Supportive Care in Cancer (2019) 27:623–630
https://doi.org/10.1007/s00520-018-4350-7

ORIGINAL ARTICLE

"Improving to where?": treatment-related health risks and perceptions of the future among adolescents and young adults after hematopoietic cell transplantation

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Received: 4 April 2018 / Accepted: 9 July 2018

Abstract

Purpose Despite the prevalence of hematological malignancies in early adulthood, very little is known about hematopoietic cell transplantation among adolescents and young adults, and even less is known about their transition from the completion of therapy to early survivorship. In this qualitative study, we investigated the impact of the cancer experience on sense of life potential and perception of the future from the perspectives of adolescents and young adults after hematopoietic cell transplantation.

Methods In-depth interviews were conducted with adolescents and young adults who underwent allogeneic or autologous hematopoietic cell transplantation between the ages of 15–29 years and were 6–60 months post-treatment. Interview transcripts were systematically coded based on constructivist grounded theory.

Results Eighteen adolescents and young adults participated and described how they came to understand the lifelong, chronic nature of cancer survivorship. "Improving to where?" was a question raised in the post-treatment period that reflected participants' confusion about the goals of treatment and expectations for survivorship. Participants reported bracing themselves for "something bad" to deal with the uncertainty of medical and psychosocial effects of treatment. They struggled to move forward with their lives given their substantial health risks and found it necessary to "roll with the punches" in order to adjust to this new reality.

Conclusions Adolescents and young adults who undergo hematopoietic cell transplantation are at significant risk for long-term and late effects in survivorship. Age-appropriate interventions are needed to support these survivors as they manage their fears about the future while enhancing health and well-being.

Keywords Cancer · Survivorship · Adolescents · Young adults · Transplantation · Late effects

Due to improvements in early detection, treatment modalities, and supportive care, there are nearly 16 million cancer survivors in the United States (U.S.) [1]. Across cancer types, some of the most rapid improvement has been observed in hematopoietic and lymphoid malignancies as treatment protocols have become more refined [2]. Hematopoietic cell transplantation (HCT) is now a standard treatment for several hematologic malignancies. Based on data from the Center for International Blood and Marrow Transplant Research from 1968 to 2009, there are approximately 108,900 HCT survivors, including 67,000 autologous and 41,900 allogeneic, in the U.S., and these numbers are expected to increase fivefold by 2030 as application for this treatment continues to expand [3]. Better HCT outcomes have been attributed to more precise clinical practice that has decreased treatment-related mortality through reduced-intensity conditioning regimens, enhanced patient-donor human leukocyte antigen (HLA) matching,

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and improved timing of HCT [4, 5]. However, the therapeutic exposures of HCT contribute to significant physical and psychological morbidity among this growing group of survivors, persisting for many years beyond treatment [4, 6–8].

With more HCT recipients living longer, survivorship is a high priority but remains a relatively new frontier, particularly for adolescents and young adults (AYA). Hematologic cancers, such as leukemia and lymphoma, are common AYA cancers and often require HCT as part of treatment [9]. More than a decade ago, the National Cancer Institute (NCI) called attention to alarming lags in survival improvements among AYAs relative to other age groups [10]. Since then, awareness of the unique issues faced by AYAs with cancer has increased substantially, but many gaps remain. Recent studies tend to describe AYAs with cancer as a whole rather than address variations across specific diagnosis and treatment subgroups, such as HCT [11, 12]. In addition, the few studies on AYAs undergoing HCT have focused heavily on the acute phase of treatment, or first 100 days after HCT, rather than post-treatment concerns [13–16]. Thus, survivorship has been identified as a key research priority for AYA oncology, with particular attention to managing long-term and late effects, addressing psychosocial issues and improving quality of life [9, 17]. In this qualitative study, we explored perceptions of therapy-related health risks and their impact on future life plans among a sample of AYAs after HCT.

Methods

After obtaining approval from the institutional review boards of the University of California, Los Angeles and City of Hope, we identified eligible participants through medical chart review. Inclusion criteria were as follows: age 15–29 years old at the time of an autologous or allogeneic HCT as treatment for a primary hematological cancer and 6–60 months post-HCT at study enrollment. Patients who were younger than 18 years at the time of the study, had relapsed since HCT, had a non-hematological primary diagnosis, had a history of more than one HCT, were documented as cognitively impaired in the medical record or unable to speak English were excluded.

Participant recruitment has been described previously [18]. The final sample was recruited from a single institution and consisted of 18 AYAs who agreed to participate after being invited via mail, telephone, or in-person contact at a follow-up clinic appointment. Reasons for direct refusal ($n = 7$) included concerns about "not having enough time" and "not wanting to talk about it"; others did not respond after multiple contact attempts.

Qualitative methodology, guided by constructivist grounded theory [19], was used to study experiences of survivorship after HCT from the perspectives of a sample of AYAs. After obtaining informed consent, data collection began with abstraction of relevant clinical variables from medical records. Participants completed a self-reported sociodemographic questionnaire, and the first author, an oncology nurse with advanced training in qualitative methodology, conducted in-depth interviews either in-person in a private room or via telephone depending on the participant's preference. A semi-structured interview guide, developed from pilot work with AYAs by the first and last authors, was used to explore the impact of cancer and HCT experiences on participants' perceptions of their potential life trajectories and future expectations (Table 1). Interviews lasted 102.4 min (range 56.4–164.2) on average and were audio-recorded and transcribed verbatim. Extensive field notes, including reflexive memos and process notes, were recorded throughout the research project. To further enhance rigor, memos were written before, during, and after each interview to maintain transparency and form an audit trail [20].

Data collection also consisted of a self-reported sociodemographic questionnaire and abstraction of relevant clinical variables from medical records.

We used a systematic process to code the data, beginning with initial coding of each transcript, followed by focused coding to identify emergent categories [19]. Data collection and analysis occurred concurrently to allow for constant comparison that informed subsequent data gathering as analysis advanced. Another strategy to enhance rigor was theoretical sampling which we used to focus successive interviews on aspects of experiences that were not well understood and elaborate categories [19, 21]. Techniques such as memo-writing, diagramming, and network mapping were implemented at each stage to deepen analysis and raise the level of abstraction. Advanced analysis allowed for the refinement and "filling out" of major categories and the relationships between them. Two or more members of the research team collaborated at each analytic stage and met regularly to resolve differences. We continued this process until major theoretical categories reached saturation. Atlas.ti software was utilized for data management (Atlas.ti, version 7.5.10) [22].

Results

The 18 participants were, on average, 23.3 years of age at HCT (range 18.5–29.7) and 32.8 months (range 8–60) post-HCT at the time of interview. They underwent allogeneic HCT using HLA-matched unrelated donors ($n = 9$), sibling donors ($n = 3$), and cord blood (n = 3) as well as autologous HCT (n = 3) in the inpatient setting. Additional sample characteristics are listed in Table 2. In this analysis, we focus on how this sample of AYA HCT survivors came to understand treatment-related health risks and the impact of the HCT/cancer experience on their perceptions of the future.

Table 1 Excerpt from semi-structured interview guide

Area of focus	Example questions and probes
Perceptions of life changes attributed to HCT	Tell me about any things that continue to be challenging since undergoing HCT. Prompt: what has been the most challenging or difficult and why? Since HCT, what has been the biggest change for you (positive or negative)? Prompt: socially (resuming social roles)? Prompt: emotionally/psychologically (fear, anxiety, depression, resilience)? Prompt: behaviorally (physically, risk-taking, health promotion behaviors)?
Impact of cancer/HCT experience on life course and plans	Looking back, when you think about how this overall experience (cancer/HCT) affected the flow of your life, what in particular stands out? How, if at all, has having cancer affected how you think about the future? Prompt: how has it affected your life plans? Prompt: how has it affected how you view the future? What would you tell someone who was just starting out on their journey of transplant and beyond?

"Improving to where?": realizing the chronic nature of survivorship

Participants only began to understand the chronic nature of cancer survivorship during the post-treatment period. Early in recovery, participants believed that they would eventually achieve a complete restoration of health and resume their pre-diagnosis lives without major long-term consequences. This was based partly on what they described as hopeful but unrealistic expectations set by their medical teams, who shared stories of "extraordinary" rather than typical cases. One participant described the shock she felt when she learned about the daily life of a survivor 11 years after HCT who had to nap for an hour during his lunch break and again for an hour before dinner with his family just to get through each day. Another participant explained how she gradually came to realize that her life was forever changed:

> Now, five years from the transplant, I feel much better from a year ago, from two years ago, from three years ago. […] But it's nowhere near where I was. […] I mean, like worlds of difference. […] So, it's taken a lot longer than we expected. […] It's just very long and slow. And it probably will just continue like this. I will get minutely better as time goes by, but it won't be fast. It won't be significant.

The discordance between participants' expectations for a "normal life" and their lived reality was reinforced by interactions with their medical teams. At follow-up appointments, participants explained that health care providers often commented on their progress. One said, "They just tell me, 'You're getting better. You're doing a lot better than you were before. Everything looks good.'" Although participants had no evidence of disease, they continued to have persistent health issues, including pain, anxiety, sexual dysfunction, abnormal liver function, chronic graft-versus-host disease, avascular necrosis, and the inability to work or in many ways, enjoy life, all of which reinforced that they were "still not 100%." One participant explained, "It's not like, oh, it happened and then I got over it. It's like it kept interfering with my life." Another stated, "Getting your life back just wasn't the same. It wasn't like, 'Okay, let's wrap it in a pretty little bow and go to the next thing.' It was hard." Receiving positive feedback from health care providers ("You're improving") while simultaneously struggling with health problems triggered confusion and caused many participants to question the ultimate goals of treatment, as one participant vehemently asked, "Improving to where?"

These realizations allowed participants to piece together their understanding of cancer survivorship and the health risks they now faced in a gradual way, months or even years after HCT. One participant said, "It's hard to tell a cancer patient, 'You don't need treatment anymore. You're fine for the rest of your life.'" Another stated, "This is the way my life is now." This sobering shift in understanding was described by another participant:

> You just have to watch for everything, [..] and just accept that, truthfully, this is not the last time I'm going to be sick. I'm only 26. So, there's a long life with a lot of health problems coming up, unfortunately, and that's just how it's going to be.

As the reality of the chronic nature of cancer survivorship became evident, many participants experienced new emotional lows. One explained:

> The doctors don't see the long term, "Hey. I'm just going to give you these meds. You're going to be okay." Okay, but what happens at home? They're not there when they have to deal with this new shit. You know, their husbands are going to leave them, they can't deal with it. Their kids are going to look at their parents like, "Mommy, why are you losing your hair? Why are you skinnier than Grandma?" You're going to have

Table 2 Sociodemographic characteristics ($N = 18$)

Characteristic	n
Sex	
Male	11
Female	7
Ethnicity	
White/Caucasian	7
Hispanic/Latino	8
Asian/South Asian	3
Highest level of education completed	
Some high school	1
High school	2
Some college	9
4-year college	5
Graduate degree	1
Total annual household income	
Do not know	5
\$19,999 or less	4
\$20,000–\$49,999	5
\$50,000–\$74,999	3
\$75,000–\$99,999	0
\$100,000 or more	1
Current school/employment status	
Enrolled in school (part- or full-time)	5
Employed (part- or full-time)	6
Enrolled in school and employed	1
Neither in school nor employed	6
Current relationship status	
Not in a significant relationship	8
In significant relationship, not living together	4
Living with spouse/partner	6
Current marital status	
Never married	14
Married	4

> problems like that. And, you know, people my age are going to go depression, suicidal, either weapons or drugs. And it's there. The signs are there.

"My luck is gonna run out": bracing for something bad

As time since HCT increased, the focus of participants' fears shifted from recurrence to HCT-related health risks in the future. They perceived these risks to be "a necessary price to pay for still being alive," but also a source of never-ending worry. Specifically, participants feared potential late effects of treatment, such as secondary malignancies, cardiovascular and pulmonary toxicities, cataracts, premature ovarian failure and infertility, and shortened life-spans. As one participant explained:

> They start telling you about risks, about further cancers and tumors, because of the radiation. And infertility. Just so many things that get pushed into your brain. You're trying to process it, and trying to not freak out at the same time. Because it's a lot of information. And you think, 'Well, there is a possibility. Like, what if it happens to me?' I mean, I never thought I'd get cancer, but I got it.

These worries manifested as a looming threat that "something bad was going to happen." A participant described "this feeling that, one of these days, something is going to happen that's not going to be good. I'm going to have some sort of very serious side effect from my treatments." Another wondered, "I've gotten by so long without anything going wrong. Am I due for something to happen?" Participants expected their "luck to run out one of these days," but had no idea when or how it would happen, and this anticipation increased their anxiety. One participant reported, "Every day of my life, everything that I do, I'm constantly worrying and thinking. […] It sucks to have to live your life constantly afraid of what's going to come." In response to these worries, participants found themselves bracing for inevitable but unknown problems in their future. In many cases, anxiety about the late effects of HCT resulted in increased social isolation. One participant explained, "My anxiety means I have less patience for people. I'll just shut myself off. […] It's hard for me to talk to other people because I think it's difficult for them to understand what I'm worrying about."

"I don't see myself getting super old": facing a future of health risks

In addition to triggering emotional distress, concerns about potential treatment effects transformed participants' perceptions of their futures. Most participants had some awareness of risks associated with HCT, but had many unanswered questions about this aspect of survivorship. One participant wondered, "I just didn't know what the future held for me. You know, am I ever going to work again? Or am I just going to be bedridden my whole life?" Another participant elaborated on his uncertainty moving forward:

> With the future, I don't see myself getting super old. […] I just don't know exactly how [my treatment's]

> going to affect me in the long run. When old people have it, they already know they have a shelf life. Like, I'm 25. I could live, what? Fifty, sixty more years? Or I could live fifteen, twenty years? Five? I don't know. It's weird. It's in the back of your mind. Like, how long really? […] I guess I just don't have that assumption that I'm going to live long, like most people my age.

The degree of uncertainty about their health risks posed several challenges for participants as they looked towards their futures. Participants were adjusting to the fact that their cancer experience would require consideration in nearly all life decisions. Many saw a changed future in which opportunities and possibilities for their lives had narrowed. One participant had learned the dangers of "pushing yourself too hard and acting like nothing happened […] because you have to be aware that some things you just can't do, some things can't happen." Another participant who was nearly 5-year post-HCT explained how worries about potential late effects complicated his life plans:

> Now I'm concerned about what sorts of things I'm going to face in the future. That causes me a lot of distress, thinking about what's going to happen. Am I going to make it to 40 or 50? I don't know. So that's a hard thing to deal with, especially when I'm thinking about, well, you know - and I'm still a little bit young for this, but when I meet a woman that I feel like I want to get married to, or if I do want to have a family, I have to ask myself, what is the responsible thing to do? What am I looking at in the future?

Several participants described the necessity of "rolling with the punches" or adapting to the inevitability of health-related events in the future, as they attempted to move forward. Participants spoke of "planning realistically," "getting practical," and "defining my own pace" as ways to adjust previous expectations and integrate their cancer-related health needs into their future plans. For example, participants expressed concerns about adequate salary and insurance coverage in the event of future health problems. As one participant shared, "When I'm looking at my career and planning out my life, in the back of my mind I always think, 'Am I going to be making enough money if something happens to me?'" Many participants also attributed changes in career aspirations to cancer-related physical limitations. One explained, "I need to look for something that my body can tolerate. I have to lay out certain options, what I can do and what I cannot do." Similarly, many participants described "getting practical" in their intimate relationships, seeking partners who would be able to handle future cancer-related issues, both emotionally and financially.

Amidst their fears about the future, many participants described a nagging undercurrent of wondering, "Where would I be today if I didn't get sick? What if I hadn't had cancer?" They tried to understand the extent to which the cancer experience was shaping their life trajectory, but as one participant concluded, "That's kind of a question you can't answer, unfortunately." Although they tried to limit these thoughts, many admitted to frequently contemplating what one called "the what-if factor" and another referred to as "the alternate universe." Unanswered and often unanswerable questions characterized the experience of wondering "what if?" Participants believed strongly that without cancer, their lives and futures would look substantially different and their curiosity about these unfulfilled life paths lingered.

Discussion

Our findings highlight major gaps and opportunities in survivorship care for AYA cancer survivors who have undergone HCT. "Improving to where?" emerged as an important question as participants pieced together their understanding of HCT-related health risks and their expectations for their futures. Well after HCT, participants came to the realization that cancer, treatment, and related sequelae were going to be part of their lives moving forward. With this awareness came the belief that "something bad" was destined to occur as a result of treatment, which mirrors the Damocles syndrome described by survivors of childhood cancer [23]. This new understanding of cancer survivorship debunked participants' previous expectations of returning to "normal," resulted in psychoemotional turmoil, and ultimately required them to reconceptualize their futures.

The combined risks faced by AYA survivors of HCT make them a particularly vulnerable group with extensive survivorship needs for the remainder of life [24]. HCT patients are consistently recognized as one of the most acutely ill cancer populations, and their long-term health risks have been well described [4, 25, 26]. These risks include late relapse, secondary cancers, and organ toxicity [6, 8, 27] as well as major psychological conditions, such as anxiety, depression, and distress [28, 29], which are in turn associated with negative outcomes such as poor physical functioning [30], lower health-related quality of life [31], and decreased survival [32, 33].

Less is known about the specific survivorship risks of AYA cancers, but limited evidence suggests that these diseases are often less responsive to standard treatment and require more intense regimens [24]. For example, reduced-intensity approaches to minimize treatment-related toxicities have become a major focus of HCT research. However, according to a large phase III clinical trial, young adults undergoing allogeneic HCT who received higher intensity, myeloablative conditioning regimens demonstrated a significant advantage against disease relapse compared to less aggressive approaches [34]. In another study, patients treated before age 40 were nearly 60% more likely to develop a secondary cancer than the general population while those treated after age 40 were only 10% more likely [35]. Thus, because high-intensity treatments may be necessary to cure disease in AYAs, it is critical to consider potentially increased risks for long-term and late effects.

Extensive post-treatment concerns and unmet needs among AYAs have been reported, and the delivery of survivorship care for this population remains a challenge [36, 37]. Multiple barriers to follow-up care for AYA survivors exist, including cost, lack of clear recommendations, skepticism, fear and avoidance, and competing life priorities [38]. Research on cancer-related anxiety has understandably placed heavy focus on fear of recurrence [39]; however, participants in this study emphasized anxiety about lifelong risks associated with toxicities of treatment, especially as time since HCT increased. Although we did not measure knowledge or awareness levels directly, our findings provide deeper insight into distress about future health risks, gaps in understanding, and the need for long-term support. In a study of 1395 AYA survivors, 78% of respondents identified information on late effects as an unmet need, second only to recurrence concerns (80%) [36]. Poor understanding of treatment-related risks may result in failure to receive appropriate care and poorer survivorship outcomes [40]. Collectively, these findings suggest that better guidance about treatment-related risks may reduce anxiety, encourage self-advocacy, and improve health outcomes of AYA survivors.

Clinical implications

Important clinical implications for AYA survivorship care are evident. Based on these findings, survivorship care plans (SCPs) may have unique benefits for AYAs who will likely experience many changes in life circumstances after they complete treatment. Mandated recently by the Commission on Cancer (CoC) [41], SCPs can enhance the quality of survivorship care and facilitate ongoing, individualized dialogues between survivors and health care providers [42, 43]. Essential elements of SCPs include information about expected recovery, potential long-term and late effects, common psychosocial issues, and clear plans for follow-up care [44].

Although evidence demonstrating a strong impact on outcomes remains limited, SCPs may facilitate more proactive, more direct, and more tailored communication about the lifelong risks associated with treatment for survivors [17, 43]. Specific to AYA survivors, those who received a written treatment summary reported fewer unmet needs related to late effects [36]. As living documents, SCPs can be revised to reflect the evolving needs and circumstances of AYAs and grow with them over time. Thus, SCPs encompass the chronic nature of cancer survivorship and can help shift the focus to long-term management, follow-up care, and health promotion. SCPs can also improve communication and long-term care coordination between multiple providers. Given the complex health risks these survivors face and the likelihood that they will interface with a wide array of specialists as they age, SCPs may be useful in providing an accurate, summative, and mobile roadmap to all involved. The results of this study suggest that better communication about long-term health risks, expectations, and plans for follow-up care may reduce distress among AYA survivors as they look towards the future. Despite these potential advantages, major barriers to the provision of survivorship care and clinical uptake of SCPs exist and need to be addressed.

Conclusion

Since the Adolescent and Young Adult Oncology Progress Review Group (2006) first convened, research in AYA oncology broadly has surged, but much of the current knowledge on AYA survivorship has been extrapolated from studies on survivors of childhood cancer, an arguably distinct patient population [45]. This qualitative study provides rich description of ongoing health issues experienced by AYAs after HCT that can inform future research, but our findings are limited by the lack of specific information on treatment and comorbidities. Larger studies are needed to develop risk-based protocols that can guide long-term management of AYA survivors, including the implementation and evaluation of SCPs [46]. Another priority is the development of resources to support AYA survivors in moving forward, especially managing anxiety about the future, through a lifetime of known health risks. Despite limitations of a small sample size from a single institution, this study enhances our understanding of cancer survivorship among a high-risk subgroup of AYAs. As these AYA HCT survivors continue to live longer, a well-coordinated, proactive approach to address physical and psychosocial long-term and late effects as well as the reality of living with such health risks is imperative.

Acknowledgements We acknowledge the support of Dr. Julie Wolfson, Dr. Saro Armenian, Dr. Stephen Forman, Lindsey Hageman, Alysia Bosworth, and Laura Gustafson.

Funding This study was supported by a dissertation research grant from the Oncology Nursing Society (ONS)/ONS Foundation and in part by a NIH/NINR Ruth L. Kirschstein National Research Service Award (NRSA) Institutional Research Training Grant [T32 NR 07077].

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

Ethical approval All procedures performed in this study which involved human participants were in accordance with the ethical standards of the institutional national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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