
Unmet needs among adolescent cancer patients: A pilot study

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ABSTRACT

Objective: Adolescents with cancer pose a unique challenge to current health systems and the professional working with them. Throughout the world, it is increasingly recognized that the needs of this particular group of patients may not be met through existing services within either the pediatric or adult systems. In Australia, this is a new area of research, and little is known about the unmet physical, psychological, and social needs of this patient group. This study reports the outcomes of a focus group conducted to explore these issues.

Methods: Six young people, with a mean age at diagnosis of 17 years and 6 months, participated in a 2-h focus group. A qualitative analytic approach was utilized to examine themes.

Results: The participants identified a number of concerns relating to three broad categories: information provision, treatment processes, and survivorship.

Significance of results: The research findings support previously documented evidence that indicate gaps in cancer services provided to this age group. Importantly, these gaps can be narrowed by improving access to adolescent multidisciplinary teams and introducing specific training for health care professionals.

KEYWORDS: Adolescence, Cancer, Oncology

INTRODUCTION

Developmental stage has implications across all realms of human functioning (Dixon & Lerner, 1992). It affects cognitive capabilities, comprehension of events, communication skills, problem-solving abilities, relationships, expectations, self-esteem, emotional stability, psychological strength, and coping skills (Palmer, 2006). A patient's stage of life is inextricably linked with how he or she understands, processes, and copes with a diagnosis of cancer.

Adolescence

Adolescence is a complex life stage. It is during this time that a young person must move away from his or her childhood by establishing a sense of identity and feelings of self-worth that form the foundation of adulthood (Erikson, 1968). The developmental demands of this stage include coming to terms with an altered body image, adapting to newly developing intellectual abilities, balancing the influence of peers and family, adjusting to society's behavioral expectations, internalizing a personal value system, investigating one's sexuality, and preparing for the workplace and other adult roles (Havighurst, 1972). With the multitude of changes and challenges occurring in the life of the "normal ado-

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lescent,” young people within this life stage are often vulnerable to additional pressures or stresses (Coleman & Hendry, 1990; Geldard & Geldard, 1999).

Adolescent Cancer

Adolescent cancer patients create a significant challenge for a health system that is dichotomized into either pediatric or adult care. These young people are neither children nor adults. Many have developed beyond the family-centered pediatric approach to cancer care but have not necessarily reached the age where the individualistic, adult cancer service can meet their needs. Adolescent cancer patients form a distinct group

Victoria is Australia's second most populous state, with a population of over five million people. Each year more than 100 Victorian adolescents aged 14 to 21 years are diagnosed with cancer (Giles & Thursfield, 2003) and, due to the current makeup of Victoria's cancer services, the majority of these young people will be treated in 1 of 67 different adult institutions (Mitchell et al., 2004; D. Thomas, personal communication). This occurs in the face of increasing evidence that suggests the adult “one-size-fits-all” system may be resulting in suboptimal outcomes. Recent data suggest that adolescents with cancer have benefited less than almost any other age group from improvements in survival over the past 30 years (Bleyer, 2002) and a lack of age-appropriate medical and supportive care in adult cancer systems may be an important contributory factor (Thomas et al., 2006).

Services for Adolescent Cancer Patients

It is only recently that attention has started to focus on treatment and provision of services for adolescents with cancer (Hollis & Morgan, 2001). Areas of concern that have been identified include delay in diagnosis, lack of age-appropriate information, exclusion from decision making, keeping up with education, being in close proximity to other young people with similar conditions, and communication with medical staff (Wilkinson, 2003; Hokkanen et al., 2004; Smith, 2004). In summary, recent research has identified that appropriate supports to assist adolescent patients with managing the combination of cancer-related concerns and normal developmental challenges are largely unavailable.

The aim of this study was to explore the experiences of adolescent cancer patients in Victoria and to identify areas of unmet physical, psychological, and social need.

METHODS

A focus group enabling in-depth discussion, interaction, and exploration of ideas (Liamputtong & Ezzy, 2005) was chosen as the method of data collection.

Participants

Six young people, with an average age at diagnosis of 17 years 6 months, participated in the research. The defining commonality was that all had been diagnosed with cancer between the ages of 14 and 21 years. Their cancer diagnoses included Hodgkin's disease, non-Hodgkin's lymphoma, melanoma, brain tumor, Ewing's sarcoma, and soft tissue sarcoma. One participant was still receiving treatment for non-Hodgkin's lymphoma whereas all other participants had completed treatment, with an average time since diagnosis of 3 years. Thus, the average age at the time of the focus group was 20 years 6 months. The two male and four female patients had received their treatment from five different institutions within Victoria.

Procedure

An existing list of 90 eligible young people aged between 14 and 21 and diagnosed with a malignant tumor between January 1, 2000, and December 31, 2003, was generated from patient records. A purposive sampling method that involved stratification according to tumor type was employed to ensure representation of a variety of cancer diagnoses, treatments, and experiences. From this procedure a selected sample of 50 young people were approached by letter to participate in the study.

This was followed by a telephone call if no response was received within 2 weeks. To ensure adequate numbers for an interactive discussion, we aimed to have a minimum of 6 and a maximum of 12 participants in the focus group (Liamputtong & Ezzy, 2005). Of the 50 young people who were approached to participate in the study, 15 (30%) consented to participate, and 6 individuals (2 male and 4 female, 12%) actually took part in the focus group. Those who did not attend reported that their parents were unable to drive them or they had schooling commitments they had not been aware of. There were no identifiable differences between this group and the six who did attend. Written informed consent was obtained from all interested patients and this included parental consent if the patient was under the age of 18 years.

The 2-h focus group was comoderated by a psychologist and a social worker, both of whom have

specialist experience working with this population. They were able to monitor the distress of participants and offer timely support if required. The session was audiotaped, and detailed notes were taken by the assistant moderator. Two verbatim transcripts of each focus group discussion were typed. Data were stored in both electronic audiotaped and paper-based versions. The study was approved by the ethics committee at Peter MacCallum Cancer Centre.

Data Analysis

Grounded theory (Liamputtong & Ezzy, 2005) was used for the data analysis. After the focus groups were transcribed, checked, and corrected (Morse & Field, 1995), the data were coded based on respondent's meanings, thoughts, and feelings by identifying recurrent words, phrases, patterns, or themes. These categories were kept as broad as possible and were then developed further by making connections between categories and developing subcategories (Morse & Field, 1995). To enhance the reliability and validity of the results, each transcript was read and coded independently by two of the principal investigators. These analyses were then refined until agreement was reached about major coding categories and subcategories.

RESULTS

Three main categories and 10 subcategories were coded from the analysis of the focus groups. The three main categories were information provision, treatment process, and survivorship (Table 1).

A. Information Provision

Most of the comments were about *how* the information was provided and how improvements could be

made. This section could alternatively have been titled "Communication."

i. Diagnosis and Decision Making

In general, young people felt they were not given adequate information about their cancer:

"I know I didn't get all the information."

"They didn't tell me everything, like from the word go. They left a lot of the hard stuff out and I got it anyway, so it really made me wish they could have told me. Like I was old enough to know, to understand, but there was a lot of information they left out."

The amount of information provided to young people and the manner in which it was provided depended on the age at diagnosis and the focus of the treating institution. For those who were younger at diagnosis, comprehensive information was often provided to parents, and the patients reported feeling excluded from discussions and decision making.

"When I found out my cancer was malignant I was in a wheelchair. They pushed me to the back of the room and, like sort of talked to my mum and dad and that was it, like I was not there. But, like it was about me and I should be, I felt like I should know, like 'cause it is about me."

In contrast, some of the older adolescents were provided with all of the information, and this brought with it feelings of fear and a sense of being overwhelmed.

"I was told, and maybe being emotional and trying to take it all in in the beginning, probably didn't have the capacity to make a decision to start with. . . . I don't know if I would have been in the right frame of mind to make one."

However, despite these uncomfortable feelings, the focus group was unanimous in their wish to participate in the decision-making process:

"I would have liked the choices."

ii. Treatment

The group agreed that young people should be offered comprehensive information about their treatment.

Table 1. *Categories and subcategories identified*

Category	Subcategory
A Information provision	i Diagnosis and decision making
	ii Treatment
	iii Fertility
B Treatment process	iv Waiting
	v Physical facilities
	vi Psychosocial support
	vii Staff
C Survivorship	viii Finishing treatment
	ix Ongoing health concerns
	x Future direction

“Put down hard facts, what is actually going to happen. I wanted to know numbers. I wanted to know side effects. I wanted to know everything and I wasn’t prepared to ask; I needed to just be told or be offered, ’cause I didn’t know what to ask but I knew I wanted to know stuff.”

One young person had been given a comprehensive timetable of treatment including details of chemotherapy, radiotherapy, and the side effects of treatment. The other focus group participants felt that a timetable would have helped them understand what was happening.

“I got, like, a timetable for my whole chemo and which drugs I was going to have this week, what the side effects were, like information about different drugs . . . then I could sort of, you know, even just like figuring out whether I was going to go to work or, you know, that kind of stuff afterwards.”

iii. Fertility

Future fertility was an important issue for the young people. However, discussions about future fertility were not perceived to be a priority for medical staff. Rather, the subject was raised by the young people themselves or their parents. This occurred with patients treated at both pediatric and adult treatment settings.

“It’s like a last minute kind of thing. Don’t worry about your fertility, you might get breast cancer but, you know, don’t worry about . . . like, it was so, yeah . . . kind of not like something they focused on particularly at the time.”

All young people thought that this area of cancer care could be managed better and that it should be raised by the medical staff as a matter of course.

“It was something I didn’t really think about when I was 16.”

B. Treatment Process

With one exception, young people were unhappy with the treatment process, particularly with outpatient processes, and felt that their treatment experience could have been managed better.

iv. Waiting

All of the participants expressed that they found the waiting to be more stressful than the actual

appointment or treatment and often left young people feeling very frightened and isolated.

“Not knowing quite what’s happening . . . you feel very isolated.”

“The waiting and, like, not quite knowing what’s happening is a lot more kind of stressful than the actual appointment and procedure.”

Young people felt that hospital staff was aware of their needs, but within the confines of the hospital process, it did not seem to make a difference to the way they were managed.

“I think there is an understanding, but it doesn’t change anything. It doesn’t make it more of a priority.”

“I guess they had the perception that a few hours is not going to make a difference. But it made a whole lot of difference. . . . Dad came in at 5 a.m. one time to pick me up ’cause I was going to get out of there as soon as I could. . . . Minutes and hours were a big deal.”

v. Physical facilities

Most young people treated as inpatients were unhappy with the physical facilities provided by the hospital. They found being in an open ward with much older or much younger patients quite distressing. All would have preferred being with other patients their own age or in their own room.

“It does sort of lower the morale a little bit; probably more, say, if you were with the elderly.”

One young person had been treated with several young people of approximately the same age and found the support provided by peers to be beneficial.

“We had 6 or 7 people at the same time and we would run into each other whenever we were in for treatment and so forth and that was extremely helpful. Still, if you needed to have your space, well, you had your space and that was fine.”

They also reported little flexibility in hospital processes and often had to conform to routines that were quite different from those of home.

“I had like major surgery, I was cut from there to there, and the next day after I had that done they

made me get out of bed at 7 o'clock so they could change the sheets."

The young people were unanimous in indicating that the tolerability of hospitalization would be improved by better food and the majority of the young people agreed that access to outdoor areas would have been good.

"That's a huge thing not having any fresh air."

"Fresh air would have been nice, 'cause I always just sat there. I hated the smell. It's like the smell . . . I still can't, I can't go back because the place smells. The smell of it. . . I just get so sick."

vi. Psychosocial Support

The degree of formal psychosocial support offered to young people during treatment varied greatly and seemed largely dependent on the treating institution. Only four of six young people had seen a social worker during their treatment, and just one had received formal psychological support.

"I never really sat down and talked about what I was going through or talked about my feelings and stuff."

All of the young people reported that due to misconceptions about their illness and its treatment they had lost some of their friends.

". . . like you've got AIDS or something."

"I lost most of my friends and still they don't think I can do the basics 'cause I had cancer, so I think somebody needs to sort other people out as well."

Young people attending school felt it was important for their peers to be informed about their illness and treatment by a suitably qualified professional.

"I would have liked, honestly, for my doctor to go to my high school and talk with all my year level, all my friends and tell them what's going on and this is why it happened, like, so everyone knows what's going on."

vii. Staff

The attitude, accessibility, and cohesiveness of staff made a large difference to the psychological well-being of young people. Young people were aware of

tensions and differences of opinion within the treating team.

"It's a bit of us and them; we're the nurses, they're the doctors, we're the allied health."

Some young people reported having a poor rapport with their treating oncologist. They felt that their oncologist showed a lack of awareness and empathy with them.

"I thought if I was doing this job I would do it differently."

The attitude of nursing staff appeared to play a significant role in influencing the ability of young people to cope with the demands of treatment.

"You really would hope and wish that your nurse was never having a bad day, because there's nothing worse."

C. Survivorship

All young people expressed ongoing concerns relating to their cancer diagnosis and the impact of treatment.

viii. Finishing Treatment

The majority of young people reported experiencing psychological problems following cessation of treatment. This reportedly arose from a number of causes including the sudden cessation of a regimented timetable of treatment and the associated withdrawal of the psychological and social support provided by familiar hospital staff.

"Everything is related to getting better but not past that point. . . There is no one there to look after you after that."

The young people found there was no readily available support for those experiencing psychological problems after treatment.

"They've cured you of having cancer so everything else is now irrelevant."

Fear of recurrence of the cancer was a universal concern. This fear was usually heightened in the days prior to follow-up scans, tests, and appointments. The young people reported that relatives and friends were not able to appreciate the anxiety that follow-up visits caused.

“There’s always that big niggling fear of the recurrence.”

ix. Ongoing Health Concerns

Most young people were concerned about their current health status. All felt they were not as healthy as they had been prior to their diagnosis. They were unclear about who they should approach to discuss their health concerns and felt unable to discuss their concerns with their specialist.

“I definitely think that other things have been affected in my body. . . . I know I’m not the same as I was before. I know I’m tired. I know I get sick really easily. I know I’m just, like I’ve been depressed, but no one talked to me about that.”

“That’s why doctors don’t hear a lot of this stuff. . . . He’s a professor, so you don’t worry him with those little things.”

x. Future Directions

The intensity of cancer treatment had a significant impact on the young people’s ability to (a) finish school, (b) find or maintain work, and (c) remain or become independent. These outcomes had left many of them uncertain about their future direction.

“I was sort of young when I got sick and it’s made it harder for me to get a job now. Like, to go and have no experience.”

“I got totally lost after I had cancer. I was told I couldn’t do my job anymore, so I was just trying to think of what I was going to do with my life now.”

“I was supposed to go to Uni and they forgot to tell my school before, what is it special consideration points, and I was 2 points off my marks and with this special consideration I could have got into Uni. So I’m stuffed.”

DISCUSSION

The adolescents participating in the focus group identified a number of areas of unmet physical, psychological, and social needs within the current service model. These issues were raised by patients who had been treated in both the pediatric and adult systems.

Findings

Many of the issues identified in this research are relevant for all ages (Whyte & Smith, 1997). How-

ever, to meet the needs of this unique group of patients, the identified issues must be addressed in an age-appropriate way. The provision of information about diagnosis, prognosis, and treatment is a good illustration of this point.

Research has shown that adolescents with cancer wish to be better informed, even if the information is bad news, such as poor prognosis or ineffective treatment (Dunsmore & Quine, 1995). However, the perceptions that professionals have about the developmental requirements and cognitive capacity of adolescents impacts on how, and if, adolescents receive such information. Within a pediatric institution, it is common practice for the oncologist to discuss information with the parents of the child. Within an adult hospital it is common practice to speak directly with the patient and rely on the patient to make informed decisions about his or her care. The outcomes of this focus group appear to indicate that neither of these options results in optimal care for the adolescent patient.

Adolescent patients may not always directly ask for information. Whether it was an issue of confidence, communication, unsatisfactory relationships with professionals, trust, or privacy, most patients indicated that there were times they did not ask questions, even though they wanted to know answers. An example of adolescent patients wanting further information but not asking for it was evidenced in the discussions about fertility among the group. The effects of cancer treatment on fertility are well documented (Kwon & Case, 2002). However, a number of the participants in the group could not recall being informed of potential reproductive problems. In one instance, all discussions about fertility were with a parent of an adolescent patient and the adolescent was only informed of potential fertility problems 2 years after completing treatment. Our research showed that not only do adolescents identify future fertility as an important issue, but they appeared to be poorly informed about their ability to have children. These issues must be clearly addressed with the adolescent patient prior to embarking on treatment.

To avoid feelings of uncertainty, alienation, loss of control, and resentment (Ishibashi, 2001) information must be provided in an age-appropriate manner. This may involve (a) presenting information directly to the patient, (b) ensuring the language used is understood, (c) allowing time for the processing of information, (d) not assuming the patient will feel confident to ask questions, (e) not assuming that the concerns of the parents are the same as the concerns of the adolescent, and (f) communicating the information in a caring manner.

The adolescent life stage is known to be a period of increased vulnerability to stress. The Australian psychosocial guidelines for working with cancer patients clearly identify this age group to be at risk of poor psychosocial functioning (National Health and Medical Research Council, 2003). However, despite this recognition, there were some adolescents participating in the focus group who had not had any contact with a social worker and only one had been provided with formal psychological support. We recommend that a preventative approach be taken with all young cancer patients that includes early psychosocial screening and appropriate intervention for every adolescent undergoing treatment for cancer.

Implications for Current Practice

Developmental stage influences every aspect of a young person's cancer journey. To provide effective care to this group of patients, the professionals working with them must be ever cognizant of the developmental implications.

Adolescent patients have reported that being accepted and understood directly affected the quality of care they received (Smith, 2004). It is increasingly recognized that to provide the best care to these patients, the professionals working with them must be specifically trained (Smith, 2004; Craig, 2006). This training must include knowledge of adolescent development, the implications of a cancer diagnosis and treatment on adolescent development, and an understanding of how these developmental differences influence the care of adolescent patients.

Many of the themes that were identified in the focus groups have been identified elsewhere (Smith, 2004). These findings have led to the development of adolescent-specific cancer units in the United Kingdom that incorporate a number of developmentally sensitive features including late wakening, open visiting hours and a "no uniform" policy for staff (Mulhall et al., 2004). However, although these units have been effective in meeting the needs of the adolescents, they do not represent the only way to improve care for these patients.

Age-appropriate, multidisciplinary support is essential (Craig, 2006) and it can be provided within current systems.

In Victoria, a multidisciplinary team of health professionals has been working exclusively with adolescent and young adult patients treated within adult institutions (Mitchell et al., 2004). Over the past 30 months, more than 320 young people have been referred to the program where they receive age-specific care. Anecdotal evidence reveals that

both the patients and the treating teams that refer the young people have found the support and guidance of the adolescent and young adult team to be highly beneficial.

Limitations

A focus group has a number of inherent methodological limitations. First, none of the invited participants knew each other and it would have taken considerable courage to agree to talk about such intimate experiences with a group of strangers. Thus, a selection bias might have meant only confident and extroverted adolescents chose to be involved. Second, although the focus group was facilitated by an experienced moderator, it is recognized that more confident individuals within the group can influence, or even dominate, other group members. Third, although six participants is considered a reasonable number for a focus group (Liamputtong & Ezzy, 2005), it remains too small to generalize any conclusions. Rather, the outcomes of this study highlight a number of important areas of possible unmet need in adolescent cancer care that require further research. Finally, although approximately three to five focus groups are recommended when working with this methodology (Liamputtong & Ezzy, 2005), this did not occur due to insufficient resources. It is anticipated that a questionnaire based on the outcomes of the focus group will soon be developed and mailed out to a large number of adolescent cancer patients in a bid to explore the issues raised in further detail.

Future Directions

All patients deserve the best care regardless of their age or stage of life. However, the provision of such care needs to be flexible enough to take into account the developmentally specific needs of patients throughout the lifespan. Currently, as has been found elsewhere in the world, the unique needs of adolescent cancer patients in Victoria may not be being met in either adult-centered or child-focused environments. The professionals involved in their care should receive training that enables them to provide holistic comprehensive care for the adolescent patient in a multidisciplinary team. If service provision for adolescents is not recognized as the distinct area of clinical health care that is so clearly is, the current inequity in service provision is in danger of continuing and there will remain significant areas of unmet need for this inherently vulnerable population group.

REFERENCES

- Bleyer, A. (2002). Older adolescents with cancer in North America: Deficits in outcome and research. *Pediatric Clinics of North America*, *49*, 1027–1042.
- Coleman, J. & Hendry, L. (1990). *The Nature of Adolescence*, 2nd ed. New York: Routledge.
- Craig, F. (2006). Adolescents and Young Adults. In *Oxford Textbook of Palliative Care for Children*, Goldman, A., Hain, R., & Liben, S. (eds.), pp. 108–118. New York: Oxford University Press.
- Dixon, R. & Lerner, R. (1992). A history of systems in developmental psychology. In M. Bornstein & M. Lamb (Eds.). *Developmental Psychology: An advanced textbook* (3rd ed.). New Jersey: Lawrence Erlbaum Associates (pp. 3–45).
- Dunsmore, J. & Quine, S. (1995). Information, support and decision-making needs and preferences of adolescents with cancer: Implications for health professionals. *Journal of Psychosocial Oncology*, *13*, 39–56.
- Erikson, E. (1968). *Identity: Youth and Crisis*. London: Faber & Faber.
- Geldard, K. & Geldard, D. (1999). *Counselling Adolescents: A Pro-Active Approach*. London: SAGE Publications.
- Giles, G. & Thursfield, V. (eds.) (2003). *Canstat: Cancer in Victoria in 2001*. Melbourne: The Cancer Council Victoria Epidemiology Centre.
- Havighurst, R. (1972). *Developmental Tasks and Education*, 3rd ed. New York: David McKay Co.
- Hokkanen, H., Eriksson, E., Ahonen, O., et al. (2004). Adolescents with cancer. *Cancer Nursing*, *27*, 325–335.
- Hollis, R. & Morgan, S. (2001). The adolescent with cancer—At the edge of no-man's land. *The Lancet Oncology*, *2*, 43–48.
- Ishibashi, A. (2001). The needs of children and adolescents with cancer for information and social support. *Cancer Nursing*, *24*, 61–67.
- Kwon, J. & Case, A. (2002). Effects of cancer treatment on reproduction and fertility. *Journal of Obstetrics and Gynaecology Canada*, *24*, 619–627.
- Liamputtong, P. & Ezzy, D. (2005). *Qualitative Research Methods*, 2nd ed. Melbourne: Oxford University Press.
- Mitchell, A., Scarcella, D., Rigutto, G., et al. (2004). Cancer in adolescents and young adults: Treatment and outcome in Victoria. *Medical Journal of Australia*, *180*, 59–62.
- Morse, J. & Field, P. (1995). *Qualitative Research Methods for Health Professionals*, 2nd ed. London: SAGE Publications.
- Mulhall, A., Kelly, D., & Pearce, S. (2004). A qualitative evaluation of an adolescent cancer unit. *European Journal of Cancer Care*, *13*, 16–22.
- National Health and Medical Research Council. (2003). *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer*. Australia: NHMRC.
- Palmer, S. (2006). Understanding the Causation, Expression, and Course of Adolescent Posttraumatic Stress within a Developmental Framework and Developing a Screening Tool to Identify the Adolescent Specific Manifestations of Posttraumatic Stress. Unpublished dissertation. University of Melbourne.
- Smith, S. (2004). Adolescent units—An evidence-based approach to quality nursing in adolescent care. *European Journal of Oncology Nursing*, *8*, 20–29.
- Thomas, D., Seymour, J., O'Brien, T., Sawyer, S., & Ashley, D. (2006). Adolescent and young adult cancer: A revolution in evolution? *Internal Medicine Journal*, *36*, 302–307.
- Whyte, F. & Smith, L. (1997). A literature review of adolescence and cancer. *European Journal of Cancer Care*, *6*, 137–146.
- Wilkinson, J. (2003). Young people with cancer—How should their care be organized? *European Journal of Cancer Care*, *12*, 65–70.