Hispanic Orientation and Cancer-Related Knowledge in Childhood Cancer Survivors

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Cancer-related knowledge among childhood cancer survivors (CCSs) has been underexplored. In particular, little is known about factors impacting knowledge of the need for lifelong follow-up care in CCSs. This secondary analysis of data examined acculturation, cancer-related knowledge, demographics, and clinical factors in 193 ethnically and culturally diverse CCSs (age at study 19.9 ± 2.8 years). Cancer-related knowledge gaps were found across all participants. Univariate and multivariable logistic regression analyses indicated that Hispanic CCSs with greater Hispanic orientation were significantly more likely to be aware of a need for lifelong follow-up care. A greater focus on targeted risk communication with CCSs is warranted.

Keywords: survivorship, Hispanic Americans, acculturation, health communication, health knowledge, attitudes, practice

Introduction

CHILDHOOD CANCER SURVIVORS (CCSs) who are diagnosed under the age of 15 are disproportionately at risk for long-term adverse health outcomes. Of particular interest are those CCSs who fall in the adolescent and young adult (AYA) age range of 15–39, as these individuals are at risk for long-term adverse health outcomes, including infertility, heart and kidney failure, liver disease, and cancer recurrence, commonly referred to as late effects.¹ To mitigate the risk of these late effects, the Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers recommend that CCSs receive lifelong monitoring to detect/prevent late effects.² However, this population commonly reports cancer-related information needs,¹ including needs related to late effects and long-term follow-up,³ which are associated with poorer mental and physical health.^{4,5} This dearth of knowledge among CCSs about the importance of cancer-related follow-up guidelines may contribute to the <50% participation in long-term follow-up care^{4,6,7} and high prevalence of chronic health conditions⁸ in this population.

Hispanic CCSs are both underserved in health care and underrepresented in the literature,^{1,9} and they may be particularly at risk for poor health outcomes due to socioeconomic inequities and other health disparities.⁶ The Institute of Medicine has called for more studies involving Hispanic CCSs.¹⁰ However, little is known about cancer-related

knowledge gaps in the Hispanic subgroup of CCSs. Most previous research indicates that higher orientation to Anglo language and culture may be associated with increased cancer-related knowledge.^{6,11–13} One recent study suggested that more Anglo-acculturated Hispanics may demonstrate less cancer-related knowledge than their less Anglo-acculturated Hispanic or non-Hispanic White counterparts.¹⁴ Acculturation, defined as the level to which an individual adopts the culture, customs, practices, and beliefs of a new group, may, therefore, be an important factor when studying cancer-related knowledge in CCSs and planning cancer risk communications. In this study, we examined cancer-related knowledge gaps in a diverse sample of CCSs and, among Hispanic CCSs, we assessed the relationship of cancer-related knowledge with acculturation.

Methods

This analysis used data from Project Forward, a population-based study designed to investigate risk and protective factors for engagement in cancer-related follow-up care in diverse CCSs from two large pediatric medical centers in Los Angeles County ($n = 193$). Study procedures have been described elsewhere.¹⁵ In brief, CCSs diagnosed between 2000 and 2007 (age at diagnosis, 9–15 years; age at time of study, 17–23 years) were identified through the Los Angeles Cancer Surveillance Program, the Surveillance, Epidemiology, and End Results Cancer Registry covering Los Angeles

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County and mailed a survey. The recruitment rate for the study was 50%, a rate comparable with or exceeding similar studies.¹⁶ 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.

Measures

Knowledge of cancer-related follow-up care

A single item assessed participants' knowledge of the need for lifelong monitoring and cancer-related follow-up care. Participants were asked, "How long do you think you should continue having cancer related follow-up care?" (defined as visits where a doctor examined and did tests for any health problems related to cancer/cancer treatment), with five response options. Responses ranged from "less than 5 years" to "my whole lifetime" (the answer corresponding with current clinical guidelines²). The item was dichotomized as (1) the answer corresponding with current guidelines versus (2) all other responses as the reference group.

Hispanic orientation

Respondents self-identifying as Hispanic responded to a 13-item measure of acculturation, a shortened version of the Acculturation Rating Scale for Mexican Americans-II.¹⁷ The shortened scale in this study included items focused primarily on language and behavioral aspects of acculturation such as "I enjoy speaking Spanish," "I write letters in English," "I enjoy Spanish language TV," or "My friends are of Anglo or White origin." These items were summed into two subscales for Hispanic and Anglo orientation, respectively. Responses ranged from 1 "Not at all" to 5 "Almost always/extremely often." Possible range of the summary scores were 6–30 (based on six items) for the Hispanic subscale and 6–35 (based on seven items) for the Anglo subscale.

Statistical analysis

Bivariate analyses were first conducted to examine the association between various health care, clinical and demographic factors, and their association with knowledge of long-term follow-up care. Statistically significant variables at $p < 0.10$ were entered into a multivariable logistic regression model using the procedures outlined by Hosmer and Lemeshow.¹⁸ Although not significant in the bivariate analyses, receipt of follow-up care within the past 2 years, treatment intensity,¹⁹ age, gender, and insurance status were included in the multivariable model as covariates (and are considered to be important in the relationship between the exposure variables and knowledge of cancer-related follow-up care). For the multivariable model the level of significance was set to $p < 0.05$, and tests were two-sided. All analyses were conducted using SAS statistical software (Version 9.4).

Results

Sample characteristics

Roughly half of the respondents were female and nearly 60% were <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. More than 80% reported some type of health insurance, and two-thirds had a usual source of care, including a cancer provider and a noncancer provider. Respondents were diagnosed between 2000 and 2007, with an average age 19.9 ± 2.8 years; age at diagnosis, 12.1 ± 3.0 years; time since diagnosis, 7.8 ± 2.0 years. Respondents and nonrespondents were not significantly different in age, race/ethnicity, or clinical variables (cancer site, cancer stage, and age at diagnosis)¹⁵ (Table 1).

Descriptive analysis of cancer-related knowledge gaps

CCSs in this study across all racial/ethnic groups demonstrated several substantial gaps in knowledge regarding plans

TABLE 1. SELECTED CHARACTERISTICS OF PROJECT FORWARD SAMPLE (N=193)

	n	%
Age at survey completion		
15–20	114	59.1
21–25	79	40.9
Gender		
Female	96	49.7
Male	97	50.3
Ethnicity		
Hispanic	105	54.4
Non-Hispanic white	88	45.6
Cancer follow-up care in past 2 years		
Yes	140	72.5
No	51	26.4
Missing	2	1.0
Regular cancer provider		
Yes	123	64.7
No	67	35.3
Regular noncancer provider		
Yes	124	64.6
No	68	35.4
Level of education		
<High school	56	29.0
High school	44	22.0
Some college	55	28.5
Associate/college degree	36	18.6
Missing	1	0.5
Any health insurance		
Yes	154	81.1
No	36	19.0
Treatment intensity		
1 (least intensive, e.g., surgery only)	15	7.8
2 (moderately intensive, e.g., chemotherapy or radiation)	65	33.9
3 (very intensive, e.g., two or more treatment modalities)	90	46.9
4 (most intensive, e.g., relapse protocols)	22	11.5
Socioeconomic status		
1 (lowest quintile)	49	25.4
2 (second quintile)	41	21.2
3 (third quintile)	31	16.1
4 (fourth quintile)	35	18.1
5 (top quintile)	37	19.2

TABLE 2. DESCRIPTIVE ANALYSIS OF CANCER-RELATED KNOWLEDGE GAPS IN SAMPLE (N=193)

	n	%
Aware of recommendation for lifelong follow-up care		
Yes	110	57
No	83	43
Received a written summary of cancer treatment		
Yes	64	33
No	129	67
Discussed future oncology-related follow-up care plans with physician		
Yes	114	59
No	79	41

for their ongoing medical care as lifelong cancer survivors. Forty-three percent of participants reported being unaware that they are recommended follow-up care throughout the lifespan. Sixty-seven percent reported never receiving a written summary of their cancer treatment, and 41% reported never discussing future oncology-related follow-up care plans with their doctors (Table 2).

Hispanic orientation and knowledge of cancer-related follow-up care

Among Hispanic CCSs, those higher orientated toward Hispanic culture were significantly more likely to be aware of a need for future follow-up care ($r=0.55$; $p=0.01$) (Table 3).

Discussion

This analysis revealed cancer-related knowledge gaps across CCSs study participants of all racial/ethnic backgrounds. Seventy-three percent of CCSs in this population reported seeing a doctor for cancer-related follow-up in the previous 2 years.¹⁵ However, 43% of participants in this study were not aware of the need for lifelong follow-up, and 41% had never discussed follow-up care with their doctors.

A greater focus on effective risk communication between patients and clinicians is, therefore, warranted. Furthermore, most participants reported that they never received a written summary of their treatment. Cancer treatment summaries include recommendations for subsequent cancer surveillance, management of late effects, and strategies for health promotion.¹⁹ This treatment summary can aid in the development of survivorship care plans, which have been recommended by the Institute of Medicine since 2006.²⁰ An emphasis on training both oncologists and patients to ask for these documents will be necessary to encourage interdisciplinary communication and successful cancer-related follow-up care.

Among Hispanics, greater Hispanic orientation was associated with increased knowledge about the need for lifelong follow-up care. This finding contrasts with previous studies indicating that Hispanic orientation is associated with more unmet information needs.^{5,11} One possible explanation for this contradictory finding is that less acculturated Hispanic cancer patients might retain health-related information better due to decreased "information overload." In other words, less acculturated Hispanic cancer patients tend to receive less overall cancer-related information, and this may prevent mixed messages and confusion.^{21,22} It is possible, then, that inundating CCSs with information about the need for future follow-up care may be an ineffective strategy for promoting adherence to recommendations.

Another explanation for this finding is that Hispanic orientation may be a proxy in this case for other factors influencing cancer-related knowledge. The "Hispanic Paradox," first described by Markides and Coreil,²³ describes a phenomenon in which Hispanics/Latinos experience lower overall mortality rates despite higher poverty rates, lower educational attainment, and lower health insurance coverage rates than non-Hispanic Whites. Although debate about the root of this phenomenon continues, research has tentatively attributed this paradox to genetic factors, certain favorable health behaviors, and family support among Latinos.²³ Similarly, factors such as health literacy, access to care,

TABLE 3. UNIVARIATE AND MULTIVARIATE ANALYSIS OF CANCER-RELATED FOLLOW-UP CARE KNOWLEDGE IN THE PROJECT FORWARD STUDY

	Full sample of CCSs (n=193), unadjusted OR (95% CI)	Full sample of CCSs (n=193), adjusted OR (95% CI) ^a	Hispanic CCSs subgroup (n=102), unadjusted OR (95% CI)	Hispanic CCSs subgroup (n=102), adjusted OR (95% CI) ^a
Health care factors				
Receipt of follow-up care within past 2 years	1.68 (0.87–3.18)	1.80 (0.85–3.83)	1.04 (0.45–2.41)	1.10 (0.37–3.29)
Clinical factors				
Treatment intensity	1.22 (0.85–1.75)	1.31 (0.88–1.95)	1.42 (0.85–2.39)	1.65 (0.88–3.07)
Demographic factors				
Age group >21 year (ref. <21)	1.01 (0.57–1.81)	1.02 (0.52–2.01)	1.38 (0.61–3.10)	1.00 (0.37–2.70)
Gender (ref. male)	0.74 (0.42–1.31)	0.70 (0.38–1.30)	0.52 (0.23–1.14)	0.49 (0.20–1.23)
Hispanic acculturation	1.09 (0.61–1.93)	1.12 (0.61–2.05)	1.73 (1.20–2.52)*	1.73 (1.17–2.58)*
Any health insurance (y/n)	0.69 (0.33–1.46)	0.63 (0.26–1.53)	0.46 (0.16–1.31)	0.43 (0.12–1.48)
Intercept		–0.56 (–1.98 to 0.82)		–2.16 (–4.45 to 0.02)

^aVariables included in the multivariable models were significant at $p<0.10$ in unadjusted models.

* $p<0.01$.

CCSs, childhood cancer survivors; OR, odds ratio.

perceived risk, and family involvement may be creating a “Hispanic Paradox” effect in this study,²² whereby less Anglo-acculturated Hispanic CCSs—whom we would expect to possess *less* cancer-related knowledge secondary to socioeconomic and racial/ethnic disparities—actually demonstrate *more* cancer-related knowledge.

Although the results of this study contradict with most previous research, one previous study by Ramírez et al. found a similar result.¹⁴ In their study, the authors found that English-speaking Latinos demonstrated less knowledge about cancer compared with both non-Hispanic Whites and Spanish-speaking Latinos. If confirmed by future studies, this finding shared by this analysis and the Ramírez et al. study¹⁴ holds particular importance since English-speaking/more Anglo-acculturated Latinos also have more behavioral risk factors than other populations.²¹ Therefore, this is a population that appears to be at disproportionate risk for poor health outcomes during cancer survivorship.

Notably, as AYA cancer survivors, many of the CCSs in this study received cancer-related information during the vulnerable transition between pediatric and adult care. This transition and the associated lack of access to care may have impacted the receipt of health-related information.¹ Future studies of cancer-related knowledge in this population should investigate the impact of transitioning away from pediatric care—particularly as this transition interacts with acculturation in various subgroups. Finally, the interplay between cancer-related knowledge, access to care, and insurance status warrants future investigation in socioeconomically diverse populations of AYA cancer survivors.

Some key limitations of this study should be noted. First, the self-report format and the length of time since diagnosis in the sample may have introduced recall bias in this study. Second, this study lacks data about the impact of family involvement on health care knowledge. Particularly during the transition out of pediatric care, family members may play a key role in gathering and retaining knowledge about cancer care recommendations. The interplay between family dynamics and knowledge of the need for lifelong follow-up care in this population warrant further investigation.

Conclusion

This study assessed cancer-related knowledge and its relationship with cultural orientation among a population of CCSs in Los Angeles County. Overall, CCSs demonstrate important gaps in knowledge about their cancer treatment and the need for lifelong follow-up care. Hispanic CCSs with lower Hispanic orientation may be at the greatest risk for not knowing follow-up care recommendations. This population should be prioritized for targeted cancer risk communications. Further research is needed to explicate the mechanisms driving the relationship between cultural orientation and cancer-related knowledge.

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