

Attendance at a survivorship clinic: impact on knowledge and psychosocial adjustment

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Abstract

Purpose Due to their heightened risk of developing late-occurring adverse outcomes, pediatric cancer survivors are advised to receive follow-up care in specialized Survivor Clinics. However, little is known about the impact of attending such clinics on psychosocial adjustment, knowledge, and morbidity. This study assesses the differences between those who attended a Survivorship Clinic and those who did not on knowledge, perception of risk, and psychosocial adjustment.

Methods We assessed 102 survivors who attended our Long-Term Follow-Up (LTFU) Clinic and 71 survivors never seen in a specialized clinic (non-LTFU). Participants were diagnosed at least 5 years prior to the assessment, were at least 20 years old, and had no evidence of active disease. Groups were matched on gender, age at cancer diagnosis, diagnosis, and race.

Results On average, participants were currently 30 years of age and had been diagnosed with cancer around age 12. Most common reasons that non-LTFU survivors did not attend the clinic were “not aware” (71 %) or “not interested” (16 %). Survivors in each group were able to accurately report their cancer diagnosis, but few knew specific treatment information. There were no significant differences regarding survivors’ perceptions of risk of future health problems with both groups similarly underestimating their

risks. A significant minority in each group reported psychological or emotional problems (16–18 %), post-traumatic stress disorder (4.2–6.9 %), and/or psychological distress (7.8–19.7 %).

Conclusions Survivors are in need of continued education about their specific cancer treatments, recommended follow-up practices, the importance of survivorship care, and their specific risks for late effects.

Implications for Cancer Survivors Among those childhood cancer survivors who do attend a Survivor clinic, a majority are in need of continued education about their specific cancer treatments, recommended follow-up practices, and risk of late effects. As many survivors of pediatric cancer appear to be unaware of the existence of Survivor clinics, improved methods of transitioning survivors after completion of treatment are needed.

Keywords Childhood cancer survivors · Long-term follow-up clinic · Survivor clinic · Psychosocial

Introduction

Over the past several decades, survival rates for childhood cancers have improved dramatically, such that in the United States, the overall 5-year survival rate is in excess of 80 % [1]. Currently, one out of every 640 young adults in the United States is a cancer survivor and more than 300,000 adult survivors of childhood cancer are estimated to reside in the United States at the present time [2].

Contemporary therapy for childhood cancer includes the use of multimodality therapies (i.e., the combination of chemotherapy, radiation therapy, and surgery) as well as aggressive multiagent chemotherapeutic regimens and is a major factor contributing to the marked decline in mortality rates over the past few decades. Unfortunately, the long-term consequences of exposing young individuals to these therapies can be considerable. Approximately two thirds of

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young adult survivors of cancer will develop some type of medical complication or disability that can be directly attributed to their previous cancer treatment [3, 4] with 42 % experiencing severe, life-threatening, or fatal conditions [3].

Many of these late complications only become clinically apparent decades after therapy has been completed. In 5-year survivors, statistically significant excess mortality rates are observed as a result of several treatment-related complications including subsequent new cancers, cardiovascular disease, and pulmonary dysfunction [5]. Although severe psychopathology is not common among young adult survivors of childhood cancer, a sizable minority of survivors experience psychological distress and a diminished quality of life as a result of their cancer experience [6]. Symptoms of posttraumatic stress, an impaired self-concept, concerns about physical appearance, and difficulties in initiating and maintaining intimate relationships have all been reported among survivors [7–11].

Many of these late effects are amenable to early detection and screening (e.g., annual mammograms and breast MRIs for female survivors exposed to chest radiation). Recognizing that potential cancer-related health complications are associated with decreased quality of life, multiple morbidities, and excess premature mortality, it is imperative that survivors receive risk-based, long-term follow-up care dedicated to the screening, prevention, and treatment of late effects [12–14]. However, the optimum means of providing these services remain a challenge.

One approach that has been adopted by many institutions and has received wide acceptance throughout the world, has been the development of specialized clinics (“survivor” or “late effects” clinics) dedicated to the care and education of cancer survivors and their families [1, 15, 16]. The Institute of Medicine published two seminal reports delineating recommendations for follow-up care of all cancer survivors [12, 17]. The cornerstone of these recommendations is for these clinics to create and disseminate a survivorship care plan, a written document containing the details of their cancer therapy, risks (late effects) associated with these therapies, as well as general guidelines for follow-up care to assist survivors and their health care providers with a roadmap for post-treatment coordination of care [12, 17, 18]. Most survivorship clinics also provide psychosocial screening and support. Dedicated survivor clinics have been endorsed by many prestigious organizations worldwide, including the American Cancer Society [16] and the International Society of Pediatric Oncology [19]. While these clinics have wide appeal among clinicians and patients, evidence-based research to support their efficacy is lacking and needed.

Several small studies have documented that, within a survivor clinic setting, providing survivors with important medical information and enhancing their awareness about the importance for vigilance in the future is feasible [20–22].

However, we have limited knowledge about who attends survivorship clinics, whether attendance helps educate survivors about their risks, and whether there is an impact on psychosocial functioning and quality of life. This study serves as an initial step in describing which young adult survivors of pediatric cancers attend a survivor clinic and compare various outcomes in this population with a matched cohort of survivors never seen in such a clinic.

Method

Participants

Young adult survivors of pediatric cancers were recruited through Memorial Sloan-Kettering Cancer Center’s (MSKCC) Department of Pediatrics. Inclusion criteria for participation included a diagnosis of cancer at least 5 years prior to study participation, currently at least 20 years of age, off treatment, and no evidence of disease. All survivors had been diagnosed and/or treated for pediatric cancer at MSKCC.

Two groups of survivors were recruited for participation in this study. The first group included those survivors who had been seen for follow-up at least once in our pediatric survivorship clinic—The Long-Term Follow-Up Program (LTFU) at MSKCC. A random sample of eligible survivors in the LTFU clinic database was initially identified. Then, a matched group of survivors who had never been seen in the survivor clinic were identified in the MSKCC Department of Pediatrics database (non-LTFU). These survivors were matched to the LTFU cohort on gender, age at cancer diagnosis, date of diagnosis, diagnosis, and race. Survivors were not randomly assigned to group; those who had attended the LTFU clinic did so either because their oncologist referred them or they were self-referred.

The MSKCC Institutional Review Board approved the research and all participants provided informed consent. Letters of introduction, with an explanation of the study, were mailed to 615 potential participants seeking their informed consent to participate. Approximately 2 weeks later, potential participants received a telephone call from a research assistant to answer any questions, encourage return of the consent form and survey, and/or to schedule a time to complete the survey by telephone. Many of the 615 potential participants could not be contacted ($n=298$) due to incorrect or outdated contact information. As a result, among those survivors with presumed valid addresses ($n=317$), 55 % agreed to participate ($n=173$) and all completed the survey by mail.

Study participants vs. non-participants Among those survivors who had attended the LTFU clinic, study participants and non-participants were very similar and only differed with respect to age at diagnosis, with non-participants

diagnosed at a younger age than participants (8.9 vs. 11.9, $p < 0.01$). For the non-LTFU survivors, non-participants were younger than participants at the time of study participation (31.1 vs. 28.8, $p = 0.001$), and differences were observed with respect to diagnosis ($p < 0.01$), with greater numbers of osteosarcoma and non-Hodgkin lymphoma survivors participating and greater numbers of ALL and Hodgkin survivors as non-participants.

Participants A total of 173 survivors agreed to participate and completed the self-reported survey. One hundred and two had attended the LTFU clinic at least once, and 71 were in the comparison group and had never attended the LTFU clinic (or any other survivor clinic). Participants' characteristics are summarized in Table 1.

Measures

We utilized self-report questionnaires to assess our outcomes of interest. Specifically, we collected data on survivors' sociodemographic characteristics, knowledge of their cancer diagnosis and treatment, health status, health behaviors, perceptions of health risks, reasons for attending/not attending the LTFU clinic, receipt of a treatment summary, quality of life, and psychological distress. In addition, diagnosis and treatment variables were measured by thorough chart review for all participants.

Knowledge of cancer diagnosis and treatment was assessed utilizing a series of open-ended questions similar to those described by Kadan-Lottick [23]. Participants were considered having correct knowledge if their responses

Table 1 Patient characteristics: LTFU and non-LTFU survivors

	Total $n=173$		LTFU $n=102$		Non-LTFU $n=71$		Adjusted p
	n	%	n	%	n	%	
Age at time of questionnaire							
Mean (SD)	30.6 (6.1)		30.1	(6.3)	31.2	(5.9)	0.31
Age at time of diagnosis							
Mean (SD)	12.6 (6.0)		11.9	(6.1)	13.5	(5.6)	0.31
Gender							
Female	104	60.1	60	58.8	44	62.0	0.88
Race/ethnicity							
Non-Hispanic White	138	79.8	78	76.5	60	84.5	0.44
Minorities	35	20.2	24	23.5	11	15.5	
Occupation status							
Employed or student	147	84.9	83	82.2	63	88.7	1.00
Other	26	15.1	18	17.8	8	11.3	
Personal income							
Less than 30,000	117	67.6	73	76.0	44	63.8	0.30
More than 30,000	48	27.7	23	23.9	25	36.2	
Health insurance							
Yes	165	95.4	97	96.0	68	95.8	1.00
Cancer treatment summary							
Yes	68	39.3	47	46.1	21	31.3	0.24
Disease diagnosis							
ALL/AML	52	30.1	31	30.4	21	29.6	0.02
CNS	11	6.4	8	7.8	3	4.2	
Ewing	14	8.1	8	7.8	6	8.5	
Hodgkin	28	16.2	14	13.7	14	19.7	
NHL	18	10.4	7	6.9	11	15.3	
Osteosarcoma	18	10.4	5	4.9	13	18.3	
Rhabdomyosarcoma	17	9.8	17	16.6	0	0	
Other cancers	15	8.7	12	11.7	3	4.2	
Treatment intensity							
Moderately intense	137	79.2	68	66.7	69	97.2	<0.01
Most intense	36	20.8	34	33.3	2	2.8	

Values in parentheses are in column percentages unless stated otherwise

about their diagnosis and treatment were verified as correct through review of their hospital record. Participants were also asked if they had ever received a treatment summary or survivorship care plan.

Risk perception was assessed by comparative risk questions asking survivors to rate their chances of having a second malignancy, heart problems, pulmonary problems, and/or fertility problems on five-point scales ranging from 1 = “being much less than others my same age and sex” to 5 = “being much more than others my same age and sex.” This variable was then dichotomized, with ratings grouped into 0, 1, 2, or 3 (little or no risk, much less, slightly less, and about the same) and 4, 5 (slightly more to greater risk). *Accurate risk perception* was then calculated by having a physician knowledgeable in childhood cancer survivors and late effects (C.A.S.), who was blind to participants’ identity, rate whether the survivor was at risk (yes/no) for each of these adverse outcomes based on their cancer diagnosis and treatment exposures. Participants were considered having accurate risk perception of future health risks if their ratings were similar to that of the physician (0–3 were considered correct if the physician rated no risk and 4–5 were correct if the physician rated them at increased risk).

Current health status was assessed utilizing questions relating to chronic medical conditions from the Childhood Cancer Survivor Study (CCSS) questionnaires that assess health outcomes in 14,000 survivors of childhood cancer (questionnaires available at <http://ccss.stjude.org>) [24].

Current health behaviors included tobacco and alcohol use, exercise, sun protection habits, and ongoing medical follow-up. These questions were modified from those used in the CCSS and NHIS [25].

Quality of life was assessed by the MOS 36-item Health Survey [26], a widely used valid and reliable self-report measure assessing physical and mental health. Overall *psychological distress* of participants was assessed using the Brief Symptom Inventory-18 [27] which consists of 18 items grouped into the following four subscales: depression, anxiety, somatization, and general distress [28]. Symptoms of *post-traumatic stress disorder* (e.g., avoidant behavior) were measured by the PTSD Checklist-Civilian version (PCL-C) [29, 30]. *Perceived benefits* were assessed by the Post-Traumatic Growth Inventory [31]. *Fear of recurrence and cancer worry* were assessed utilizing two validated and reliable measures, Fear of Recurrence Questionnaire (FRQ) [32] and the Impact of Events Scale—Revised (IES-R) [33].

Intensity of treatment ratings were created by following similar validated methodology that has been used and published previously [34]. Treatment intensity was calculated by a physician (C.A.S.) and categorized into three categories: least intensive treatments, moderately–very intensive treatments, and most intensive treatments.

Statistical analysis

Frequency distributions of patient characteristics were summarized. Fisher exact tests and the Wilcoxon rank sum tests were used to examine differences between LTFU and non-LTFU survivors. Differences between participants and non-participants were calculated on sociodemographics and medical characteristics. Then, *p* values from the univariate analyses, comparing LTFU and non-LTFU patients on patient sociodemographic characteristics, health behavior/health promotion, and psychosocial morbidity, were adjusted using the False Discovery Rate method for multiple comparisons [35]. All analyses were performed using SAS version 9.1 (SAS Institute Inc., Cary, NC, USA).

Results

Overall, the mean age of participants at the time of questionnaire was 30.6 years (SD = 6.1). Mean age at diagnosis was 12.6 years (SD = 6.0). Sixty percent of the participants were female; the majority were non-Hispanic White (79.8 %), highly educated (72 % had a college or graduate degree), and had health insurance (95.4 %). The most common cancer diagnoses included leukemia (30.1 % with acute lymphoblastic leukemia or acute myeloid leukemia), Hodgkin lymphoma (16.2 %), non-Hodgkin lymphoma (10.4 %), and osteosarcoma (10.4 %).

Differences between survivors who attended the LTFU clinic and those who did not (non-LTFU) in terms of sociodemographic and medical characteristics are summarized in Table 1. There were no significant differences between the two groups with respect to sociodemographic variables such as age, race/ethnicity, marital status, and education level. A greater proportion of survivors who attended the LTFU clinic had received radiation therapy (77.5 % vs. 50.7 %, $p=0.01$). Finally, a greater proportion of LTFU survivors had undergone the most intensive treatment (33.3 % vs. 2.8 %, $p<0.01$) as compared to those who did not attend the clinic.

Of the participants who attended the LTFU clinic at least once, only 60 % were able to accurately report that they had ever been seen in a survivorship or long-term follow-up clinic. However, one quarter of our LTFU sample attended only one session in the follow up clinic. Of non-attendees, 21 % incorrectly reported being followed in a long-term follow-up clinic. Non-LTFU participants were asked about reasons they did not attend the LTFU clinic and the majority said that they were not aware of such a clinic (71 %) while only 16 % stated they were “not interested”.

Of the survivors who had been seen in the LTFU clinic, only 46 % reported ever having received a treatment summary despite the fact that all survivors attending the LTFU

clinic are provided with a survivorship care plan at their initial visit, which includes a summary of their cancer treatment. Both groups were able to accurately report their cancer diagnosis and whether they had undergone chemotherapy and/or radiation therapy (Table 2). When asked to report more detail about their treatment history, almost none of the participants in either group was able to accurately name the chemotherapeutic agents they had been given.

Overall, our participants reported being in good to excellent health (90 % LTFU vs. 85.9 % non-LTFU) (Table 2). A significantly greater proportion of survivors in the LTFU group reported hormone or endocrine problems (40.2 % vs. 17.4 %), but there were no other significant differences in self-reported late effects between groups (see Fig. 1).

We examined the accuracy of survivors’ perceptions of their risks of developing various late effects by comparing self-reported risk with physician rated risk. Table 2 depicts the accuracy of risk perception between the two groups. Accuracy ranged between 55 % and 82 % with participants in both groups being most accurate in their perception of risk of infertility. While no significant differences were observed between the groups, there was a greater proportion of survivors in the LTFU group who accurately rated their risk, especially their risk of a second cancer. Most strikingly, both groups of participants underestimated their risks in every category. Despite underestimating their risk of a second cancer, participants in both groups reported fairly high fears of a second cancer (71.5 % LTFU and 69.3 % non-LTFU).

With regard to survivors’ health behaviors, the majority of survivors reported that they receive a general physical examination approximately every 2 years (82–88 %); however, they were less likely to report breast self-examination, monthly testicular examination, or receiving a routine check up from a cancer-related specialist every 2 years (see Table 3). While no significant differences were observed between groups, there were trends suggestive of increased surveillance in the LTFU group. Very few survivors reported current tobacco use ($n=9$), but more reported ever smoking

at least 100 cigarettes with no significant difference between groups. More non-LTFU survivors reported using alcohol on at least 10 of the previous 30 days compared to LTFU survivors; however, this difference was not significant. About half of participants in each group reported using sunscreen either inconsistently or not at all, and only a minority of survivors reported ever using a tanning bed.

Finally, we examined the psychosocial morbidity among LTFU and non-LTFU survivors. We examined optimism, quality of life, post-traumatic growth, and post-traumatic stress disorder (PTSD). There were no significant differences between groups on psychological or emotional problems (Table 4), though between 16 % and 18 % of participants reported that they had psychological or emotional problems, 4.2–6.9 % participants met criteria for PTSD, and between 7.8 % and 19.7 % of participants met the clinical cutoff for psychological distress on the Brief Symptom Inventory.

Discussion

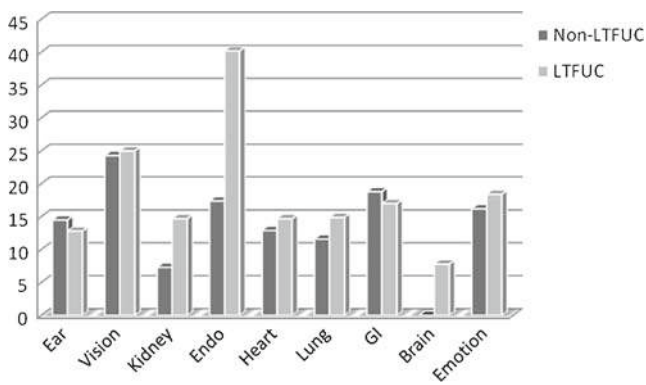
In this study, we sought to compare young adult survivors of pediatric cancers who attended a long-term follow-up clinic with those who did not. Some of the differences between our two groups may reflect differences in referral patterns to our program (e.g., a greater proportion of LTFU survivors had endocrine or hormone problems and were more likely to have received the most intensive therapies). We anticipated that attendance might result in differences in psychosocial adjustment knowledge and health-related outcomes. Overall, our two groups did not differ significantly on any of these outcomes.

Additionally, our two groups did not differ significantly on psychosocial distress or PTSD, indicating that attending a LTFU clinic does not significantly increase survivors’ worries or health-related anxiety, alleviating any concerns about any negative psychological ramifications about being part of a survivorship program. However, our findings also

Table 2 Survivors’ health and knowledge

	LTFU $n=102$		Non-LTFU $n=71$		Adjusted p
	n	%	n	%	
Current health					
Excellent/very good/good	92	90.2	61	85.9	0.24
Fair/poor	10	9.8	10	14.1	
Correct chemotherapy knowledge	94	93.1	70	98.6	0.31
Correct radiation therapy knowledge	92	90.2	70	98.6	0.22
Accurate risk perception of second cancer	73	71.6	39	55.7	0.22
Accurate risk perception of heart problems	73	74.5	47	66.2	0.44
Accurate risk perception of pulmonary problems	59	57.8	52	73.2	0.88
Accurate risk perception of fertility problems	84	82.4	52	73.2	0.38

The p values were adjusted by using false discovery method for multiple testing



*Endo = endocrine

Fig. 1 Chronic diseases/late effects (percent). *Endo* endocrine

indicated that a significant minority of survivors in both groups had what appeared to be untreated psychosocial

distress, further highlighting the need for screening, detection, and appropriate services for these young adult survivors of pediatric cancers. Given that both groups had untreated psychosocial distress, it is imperative that LTFU programs and those clinicians who treat survivors of pediatric cancers routinely screen for psychosocial distress and provide appropriate psychosocial referrals.

Another important finding in this study is that between 10 % and 14 % of survivors in our study reported that they were in fair to poor health; this may indicate that our survivors' medical needs may not be getting addressed or simply a reflection of the significant minority with complicated long-term medical needs. Many of our LTFU survivors reported endocrine problems which may reflect biases in referrals to the program or might reflect an under-diagnosis of endocrine disorders in those not being followed in a dedicated survivor program [36]. Participants' perceptions about their risk for late

Table 3 Survivors' health behaviors

	LTFU <i>n</i> =102		Non-LTFU <i>n</i> =71		Adjusted <i>p</i>
	<i>n</i>	%	<i>n</i>	%	
General physical examination					
Within past 2 years	89	88.1	58	82.9	0.62
Last dentist examination					
Within past 2 years	97	92.1	62	87.3	0.26
Breast examination (self)					
Once at least every 2 months	29	48.3	17	38.6	0.63
Clinical breast examination					
Within past 2 years	57	96.6	38	86.4	0.22
Last pap smear					
Within past 2 years	54	90.0	37	84.1	0.63
Have you ever had a mammogram					
Yes	26	43.3	16	36.4	0.75
Monthly testicular examination					
Regularly/occasionally	25	60.9	11	40.7	0.30
Routine check-up with internist or family physician					
At least once every 2 years	55	71.4	64	66.6	0.81
Visit with oncologist or other cancer specialist for cancer-related check-up					
At least once every 2 years	77	75.5	42	60.0	0.22
Smoked at least 100 cigarettes (lifetime)	14	13.8	18	25.7	0.12
Current tobacco use	1	7.1	8	44.4	0.12
Number of days in past month use alcohol					0.12
0 days	26	25.5	13	18.3	
1–9 days	63	61.7	40	56.3	
10 or more days	13	12.7	18	25.4	
Sunscreen use					0.63
Sometimes/seldom/never	53	51.9	33	46.5	
Always/nearly always	49	48.1	38	53.5	
Never used a tanning bed	87	85.3	52	73.2	0.12
Participation in physical activities	83	81.3	56	78.8	0.70

The *p* values were adjusted by using false discovery method for multiple testing

Table 4 Psychosocial morbidity between LTFU and non-LTFU survivors

	LTFU <i>n</i> =102		Non-LTFU <i>n</i> =71		Differences between psychosocial morbidity ^a		Adjusted <i>p</i>
	Mean	Std	Mean	Std	Mean	95% CI	
Optimism							
LOT total score	21.66	6.89	21.27	5.4	-0.38	(-2.35–1.58)	0.63
Quality of life (SF-36)							
Physical component	50.7	9.4	52.6	9.3	1.88	(-1.00–4.76)	0.33
Mental component	49.3	9.8	47.1	10.4	-2.23	(-5.31–0.84)	0.35
Post-Traumatic Growth Inventory							
Total score	67.3	21.7	65.4	21.7	-2.01	(-9.11–5.08)	0.75
Distress: Brief Symptom Inventory							
Global severity index	49.53	9.49	50.57	11.23	1.69	(-1.35–4.73)	0.58
Fear of recurrence							
Total score	71.5	15.1	69.3	14.4	1.15	(-1.89–4.21)	0.79
Post-Traumatic Stress Disorder Civilian checklist							
Total score	29.7	12.1	27.7	9.9	-2.02	(-5.44–1.41)	0.75
IES measure							
Total score	11.0	13.0	9.5	11.6	-1.60	(-5.41–2.19)	0.75

The *p* values were adjusted by using false discovery method for multiple testing

^a Difference between non-LTFU and LTFU survivors

effects were largely inaccurate. In most cases, survivors underestimated their risk, highlighting the need to further educate survivors about their long-term health risks and the importance of continued surveillance. Given that both groups underestimated their risk, we clearly have an obligation to educate survivors on an ongoing basis to ensure that they understand the long-term health consequences of their cancer treatments. Survivors may not be receiving the appropriate risk based follow-up care and surveillance because of their lack of knowledge and underestimation of their risks.

The magnitude of the problem is underscored by a study in which adult survivors’ knowledge of their past diagnosis and treatment was assessed [23]. Only 70 % of the 635 adult survivors of childhood cancer surveyed knew their precise cancer diagnosis and no one was able to provide a detailed, accurate summary of their diagnosis and cancer treatment. Among those treated with the anthracycline class of drugs, agents documented to cause serious long-term damage to the heart, only 30 % were able to recall this information. Having a treatment summary is one of the key factors in educating survivors about their long-term risks and recommended health practices, but is clearly not the sole solution to this problem.

Another area where survivors’ knowledge was lacking included knowledge about what type of follow-up care they were receiving. Surprisingly, when participants were asked whether they had ever been seen in a long-term follow-up or survivor clinic, 40 % of LTFU participants and 21 % of non-LTFU participants were inaccurate. Therefore, there were a large proportion of survivors who did not know they have

been seen in such a specialty clinic. Also, only a small proportion of our LTFU participants (46 %) reported ever having received a cancer treatment summary or survivorship care plan. Additionally, 71 % of non-LTFU survivors reported that they were unaware of a LTFU clinic, highlighting a need to have pediatric oncology providers systematically provide information about LTFU services at the end of treatment as well as have in place some transitional service to seamlessly transfer care from oncologist to post-treatment provider.

These gaps in knowledge further highlight the need to provide ongoing education to survivors in order to make them aware about the purposes of a long-term follow-up or survivorship clinic, survivorship care plans, and risks for late effects. Survivors of childhood cancer are often very young at the time of their initial diagnosis and treatment, and are therefore not likely to be familiar with or aware of the specifics of their cancer therapy or of the long-term health risks associated with their diagnosis and its treatment. It is also likely that at the time of their initial visit to the LTFU clinic, the focus may have been directed to their parents. Therefore, as survivors age it is imperative that the focus of the visit shift from parents to survivor. Additionally, it highlights the need for LTFU programs to have ongoing discussions with survivors that check their understanding and knowledge while reiterating important clinical information, such as treatment details and risk of late effects. Several small studies have documented that, within a survivor clinic setting, providing survivors with important medical information and enhancing their awareness about the importance for vigilance in the future is feasible

[20–22]. However, many of these studies do not include a comparison group of survivors not followed in survivorship clinics. The only study to include a comparison group found that a history of attending a survivor clinic was not associated with greater knowledge about follow-up care; however, these findings are limited by significant heterogeneity of sample (participants had been treated at 25 different centers throughout North America and over several decades) and low rates of receiving treatment summaries or care plans [23].

Limitations of this study include the fact that attendance in the LTFU clinic was not randomly assigned, which may have biased the results. Some of our data was self-reported and subject to inaccuracies or recall bias, though it is unlikely that the two groups would be different in this regard. Additionally, recruitment was complicated due to a high proportion of survivors who were lost to follow-up, leaving us with a fairly modest-sized sample. However, when we compared study participants to our non-participants, we found very few differences between groups, leading us to believe that our study sample was fairly representative and generalizable to the greater cohort of pediatric survivors at our institution. Another limitation is that our data was cross-sectional and we cannot infer change over time or how participation in a survivorship clinic might alter some of our outcomes of interest. We did attempt to minimize the influence of sociodemographic characteristics on our outcomes by matching our LTFU participants to a similar group (age, race, etc.) of non-LTFU survivors. Finally, another limitation is the fact that one quarter of our LTFU sample attended only one session in the follow up clinic. This may have attenuated differences we might expect from repeated attendance in the LTFU program for this group. However, the average number of visits participants had to the LTFU clinic was 5 (range = 1–27), giving the rest of the cohort ample opportunity to receive ongoing education about their treatment history and late effects.

Despite these limitations, we found that survivors are in need of continued and ongoing education about their specific cancer treatments, recommended follow-up practices, the importance of survivorship care, and their specific risks for late effects. This is a group that would likely benefit from added educational interventions between clinic visits which are age appropriate and are especially targeted to older adolescents and young adults as they transition into taking ownership over their long-term health care. Finally, we found that being part of a LTFU program did not increase health-related anxiety or distress.

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Conflicts of Interest The authors declare they have no conflicts of interest

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