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RESEARCH ARTICLE

Identifying Predictors of Longitudinal Decline in the Level of Medical Care Received by Adult Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study

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Objectives. Characterize longitudinal changes in the use of medical care in adult survivors of childhood cancer.

Data Sources. The Childhood Cancer Survivor Study, a retrospective cohort study of 5+ year survivors of childhood cancer.

Study Design. Medical care was assessed at entry into the cohort (baseline) and at most recent questionnaire completion. Care at each time point was classified as no care, general care, or survivor-focused care.

Data Collection. There were 6,176 eligible survivors. Multivariable models evaluated risk factors for reporting survivor-focused care or general medical care at baseline and no care at follow-up; and survivor-focused care at baseline and general care at follow-up.

Principal Findings. Males (RR, 2.3; 95 percent CI 1.8–2.9), earning <\$20,000/year (RR, 1.6; 95 percent CI 1.2–2.3) or ≤high school education (RR, 2.5; 95 percent CI 1.6–3.8 and RR 2.0; 95 percent CI 1.5–2.7 for <high school and high school, respectively) were associated with no care at follow-up. Survivors with severe or life-threatening conditions at baseline (RR 0.5; 95 percent CI 0.3–0.6) were less likely to report no care at follow-up.

Conclusions. While the incidence of late effects increases over time for survivors, the likelihood of receiving survivor-focused care decreases for vulnerable populations.

Key Words. Childhood cancer survivors, health insurance, health care access, survivorship, delivery of health care

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The improvement in long-term survival of children with cancer to over 83 percent is one of the major success stories in oncology (Howlader et al. 2013). Consequently, there are more than 360,000 childhood cancer survivors alive in the United States, two-thirds of whom will develop a chronic health problem (late effect) as a result of their cancer and/or its therapy (Hudson et al. 2003; Oeffinger et al. 2006; Geenen et al. 2007; Mariotto et al. 2009; Armstrong et al. 2014; Cox et al. 2014). These late effects include a variety of physical, psychological, and social conditions that result in excess early morbidity and a risk for premature mortality compared to age-matched norms in the general adult population (Zebrack et al. 2002; Wenzel et al. 2005; Gurney et al. 2009; Meadows et al. 2009; Friedman et al. 2010). The Institute of Medicine has advocated that cancer survivors receive lifelong medical care targeted at surveillance, prevention, and treatment of late effects (Hewitt, Weiner, and Simone 2003). We have previously defined the construct of regular medical care with targeted screening, prevention, and treatment of late effects as "survivor-focused care" (Nathan et al. 2008). Receipt of survivor-focused care provides opportunities for early detection and intervention to preserve health. As the cumulative risk for late effects increases as survivors age, an understanding of the factors that influence utilization of medical care over time is necessary to inform strategies that ensure lifelong receipt of survivor-focused care (Armstrong et al. 2009; Mulrooney et al. 2009; Nottage et al. 2011).

A previous study of 8,522 adult survivors of childhood cancer enrolled in the Childhood Cancer Survivor Study (CCSS) revealed that although most survivors (89 percent) reported at least one medical visit within the 2 years

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preceding the survey (completed in 2002–2003), less than one-third of survivors reported a survivor-focused visit (Nathan et al. 2008). Since that survey, several factors were expected to increase the proportion of survivors who receive survivor-focused care. First, because the risk for late effects increases over time, it is likely that survivors with emerging health problems would have increased medical care utilization (American Academy of Pediatrics Section on Hematology/Oncology, and Children's Oncology Group's 2009). Second, in 2003, the Children's Oncology Group (COG) published guidelines that provided recommendations for the care of long-term survivors of childhood cancer (Landier et al. 2004). These guidelines recommend an annual survivor-focused follow-up visit. The COG guidelines were developed as a resource for clinicians who provide long-term care for childhood, adolescent, and young adult cancer survivors and include complementary patient education materials called "Health Links," which were expected to impact health care utilization by increasing survivors' knowledge and awareness of their risks. However, prior cross-sectional studies in the CCSS cohort suggest that survivor-focused medical visits decrease with increasing time from completion of cancer therapy (Oeffinger et al. 2004). In essence, as risk for late effects increases, survivor-focused care appears to decrease. These earlier cross-sectional studies did not allow for identification of factors that predict whether survivors will receive optimal or suboptimal medical care as they age. Knowledge of the factors that predict a decrease in the level of medical care over time is critical as survivors' risk for morbidity and mortality increases as they age. Identification of these risk factors will inform the development and implementation of targeted interventions to address disparities in care.

The purpose of the present study was to characterize longitudinal changes in the use of survivor-focused care in a cohort of adult survivors of childhood cancer enrolled in the CCSS and to explore predictors of decreases in the level of medical care utilized by survivors over time.

METHODS

Childhood Cancer Survivor Study

The methodology and characteristics of participants in the CCSS have been published previously (Robison et al. 2002, 2009; Leisenring et al. 2009). Briefly, the CCSS is a multi-institutional study of individuals who were diagnosed with cancer prior to 21 years, treated at one of 26 collaborating institutions in the United States and Canada between January 1, 1970, and

December 31, 1986, and survived ≥5 years after diagnosis. The Institutional Review Board at all participating institutions approved the study. Informed consent was obtained from each participant.

Survivors were eligible if they had completed the "baseline" CCSS questionnaire administered between 10/1992–12/2002 and at least one follow-up questionnaire (the "2003" questionnaire which was administered between 11/2002–4/2005 and/or the "2007" questionnaire which was administered between 7/2007–11/2009). We excluded subjects who were <18 years at the time of the baseline questionnaire, had incomplete medical care or treatment records, were diagnosed with a second malignant neoplasm, or were deceased at last contact. We analyzed data regarding medical care utilization from the baseline questionnaire and the most recently completed subsequent questionnaire.

Primary Outcome Measures

Levels of Medical Care. The CCSS questionnaires include items that assess the medical care utilized by survivors within the 2 years preceding questionnaire administration. As previously reported, "participants were asked whether they had visited a health care provider (physician or nurse) within the preceding 2 years, whether the visit was related to their previous cancer, and whether their health care provider had given them advice on how to reduce their risks or discussed or ordered screening tests for cancer-related sequelae" (Nathan et al. 2008). Responses to these questions were used to categorize health care into one of three hierarchical and mutually exclusive groups: (1) no health care; (2) general medical care (defined as ≥1 medical visits to a health care provider [e.g., physician, nurse], none of which focused on their previous cancer or surveillance strategies or prevention of late effects); or (3) survivor-focused care (defined as a medical visit related to the prior cancer, or one at which the survivor was counseled about how to reduce risks for late effects or had surveillance tests ordered or discussed). The type of care received was classified independent of provider or the location of care. Study questionnaires are available at http://ccss.stjude.org.

Decrease in Levels of Medical Care. Participants' level of medical care was categorized at two time points—baseline and at the last completed questionnaire. We defined two categories of decreased care: (1) a survivor who reported survivor-focused care or general medical care at baseline but no care at follow-up;

or (2) a survivor who reported survivor-focused care at baseline but general care at follow-up.

Predictors of Decreases in the Level of Medical Care

Demographic and Treatment Variables. Sociodemographic data (gender, income, health insurance, education, and employment status) were obtained from the baseline and most recently completed questionnaire. Health insurance was classified as U.S. insured, Canadian resident, or no health insurance. Based on self-reported race/ethnicity, participants were categorized as non-Hispanic white, non-Hispanic black, Hispanic, or other. Cancer diagnosis and treatment variables were abstracted from medical records.

Baseline Chronic Health Conditions and Health Status. We determined the prevalence and severity of chronic health conditions at baseline to assess the influence of chronic health conditions on health care utilization over time. As previously described, the severity of each chronic health condition was classified according to the National Cancer Institute Common Terminology Criteria for Adverse Events (version 3) as mild (grade 1), moderate (grade 2), severe (grade 3), or life-threatening or disabling (grade 4) (Oeffinger et al. 2006). Health status was assessed at baseline using a previously published set of domains (general health, emotional health; Derogatis 2000; Hudson et al. 2003), physical functioning (Ware and Sherbourne 1992), cancer-related pain, cancer-related anxiety, and fear (Hudson et al. 2003).

Statistical Analysis

We generated descriptive statistics for each of the sociodemographic, cancer diagnosis and treatment, chronic health conditions, health status, and levels of medical care variables at baseline and follow-up. Time-dependent sociodemographic factors were compared between baseline and the last follow-up. Statistical significance was evaluated using a bootstrap technique that takes into account the within-subject correlation between two time points (Efron and Ibshirani 1993). We examined decreased levels of survivor-focused medical care between baseline and the most recent follow-up in two ways. First, among survivors who reported survivor-focused or general care at baseline, we determined the proportion that reported no care at follow-up. Second, among those who reported survivor-focused care at baseline, we determined the proportion that reported general care at follow-up. A backward variable-selection method was employed to build separate summary models describing the independent and simultaneous associations of decreased care with baseline demographic and clinical factors. Multivariable logistic regression models were used to estimate the association between the variables in the final model with the decreased care over time (Savu, Liu, and Yasui 2010). Associations were quantified as odds ratios (OR) with corresponding large-sample 95 percent confidence intervals (CI). We conducted sensitivity analyses using the inverse probability weighting (IPW) technique to evaluate the potential for bias due to nonparticipation (Little and Rubin 2002). Although IPW results differed very little from unadjusted results, the IPW-adjusted results are presented. Statistical analyses were performed using *SAS Version 9.2* (SAS Institute 1996). Two-sided statistical inferences were employed throughout the analyses.

RESULTS

Of the 14,358 childhood cancer survivors who completed the baseline CCSS questionnaire, 7380 were eligible and 6,176 were included in the final analysis (see consort diagram in Figure 1). We found statistically significant differences between those survivors who were eligible for inclusion in the analysis and the nonparticipants, which included the 2,342 who did not complete any follow-up questionnaire (either the 2003 or 2007 CCSS questionnaire) and the 727 survivors who had no medical records. Nonparticipants were more likely to be male, greater than 20 years from diagnosis, non-Hispanic black or Hispanic, less educated, lower income, and uninsured.

Table 1 displays the diagnostic, treatment, and baseline sociodemographic characteristics of the participants. The most recently completed CCSS questionnaire was the 2007 questionnaire by 5,076 (82.2 percent) survivors and the 2003 questionnaire by 1,100 (17.8 percent) survivors. The mean time between the baseline and most recently completed questionnaire was 11.5 years (SD = 2.2) and the median time was 12.3 years (interquartile range = 10.3–13.0). A significant increase was found for the time-dependent characteristic of being insured in the United States (an increase from 80.2 to 83.7 percent, $p < .001$).

These data demonstrated a series of patterns in the receipt of longitudinal medical care. At baseline, of the 6,176 survivors included in the analysis, 696 (IPW proportion: 12.2 percent) reported no medical care, 2,965 (IPW proportion: 47.5 percent) reported general medical care, and 2,515 (IPW proportion: 40.3 percent) reported survivor-focused care. At their most recent follow-up, 473 (IPW proportion: 8.2 percent) reported no medical care, 3,840 (IPW proportion: 61.6 percent) reported general medical care, and 1,863 (IPW proportion: 30.2 percent) reported survivor-focused care. Figure 2 displays the distribution of survivors who reported each level of care at their most recent follow-up, stratified by their level of care at baseline. Of the 5,480 par-

Figure 1: Consort Diagram of Eligible Participants

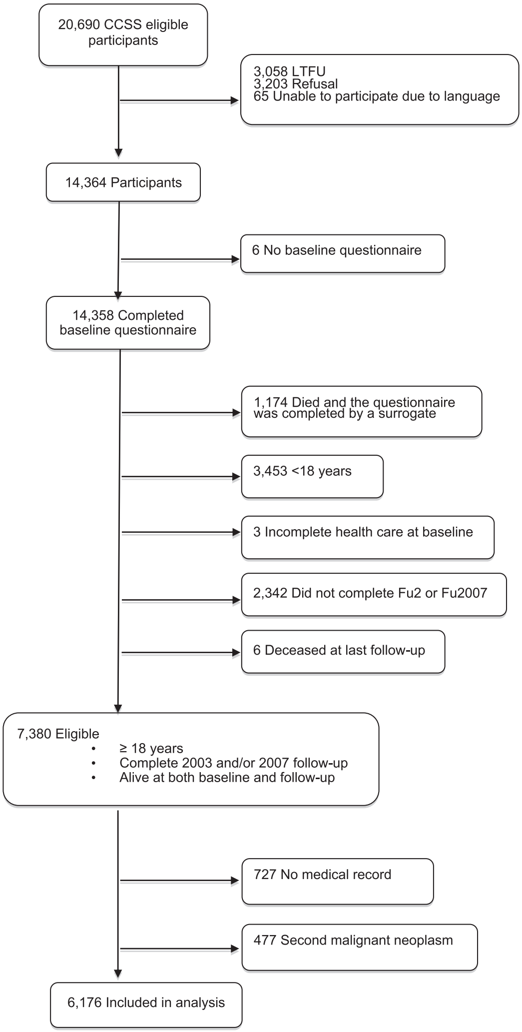


Table 1: Cohort Characteristics at Baseline and Most Recent Follow-Up Questionnaire (2003 or 2007) ($n = 6{,}176$)

	Baseline Questionnaire	*Most Recent Questionnaire*	*p-value**
Age at questionnaire			
Mean ± SD	27.1 ± 6.0	38.6 ± 6.2	
Median	26.3	38.0	
Range	18.0–48.0	23.5–58.9	
Age at diagnosis			
Mean ± SD	9.9 ± 5.6		
Gender, *N* (%)			
Male	3,227 (52.3)		
Female	2,949 (47.7)		
Race/Ethnicity, *N* (%)			
Non-Hispanic white	5,592 (90.8)		
Non-Hispanic black	162 (2.6)		
Hispanic	246 (4.0)		
Other	156 (2.5)		
Health insurance status, *N* (%)			
Yes, United States	4,875 (80.2)	5,157 (83.7)	<.001
No, United States	859 (14.1)	621 (10.1)	
Canadian resident	348 (5.7)	384 (6.2)	
Current annual household income, *N* (%)			
<$20,000	1,159 (20.7)	659 (11.4)	<.001
$20,000–$39,999	1,668 (29.8)	1,065 (18.4)	
$40,000–$59,999	1,254 (22.4)	1,069 (18.4)	
$60,000+	1,519 (27.1)	3,009 (51.9)	
Education (highest level of attainment), *N* (%)			
<High school	523 (8.9)	198 (3.2)	<.001
High school	3,328 (56.9)	2,731 (44.3)	
College graduate	2,000 (34.2)	3,234 (52.5)	
Current employment status, *N* (%)			
Employed	5,379 (88.2)	4,721 (76.5)	<.001
Unemployed	723 (11.8)	1,451 (23.5)	
Cancer diagnosis, *N* (%)			
Leukemia	1,915 (31.0)		
CNS tumor	794 (12.9)		
Hodgkin lymphoma	960 (15.5)		
Non-Hodgkin lymphoma	559 (9.1)		
Wilms tumor	431 (7.0)		
Neuroblastoma	248 (4.0)		
Sarcoma	604 (9.8)		
Bone tumor	665 (10.8.)		
Radiation therapy (RT), *N* (%)			
Both brain and chest	113 (1.8)		
Brain only	1,889 (30.6)		

Continued

Table 1 *Continued*

	Baseline Questionnaire	*Most Recent Questionnaire*	*p-value**
Chest only	1,188 (19.2)		
RT, but not brain or chest	1,019 (16.5)		
RT, but brain/chest RT status unknown	128 (2.1)		
No RT	1,839 (29.8)		
Cardiotoxic therapies, *N* (%)			
Anthracyclines, no chest RT	1,793 (29.0)		
Chest RT, no anthracyclines	868 (14.1)		
Anthracyclines + chest RT	432 (7.0)		
No anthracyclines, no chest RT	2,950 (47.8)		
Missing	133 (2.2)		
Alkylating agent dose, *N* (%)			
None	3,043 (49.3)		
First tertile	1,166 (18.9)		
Second tertile	852 (13.8)		
Third tertile	560 (9.1)		
Missing	555 (9.0)		

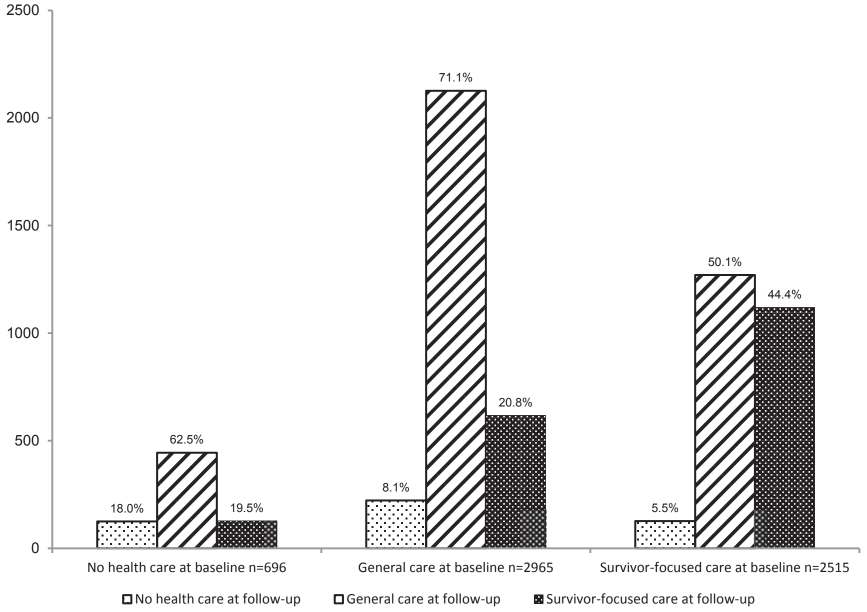
**p*-value for comparison of distribution between baseline and most recent questionnaire.

ticipants who reported survivor-focused or general care at baseline, 348 (IPW proportion: 6.9 percent) reported no care at their most recent follow-up. Of the 2,515 survivors who reported survivor-focused care at baseline, 1,396 (IPW proportion: 55.6 percent) reported a lower level of care at follow-up, 1,270 (IPW proportion: 50.1 percent) reported general care, and 126 (IPW proportion: 5.5 percent) reported no care.

Table 2 presents the final multivariate model describing the association between baseline factors and the likelihood that survivors who reported some form of medical care at baseline (either survivor-focused or general) would report no medical care at follow-up. Results adjusted for potential bias due to differential nonparticipation using the IPW method are presented here and in Table 3. Among survivors, male sex, an annual household income of <\$20,000/year, and ≤high school education at baseline were independently associated with an increased risk of reporting no care at follow-up. In contrast, survivors who reported any chronic health condition at baseline were less likely to report no care at follow-up.

Factors independently associated with the likelihood that patients who reported survivor-focused care at baseline were receiving general care at follow-up are provided in Table 3. Uninsured survivors were more likely to report a reduction from survivor-focused to general care. Survivors who

Figure 2: Number of Survivors Reporting Each Level of Care at Follow-Up Stratified by Level of Care at Baseline



reported a physical limitation, decreased emotional health or pain at baseline, had a chronic health condition at baseline, or received radiation were less likely to report a decrease in care from survivor-focused to general care.

DISCUSSION

In this study, we characterized the longitudinal patterns of medical care received by more than 6,000 adult survivors of childhood cancer over an average of 12 years. There were several notable findings that extend the observations of previously published cross-sectional studies on medical care utilization among childhood cancer survivors (Oeffinger et al. 2004; Skinner, Wallace, and Levitt 2006; Nathan et al. 2008). At entry into the CCSS cohort, almost 90 percent of survivors reported having received medical care within the preceding 2 years. By their most recent follow-up, 6.9 percent of these survivors reported that they were no longer receiving regular medical care of any kind. Survivors who were male, had a low household income, or limited

Table 2: Multivariable Model of the Likelihood of Reporting a Decrease from Survivor-Focused or General Care Baseline to No Care at Most Recent Follow-Up*,†

Baseline Predictor Variables	*OR§ (95% CI)*	*p-value*
Gender		
Male	2.3 (1.8–2.9)	<.001
Female	Ref	
Race/ethnicity		
Non-Hispanic white	Ref	
Non-Hispanic black	1.6 (0.9–2.9)	.14
Hispanic	1.3 (0.7–2.2)	.40
Other	2.1 (1.2–3.7)	.01
Current annual household income		
<$20,000	1.6 (1.2–2.3)	.005
$20,000–$39,999	1.4 (1.0–1.9)	.07
$40,000–$59,999	1.0 (0.7–1.4)	.84
$60,000+	Ref	
Chronic disease status‡		
Grade 3–4	0.5 (0.3–0.6)	<.001
Grade 1–2	0.7 (0.5–0.9)	.004
Grade 0	Ref	
Education		
<High school	2.5 (1.6–3.8)	<.001
High school	2.0 (1.5–2.7)	<.001
College graduate	Ref	

*n = 2,965 general care at baseline, 2,515 survivor-focused care at baseline; among them 348 became no care.

†Age at diagnosis, years since diagnosis, gender, race, insurance, income, education, ever had a job, general health, anxiety due to cancer, physical limitation, cancer pain, emotional health, chronic disease status, RT status, alkylating agent score, and anthracycline dose are all candidates of the model. Backward selection resulted in a model containing only the variables shown in the table.

‡At baseline, the severity of chronic health conditions reported by participants was scored according to NCI Common Terminology Criteria of Adverse Events version 3.

§Results from analyses were adjusted using IPW to account for potential bias due to nonparticipation.

education were at particular risk for receiving no medical care at follow-up, highlighting the impact that socioeconomic status has on access to and use of appropriate medical care. Survivors who reported no morbidity at baseline were also at risk for no longer receiving regular medical care, despite their well-established elevated risks for morbidity and mortality. This is unfortunate and indicates potentially missed opportunities for implementation of proactive risk-reducing interventions in asymptomatic survivors.

Table 3: Multivariable Model of the Likelihood of Reporting a Decrease from Survivor-Focused Care at Baseline to General Care at Most Recent Follow-Up*,†

Baseline Predictor Variables	*OR¶ (95% CI)*	*p-value*
Gender		
Male	1.3 (1.0–1.5)	.01
Female	Ref	
Years since diagnosis		
<10 years	1.3 (0.9–1.8)	.21
10–<15 years	1.4 (1.1–1.8)	.01
15–<20 years	1.4 (1.1–1.8)	.009
20+ years	Ref	
Health insurance status		
Yes, United States	Ref	
No, United States	1.6 (1.2–2.1)	.003
Canadian resident	0.8 (0.6–1.0)	.07
Physical limitation		
Yes	0.7 (0.5–0.9)	.002
No	Ref	
Poor emotional health‡		
Yes	0.6 (0.4–0.9)	.006
No	Ref	
Pain		
Adverse outcome	0.8 (0.6–1.0)	.07
No adverse outcome	Ref	
Chronic disease status§		
Grade 3–4	0.6 (0.5–0.7)	<.001
Grade 1–2	0.6 (0.5–0.8)	<.001
Grade 0	Ref	
Radiation therapy		
Both brain and chest	0.3 (0.2–0.7)	.001
Brain only	0.6 (0.4–0.7)	<.001
Chest only	0.4 (0.3–0.6)	<.001
RT, but not site brain or chest	0.6 (0.5–0.8)	<.001
Had RT but site for brain/chest unknown	0.4 (0.2–0.8)	.004
No RT	Ref	

*n = 2,515 survivor-focused care at baseline, among them, 1,270 became general care, 1,119 remained survivor-focused care, and 126 became no care.

†Age at diagnosis, years since diagnosis, gender, race, insurance, income, education, ever had a job, general health, anxiety due to cancer, physical limitation, cancer pain, emotional health, chronic disease status, RT status, alkylating agent score, and anthracycline dose are all candidates of the model. Backward selection resulted in a model containing only the variables shown in the table.

‡GSI of ≥63 from the BSI, BSI = Brief Symptom Inventory-18; GSI: General Sensitivity Index (Derogatis 2000).

§At baseline, the severity of chronic health conditions reported by participants were scored according to NCI Common Terminology Criteria of Adverse Events version 3.

¶Results from analyses were adjusted using IPW to account for potential bias due to nonparticipation.

Uninsured survivors were at risk for a decrease in their level of care from survivor-focused care to general care over time. The importance of maintaining health insurance, particularly among those who are socially disadvantaged, is a timely finding given the passage of the Affordable Care Act in the United States in 2010. Research among adults with cancer, including data from the U.S. National Health Interview Survey (Weaver et al. 2010), demonstrates that cost is a significant barrier to receiving appropriate medical care, even among survivors with health insurance (American Cancer Society 2008; Finkelstein et al. 2009; Tangka et al. 2010). The Affordable Care Act includes key provisions that ensure access to care that is affordable, prohibits health insurers from charging different rates based on medical histories or gender, does not allow insurers to deny coverage for preexisting conditions, and allows young adults to remain on their parent's health insurance plans until 26 years of age. These provisions are expected to benefit young adult survivors of childhood cancer directly and will hopefully ameliorate some of the observed disparities in care (Senate and House of Representatives of the United States of America 2010; Park et al. 2012).

The Institute of Medicine and international groups have strongly endorsed the need for the long-term care of survivors to include regular surveillance and prevention strategies focused on the specific risks arising from their prior cancer and its treatment (Hewitt, Weiner, and Simone 2003; Skinner, Wallace, and Levitt 2006; Blaauwbroek et al. 2008; Kremer et al. 2013). At baseline, only 40 percent of survivors in the cohort reported receiving such survivor-focused care. Despite our expectation that need for such care would increase as survivors aged and new late effects emerged, and the publication of guidelines for the care of survivors in North America and elsewhere, only 30 percent of the cohort continued to receive survivor-focused care at their most recent follow-up (Skinner, Wallace, and Levitt 2006; Kremer et al. 2013). Most of those who no longer reported survivor-focused care were still engaged with the medical system and reported receiving general medical care within the preceding 2 years. This finding suggests that rates of survivor-focused care might be improved through better partnerships with primary care physicians in survivors' communities. In fact, two studies that surveyed a random sample of North American internists and family physicians assessed their comfort with knowledge regarding the care of childhood cancer survivors and revealed that although these physicians were willing to care for survivors, they were generally unfamiliar with the guidelines for survivor care. Among those that had one or more survivors in their practice, most had not received a treatment summary or care plan from the treating cancer center that outlined the necessary surveillance and health promotion counseling. (Nathan et al. 2013; Suh et al. 2014) Primary care providers have been shown to value the receipt of a treatment summary/survivorship care plan. One study demonstrated that summaries increase primary care providers' knowledge about survivors' cancer histories and recommended surveillance care and positively influence patient care (Shalom et al. 2011). Our findings build upon this research and suggest several opportunities for future research and program development. These include conducting randomized clinical trials assessing the impact that treatment summaries/survivorship care plans have on patient and provider reported outcomes for childhood cancer survivors, similar to those studies that have been conducted successfully conducted in adult cancer survivor populations (Grunfeld et al. 2011; van de Poll-Franse et al. 2011). Implementing core competency training for primary care providers that includes survivorship care might also increase comfort and knowledge, and would leverage new educational and other resources that have become available for general practitioners (National Cancer Survivorship Resource Center 2014; Nekhlyudov and Wenger 2014). The American Society of Clinical Oncology and other professional societies have published recommendations on how to expand and coordinate educational offerings for medical professionals in areas that are essential to survivorship care (McCabe et al. 2013). Lastly, development of interventions that focus on effective patient-centered communication and shared decision making between the provider and the cancer survivor have been shown to improve the quality of cancer care for survivors (Epstein and Street 2007; Nekhlyudov and Wenger 2014).

Those patients with poor emotional health, physical limitations, anxiety about their prior cancer, or the presence of a chronic medical condition at baseline were more likely continue receiving survivor-focused care, suggesting that existing physical or psychological sequelae of the childhood cancer are the primary drivers of the receipt of survivor-focused care. As the risk for late effects and premature mortality increases without apparent plateau as survivors age (Ganame et al. 2008; Nathan et al. 2008; Armstrong et al. 2009; Castellino et al. 2011; Nagarajan et al. 2011; Oeffinger et al. 2011), it is vital that strategies be developed to ensure that survivors who are well at the time they enter adulthood continue to engage in survivor-focused care. These asymptomatic survivors need to be equipped with tools that allow them to understand their prior cancer therapy and its long-term risks, and that empower them to seek appropriate care and engage in health promoting behaviors (Hewitt, Weiner, and Simone 2003; Hewitt, Sheldon, and Stovall 2005; Underwood et al. 2012).

Similar to the findings above targeting interventions to improve providers' knowledge of survivorship care, patient-centered care research in young adult cancer survivors has demonstrated that the receipt of a survivorship care plan is associated with the survivors reporting increased confidence in seeking appropriate medical care (Casillas et al. 2011). Among survivors of childhood Hodgkin lymphoma, receipt of a one-page cancer survivorship care plan was shown to improve compliance with recommended screening (Oeffinger et al. 2011). Consequently, there are ongoing efforts in the United States and in Canada to ensure that all cancer survivors receive a survivorship care plan prior to transition out of the pediatric cancer environment, including a mandate from the Commission on Cancer by the American College of Surgeons (ACoS) that will make the provision of a survivorship care plan a mandatory requirement for accreditation as a cancer center in 2015 (Hewitt, Weiner, and Simone 2003; Hewitt, Sheldon, and Stovall 2005; Ganz, Casillas, and Hahn 2008; Stricker et al. 2011; Fashoyin-Aje, Martinez, and Dy 2012). It is recognized that the new survivorship care plan requirement from the Commission on Cancer is less applicable to free-standing children's hospitals serving childhood cancer survivors. However, for those Cancer Centers that care for survivors of both pediatric and adult malignancies, this requirement will impact the delivery of patient-centered care. Currently, only a minority of young adult cancer survivors report receiving such plans even when cared for within cancer centers (Casillas et al. 2011; Nathan et al. 2013; Suh et al. 2014).

The findings of this study should be interpreted in the context of using self-reported data to classify medical care. Survivors who developed late effects of their therapy may be more likely to identify health care visits as being related to their prior cancer history. Survivors without any late effects may not have recognized that their medical care provider was adapting their visit to their prior cancer history resulting in an underestimation of the frequency of survivor-focused care by some participants. Future work exploring the correlation between the individual survivor's knowledge regarding survivorship care to influence his or her willingness and actual receipt of recommended survivorship screening or health promotion is an important area for future investigation.

We identified differences between participants in the study and those who were nonparticipants. The cohort's members represent a group that is more likely to have health insurance, to be educated, and to be employed when compared to nonparticipating survivors. Although we accounted for this by applying IPW in our analysis, our results may not be completely generalizable to the broader population of childhood cancer survivors. However, given this is one of the largest cohorts of long-term childhood cancer survivors and the first to identify predictors of a longitudinal decline in the level of medical care received by adult survivors of childhood cancer, these findings will inform the development of targeted interventions to improve the long-term rates of survivor-focused care and eliminate disparities in access to needed care.

CONCLUSIONS

While the incidence of chronic health conditions is increasing, less than a third of adult survivors of childhood cancer report regular survivor-focused care with rates of such care decreasing over time among specific vulnerable populations. Survivors who have significant chronic health conditions or psychological sequelae of their cancer are more likely to report receiving appropriate care. In contrast, survivors with low income and education levels may fail to receive any medical care at all. Uninsured survivors are at particular risk for having a decrease in their level of care from survivor-focused care to general care over time. Targeted interventions, such as transition planning visits and the provision of survivorship care plans created by the oncology team, will empower survivors to be knowledgeable health care consumers. Such interventions will be particularly important for at-risk populations so that preventive and risk-reducing opportunities are not lost. Future research exploring the impact of not having survivor-focused care on morbidity and mortality is an important area for future investigation.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article:

Appendix SA1: Author Matrix.