



Research Article

Providers' Perspectives on Addressing Health Risk Behaviors and Mental Health among Young Adult Survivors of Childhood Cancer

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Objectives: We examined healthcare providers' perspectives on how childhood cancer impacts young adult health behaviors and psychosocial functioning, how healthy lifestyle and psychosocial issues are addressed in this population, challenges related to addressing these issues, and potential resources for addressing them.

Methods: In 2012, we recruited 21 healthcare providers (e.g., oncologists, nurses, social workers) who treat young adult survivors of childhood cancer from a children's hospital and a cancer center in the Southeastern U.S. to complete telephone-based semi-structured interviews.

Results: Our sample was an average of 45.95 (SD=7.57) years old, 52.4% female, and 81.0% MDs. Most mentioned that the impact of cancer on health risk behaviors and psychosocial functioning depended on several things including social support and other environmental factors. Participants indicated several general activities and approaches aimed at addressing healthy lifestyles among this population. Participants reported a range of health education, from minimal education to continuous education throughout treatment and survivorship. Providers indicated a team-oriented approach to addressing psychosocial issues and that the survivorship program addressed the complications of obtaining insurance, education and employment, and reproductive health within this population. A major factor was the involvement of the family in addressing these issues. Providers' challenges in intervening included limited time, resources, financial support, and referral options. Participants suggested resources to address these challenges.

Conclusions: Several resources are needed to address the challenges faced by practitioners in addressing young adult survivors' issues, including physical resources, social support resources, education for patients and healthcare providers, and programs to provide financial support.

Keywords: Survivorship care; young adults; childhood cancer; health behavior; health promotion; mental health

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Introduction

Over 60% of young adult survivors believed that it was more important for cancer survivors to engage in healthy behaviors compared to most other people [1]. However, this belief in increased vulnerability is inconsistently expressed in the patient's health behaviors in terms of engagement in health promoting or compromising behaviors [1]. Young adult survivors of childhood cancer are at risk for substance use, yet it is unclear if rates of substance use among young adult survivors of childhood cancer differ from those of healthy teens [2, 3]. Engaging in these behaviors is particularly important among cancer survivors given the risk of secondary malignancies, liver damage, and other health problems associated with their prior cancer and its treatment [4]. In addition, young adult survivors of childhood cancer are at risk for low physical activity [5], and higher rates of obesity are found among cancer survivors [6]. Finally, young adult cancer survivors have greater psychological distress than the general population [7], with symptoms of post-traumatic stress disorder related to the cancer experience and social withdrawal [8] being particularly relevant [7].

Function of survivorship care plans (SCPs) include advising on maintaining and improving health and addressing psychological and social support [9]. Unfortunately, there is little data regarding how the various dimensions of the SCP, particularly addressing health risk behaviors or psychosocial issues, are being addressed either in the plan or in the clinical setting. Thus, we examined healthcare providers' perspectives on how childhood cancer impacts young adult health behaviors and psychosocial functioning, how healthy lifestyle and psychosocial issues are addressed in young adult survivors of childhood cancer, challenges related to addressing these issues, and potential resources for addressing them.

Methods

Participants and Procedures

The Emory University Institutional Review Board approved this study, IRB# 00055570. In 2012, we recruited 21 healthcare providers of young adult survivors of childhood cancers from a university-affiliated children's hospital and a National Cancer Institute-designated cancer center in the Southeastern U.S. Of the 30 providers identified, 21 (70.0%) providers consented and completed the interviews.

Measures

The first author consented participants and facilitated the interviews. We assessed sociodemographics, their training, and nature of their work. The interview which was guided by a semi-structured interview guide focusing on: 1) providers' perceptions of the goals of SCPs; 2) their communication regarding substance use, nutrition, and physical activity for young adult cancer survivors; 3) how psychosocial issues are addressed in the context of cancer survivorship care; and 4) potential resources that might help to address these issues.

Data Analysis

Audiorecordings were transcribed, qualitative data were analyzed, and NVivo 10.0 (QSR International, Cambridge, MA) was used. Transcripts were independently reviewed by three team members to generate preliminary codes, which then were refined to primary and secondary codes. Two independent coders then coded

all interviews using the refined coding tree. Themes were identified, and representative quotes were selected.

Results

Table 1 provides sociodemographic, educational, and practice-related characteristics of our study participants. Below we outline the major topics covered, the primary themes that emerged, and some secondary themes (see Table 2 for representative quotes).

Table 1 Participant characteristics

Variable	M (SD) or N (%)
Age (SD)	45.95 (7.57)
Gender (%)	
Male	10 (47.6)
Female	11 (52.4)
Race/Ethnicity (%)	
White/Caucasian	15 (71.4)
Black/African American	1 (4.8)
Hispanic/Latino	1 (4.8)
Asian/Asian American	2 (9.5)
Other	2 (9.5)
Educational background (%)	
MD	17 (81.0)
NP	2 (9.5)
RN	1 (4.8)
Social worker	1 (4.8)
Number of years in practice (SD)	15.45 (7.18)
Number of years working with cancer patients/survivors (SD)	16.76 (7.29)
Primary specialty (%)	
Pediatric hematology oncology	13 (61.9)
Pediatrics, other	1 (4.8)
Radiation oncology	1 (4.8)
Medical oncology	1 (4.8)
Hematology and oncology	5 (23.8)
Location (%)	
Cancer center	6 (28.6)
Children's center	8 (38.1)
Both	1 (4.8)
Other	6 (28.6)
Primary work with cancer patients (%)	
During treatment	3 (14.3)
Post treatment	1 (4.8)
Both	17 (81.0)

Table 2 Themes and sample responses regarding the goals of cancer survivorship care, barriers to engagement in care, and communication about health behavior risks among healthcare providers of young adult cancer survivors

Theme	Sample Quote
Addressing Healthy Lifestyle	
<i>Impact of Cancer</i>	I think it spans the whole spectrum in terms of how survivors act, and that some of them become very focused on their own health and seek medical care for the smallest of problems. I've had some patients who maybe had some degree of survivorship guilt that led to psychiatric problems, and then other patients who maybe have more of an immortality type response where they've already survived cancer, so what else can happen. I guess it's really different for different patients.
Activities and Approaches	
<i>Minimal education</i>	When I have young adults who complete their treatment, usually I just get a one-time for certain you've made it through therapy so we don't want to be doing risky behavior. We don't want to be getting in trouble with the law, getting unwanted pregnancies, and all that kind of stuff. I just have kind of a general discussion usually when they finish. It's not something that we routinely go over

	<p>every time they come back then.</p> <p>I just impress upon them you look great, you're feeling great, the data suggests that you are very likely to remain healthy, but we honestly don't know 50 years, 60 years down the line to what extent any of this is going to be catching up with you. So please, take care of yourself. Don't smoke. Try to get some exercise. Try to get enough sleep. Just do all the things that everybody else ought to be doing but try to embrace it more because of everything that your body has been through already. I think they hear that and I think many of them act upon it.</p>
<i>Continuous education</i>	<p>Generally we start talking to children about smoking around age 10 and 11. We usually will spend some time talking to them about it within the context of their cardiac risk because it tends to be an area that most children will understand. They may have grandma or grandpa who is on blood pressure medicine or something like that, so we start talking to them about that. We also do counseling with some of the older teenagers about safe sex practices and I do basic substance use screening on everyone starting around age 14 plus or minus, just kind of depending on that child's readiness for conversation. Everyone at 18 gets a very in-depth sexual health/prevention talk. I have, depending on some of the screening responses; I do some more in-depth substance use/abuse counseling. And if we do identify someone that appears to have some risky behaviors, we usually involve psychology at that time.</p>
<i>Tailored counseling</i>	<p>There are different levels of intervening. So for example, a college student who is binge drinking on the weekend and experimenting with marijuana, I will usually talk to them about specific reasons and how that might relate to their late effects risk factors, so that tends to be very individualized to what that child is at risk for. We talk about liver damage and things like that. It really is a bit tailored to what they're doing, so what specific drugs they may be experimenting with or things like that because the increased risk that comes from that will be slightly different, depending on what they're doing.... So I tend to do some very focused counseling. If I have a concern or they endorse a concern about their substance abuse, typically psychology sees them and will refer them to the appropriate program for substance abuse management. Most of our patients have been referred for outpatient intervention. We've only had a handful that required that. Sometimes they're not interested in that support.</p>
<i>Promoting optimism/positive thinking</i>	<p>You have to make the positive part. They get tuned out if you say "don't smoke, don't drink, don't whatever", but if you give them a positive, it gives them a reason for being, for living—I am somebody. These people who feel good about themselves are less likely to do harmful things to themselves.</p>
Addressing Alcohol, Tobacco, and Other Drugs	
<i>Impact of Cancer</i>	<p>There are a lot of my patients who survived and were doing well, but then got all caught up in doing drugs, and drinking, and in trouble with the law. On the flip side, I've had patients who are the kind you want to take home and you'd be proud to have as your daughter or son, too. It depends on who they are, where they grew up, what kind of support they had as they were going through treatment.</p>
Activities and Approaches	
<i>Automated prompts for assessments</i>	<p>In the review of symptoms is an automatic prompt for both alcohol, drugs, and then cigarettes and also kind of a sex education, so there are prompts for that.</p> <p>There are different team members in the comprehensive setting who can do that. The social worker comes in and talks about drug and alcohol use and all the different behaviors because the physician is doing the medical part of things or whatever the case may be.</p> <p>I can't say that I've ever encountered anybody that I felt I needed to aggressively intervene on. But I would say that if I did identify that, it would be somebody that we would refer, recommend that they get assistance, if there was an identifiable problem. Usually, we talk to them about it in clinic. To be honest, I really haven't encountered that many patients that are engaging in activities that make me highly concerned.</p>
<i>Highlighting specific risks for cancer survivors</i>	<p>We tell them they're certainly at high risk, and we tell them that the fact that they've already had one cancer and they received cancer treatment, which is our known carcinogens being radiation therapy and chemotherapy, that they're already at a higher risk than the average population for developing even secondary malignancies, and adding each additional lifestyle such as smoking or drinking can increase their risk for certain adult cancers, so we really discourage them and tell them to take very good care of themselves, and we do a lot of anticipatory guidance on teaching them not to do those things.</p>
Alcohol	<p>I address alcohol with almost all the students. Primarily when they go off to college, I guess, is probably the time point that I am probably the most consistent with talking about it. I talk about it with overall I think for everyone, but particularly for kids that had medications that could affect</p>

	<p>their liver function, but I do sort of stress to them that heavy alcohol consumption, which is not uncommon in college, would potentially be harmful, more harmful than even to other kids because of the risk of liver damage.</p>
Smoking	<p>Smoking, I personally tend to talk a lot about in terms of the risk of chronic health issues and that there are greater risks for these complications of say smoking because of their prior exposure to chemotherapy drugs and prior diagnosis of cancer.</p> <p>I talk to them about smoking and the risk of secondary malignancies, the risk of a malignancy being higher in anyone who's had a primary malignancy. I definitely talk to them about the risks of smoking.</p>
Promoting abstinence	I tell them the risks are completely unacceptable and that they're never allowed to do any of those things.
Promoting moderation	<p>I can think of one or two other patients I've had that have come in who were college students with whom I had raised the subject of drinking and haven't been sort of tyrannical about it but I've been willing to say look, you're in college. People drink. I'm not going to expect you not to drink, but just think very carefully about what you're doing and keep in mind that you've got organs that you want to be functioning when you're 70, 80 years old, and everything you're doing when you're younger has cumulative ill effects. So I raise that issue a little bit.</p> <p>Illegal drugs, I've had a couple of kids who will confide to me that they smoke marijuana. I have kind of the same conversation with them; that I think in limited quantities marijuana is probably pretty harmless, but it's certainly not something you want to do habitually.</p>
Involving family/parents	<p>I have talked to both parents, who were concerned for their young male children, who were using drugs or both parents were involved with getting them into rehab and were aware that this was a problem. Sometimes it is a heavy subject for me to talk to some young guy and say 'you know you shouldn't be smoking pot.' But at least, the parents were involved in getting him into rehab in residence face to face and the surprising thing is these people admit to what they are doing.</p> <p>If I know that a child's parents are smokers, my usual song and dance is that early in game, when their child has just been diagnosed and they're under a great deal of stress, I tell them 'look, someday I want you to quit smoking, but I'm not going to lecture you right now because you're going through a whole lot of stress and this is not the time to do it.' Later on I try to circle back to the parents and try to convince them to stop smoking, because obviously I think children to a certain extent are going to mimic what they see their parents doing.</p>
Referring to outside programs	The other thing was one of my patients I referred to Alcoholics Anonymous, and we have many patients that have drug addictions. They come in with acute pain. We give them pain medicines, benzodiazepines. Well, two years later they are still taking those and nobody seems to know why. 'Where is the pain?' They say 'it helps me sleep better.' So if we could have resources where they could go and not feel like they are being targeted, not me walk up to this guy and say these are the Alcoholics Anonymous places in town, but some sort of resource where they can quietly look up and know that these things are out there to help them.
Prescription drugs	I would say we probably spend more time addressing the issues about abuse of prescription drugs than illicit drugs, and I think one of the major challenges is the transition from use to abuse there, because many of these patients are patients that have pain-related issues that come about as a part of their cancer, but may have problems with prescription narcotics after completion of cancer therapy, and sometimes other prescription medications after completion of therapy and transitioning back into their usual care without those medicines.
Challenges	
Assumption patients are lying	We don't monitor it, and I don't know if the survivor clinic monitors it, but I do know that every time you ask people, even adults like us, people lie. It's hard to monitor. You can only recommend to not use these agents, but it's very hard with this generation. I know people are using herbs and other medicinals, and I can pretty well tell the people who are using marijuana and other things from just smelling. It's pretty obvious.
Minimal/no assessment	<p>I think it is an afterthought, so if I happen to notice that they are still smoking, I may encourage them not to and ask them if they would like help quitting. I ask them if they need some sort of assistance with medications and things like that, and that's probably about it.</p> <p>Illicit drugs, once again, I would have to say I'm not good at bringing it up myself. When I know that I have patients that are doing illicit drugs, I address it with them as, once again, something I feel is potentially dangerous to them, either because they've had previous toxicity, so I think it increases risk, and just in general it's probably not a great idea.</p>
Addressing Physical Activity and Nutrition	

<i>Impact of Cancer</i>	I think, in terms of healthy living and nutrition and things like that, I think we see some patients that coped with their illness, usually the other family, by rewarding them with food and things like that and those are probably more likely to be the ones that are overweight, etc., kind of breaking them out of that cycle. But I don't know. It's varies, I think, depending on the individual patient.
<i>Activities and Approaches</i>	
<i>Assessment but limited intervention</i>	I don't think that I intervene very much. I don't know if that's an appropriate answer, but... that is, I actively ask the parents and the children about that at every visit, but beyond that, I don't have any specific intervention.
<i>Continuous assessment and education</i>	<p>Physical activity is something that at least I personally address every visit. Nutrition is something that is regularly addressed. We have a nutritionist available if nutrition is identified as a problem. Problems with weight gain after completion of cancer therapy, that's probably the most common problem, with inadequate weight gain. Sometimes in a distant period after cancer therapy, there is excessive weight gain and that also can be addressed by a nutritionist.</p> <p>I do think we address that on an ongoing basis. I think that we talk about it at diagnosis, the importance of good nutrition, that we don't want them to become more sedentary than they are, you know. We want them to stay active, and I think when they're off therapy, I think we continue to try to push the good nutrition and to maintain, you know, a decent activity level. And I think we have that conversation pretty much ongoing with those families, that those things are important.</p>
<i>Highlighting specific risks for cancer survivors</i>	I always try to put it back into the context of chemotherapy, saying things like chemotherapy has already stressed out a lot of the things in your body, including its ability to handle things like glucose and some fat, so therefore, it's important that you stay as healthy as possible because your body is more at risk for those things because of the chemotherapy that you got. Anything you can do to prevent that is really good. I particularly talk about the role of obesity and try to encourage them to get 30 minutes of exercise a day. I tell them that's standard for anybody whose body hasn't even undergone what their body has, that it's just a good, healthy recommendation.
<i>Focusing on obese patients</i>	<p>I'd say the time that I concentrate most on that is in the HL [Hodgkin Lymphoma] patients, many of whom have obesity. It's those patients that I talk to more about the importance of daily aerobic exercise and good diets. I focus on that in the HL patients and then other patients who have obesity, but in kids who don't have overweight issues, I don't know that I address it thoroughly in a visit.</p> <p>In our obese patients, we talk a lot about how in our case they are very likely cured of their disease and the obesity and the complications of obesity may actually be a bigger health risk for them down the road than the diagnosis of cancer. In that context, we talk a lot about physical activity and appropriate restriction of caloric intake. That's probably the extent of it. I don't tend to talk a lot about specific nutritional benefits of vegetables or whatever; more general I guess.</p> <p>Certainly we look at their growth chart and look at their height and weight. Many of the leukemia, lymphoma patients have difficulty with weight gain and obesity, and we do counsel them on that. We offer nutritional counseling if they would like it, and we do talk to them about healthy eating habits, encourage exercise, encourage daily activity, so those types of things. It's just standard anticipatory guidance that they would get at their regular office visit if they were going to see a pediatrician.</p>
<i>Leveraging nutritionists</i>	I'll just tell them a regular, healthy balanced diet. No specifics. Occasionally there will be one or two patients a year that may ask to see a nutritionist and I'm open to them seeing the nutritional therapist.
<i>Involving the family/parents</i>	Our intervention also includes a question about family interest in making change and so we usually review that questionnaire before we go see the children and the providers in the survivor program receive training about doing intervention, ways to do effective intervention to increase healthy behaviors. If families report that they're not interested in changing any of their healthy habits, we usually just summarize some reasons to maybe think about change and invite them to let us know when they are ready. So we do that. If they identify it, if they endorse being interested in starting to do some more healthy behaviors, we usually will target one or two and do limited goal setting. So they might say, 'You know, I'm not really ready to quit eating fast food three times a week, but I would be ready to try drinking more water.' So we work with them to identify a goal that they feel is attainable. As part of that, there is a prescription pad that comes with it, so we usually write whatever the goal was on there and then the time frame for reassessment.
<i>Challenges</i>	
<i>Lack of resources</i>	I think resources, telling people that you should behave and eat right and do this and do that. I

	don't think that that necessarily has an impact on people. It's like telling a child to be good.
<i>Minimal/no assessment of intervention</i>	<p>I don't get real specific about it but I'm more than happy to talk to patients about their BMI, show them their growth curves and if they're overweight, talk to them about, in broad strokes, what it takes to lose weight; calories in versus calories out, physical activity, and that weight loss is a slow, prolonged process, that there are no quick fixes.</p> <p>I don't have a way to intervene. Other than telling them to eat well and exercise, there's really no way other than asking them for follow up visits, there's no way to intervene.</p>
Addressing Psychosocial Issues	
<i>Impact of Cancer</i>	For our older kids and adolescents, the experience of having cancer is very profound. It does affect their choices down the road but surprisingly it doesn't always affect it in a positive way. It's my impression that some of our survivors that were a little bit older at diagnosis tend to be less motivated. They tend to become more dependent on their parents during their—this is my theory—they become more dependent on their parents to take care of them during a time period when they should be achieving a certain degree of independence. I think that's driven both by the patient and by the parent who finds it even harder to sort of separate, and that that kind of behavior during that critical time period sometimes seems to lead to sort of lack of ability to get out there, get a job, complete college, etc. We do see the opposite. We see some high achievers that take their diagnosis of cancer and really use it to motivate tremendously. But I also see this other group of patients that just don't seem like they're going to make anything of their life, even though they went through such a profound experience as having had cancer.
<i>Activities and Approaches</i>	
<i>Team-oriented approach to psychosocial health</i>	In addition, the whole psychosocial aspect of survivorship care is addressed by a team approach of our psychiatrists and our social workers and clinicians to try and help readjustment into the psychosocial aspects that are associated with completing cancer therapy and returning to usual activities.
<i>Addressing insurance</i>	We have some issues for cancer survivors, especially children who are approaching young adulthood, in terms of educating them about health insurance and access to care and how that may change for them as they age out of the pediatric system. In addition to that, we also provide, I think, additional support for children who are aging out of the Medicaid system, who have the potential of becoming uninsured and trying to assist them with their options.
<i>Addressing education/employment</i>	In the past that has included things like social work involvement, connecting some young adults to vocational tech programs that may allow them to gain employment that would include health insurance.
<i>Reproductive health as an important psychosocial issue</i>	<p>I have given them some information on adoption. I just tell them if they can't have children to consider adoption, and if they ask me about having children, I give them resources.</p> <p>I think we have spent some time, mostly in the beginning. That's probably something at least from my standpoint, I don't do enough later on, when they become adults. But in the beginning, I think we're pretty up front with families about risks based on the chemotherapy that they're going to get and understanding those risks. We do inform our older, particularly the older, sexually active individuals, to let them know that just because we think there's a chance they're sterile from their chemotherapy, that's not a hundred percent, and so they have to still take the usual precautions regarding pregnancy, because we can't say a hundred percent without them being evaluated. That is one thing that we do talk about if they're discussing that with us.</p>
<i>Involving the family</i>	If there's a family that we're particularly concerned about, we do offer counseling, and then we also have our social worker go in and do a psychosocial assessment on them and we try to work between the two of us to try to determine if there is counseling services, one, appropriate for them in their area, and if not, we try to find them something in that way.
<i>Challenges</i>	
<i>Lack of integration in survivorship care</i>	I think some of the psychosocial goals that I just mentioned are important ones to address that we don't address very well, so job retraining, readjustment into society, either into their usual role or into a new role, readjusting into the family after completion of cancer care, body self-image, other things like whether there's needs for direct psychiatric care or other kinds of psychosocial care I think... I wish we could address much better.
<i>Insurance coverage for mental health</i>	I think people like that need a lot of support and education. The question is does our country have the support to give those people. Our mental health system is awful. I think we have to make it really important that they do get help, and we include the family and the survivor in the same way. You've been through something, you may need some therapy, you may need more things, and you should try to have a healthy life.
<i>Lack of knowledge about what is</i>	I think, honestly, overall there is a lack of really addressing that as a specialty. We have the

<i>addressed in survivorship care</i>	survivorship team, and I don't know exactly what protocols they have, so I guess overall there has not been a focus on that.
Resources for Promoting a Healthy Lifestyle	
Physical Resources	
<i>Wellness center</i>	It's more the support, the tangible things that we can do for them, like a wellness center. I know that if we had a wellness center people would go, my patients would go, if it were free, so I think it is more resources.
Social Support	
<i>Peer counseling</i>	One of the things that we noticed, we have this summer camp that is sort of a mish-mash of long-term survivors with kids newly diagnosed and kids part way through (the whole gamut), and that's really very profound. The kids tend to really, all of the kids, no matter where they are; if they're older and they're survivors sort of serving a mentorship role or the new diagnosed kids that can see the survivors and see wow, I can really be okay. That's very profound. Kids tend to really love it. There is the potential that that kind of peer interaction of survivors and newly-diagnosed patients could be very helpful.
<i>Support groups</i>	I've talked to our nutritionist ... we have a sarcoma support group, so giving some of the patients information or a lecture on diet and exercise long-term. I don't think we address it very well, and I wish we did better.
Education	
<i>Patient education</i>	<p>If there were either some brochure (and maybe it's out there) that says now you've finished therapy. What do I do next? A pamphlet like that, and then it says now they say I don't have to come back to the oncologist. What do I do now? What do I look for now? What would everybody want to know? It's not quite a consent form but what are the things that people would want to know? You could put them into some of the things you talked about. You could put them into a combination of... I mean we have this discharge thing. You could almost have an information box that says, you put in what therapies they got and then automatically it comes up with the long-term effects, and then you have a nutritional piece, you have a bio-psychosocial piece, and you have a risk factors piece based on age and then other things. It could be like three pages. A lot of it's going to be the same. But if they've got diabetes and hypertension, it might be a little different. If they'd already had end stage renal disease it might be a little bit different. I hate to say it but there should be an app for that. It's almost like a formula. You put in how old they are, you put in what they had, you put in what treatment they had and where and what their diagnosis was, and it should spit back out to you what are the top five things they're going to die from, what are the things they need to look for from their treatment, and what are good health issues?</p> <p>There's relatively little information that's available in a patient-education standpoint about... you know, there's good information about nutritional risk. There's good information about smoking cessation. There's good information about exercise, but there's not really good information about how all of those specific risks relate to somebody who's completed cancer therapy or is a cancer survivor and how those might be different from the general population.</p>
<i>Physician education</i>	I think having, first of all, education for the physician, and then secondly, literature to give to patients about healthy nutrition, exercise. It would be good to have something to give to patients.
<i>Nutritionists</i>	I think, again, having access to a nutritionist, if we identify those risk factors, and somebody that can really help us work with them, would be really good.
<i>Technology-based education</i>	<p>Probably something electronic that gives them percentages with regard to what are the risks for them. I hate to say it but it's the same thing as diabetes or hypertension. It's the same thing that's a factor in the rest of the country is people aren't going to do it unless... most people aren't going to be prophylactic about stuff.</p> <p>I think that's what speaks to this generation, anything that is in the form of a video game, in the form of social media, in the form of, you know, the Twitter, the Tumbler, anything electronic to get the message to them. I think that's how we reach this generation.</p>
Financial Support	
<i>Insurance</i>	I just feel like for some of these patients are taken care of until they are 21 and a lot of times it's like they are kicked off because they don't have insurance anymore and the clinics won't see patients that they have taken care of, so I felt that there needs to be something written that we can't just drop these kids because they turned 21, and they aren't able to work, they can't get insurance, but yet they have had healthcare up until now, and then bam, and then they are going to ER and this and that for their primary care.
<i>More financial support from nonprofits post-treatment</i>	I think if more agencies covered families... you know, when kids are on therapy, the American Cancer Society is very good about trying to provide some reimbursement for mileage and those

	<p>kind of things, maybe even help with lodging in a town if Ronald MacDonald House happens to be full, you know, helping them with lodging to a max amount. The Leukemia Society does the same thing. They help pay for mileage for kids that are actively on therapy.</p> <p>Medicaid is wonderful, but it's as the kids come off therapy, they can't keep that kind of resource; so I think if more agencies included the survivors or the off-therapy patients, then maybe we wouldn't have quite the problem we have now....There's not that many places, if any, that will support just the kids that are needing survivorship, or the adults, for that matter, that need that kind of care.</p>
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Addressing Healthy Lifestyle

Some providers indicated that they thought that young adult survivors of childhood cancers were more cautious about engaging in healthy behaviors (i.e., not using substances, exercising, attending to nutrition), while others believed that there was a sense of indestructibility after having gone through cancer and greater likelihood of engaging in risky behaviors. Most said that there were some in either category, depending on social support or other environmental factors. Participants reported a range of education aimed at addressing healthy lifestyles, from minimal education to continuous education throughout treatment and survivorship. They also endorsed tailored counseling and promoting a healthy lifestyle through encouraging optimism and positive thinking regarding their health and future.

In relation to substance use, some said that they demanded or promoted abstinence from these substances while others promoted moderation. Many indicated that they involved the family or parents in addressing substance use, and a couple indicated addressing parental tobacco use. Finally, a few said that addressing prescription drug abuse was difficult given the difficulty deciphering the extent to which they were used for pain or other reasons. One challenge in assessment was concern that patients would lie about substance use.

In relation to physical activity and nutrition, the majority indicated that they highlighted the specific risk of sedentary lifestyle, poor nutrition, and obesity for cancer survivors. Several providers said that these issues were mainly addressed among obese patients. Many reported that involving the family in discussions around this topic was crucial. One major challenge regarding addressing physical activity and nutrition was a lack of resources (e.g., access to a wellness center, time, referral options).

Addressing Psychosocial Issues

Some providers believed that patients were more resilient and more focused on living a purposeful life due to their cancer experience; some believed that the experience hindered patients' development. However, most believed that the impact of cancer on their patients depended on the individual patient, social support system, and environment. Many providers indicated a team-oriented approach to addressing psychosocial issues, including social workers, psychologists, and psychiatrists alongside their medical practitioners. A major factor was also the involvement of the family in addressing some of these psychosocial issues. Major challenge in addressing psychosocial issues included limited access to mental health care providers, limited referral sources, limited insurance coverage for this type of care, and lack of knowledge about what can be addressed in the context of survivorship care.

Resources for Promoting a Healthy Lifestyle

Participants mentioned the need for: physical resources, such as a wellness center where patients would be able to access equipment for physical activity and potentially information regarding other health-related topics; social support, with specific mention of peer counseling or support groups; education, both of patients and of healthcare providers, around the specific needs of cancer survivors in relation to health behaviors and mental health and regarding the functions of a survivorship program; nutritionists in the context of survivorship care; technology-based approaches to engaging patients in monitoring and altering their health behaviors; and financial support in addressing healthy lifestyles and psychosocial functioning among this population, including the expansion or improvement of insurance coverage for young adult cancer survivors, as well as the support from non-profit organizations for addressing these needs.

Discussion

Healthcare providers reported a range of activities and approaches aimed addressing healthy living and psychosocial functioning and various challenges in doing so. Almost universally, providers indicated that having cancer impacted patients differently, ranging from promoting healthy living and demonstrating individual resilience to individuals engaging in high risk behaviors due to feeling indestructible or cancer hindering their development. A major factor that was mentioned as critical in shaping the individual response to having cancer was social support and the family context, and many participants reported including the family in discussions regarding healthy lifestyles and mental health. This is critical, as social support is associated with engaging in positive health behaviors and cessation of negative health behaviors [10].

Other major themes that emerged across topics were the importance of highlighting the specific risks of engaging in unhealthy behaviors and the particular psychosocial issues that are relevant for cancer survivors. A team-oriented approach to addressing these issues was also conveyed, such that there was an integration of nutritionists, social workers, psychologists, and psychiatrists working together. A major concern is that some participants reported limited attention to health risk behaviors or psychosocial issues among their patients, in part due to time constraints, limited resources, limited referral options, lacking financial support for conducting these types of activities within the clinical encounter, and lack of awareness regarding the resources available within survivorship programs. Participants reported several resources that would help to ameliorate these challenges and circumstances, including access to physical resources, education regarding the specific needs of cancer survivors for patients and healthcare providers, use of technology-based resources, financial support in addressing healthy lifestyles and psychosocial functioning among this population,

Limitations of this study include small sample size, recruitment from only two institutions, limited generalizability, and lack of exhaustive information regarding the constructs and processes investigated within these brief interviews. Further research is needed to systematically examine the activities conducted within survivorship programs and evaluate their outcomes in order to inform best practices.

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Conflicts of interest

The authors declare no conflict of interest.

References

1. Mulhern RK, Tyc VL, Phipps S, Crom D, Barclay D, Greenwald C, Hudson M, Thompson EI. Health-related behaviors of survivors of childhood cancer. *Med Pediatr Oncol.* 1995, 25(3):159-165
2. Clarke SA, Eiser C. Health behaviours in childhood cancer survivors: a systematic review. *Eur J Cancer.* 2007, 43(9):1373-1384
3. Carpentier MY, Mullins LL, Elkin TD, Wolfe-Christensen C. Prevalence of multiple health-related behaviors in adolescents with cancer. *J Pediatr Hematol Oncol.* 2008, 30(12):902-907
4. Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT, Friedman DL, Marina N, Hobbie W, Kadan-Lottick NS, Schwartz CL, Leisenring W, Robison LL; Childhood Cancer Survivor Study. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med.* 2006, 355(15):1572-1582
5. Tercyak KP, Donze JR, Prahlad S, Mosher RB, Shad AT. Multiple behavioral risk factors among adolescent survivors of childhood cancer in the Survivor Health and Resilience Education (SHARE) program. *Pediatr Blood Cancer.* 2006, 47(6):825-830
6. Coups EJ, Ostroff JS. A population-based estimate of the prevalence of behavioral risk factors among adult cancer survivors and noncancer controls. *Prev Med.* 2005, 40(6):702-711
7. Hobbie WL, Stuber M, Meeske K, Wissler K, Rourke MT, Ruccione K, Hinkle A, Kazak AE. Symptoms of posttraumatic stress in young adult survivors of childhood cancer. *J Clin Oncol.* 2000, 18(24):4060-4066
8. Krull KR, Huang S, Gurney JG, Klosky JL, Leisenring W, Termuhlen A, Ness KK, Kumar Srivastava D, Mertens A, Stovall M, Robison LL, Hudson MM. Adolescent behavior and adult health status in childhood cancer survivors. *J Cancer Surviv.* 2010, 4(3):210-217
9. National Research Council, From Cancer Patient to Cancer Survivor: Lost in Transition. 2005, *The National Academies Press*
10. Emmons KM, Butterfield RM, Puleo E, Park ER, Mertens A, Gritz ER, Lahti M, Li FP. Smoking among participants in the childhood cancer survivors cohort: the Partnership for Health Study. *J Clin Oncol.* 2003, 21(2):189-96