

Barriers and Facilitators of Healthy Diet and Exercise Among Adolescent and Young Adult Cancer Survivors: Implications for Behavioral Interventions

Yelena P. Wu, PhD,^{1,2} Jaehee Yi, PhD,³ Jessica McClellan, MPH,¹ Jonghee Kim, MSW,³ Tian Tian, PhD,³ Bridget Grahmann, BS,¹ Anne C. Kirchhoff, PhD,^{2,4} Avery Holton, PhD,⁵ and Jennifer Wright, MD⁴

Purpose: This study uses qualitative methods to identify barriers to and facilitators of exercise and healthy eating among adolescent and young adult (AYA) cancer survivors (survivors currently aged 18–39 years and diagnosed with cancer anytime in their lives), as reported by survivors and their primary supporters.

Methods: Survivors ($M_{\text{age}}=27.6$ years, $SD=6.6$ years) had completed active cancer therapy. Survivors and supporters (i.e., nominated by survivors as someone who was a main source of support) attended separate focus group sessions (five survivor focus groups, five supporter focus groups) and were asked to complete a self-reported questionnaire assessing demographic and cancer history and engagement in exercise and healthy eating.

Results: In total, 25 survivors and 19 supporters participated. The three overarching themes identified were barriers to exercise and healthy eating (e.g., lack of resources, negative thoughts and feelings, negative social and environmental influences), facilitators of exercise and healthy eating (e.g., cognitive motivators, tools for health behavior implementation, social relationships), and intervention implications (e.g., informational needs, desire for social support).

Conclusion: AYA cancer survivors and their supporters identified barriers to and facilitators of healthy lifestyle behaviors, which should be considered when designing interventions to improve the long-term health of survivors.

Keywords: health behaviors, qualitative, healthy lifestyle, adherence, social support

FOLLOWING CANCER TREATMENT, patients experience an acute shift from frequent medical appointments to a long-term focus on health promotion and surveillance aimed at decreasing risk and monitoring for cancer recurrence or secondary cancers. Recommended healthy lifestyle behaviors for survivors include healthy eating and engaging in physical activity.¹ These health behaviors are expected to reduce risk for recurrence and new cancers,^{2–4} to improve quality of life, and to extend survival.⁵ Adolescent and young adult (AYA) survivors, a substantial and growing population,⁶ demonstrate poor adherence to these recommendations,^{7–10} which is alarming given their increased risk for cancer recurrence, long-term health problems, and poor quality of life.^{11–20}

While AYA oncology guidelines stipulate that patients should receive nutrition and exercise guidance,²¹ there are limited evidence-based interventions tailored for this group and limited literature on how best to deliver health interventions to AYA survivors.²² Before designing such interventions,

consistent with the Intervention Mapping framework,^{23,24} it is important first to identify the barriers to and facilitators of survivors' health behaviors. Drawing on the Socio-Ecological Framework and Social Cognitive Theory,^{25,26} these barriers and facilitators to health behaviors are expected to occur on several levels (i.e., individual, family, peer, healthcare) and to involve social influences (e.g., social support, others' health behaviors), outcome expectancies (e.g., the survivor's anticipated consequences of the health behaviors), and survivors' self-efficacy (i.e., the survivor's belief that he/she can implement the health behaviors). Consistent with these models, some studies have identified individual-level barriers such as fatigue, limited time, feelings of discouragement, as well as negative social influences.^{10,27} However, fewer studies have been qualitative¹⁰ or have focused on potential facilitators to healthy eating and exercise among AYA survivors, such as in-person or online peer support groups.²⁸ It is essential to identify facilitators so that interventions can both decrease

¹Department of Family and Preventive Medicine; ³College of Social Work; ⁴Department of Pediatrics; ⁵Department of Communication; University of Utah, Salt Lake City, Utah.

²Department of Cancer Control and Population Sciences, Huntsman Cancer Institute, Salt Lake City, Utah.

barriers and promote facilitators. In addition, prior studies have not included perspectives on healthy lifestyle behaviors from individuals who support survivors, such as family or close friends. Incorporating these perspectives is particularly important for AYA survivors because the AYA developmental period is marked by significant changes to the social support system.²⁹

To address these gaps, the current study used qualitative methods to identify barriers to and facilitators of exercise and healthy eating among AYA cancer survivors (survivors currently aged 18–39 years and diagnosed with cancer anytime in their lives), as reported both by survivors and their primary supporters. Following the socio-ecological and social cognitive theories, it was hypothesized that survivors and their supporters would cite barriers and facilitators on multiple levels (e.g., individual, family, peer, healthcare), including social factors (e.g., social support), health behavior-specific outcome expectancies, and the need for increased self-efficacy for implementing health behaviors.

Materials and Methods

Participants

Cancer survivors were eligible to participate if they were between the ages of 18 and 39 years at the time of screening and if they had completed active therapy for cancer. Survivors were recruited from clinics at a NCI-designated cancer center, self-referral in response to advertisements through cancer advocacy organizations, a registry of survivors who had participated in a prior study, and recruitment letters mailed to potentially eligible patients. After eligibility screening, survivors were asked to nominate individuals who provide them with support: “Are there one or more people in your life who you feel close to or who support you, and who live close enough that they could attend a focus group with you?” If the survivor nominated more than one person, they chose which support person the research team contacted first about participation.

Measures and procedures

Survivors and supporters attended one of five focus group sessions. Separate but concurrent focus groups were held for survivors and supporters. Individual interviews were conducted with three survivors who were unable to attend focus groups. Focus groups were moderated by a clinical psychologist and an advanced clinical psychology graduate student and were audio-recorded. At the focus groups, both survivors and supporters were asked open-ended questions about survivors’ barriers to and facilitators of exercise and healthy eating and their preferences for survivor-focused health behavior interventions using a semi-structured interview guide (e.g., “What are some reasons that being physically active is challenging for you?” “What makes being physically active doable or easier for you?”). Participants were asked to complete self-report questionnaires with questions on demographics, cancer history (for survivors), and engagement in healthy lifestyle behaviors. Health behavior engagement items were drawn from the Behavioral Risk Factor Surveillance System,³⁰ the National Health Interview Survey,³¹ and the National Health and Nutrition Examination Survey.³² All procedures were approved by the authors’ Institutional Review Board.

Analysis

Audio-recordings of the focus group were transcribed verbatim. Five team members were involved in data analysis, which included repeated readings of transcriptions and focus group field notes, individual coding (two coders read each focus group transcript), team discussions for consensus building, and finalization of themes, subthemes, and representative quotes. Open coding of transcripts was used to condense data into analyzable units,³³ and the constant comparative method based on grounded theory approaches was used to cluster codes into categories.³⁴ Descriptive statistics for questionnaire responses were calculated using SPSS Statistics for Windows v20.0 (IBM Corp., Armonk, NY).

Results

In total, 25 survivors and 19 supporters were included in the current analysis. Of the 25 survivors, seven did not have a supporter who participated in the study (one survivor could not identify a supporter and six had supporters unable to participate), and one survivor brought two supporters (i.e., parents). Participant demographic characteristics and engagement in physical activity and healthy eating are provided in Table 1. Survivors reported engaging in physical activity an average of 3.7 days per week for 47 min per day, while supporters reported engaging in physical activity an average of 4.5 per week, also for 47 min per day. Survivors and supporters each reported consuming approximately two servings of fruit per day and two servings of vegetables. As summarized in Table 2, barriers and facilitators to exercise and healthy eating and intervention implications emerged as major themes.

Barriers to exercise and healthy eating

Lack of resources. Survivors and supporters indicated that lack of resources (financial, professional services) were barriers to their engagement in healthy behaviors. Financial considerations were particularly salient for survivors who had spent significant sums of money on their cancer treatment or who were not yet financially independent. Given limited financial resources, participants discussed that purchasing fresh food was more expensive than eating frozen or fast food (Table 2). Paying for exercise facilities, programs, and professionals that would facilitate exercise was also a challenge. A supporter mentioned that everything “to get into, [and] to get started” with exercise cost money, and the stress associated with financial burden might “undo some of the [physical activity] benefits.”

Survivors and supporters discussed the challenge of finding legitimate resources to guide their exercise and eating, particularly given the overwhelming amount of information on the Internet. Survivors sought information from professionals (e.g., physicians, dietitians, physiotherapists) who may have a better understanding of a survivor’s unique needs after cancer. However, they did not always obtain the information they wanted. One supporter explained that the nutrition information her daughter’s physician provided, such as “eat meat as a condiment, lose some weight and eat lots of fruit and vegetables,” was too general to be useful for changing behavior.

Negative thoughts and feelings. Survivors reported negative thoughts and feelings that made exercise and healthy eating challenging. Survivors felt “depressed,” “embarrassed,” and

TABLE 1. DEMOGRAPHIC CHARACTERISTICS AND ENGAGEMENT IN HEALTHY LIFESTYLE BEHAVIORS AMONG AYA SURVIVORS AND THEIR SUPPORTERS

	Survivors (N=25)		Supporters (N=19)	
Age, years				
Current age, <i>M (SD)</i>	27.6	(6.6)	40.4	(13.1)
Age at cancer diagnosis, <i>M (SD)</i> ^a	17.3	(12.2)	—	—
Type of cancer				
Leukemia/lymphoma	10	(40)	—	—
Solid tumor	12	(48)	—	—
Brain tumor	3	(12)	—	—
Sex				
Male	8	(32)	10	(53)
Female	17	(68)	9	(47)
Employed or in school?				
Yes	24	(96)	12	(63)
No	1	(4)	7	(37)
Education level				
High school or less	1	(4)	4	(21)
Some college	12	(40)	8	(42)
College graduate	7	(28)	4	(21)
Post-graduate level	5	(20)	3	(16)
Marital status				
Single/never married/never lived with partner as married	13	(52)	1	(5)
Married	10	(40)	18	(95)
Divorced	2	(8)	0	(0)
Hispanic/Latino?				
No	24	(96)	18	(95)
Yes	1	(4)	1	(5)
Race				
White	25	(100)	18	(95 ^b)
Total household income last year				
<\$20,000	6	(24)	3	(16)
\$20,000–39,999	2	(8)	2	(11)
\$40,000–59,999	3	(12)	3	(16)
\$60,000–79,999	2	(8)	5	(26)
\$80,000–99,999	4	(16)	1	(5)
>\$100,000	4	(16)	5	(26)
Don't know	4	(16)	0	(0)
Healthy lifestyle behaviors				
Physical activity				
Number of days per week, <i>M (SD)</i>	3.7	(1.7)	4.5	(1.3)
Number of minutes per day, <i>M (SD)</i>	46.7	(39.5)	47.4	(22.2)
Diet				
Fruit consumption, <i>M (SD)</i> times per day	1.8	(0.9)	1.9	(0.9)
Vegetable consumption, <i>M (SD)</i> times per day	2.3	(1.2)	1.9	(1.0)

Values are *n (%)* unless otherwise indicated.

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

^bOne participant did not provide this information.

AYA, adolescent and young adult.

“frustrated” about not being able to do physical activities in the same way as before cancer. These feelings led some survivors to exercise less often. Survivors also expressed that fatigue prevented them from exercising. This was particularly true for survivors who had children. One survivor said that after putting her kids to bed, “to sit round and listen to the workout video or do sit ups is the last thing in the world I want to do.” Regarding healthy eating, survivors reported that their cancer experience led them to hold certain attitudes about healthy eating during survivorship. Participants shared that after cancer treatment, they deserved to enjoy food (Table 2).

Negative social and environmental influences. Both survivors and supporters noted that others made engagement in healthy lifestyle behaviors more difficult, particularly if family, friends, and co-workers did not have the same health goals. Survivors discussed the challenge of having unhealthy snacks available at work meetings, finding healthy dishes to eat at social gatherings, and feeling isolated at social events (Table 2). Some survivors discussed that they were tempted to make unhealthy choices because they wanted a break from worrying about health. Even for survivors who had family or friends who were interested in healthy lifestyles, hearing

TABLE 2. SUMMARY OF THEMES IDENTIFIED

<i>Main themes</i>	<i>Sub-themes</i>	<i>Third-tier sub-themes</i>	<i>Sample survivor quotes</i>
Barriers to exercise and healthy eating	Lack of resources	Financial challenges Insufficient information	“Being whatever, a college student, or whatever it is, it’s easier to get a dollar cheeseburger at McDonald’s than to make a meal, and buy fish. You know, I like it, but it’s more expensive to eat healthy than it is not to.”
	Negative thoughts and feelings	Emotions, fatigue Cognitive factors (attitudes, goals)	“When you finish cancer and they say, ‘Okay, no more. We’re going to call you in remission. Go ahead.’ It’s like, ‘Okay, the walls are coming down, honey! I’m eating whatever and as much as I want because I would have been dead by now if I hadn’t had chemo.’”
Facilitators of exercise and healthy eating	Negative social and environmental influences	Environmental influences (family, co-workers) Lack of social support for healthy lifestyle behaviors Advice “overload”	“Lots of times when I go to family gatherings, if I’m not sure what food will be served, I’ll bring something of my own, and people give you a hard time.”
	Cognitive motivators	Belief in and evidence of positive effects of healthy behaviors Perceived control over health Fear of consequences Setting goals	“It’s like I woke up one night and I felt stressed out, felt overweight, just felt sick, and I was like, man, I’m going to die of a heart attack or something, and for me that thought was frightening enough that I was like I need to do something... I think that’s what sparked me to start working out again, and hit the gym, and just starting somewhere.”
	Tools for health behavior implementation	Access to resources Skill acquisition Building new habits, sustaining changes	“I went to the wellness center and found out about their nutrition program, I found out about their exercise program. I started working with [the wellness center] the day that I stopped radiation, and that helped me so much because I was never an exercise person.”
	Social relationships	Companionship Accountability to others	“Something that’s been a lot easier for me—I have a three-year-old daughter—and so it’s been easier for me because I don’t have to just worry about myself. I have to feed her right, too. That’s been helpful for me.”
	Information and education	Improve motivation Knowledge of and managing physical, psychological effects of cancer Develop new interests and skills for health behaviors	“Introducing people to new sports or activities that they maybe haven’t done before and then helping them get ready for, ‘Hey, want to do a triathlon? Great, here’s some information. Here’s what you need to do to do that.’ Similarly, introducing interesting activities, such as video games involving physical activities, can motivate survivors, particularly young ones, to do exercise.”
Intervention implications	Social support	Interaction with other AYA survivors	“What if you [survivor] could sign up to be a supporter, so if they [patients] had survivors up there or people going through treatment and the people, of course treatment isn’t the most pleasant thing, so why not have somebody up there to motivate you.”
	Survivor-specific needs	Programs tailored to abilities and needs of survivors	“Even do a gym that would cater to different physical abilities and make it more comfortable for them, because it could be intimidating to go to a normal gym... so maybe a cancer survivor only gym that does have all the different levels of weights for them.”

excessive concerns or unsolicited advice were burdensome and frustrating.

All my aunts and uncles and everybody has [have] their thing that they're doing and that's what I need to be doing. Well, first of all, I can't do them all. Second of all, it's fine for you to tell me, but you have to know your boundary and give me a little bit, and if I bite and want to know more, I'll ask for more, but don't push it all on me. They're trying to be helpful, but it can come across annoying.

Facilitators of exercise and healthy eating

Cognitive motivators. Survivors and supporters described a number of motivators, including health beliefs, body image, fatigue, fear, goals, and varied activities that helped them sustain engagement in health behaviors. Some participants expressed their belief that survivor engagement in health behaviors would prevent future health problems, including cancer, or help them regain control over current health problems. For other survivors, fear motivated them to make healthier choices. For instance, a survivor described that his fear of dying from a health problem motivated him to make healthy lifestyle changes (Table 2).

Participants reported that having a goal and routine helped survivors sustain healthy habits. For instance, one survivor registered for a running race, which encouraged him to run regularly. Survivors and supporters also highlighted the benefit of trying different types of activities to maintain motivation:

I think doing something different every day so you're not just repetitively doing the same thing makes it more fun to work out. I do something different every day just because I get sick [of it], because I don't like running either and it's hard for me, too. So that's not something I do every day. I do something different.

Tools for health behavior implementation. Survivors and supporters noted a number of "tools," such as gardens, gym memberships, wellness programs, and skill-building that facilitated survivors' engagement in healthy behaviors. Survivors indicated that increased access to fresh fruits and vegetables, particularly through gardens or farmers markets, facilitated healthy eating. Participants who had gym memberships or attended wellness programs expressed that they experienced added motivation for healthy lifestyle changes (Table 2). Survivors and supporters shared that healthy lifestyle changes required them to build new skills in food preparation and meal planning. Survivors built these skills with guidance from experts, such as dietitians, and through their own exploration.

Social relationships. Survivors and supporters expressed that engagement in healthy behaviors was easier if friends and family provided companionship during these activities. One survivor reported being more motivated to cook healthy food when others, such as family and especially children, relied on them (Table 2).

Intervention implications

Information and education. Survivors expressed their wish to receive interventions for health behaviors as well as information on late effects of cancer treatment immediately

after treatment. They requested assistance with improving motivation and managing the physical and psychological consequences of cancer so that they could most effectively make health behavior changes. Survivors also requested interventions that would help them develop new interests and skills related to health behaviors. For example, they wanted to work with personal trainers and find new activities that would make exercise more interesting (Table 2). For healthy eating, both survivors and supporters suggested that nutrition and cooking classes would help survivors make informed decisions about healthy foods.

Social support. Some survivors wanted health behavior programs that would allow them to interact with other survivors who were also AYAs, such as a group exercise program. These programs may be helpful even starting during active therapy (Table 2). One of the proposed benefits in bringing survivors together for health behavior programs would be for survivors to provide and receive social support from others who understood:

Now I have to worry about college, and having a social life, and all those things on top of just this feeling of having your whole life disrupted, nothing's normal ... I remember at the time looking specifically for support groups, and a lot of them were adult type of support groups, like adult survivor groups, or this or that. I felt like there was nothing targeted at [teens].

Such support was particularly desired because some participants found the transition from active treatment to survivorship difficult.

It's like okay, boom, you're out the door, you're on your own, especially being an adolescent, I literally was out the door and on my own. I felt like for a while I just kind of meandered, and went through a tailspin, and just really didn't really know how to just get my life back to some sort of normal.

Survivor-specific needs. Both survivors and supporters emphasized that interventions should be tailored to address the unique needs of survivors, for example survivors reported feeling embarrassed when they went to a regular gym if they were restricted in their abilities due to physical limitations from cancer (Table 2).

Discussion

AYA cancer survivors are a unique patient population who are not treated at major cancer centers as often as pediatric patients and older adult patients.^{35,36} As a result, AYA survivors may lack access to survivor-focused supportive care services that promote healthy nutrition and exercise. Findings in the literature are mixed as to whether AYA survivors' engagement in health behaviors is worse or better than that of their healthy peers.^{37,38} However, for AYA survivors with suboptimal adherence to recommended health behaviors, supportive care services could be tailored to their needs and address their unique challenges and barriers to accessing such services (e.g., time limitations due to raising young children, financial challenges after cancer treatment, and starting one's career).³⁹⁻⁴²

The current study of AYA cancer survivors and their supporters identified a number of barriers to and facilitators

of healthy lifestyle behaviors that could be useful when designing AYA-specific health interventions. Consistent with the hypotheses, these barriers and facilitators occurred on multiple levels ranging from survivors to their family members, peers, and healthcare providers, and included social factors, survivors' outcome expectancies, and self-efficacy. Barriers to healthy diet and exercise included lack of resources, negative thoughts and feelings, and negative social and environmental influences. Facilitators included cognitive motivators, tools for healthy behavior implementation, and positive social relationships. Survivors and supporters identified the need for additional information and education and support that is survivor specific.

The present findings are in line with prior research with cancer survivors of other ages as well as with AYA survivors, specifically. Barriers and facilitators identified in other cancer survivor age groups similarly included motivation, disease-specific physical limitations, cost, and health behaviors of other family members.⁴³⁻⁴⁵ Particularly unique to AYA populations, participants noted their desire to connect with other AYA survivors around health behaviors. Further, the barriers and facilitators that were identified among AYA survivors are consistent with prior findings that AYA survivors have unmet informational needs, want assistance with healthy lifestyle behaviors, including via peer support, but could experience barriers to engaging in intervention programs.^{10,28,46,47}

The results have several implications for interventions aiming to support AYA survivors' adherence to exercise and physical activity recommendations. First, the findings on barriers and facilitators indicate that there is a variety of modifiable factors (e.g., motivation, mood, self-efficacy) that interventions could target. Second, AYA survivors may be more willing to participate in interventions that facilitate interactions with other AYA survivors and families. Third, AYA survivors may be most amenable to interventions that involve some content delivered by healthcare providers. Fourth, participants desired programs held in "safe" settings (e.g., exercising with other survivors who would understand their physical limitations). Fifth, consistent with results of prior studies, participants expressed that health behavior intervention programs could be useful at different stages in their cancer journey ranging from during active therapy to immediately after active therapy concluded.^{43,48} Overall, the ideas raised by participants in the current study complement prior findings that stress other important aspects of health behavior programs for AYA survivors, such as choice, flexibility, and convenience.¹⁰ Encouragingly, initial health behavior interventions for AYA survivors have shown promise, and AYA survivors express interest in web-based programs.^{42,49}

The current study had both strengths and limitations worth noting. A strength of the study is the inclusion of the supporter's perspective. Prior studies have focused only on the survivor's perspective and have not considered the perspectives of supporters, who may comprise survivors' families of origin and also romantic partners.²⁹ Importantly, these supporters could be key partners to integrate into health behavior interventions for AYA survivors. Limitations of the study include the relatively small sample size and that the results may have limited generalizability to AYA survivors beyond the authors' geographic region. The current study focused on exercise and healthy eating because of the documented poor

adherence of childhood cancer survivors and AYAs to these health behaviors, the relevance of these health behaviors to multidisciplinary teams serving survivors that include dietitians and physical therapists, and that evidence-based interventions addressing these behaviors share common components and often address diet and exercise concurrently.^{17,50-53} However, there are other health behaviors, such as limiting smoking and drinking alcohol and implementing sun protection, which should also be examined in future studies.

Studies with larger samples could use mixed methods to examine the concordance between barriers and facilitators cited through quantitative and qualitative methodologies, the frequency with which survivors with different demographic or health behavior characteristics endorse different barriers and facilitators, and the extent to which endorsement of different barriers and facilitators predicts adherence to healthy lifestyle behaviors. Future studies could also examine the degree to which barriers and facilitators differ between AYA survivors diagnosed in childhood versus in their adult years. More work is needed to understand the role that supporters play in promoting and hindering adoption of healthy lifestyle behaviors by AYA survivors.

AYA cancer survivors experience unique barriers to and facilitators of healthy lifestyle behaviors, which can inform future development of interventions to improve adherence to these healthy lifestyle behaviors. Effective interventions tailored to the needs of the AYA survivor population are critical for improving survivorship clinical services and ultimately for promoting survivor's long-term health and quality of life.⁵⁴

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Address correspondence to:

Yelena P. Wu, PhD

Department of Family and Preventive Medicine

University of Utah

375 Chipeta Way, Suite A

Salt Lake City, UT 84108

Email: Yelena.Wu@utah.edu