here.
When young people begin intimate relationships, health professionals could also encourage them to contemplate how their cancer history and its effects might be accommodated into life with their partner. This can range from relatively straightforward processes such as regular medical appointments to more complex and difficult activities such as a couple deciding to have children using in-vitro fertilisation. In this latter scenario, CanTeen’s free resource *Maybe Later Baby* provides clear and accurate information to help young people understand their fertility options before and after treatment.²¹ It also contains information for health professionals working with these young people.

Health professionals could support the young person and their partner by including them in medical consultations with the young cancer survivor’s consent. This would allow them to address issues of communication, intimacy, and sexuality. Empowering young people as actors in their own relationships is an important part of scaffolding independence for older adolescents and young adults. Such strategies may present challenges in medical settings where romantic partners are not usually present, especially in paediatric clinics, or for parents who are used to being the primary support in the young person’s medical engagements. However, we see no reason why these challenges could not be addressed with sensitivity and perseverance.

**Conclusion**

Young people who have had cancer correctly perceive that others have difficulty understanding their cancer experience and what the implications are for their future. While educating parents, friends, and partners is undoubtedly beneficial, it cannot negate the challenges that young people often face as they try to accommodate the
ongoing impact of cancer on their relationships. Even the best resourced young people are likely to undergo challenging periods when they need extra support from experienced and well-informed health professionals.

There are many ways health professionals working as members of a MDT can work with young people, their parents, and peers to support the development and maintenance of rich and mutually satisfying relationships. Empirical research on the experiences of young cancer survivors, such the Growing Up with Cancer project, provides valuable insights into how current practice can be improved to better meet their needs. Any improvement requires recognition that cancer is experienced not just in health care contexts, but in social contexts; that cancer challenges many of the tasks of adolescence, and that cancer disrupts relationships that are of great importance to young people.

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