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Factors associated with recruiting adult survivors of childhood cancer into clinic-based research

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Abstract

Background—A high proportion of pediatric cancer patients are now surviving into adulthood, but are at increased risk for late morbidity and premature mortality related to their diagnosis and therapeutic exposures. Little is known about the potential success of recruiting adult survivors of childhood cancer into research projects that would require a risk-based health evaluation within a clinical setting.

Procedures—Pediatric cancer survivors and siblings eligible for the current study were Childhood Cancer Survivor Study participants who lived within 100 miles of one of five Consortium for Pediatric Intervention Research institutions, regardless of where they were initially diagnosed and treated. A short survey was mailed to 829 survivors and 373 siblings to identify factors that predict interest, potential barriers, and motivators, to participation in research including a risk-based clinical evaluation.

Results—Overall, 92% of survivors responding to the survey were very interested/interested in participating in a research study requiring a visit to a local hospital clinic. Siblings of survivors were less interested than survivors in participating in such a study, with only 78% indicating that

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Conflict of Interest Statement

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they were very interested/ interested. Potential motivators to participation included visiting their treating hospital and receiving health information. The primary barrier to participation was related to taking time off from work.

Conclusions—This study demonstrates that a subgroup of survivors would be willing to return to a long-term follow-up center to participate in intervention-based research. Identified motivating factors and perceived barriers need to be considered in determining the feasibility, design and execution of future research.

Keywords

pediatric cancer; survivors; recruitment; risk-based evaluation; cohort study

Introduction

The majority of children and adolescents diagnosed with cancer have an excellent prognosis for long-term survival. Data from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program show that the overall 5-year survival rate for childhood cancer patients has increased from 57% in the mid to late 1970's to over 80% in 2003–2009 [1]. It is estimated that one in every 640 young adults is now a survivor of childhood cancer, and that, as of 2010, there were 379,100 persons in the U.S. who have survived cancer diagnosed before the age of 20 years.

Childhood cancer and its subsequent treatment predispose survivors to a higher risk of certain life-threatening, debilitating, and fatal diseases [2–4]. As these pediatric cancer survivors are being followed long-term, the estimated cumulative incidence 45 years after diagnosis of chronic health conditions is 95%, and 81% of these survivors have conditions graded as severe, life threatening, disabling or that have resulted in death [4]. Due to this increased risk for late morbidity and premature mortality related to their diagnosis and therapeutic exposures, risk-based health evaluations were recommended by the Institute of Medicine in a seminal report on pediatric cancer survivorship [5] and subsequently established through the Children's Oncology Group long-term follow-up guidelines [6, 7].

Current research has provided important insights into the identification of survivors at high-risk for adverse outcomes [8, 9]. There is a need to translate these observational findings into intervention-based studies to prevent or ameliorate late effects of therapy. Translation of research findings to interventions will generally require clinical contact with survivors to confirm eligibility, carry-out the intervention and evaluate its effectiveness. To determine the potential feasibility of recruiting adult survivors of childhood cancer into such clinical research projects, we surveyed participants in the Childhood Cancer Survivor Study (CCSS) living within five geographic regions. The overall goal of this study was to understand factors that predicted interest, potential barriers, and motivators, to participation in research involving a risk-based clinical evaluation.

Methods

Subject Population

This study was conducted as part of the CCSS, a multicenter NIH-funded cohort study consisting of five-year survivors of cancer diagnosed before 21 years of age with leukemia, CNS cancer, Hodgkin lymphoma (HL), non-Hodgkin lymphoma (NHL), kidney tumor, neuroblastoma, soft-tissue sarcoma, or bone cancer between January 1, 1970 and December 31, 1986 at one of 26 participating institutions within the United States and Canada. Details of the study design and descriptions of the cohort have been published previously [10,11]. The CCSS protocol and contact documents were reviewed and approved by the human subjects committee at each participating institution. The 14,370 active participants in the CCSS cohort completed a baseline, self-administered questionnaire. Subsequently, three follow-up surveys were mailed to cohort members. Copies of all surveys are available for review at <http://ccss.stjude.org>.

To assess the prevalence and severity of self-reported chronic medical conditions by survivors and siblings, data on medical conditions from the baseline questionnaire were mapped to organ-specific toxicities listed in the National Cancer Institute's Common Toxicity Criteria for Adverse Events (CTCAE 3.0), using a 5-point severity scale from mild (severity score of 1) to life-threatening or disabling (score of 4) or fatal (score of 5) [2, 12].

Recruitment

Adult survivors of pediatric cancer and siblings eligible for the current study were CCSS participants who lived within 100 miles of one of the five institutions participating in the St. Jude Consortium for Pediatric Intervention Research (CPIR) and not eligible for recruitment to an active CCSS intervention-based study. The CPIR was established with the goal of conducting pilot studies, preferably randomized, of interventions to prevent or ameliorate the short and/or long-term adverse outcomes associated with treatments for childhood cancer. The five participating institutions include the University of Michigan, Ann Arbor, Michigan; City of Hope, Duarte, California; Emory University, Atlanta, Georgia; Hospital for Sick Children, Toronto, Ontario, Canada; and St Jude Children's Research Hospital, Memphis, Tennessee. Potentially eligible participants were sent a recruitment packet from the CCSS Coordinating Center that included an introductory letter and a brief survey. If the completed survey was not returned within three weeks of the original request, a follow-up telephone call was made to the participant by a trained interviewer to discuss the project, answer questions, and encourage participation. If the telephone call(s) did not result in contact, a second recruitment packet was sent.

The survey asked respondents to consider how they would respond if asked to participate in a research study visit that would require: Traveling to the clinic at no cost (expenses associated with gas and parking will be paid), within 100 miles of where they live; A clinic visit at no cost that will take approximately 4–6 hours; A physical exam at no cost performed by a medical team with expertise in the care of survivors of childhood cancer or a similar illness; Providing blood and urine samples.

Participants would receive—A written summary of their test results; A check in the amount of \$100 for participation.

Questions were designed to estimate rates of future participation in risk-based medical interventions, by focusing on interest in participating in such a clinic visit. In addition, questions were included to examine issues important in the decision-making process such as potential motivational factors and barriers. Participants were also asked to rank the importance of their chosen preferences.

Statistical Analyses

Differences between the participants and non-participants returning a survey with respect to treatment, demographic and socioeconomic factors were compared using Chi-square test for categorical variables and Wilcoxon Rank Sum test for continuous variables. A similar analysis was undertaken for the sibling cohort for assessing demographic and socioeconomic differences between the participants and non-participants.

Descriptive statistics were utilized to determine factors (demographic, treatment exposures, affiliation to CCSS institution) that predicted interest in, and possible barriers to, participation in intervention studies that would require one (or more than one) visit to a CPIR center. The question of “overall interest in participating in a research study” was evaluated within survivor and sibling cohorts by using Chi-square test for categorical variables and Kruskal-Wallis test for the continuous variables. An alpha level of 0.05 was utilized for all statistical tests. All analyses were performed using SAS 9.2 (Cary, NC, USA).

Results

Review of the CCSS cohort identified 1245 survivors and 387 siblings who lived within 100 miles of a CPIR institution of whom 416 were ineligible for recruitment as they were currently participating in a non-clinical CCSS intervention-based study. Thus, 829 survivors and 373 siblings were mailed a survey.

Overall, 455 (55%) survivors and 136 (36%) siblings returned the survey. The description and comparison of the characteristics for participants and non-participants are provided in Table 1. Among survivors, participation differed according to sex, marital status, and health insurance status, with females, those married or living as married, and those insured being more likely to return the survey. The same three factors were also found to predict survey completion among the siblings.

When asked about interest in participating in a research study requiring a visit to a local hospital clinic, 53.9% of survivors were 'very interested' and 38.0% were 'interested' in participating in such a study (Table 2). When comparing differences by demographic characteristics, females were more likely than males to be very interested (60.2% vs. 45.7%). Survivors who did not have health insurance were more likely than those with health insurance to be very interested in participating (73.2% vs. 52.0%). No differences were seen in level of interest with respect to age at diagnosis, diagnosis, race/ethnicity,

marital status, household income, or distance to center. Siblings were less interested than survivors in participating in such a study, with only 34.6% indicating that they were 'very interested', and 43.6% 'interested'. Among siblings, there were no significant differences in interest levels by demographic characteristics.

Potential motivators to participation (Figure 1) included: visiting with individuals involved in their care (77%), wanting additional health information (i.e. learning about health problems (35%), how to communicate with primary care doctors (36%), and information on health screening (51%)), and altruistic factors (helping other pediatric cancer survivors (76%) and helping other children with cancer (76%)). Survivors did not indicate that they would be motivated by receiving payment for the visit (13% stated 'very important'). Siblings expressed that a medical check-up (25%), information on health screening (41%), and how to communicate with primary care doctors (24%) were 'most important'. Similar to survivors, a low proportion of siblings indicated they would be motivated to participate by receiving payment for the visit (13%).

When considering potential barriers to participation, the highest ranked and primary reasons were missing work and having to use vacation/sick time to attend the visit (Table 3). However, 32% of survivors did not perceive any of the activities listed in the table as barriers to participation in a clinic visit. A similar pattern was seen among siblings. When asked to rank what factor would be most difficult, over 50% of both survivors and siblings ranked 'missing work' as the number one barrier to participating in a research clinic visit.

Participants were also asked to consider what aspect of a research clinic visit would be least appealing to them (Table 4). For both survivors and siblings, traveling to the clinical center was considered to be the least appealing aspect to participation. Survivors also stated that being in a hospital setting and bringing back old memories were not appealing aspects of a potential visit.

Discussion

The CCSS has provided a resource for research documenting the long-term effects of childhood cancer and its treatment, including increased risks for premature mortality and late morbidity among adult survivors. These primarily self-report data have contributed to the understanding of treatment-related risks for adverse outcomes, many likely reported because of presentation of clinical symptoms. This contention is supported by CCSS data, as not all survivors report receiving recommended risk-based care to detect disease early enough to provide meaningful intervention. When asked if they had received any health care in the previous two years, 71% reported receiving a general physical exam, but only 42% reported a cancer-related visit, and only 19% a visit to a cancer center [13]. The likelihood of reporting a cancer-related visit or general physical exam decreased significantly with age and with time since diagnosis, which is the period when the prevalence of late effects increases. These findings have been substantiated by a recent report describing similar results, based on screening for chronic health conditions as recommended by the Children's Oncology Group, and confirming that many survivors would likely benefit from risk-based health evaluations and health-preserving interventions [4,6,14,15].

Currently, the feasibility of recruitment of adult survivors of childhood cancer into clinical research, such as health monitoring and early intervention studies, is not known. There are potential barriers that may prevent an individual from participating, particularly if an overnight stay may be required due to distance. Recent reports support the feasibility of such investigations when the financial barriers associated with participation in a clinical assessment and access to a health care team are eliminated. Within the framework of a national health care system, Dutch investigators initiated a single-center cohort study of 5-year childhood cancer survivors in 1996. Among 1822 eligible for recruitment, 1,452 (79.7%) survivors (median time from diagnosis, 17.7, range 5.0 to 42.5 years) have returned for regular outpatient medical assessments [16]. Similarly, St. Jude investigators have been successful in organizing a cohort study of > 10 year survivors (median time from diagnosis, 25 years, range 10 to 47 years) to facilitate longitudinal evaluation of health outcomes in aging adults surviving pediatric cancer [17]. Among 2843 eligible for recruitment for the St. Jude Lifetime Cohort Study (SJLIFE), 1837 (64.4%) have enrolled on the study and 1713 (60.3%) have completed a comprehensive two to three-day battery of outpatient clinical assessments [4]. This is not necessarily a representative study, as it eliminates key barriers to SJLIFE participation by funding research costs related to all medical assessments and providing travel and lodging for study participants. In addition, participants are compensated a per diem rate to cover costs from missed days at work or childcare expenses. Both the Dutch and the SJLIFE studies have published investigations evaluating a wide range of treatment-related late-effects to accurately reflect the prevalence of subclinical disease, and to characterize risk profiles for adverse outcomes, informing refinement of health screening recommendations for childhood cancer survivors.

This survey-based study was initiated through the member institutions of the Consortium for Pediatric Intervention Research (CPIR) to specifically investigate the feasibility of conducting clinically-based research involving long-term survivors of childhood cancer participating in the Childhood Cancer Survivor Study (CCSS). Given this well-defined objective, it is important to recognize the unique features of the study population, which have direct implications on the generalizability of the findings. CCSS participants reflect a population of survivors who could be successfully located and subsequently actively engaged in research. Therefore, findings from this survey may reflect individuals who are aware of the importance of survivorship care, and are more motivated to participate in future intervention studies. Moreover, because of resource limitations and concerns for excessive burden on the eligible CCSS participants, the survey methodology did not include comprehensive follow-up procedures for non-responders to the survey to maximize the rate of participation. The low participation rate achieved further contributes to the potential selection of the study population. Only survivors residing in selected geographic areas (i.e., within a defined radius of a participating CPIR center) were eligible to participate. While these regions are geographically diverse, it is possible that a more broadly defined population of survivors may have provided different results. Nonetheless, our findings from this select survivor population do provide insights into the level of interest and some of the motivators for participation in clinically-based research.

Barriers and motivators identified in the current study could be used to improve participation in studies, particularly intervention studies that require a clinic-based visit. Of interest,

survivors positively affirmed their interest in visiting with individuals involved with their care and in helping other survivors of childhood cancer. In contrast, for both survivors and siblings, the most significant barrier to participating in a clinic-based visit is missing work and using up sick/vacation time to attend such a visit. Possible strategies for understanding motivating factors and overcoming this barrier would be consideration of clinic visits on weekends, or possibly evenings if the visit was of a shorter duration. Motivators to participate in such a study could be in the form of education strategies and/or incentives, such as free access to diagnostic tests that would help overcome barriers to receiving a risk-based health evaluation, particularly for those who are un- or under-insured. Our data also suggest that emphasis on the importance of motivation factors, such as obtaining additional information about late effects and the altruistic aspects of the visit, would increase participation in a risk assessment study.

Our findings from this survey need to be considered within the context of the study limitations. Use of survivors who are currently participating in survivorship-based research, the low participation rate for the mailed survey, and exclusion of some eligible survivors because of competing studies does have implications on the generalizability of our findings. In particular, CCSS is a highly motivated group of long-term participants, and we have chosen potential participants for this survey from five large, geographically diverse centers with the capacity to clinically evaluate survivors eligible for recruitment to an intervention-based study. Therefore, findings from this survey may represent individuals who are aware of the importance of survivorship care, and are possibly more motivated to participate in future intervention studies. However, even if the overall participation rate in this survey may be lower than is generally desired and participants not fully representative of the eligible source population, results from this study provides insight into possible incentives and strategies to remove barriers that could be considered for future intervention studies. In addition, we were not able to fully address this question in all large pediatric cancer centers, however, utilizing these suggested strategies should not negatively impact the internal integrity of results obtained from a well-designed comparative intervention study. Rather, the limitation would be the degree of generalizability of the results from the intervention.

It is encouraging that a substantial proportion of survivors indicated their willingness to return to their original treating institution or to a long-term follow-up center located within a reasonable distance from their current residence to participate in research. Even though not statistically significant, survivors who were further from the institution were more interested in attending, suggesting such a clinic visit would be incentive for additional follow-up care. In addition, survivor's interest in education regarding the impact of their past exposures on their current and future health is encouraging for future motivational and therapeutic interventions. With the lack of well designed studies evaluating the effectiveness of any intervention to increase the utilization of preventive health services by childhood cancer survivors, this information will also give us guidance regarding those factors that influence a person's decision to participate, and what barriers need to be addressed to increase participation in future risk-based medical intervention studies.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.

Potential motivators when deciding whether to participate in a clinic visit (questions listed as 'mark all that apply')

Table 1

Comparison of participants and non-participants among survivors and siblings

	Survivors		P-value	Siblings		P-value
	Completed survey Number (%)	Passive refusal Number (%)		Completed survey Number (%)	Passive refusal Number (%)	
Overall	456 (55)	373 (45)		136 (36)	237 (64)	
Age at diagnosis Median (range)	6.2 (0.02–20.9)	5.1 (0.03–20.9)	0.07	--	--	
Diagnosis			0.65			
Leukemia	168 (37)	155 (42)		--	--	
CNS tumor	50 (11)	35 (9)		--	--	
Hodgkin disease	59 (13)	40 (11)		--	--	
NHL	40 (9)	26 (7)		--	--	
Wilms tumor	35 (8)	38 (10)		--	--	
Neuroblastoma	37 (8)	28 (8)		--	--	
STS	34 (7)	27 (7)		--	--	
Bone tumor	33 (7)	24 (6)		--	--	
Sex			<0.001			0.07
Male	202 (44)	220 (59)		56 (41)	121 (51)	
Female	254 (56)	153 (41)		80 (59)	116 (49)	
Race/Ethnicity			0.055			0.13
White, not Hispanic	382 (84)	293 (79)		119 (88)	193 (81)	
Other	74 (16)	80 (21)		17 (13)	44 (19)	
Marital status			0.002			0.04
Married/living as married	248 (55)	161 (44)		103 (77)	155 (67)	
Not married	206 (45)	207 (56)		31 (23)	78 (33)	
Household income (US \$)			0.09			0.19
< 20,000	39 (9)	36 (12)		4 (3)	14 (7)	
20,000 – 59,999	143 (35)	124 (40)		30 (23)	59 (28)	

	Survivors		Siblings		P-value
	Completed survey Number (%)	Passive refusal Number (%)	Completed survey Number (%)	Passive refusal Number (%)	
60,000	232 (56)	147 (48)	97 (74)	141 (66)	
Health Insurance					0.06
Yes/Canadian	413 (91)	320 (86)	130 (96)	213 (90)	
No	41 (9)	52 (14)	6 (4)	23 (10)	
Distance to center					0.90
20 miles	124 (27)	116 (31)	45 (33)	73 (31)	
20–50 miles	180 (39)	133 (36)	46 (34)	83 (35)	
51–100 miles	152 (33)	124 (33)	45 (33)	81 (34)	
Any Grade 3 or 4 chronic condition					0.51
Yes	125 (27)	87 (23)	6 (4)	7 (3)	
No	331 (73)	286 (77)	129 (96)	219 (97)	

Table II
Overall interest in participation in a research study that requires a visit to a local hospital clinic among 442 survivors and 133 siblings

	Survivors (n=442)			p-value	Siblings (n=133)			p-value
	Very interested	Interested	Not Interested		Very interested	Interested	Not Interested	
Overall	238 (53.9%)	168 (38.0%)	36 (8.1%)		46 (34.6%)	58 (43.6%)	29 (21.8%)	
Age at diagnosis Median (range)	6.4 (0.1 –20.5)	5.9 (0.0 –20.9)	6.3 (0.4 –7.1)	0.62	-	-	-	
Diagnosis				0.07				
Leukemia	96 (58.5)	58 (35.4)	10 (6.1)		-	-	-	
CNS tumor	21 (45.7)	16 (34.8)	9 (19.6)		-	-	-	
Hodgkin disease	32 (55.2)	24 (41.4)	2 (3.4)		-	-	-	
NHL	20 (52.6)	11 (28.9)	7 (18.4)		-	-	-	
Wilms tumor	20 (57.1)	13 (37.1)	2 (5.7)		-	-	-	
Neuroblastoma	18 (48.6)	16 (43.2)	3 (8.1)		-	-	-	
STS	16 (53.3)	12 (40.0)	2 (6.7)		-	-	-	
Bone tumor	14 (42.4)	18 (54.5)	1 (3.0)		-	-	-	
Sex				0.007				0.76
Male	90 (45.7)	86 (43.7)	21 (10.7)		21 (38.2)	23 (41.8)	11 (20.0)	
Female	147 (60.2)	82 (33.6)	15 (6.1)		25 (32.1)	35 (44.9)	18 (23.1)	
Race/Ethnicity				0.72				0.26
White, not Hispanic	199 (53.5)	144 (38.7)	29 (7.8)		43 (37.1)	48 (41.4)	25 (21.6)	
Other	38 (55.1)	24 (34.8)	7 (10.1)		3 (17.6)	10 (58.8)	4 (23.5)	
Marital status				0.70				0.95
Married/living as married	129 (53.3)	95 (39.3)	18 (7.4)		35 (35.0)	43 (43.0)	22 (22.0)	
Not married	108 (54.8)	71 (36.0)	18 (9.1)		11 (35.5)	14 (45.2)	6 (19.4)	
Household income (US \$)				0.22				0.78
< 20,000	83 (61.5)	40 (29.6)	12 (8.9)		2 (50.0)	2 (50.0)		
20,000 – 59,999	22 (57.9)	14 (36.8)	2 (5.3)		11 (36.7)	11 (36.7)	8 (26.7)	
60,000	115 (50.4)	95 (41.7)	18 (7.9)		32 (34.0)	41 (43.6)	21 (22.3)	
Health Insurance				0.03				0.39

	Survivors (n=442)			p-value	Siblings (n=133)			p-value
	Very interested	Interested	Not Interested		Very interested	Interested	Not Interested	
Yes/Canadian	207 (52.0)	157 (39.4)	34 (8.5)		43 (33.9)	55 (43.3)	29 (22.8)	
No	30 (73.2)	10 (24.4)	1 (2.4)		3 (50.0)	3 (50.0)	0 (0.0)	
Distance to center				0.51				0.82
20 miles	58 (50.4)	46 (40.0)	11 (9.6)		15 (34.1)	20 (45.5)	9 (20.5)	
20–50 miles	92 (52.0)	73 (41.2)	12 (6.8)		13 (28.9)	21 (46.7)	11 (24.4)	
51–100 miles	87 (58.4)	49 (32.9)	13 (8.7)		18 (40.9)	17 (38.6)	9 (20.5)	
Any Grade 3 or 4 chronic condition				0.56				0.48
Yes	60 (50.4)	47 (39.5)	12 (10.1)		1 (16.7)	4 (66.7)	1 (16.7)	
No	177 (55.0)	121 (37.6)	24 (7.5)		45 (35.7)	53 (42.1)	28 (22.2)	

Potential barriers to participate in a clinic visit at [Institution] (questions listed as ‘mark all that apply.’)

Table III

Activity	Survivors # Indicated ‘yes’ (Total N=445)			Siblings # Indicated ‘yes’ (Total N=136)		
	Overall	Male	Female	Overall	Male	Female
Need for childcare	39	11	28	17	2	15
Cannot travel alone, need assistance	31	13	18	3	2	1
Missing work (workload, deadlines, difficulty getting permission)	135	70	65	38	16	22
Missing work (cannot afford loss of wages)	97	41	56	21	10	11
Having to use my own sick leave or vacation time	93	39	54	19	10	9
Missing school	15	5	10	8	3	5
Need for someone to take care of my pets	11	9	2	2	0	2
None of the above	143	61	81	37	19	18
Other	47	24	23	9	2	7

Table IV
Factors that would be least appealing to participation in a clinic visit (questions listed as ‘mark all that apply’)

Activity	Survivors # Indicated ‘yes’ (Total N=445)			Siblings # Indicated ‘yes’ (Total N=136)		
	Overall	Male	Female	Overall	Male	Female
Traveling	89	43	46	27	11	16
Seeing a particular doctor	8	3	5	1	1	0
Being in a hospital setting	31	14	17	11	4	7
Having tests run	51	20	31	17	7	10
Bringing up old memories of when I was sick	48	22	26	-	-	-
Being asked to go to a hospital other than the one at which I received my treatment for cancer	34	16	18	-	-	-
None of the above	219	94	124	53	25	28
Other	22	10	12	3	2	1

- Question not applicable to sibling