Adolescent and Young Adult Cancer Survivors' Perspectives on Their Internet Use for Seeking Information on Healthy Eating and Exercise

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Purpose: To explore adolescent and young adult (AYA) cancer survivors' internet use in seeking healthy lifestyle behavior (HLB) information on diet and exercise.

Methods: Twenty-five AYA cancer survivors participated in focus groups or interviews. Data were analyzed using qualitative content analysis.

Results: Most survivors (92%) sought HLB information from internet sources. Key issues included the following: (1) too much information available, (2) information not meeting survivors' unique needs, and (3) concerns about trustworthiness of information.

Conclusion: Although AYA cancer survivors use the internet to seek HLB information, internet resources could be modified to better meet the needs of AYA cancer survivors.

Keywords: healthy lifestyle behavior, internet use, information seeking, qualitative, adherence, survivorship

Introduction

WITH CONTINUED ADVANCES in the treatment of childhood and adolescent and young adult (AYA) cancer, there is a growing population of 18–39-year-old AYA cancer survivors who were diagnosed with cancer during childhood or during AYA years.^{1,2} AYA cancer survivors are at risk for significant health issues related to their cancer history, such as unresolved symptoms, emerging late effects, and second cancers.^{3,4} All cancer survivors, including AYA survivors, are recommended to continue active medical surveillance and to adopt and maintain healthy lifestyle behaviors (HLBs), including eating a healthy diet and engaging in regular physical activity.^{5,6}

Maintenance of HLBs reduces the occurrence of second cancers and protects against poor long-term health outcomes in both adults and AYAs.^{7–9} Yet, studies have shown that AYA cancer survivors demonstrate poor behavioral adherence.^{6,10,11} Reasons for nonadherence include lack of understanding about the importance of these behaviors and a lack of informational resources on HLB adoption.^{12–14}

Although healthcare providers are considered a key resource for HLB information, the internet is also an important tool.^{15–18} The vast majority of AYAs, regardless of cancer history, are

proficient in using the internet and frequently seek internet-based health information.^{16,19,20} In one study of the general population, 31% of adolescents and 73% of young adults reported searching the internet for information about at least one health topic.^{21,22} However, it is unknown whether AYA cancer survivors find information on internet-based HLBs a useful resource.²³ The aims of this study were to explore AYA cancer survivors' experiences using the internet to obtain information on HLBs, to identify potential unmet needs related to internet resources, and to provide initial ideas that could contribute to future development of internet resources for AYA survivors' HLBs.

Materials and Methods

Participants

Cancer survivors 18–39 years of age were eligible to participate if they had been diagnosed with cancer before the age of 39. In addition, they had to have completed active treatment at least 6 months before study screening.

Measures and procedures

Recruitment occurred through invitation letters or in person at a National Cancer Institute (NCI), a designated cancer

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center and a pediatric tertiary care hospital in the United States. Recruitment flyers were posted in clinics and through cancer advocacy organizations. Potential participants were invited from (1) the late effects clinic at the cancer center, (2) a registry of patients treated in the pediatric oncology clinic at the tertiary care hospital, (3) a participant pool from a prior AYA survivor study, and (4) the cancer center's social media site. Recruitment letters were sent to 82 potential participants and an additional 17 contacts were made in the cancer center clinic. From these contacts, 61 survivors indicated initial interest in the study and 22 enrolled and participated in one of five focus groups. Three participants who had scheduling conflicts with focus groups participated through individual phone interviews. Reasons that survivors declined participation included lack of time or difficulty traveling to attend focus groups.

Focus groups were facilitated by a clinical psychologist and a clinical psychology graduate student. Participants were asked open-ended questions about their experiences using internet resources for seeking information related to health behaviors (specifically, diet and exercise) after cancer treatment (focus group protocol available from corresponding author on request). Participants were asked to complete a self-report questionnaire on demographic and disease information and their internet use (5-point scale ranging from "not at all" to "every day"). The University of Utah Institutional Review Board approved all study procedures.

Analytic plan

Audio recordings of the focus groups and interviews were transcribed verbatim by a professional transcription service. Content analysis, a standard approach to analyze qualitative data, was utilized to determine themes.²⁴ Two research team members independently performed analysis of the transcript content. First, all content related to survivors' internet use for seeking HLB information was extracted. Second, the content was coded in NVivo 11 using the constant comparison method to identify emergent themes.²⁴ Questionnaire responses were summarized using descriptive statistics.

Results

Twenty-five AYA cancer survivors participated (Table 1; mean age = 28 years). More than half of participants were female (68%) and all (100%) were white. With an average age at diagnosis of 17.5 years, cancer diagnoses included solid tumors (48%), leukemia or lymphoma (40%), and brain tumors (12%). Survivors reported accessing the internet every day (88%) or at least a couple of times a week (12%). The vast majority of AYA cancer survivors (92%) reported that they had used the internet to seek health information.

Three primary themes about participants' experiences with internet use for healthy lifestyle information were identified. Specifically, AYA cancer survivors reported that (1) there was too much HLB information on the internet, (2) this information is not specific to the needs of AYA survivors, and (3) this information may not be trustworthy.

Too much HLB information available

Some survivors (Table 2) expressed that there was too much information on the internet related to HLBs. Survivors reported being overwhelmed by an abundance of seemingly

TABLE 1. DEMOGRAPHIC CHARACTERISTICS AND INTERNET USE AMONG ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS

	Survivors (N = 25)
Age (years)	
Age at study, <i>M</i> (<i>SD</i>)	27.6 (6.6)
Age at cancer diagnosis, <i>M</i> (<i>SD</i>) ^a	17.3 (12.2)
Type of cancer	n (%)
Leukemia/lymphoma	10 (40)
Solid tumor	12 (48)
Brain tumor	3 (12)
Sex	
Male	8 (32)
Female	17 (68)
Employed or in school	
Yes	24 (96)
No	1 (4)
Education level	
High school or less	1 (4)
Some college	12 (40)
College graduate	7 (28)
Postgraduate level	5 (20)
Marital status	
Single/never married/never lived with partner as married	13 (32)
Married	10 (40)
Divorced	2 (8)
Race	
White	25 (100)
Hispanic/Latino	
Yes	1 (4)
No	24 (96)
Total household income last year	
<\$20,000	6 (24)
\$20,000–39,999	2 (8)
\$40,000–59,999	3 (12)
\$60,000–79,999	2 (8)
\$80,000–99,999	4 (16)
>\$100,000	4 (16)
Do not know	4 (16)
Frequency of internet use	
Every day	22 (88)
A couple of times a week	3 (12)
Have used the internet for health purposes	22 (92)

^a*n* = 16 diagnosed before the age of 18, *n* = 9 diagnosed at age 18 or older.

unorganized HLB information that made it difficult to find what they were seeking. One survivor commented, "And even when it is supposedly well-organized, it still seems like just masses of information that aren't well separated." Survivors expressed that they did not want to spend time searching through vast amounts of information.

Information on the internet does not meet AYA cancer survivors' needs

Although participants sought internet information on HLBs, they reported finding information that was not tailored to their unique challenges and needs as AYA cancer survivors (Table 2). Some survivors expressed that there was a dearth

TABLE 2. SUMMARY OF THEMES ABOUT INTERNET HEALTHY LIFESTYLE BEHAVIOR INFORMATION

Theme	Exemplar quotations
Too much healthy lifestyle behavior information available	<p>“I’ve never gone online. It just could be bad. One, I don’t even know what you look at. Type in <i>clean eating</i> and a thousand things are going to pop up, so it’s like what do I choose, so I’ve never done any research on anything like for that.”</p> <p>“So just doing some basic internet search you can find the whole smorgasbord, but I guess it’s hard to bring in what I consider the authoritative sources without creating the data overload, because even within the academic community of cancer, there’s just so much out there.”</p>
Information found on the internet does not meet AYA cancer survivors’ needs	<p>“Or just kind of disconnected. You’ll find a lot but it’s not really totally applicable or it’s not comprehensive enough.”</p> <p>“If you’re talking about how you’re doing today, how you’re feeling, did you eat okay, posting that kind of stuff, I agree that there are a lot of web sites that are similar, but maybe not with a cancer focus.”</p>
Questioning the trustworthiness of internet-based healthy lifestyle behavior information	<p>“Even with what are supposed to be the good sources you can still see some conflicting information from one hospital to another or one study to another. It would be nice to have a centralized place that you knew was all right, but I don’t know if there’s a way to do that.”</p> <p>“Even just a place to look something up. It’s 2:00 in the morning and you want to look at something, you could just jump on there instead of having to wade through all the junk on the internet to find something.”</p>

of internet information on HLBs for AYA survivors in particular. For example, survivors discussed that the HLB information they found was primarily directed at individuals on active treatment. One participant stated, “For survivorship I’d say there’s probably too little [information]. You can find everything about during cancer. You can find all that, but after [cancer], not a lot.” Some survivors commented that when they found information targeted to the post-treatment period, the information was for older survivors and not for AYAs. As one survivor described, “The other thing when I was looking up resources and things locally, no matter where I’ve lived I’ve always run into the problem of being the youngest person by far.”

Other AYA cancer survivors found that information was not tailored to individuals with a cancer history or was not specific to different cancer diagnoses. One AYA cancer survivor stated, “Everybody is different, so there would need to be some specialized programs based on your diagnosis and what’s recommended.” AYA cancer survivors expressed a need for more personalized healthy lifestyle information on the internet that is specific to their cancer history, limitations they may experience as a result of treatment (e.g., diminished physical capabilities), and tailored to their age and lifestyle.

Questioning the trustworthiness of internet-based HLB information

The vast majority of survivors reported a desire for trustworthy internet sources on HLB (Table 2). For example, one survivor stated, “If there was one site that you knew you could trust, that would be something nice. We’re always told where *not* to go, but we’re never told where *to* go.” Some survivors described searching for HLB information on the internet exclusively from medical journals and trusted sources (e.g., Google Scholar and PubMed). However, survivors viewed other sources of information on the internet as potentially untrustworthy. One survivor explained, “If I really want information, I use my resources as a student to get at a research library and do it that way—.org, .edu, those [web-

sites].” Other survivors expressed a need for receiving HLB information from a healthcare professional: “It would be nice to have something that’s actually from a doctor, because you get on the internet and who knows what you’re going to come across.” One survivor acknowledged the importance of checking the accuracy of information found on the internet with a healthcare professional: “I still think that even if you do find something online it’s good to ask your doctor anyway, because you never know.”

Many survivors reported finding conflicting HLB information on the internet. The conflicting information led survivors to question whether any of the information online could be trusted. One survivor described how she reconciled conflicting internet information: “Should you go natural, well you shouldn’t go natural, you should take vitamins, don’t take vitamins. They’re just so subjective that it really comes down to you personally and what works for you rather than a general what’s right.”

Conclusion

There is increasing evidence that adoption of HLBs is beneficial for AYA cancer survivors, yet resources to help AYA survivors adopt and maintain these behaviors may have notable limitations.^{7–9,12} The internet could be leveraged as a platform for engaging AYA survivors around HLBs, particularly because AYAs, including cancer survivors, regularly use the internet to seek health information.^{16,19–21} However, the current findings indicate that survivors perceive limitations to current internet resources for HLBs. Concerns such as being overwhelmed with the quantity of HLB information found online, having difficulty finding appropriate HLB information, and skepticism about the trustworthiness of HLB information on websites were commonly expressed among cancer survivors of a variety of ages. A unique concern expressed by AYA participants in this study was their desire for websites tailored to their needs as a young cancer survivor. Although the vast majority of participants indicated that they regularly use the internet for health information, there was

consensus that internet sources do not adequately meet their needs. Internet sources should ideally be readily identifiable as pertinent to AYA cancer survivors and provide age-appropriate strategies for adopting HLBs.

The results provide implications for the development and refinement of internet resources designed to support AYA survivors in adopting HLBs. First, AYA survivors indicate that there is too much information to absorb. Future work could seek to understand the appropriate level and type of information different subgroups of AYA survivors find helpful. Second, AYA cancer survivors are frustrated by the difficulty of finding appropriate websites. They desire websites that have tailored information to their experience as a young survivor of cancer and want recommendations for their age group. Third, there was a consistent concern about the trustworthiness of internet sites. Participants indicated that they would prefer information from an established medical authority. Internet resources should consider involving healthcare providers and other professionals (e.g., sports medicine expert and dietician) in designing and adding credibility to information about HLBs pertinent to AYA survivors. Although providing appropriate HLB information is an essential foundation for enacting behavior change, intervention programs would also benefit from the incorporation of evidence-based behavior change techniques, such as self-monitoring and goal setting, which are grounded in health behavior theories.^{13,25}

This study had both strengths and limitations. The qualitative methods utilized provided a detailed perspective from AYA cancer survivors on their internet experiences when seeking HLB information. However, the study was limited in its sample size and racial/ethnic diversity of participants. Although the sample was representative of individuals in the geographic area served, future research could target recruitment of a more diverse sample to better understand potential variation in needs. Also, this study was unable to explore the full range of HLBs relevant to survivors. For example, smoking and alcohol consumption could be examined in future studies. Future studies could also assess whether authoritative websites (e.g., American Cancer Society) are perceived by AYA survivors to be trustworthy. Despite these limitations, the study findings can help to guide the development of internet resources to support AYA cancer survivors in adopting and maintaining HLBs over the long term. Future research could explore the desired depth and focus of HLB information among AYA cancer survivors to maximize survivors' health outcomes and ability to thrive after cancer.

Acknowledgments

This work was supported by the Health Studies Fund (Department of Family and Preventive Medicine, University of Utah), the Huntsman Cancer Institute Cancer Center support grant (NCI P30CA042014), the Huntsman Cancer Foundation, and the National Cancer Institute of the National Institutes of Health (NIH) K07CA196985 (Y.P.W.) and K07CA174728 (K.A.D.). The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Disclosure Statement

No competing financial interests exist.

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