Distribution Agreement

In presenting this thesis or dissertation as a partial fulfillment of the requirements for an advanced degree from Emory University, I hereby grant to Emory University and its agents the non-exclusive license to archive, make accessible, and display my thesis or dissertation in whole or in part in all forms of media, now or hereafter known, including display on the world wide web. I understand that I may select some access restrictions as part of the online submission of this thesis or dissertation. I retain all ownership rights to the copyright of the thesis or dissertation. I also retain the right to use in future works (such as articles or books) all or part of this thesis or dissertation.

Signature:

Meera Shah

Date

Impact of Demographics on Severity of Late Effects and Survivorship Clinic Attendance in Young Adult Childhood Cancer Survivors

By

Meera Shah MPH

Epidemiology

Dr. Ann C. Mertens Faculty Thesis Advisor Impact of Demographics on Severity of Late Effects and Survivorship Clinic Attendance in Young Adult Childhood Cancer Survivors

By

Meera Shah

BS Emory University 2012

Faculty Thesis Advisor: Dr. Ann C. Mertens, PhD, MS

An abstract of A thesis submitted to the Faculty of the Rollins School of Public Health of Emory University in partial fulfillment of the requirements for the degree of Master of Public Health in Epidemiology 2017

Abstract

Impact of Demographics on Severity of Late Effects and Survivorship Clinic Attendance in Young Adult Childhood Cancer Survivors

By Meera Shah

Background: With the advent of improving cancer therapies, there has been a significant increase in numbers of childhood cancer survivors. From 1975 to 2010, five year survival rate increased from 50 to 80% for cancer diagnosed before age 20. Late effects are cancer related sequelae that develop five years or more after cancer therapy. Forty percent of them had a serious health problem as young adults, thus it is of utmost important that these effects are monitored in survivors as part of their overall healthcare annually.

Methods: One hundred twenty childhood cancer survivors age 21-30 were recruited at Emory's Survivorship Clinic. Each patient was consented and given a survey document with questions regarding demographics as well as patient knowledge. Chi-square analysis was completed with 93 patients who had complete survey and healthcare record data, to explore relationships between various variables including demographics, severity of late effects and adherence to survivorship clinic.

Results: 76% of the population was white, 91% had late effects. Lastly, patients who identified that their cancer therapy could cause future health problems were more likely to have severe late effects than those who were not aware of the potential late effects (p=0.0509). Patients who were currently employed had significantly better clinic adherence than those who were not employed (p=0.0364). Patients who had attained a higher level of education were more likely to have attended clinic for a longer period of time (p=0.0013).

Conclusion: Cancer survivorship clinic is important in identifying and screening for late effects in cancer therapy given that 91% of patients experience late effects. The severity of these late effects is not significantly modified by demographic factors, although patients with higher maternal education level and understanding that cancer treatment could cause future problems tended towards less severe late effects.

Length: The Abstract may not exceed one page, formatted according to the regular page formatting instructions (margins, spacing, font). The text itself cannot exceed 350 words (not counting the title etc.). The Abstract may be single-spaced.

Impact of Demographics on Severity of Late Effects and Survivorship Clinic Attendance in Young Adult Childhood Cancer Survivors

By

Meera Shah

BS Emory University 2012

Faculty Thesis Advisor: Dr. Ann C. Mertens, PhD, MS

A thesis submitted to the Faculty of the Rollins School of Public Health of Emory University in partial fulfillment of the requirements for the degree of Master of Public Health in Epidemiology 2017 Acknowledgements: Dr. Natia Esiashvili, Dr. Rohit Gunan Ganju, Dr. Jordan Marchak

Table of Contents

Background	
Specific Aims	
Methods	
Results	
Discussion	9
Limitations	
Conclusions and Future Directions	
References	
Tables	

Background:

With the advent of new treatments, increasing numbers of childhood cancer patients are surviving into adulthood. From 1975 to 2010, the five year survival rates increased from 50% to more than 80% for children diagnosed with cancer before age 20 [1, 2]. There were approximately 380,000 adult survivors of pediatric cancer as of January 2010 in the United States [3]. Increased survival into adulthood necessitates the surveillance for long term effects of a patient's cancer diagnosis, as well as the treatment's impact on psychosocial development [4]. Surveillance could be helpful in screening for late effects, which are cancer-related sequelae that "persist or develop five or more years after completion of cancer therapy, that are of primary concern among those who survivor childhood cancer" [5]. In a recent study, almost 75% of pediatric cancer survivors who were treated in the 1970's and 1980s had long term health concerns and more than 40% of them had a serious health problem as young adults. The number of health conditions has only increased with time, meaning that it is of utmost importance to monitor survivors as part of their overall healthcare [6]. Thus, researchers are currently exploring protocols to optimize screening for adult survivors of pediatric cancer. Part of these protocols consist of survivorship clinic visits, and it is thought that survivorship clinic may detect late effects, recurrence of disease, organ toxicity, as well as provide psychosocial support, and education for survivors. Despite the possible benefits of survivorship screening, a large fraction of patients do not seek care in these clinic visits [7] Those who do attend survivorship clinic need disease or treatment specific education in order to appropriately screen for late effects over the years. However, some patients

are unaware that survivor clinics exist and therefore, improved methods of transition of care are needed after cancer therapy [8].

In order to better understand the challenges in transition from pediatric to adult care, studies explore why patients fail to attend survivor clinic. Patient factors that negatively impact survivor follow up include loss to follow up in non white racial groups, a diagnosis at an older age, and patients with a cancer diagnosis other than leukemia or lymphoma [9]. Other studies cite barriers to survivor follow up such as patients forgetting appointments, appointment cancellations, patient illness, problems getting time off from work, transportation difficulties, poor communication from the provider on follow up recommendations, fear of secondary malignancy, lack of perceived risk and life responsibilities [7, 10]. Further studies explore disease and treatment related factors that increase risk of psychosocial late effects, which might also impact willingness to follow up in survivorship clinic. For example, one study indicates that treatment with cranial radiation doses of 25 Gy or higher was associated higher odds of unemployment, and related poor physical functioning, as well as lower education and income [11] Moreover, survivors were more than twice as likely to live independently than their siblings [12].

Thus far, studies have explored the impact of various demographics on patient survivorship follow up, treatment predictors of late effects, and barriers to patient survivorship clinic attendance. However studies have not yet understood which demographic factors might impact the severity of late effects in those at risk. This is important to understand in that clinicians might be able to warn patients of their increased risk of late effects if they fall into a particular demographic group. Additionally, as researchers work on shaping protocols for future patients survivorship plans, researchers have not yet studied the benefits of survivorship clinic [13]. While survivorship clinic does increase screening for late effects risk, researchers do not have an understanding for how survivorship clinic adherence impacts severity of late effects. This study will explore these two research aims.

Specific Aims:

Question 1: Do demographic factors moderate severity of late effects of cancer therapy on those who are at risk?

Question 2: Do demographic factors and severity of late effects moderate adherence to survivorship clinic visits?

Methods

Participants

Patients were recruited for this single center, cross-sectional study 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. It is recommended that survivors return to clinic on an annual basis.

Patients were eligible for participation in this study if they were at least 18 years old, diagnosed with cancer prior to 21 years of age, and had transitioned from pediatric oncology and/or oncology 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 lasted from December 2012 until 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). In an effort to focus on a younger cohort, four patients over the age of 30 were excluded from the analysis. Of the 110 enrolled participants, 106 had medical record data available, and 93 returned completed survey data (84.5%; N= 93/110). Data analyses included 93 survivors who had both sources of data available

The patients were offered participation in this study during their clinic visit to the young adult survivor program, with written informed consent obtained prior to completion of the surveys. Patients were given an opportunity to complete surveys at home or in the clinic. Consent to collect current information from their medical records was obtained. The study protocol was reviewed and approved by the Emory Institutional Review Board. Hypothesis: Patients who were socioeconomically advantaged, educated, and older, had fewer, severe, late effects compared to their counter parts. Furthermore, adherence to survivorship clinic is hypothesized to be improved based on the same factors.

Measures

Patient Knowledge Survey. Survivors completed a Patient Knowledge Survey, derived from the Childhood Cancer Survivor Study (CCSS) knowledge questionnaire [14] 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 healthcare visit. 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.

Late Effects. Patients were consented to have continued access to their medical records throughout their visits to the survivorship clinic. A search of the medical records was performed in February 2016 to assess for the presence of treatment-related adverse effects. Each effect was graded based on the Common Terminology Criteria for Adverse Events version 4.03 available from the National Cancer Institute (Cancer Therapy Evaluation Program). The Criteria grade scale goes from mild (grade 1) to fatal (grade 5). For the purposes of this study, patients with grade 1-2 conditions were combined and patients with grade 3-4 were combined. If the patient had multiple conditions, they were assigned a grade based on the most severe condition. Adverse psychosocial outcomes were not included in this analysis. Prior to data analysis, at least two authors had to agree on all scores.

Statistical Analyses

Descriptive statistics were generated for general patient characteristics such as demographics, late effects and knowledge variables using frequencies and percentages. Demographic and measure-level statistics were calculated and compared across patient responses using Chi-square tests of independence in discrete cases. Categorical variables including demographic variables and survivorship clinic visits were compared across late effects groups (dichotomized as none, stage 1 and 2, versus stage 3 and 4) using chi-

squared tests or Fisher's Exact test where appropriate. Statistical significance was assessed at the 0.05 level and the statistical analysis was performed using SAS 9.3.

Variables Assessed

Gender, race, student status, employment status, insurance, patient education level, parent education level, ability to identify disease correctly, knowledge that cancer treatment could cause future health problem, total survivorship clinic visits, late effects, and severity of late effects were the variables measured and analyzed. These variables, which were obtained from the survey document, gave the researcher an idea of demographic, severity of late effect and impact of knowledge on late effects.

Results

The demographic characteristics of this study population are shown in Table 1. Of note, approximately 76% of the population was white, 68% had private insurance and 54% were college graduates or had graduate or professional degrees. Table 2 demonstrates that 91% of patients experienced any late effects, and 40% experienced severe late effects.

Table 3 demonstrates that women tended toward having more significant late effects (31.9% male and 45.7% female, p=0.368). Additionally, currently employed survivors were more likely to have lower severity, grade 1-2, late effects (employed 60.0% vs. 39.4% unemployed p=0.143). Those who had private insurance had lower severity late effects than those with Medicaid, though this relationship was not statistically significant (p=0.592). Those individuals with graduate or professional degrees had higher severity of late effects, though the difference in late effects in those with a college education or less was not significant (p=0.240). Simultaneously, those patients whose mother's education level was less than a college degree tended to have more severe late effects (p=0.054). Lastly, patients who identified that their cancer therapy could cause future health problems were more likely to have severe late effects than those who were not aware of the potential late effects (p=0.051). Number of survivorship clinic visits were not linked to severity of late effects (p=0.775).

Table 4 shows that women tend to come to clinic for longer than do men (p=0.185). Those patients who were currently students were also more likely to come to clinic for longer periods of time. Additionally, young adult survivors who were currently employed were more likely to continue attending survivorship clinic until a later age (p=0.036). Patients who had attained a higher level of education were also significantly more likely

to attend clinic for a longer period of time (p=0.001). Maternal education level showed a trend that the less education a mother had, the less amount of time a patient spent attending survivor clinic (p=0.139). Lastly, those patients who knew their cancer therapy could cause future problems were significantly more likely than those without that knowledge to attending survivorship clinic consistently.

Discussion

Healthy People 2020 objectives include one that increases the number of patients who live five years or longer after their cancer diagnosis, and improve survivors' mental and physical health. In order to improve the health of childhood cancer survivors, understanding late effects is an important component. These patients are vulnerable to late effects and long term follow up programs have been started at 75% of centers that treat childhood cancer [15]. While efforts have been made to increase long term follow up, it remains unknown what factors, including demographics, moderate severity of late effects of cancer therapy. This study also explored the effects of demographic variables and severity of late effects on survivorship clinic adherence.

Gender

In this study, female survivors appeared to have higher likelihood of having more severe late effects (p=0.368), though this finding was not significant. However, being female has been shown to predispose survivors to late effects including cardiac damage, obesity, as well as psychological late effects such as mood disturbances and depression [16] Another study demonstrates that there are significantly more sexual function related late effects in females than in males [17]. Considering that females are predisposed to having a variety of late effects, our small patient population is possibly a reflection of these results. However without more participants, significance cannot be demonstrated.

With respect to survivorship clinic attendance, there was no significant difference between males and females, though women tended to have better long term clinic attendance than men. Another study that examined the demographic factors which impact survivorship non-attendance also agreed that there was not a significant relationship with gender [18]

Employment Status

This study demonstrated that those individuals who were currently employed had fewer severe late effects than those who were not employed at the time of survey (p=0.143). Other studies have shown that patients, who were employed at the time of survey, were likely the ones who experienced fewer psychosocial stressors from cancer therapy at critical developmental life stages [19]. These cancer related social disruptions secondary to late effects of chemotherapy are associated with problems in employment [19]. Individuals who have long breaks in schooling due to cancer therapy are more likely to have academic challenges, which could explain challenges in employment. Furthermore, these individuals with more severe late effects may have been those who were too sick to work [1, 20] Our study's results support these previous findings.

Those individuals who were currently employed were also more significantly likely to attend clinic consistently (p=0.0364). This relationship has not been previously explored, however those patients who are employed are likely to have better socioeconomic status and it has been shown that those with low socioeconomic status are likely to be non-attenders of survivorship clinic (p<0.05) [5]. Additionally, it is possible that currently employed individuals have insurance through work and are able to attend survivorship clinic visits.

Insurance Status

Patients in this study with private insurance had no difference in severity of late effects when compared with patients with other types of insurance, and there was no difference in survivorship clinic adherence (p=0.610, p=0.613). These results are interesting given that patients with private insurance have previously been shown to be more likely to attend clinic than those patients with public health insurance (p=0.02) [21]. One study supports these results in that patients without insurance were more likely to not attend long term follow up clinic for childhood cancer (OR=2.36,95% CI=1.98 - 3.79) [5]. It is possible that those patients who attend clinic more frequently with private insurance are likely to be screened more frequently for late effects than those with public insurance. Therefore, they may be able to get effective treatment before they progress in severity. Patient Education Level

Patient education level trended towards more severe late effects as patients had more education (p=0.240). While this was not a significant finding, existing data shows a dramatic trend and would be interesting to explore this further in a larger study. Previous studies in childhood cancer survivors have demonstrated lower educational attainment associated with adverse health outcome (OR, 2.0; 95% CI, 1.8-2.5; P<0.001) [22] . It is concerning in this study that those individuals who are highest achieving may have the most severe late effects, given that education has previously been linked to better health outcomes [23]. It is possible that graduate level degree career related time constraints create subsequent inability to attend clinic regularly for late effects screening.

However, those patients who were mostly highly education were most likely to attend survivorship clinic. Given that attendance of survivorship clinic provides opportunities to screen this at risk group for late effects at a consistent time increment, the highly educated patients who attend clinic would have better chances of catching late effects early, prior to progression of disease.

Mother's Education Level

Patients with mother's who have not completed college had higher frequency of severe late effects. This relationship was insignificant, likely due to low patient enrollment in this study, but it did indicate that mothers with higher levels of education whose children had cancer were more likely to have fewer severe late effects (p=0.054). Previous studies have demonstrated a strong correlation between maternal education and markers of child health [24]. If a mother is more educated, it is possible that she is more likely to be aware of late effects and continue to have her child screened regularly as they become young adults.

Furthermore, this study demonstrates increased survivorship clinic visits in patients whose mother's have attained higher education level. "Concern for child's health and well-being" was the number one reason for why mothers accompany their young adult survivor to clinic and it is possible that a more educated mother is more likely to encourage their child to attend survivorship clinic [25].

Awareness of Cancer Treatment and Late Effects

Patients who were aware of the possible late effects of cancer therapy were more likely to develop severe late effects than their counterparts who did not have this knowledge (p=0.0509). While it is concerning that 91% of patients in this study developed late effects, it is more concerning that so many patients were unaware of the consequences of cancer therapy. Information about late effects is one of the most frequently reported unmet needs amongst survivors of cancer at a young age [19] and often times these childhood cancer survivors are responsible for advocating for themselves to healthcare providers who often lack knowledge regarding late effects of childhood cancer given how

rare it is [26]. Furthermore, previous studies have shown that the primary care providers who are caring for these young adults have limited knowledge of late effects [27]. Thus it is essential that future study explore methods to increase young adult survivor awareness of late effects in hopes to link patients to long term follow up and increase early detection of late effects [28]. Based on the results of this study, patients who are aware that their cancer treatment could cause future health problems are more likely to attend survivorship clinic long term (p=0.0288).

Survivorship Clinic Visits

While it was hypothesized that more survivorship clinic visits might have lead to fewer late effects, this study data did not demonstrate this relationship. There have been no studies done to explore the impact of survivorship clinic adherence to severity of late effects. With a larger group of patients, this relationship may have been studied more closely, however in this patient population there was no obvious trend.

Limitations

Limitations of this study include the sample size. As a result of there being only 110 patients in the study, it is difficult to determine which of these trends would hold true in a larger sample size. Given that these patients were also recruited from a survivorship clinic, perhaps this patient population may not be representative of all cancer survivors. These patients are likely to be more responsible and aware of the impact of childhood cancer therapy on adult life, and therefore are more motivated to come to survivorship clinic than the average cancer survivor. Given that many patients are undereducated on late effects, it is possible that many patients who are at risk of developing severe late effects were not enrolled in this study.

Conclusions and Future Direction

This study supports the importance of studying this vulnerable patient population as we have a growing number of survivors susceptible to late effects. While there are certain predictors such as gender, education status, and employment status that may be helpful predictors of severe late effects, it is important to continue this study on a larger scale to follow these trends on a large population scale. Future study may examine the impact of primary care provider knowledge of late effects on number of cancer survivors who have stage 1-2 versus stage 3-4 late effects. Primary care provider education is also crucial to catching childhood cancer survivors' late effects in that some patients may not be as apt to attend survivorship clinic, but typically will have an annual physical exam. If these providers are able to serve as a screen for late effects, the goals of helping these survivors achieve a healthier mental and physical life could be accomplished.

References

1) Ries LAG, Smith MA, Gurgney JG. Cancer Incidence and Survival among Children and Adolescents: United States SEER Program 1975-1995. *PsycEXTRA Dataset*. 1999;

2) Howlader N, Yasui Y, Hobbie W, et al. SEER Cancer Statistics Review, 1975-2011. *Surveillance, Epidemiology, and End Results Program*. (https://seer.cancer.gov/archive/csr/1975_2011/). (Accessed April 6, 2017)

3) Ward E, Desantis C, Robbins A, et al. Childhood and adolescent cancer statistics, 2014. *CA: A Cancer Journal for Clinicians*. 2014;64(2):83–103.

4) Zeltzer LK, Lu Q, Leisenring W, et al. Psychosocial Outcomes and Health-Related Quality of Life in Adult Childhood Cancer Survivors: A Report from the Childhood Cancer Survivor Study. *Cancer Epidemiology Biomarkers & Prevention*. 2008;17(2):435–446.

5) Klosky JL, Cash DK, Buscemi J, et al. Factors influencing long-term follow-up clinic attendance among survivors of childhood cancer. *Journal of Cancer Survivorship*. 2008;2(4):225–232.

6) Oeffinger KC, Mertens AC, Sklar CA. Chronic Health Conditions in Adult Survivors of Childhood Cancer. *Oncology Times*. 2007;29(1):26.

7) Johnson R. Hospital attendance patterns in long term survivors of cancer. *Archives of Disease in Childhood*. 2004;89(4):374–377.

8) Ford JS, Chou JF, Sklar CA. Attendance at a survivorship clinic: impact on knowledge and psychosocial adjustment. *Journal of Cancer Survivorship*. 2013;7(4):535–543.

9) Rokitka DA, Curtin C, Heffler JE, et al. Patterns of Loss to Follow-Up Care Among Childhood Cancer Survivors. *Journal of Adolescent and Young Adult Oncology*. 2017;6(1):67–73.

10) Smits-Seemann RR, Kaul S, Zamora ER, et al. Barriers to follow-up care among survivors of adolescent and young adult cancer. *Journal of Cancer Survivorship*. 2016;11(1):126–132.

11) Late Effects of Treatment for Childhood Cancer. *National Cancer Institute*. (https://www.cancer.gov/types/childhood-cancers/late-effects-hp-pdq#link/_280_toc). (Accessed April 7, 2017)

12) Kunin-Batson A, Kadan-Lottick N, Zhu L, et al. Predictors of independent living status in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Pediatric Blood & Cancer*. 2011;57(7):1197–1203.

13) Wallace WHB, Blacklay A, Eiser C, et al. Regular review: Developing strategies for long term follow up of survivors of childhood cancer. *Bmj*. 2001;323(7307):271–274.

14) Kadan-Lottick NS, Robison LL, Gurney JG, et al. Childhood Cancer Survivors' Knowledge About Their Past Diagnosis and Treatment. *Jama*. 2002;287(14):1832.

15) Fish J. 5 Facts About Childhood Cancer Survivors | St. Baldrick's Blog | Childhood Cancer Stories & Research. *St. Baldrick's Foundation*.
(https://www.stbaldricks.org/blog/post/5-facts-about-childhood-cancer-survivors/).
(Accessed April 9, 2017)

16) Bottomley SJ. Childhood Cancer Survivorship: Improving Care and Quality of Life. *The Lancet Oncology*. 2004;5(6):389.

17) Zebrack BJ, Foley S, Wittmann D, et al. Sexual functioning in young adult survivors of childhood cancer. *Psycho-Oncology*. 2009;19(8):814–822.

18) Klosky JL, Cash DK, Buscemi J, et al. Factors influencing long-term follow-up clinic attendance among survivors of childhood cancer. *Journal of Cancer Survivorship*. 2008;2(4):225–232.

19) Zebrack B. Information and service needs for young adult cancer survivors. *Supportive Care in Cancer*. 2008;17(4):349–357.

20) Anne C. Kirchhoff, W. L., Kevin R. Krull, Kirsten K., et al. (2010). "Unemployment among Adult Survivors of Childhood Cancer: A report from the Childhood Cancer Survivors Study." <u>Med Care</u> 48(11).

21) Zheng DJ, Sint K, Mitchell H-R, et al. Patterns and predictors of survivorship clinic attendance in a population-based sample of pediatric and young adult childhood cancer survivors. *Journal of Cancer Survivorship*. 2015;10(3):505–513.

22) Hudson MM. Health Status of Adult Long-term Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study. *JAMA: The Journal of the American Medical Association*. 2003;290(12):1583–1592.

23) Zimmerman E. B., S. H. W., Haley, A. Population Health: Behavioral and Social Science Insights, Understanding the Relationship Between Education and Health. *AHRQ*

24 Desai S, Alva S. Maternal Education and Child Health: Is There a Strong Causal Relationship? *Demography*. 1998;35(1):71.

25) Doshi K, Kazak AE, Hocking MC, et al. Why Mothers Accompany Adolescent and Young Adult Childhood Cancer Survivors to Follow-up Clinic Visits. *Journal of Pediatric Oncology Nursing*. 2014;31(1):51–57.

26) Landier W, Wallace WHB, Hudson MM. Long-term follow-up of pediatric cancer survivors: Education, surveillance, and screening. *Pediatric Blood & Cancer*. 2005;46(2):149–158.

27) Nekhlyudov L, Aziz NM, Lerro C, et al. Oncologists' and Primary Care Physicians' Awareness of Late and Long-Term Effects of Chemotherapy: Implications for Care of the Growing Population of Survivors. *Journal of Oncology Practice*. 2014;10(2)

28) Lie HC, Loge JH, Fosså SD, et al. Providing information about late effects after childhood cancer: Lymphoma survivors' preferences for what, how and when. *Patient Education and Counseling*. 2015;98(5):604–611.

Tables

Table 1. Frequencies (N=93)	
Variable	N (%)
Gender	
Male	47 (50.54)
Female	46 (49.46)
Race	
AA	13 (13.98)
Asian	1 (1.08)
White	71 (76.34)
Hispanic	3 (3.23)
Native American	3 (3.23)
Other	2 (2.15)
Currently a student	
Yes	40 (43.01)
No	53 (56.99)
Currently employed	
Yes	60 (64.52)
No	33 (35.48)
Insurance	
No medical insurance	5 (5.32)
Private Insurance	64 (68.09)
Medicaid	11(11.70)
Other	14 (14.89)
Patient education level	
$< 9^{\text{th}}$ grade	0 (0)
Partial High School	1 (1.08)
High School Graduate	13 (13.98)
Partial College	29 (31.18)
College Graduate	40 (43.01)
Graduate or professional degree	10(10.75)
Mother's Education Level	
$< 9^{\text{th}}$ grade	2 (2.15)
Partial High School	1 (1.08)
High School Graduate	18 (19.35)
Partial College	19 (20.43)
College Graduate	31 (33.33)
Graduate or professional degree	22(23.66)
Father's Education Level	
< 9 th grade	3 (3.23)
Partial High School	3 (3.23)
High School Graduate	20 (21.51)
Partial College	17 (18.28)
College Graduate	29 (31.18)
Graduate or professional degree	21 (22.58)
Disease correctly identified	
Yes	77 (82.80)
No	16 (17.20)

Cancer treatment could cause future health problem	
Yes	
No	57 (61.96)
	35 (38.04)
Missing	1 (0.01%)
Total Survivorship Clinic Visits	
1 Visit	9 (9.68)
2 Visits	24 (25.81)
3 Visits	20 (21.51)
4 Visits	15 (16.13)
5 Visits	8 (8.60)
6 Visits	7 (7.53)
7 Visits	4 (4.30)
8 Visits	5 (5.38)
9 Visits	0 (0.00)
10 Visits	0 (0.00)
11 Visits	1 (1.08)

Table 2. Late effects (N	(=93)
Variable	N (%)
Late effects*	
Yes	85 (91.40)
No	8 (8.60)
Severity*	
Grade 1-2	83(93.3)
Grade 3-4	36(40.0)

Table 3. Impact of Demographic					
Factors on Severity of Late Effects					
(N=93)					
Variable (N, %)	No Late	Grade 1-2	Grade 3-4	Chi	P-Value
	Effects			Square	
Gender					
Male	5(10.64)	27 (57.45)	15(31.91)	1.99	0.3679
Female	3(6.52)	22 (47.83)	21(45.65)		
Race		, , , ,	, , ,		
AA	1(7.69)	7(53.85)	5 (38.46)	0.29	0.9902
White	6(8.45)	38(53.52)	27(38.03)		
Other	1(11.11)	4(44.44)	4(44.44)		
Currently a student			, í		
Yes	2(5.00)	20(50.00)	18(45.00)	1.87	0.3921
No	6(11.32)	29(54.72)	18(33.96)		
Currently employed		, , , , , , , , , , , , , , , , , , ,	, , ,		
Yes	5(8.33)	36(60.00)	19(31.67)	3.89	0.1425
No	3(9.09)	13(39.39)	17(51.52)		
Insurance		, ,	, ,		
No medical insurance	0(0)	2(40.00)	3(60.00)	2.79	0.5920
Private Insurance	8(10.26)	42(53.85)	28(35.90)		
Medicaid	0(0)	5(50.00)	5(50.00)		
Patient education level					
High School Graduate or below	2(14.29)	6(42.86)	6(42.86)	7.98	0.2396
Partial College	3(10.34)	14(48.28)	12(41.38)		
College Graduate	3(7.50)	26(65.00)	11(27.50)		
Graduate or professional degree	0(0)	3(30.00)	7(70.00)		
Mother's Education Level					
High School Graduate or below	1(4.76)	8 (38.10)	12(57.14)	12.38	0.0540
Partial College	3(15.79)	6(31.58)	10(52.63)		
College Graduate	3(9.68)	22(70.97)	6(19.35)		
Graduate or professional degree	1(4.55)	13(59.09)	8(36.36)		
Father's Education Level					
High School Graduate or below	3(11.54)	14(53.85)	9(34.62)	3.31	0.7691
Partial College	2(11.76)	6(35.29)	9(52.94)		
College Graduate	2(6.90)	17(58.62)	10(34.48)		
Graduate or professional degree	1(4.76)	12(57.14)	8(38.10)		
Disease correctly identified					
Yes	6(7.79)	39(50.65)	32(41.56)	1.63	0.4420
No	2(12.50)	10(62.50)	4(25.00)		
Cancer treatment could cause future					
health problem*					
Yes	4(7.02)	26(45.61)	27(47.37)	5.96	0.0509
No	4(11.11)	24(66.67)	8(22.22)		
Total Survivorship Clinic Visits**					
1 Visit	1(11.11)	5(55.56)	3(33.33)	13.27	0.7751
2 Visits	3(12.50)	14(58.33)	7(29.17)		
3 Visits	2(10.00)	11(55.00)	7(35.00)		
4 Visits	0(0.00)	5(33.33)	10(66.67)		
5 Visits	0(0.00)	5(62.50)	3(37.50)		

6 Visits	1(14.29)	4(57.14)	2(28.57)	
7 Visits	0(0.00)	3(75.00)	1(25.00)	
8 Visits	1(20.00)	2 (33.33)	2(40.00)	
9 Visits	0(0.00)	0(0.00)	0(0.00)	
10 Visits	0(0.00)	0(0.00)	0(0.00)	
11 Visits	0(0.00)	0(0.00)	1(100.00)	

Table 4. Impact of Demographic					
Factors and Severity of Late Effects					
on Adherence to Survivorship Clinic					
Visits (N=93)					
Variable (N, %)	1-2 Years	3-4 Years	5 + Years	Chi	P-Value
				Square	
Gender				1	
Male	17(36.17)	21(44.68)	9(19.15)	3.37	0.1845
Female	16(34.78)	14(30.43)	16(34.78)		
Race	, , , , , , , , , , , , , , , , , , ,				
AA	4(30.77)	7(53.85)	2(15.38)	2.6043	0.6261
White	25(35.21)	26(36.62)	20(28.17)		
Other	4(44.44)	2(22.22)	3(33.33)		
Currently a student			/		
Yes	16(40.00)	18(45.00)	6(15.00)	5.1013	0.0780
No	17(32.08)	17(32.08)	19(35.85)		
Currently employed					
Yes	17(28.33)	22(36.67)	21(35.00)	6.6242	0.0364
No	16(48 48)	13(39.39)	4(12.12)	0.0212	0.0001
Insurance	10(10110)	10(0)(0))	.()		
No medical insurance	3(60.00	2(40.00)	0(0,00)	4 4743	0.6128
Private Insurance	26(33,33)	30(38.46)	22(28,21)	1.1715	0.0120
Medicaid	4(40,00)	3(30,00	3(30.00)		
Patient education level	1(10.00)	5(50.00	5(50.00)		
High School Graduate or below	9(64.29)	5(35.71)	0(0,00)	21 8123	0.0013
Partial College	12(41.38)	14(48,28)	3(10,34)	21.0125	0.0015
College Graduate	9(22,50)	15(37.50)	16(40.00)		
Graduate or professional degree	3(30,00)	10(37.50) 1(10.00)	6(60,00)		
Mother's Education Level	5(50.00)	1(10.00)	0(00.00)		
High School Graduate or below	7(33 33)	10(47.62)	4(19.05)	9 6763	0 1390
Partial College	8(42.11)	6(31.58)	5(26.32)	2.0705	0.1570
College Graduate	15(48.30)	10(32.26)	5(20.32) 6(10.35)		
Graduate or professional degree	3(13.64)	0(10(32.20))	10(45,45)		
Eather's Education Level	5(15.04)	9(40.91)	10(43.43)		
High School Graduate or below	10(38.46)	12(46.15)	4(15.38)	8 1647	0 2263
Partial College	6(35,20)	7(40.13)	4(13.36) 4(23.53)	0.1047	0.2203
College Greduete	0(33.29) 13(44.83)	7(41.18) 9(31.03)	4(23.33) 7(24.14)		
Graduate or professional degree	13(44.83) 4(10.05)	7(33.33)	10(47.62)		
Disease semestly identified	4(19.03)	7(33.33)	10(47.02)		
Vac	28(26.26)	20(26.26)	21(27.27)	0.2151	0 9542
I es No	20(30.30) 5(31.25)	20(30.30) 7(42.75)	21(27.27)	0.3131	0.6542
	3(31.23)	7(45.75)	4(23.00)		
Cancer treatment could cause future					
Nea	19(21 50)	10(21 50)	21(26.94)	7.0052	0 0 2 9 9
	18(31.38)	10(31.38) 16(45.71)	21(30.84)	1.0952	0.0288
	13(42.80)	10(43./1)	4(11.43)		
Severity	4(50.00)	2(25.00)	2(25.00)	0.0700	0.5700
INONE Creade 1.2	4(50.00)	2(25.00)	2(25.00)	2.8/89	0.5/83
Grade 1-2	19(38.78)	10(32.65)	14(28.57)		
Grade 3-4	10(27.78)	17(47.22)	9(25.00)		