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Supporting long-term follow-up of young adult survivors of childhood cancer: Correlates of healthcare self-efficacy

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Abstract

Background—Healthcare self-efficacy (HCSE), the perceived confidence to manage one's health care, has been identified as a critical component in the transition process from pediatric to adult-oriented care for childhood cancer survivors (CCSs). HCSE is amenable to intervention and associated with long-term follow-up care among CCSs. However, factors associated with HCSE have not been fully explored among CCSs.

Procedure—We identified correlates of HCSE among a sample of CCSs (n = 193). Descriptive statistics and linear regression methods were used in this cross-sectional analysis.

Results—In univariate analyses, higher physical and psychosocial quality of life, posttraumatic growth, and religious/spiritual importance were associated with higher HCSE. Attendance at a survivorship clinic, having a regular source of care (both noncancer and oncologist), and any type of health insurance were also associated with HCSE. Hispanic ethnicity was negatively associated with HCSE relative to non-Hispanics. In a multivariable model, psychosocial quality of life, religious/spiritual importance, survivorship clinic attendance, having a regular oncologist, and Hispanic ethnicity remained significantly associated with HCSE.

Conclusions—CCSs who reported greater well-being, who rated religion and spirituality of high importance, and who accessed specialized cancer services expressed greater HCSE. Hispanic CCSs, however, reported less HCSE than non-Hispanics. Interventions that attend to the quality of life and spiritual needs of CCSs have potential to build HCSE to support the healthcare transition process. Because Hispanic CCSs may be at risk of lower perceived confidence to navigate their health care, culturally competent, efficacy-enhancing interventions are needed for this population.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

Keywords

adolescent; cancer; child; self-efficacy; survivorship; young adult

1 INTRODUCTION

Long-term follow-up (LTFU) care is critical to the well-being of childhood cancer survivors (CCSs). Recommended guidelines call for lifelong risk-based surveillance for detection of late-onset complications resulting from cancer treatment.¹ However, the majority of CCSs do not engage in LTFU care despite the proliferation of dedicated survivorship clinics.^{2,3} Less than one third of young adult CCSs report attending survivor-focused care,⁴ and these figures decline as time from treatment increases.³ The suboptimal uptake of LTFU results in missed opportunities for early detection of late effects and delivery of secondary preventive interventions, health education, and psychosocial support to enhance survivor well-being.

An important determinant of engagement in LTFU is transfer from the pediatric to adult-oriented care setting that is accomplished through successful healthcare transition.^{5,6} For older adolescent and young adult (AYA) CCS, the process of survivorship care transition presents significant challenges, in part because it coincides with other developmental transitions of emerging adulthood that influence the acquisition of skills necessary for independent healthcare self-management. Barriers to transition include emotional dependence on family and/or pediatric providers, financial and insurability issues as young adults age out of parental coverage, and difficult psychosocial adjustment to life posttreatment.^{7,8} In addition, health beliefs including a personal sense of responsibility for one's health and perceived risk for late term effects influence engagement in LTFU.⁹⁻¹¹

Healthcare self-efficacy (HCSE), the sense of confidence in one's ability to manage their own health care, is a critical concept to the successful transition of late adolescents and young adults to adult-oriented care.¹¹ As CCSs transition from adolescence to early adulthood, their belief in their own capabilities to navigate the healthcare system and achieve appropriate care may increase their utilization of healthcare services.¹¹ The relationship between HCSE and postcancer follow-up care has been examined among adult survivors, where it has been positively associated with healthcare follow-up and optimal self-management behaviors.¹² Among survivors of AYA cancer (those diagnosed between the ages of 15 and 39 years), better survivorship care planning (e.g., receipt of a written treatment summary and risk-based care plan) has been found to increase HCSE.^{13,14}

Among CCSs, greater self-efficacy has been positively associated with follow-up care.¹⁵ However, factors that may influence HCSE have not been fully explored among young, recently treated survivors of childhood cancer. Understanding those variables salient to survivors' self-confidence to navigate their health care may guide future interventions and support successful transition for this population, thereby increasing engagement in recommended LTFU care.

The aim of the present study was to identify key correlates of HCSE among a sample of Hispanic and non-Hispanic CCSs in the early phases of survivorship follow-up. We focused

on both physical and psychosocial characteristics of survivors. Our hypothesis was that greater emotional and physical well-being may increase CCSs' perceived capability and sense of confidence to navigate adverse or challenging circumstances.¹⁶

We additionally hypothesized that, as with older AYA survivors, better survivorship care planning and other healthcare access measures such as having a regular source of care (primary care physician and/or oncology specialist) would be associated with greater self-efficacy among CCSs. Finally, we hypothesized that Hispanic CCSs would have lower HCSE relative to non-Hispanic CCSs. As Hispanic CCSs have been found less likely to access follow-up care,¹⁵ lower perceived confidence to independently navigate the healthcare system may potentially contribute to this disparity in LTFU.

2 METHODS

Data from the Project Forward pilot study were used for the present analysis, comprising a cohort of CCSs diagnosed with any type of cancer from two large pediatric medical centers in Los Angeles County (n = 193). Patients with Hodgkin lymphoma were excluded because these patients were included in another registry study, and cancer surveillance program policies prohibit enrollment of cases to more than once study to reduce patient burden. Participants were diagnosed between the ages 5 and 18 years and were between 15 and 25 years at the time of data collection; all participants were 2 or more years from treatment for their cancer. Study procedures have been described elsewhere,¹⁵ briefly, CCSs were identified through the Los Angeles Cancer Surveillance Program, the Surveillance, Epidemiology, and End Results (SEER) Cancer Registry covering Los Angeles County, and were mailed a survey to complete. After extensive follow-up efforts, the recruitment rate for the study was 50%, comparable to or exceeding similar studies.¹⁷ No differences were found between respondents and nonrespondents in comparisons of registry data for age, race/ethnicity, or clinical variables. Only sex and socioeconomic status of census tract of residence were found to be significantly different, with females more likely to respond to the survey than males, and those from higher income areas more likely to respond than those from lower income areas. The study was approved by the California Committee for the Protection of Human Subjects, the California Cancer Registry, and the Institutional Review Boards at the University of Southern California and both pediatric hospitals.

2.1 Outcome measure

2.1.1 Healthcare self-efficacy—The HCSE scale was adapted from the Stanford Patient Education Research Center Chronic Disease Self-Efficacy scales.¹⁸ The scale included three items related to survivors' perceived confidence in discussing concerns with their physicians, making appointments with physicians, and obtaining cancer follow-up care in the next 2 years (Table 1). Responses comprised a three-point Likert-type scale ranging from "not confident/not sure" to "very confident." Items were summed to form a continuous composite score (ranging from 3 to 9), with higher scores indicating greater HCSE. Cronbach alpha for this sample was 0.64.

2.2 Independent variables

2.2.1 Survivorship care planning/regular source of care—Participants were asked four items to ascertain survivorship care planning and whether they had a regular source of care. Items included survivors' attendance at any survivorship clinic, receipt of a written summary of their cancer treatment, whether they had a physician for regular noncancer treatment (e.g., primary care physician), and a physician for cancer follow-up care (oncology specialist). All items were dichotomized (yes/no).

2.3 Psychosocial characteristics

2.3.1 Health-related quality of life—Health-related quality of life (HRQOL) was assessed with the Pediatric Quality of Life Inventory (PedsQL), a validated scale measuring HRQOL in pediatric patients.^{19,20} The Young Adult version of the PedsQL was used to ensure age-appropriate measures for this sample of later AYAs. For the present analysis, the Physical Health Summary and Psychosocial Health Summary Scores were used. The Physical Health Summary Score is an eight-item scale assessing physical functioning and the Psychosocial Health Summary Scores is a 15-item scale comprising the average of three subscales (Emotional, Social, and School Functioning). Items are reverse coded on a scale from 0 to 100, with higher scores indicating higher HRQOL. Cronbach alpha for this sample was 0.88 for the Physical Health Summary Score and 0.93 for the Psychosocial Health Summary score.

2.3.2 Posttraumatic growth—The Post-Traumatic Growth Inventory (PTGI) short form is a 10-item measure of personal growth experienced by individuals who have undergone a traumatic event, in this case cancer.²¹ Items reflect different areas of growth, including relating to others, new possibilities, personal strength, spiritual change, and appreciation of life. Responses are based on a six-point scale ranging from 0 ("I did not experience this change") to 5 ("I experienced this change to a very great degree"). A total PTGI mean score was calculated, with higher scores indicating greater posttraumatic growth. Cronbach alpha for this sample was 0.90.

2.3.3 Religious/spiritual importance—Religious and/or spiritual importance was assessed with a single-item question asking participants "how important is your religion or spirituality to you?" Scores were dichotomized as "don't know/not important" versus "somewhat/very important."

2.3.4 Social support—Social support was assessed by a single item that asked participants to indicate how many people they could count on for help. Scores were recorded on a three-point ordinal scale ranging from "none" to "three or more" and used as a continuous measure, with higher scores indicating greater social support.

2.3.5 Family involvement with health care—Parental involvement with survivor's health care was assessed with a single item that asked participants how often their family had influenced their healthcare decisions. Scores were recorded on a four-item Likert-type scale (often, occasionally, never, not sure) and dichotomized to reflect family participation (1, often/occasionally) versus nonparticipation (0, never/not sure) in healthcare decisions.

2.4 Clinical factors

The number of years between diagnosis and completion of the survey was obtained by using the diagnosis date from the cancer registry and the date the survey was returned. Intensity of prior cancer treatment was categorized using the Intensity of Treatment Rating Scale 2.0 (ITR-2),²² a validated scale derived from cancer registry data and medical chart review. Treatment was categorized by four levels of intensity: 1 = least intensive (e.g., surgery only), 2 = moderately intensive (e.g., chemotherapy or radiation), 3 = very intensive (e.g., two or more treatment modalities), and 4 = most intensive (e.g., regimens for relapsed disease including hematopoietic cell transplantation).

2.5 Covariates

Covariates included current age at time of survey, ethnicity (Hispanic vs. non-Hispanic), sex, and health insurance status. Current age was dichotomized as less than 21 years and 21 years or older, as this distinction represents the age of transfer from pediatric to adult-centered healthcare providers at the study sites. Health insurance status was dichotomized as any health insurance (public or private) versus no insurance coverage.

2.6 Statistical Analysis

Descriptive statistics including frequencies and correlations were conducted between independent variables and the outcome variable, HCSE. Univariate and multivariable linear regression analyses were performed to assess factors associated with the outcome variable. Variables that were associated with the outcome at P less than 0.10 in univariate analyses were selected for inclusion in the multivariable linear regression model. The final model included both HRQOL scales, posttraumatic growth, social support, religious and spiritual importance, attendance at a survivorship clinic, regular cancer and non-cancer providers, ethnicity, and health insurance status. Although non-significant in the univariate model, current age and sex were included in the multivariable model, as these covariates are of theoretical importance in the relationship between the exposure variables and HCSE. The level of significance was set to alpha less than 0.05 and tests were two-sided. All analyses were conducted using SAS statistical software (Version 9.4) (SAS Institute, Cary, North Carolina).

3 RESULTS

3.1 Selected characteristics of sample

Sociodemographic data are presented in Table 2. Roughly half of respondents were female and nearly 60% were below 21 years of age, with a median age of 21 years. Fifty-four percent of CCSs surveyed were Hispanic, reflective of population demographics in Los Angeles County. A quarter of the respondents reported attending a survivorship clinic, and a third had received a treatment summary. Over 80% reported some type of health insurance, and two-thirds had a usual source of care, including a cancer provider and a noncancer provider. Mean, median, and standard deviation (SD) for all continuous scaled variables in this study have been reported elsewhere,^{15,23} save social support, which had mean $\pm$ SD of 1.5 ± 0.60 and a median of 2.

3.2 Univariate analyses

In univariate analyses, higher HCSE was positively associated with both physical and psychosocial HRQOL, posttraumatic growth, religious and spiritual importance, attendance at survivorship clinic, having a regular source of care (both cancer and noncancer providers), and any type of insurance (Table 3). Greater social support showed a trend toward a positive association with higher HSCE but fell short of statistical significance ($P = 0.051$). Similarly, Hispanic ethnicity relative to non-Hispanic showed a trend toward a negative association with higher HSCE but fell short of statistical significance ($P = 0.052$). HCSE was not associated with receiving a treatment summary, years since diagnosis, or treatment intensity.

3.4 Multivariable analyses

In the multivariable model, psychosocial HRQOL, but not physical, remained significantly associated with HCSE, as did religious and spiritual importance (Table 3). Attendance at a survivorship clinic and having a regular cancer provider remained significant, but having a noncancer provider did not retain significance in the adjusted model. Hispanic ethnicity was significantly negatively associated with HSCE in the multivariable model.

4 DISCUSSION

The present study examined factors associated with HCSE in CCSs who were 2–10 years postdiagnosis. We hypothesized that greater physical and emotional well-being, better survivorship planning, and a regular source of physician care would be associated with higher HCSE, and that Hispanic CCS would have lower HCSE relative to non-Hispanics. Our results confirm that higher HRQOL is associated with greater HCSE, although only psychosocial rather than physical quality of life was a significant correlate in the adjusted model. HCSE has been associated with enhanced quality of life among adult cancer patients,²⁴ and efficacy-enhancing interventions may improve well-being by empowering patients to self-manage their care.^{12,25} Such effects may be more relevant to psychosocial quality of life for younger CCSs who may not yet have experienced significant adverse late effects of treatment leading to physical limitations.²⁶

Spirituality and/or religiosity were associated with higher HCSE, a finding consistent with prior research concerning psychological adjustment, coping, and quality of life.²⁶ As Peteet et al.²⁶ have detailed, religion and spirituality, both independently and as a combined concept, support survivors' sense of self, engender hope, maintain meaning and life purpose, and promote connectedness to others. While spiritual support may be more commonly found in palliative care,²⁷ attending to spiritual or religious needs may also play a role in supporting the transition process by bolstering qualities that better prepare survivors for personal responsibility and self-care. Such care need not necessarily be faith-based; for nonreligious CCSs, spiritual care may involve mindfulness, meditation, or spiritual counseling.²⁶

We observed that attending a survivorship clinic was associated with greater self-efficacy for CCSs, but receipt of a written treatment plan was not. While provision of a treatment summary has been found effective in motivating LTFU among older CCSs,²⁸ such

summaries may not yet be relevant to younger CCSs who comprise the present study population, particularly if they are still under care from an oncologist. Because many survivorship clinics offer transition services, they may be well-positioned to enhance HCSE. However, the majority of survivors do not attend such clinics, with only 24% reporting survivorship clinic attendance in the present study, a figure consistent with previous reports.⁴ While increasing survivorship clinic attendance may be an important focus for increasing greater HCSE leading to improved follow-up care, development of innovative, potentially more effective models may also be warranted to build self-confidence among survivors, such as personalized self-management tools (e.g., eHealth) that may efficiently adapt to patient norms, preferences, or lifestyles and serve as a means for overcoming barriers of geographic distance and access to conventional clinic-based survivorship care.²⁹

Having a usual source of care was associated with increased HCSE for CCSs. However, having a regular oncologist, rather than noncancer physician, emerged as significant in the adjusted analysis. While the strong bonds formed between CCSs and their oncologists may increase confidence in healthcare self-management,⁵ pediatric generalists or primary care providers acknowledge limited mastery of cancer survivorship issues³⁰ and specialized transition services may be lacking, leaving CCSs feeling less connected, less supported, and less confident in their healthcare self-management. As survival continues to improve and the prevalence of adult CCSs increase, primary care physicians will need to play an enhanced role in caring for this population.^{31,32} Thus further research is needed to investigate how generalist physicians can enhance CCS self-efficacy to facilitate optimal longitudinal survivorship care.

Finally, we observed lower healthcare self-confidence among Hispanics relative to non-Hispanic CCSs, a finding that accords with previous research among primarily posttransition (AYA) cancer survivors.¹³ The causes for lower self-confidence among Hispanics are likely multifactorial: Hispanic cancer patients and survivors report worse experiences with the healthcare system than non-Hispanics, including poorer coordination of and access to care, less confidence in their providers, and poorer patient-provider communication.^{33,34} In addition, recently treated Hispanic CCSs report greater levels of depression and lower HRQOL,³⁵ which could adversely affect their perceived confidence to manage their health care. Thus, the key to improving HCSE and follow-up care adherence for Hispanic CCSs may necessitate addressing upstream factors related to the healthcare delivery system, for example, provision of culturally competent care, as well as more proximal factors such as psychosocial assessment for symptoms of depression or reduced quality of life.

The current study has limitations, including a cross-sectional design that limits conclusions to associations and not causality. A longitudinal study is needed to determine how the correlates identified here influence survivors' HCSE over time. Patients from only two major treating hospitals in Los Angeles were included in the study, and Hodgkin lymphoma patients were excluded, which may limit the generalizability of the results. Response bias may have affected our results, with individuals with higher HCSE more likely to respond to the survey than those with lower HCSE. If so, our results may not fully capture variables important for survivors with low HCSE. In addition, Hispanics are a heterogeneous population, and this study did not collect data on more nuanced discriminators such as

birthplace, country of origin, or details concerning specific religious/spiritual beliefs. Finally, this study was set in the context of U.S. health care before the implementation of the Affordable Care Act, which differs from other international models. Thus, the findings of this study may be most pertinent for young adult survivors navigating the U.S. health care delivery system.

Strengths of the study include a large proportion of Hispanic CCSs, a consistently underrepresented population in cancer survivorship studies, as well as a recruitment rate (50%) that is comparable to or exceeding similar studies.¹⁵

In summary, we identified several key correlates of HCSE that may guide development of efficacy-enhancing interventions for CCSs. Future work should delineate the unique services provided by survivorship clinics and oncologists that may foster this confidence. At the individual level, integrating services that address both psychosocial quality of life and religious/spiritual importance may also benefit HCSE. We also conclude that Hispanic CCSs who reported low levels of HCSE and demonstrate lower cancer-related follow-up care may need targeted or prioritized, culturally competent interventions to improve healthcare confidence.

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Abbreviations

AYA	adolescent and young adult
CCS	childhood cancer survivor
HCSE	healthcare self-efficacy
HRQOL	Health-related quality of life
ITR-2	Intensity of Treatment Rating Scale 2.0
LTFU	long-term follow-up
PedsQL	Pediatric Quality of Life Inventory
PTGI	Post-Traumatic Growth Inventory
SEER	Surveillance, Epidemiology, and End Results

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TABLE 1

HCSE items

	Mean (SE)
How confident are you that you could ask your doctor about things that concern you?	1.64 (0.04)
How confident are you that you could make your own doctor's appointments or decide when you needed care?	1.32 (0.06)
How confident are you that you could get the cancer follow-up care you need over the next 2 years?	1.17 (0.06)

Response options on a Likert-type scale were: (1) not confident, (2) confident, (3) very confident.

TABLE 2

Selected characteristics of sample (n = 193)

	n	%
Age at survey completion		
15–20 years	114	59.10
21–25 years	79	40.93
Gender		
Female	96	49.7
Male	97	50.26
Ethnicity		
Hispanic	105	54.40
Non-Hispanic white	88	45.60
Attendance at survivorship clinic		
Yes	47	24.35
No	146	75.65
Written treatment summary		
Yes	65	33.85
No	127	66.15
Any health insurance		
Yes	154	81.05
No	36	18.95
Regular cancer provider		
Yes	123	64.74
No	67	35.26
Regular noncancer provider		
Yes	124	64.58
No	68	35.42

TABLE 3

Univariate and multivariable models of correlates of health-related self-efficacy among CCSs (n = 193)

	Univariate b (SE)	Multivariable b (SE)
<i>Demographics</i>		
Age group >21 years (ref: <21 years)	−0.17(0.20)	0.11(0.22)
Sex (ref, male)	−0.05 (0.19)	0.01 (0.18)
Hispanic (ref, non-Hispanic)	−0.38 (0.19) ⁺	−0.42 (0.20) [*]
Any health insurance (yes/no)	0.57(0.25) [*]	0.33 (0.28)
<i>Psychosocial characteristics</i>		
PedsQL Physical Summary Scale ^a	0.01 (0.01) [*]	−0.001 (0.01)
PedsQL Psychosocial Summary Scale ^a	0.02 (0.01) [*]	0.018 (0.01) [*]
Posttraumatic growth ^a	0.02 (0.01) [*]	0.012 (0.01)
Social support ^a	0.32 (0.16) ⁺	0.08 (0.16)
Family involvement with healthcare (yes/no)	0.30 (0.31)	–
Religious/spiritual importance (ref, not important/do not know)	0.29 (0.02) [*]	0.33 (0.13) ^{**}
<i>Survivorship care</i>		
Attendance at survivorship clinic (yes/no)	0.61 (0.22) ^{**}	0.45 (0.22) ^{**}
Written treatment plan (yes/no)	0.28 (0.20)	–
Regular cancer provider (yes/no)	0.90 (0.19) ^{***}	0.64 (0.24) ^{**}
Regular noncancer provider (yes/no)	0.49 (0.20) [*]	0.08 (0.21)
<i>Clinical factors</i>		
Years since diagnosis ^a	0.03 (0.05)	–
Treatment intensity ^a	0.01 (0.12)	–
Intercept	–	3.61 (0.68) ^{***}
R ²	–	0.26

^aContinuous variable.⁺ $P < 0.10$;^{*} $P < 0.05$;^{**} $P < 0.01$;^{***} $P < 0.001$.

SE, standard error.