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The Effect of Transition Clinics on Knowledge of Diagnosis and Perception of Risk in Young Adult Survivors of Childhood Cancer

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Abstract

Background—Improved treatment for pediatric cancers has ensured an evergrowing population of patients surviving into adulthood. The current study evaluated the impact of previous engagement in survivor care on patient knowledge and awareness of health risks as young adults.

Procedure—Young adult survivors of childhood cancers ($N = 93$, $M_{age} = 23.63$ y) were recruited during their annual survivor clinic visit. Participants completed self-reported measures of demographics, treatment knowledge, perception of future health risks, participation in previous survivor care, and neurocognitive functioning.

Results—In total, 82% of patients ($N = 76/93$) reported previously participating in survivorship care. These patients were more likely to have knowledge of their radiation treatment ($P = 0.034$) and more likely to recognize risk for future health effects from their treatment ($P = 0.019$). Income between \$10,000 and \$24,999 (odds ratio = 0.168; 95% confidence interval, 0.046–0.616; $P = 0.031$) was associated with decreased patient knowledge regarding diagnosis. Male sex (odds ratio = 0.324; 95% confidence interval, 0.135–0.777; $P = 0.012$) was associated with less knowledge of future health risks. Patients with self-reported difficulties on the CCSS-NCQ were more likely to regard their cancer treatment as a future health risk.

Conclusion—Participation in survivor care plays an important role in imparting information to young adult survivors of pediatric cancer regarding their disease history and risk for future health problems.

Keywords

late effects of cancer treatment; behavioral studies; pediatric oncology; transition clinics

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The field of childhood cancer survivorship is rapidly growing as improved treatment has increased long-term survival in pediatric cancer to over 80%.¹ As the population of survivors continues to grow, there is an increased concern for late effects and early mortality from cancer treatment.^{2,3} Despite these well-known risks, studies have demonstrated inadequate access to and adherence with survivorship-focused medical care for adult survivors of pediatric cancers.^{4,5} The Children's Oncology Group has recommended regular survivorship care into adulthood for early detection of late effects including secondary malignancies, organ dysfunction, and psychosocial issues.⁶ To continue care in adulthood, when many of these late effects occur, transition from pediatric to adult survivor care must occur and often requires a change in care providers or institutions.⁷

The transition of care from the pediatric to adult health care setting can be complicated for young adult survivors of childhood cancer. Challenges faced include physical, emotional, social, and financial constraints,⁷ as well as greater psychosocial stress than their older adult counterparts.⁸ A lack of knowledge regarding future health care risks and barriers to access due to changes in residence and loss of insurance may also impede this transition.^{7,9} Programs designed specifically to follow cancer survivors have been instituted to better detect and treat late effects of childhood cancer therapy, and thus improve quality of life and decrease complication-related health care costs.⁶ Dedicated programs for young adult survivors of childhood cancer can help fill the gaps in the health care system that survivors currently encounter with this transition of care and promote adequate health care access as needed for these patients. In addition, they may serve to promote health self-management and long-term healthy behaviors.

A transitional clinic for young adult survivors of childhood cancer is an evolving model and at present, there is little research evaluating the benefits, implementation, and efficacy of these clinics for pediatric cancer survivors. Although the adverse effects of cancer treatments are well known and national guidelines for surveillance of late effects in this population have been available for over a decade,⁶ research into the adequacy of these programs to meet the health care, psychosocial, and educational needs of survivors is in its infancy. The objective of the current study was to evaluate knowledge of diagnosis, treatment history, and adverse health risks as well as perceived risk of future complications in survivors receiving care in a dedicated clinic for young adult survivors of childhood cancer. In addition, we aimed to identify any demographic factors, treatment exposures, or neurocognitive impairments that may impact patient knowledge and perceptions of health risks. We hypothesized that patients who reported participating in survivorship care in the past would demonstrate greater knowledge of their past treatment and current health risks than those who had not.

MATERIALS AND METHODS

Participants

Patients were recruited through the Young Adult Transition Clinic at Emory's Winship Cancer Institute. This clinic is designed for young adult survivors of childhood cancer who have transitioned from the affiliated pediatric cancer program at the Aflac Cancer Center at Children's Healthcare of Atlanta or have moved from another institution to the Atlanta area.

Patients are typically first seen in the clinic at 21 years of age as at this point they can no longer be followed by pediatric oncologists at our institution; however, young adult survivors ages 18 to 20 years old may elect to transition to the Young Adult Transition Clinic before their 21st birthday. Patients were eligible for participation in this study if they were at least 18 years old, diagnosed with cancer before 21 years of age, and had transitioned from pediatric oncology and/or survivor care. Patients were ineligible for participation if they experienced any of the following during the study period: disease recurrence, death, or relocation with transfer of care. Patients were also excluded if they were unable to fill out the survey independently due to cognitive impairment. The enrollment period was from December 2012 to January 2014, during which 120 total patients were seen at the Survivorship Clinic. Six patients were excluded due to cognitive impairment. Four patients who were eligible for the study declined to participate (3.5%, N = 4/114). Of the 110 enrolled participants, 93 returned completed survey data (84.5%, N = 93/110). Three patients did not complete the Childhood Cancer Survivor Study Neurocognitive Questionnaire (CCSS-NCQ) and were thus excluded from analyses involving the CCSS-NCQ. Participant demographics are shown in Table 1.

The patients were offered participation in this study during their clinic visit to the young adult survivor program, with written informed consent obtained before completion of the surveys. Patients were given an opportunity to complete surveys at home or in the clinic. Information on demographics, disease, and health status was extracted from the Survivorship Healthcare Plan (SHP), a medical summary and long-term follow-up plan provided at transition from pediatric to adult survivor health care. The SHP is typically reviewed with patients during their clinic visit and includes data on the patient's diagnosis, treatment, and potential long-term effects for the patient. If a SHP was unavailable, standard review of systems and medical history forms were used to extract medical history data. The study protocol was reviewed and approved by the Emory Institutional Review Board.

Measures

Demographics Questionnaire—A demographics questionnaire designed to capture patient demographics, socioeconomic status, and education was completed by all young adult survivors.

Patient Knowledge Survey—Survivors completed a Patient Knowledge Survey, derived from the CCSS knowledge questionnaire.⁴ The Patient Knowledge Survey was used to assess disease, treatment knowledge, perception of ongoing health risks, and history of previous participation in a survivor-focused health care visit. Previous engagement with survivor care was measured in response to the question, "Have you ever attended a clinic for the purpose of late effects follow-up?" Participants who marked "no" or "don't know" were assumed to be making their first visit to a survivorship clinic. Those who marked "yes" were classified to have had previous engagement with a survivorship clinic for the purposes of analyses. Participants' perceptions of ongoing health risks were measured in response to the question, "Do you feel that past cancer treatment could cause serious future health problems?" Participants who marked "no" or "don't know" were classified as being unaware of survivor-related health risks. Self-reported knowledge of prior treatment exposures and

potential health risks from the Patient Knowledge Survey were cross-referenced with true exposures and risks from the medical record and Children's Oncology Group Long Term Follow-Up Guidelines.⁶

CCSS-NCQ—The CCSS-NCQ is a 25-item self-report survey which was completed by survivors to evaluate potential neurocognitive difficulties typically associated with exposure to some childhood cancer therapies.¹⁰ The CCSS-NCQ has demonstrated good psychometric properties and is divided into 4 domains including organization, emotional regulation, task efficiency, and memory.

The Intensity of Treatment Rating Scale (ITR-3)—The ITR-3 is an empirically validated measure of childhood cancer treatment intensity based on diagnosis, staging, and treatment modalities.¹¹ Four levels of intensity are outlined on the ITR-3 ranging from least intensive (level 1) to most intensive (level 4). Ratings were made using diagnosis, protocol, and treatment history information from patient's electronic medical records.

Statistical Analyses

Descriptive statistics were generated for demographics and socioeconomic variables. Categorical variables, such as knowledge of chemotherapeutic agents, knowledge of radiation treatment/sites, knowledge of surgery intended to treat, and perceived risk of late effects, were compared across survivorship follow-up groups using either χ^2 tests or Fisher exact tests, where appropriate. The odds of accurate knowledge of diagnosis were modeled through univariate logistic regression models as a function of treatment, demographics, socioeconomic variables, and CCSS-NCQ variables. The odds of perceived risk of late effects were also modeled through univariate logistic regression models as a function of the same covariates. For the purposes of analyses, the CCSS-NCQ variables were dichotomized using their median values. Statistical significance was assessed at the 0.05 level, and the statistical analysis was performed using SAS 9.3.

RESULTS

Descriptive characteristics regarding survivorship follow-up, treatment intensity, and patient knowledge are shown in Table 1. Ninety-three participants completed the Patient Knowledge Survey, whereas 90/93 participants (96.7%) completed the CCSS-NCQ. The age of the participants ranged from 19 to 32 years, with a mean of 23.63 years (SD = 2.75 y)

Survivor Knowledge

Survivor knowledge of diagnosis, therapeutic exposures, and risks are shown in Table 2. Patients who had not previously engaged in survivorship care demonstrated a statistically significant lack of knowledge as to the site of their previous radiation treatment ($P=0.03$). No significant differences were found in patient knowledge of diagnosis, chemotherapy agents, or surgery sites between participants who had previously engaged in survivor care and those who had not. No knowledge differences were found between patients who had low versus high self-reported neurocognitive difficulties on the CCSS-NCQ.

The only demographic factor associated with poor patient knowledge of diagnosis was an income level from \$10,000 to \$24,999 ($n = 19$) compared with those patients who made $< \$9999$ (odds ratio [OR] = 0.17; 95% confidence interval [CI], 0.05–0.62; $P = 0.031$). There was no significant difference in knowledge in patients with incomes between \$25,000 and \$49,999 and $> \$50,000$. Other demographic information, such as age, sex, insurance type, patient education level, as well as increased intensity of treatment were not significantly associated with patient's knowledge of diagnosis.

Perceived Health Risk

Patients who had not previously engaged in survivorship care demonstrated a lack of knowledge in perceived risk for future health problems caused by previous cancer treatments (Table 2) ($\chi^2 = 5.519$, $P = 0.019$). Univariate analyses showed that men were less likely than women (OR = 0.32; 95% CI, 0.14–0.78; $P = 0.012$) to believe themselves to be at future risk from their cancer treatment. Other demographic factors did not have a statistically significant effect on patient's perceived risk of future health risks.

Patients with higher self-reported difficulties with task efficiency (OR = 2.57; 95% CI, 1.10–6.14; $P = 0.033$), emotional regulation (OR = 3.57; 95% CI, 1.46–8.75; $P = 0.005$), and memory (OR = 2.90; 95% CI, 1.21–6.93; $P = 0.017$) on the CCSS-NCQ were more likely to regard their cancer treatment as putting them at risk for future health risks (Table 3).

DISCUSSION

The primary objective of this paper was to evaluate the impact of previous engagement in survivor care on patient knowledge and awareness of health risks. We also sought to identify any demographic or neurocognitive barriers to survivor-focused education among young adult survivors of childhood cancer. Patients who had not previously visited a clinic for the purpose of monitoring late effects were shown to have diminished knowledge of radiation therapy compared with those who had. In addition, these patients were shown to be less concerned with future health effects from past treatment than those who had visited a survivor clinic in the past. Although there was no statistically demonstrable difference in knowledge of chemotherapeutic and surgical treatment, these data demonstrate the importance of attendance in these clinics to inform survivors about their past treatments and reinforce future risks. Furthermore, this demonstrates the utility of perception of future health problems as a proxy for patient knowledge. On the basis of patient survey answers, it may be unrealistic to expect a patient to remember their chemotherapeutic regimen; however, an understanding of potential future morbidities from past treatment is a good marker of an informed patient given the difference between those who had attended clinic and those who had not previously attended.

We also examined other factors that might impact patient's knowledge and perceived risk of health effects from past treatment. Individual income was the only demographic factor that had an impact on patient knowledge of diagnosis. Specifically, patients who made between \$10,000 and \$24,999 were less likely to have knowledge of their diagnosis when compared with the other income groups, including the $< \$9999$. Although not intuitive, this is likely due to the fact that 73.9% ($N = 34/46$) survivors within the $< \$9999$ category were either

full-time or part-time students. Thus, it seems that among those no longer in school, a lower income correlates with less knowledge. Male sex was found to correlate with a lack of perceived risk of future health effects from cancer treatment. This correlates with other studies that have demonstrated that men generally perceive less health risk than women.¹² Also associated with an increase in perceived risk were patients who reported more difficulties with task efficiency, emotional regulation, and memory components of the CCSS-NCQ. These findings indicate that patients who are already experiencing symptoms typically associated with neurocognitive late effects of treatment are more aware of other potential health risks and are consistent with reports in the literature that survivors with higher difficulties on the CCSS-NCQ are more likely to participate in survivor health care.¹⁰ Surprisingly, intensity of treatment did not correlate with greater perceived risk. Taken together, these data seem to indicate that patients are more likely aware of their health risks based on their current health states, not the intensity or duration of their treatment.

There are limitations of this study which are important to review here and address in future research. This study evaluated a single young adult transitional clinic at 1 institution. Findings would need to be replicated at other institutions to provide more general recommendations regarding survivorship care in a pediatric population. In addition, this study had a small sample size of $N = 93$. As such, our analyses may have been underpowered to detect smaller effects influenced by previous engagement with survivor care. All patients studied here were those who presented to young adult survivorship clinic for long-term follow-up care. However, many patients who complete care at children's cancer centers do not successfully transition to adult survivor care; thus, perception of risk and knowledge of diagnosis is not likely to be representative of patients who do not engage in survivor care during adulthood. Because this investigation was based on self-reported data, information regarding previous survivorship visits was subject to the patient's recall. Specific data regarding dates and frequency of previous survivor clinic visits were not collected. Patients who could not answer the surveys independently due to cognitive deficits were excluded; these patients likely would have also lacked knowledge of their diagnosis and future risks, as well as had significant impairments on the NCQ. In addition, these patients skewed toward CNS diagnoses, which may have further affected our results.

Future directions of research include analysis of the role of caregivers and their impact on patient knowledge and follow-up in survivorship clinics. Pediatric and adolescent patients, especially those diagnosed at younger ages, are likely more dependent on their caregivers to provide them with health information before attending a survivor program; it may be valuable to investigate parent's knowledge, engagement, and attendance at the clinic as potential predictive factors of patient's knowledge. In addition, one of the roles of survivorship clinics is to help young adults navigate the health care system as the responsibility for health care shifts from caregivers to the young adult survivors. Future studies may then objectively measure whether responsibility for one's individual health correlates with knowledge of and engagement with survivor care.

In conclusion, the evidence regarding the need for survivorship clinics to care for adult survivors of childhood cancer continues to grow. Specialized survivorship programs for young adult survivors of childhood cancer can be developed and implemented to address any

remaining knowledge gaps and deficits in health self-management following survivors' transition from pediatrics to adult care. The results of this investigation indicate that participation in a young adult survivorship clinic promotes survivor's education about their future health risks and understanding of the need for surveillance throughout adulthood to support optimal health and quality of life.

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TABLE 1

Characteristics of Childhood Cancer Survivors Seen in Young Adult Survivorship Clinic

Patient Categories	Characteristics	N (%)
Diagnosis	Leukemia	32 (34.4)
	CNS tumor	7 (7.5)
	Hodgkin lymphoma	15 (16.1)
	Non-Hodgkin lymphoma	16 (17.2)
	Wilms tumor	5 (5.4)
	Neuroblastoma	1 (1.1)
	Soft-tissue sarcoma	3 (3.2)
	Bone sarcoma	10 (10.8)
	Other	4 (4.3)
Intensity of treatment	1	1 (1.1)
	2	36 (38.7)
	3	30 (32.3)
	4	26 (28)
Age at diagnosis	0–5	16 (17.2)
	6–10	13 (14)
	11–15	22 (23.7)
	16+	42 (45.2)
Sex	Male	47 (50.5)
	Female	46 (49.5)
Insurance type/status	No medical insurance	5 (5.4)
	Private	75 (80.6)
	Medicaid	13 (14)
Patient education level	Partial high school	1 (1.1)
	High school graduate	13 (14)
	Partial college	29 (31.2)
	College graduate	40 (43)
	Graduate/professional degree	10 (10.8)
Individual income	Under \$9999	46 (50)
	\$10,000–\$24,999	19 (20.7)
	\$25,000–\$49,999	19 (20.7)
	\$50,000–\$74,999	5 (5.4)
	\$75,000–\$99,999	2 (2.2)
	\$125,000–\$149,999	1 (1.1)
	Missing	1
Treatment-related neuropsychological risk factors	0	40 (43)
	1	14 (15.1)
	2	13 (14)

Patient Categories	Characteristics	N (%)
	3	12 (12.9)
	4	8 (8.6)
	5	6 (6.5)

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TABLE 2

Previous Survivorship Health Care and Young Adult Patient Knowledge

Patient Categories	Characteristics	N (%)
Participated in previous survivor-focused health care	Yes	76 (83.5)
	No	12 (13.2)
	Don't know	3 (3.3)
	Missing	2
Knowledge of diagnosis	Accurate	77 (82.8)
	Inaccurate	16 (17.2)
Knowledge of chemoagent	Accurate	20 (22.5)
	Inaccurate	69 (77.5)
	Missing	4
Knowledge of radiation sites	Accurate	38 (82.6)
	Inaccurate	8 (17.4)
	Missing	47
Knowledge of surgery	Accurate	25 (83.3)
	Inaccurate	5 (16.7)
	Missing	63
Aware of treatment-related health risks	Yes	56 (60.9)
	No	22 (23.9)
	Don't know	14 (15.2)
	Missing	1

Patient Knowledge	Previous Participation in Survivor Care (n [%])	Denied/Unsure of Previous Participation in Survivor Care (n [%])	P *
Knowledge of chemoagent			
Accurate	19 (25.7)	1 (7.7)	0.283
Inaccurate	55 (74.3)	12 (92.3)	
Knowledge of radiation sites			
Accurate	32 (91.4)	6 (60)	0.034
Inaccurate	3 (8.6)	4 (40)	
Knowledge of surgery			
Accurate	23 (85.2)	2 (66.7)	0.433
Inaccurate	4 (14.8)	1 (33.3)	
Aware of treatment-related health risks			
Yes	50 (65.8)	5 (33.3)	0.019
No/unsure	26 (34.2)	10 (66.7)	

* The P -value is calculated by χ^2 test or Fisher exact test, where appropriate.

The bold values represent statistically significant values.

TABLE 3

Effect of Neurocognitive Abilities on Perception of Risk

NCQ Domain	N	OR (95% CI)	P
Task efficiency (median cutoff)			
High	45	2.57 (1.10–6.14)	0.033
Low	45	—	
Emotional regulation (median cutoff)			
High	56	3.57 (1.46–8.75)	0.005
Low	34	—	
Organization (median cutoff)			
High	56	1.32 (0.55–3.13)	0.535
Low	34	—	
Memory (median cutoff)			
High	49	2.90 (1.21–6.93)	0.017
Low	41	—	

CI indicates confidence interval; NCQ, Neurocognitive Questionnaire; OR, odds ratio.