

Disease self-management needs of adolescents with cancer: perspectives of adolescents with cancer and their parents and healthcare providers

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Abstract

Purpose The ability for adolescents with cancer (AWC) to engage in disease self-management may result in improved cancer outcomes and quality-of-life ratings for this group. Despite this, a comprehensive self-management program for this group is yet to be developed. To ensure that self-management programming developed for AWC meets the needs of this group, discussion with key stakeholders (i.e., AWC, parents, and healthcare providers) is required.

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Methods A descriptive qualitative design was used. Adolescents ($n=29$) who varied in age (12 to 18 years) and type of cancer, their parents ($n=30$) and their healthcare providers ($n=22$) were recruited from one large tertiary-care oncology center. Audio-taped semi-structured individual and focus-group interviews were conducted with participants. Transcribed data were organized into categories that reflected emerging themes.

Results Four major themes, which captured the self-management needs of AWC, emerged from the data. These themes were: (1) disease knowledge and cancer care skills, (2) knowledge and skills to support effective transition to adult healthcare, (3) delivery of AWC-accessible healthcare services, and (4) supports for the *adolescent* with cancer.

Conclusions In order to provide comprehensive, relevant, and acceptable self-management programs to AWC, the voices of this population, their parents, and healthcare providers should be considered. Findings from this study will be used to develop and evaluate cancer self-management programming for AWC.

Implications for cancer survivors Self-management represents an important avenue for exploration into improving cancer outcomes and quality of life for survivors of cancers during adolescence.

Keywords Adolescent · Cancer · Self care · Self-management · Qualitative · Neoplasms

Introduction

Over the last 25 years, the proportion of children with cancer who become long-term survivors has steadily increased and now, about 80 % of newly diagnosed children are expected to be cured [1]. However, adolescents with

cancer (AWC) have emerged as a unique subgroup of pediatric cancer patients and survivors with health-related quality-of-life (HRQL) ratings that have lagged behind those of younger children and adults [1, 2]. Unique characteristics related to developmental stage may result in this population being especially susceptible to the emotional stresses of the cancer experience [3]. Adolescence is a period of life fraught with role-changes, shifting expectations and new and challenging social interactions. These qualities, combined with underdeveloped abilities to cope with cancer and its treatment sequelae [3] can result in treatment non-adherence [4, 5] and reduced quality of life compared with these other groups [6].

Self-management has been suggested as one strategy to improve these adherence rates and outcomes [7–10]. Self-management has been broadly defined as the ability of an individual to manage the symptoms, treatment, lifestyle, physical, and psychological consequences of living with chronic [11] or life-limiting illnesses such as cancer [12]. Self-management interventions typically encompass information-based material and cognitive-behavioral strategies designed to achieve disease-related learning and changes in the participant's knowledge, understanding, beliefs and skill acquisition as well as establish meaningful social support networks [11, 13, 14]. Studies in both adult [15–19] and pediatric chronic illness [20–25] have shown that comprehensive self-management interventions lead to symptom reduction and improved HRQL compared with care that is strictly medically focused. This effect is expected to result from a sense of enhanced self-efficacy and empowerment over the disease and symptom management [26, 27].

Presently, a limited body of knowledge related to the cancer experiences of adolescents exists [28–30], but no study has uncovered which practical strategies AWC require to engage in effective cancer self-management. To inform the development of self-management programming for AWC, a broad and rich understanding of what the key stakeholders in adolescent cancer care (i.e., AWC, parents, and healthcare providers) think adolescents need to self-manage their cancer experiences is needed. The intent of the present study was to gain insight into AWC self-management needs from the perspectives (i.e., expressed opinions and experiences) of the adolescents, parents, and healthcare providers to inform the development of self-management programming for AWC.

Methods

The study of the self-management needs of adolescents with cancer lends itself to a qualitative descriptive study design [31]. Individual or family semi-structured interviews were conducted to gain deeper insight into self-management issues [32]. Focus-group interviews were conducted to

capitalize on shared interaction between participants and to confirm insights gained in individual interviews [33]. The study was approved by the research ethics board at the participating center.

Setting and sample

Participants were recruited from one large university-affiliated tertiary hematology/oncology care center in Toronto, Canada over an 8-month period in 2010. Adolescents were eligible to participate if they were: (a) 12 to 18 years of age, (b) diagnosed with and actively being treated for cancer, or within 2 years of cancer therapy completion, (c) able to speak and read English, and (d) being seen on an in- or out-patient basis by the hematology/oncology team. Adolescents were excluded if they had severe cognitive impairments or major comorbid medical or psychiatric illnesses that would preclude assessment of needs and/or if they had been referred to an after-care program. Parents were eligible to participate if they had an adolescent diagnosed with cancer who was actively being treated or within 2 years of treatment. Adolescents were able to participate on their own if their parent/caregiver was not interested; similarly parents were able to participate without their adolescents. Any healthcare provider working in the neuro-oncology, leukemia/lymphoma, and solid tumor programs at the hematology/oncology care center was eligible to participate in the healthcare provider focus-groups. Convenience sampling was used, supplemented by purposive sampling to achieve maximum variation in age, sex, diagnosis, and in- or out-patient status. This sampling strategy provided information-rich cases and helped to ensure expert insight from a heterogeneous sample.

Twenty-nine AWC participated in the individual interviews ($n=27$) and one focus group interview ($n=2$). This focus group had six AWC scheduled to participate in it; however, four were absent on the arranged day. Of the 29 AWC, 12 were on-treatment and 17 were off-treatment. Thirty parents participated in individual interviews ($n=21$) and two focus groups ($n=9$). Three focus groups were also conducted with healthcare providers ($n=22$). Healthcare providers were diverse in professional training (eight registered nurses, three hematologist/oncologists, three advanced practice nurses, two oncology fellows, one pharmacist, one social worker, one psychologist, one psychiatrist, one speech language pathologist, and one dietitian) and had a mean of 20.7 years experience ($SD=10.08$ years; range=7–40 years). The acceptance rate for the healthcare provider group was 92%. Demographic characteristics of the AWC sample are summarized in Table 1.

Procedures

Consent was obtained prior to each interview and participants completed a brief questionnaire on demographic

Table 1 Demographic characteristics of the adolescent with cancer sample

Characteristic	M±SD	n (%)
Age (years)	15.1±1.9	
Sex		
Female		15 (52)
Male		14 (48)
Type of cancer		
Brain tumor		7 (24)
Leukemia/lymphoma		12 (41)
Solid tumor		10 (35)
Relapse?		
No		19 (66)
Yes		10 (34)
Treatment type		
Chemotherapy		25 (86)
Radiation		12 (41)
Surgery		12 (41)
Duration of illness (years)	3.0±3.4	

Data are for $n=29$ adolescents

characteristics. Additional demographic and disease-related data were gathered from medical charts by a research assistant. Individual interviews lasted between 25 and 60 min and focus groups lasted between 47 and 88 min. All interviews and focus-groups were conducted by one interviewer experienced in interviewing both adolescents and adults. Techniques were used during interviews (i.e., ice breakers to get to know the participants, use of simple non-medical language, arranging seating to be at eye level with participants, when appropriate conducting individual interview with family members to maximize the participants comfort level, employing reciprocity in conversation exchange) to minimize any effect of a power differential on discussions [32]. All interviews and focus groups were audio-taped and field notes were made during or immediately following interviews to record the interviewer's impression of the participants' responses to questions and comfort level with the interviewing process.

A general introductory question was asked followed by broad questions and probes to encourage participants to elaborate on their thoughts and opinions. Questions were compiled from reviews of relevant literature and the clinical experience of the research team. The list of questions was modified during the course of the interview process in light of emerging themes.

Data analysis

Demographic data were analyzed using SAS version 9.1.3 [34]. Audio-taped interviews were transcribed verbatim. All transcripts were verified against the tapes by one author (MW) and imported into NVivo 8.0 [35] for coding. Field

notes taken during the interviews were also transcribed and included in the analytic process. The analysis was conducted independently by two members of the research team (MW and LJ) and coding disagreements (e.g., wording of themes) were handled through consensus by three authors (JS, MW, and LJ). Using grounded theory latent coding [36], an accepted qualitative approach [37, 38] data were coded according to study objective and categorized to reflect emerging themes. Hierarchical coding [39] was then used to further delineate the themes. These techniques allowed us to build a theoretical framework of the self-management needs of AWC, using the perspectives of all participant groups. The raw data were regularly revisited during analysis to ensure that the codes and resulting themes were grounded in the data [31]. Theoretical saturation was reached when no further themes could be identified [40]. Charts and matrices were used to construct a more unified and integrated understanding of the data [31].

Initially, the individual and focus group interviews were analyzed separately; however, the codes from these data sets were compared continually throughout the analytic process. As analysis progressed, it became clear that the data were similar as neither individual nor focused group data yielded any unique codes and thus provided a strong source of triangulation for the developing themes. Accordingly, the data from the focus groups and individual interviews are presented together.

Results

Transcript analysis revealed four distinct themes, which captured the self-management needs of AWC: (1) disease knowledge and cancer care skills, (2) knowledge and skills to support effective transition to adult healthcare, (3) delivery of AWC-accessible healthcare services, and (4) supports for the *adolescent* with cancer. Each of these overarching themes encompassed several subthemes (see Table 2), which are described in detail below. In all cases but one, each of these themes subthemes were borne out of data collected from all participant groups, and therefore represent the convergent perspectives of these groups. The one subtheme that was not endorsed by all participant groups was, "practical skills to manage the cancer." This self-management need was discussed by AWC and parents but was not mentioned by healthcare providers.

Disease knowledge and cancer care skills

Participants identified several aspects of disease knowledge and cancer care skills that were central to developing effective self-management strategies for AWC. These included the development of a working knowledge of cancer as a disease, an understanding of available treatments, therapies

Table 2 The disease self-management needs of adolescents with cancer: themes and subthemes

Theme	Subtheme
Disease knowledge and cancer-care skills	Working knowledge of the disease
	Working knowledge of treatments, therapies and procedures
	Practical skills to manage the cancer
Knowledge and skills to support effective transition to adult care	Knowledge of adult care and the transition process
	Skills supporting self-advocacy and communication with the healthcare team
	Knowledge of late effects to support survivorship
Delivery of AWC-accessible healthcare services	Developmentally appropriate services and resources
	Up-to-date, trustworthy information delivered at opportune times
Supports for the adolescent with cancer	Body image and lifestyle information
	Connection with other adolescents
	Information about available resources and financial supports

and procedures and the development of practical skills to manage the disease.

Working knowledge of the disease A working knowledge of cancer was viewed as a key requirement to support the cancer self-management by AWC. Ideally, this knowledge should encompass general information about the pathology of the disease, possible causes, prevalence and incidence and adverse disease effects. This was articulated by one adolescent who discussed the nature of disease-knowledge AWC need:

Like umm, could the cancer spread and stuff, why do I need this particular test and like umm, how will a surgery affect the rest of my life, and what could I do and could I not do because I had a choice between two surgeries, like questions of which one is better.

Working knowledge of treatments, therapies and procedures The development of a knowledge base focused on the multitude of available cancer treatments, therapies and procedures was also required for AWC to self-manage cancer. With respect to treatment, knowledge of medications was viewed as an important need as highlighted by the following AWC:

It’s like, there are a whole lot of medications in me and I don’t know where they’re going, what they’re doing, how they gather or how they help each other.

In addition, it was expected that treatment information extend beyond conventional medicine to include information on physical therapy, psychological therapy and complementary and alternative medicine. For instance, a healthcare provider described how that teaching AWC about these complementary medicines is needed because of the potential positive effects of these therapies:

And it might not hurt to encourage other things, like meditation, or yoga, or deep breathing exercises. All of those other things that are used to manage anxiety and manage symptoms and pain control.

Practical skills to manage the cancer In order to begin to take control over the disease, adolescents must develop a cancer care skill-set. Developing this skill-set was a source of pride and empowerment for AWC. Skills that were perceived as important to master included those focused on managing treatment side-effects and coping with painful procedures (i.e., learning distraction techniques). For instance, one adolescent described the potential usefulness of providing AWC with “tips” to manage chemotherapy-related nausea:

It would probably help kids if they didn’t like it and wanted to get past it faster, tips would be better. So like, they could keep themselves occupied and their minds off of it and stuff. So you’re not just sitting there just feeling it.

Knowledge and skills to support effective transition to adult healthcare

To successfully self-manage cancer, AWC require knowledge and skills to support the transition from pediatric to adult healthcare. It was perceived that these knowledge-pieces and skills should come in the form of: (a) information related to the adult healthcare system and the transition process, (b) the development of self-advocacy and communication skills and (c) information on the late-effects of cancer to support cancer survivorship.

Knowledge of adult care and the transition process All participant groups articulated the need for AWC to develop an understanding of the adult healthcare system and the necessary transition process to adult care (and adulthood). Healthcare providers as a group understood that the adult care system demands more active participation from patients compared with pediatric-care and AWC should be prepared for this change. In a joint interview with a parent and AWC, a mother articulated her fears about her adolescent’s readiness to assume this responsibility over cancer care:

Because kids need to know, you know, “what am I suppose to be doing afterwards”, if God-forbid something was to happen to myself and your dad. Who is going to be the, you know, who is going to help you ask the right questions and make the right decisions and continue on?

Skills supporting self-advocacy and communication with the healthcare team Participants also indicated that to develop effective disease self-management skills, AWC should be able to advocate for themselves and communicate clearly with their healthcare team. It was recognized that because of their developmental stage and the shifting levels of responsibility between AWC, their parents and their healthcare team, assisting AWC in developing these skills is vital. Helping AWC to become their own advocates was also underscored as an area parents and healthcare providers needed to improve upon. As one healthcare provider detailed, the current common practice is to focus cancer information on parents rather than adolescents:

I think that there are times that the child or the teen should be more actively involved and is not...I don't always think we do such a great job at helping teens become owners of their information. I think because we're such a children's hospital, I think our focus is usually still on speaking with the parents and getting the parents to understand. I don't think we're always very good with those kids who are 16, 17, regardless of how mature or immature, I mean we should still be having that dialogue with them.

Knowledge of late effects to support survivorship All participants discussed the need for AWC to build knowledge of the late effects of childhood cancer treatment and survivorship. To facilitate cancer self-management AWC should understand the effects of cancer treatment, how to protect health and how to plan for the future. Two separate AWC discussed the information they felt was needed to understand late effects and to begin a life as a cancer survivor:

Stuff to like help your body out, because it went all through these drugs and stuff and it can affect you in the long-run. Like, you might have troubles, heart troubles, liver troubles, all that kind of stuff.

At this age you're thinking about like going to university and stuff. So yeah, I think [survivorship] would be a good thing to talk about. Cause it's just looking forward into the future, what can you expect and stuff. As much information as possible about your future is always good.

Delivery of AWC-accessible healthcare services

Healthcare services which are accessible to adolescents represented a third major theme seen as a self-management requirement for AWC. Adolescent-accessible healthcare involved: (a) services and resources that are developmentally appropriate for the adolescent demographic and (b) information that is up-to-date, trust-worthy, and delivered at opportune times.

Developmentally appropriate services and resources The importance of having services that are aimed at the developmental needs of adolescents was stressed as a self-management need for AWC. Participants indicated that currently available services and resources are generally aimed at adults or younger children, leaving adolescents “without a home” for cancer care. This was illustrated by the following two participants (a parent and a healthcare provider) who described the different experiences of caring for children with cancer and adolescents with cancer:

I find, again having gone through this twice at age 11 and at 16, it's a whole different ball game, when you're 16. When you're 11...there was a lot of um activities for kids at that age level. When you're 16, it's a whole different ball game...it's just very brutal time when you're 16 and you're sick.

So I don't think sometimes our mindset shifts enough to say, ‘Oh, wait this is a 16-year old!...I need to talk about sex and drugs and smoking and all those other important things’. I think sometimes you're just in a mode of 3- and 4-year olds—eating, drinking, pooping? Everything's good.

Up-to-date, trustworthy information delivered at opportune times It was also indicated that information given to AWC to help develop cancer self-management strategies be recent, relevant and from a trustworthy source. In addition, parents and AWC often felt overwhelmed by information delivered by healthcare providers and thought the ability to review information at times convenient for them would be beneficial. This idea of needing up-to-date information is described by an AWC:

You never know what you are reading, something that was ... modern five years ago may be different today ... So you want to have a sense that people are updating it and reviewing it and I mean when I go to a website that's what I would look for.

Supports for the adolescent with cancer

Finally, to build cancer self-management strategies AWC require supports to navigate the typical issues associated

with the adolescent developmental stage. It was indicated that these supports should include: (a) information about body image issues and lifestyle choices, (b) the ability to connect socially with other adolescents and (c) information about resources and financial supports to facilitate a normative adolescent experience.

Body image and lifestyle information All participant groups emphasized the need for AWC to have access to information about body image and lifestyle choices. The following two references were made by healthcare providers regarding information that should be available to AWC highlight this:

Body image. Because I think body image is an issue for every adolescent regardless of whether you have a chronic or life threatening illness. It's huge.

How is it going to affect what they do everyday—if they play sports, or if they like to party and drink, if they use marijuana? They want to know, alright, what is it going to do to me? How is it going to affect the way I live my life?

The reference from an AWC below further demonstrates the level of importance placed on body image to the adolescent group, as well as the need for careful education around potentially harmful behaviors:

Yeah like if you can't tan, what are other options you have for getting tanned. Like, [laugh] stuff like that.

Connection with other adolescents Establishing a connection with other adolescents was seen as critical to supporting normative adolescent development and was an integral to developing self-management skills for AWC. Adolescents expressed a strong desire to communicate with other AWC. They were also interested in developing skills to communicate their experience and connect with adolescents without cancer. Participants discussed the need to find this social support, as articulated by the following AWC and parent:

Well um, I have two really close friends that come and visit me most of the time. And then I have another best friend of mine that came quite a bit ago—and yeah, I'll probably have them over again because um, sometimes you just, sort of start to miss them.

My son and three other kids became extremely close—[they] all had the same diagnosis, practically all the same age and they would meet in the hall and they would play together and it was the absolute best therapy I have ever seen in my life.

Information about available resources and financial supports To facilitate “the adolescent experience” AWC required

information about cancer care resources and how to acquire these resources financially. These resources included assistive technology to improve accessibility for AWC with mobility issues and academic and vocational assistance for AWC with learning disabilities resulting from disease or treatment. The experience of struggling to access these resources for her daughter is described by an AWC mother:

And we didn't learn about things right away which was difficult for us financially. For example, her wheelchair. We didn't know that there was a special program that would fund her wheelchair, so we rented the cheapest wheelchair from the drugstore for over a year, and she was sitting in the wrong wheelchair.

Discussion

Adolescents with cancer, their parents and healthcare providers provided their perspectives on the practical requirements needed for AWC to effectively engage in cancer self-management. All participant groups cited knowledge about cancer as a disease and cancer treatments and associated procedures as necessities. It was also indicated that AWC require knowledge related to adult healthcare and the process of transition to the adult system. Participants also highlighted the need for the delivery of healthcare services that were appropriate, and therefore accessible, to the adolescent developmental stage. Finally, to develop self-management strategies, it was indicated that AWC need to be supported in engaging in the same adolescent experiences as their peers without cancer. Interestingly, the only subtheme not constructed using data from all of the participant groups was “practical skills to manage the cancer,” which was not discussed by healthcare providers, but dealt with the cancer-management “tips and tricks” acquired by AWC during their treatment. These practical “tricks” were viewed as important accomplishments by AWC and the divergence in self-management opinion may hint at a growing need for adolescents to develop a sense of autonomy that is not being recognized by providers.

Although to our knowledge no study has specifically addressed the strategies adolescents need to develop cancer self-management skills, our results on the information needs of AWC are in agreement with those published. For example, an exploration of the specific information needs of adolescents newly diagnosed with cancer and those within 1 to 3 years of diagnosis found AWC wanted information on treatment and side effects, social issues, personal/emotional issues and how to deal with stress and uncertainty regarding their illness [28]. These findings are echoed in our own study; however our study also raised awareness around the

need for AWC to have information on transitional care and late effects to support self-management as they transition to after care or adult care. In addition, studies into self-management in other chronic diseases (i.e. genetic syndromes, diabetes and arthritis) found similar informational and self-care needs [41–44]. Adolescents in these studies required communication and self-care skills and social support from peers. Our results departed from these other studies in that supports for normative development were of key importance to AWC and not explicitly underscored as required for adolescents with other chronic diseases. In addition, these other studies often focused on problem-solving skill development by adolescents with chronic health conditions, a concept not revealed by our thematic analysis. AWC in our study were not as focused on the ability to manage their condition across their life span as many children with cancer will be cured or go into remission. This is important for clinicians who work with AWC as many of these youth did not realize the need for lifelong monitoring for late effects of their cancer treatment.

Uncovering and addressing these unmet needs may be of great importance to the care of AWC. For instance, the health behaviors of youth and young adults with cancer have been identified as being less than optimal with survivors losing contact with healthcare system and not engaging in follow-up appointments and engaging in unhealthy activities such as smoking [45, 46]. In addition, unmet information needs and knowledge deficits have been identified among adult patients and survivors of childhood cancers [47, 48]. Therefore the development of education (i.e., on the immediate impacts of cancer, long-term health risks and surveillance/monitoring) and self-management strategies specifically for AWC to increase adherence to medical treatments and rates of successful transition to aftercare and/or adult healthcare are critical.

Furthermore, our study shows that in order to engage in cancer self-management AWC must be supported in engaging in a normative adolescent experience. All participant groups highlighted the need for adolescents to receive information to support the development of a healthy body image and information about potential lifestyle choices. Adolescents also required information about the resources they could access to facilitate engaging in this experience. Based on the current study's findings it is apparent that as cancer information takes precedence during treatment, AWC are not receiving the lifestyle information, information about risk-taking behaviors, sexuality, and maintaining social relationships that they desire. The need for the healthcare system to engage with AWC around developmentally appropriate issues such as these has been stressed in the past with dedicated teenage cancer units being suggested as an important avenue for exploration [49, 50].

Social support was also indicated as an important AWC self-management need. This is in agreement with previous research showing that social support is viewed as extremely important by adolescents with cancer [51]. The cancer experience can be trying on the adolescent social support network. Adolescent cancer survivors have reported changes in established friendships due to lack of time to socialize because of the demands of the illness and treatment [52]. Therefore, given the known therapeutic benefits of social support [53] and the importance of adolescent peer relationships to normative development [54]; helping AWC develop skills to communicate with peers about their cancer and maintain peer connections may be beneficial in helping AWC achieving the best possible quality of life.

It has previously been suggested that because of the different and necessary roles patients, families and various healthcare providers play in self-management; all of these stakeholders must be involved from the early stages of program planning and development [55–57]. The themes presented in our study were established based on the voices of all of these important stakeholders. It is hoped that, moving forward, this will allow for the development of comprehensive and effective self-management program that is relevant, meaningful and useful for AWC.

The rigor of this study was enhanced by using analyst triangulation (e.g., several researchers involved in data analyses) and methodological triangulation (e.g., multiple data collection methods). This integrated multifaceted process provided different types of cross-data validity checks and reduced the likelihood of bias [31]. Limitations included the heterogeneous sample in terms of wide age range and types of cancer and that the sample was drawn from one centre possibly leading to our inability to find differences in the themes based on these factors. Further research on the influence of these factors on adolescents' self-management and transition needs is warranted. Finally, we were only able to interview each participant once and were not able to perform member checking to verify the themes.

In conclusion, the key cancer self-management needs of adolescents have been identified by AWC, their parents and their healthcare providers. All groups have highlighted the importance of cancer and transition knowledge, healthcare that is AWC-appropriate and supports for the *adolescent* with cancer to assist self-manage the disease. Our study therefore provides an important foundation on which to develop self-management programming for AWC. Knowledge acquired through this research will help to ensure that the content and format of developed interventions are relevant and acceptable to AWC. Next steps will involve development and testing of the usability and feasibility of an Internet-based self-management intervention for AWC prior to conducting a definitive multi-centered randomized controlled trial.

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Conflict of interests The authors have no conflict of interests to disclose.

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