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Factors Influencing Long-Term Follow-Up Clinic Attendance Among Survivors of Childhood Cancer

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Abstract

Introduction—Attendance at long-term follow-up clinic is necessary for survivors of childhood cancer to facilitate education about cancer-related health risks, early detection of treatment-related morbidity, and implementation of health-promoting interventions. Despite the need for continued care, barriers to clinic attendance exist. The purpose of this prospective study was to identify the demographic, medical, and logistic factors impacting clinic attendance and long-term follow-up care among survivors of childhood cancer.

Methods—Adherence to clinic attendance was monitored among 941 long-term childhood cancer survivors scheduled for evaluation at our institution. Patients were classified as "attenders" or "non-attenders" based on the outcome of their first scheduled clinic appointment over a one year period. Social work staff contacted non-attenders by telephone to determine reasons for missed appointments.

Results—Nearly 15% of survivors were classified as non-attenders. Univariate findings revealed that older age, lower SES, being non-white, less medically insured, traveling by car, living shorter distance from clinic, having a scheduled social work consultation, and entering or exiting survivorship clinic were associated with clinic non-attendance (all p values <.05). The final multivariate model indicated that non-whites (OR=1.88, 95% CI=1.19–2.97), patients without insurance (OR=2.36,95% CI=1.98 – 3.79), those traveling by car (OR=12.74, 95% CI=3.97 – 40.86), and those who have not experienced secondary cancer events (OR=1.76, 95% CI=0.94–3.28) were more likely to be non-attenders. Work or school conflicts were the primary reasons cited for missed appointments.

Discussion/Conclusions—Despite mechanisms designed to reduce financial burdens associated with attending survivorship clinic at our institution, demographic, medical, and logistic barriers exist which impact participation in long-term follow-up.

Implications for Cancer Survivors and Providers—These results highlight the importance of developing tailored outreach strategies for survivors of childhood cancer at-risk for clinic nonattendance, particularly among underserved populations.

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Keywords

Clinic Attendance; Oncology; Adolescent/Young Adult; Follow-up; Survivorship; Childhood Cancer

INTRODUCTION

The majority of patients treated for childhood cancer are living to adulthood as a result of therapeutic advances in pediatric oncology. Presently, almost 80% of children and adolescents with cancer survive 5 or more years from diagnosis and are effectively cured of their disease [1]. In the United States, this success represents almost 300,000 survivors, or 1 in 640 young adults between the ages of 20 and 39 years [1]. Unfortunately, despite these improvements in survival rates, cancer and its therapy predispose patients to a variety of adverse health conditions including organ dysfunction, psychosocial maladjustment, and subsequent malignancies that may negatively impact quality of life and result in early mortality [2,3]. Therefore, as survival rates increase, so do the number of patients at-risk for the development of deleterious late effects associated with cancer treatment.

Late effects, or cancer-related sequelae that persist or develop five or more years after completion of cancer therapy, are of primary concern among those who survive childhood cancer. Recently, findings from the Childhood Cancer Survivorship Study (CCSS) revealed the estimated cumulative incidence of chronic health conditions among pediatric cancer survivors to be 73% at 30 years post cancer diagnosis, with 42% experiencing severe or life threatening conditions including death [4]. Despite the high incidence of both chronic and life threatening conditions within this population, extensive research has linked specific therapeutic interventions for childhood cancer to adverse sequelae, thereby providing an opportunity for clinicians to identify at-risk survivors for health screening and intervention [5]. Therefore, regular medical follow-up is essential for childhood cancer survivors to enable the early detection of morbidity [6]. Specifically, follow-up assessments are important in defining factors that influence cancer-related risks and informing the development of health promoting interventions, screening guidelines, and future treatment approaches.

In addition to serving as an important venue for assessment and detection of potential late effects, follow-up clinic visits provide an ideal context and opportunity to educate patients and their families regarding behavioral risk reduction and improvement of self-care activities. For example, patients who attend follow-up clinic receive informative health promotion messages that may serve to prevent or reduce engagement in risky health behaviors [7,8]. Such education from health care providers about the consequences of risky health behaviors (i.e. tobacco use, drug and alcohol use, poor eating habits, etc.) has been associated with reduced risk for organ damage and the development of second malignancies [9,10]. Education of this nature is particularly crucial for adolescent survivors as they transition to adult care and begin taking responsibility for their own behavior and medical needs [7,11]. Finally, it is advantageous for family members who accompany survivors to clinic visits to be educated about increased health risks due to shared genetic and environmental factors that have also been implicated in the etiologies of some cancers [12].

Despite the need for continued follow-up care for survivors of childhood cancer, demographic, medical, and logistic factors serve as barriers to clinic attendance. For example, Johnson and colleagues [6] examined sociodemographic factors as predictors for attendance or non-attendance in a follow-up clinic serving survivors of childhood cancer in the United Kingdom. Survivors less likely to attend survivorship follow-up clinic included patients who were older, of lower socioeconomic status, and had been off treatment longer. In addition, unemployment was positively associated with non-attendance. Other barriers faced by childhood cancer survivors are lack of medical insurance and knowledge regarding their history of cancer treatment and future health risks [13]. Although these relationships have been explored elsewhere among adult survivors of childhood cancer and within globally diverse systems of health care, these relationships have not yet been studied prospectively or among US pediatric and adolescent survivors of childhood cancer. In order to develop better patient recruitment and retention strategies related to follow-up clinic participation, we must first identify variables that best predict clinic attendance/non-attendance in this high risk group.

The purpose of this study was to identify demographic, medical, and logistic differences between survivors of childhood cancer who attend or do not attend their scheduled long-term follow-up clinic appointments. Although previous studies have identified sociodemographic factors related to survivorship clinic attendance, this study is the first study to examine such factors among pediatric and adolescent survivors of childhood cancer in the U.S. Furthermore, past studies have examined sociodemographic factors only, and have not explored the role of medical and logistic factors which may have important implications for clinic attendance. The current prospective study improves on previous work by examining demographic, treatment-related, *and* logistic variables that directly impact survivorship clinic attendance, thus informing future recruitment and retention interventions within the childhood cancer survivor population.

METHODS

Participants

Study participants included those patients scheduled for appointments in the After Completion of Therapy (ACT) Clinic at St. Jude Children’s Research Hospital (SJCRH) between June 1, 2005 and May 31, 2006. Patients are eligible to participate in the ACT Clinic once they are five years post cancer diagnosis and have been disease free for at least two years. Once admitted to the ACT Clinic, patients receive annual follow-up until they are 10 years post cancer diagnosis or until high school graduation, whichever occurs later. Appointments are organized as either initial visits (official transfer from active clinics and orientation to the ACT Clinic), annual follow-ups (ACT Clinic visits), or final visits (a.k.a. “alumni” visits after which survivors are officially discharged from ACT Clinic follow-up and transferred to adult care in their community).

Design

A prospective non-experimental design was utilized to examine demographic, medical, and logistic factors associated with clinic attendance/non-attendance. “Attenders” were defined as those who attended their ACT Clinic appointment within 6 months of their first scheduled appointment date within the aforementioned 12 month study period. Those who did not attend their scheduled appointment within 6 months of their clinic date (e.g. failed to show to clinic, repetitive re-scheduling, etc.) were defined as “non-attenders.” This operationalization of attenders and non-attenders was chosen based on the annual recommended schedule in which survivors of childhood cancer should be evaluated [14]. By arriving to clinic greater than 6 months post scheduled clinic appointment date, the patient has essentially “missed” one year of screening and is, in a sense, “early” for the next year’s appointment.

Procedures

In this Institutional Review Board-approved study, ACT Clinic schedules were reviewed weekly in order to identify eligible study participants. Data were obtained from active hospital databases containing patient demographic, medical, and travel/logistic information. Patients who failed to show for their appointment visit were contacted by mail via established clinic policies. For the purposes of this study, social workers telephoned patients who were classified as non-attenders and documented reasons for missed appointments.

Demographic, medical, and logistic information was collected for each patient. Demographic information collected included gender (male/female), race (White/Black/Other), age (in years), and socioeconomic status (SES) which was based on the Hollingshead Four Factor Index, and subsequently collapsed into low (index=1–3), medium (index =4–6), or high (index =7–9) SES for analytic purposes. Medical information consisted of diagnosis (leukemia/lymphoma, CNS disease, or solid tumor), time since diagnosis (in years), time off therapy (in years), visit acuity level (ranging from physical exam and labs only to physical exam, labs, diagnostic imaging and 2 or greater subspecialty evaluations), additional cancer event (relapse, progressive disease, or second malignancy), and insurance status (none, public, or private). Logistic information included distance from patient's home to hospital (in miles), type of ACT Clinic visit (initial, annual, follow-up, or final), scheduled social work consultation (yes/no), season of scheduled appointment (summer/non-summer), and mode of transportation used to attend clinic appointments (airplane, bus, or car).

Statistical Approach

The association of demographic, medical, and logistic variables with ACT Clinic attendance was investigated via chi-square tests for categorical variables and nonparametric Wilcoxon rank sum tests for continuous variables. Logistic regression was used to explore which variables maintained significance after adjusting for other variables in the model. Variables significant at $p<.10$ were candidates for inclusion in the final multivariate model. Final selection for the model was done using the stepwise method as implemented in SAS Release 9.1.3 (SAS Institute, Cary, NC), which sequentially enters the most significant variable with $p<.10$ and then after each entered variable removes variables that do not maintain significance at $p<0.10$.

RESULTS

The study cohort was comprised of 941 patients with ACT Clinic appointments scheduled between June 2005 and May 2006. Approximately 79% of the participants were Caucasian and 48% were female. The median age was 18.2 years (range, 7.3–39.5 years). Additional participant characteristics are reported in Table I. Of the patients enrolled in the study, 801 (85.1%) attended their scheduled ACT clinic appointment within 6 months of the initial appointment, and 140 (14.9%) patients did not.

Reasons for failing to show for ACT appointments were categorized into 13 categories and coded separately by two independent raters with 100% agreement obtained. These 13 categories were eventually reduced to 9 categories due to covariation and for ease of presentation. Approximately 43% of non-attenders were coded as unable to be reached if their telephone numbers were disconnected, or if they did not return phone calls after up to six attempts. It should be emphasized that these unreachable patients were included in our analyses as their demographic, medical, and logistic data were available. Over 31% of the non-attenders reportedly had either work or school conflicts, or personal/family health problems that interfered with attending scheduled clinic appointments. A complete list of patient self-reported reasons and frequencies for missed appointments is presented in Figure 1.

Univariate findings (Table I) revealed that compared to those who attended their scheduled clinic appointments, non-attenders were more likely to be older ($p=.010$), of lower socioeconomic status ($p=.006$) and non-White ($p=.001$). Of the medical variables that were considered, significant differences existed by insurance status, with differential trends being identified on additional cancer event (relapse, progressive disease or second malignancy) and time since diagnosis. Specifically, individuals who were less medically insured ($p<.001$), had less time from diagnosis (p=.087), and were free of additional cancer events (p=.080), were more likely to be non-attenders to the ACT Clinic. Analysis of logistic variables revealed that non-attenders were more likely to travel to the hospital by car (p<.001), live closer to the hospital (p<.001), be scheduled for a social work consultation as part of the clinic visit (p=.049) and be scheduled for either an initial or final survivorship appointment (p=.042).

A logistic regression model was utilized to determine which variables were associated with clinic attendance after adjusting for other important factors. Variables considered in the stepwise variable selection procedure were those with univariate findings significant at the p<.10 level. The variables meeting this criterion included age, SES, race, years from diagnosis, additional cancer event, insurance status, means of travel, distance from hospital, scheduled social work consultation, and type of ACT Clinic visit. Four variables were retained in the resulting model (Table II), which revealed that after adjusting for other variables, non-whites were nearly 2 times more likely to be non-attenders compared to Caucasians (p=.007), and patients without insurance (p=.001) were 2.4 times more likely to be non-attenders than those with private insurance. Those who traveled by car were approximately 13 times more likely to be non-attenders as compared to those who traveled by airplane (p < .001). Finally, there was a trend for patients who remained cancer free (i.e. did not experience an additional cancer event) to be 1.8 times more likely to be non-attenders (p=.075).

DISCUSSION

Annual attendance at long-term follow-up clinic is important for survivors of childhood cancer to facilitate education about cancer-related health risks, early detection of treatment-related morbidity, and implementation of health-promoting interventions. Attendance at scheduled clinic appointments is necessary for the maintenance of time efficient and cost effective clinics that reduce hospital-based cost intensive resources associated with no-shows and late re-schedulers. This study found that 15% of survivors of childhood cancer did not attend scheduled clinic visits within 6 months post appointment date, and identified demographic, medical, and logistic factors which influenced long-term follow-up care among patients surviving childhood cancer. Although preliminary, these findings suggest that modifiable variables exist which relate to clinic attendance and should be targets for future interventions.

Our data revealed that variables such as being non-white, less medically insured, and having low SES independently associated with non-attendance to clinic. These relationships remain despite our hospital’s policies which provide free medical care, meals, lodging, and transportation to patients attending survivorship clinic at our institution. Although providing this type of assistance alleviates financial barriers to clinic attendance, other variables associated with lower SES remain (e.g. single parenting, increased family/child care needs, skepticism of health care teams, overall stress burden) which may adversely affect clinic attendance. As demonstrated by the data presented in Figure 1, a substantial proportion (43%) of patients who did not attend clinic were unable to be contacted (primarily due to lack of telephone service), with another 19% missing clinic appointments due to work/school conflicts. These results support the need for future interventions which meet the needs of underserved populations who are significantly more likely to miss their scheduled survivorship appointments and who may have fewer resources to manage medical or psychological late effects that may present over time.

Survivorship clinic attendance also appears to vary as a function of appointment timing with relative increases in non-attendance occurring at initial and final survivorship clinic visits. Patient education, whether related to cancer diagnosis and treatment, future health risks, medical screening and self monitoring, developing healthy lifestyle and behaviors, or transitioning to adult care, is a key component of survivorship clinic programs that begin during the initial clinic visit. Missing the initial ACT appointment therefore impedes the educational process, while at the same time placing one at risk for unsuccessful transition from treatment clinic to survivorship clinic. In contrast, patients who actively participate in survivorship clinic frequently become overly comfortable operating within the pediatric hospital system which may then express as distress during the pediatric to adult care transition period. Hence, the final (or “alumni”) clinic appointments are more often missed presumably to postpone this impending discharge event. Transition is further complicated by challenges in securing community primary care as some medical professionals may be unfamiliar and/or uncomfortable with meeting the needs of these patients [15]. Participation in long-term follow-up programs offers survivors services such as self-advocacy, assertive communication, information regarding insurance and employment rights, and methods to independently navigate health care systems, which are designed to facilitate the transition from pediatric to adult care. Once transition has occurred, our expectation is that survivors will utilize their survivorship knowledge and expertise to educate primary care teams, which in return, should create more informed and appropriate health care for all survivors within their home communities [16]. This type of communication will also facilitate a shared care approach (cancer center oncology team in coordination with community physician groups) which has been identified as the optimal model for childhood cancer survivor care [17,18].

Medically speaking, those patients who were free of secondary cancer events and were closer in time to cancer diagnosis, were also more like to miss ACT clinic appointments. This latter finding is consistent with those of Oeffinger and colleagues (2004) who reported an inverse relationship between time since diagnosis and rates of cancer-related or cancer center medical visits among adult survivors of childhood cancer [19]. It may be that survivors are more likely to miss appointments if they are healthier, and have a reduced number of late effects (due, in part, to the relatively reduced time since diagnosis). Yet, our data revealed that there is no relationship between acuity of medical appointment (our surrogate variable for severity of late effects) and clinic attendance. Perhaps more globally, those patients who are more recently released from treatment and remain cancer free have a perceived sense of invulnerability which predisposes them to miss survivorship appointments. Among adult survivors of childhood cancer, lack of concern for future health has been associated with decreased cancer-related follow-up care [19]. Yet, these types of patients would benefit most from behavioral risk counseling in that the low costs associated with adapting to a healthy lifestyle could yield solid benefits in terms of preventing, delaying, or minimizing specific late effects associated with cancer treatment.

Interestingly, several factors that we examined significantly influenced clinic attendance but in the unexpected direction. Those living closer to the hospital and traveling by car were less likely to attend their scheduled survivorship appointments. Although differences in hospital travel reimbursements exist at our institution (i.e. reimbursement for travel only provided to those living greater than 35 miles from our institution), van service is available for all local patients, suggesting that financial differences do not directly account for these differences. It may be that patients who live closer to survivorship clinic perceive medical services as being more available and utilize the clinic when problems develop, as opposed to consistent annual monitoring as recommended. Furthermore, the structure associated with flying to our institution (i.e. coordination of airline reservations, financial penalties for flight changes, specific time of flight departure, etc.) may prioritize survivorship clinic appointments among those who fly to our institution to attend clinic, as opposed to those who drive.

The findings of our study must be interpreted within the context of its limitations. First, many of the factors investigated as part of this study are correlated (e.g., age, time from diagnosis, and additional cancer event), so alternative multivariable models may exist that would be valid based on other variable selection procedures. Additionally, many psychological factors (e.g.

health beliefs and perceptions, post traumatic stress symptoms, knowledge of late effects risk), physical factors (e.g. wheel chair use, fixed joints/prosthetic use, bowel or bladder impairment, pain-related disorders), and cognitive factors (ranging from mild executive functioning deficits to complete devastation) may relate to traveling difficulty and/or participating in survivorship clinic appointments, but were not considered here. Also, we did not consider the number or severity of late effects experienced by our patients, but rather relied on a surrogate variable (i.e. visit acuity) as a measure of appointment intensity. Finally, it is possible that those who did not attend survivorship clinic were actively pursuing care from providers in their home communities. Future studies should expand beyond the demographic, medical, and logistic variables that were considered in this study to include psychological, cognitive, and physical functioning variables in order maximize the likelihood of identifying factors which may be integrated into survivorship clinic recruitment and retention efforts.

Based on these findings, improvements have been made to our standard operating procedures as it relates to patient recruitment and retention. Specifically, we are taking a more active role in the transition of patients from the treating to survivorship clinics to enhance survivor/family understanding regarding the purpose and benefits of participation in long-term follow-up. We are also now partnering with oncologists from active treatment sections who now assist in contacting and recruiting their former patients who miss initial survivorship appointments. This is just one example of tailoring an intervention so that the established relationship between the patient and their pediatric oncologist is utilized to increase survivorship clinic participation. Our preliminary experience with this approach suggests that patients who attend their initial ACT visit will continue to participate in subsequent survivorship visits. Therefore, this initial time point has been of focus in developing recruitment and retention protocols. Further efforts have included increased telephone contact among all patients who fail to show for appointments (regardless of appointment type) while documenting the details of attendance/non-attendance on a newly developed Follow-Up Scheduled Appointment Tracking Form available to all survivorship clinic staff. We plan to use this data to improve overall clinic operations with intentions of examining these research driven operational changes and their resulting impact on survivorship clinic attendance.

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Table I

Demographic, Medical, & Logistic Features of Patients in Study Cohort (N=941)*

	n	**All Patients N=941**	**Attenders N=801**	**Non-attenders N=140**	**P-value**
Demographic					
Age in Years - Median (Range)	941	18.2 (7.3–39.5)	17.9 (7.3–39.5)	19.7 (8.8–30.8)	.010
SES - %					
Low	280	32.0	79.3	20.7	.006
Middle	386	44.0	87.3	12.7	
High	210	24.0	88.1	11.9	
Gender - %					
Female	455	48.4	86.6	13.4	.22
Male	486	51.6	83.7	16.3	
Race - %					
White	745	79.2	87.3	12.8	.001
Black	177	18.8	77.4	22.6	
Other	19	2.0	70.6	29.4	
Medical					
Diagnosis - %					
CNS	166	17.7	86.8	13.3	.27
Leukemia/Lymphoma	372	39.5	82.8	17.2	
Solid tumor	403	42.8	86.6	13.4	
Years from Diagnosis - Median (Range)	941	11.7 (6.4–36.8)	11.8 (6.4–36.8)	11.1 (6.8–26.6)	.087
Years off Study - Median (Range)	845	10.2 (2.1–26.3)	10.3 (2.1–21.9)	9.8 (3.3–26.3)	.19
Additional Cancer Event** - %					
No	809	86.0	84.3	15.7	.080
Yes	132	14.0	90.2	9.9	
Insurance - %					
None	193	22.1	80.3	19.7	<.001
Public	199	22.8	79.4	20.6	
Private	482	55.1	89.6	10.4	
Logistical					
Transportation - %					
Airplane	171	18.2	98.3	1.8	<.001

	n	All Patients N=941	Attenders N=801	Non-attenders N=140	P-value
Car	767	81.5	82.1	17.9	
Bus	3	0.3	100.0	0.0	
Miles from SJCRH - Median (Range)	941	164 (0–11747)	183 (0–11747)	23.5 (0–4459)	<.001
Season- %					
Summer	316	33.6	87.3	12.7	.17
Non-Summer	625	66.4	84.0	16.0	
Social work consult scheduled					
No	317	33.7	88.3	11.7	.049
Yes	624	67.3	83.5	16.5	
Type of ACT Visit - %					
First	172	18.3	79.7	20.4	.042
Annual	595	63.2	87.4	12.6	
Follow-up	40	4.3	87.5	12.5	
Last	134	14.2	81.3	18.7	
Acuity of ACT Visit - %					
ACT annual	149	15.8	82.6	17.5	.20
ACT annual+DI	194	20.6	86.6	13.4	
ACT annual+DI+1 Subspecialty	245	26.0	82.0	18.0	
ACT annual+DI+≥2 Subspecialty	353	37.5	87.5	12.5	

[*] Observations for SES and Insurance status do not total 941 due to missing data. Years off study is provided for participants who were treated on institutional protocols only.

[**] Progressive disease, relapse, or second malignancy

Abbreviations: ACT – After Completion of Therapy; DI – diagnostic imaging.

Table II

Logistic Regression for variables predicting non-attendance (n=872)

Variable	β	χ^2	P-Value	Odds ratio	95% Confidence Interval (CI)
Intercept	−1.70	24.29	<.001		
Race					
Non-White vs White	.63	7.27	.007	1.88	1.19 – 2.97
Insurance Status					
None vs Public	.23	.72	.40	1.25	0.74 – 2.15
None vs Private	.86	12.55	<.001	2.36	1.98 – 3.79
Cancer Event[**]					
None vs. Event	.57	3.16	.075	1.76	0.94–3.28
Means of travel					
Car vs. Plane/Bus	2.54	18.32	<.001	12.74	3.97 – 40.86

[**] Progressive disease, relapse, or second malignancy