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Barriers to follow-up care among survivors of adolescent and young adult cancer

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Abstract

Purpose—Though the need for risk-based follow-up care for survivors of adolescent and young adult (AYA) cancer has been documented, survivors often report forgoing recommended care due to cost. We sought to understand whether additional barriers to follow-up care exist for AYA survivors.

Methods—We recruited survivors who were diagnosed with cancer between the ages of 15 and 39 using the Utah Cancer Registry (UCR). Overall, 28 survivors participated in 6 focus groups held between March and May 2015 in Salt Lake City and St. George, UT. Focus group discussions focused on the reasons survivors may or may not attend recommended medical visits after completing therapy.

Results—Survivors reported myriad barriers to follow-up medical visits, including lack of clear provider recommendation, fear of recurrent cancer diagnosis, wishing to move on with life, competing life responsibilities due to work and children, and not perceiving the need for a visit due to lack of symptoms.

Conclusions—Though cost likely plays a major part in follow-up care adherence for survivors of AYA cancer, in our focus groups, participants indicated there were many other psychosocial and logistic barriers to care. Such factors play an important role in the day-to-day lives of survivors and are critical in medical decision-making.

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Compliance with ethical standards

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

Implications for cancer survivors—Several factors impede follow-up care adherence for survivors of AYA cancer that are amenable to interventions, including clearer provider recommendations, flexible appointment times, and childcare availability in clinics.

Keywords

AYA cancer; Survivorship; Barriers to care; Risk-based follow-up care

Introduction

Follow-up medical guidelines tailored to diagnosis and treatment have been established for survivors of adolescent and young adult (AYA) cancer diagnosed ages 15–39 [1–3]. Despite these guidelines and their risk for developing health problems (i.e., late effects) due to their cancer diagnosis or associated therapy [4, 5], survivors of AYA cancer often forgo routine medical care. Most of the literature on barriers to care for cancer survivors, including those of younger and older survivors, have used closed-ended methods and has focused on cost of medical care [6], access to care [7], and health insurance status [8, 9]. Specific to the AYA cancer population, survivors report greater cost-related barriers to care [7], inability and delay in receiving necessary care (e.g., dental care) [9], and rate the quality of their healthcare lower than individuals from the general population [10].

In addition to cost and access to care concerns, patient knowledge may play a role in AYA survivors' follow-up care behaviors. One study found that survivor of AYA cancers' lack of knowledge about the post-treatment need for care negatively influenced their follow-up care use [8], which may relate to breakdown in patient-provider communication about recommended care [11]. Similarly, survivors have reported lack of information and unmet needs during the transition to survivorship once formal cancer treatment has concluded [12, 13]. However, to date, little is known about how AYA survivors interact with their care providers after the end of their cancer therapy.

Another dimension unique to the AYA cancer experience is the developmental stage of life patients are in when they receive their cancer diagnosis [14, 15]. AYAs diagnosed with cancer in late adolescence and early adulthood are in the midst of a period of many life changes including transitions toward independence, establishing identity, and career exploration [16]. For example, AYAs may be achieving financial independence, accepting more personal responsibility for their actions, solidifying individual beliefs, and perceiving themselves as equal peers with their parents [15]. At the same time as their cancer treatment, AYAs are in a stressful developmental period of rapid cognitive, emotional, and social growth [17]. They may be establishing a career and/or family, both of which require reprioritization of responsibilities. As a cancer survivor, these important life changes and responsibilities may undermine or interact with their needs for follow-up medical care.

However, despite the acknowledged issues of cost and insurance barriers to follow-up care, few studies have qualitatively explored barriers to care in this population to identify the spectrum of concerns for this population. In particular, there is a need to understand the factors that impact healthcare seeking behaviors in this developmental period of adolescence and young adulthood. The purpose of the present study was to provide an opportunity to

survivors of AYA cancer to express and discuss perceived barriers to obtaining recommended follow-up care. Using an open-ended qualitative research design, we allowed survivors to define and discuss their perspectives of a wide range of barriers to obtaining follow-up care.

Methods

Eligibility and recruitment

Survivors were eligible to participate if they were diagnosed with cancer when they were between 15 and 39 years of age, were 18 years or older at study participation, were at least 1 year from initial cancer diagnosis, had completed active cancer therapy, and were currently living within Salt Lake or Washington counties in Utah. We also limited our focus to diagnoses occurring on or after 1/1/2006 as we were interested in survivors who had more recently experienced cancer therapy and the transition to survivorship. Survivors of non-melanoma skin cancer and in situ diagnoses were not included.

Two hundred eligible survivors were randomly identified through the statewide Utah Cancer Registry (UCR), a population-based Surveillance, Epidemiology, and End Results Program (SEER) cancer registry. The UCR contacted patients directly by mailing letters that contained a study introductory cover letter and a consent-to-contact form with a postage-paid envelope. Patients who did not respond to the mailing within 2 weeks were contacted by phone up to 3 times at varying times of day and week. Given no response, a second mailing was sent, also containing a study introductory cover letter, and a consent-to-contact form with a postage-paid envelope. If there was no response within 2 weeks of this mailing, eligible survivors were contacted by phone, up to 3 times at varying times of day and week. Of the 200 survivors, UCR was unable to deliver mailings to 44 individuals making them ineligible for our study. Of the remaining, 13 were deemed ineligible given updated information, 64 agreed to be contacted by our research team, 69 did not respond, and 10 declined to participate. We compared age at diagnosis and gender of those who did not respond, or who were unable to be contacted to those who participated using chi-square tests and found no statistically significant differences. Twenty-eight survivors participated in focus groups, resulting in a 44 % participation rate of those contacted by the research team.

Focus groups

Six focus groups were conducted between March and May in private rooms in community locations (e.g., local library), and each consisted of 3–8 survivors. After providing informed consent, participants were asked to complete a survey containing questions on demographic information, cancer history, and other items (results not reported here). Focus groups were moderated by a trained moderator (EZ). The moderator used a semi-structured focus group guide to lead discussions concerning health insurance knowledge, perceived benefits of follow-up care, barriers to the receipt of care, and willingness to pay for follow-up care. The focus of the current report is survivors' reported barriers to the receipt of care. Survivors provided information on their perceived barriers throughout the focus group, and in response to the following question: "Research has shown that as survivors get older, and longer from their diagnosis, they get less follow-up cancer care. Why do you think that is?" The

moderator also asked several probe questions related to this topic (see Appendix 1). At the conclusion of the focus groups, participants were thanked with a \$25 gift card for a local store.

Analysis

Focus group discussions were audio recorded and transcribed by an external transcription service. NVivo was used for qualitative coding and to summarize themes. After reviewing transcripts, one researcher (SK) used conventional content analysis to generate a thematic structure describing survivors' perceived barriers to follow-up care [18]. The coding scheme was revised based on discussion with two other researchers (EZ, RS). The first focus group was consensus coded by three researchers (EZ, RS, SK), and the thematic structure was modified slightly. The remaining transcripts were coded independently by two researchers (EZ, RS, percent agreement = 97.8 %), and all differences were reconciled through discussion and mutual agreement.

All study procedures were approved by the University of Utah Institutional Review Board.

Results

Participant characteristics

In total, 28 survivors participated in focus group discussions. More participants were female ($n = 16$, 57 %), the majority completed more than a high school education ($n = 23$, 82 %), and were married ($n = 15$, 53.6 %) (Table 1). Survivors were diagnosed on average when they were 24.6 years old ($SD = 5.8$) and were an average of 6.2 years since their diagnosis ($SD = 1.6$). The majority had health insurance at the time of the study participation (89.3 %).

Barriers to care

Lack of provider clarity on need for medical visits after therapy—One consistent issue for survivors of AYA cancer was confusion about their healthcare needs after cancer therapy ended. Though many still had a relationship with their oncologist, participants mentioned uncertainty in how they should approach follow-up care because their provider did not give specific recommendations. Others reported seeking and not getting clear information from providers:

I've asked my doctor several times, 'okay, does my having cancer increase my risk in getting other types of cancer?' It's always this vague response, and then I ask them, 'should I start doing things earlier than normal, like getting a mammogram and doing other things?' ...Can't somebody just give me an answer?

In fact, survivors received information from their doctor that led them to believe that follow-up care was not essential. One stated:

It's [follow-up care] a little bit of a waste of money, but my doctor said once that this is why he stopped doing it, that no amount of scans or post follow-up is going to know your body more than what you know of your body. He said the best thing you can do is just to be in tune, and then if something's persistent over two weeks, to maybe call and then talk about it, or bring it up at the next visit if it's close.

Skepticism about follow-up care—Survivors expressed skepticism concerning the effectiveness of follow-up medical visits. For some survivors, whose initial cancer was difficult to diagnose and required substantial testing, they perceived the tests included in the follow-up visits as potentially inadequate and not worth the costs.

I had a big, gigantic tumor in my chest, and they did bloodwork, they did all kinds of everything, and the only reason they found it is they finally took a CT. The only thing that happened with my follow-up visits is ‘here, let’s draw your labs.’ It’s like what’s the point if they’re not going to find it anyway?

Confidence and security—In addition to doubt about the efficacy of follow-up visits, survivors expressed their confidence in understanding their own body, without the need for medical tests. Survivors did not see the need to make follow-up visits a priority when they were healthy and otherwise not experiencing symptoms.

If I feel good, it’s not something that I worry about. If you’re feeling pretty good and you’re not having any problems, you don’t really think about going in or make it a priority to go in.

If you don’t feel ill, it’s easier to put that appointment date to the back of your mind and let everything else cover up your mind.

Autonomy and moving forward—Survivors were often tired of dealing with their cancer. One survivor stated, “I can see why some people would taper off, because you’re just tired of the topic; you’re tired of visiting [the clinic].” For some survivors, their cancer occurred when they were transitioning from adolescence to young adulthood. Many of them viewed cancer as a part of their adolescence and expressed the desire to move on with their adult life, which entailed new and additional responsibilities.

I think there’s a big focus in the twenties on becoming your own person, and living your own life, and once you’re done with cancer, it’s just so much easier to not have to deal with that issue, like not going back to follow-up visits, maybe.

Another survivor echoed this sentiment and also touched on the emotional stress of seeing a doctor for cancer-related care after the end of therapy:

You just want to put that chapter of your life behind you, so it’s more of a choice because it’s more of an emotionally-driven response, versus... Not necessarily financial, but just because of your emotion[s].

Competing responsibilities—In addition to the emotional burden of going to see a provider for follow-up care, survivors reported experiencing competing responsibilities, such as career and family, which made allocating time for follow-up visits difficult. In particular, the demands of children made going to the doctor a challenge. Two survivors described this as:

It has been difficult for me sometimes because it’s about a 30-minute drive and I have three small kids, so I’ve missed appointments because it’s too far.

For me, it's balancing a schedule. My kids go to school at this time, and then I have this one, and so I need to find a babysitter, and sometimes you're waiting two hours for your visit, because you never know if your doctor was called for an emergency someplace else.

Aside from the logistical difficulties of attending appointments, competing responsibilities resulted in some survivors prioritizing their family's needs over their own.

Our lives get busier, especially with work, marriages, children, and the time for yourself just isn't there.

I get busy taking care of everyone else. I'm a mother and a wife and a full-time job on top of doing all that. You put yourself in last place.

Fear and avoidance—The fear of getting sick again and receiving another cancer diagnosis led survivors to avoid the possibility of receiving bad news by not going in for regular care. One survivor chose not to go to the doctor to avoid putting his family through the cancer experience again.

Sometimes you don't want to go back because you're afraid that they're going to give you bad news. You kind of want to put your head in the sand, hoping it's not going to come back. So you say, 'if I don't go, then I'll never know', which is a really bad thing to do, but it's for me kind of what happens. So part of me is afraid to go back for me because the chances of getting sick are there, or going back and having to put my family through it again. I don't want to do that to them. So there are those days when I'm just like, out of sight, out of mind. I'm just going to ignore it.

Discussion

While high cost of care, lack of insurance, and low knowledge have been cited as potential reasons for forgoing follow-up care among survivors of AYA cancer [19, 20], our qualitative study identified several other important factors that may prevent AYA cancer survivors from engaging with their medical providers. While the Children's Oncology Group guidelines recommend that survivors of AYA cancer visit their doctor at least once annually following treatment [21], we found that many survivors are skipping follow-up care due to provider communication issues, and factors inherent in the AYA period such as a growing autonomy and the changing responsibilities that overlap with transitions, such as starting family or career. Importantly, nearly 90% of our participants had private health insurance coverage, allowing us to identify barriers other than access to health insurance that affected their receipt of care.

A few survivors in our focus groups reported that their providers did not give clear guidance about what to do for their medical care after the end of their therapy. This ranged from getting non-committal responses from their physician to providers telling patients to be in tune with their body and seek care as needed. This is concerning as risk-based follow-up care may be crucial for managing survivors' long-term health, and preventing late effects [21, 22]. While we did not specifically clarify the types of providers seen by our

participants, many described in the focus group discussion that they still saw their oncology provider, and preferred to do so. Our findings suggest that oncologists need to prioritize giving patients long-term recommendations for care, while at the same time efforts need to be made to better raise awareness among both oncologists and primary care physicians of the need for survivor-specific care so that patients do not receive mixed messages concerning the need and importance for long-term care.

Potentially related to the need for clearer provider recommendations were survivors' perceptions that follow-up visits were only needed if they had symptoms or perceived an imminent healthcare need. For example, if survivors were asymptomatic and were confident about their health, they felt they did not need to see a doctor. Therefore, efforts to increase receipt of follow-up care among AYAs may need to target improving provider recommendations while at the same time targeting survivors' knowledge of risk-based surveillance and how this differs from self-perceived health status.

Raising survivors' awareness of long-term care may not be sufficient without also targeting their beliefs about the efficacy of care. Survivors were particularly concerned about the effectiveness of follow-up visits. Prior to diagnosis and throughout treatment, survivors undergo numerous tests and procedures conducted as per standard of care. In contrast, follow-up visits may entail fewer tests, which were perceived as lacking efficacy in detecting health problems or recurrence and not being worth the time or money. Furthermore, a recent study found that long-term survivors of AYA cancer perceived their healthcare quality to be lower, reported not having enough time with providers, and that providers do not show them respect more often than individuals without a history of cancer [10]. Survivors also report avoiding medical follow-up due to anxiety about potential cancer recurrence, consistent with literature documenting links between anticipatory anxiety and greater perceived health risks [23]. Future studies should investigate how survivors' perception of quality of care, effectiveness, and issues of medical anxiety influence their actual receipt of follow-up care.

Other issues that emerged from our focus groups were related to the psychosocial and developmental concerns of AYAs. Survivors described a need to gain emotional autonomy in an attempt to move past their cancer diagnosis and treatment-related experiences, particularly for survivors who experience cancer in late adolescence, a time of growing independence [24]. For some survivors, the desire to move on manifested in their avoidance of follow-up visits with their providers. Another issue survivors expressed was the prioritization of other responsibilities, such as their children's schedule, which led to their lack of ability to attend medical appointments. Medical facilities who serve AYA survivors may want to incorporate strategies that help survivors manage competing responsibilities in order to receive timely care. For example, facilities could offer extended office hours with a potential to have appointments during the weekend, or offer onsite childcare options.

Our study provides a unique perspective to the literature on management and transition to follow-up adult care for AYAs with chronic conditions, which is an important area of ongoing research and policy [25]. Transition to follow-up care may be especially challenging for survivors of AYA cancer in comparison with survivors of childhood or adult cancer because of the unique psychosocial challenges occurring in the AYA years.

Survivors' effort toward gaining autonomy and taking charge of other responsibilities can be made smoother by providing targeted medical and psychosocial supportive care [26, 27]. Other supports could include the development of AYA survivorship-related transition plans to ease the process of transitioning from primary oncologists to adult primary care providers [28].

A few limitations exist in our study. Our data are self-reported and the focus groups were conducted in a single state that may limit the generalizability. The sample size for our exploration was relatively small and we recommend that future studies investigate barriers to follow-up care with a larger sample, which can allow for an additional analysis to include cancer types and time since diagnosis. Our sample included those diagnosed within the past 10 years, meaning that we did not capture the perspectives of longer-term survivors. Finally, focus groups have the tendency to report acceptable opinions which may also bias the study findings [29] or provide less comprehensive understanding of barriers.

In summary, our results lend to the growing literature on potential care needs for AYAs with cancer in the transition to survivorship after cancer therapy. The fragmented state of survivorship care in the USA [30], including providers' lack of support for follow-up care, may affect survivors' willingness to routinely use medical care. Furthermore, survivors of AYA cancer may be occupied with life-course transitions or shifting priorities (e.g., starting college and work, building new relationships, having children) that may elevate the risk of non-engagement with the medical system. Aside from the material barriers to follow-up care (e.g., insurance), there are several emotional, psychological, knowledge, and logistical barriers that also interact to determine whether survivors obtain recommended care. Increased provider-patient communication and supportive care services are needed to enable survivors to obtain the risk-based follow-up care that is recommended. In addition, effective collaboration and communication among multidisciplinary healthcare teams (e.g., social workers, patient navigators, and nurse) may support improved follow-up care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1Demographic characteristics of focus group participants ($N = 28$)

	Number	Percent
Gender		
Male	12	42.9
Female	16	57.1
Age at diagnosis		
15–22	12	42.9
23–29	10	35.7
30–37	6	21.4
Average (SD) years since diagnosis	6.2 (1.6)	
Ethnicity		
Non-Hispanic White	25	89.3
Hispanic	3	10.7
Diagnosis		
Hepatic tumors	11	39.3
Solid tumors	17	60.7
Education		
High school or less	5	17.9
Some training or college	10	35.7
College graduate	13	46.4
Insurance		
Private	25	89.3
Uninsured/other	3	10.7
Household income		
25,000	8	28.6
25,001–50,000	7	25
50,001–100,000	8	28.6
>100,000	5	17.9
Marital status		
Married	15	53.6
Single	13	46.4
Sexual orientation		
Heterosexual	21	75
Homosexual or bisexual	5	17.9
Unspecified	2	7.1