Follow-Up Care Provider Preferences of Adolescent and Young Adult Cancer Survivors

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Purpose: To explore the experiences and perspectives of adolescent and young adult (AYA) cancer survivors regarding patient–provider relationships and their preferences surrounding type of healthcare provider for follow-up care.

Methods: We recruited AYA cancer survivors who were diagnosed between the ages of 15 and 39 using the Utah Cancer Registry. Twenty-eight survivors participated in six focus groups held between March and May of 2015 in Salt Lake City and St. George, Utah. This analysis focuses on how survivors' preferences about type of healthcare provider may influence their transition into, and utilization of, follow-up care.

Results: On average, survivors were 6.3 (standard deviation = 1.7) years from their cancer diagnosis. A majority of survivors expressed a desire not to transition to a new provider and preferred continuing to see their oncologist for follow-up care. For these survivors, this was due to already having a close relationship with their oncologist and because they trusted their provider's knowledge about cancer and how to handle late effects. However, survivors placed emphasis on being comfortable with their healthcare provider, regardless of provider type.

Conclusions: Our findings demonstrate the importance of formalizing provider transitions and roles after cancer therapy to improve patient comfort with new providers. By understanding the complexities of the transition from active cancer treatment to follow-up care for AYA survivors, these findings can inform programs undertaking post-care educational activities to ensure a seamless transition into survivorship care. Survivorship care plans can facilitate these transitions and improve patient confidence in follow-up care.

Keywords: survivorship, follow-up care, late effects, qualitative, healthcare providers

Introduction

FOLLOW-UP CARE is an important aspect of healthy cancer survivorship, as it is crucial for identifying and managing late effects in addition to providing general and preventive healthcare.^{1–3} The transition from treatment to follow-up care can be a period of uncertainty about roles, expectations, and responsibilities for both healthcare providers and patients, which increases the likelihood that cancer survivors will become disconnected from the healthcare system.^{4–10} Survivors of adolescent and young adult (AYA) cancer, diagnosed between the ages of 15 and 39 years, experience challenges during cancer that can affect their psychological, physiological, and social development.^{11,12} Throughout cancer diagnosis, treatment, and into survivorship, AYAs frequently face interruption of education or work leading to

difficulty assimilating back into social realms.¹³ These issues can affect AYA survivors' abilities to manage their long-term health due to gaps in health insurance, competing responsibilities, and transition from pediatrics to adult care.^{1,14–19}

Various models of survivorship care have been proposed for AYAs, including care led by an oncology team or specialized survivorship clinic, primary care providers (PCPs) overseeing both follow-up and general care, and shared-care models where care is led by a team from both PCP and oncology settings. Regardless of which care model is selected, the transition should involve communication between the survivor and both the treating and follow-up providers.^{1,8,20,21} However, there is a clear need for more structure defining healthcare provider roles following cancer treatment as demonstrated by earlier studies that have shown that oncologists and PCPs often report poor communication, uncertainty, or

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differences in views regarding their respective roles in follow-up care.^{6-8,22-25} As a result, survivors can experience unsuccessful transitions leading to gaps in receipt of general preventive healthcare, follow-up care, or both as the transition period is highly influential in determining healthcare utilization patterns and practices among AYA cancer survivors.^{8-10,26,27}

There is little research on the role of healthcare providers during AYA cancer survivorship. Adult and childhood cancer survivors stress the importance of having a relationship with their provider and the provider's knowledge about cancer. For many survivors, there is a preference for continuing to see their oncologist for survivorship care.^{5,9,20,28-32} However, it is unclear whether these results translate to patients diagnosed during the AYA age range. For example, childhood cancer survivors report a strong preference for autonomy, while at the same time wanting their parents to be involved with transitions after treatment.⁹ In contrast, survivors who were diagnosed as AYAs typically take more of an active decision making role in their transition and healthcare, which may differentially influence their experiences with survivorship care.^{8,11,12}

This study was conducted to explore the patient-provider experiences reported by AYA survivors and how these may impact follow-up care utilization, either from their oncologist or a different provider. Through a series of focus groups, AYA survivors illustrated their experiences and perspectives regarding an extensive range of concerns surrounding follow-up care, with the goal of identifying targets for better transition support after treatment.

Methods

This analysis was conducted as part of a larger study examining the perceptions and attitudes of AYA cancer survivors about the benefits of and barriers to follow-up care and their willingness to pay for follow-up care. Here, we focus on questions relating to how relationships with providers and preferences about type of provider influences the transition to and utilization of, follow-up care. All study procedures and materials were approved by the University of Utah Institutional Review Board.

Participants and recruitment

Potential participants were identified through the statewide Utah Cancer Registry (UCR), a population-based Surveillance, Epidemiology and End Results program (SEER) cancer registry. Survivors were eligible if they met the following criteria: English speaking, 18 years or older, diagnosis from 15 to 39 years old, at least 1 year from diagnosis, had completed active cancer therapy, and were currently residing in either Salt Lake or Washington counties in Utah. Survivors were excluded if they were diagnosed before January 1, 2006 or if they had a diagnosis of nonmelanoma or *in situ* cancer. These exclusions were made to limit the focus to more recent survivors and due to differences in the extent and type of treatments for nonmelanoma and *in situ* cancers relative to invasive cancers.

As this analysis was part of a larger study, recruitment procedures have been previously described.^{19,33} Briefly, the UCR attempted to contact 200 potential subjects. Of these, 44 could not be contacted, 69 did not respond, and 13 were

ineligible based on updated information. Of the remaining 74, 10 refused and 64 agreed to be contacted by our research team. Following contact by the research team 28 survivors participated in focus groups for a participation rate of 44%. Participants did not differ significantly in age at diagnosis or gender from those who did not agree to participate or could not be reached.

Data collection and analysis

Six focus groups were conducted March–May of 2015 in community locations, with an average of five participants per group. Following the informed consent process participants were asked to complete a survey and participate in a group discussion. The survey included questions on demographic information and cancer history. A trained moderator (E.R.Z.) led the discussions using a semi-structured focus group guide with open-ended questions and probes about health insurance, perceived benefits of follow-up care, barriers to follow-up care, and willingness to pay for follow-up care. Discussions were recorded and transcribed. Participants received a \$25 gift card.

A coding scheme was created using conventional content analysis by one member of the research team (S.K.), to generate a thematic structure.^{19,33,34} The scheme was then revised through discussion with two other team members (E.R.Z., R.R.S.S.) following consensus coding of the first focus group transcript by S.K., E.R.Z., and R.R.S.S. A total of 43 descriptive codes were used within the larger themes of follow-up over time, payment mode, treatment doctor versus specialist, and value. E.R.Z. and R.R.S.S. independently coded the remaining transcripts (percent agreement = 97.8%) using NVivo with all differences resolved through discussion.

This analysis focused on the following discussion question about follow-up care: Would AYA survivors prefer to see the doctor they had during treatment or someone who specializes in follow-up care? Additional probes explored these preferences. Based on these questions three common themes emerged: (1) relationship with the provider, (2) provider knowledge about late effects and follow-up care, and (3) transition to a new provider.

Results

Sample characteristics

Among the 28 participants, the average age was 30.9 years (standard deviation [SD] = 5.6) with an average age of 24.6 years (SD = 5.8) at diagnosis. All survivors were at least 4 years from diagnosis (mean 6.3, SD = 1.7). Participants were mostly female (57.1%), non-Hispanic white (82.1%), and had completed at least some education post-high school (Table 1). The most common diagnoses were lymphomas (39.3%) followed by gonad/germ cell cancers (28.6%). Nearly all participants had private health insurance during the study (92.9%).

Patient-provider relationships and continuity

Several AYA survivors emphasized the importance of having a positive relationship with their provider and expressed unwillingness to change to a new provider after they finished treatment. Moreover, survivors tended to prefer continuing to see their oncologist for follow-up care as they had an established relationship. As a result, survivors often

TABLE 1. SAMPLE CHARACTERISTICS (N=28)

	n (%)
Age, years	
19–24	3 (10.7)
25–29	15 (53.6)
35–45	10 (35.7)
Age at diagnosis, years	
15–22	12 (42.9)
23–29	10 (35.7)
31–37	6 (21.4)
Sex	
Male	12 (42.9)
Female	16 (57.1)
Race/Ethnicity	
White, not Hispanic/Latino	23 (82.1)
Hispanic/Latino	3 (10.7)
Other Race, not Hispanic/Latino	2 (7.1)
Cancer diagnosis	
Lymphoma	11 (39.3)
Gonad/germ cell	8 (28.6)
Breast	3 (10.7)
Thyroid	2 (7.1)
Other	4 (14.3)
Annual income	
\$25,000 or less	8 (28.6)
>\$25,000–\$50,000	7 (25.0)
>\$50,000–\$100,000	8 (28.6)
>\$100,000	5 (17.9)
Education	
High school or less	5 (17.9)
Some college/technical school	10 (35.7)
College graduate or more	13 (46.4)
Insurance	
Uninsured	2 (7.1)
Insured (private)	26 (92.9)
Marital status	
Never married	12 (42.9)
Married or living as married	15 (53.6)
Divorced, separated, or widowed	1 (3.6)

did not have a primary care physician, which was described as follows:

“I know everybody asks who my physician is, and I’m like it’s my oncologist. I feel like he knows me the best, so he’s the one I go to. I don’t really see a family physician or anything like that.”

Continuity and security were important reasons to survivors for preferring to see their oncologist due to their familiarity with their treatment history (“I like the continuity of the original provider”). Survivors strongly felt that their provider should understand their treatment history. This idea was very tightly entwined with having a positive relationship with their provider, and survivors often used the concepts of history and relationship interchangeably. However, history moved beyond just having a good relationship with their provider to include trust. Survivors had more trust in their provider’s healthcare recommendations when the survivor felt that the provider understood the cancer experience and their specific

history. Survivors worried about whether a new provider would adequately understand their health history. One survivor stated the following:

“It can be hard to trust somebody that wasn’t there [during treatment]. There’s so much to catch them up on, nuance and things, unless it’s really that standardized.”

Conversely, a few survivors reported having negative experiences/relationships with their oncologist and cancer care team. One participant expressed this as follows:

“I just want to see my follow-up guy, because the multitude of doctors I saw during the cancer treatment, none of them care now. It was the surgeon, and the family practice guy, but they would be like what would you want me to do? I’ve already cut that out, I can’t do it again.”

Similarly, another survivor stated they did not go to their oncologist after the end of cancer treatment: “I don’t particularly care for my doctor, and that plays a huge part in my not going to see her, so I think it’s pretty big.” Due to their negative relationships these participants expressed a preference for seeing other providers, whereas others opted to avoid follow-up care entirely.

Provider knowledge of late effects

Many AYA survivors expressed that they preferred to stay with their oncologist due to concerns that PCPs would not understand cancer-related side effects or late effects. One survivor stated the following:

“[Oncology providers] have more people coming out of [cancer treatment], and getting sick, and having cancer, and it would be nice to not have to go to someone new who doesn’t understand cancer, or doesn’t understand all of the side effects that go along with treatment long-term and short-term.”

In some cases, survivors reported that PCPs did not appear to be interested in providing follow-up care or taking an active role in providing appropriate follow-up care. This was expressed as follows:

“You go in [to your PCP] and you’ve got to go tell him your whole history. I’m sure they could look it up and find everything, but they’re not going to take that time for a family visit. They’re just going to ‘okay, you had cancer. Cool. What do you want us to test?’”

“I have to explain everything. OK, so I’ve had cancer. ‘Why don’t you talk to your cancer doctor?’”

Survivors also felt concerned that seeing a provider other than their oncologist or a follow-up specialist would place them at a disadvantage if they developed a second cancer or relapsed.

“So it would be nice if there was a follow-up specialist you could transition to. I don’t mind seeing a regular doctor, but I don’t want to have to go through the whole hassle of starting at ground zero if I were to ever have cancer again, because there’s always that chance.”

Transitions to new providers

Some survivors had transitioned to a new provider or back to their PCP once their therapy ended. A vast majority of these transitions were not voluntary and instead reflected circumstances that forced them to change providers. Typical reasons for transitioning were because their oncologist did not offer follow-up care, had retired, or had moved. For a few others, they had aged out of pediatric care. This was described by one survivor:

“My doctor is at [children’s hospital], and this was my last time getting to see him, because we’ve moved to the [adult cancer center], so I’m pretty stressed about it, because I don’t know the doctor I’m going to see. She’ll have my information, so I’m not scared about that. I’m just scared that I won’t like her, or that I won’t agree with what she has to say, so I don’t know. I’m pretty nervous about it.”

Survivors who reported successfully transitioning to a new provider tended to have recently completed treatment and still needed significant follow-up care, which motivated or required them to see the new provider. If a transition took place further from treatment, when the survivors perceived their medical needs to be lower, participants tended to report not finding or going to see a new provider. In addition, once a transition had taken place there was a strong preference for not wanting to change providers again. One survivor described reticence about potential provider changes:

“I didn’t want to go to anyone else because they don’t know my history, and they don’t know what I went through, and my doctor was there every step of the way. I put a wall up, and I didn’t want to go to this new guy, and I had to because I was still so fresh out of it that I had to keep going. I still required medication, follow-up, and stuff, so I’m glad I did go. Now, if he were to move away, I honestly don’t know, because I feel fine. I don’t know that I would go to another doctor because I feel fine.”

Survivors also preferred for their oncologist to be involved in any care transitions. Involvement of their oncologist led to them feeling more comfortable with a new doctor and gave them time to form a relationship with the new provider without immediately losing their old relationship.

“I think I would trust my [oncology] doctor’s opinion when it comes to having a referral. I can trust his judgment on passing me to another doctor.”

“If somebody is retiring or something, there can be a transition period where it’s not just you and this doctor. They’re gone and you’re just left there. All three of you can work together for a minute.”

Overall, our results demonstrated that most AYAs are reticent to transition to new providers and that trust is paramount in these relationships.

Discussion

Appropriate long-term follow-up care for AYA cancer survivors is essential to managing their health and avoiding problems later in life.^{1–3} Although financial and knowledge

barriers, as well as fears about recurrence, have been identified as reasons AYAs avoid follow-up care, little attention has been paid to survivors’ preferences regarding which healthcare providers they see for follow-up care.^{1,14–19} We found that many AYA cancer survivors feel strongly about seeing a provider who knows and understands their cancer history, who they can trust, and who takes their concerns seriously. As such, many of survivors reported only seeing an oncologist for care after completing their cancer treatment, as they value the continuity in this relationship.

Our study identified several common themes surrounding provider roles and preferences in the care of AYA cancer survivors. Consistent with what has previously been observed in childhood and adult cancer studies, most AYA survivors placed strong importance on having a positive relationship with their provider. Survivors who did not like or trust their provider or who felt that their provider did not know (or care about) their history were less likely to seek follow-up care.^{5,9,20,28–32} AYA survivors also expressed a preference for continuing to see their oncologist for follow-up care because they were concerned that PCPs would not be as knowledgeable about cancer or late effects, or some felt their PCP did not care about their previous cancer history. Finally, AYAs were extremely reluctant to transition to a new provider unless they had a negative relationship with their oncology provider or other circumstances forced it. Transitions were most successful if perceived or actual healthcare needs were high such as immediately following therapy, or if the original provider was involved in the process, suggesting important avenues for improving care after cancer for this age group.

Within our focus groups, there was an emphasis on comfort with providers rather than on seeing a specific type of provider. This shows promise for PCP-based or shared care follow-up care models, provided that the transition into survivorship involves a coordinated handoff building trust from the old to new provider, as has been important among AYA survivors of childhood cancer.^{5,8,9} Related, AYA survivors also expressed a preference that their follow-up provider be familiar with their cancer history, late health effects, and cancer, which led to concerns about seeing a PCP. Most PCPs are not comfortable independently caring for survivors and prefer to care for survivors either in consultation with a follow-up program or oncologist.^{6–8,22–25} One tool to address communication issues and promote shared care between oncologists and PCPs are patient-specific survivorship care plans (SCPs).^{6,7,35,36} SCPs provide a summary of the patient’s diagnosis and treatment, an explanation of potential long-term and late effects from their treatments, and a plan for ongoing care, addressing both cancer-related and primary care health needs.⁶ Ensuring that AYAs have access to a SCP and are involved in conversations about the SCP and transitions with their care team could help ease concerns about seeing a different provider as well as improving PCP comfort with treating survivors.^{10,35–39}

Based on our findings, we suggest that oncologists prioritize a deliberate, risk-based transition from treatment to survivorship with their AYA cancer patients. Depending on patient needs, this transition could be to a survivorship clinic, a PCP, or continuing to see their oncologist as a survivor. This transition should include provider role delineation and the provision of an SCP to all involved parties, including

clinical staff involved in the care. Clear patient–provider communication related to expectations about care and roles is needed during this transitional phase when many survivors drop out of the healthcare system, as previously shown for AYA survivors of childhood cancers.^{5,9,40,41}

Limitations within our study exist. These data are self-reported and the focus groups were all conducted within a single state, making it difficult to confirm the extent to which our results reflect all AYA survivors. Also, by design, we did not include opinions from longer-term survivors. However, we did attempt to increase geographic diversity by recruiting AYAs from two counties in Northern and Southern Utah. Additionally, our sample size was relatively small ($n=28$) and reflected only 44% participation, which could potentially result in selection bias. However, demographic and diagnosis characteristics were available for nonparticipants and we did not observe any significant differences in these characteristics between subjects and nonparticipants. As such, we recommend that future studies on survivors' provider experiences examine larger, more diverse samples and include analysis within cancer types and time since diagnosis. Finally, focus groups tend to express opinions accepted by the group that could limit diversity in themes surrounding provider experiences or follow-up care barriers.⁴²

This study adds to the body of knowledge on survivorship care for AYAs and is the first to address the role that survivors' relationships with and preferences about healthcare providers play in the transition into and utilization of follow-up care. Because of the importance AYA survivors place on having good patient–provider relationships, future studies should consider the improvement of these relationships as a strategy for increasing compliance with follow-up care guidelines and improving health for survivors. Collaborative follow-up care and deliberate transitions aided by personalized SCPs will enable providers to give clear guidelines and care recommendations as well as build a positive relationship with AYA patients by demonstrating understanding of their specific history and needs.

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Authors' Contributions

S.K., E.Z., and R.S.-S. were at the Huntsman Cancer Institute at the time of data collection and analyses.

Author Disclosure Statement

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