



Published in final edited form as:

J Health Commun. 2021 February 01; 26(2): 83–91. doi:10.1080/10810730.2021.1895919.

Parental cancer-related information seeking, health communication and satisfaction with medical providers of childhood cancer survivors: Differences by race/ethnicity and language preference

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Abstract

For childhood cancer survivors (CCS), parents play an important role in communicating with providers and conveying patient's needs. This exploratory study examined the prevalence of cancer-related information-seeking among parents of CCS and investigated the association between parents' race/ethnicity and language preference with health communication and satisfaction with child's medical providers. 160 CCS and their parents from two hospitals in Los Angeles County were recruited from the SEER registry. Multivariable logistic regression analyses assessed associations between parents' race/ethnicity and language preference and their health communication with their child and with their child's medical care providers. Among the parents, 29% were Spanish-speaking Hispanics, 27% English speaking Hispanics, and 43% English speaking non-Hispanics. Regardless of language preference, Hispanic parents were more likely than non-Hispanic parents to receive health information about their CCS's cancer from hospital sources versus the internet. There was no difference by ethnicity/language in parent satisfaction with their CCS's medical provider. Spanish-speaking Hispanic parents were more likely to report talking to their CCS about the need for cancer-related follow-up care compared to non-Hispanic English-speaking parents. These findings point to the potential importance of parents' ethnicity and language for sources of health information and frequency of communication with their CCS about their cancer care.

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Compliance with ethical standards

All procedures performed in this study involving human participants were in accordance with ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

Conflict of interest The authors declare that they have no conflict of interest.

Keywords

Languages; Parents; Survivors of Childhood Cancer; Parent satisfaction; Health Communication

INTRODUCTION

Since the 1970s there has been an increase in the prevalence of childhood cancer survivors (CCS) (SEER Cancer Statistics, 2015). While approximately 84% of childhood cancer survivors now survive greater than 5 years, the majority will experience a chronic condition, often related to their cancer treatment(s), later in life (Phillips et al., 2015). Given the high burden of long-term morbidity and potential mortality, long-term follow-up health care is important for this population. However, cancer-related follow-up is suboptimal with fewer than half of CCS receiving recommended long-term care (Milam et al., 2015; Nathan et al., 2008).

Parents of CCS experience significant responsibilities for their child's health care and medical decision-making (Jones, 2012). Specifically, they take responsibility for coordinating cancer care, interacting with healthcare systems, and oftentimes helping their children transition from pediatric to adult care. The parent-child relationship can facilitate children's long-term adjustment and achievement, including effective engagement with healthcare (National Academies of Sciences et al., 2016; Schepers, Long, Russell, & Phipps, 2018). Thus, parents' interactions and open communication with medical providers can lead to improved awareness of health risks on the part of the child, and greater motivation to seek healthcare while gaining autonomy later as an adolescent and young adult (Zamora et al., 2016). Both CCS and their parents are often unaware of the risk of long-term side effects from treatment, which can reduce their engagement in long-term follow-up care (Cherven et al., 2014; Kaye & Mack, 2013; Signorelli et al., 2017).

Patient and family-centered care encourages information sharing (Rawson & Moretz, 2016) among survivors, parents, and medical providers. Parents value communicating with medical providers regarding their child's specific symptoms (Casillas et al., 2010) and receiving frequent information from healthcare providers (i.e. daily plan of action for the child's care) (Fisher & Broome, 2011; Uhl, Fisher, Docherty, & Brandon, 2013). Parent and child communication about the cancer experience can also assist survivors with taking an active role in their decision-making (Zwaanswijk et al., 2007) and closing the gaps in information needs about late effects and follow-up care (Vetsch et al., 2017). It is also important to know the sources of information that parents access to understand their child's cancer diagnosis as research has emerged demonstrating that caregivers of older adults seek information from a range of sources including medical providers (in person and online via portals), mass media and web-based sources, other survivors, and family members (Bangerter, Griffin, Harden, & Rutten, 2019; Oh, 2015).

A history of cancer involves the understanding and sharing of information, such as how to navigate the healthcare system and future healthcare need, and culture and language factors are believed to influence communication and health information seeking and sharing. Language barriers compromise the quality of care received by limited English-proficient

individuals (VanderWielen et al., 2014). There is evidence that Hispanics are less likely to access health information from the internet compared to non-Hispanic whites (Peña-Purcell, 2008). Previous research has also suggested that immigrant and Spanish-speaking Hispanic/Latinos from safety net clinics may have less access to the internet and often require family or friend's assistance in accessing the internet (Selsky, Luta, Noone, Huerta, & Mandelblatt, 2013). Satisfaction with care received and the relationship between the parent and provider may also be affected by language barriers when the parent does not speak English or the provider does not speak Spanish, even when translators are available (Hadler, Chen, Gonzalez, & Roby, 2012; Mier-Chairez, Arellano, Tucker, Marquez, & Hooper, 2019; Taira, Kim, & Mody, 2019). Hispanic cultural values such as familismo (Organista, Marín, & Chun, 2018), which emphasize the importance of unity within the immediate and extended family, including the responsibility to take care of family members and discussions for medical decision-making may influence the frequency of communication within parents and CCS. For example, a study among Spanish-speaking Latino/Hispanic patients with language concordant providers found that patients relied on family members for communication, not due to language barriers but to help manage the decision-making (Zamudio, Sanchez, Altschuler, & Grant, 2017). Yet, few studies have examined the role language plays in cancer-related information seeking, communication between CCS, their caregivers, and medical providers (Levit, Balogh, Nass, & Ganz, 2013; McGinnis, Stuckhardt, Saunders, & Smith, 2013).

Given the importance of communication in cancer care between family members as well as with medical providers, and the documented healthcare disparities as a result of language barriers, the purpose of this exploratory study was to examine and explore how parent language preference affects information seeking, communication, and satisfaction with medical care. The aims of this study were (1) to describe the sources of information that parents of CCS use for accessing cancer-related information by parent language preference and (2) to examine the association between language preference and the health care-related satisfaction and health communication experiences of Hispanic and non-Hispanic parents of CCS.

METHODS

Data for this analysis were from the Project Forward pilot study, a cross-sectional study that used population-based survey methods to evaluate factors associated with receiving follow-up care among CCS and their parents' role in their cancer care (Milam et al., 2015). CCS were selected from the Los Angeles Cancer Surveillance Program, the Surveillance, Epidemiology, and End Results (SEER) program cancer registry for Los Angeles County ("Cancer Surveillance Program," 2019). Eligibility included being diagnosed with cancer between the ages of 5–18 and being treated between 2000 and 2007 at two large pediatric medical centers in Los Angeles County. CCS with any cancer except for Hodgkin Lymphoma (who were ineligible because they were enrolled in another cancer registry study), who were at least two years from diagnosis, and who were aged 15 to 25 years in 2009 were eligible for this study. Exclusion criteria included inability to speak English or Spanish, and patients deemed to be incapable of completing a survey due to illness or significant cognitive impairment.

Parents of CCS were recruited via two methods. If CCS were minors, an initial packet was mailed to the parent inviting both the parent and child to participate in the study. If CCS were adults, materials were mailed directly to patients and then patients were asked for parental contact information and permission to mail survey materials to the parent. Both CCS and their parents received a \$20 gift card as compensation for the completion of the survey that took 30–45 minutes to complete. Participants had the option to complete the survey by paper, online or over the phone (in Spanish or English).

All parents who participated provided informed consent for themselves. For parents of minor CCS (ages 15–17), parental permission was obtained for requesting their children’s participation in the study. Minor CCS then provided written or verbal assent for their own participation. CCS ages 18 or older were contacted directly and provided informed consent. All study procedures were approved by the California Committee for the Protection of Human Subjects, California Cancer Registry, and by human subjects’ committees at the University of Southern California, Children Hospital of Los Angeles, and Miller Children’s Hospital.

Among 470 eligible CCS, a total of 171 parents participated; however, for 11 of them, their CCS did not participate due to illness or other reasons. Thus, of these 171, our analytical sample consisted of these 160 participants were both parent and CCS patient responded to the survey. The overall response rate for parents was 34.2% (Hamilton et al., 2018). There were differences in response rate by ethnicity, such that Hispanic parents (36.6% vs 46.7%, $p=0.001$) were less likely to respond compared to non-Hispanic white parents, and parents of younger CCS were more likely to respond than those of older CCS (Hamilton et al., 2018).

Measures

Parent’s ethnicity/language.—Two variables were used to create one new categorical variable. The first variable consisted of participants’ self-identification of their ethnicity. Those who selected Hispanic or Latino were classified as Hispanic, while participants who did not self-identify as Hispanic or Latino were classified into the non-Hispanic category. The second variable used was parents’ preferred language for the survey (Spanish vs English). The final, combined variable had three categories: Spanish-speaking Hispanics, English speaking Hispanics, and English-speaking non- Hispanics.

Parent’s sources of information.—Parents were asked, “In the past two years, have you gotten information (or looked for information) about your child’s cancer from any of the following?” with 13 response options. These “check all that apply” responses were categorized into four information domains (1) hospital resources; (2) social media and the Internet; (3) information obtained from other survivors; and (4) information obtained from family members (Miller et al., 2018). Each domain was dichotomized to represent participant endorsement of seeking information from that source (1), or non-endorsement (0).

Dependent variables

Satisfaction with child's regular doctor.—Parents were asked the question, “Does your child have a regular doctor whom he/she usually sees for regular check-ups or illnesses that are not related to his/her cancer?” with three response options “yes, no, or not sure”. If parents responded that their child did have a regular doctor, they were then asked four questions that assessed, “How satisfied are you with how this doctor listens, understands, handles, and gives advice”, which was adapted from the Primary Care Assessment Survey communication scale were used (Safran et al., 1998). Responses ranged on a 5-point Likert-scale from very satisfied, satisfied, neither satisfied nor dissatisfied, dissatisfied, and very dissatisfied. The scores of these four questions were summed up to create one score for parental satisfaction with child provider, ranging from 0–20. Psychometric properties for this scale were considered reliable (Cronbach alpha = 0.96). If a parent answered that their child did not have a regular doctor, then they did not answer these four questions and were coded as missing.

Health communication.—To assess parent-CCS communication and parent-provider verbal and written communication, a series of seven single item questions were asked to parents. In order to determine the degree of health care communication between parent and child, parents were asked how often they discussed: (1) his/her cancer experience; (2) the need for cancer-related follow up care; and (3) health insurance issues. Response options were never, occasionally, or often. To assess the type of communication that parents engaged in with their child's doctors, they were asked: (1) if they had discussed their child's future health care needs with the doctor; and (2) if they had received a written summary of their child's cancer treatment from their child's cancer provider, also known as survivorship care plan. Response options were no, not sure, or yes. Parents were also asked two questions that assessed if parents had communication problems with their child's health care provider. These questions were (1) Since your child completed cancer treatment, how often have you had problems because of difficulty with written information?; and (2) In the past two years, how often did you have a hard time speaking with your child's doctor because you spoke different languages? Communication variables were dichotomized to reflect whether parents endorsed or did not endorse communication barriers in discussions with doctor, receiving a written treatment summary, and in understanding written information or speaking with their child's doctor. Additionally, communication variables between parent and child were dichotomized to reflect whether the parents frequently talked to their child about their health care experiences (i.e., low communication = never/occasionally versus high communication = often).

Control variables

For multivariable models, control variables included child's demographic and clinical information and parent demographic information. SEER data from the CCS cancer diagnosis and the CCS survey responses were used to provide age at the time of the survey, gender, health insurance, time since diagnosis, and treatment intensity (ITR-2), a 4-level validated scale ranging from 1=least intensive treatment (surgery only) to 4=most intensive (e.g., bone marrow transplant, relapse therapies) (Werba et al., 2007). Parent demographic information was self-reported and included age at the time of the survey, income, and educational level.

Statistical analysis

ANOVA and chi-square tests were conducted to compare associations between independent variables and dependent variables and to identify significant covariates. Based on the bivariate results only two dependent variables were significantly associated with parent's ethnicity/language. We then conducted a sensitivity analysis, where we did multiple comparisons by running six additional chi-square tests where we compared the three pairs of groups between the two dependent variables (e.g., (1) Spanish-speaking Hispanics vs English-speaking Hispanics; (2) Spanish-speaking Hispanics vs English-speaking non-Hispanics; and (3) English-speaking Hispanics vs English-speaking non-Hispanics. Lastly, two multivariable logistic regression models were performed to examine the association between the two outcomes (frequent parent-child communication about follow-up care and endorsing difficulties due to language) with the combined ethnicity/preferred language variable as the major independent variable. In addition, CCS age at survey administration, treatment intensity, time since diagnosis, CCS gender, CCS health insurance, and parents age, income and education were included as covariates in the multivariable models based on significant bivariate associations and theoretical considerations. A second sensitivity analysis was conducted, where we included the parental reported variable on whether their child had a regular doctor into the two models. All tests were two-tailed, with an alpha criterion of $p < 0.05$, conducted using SAS statistical software (9.4).

RESULTS

Participants' socio-demographic, clinical, and information seeking sources characteristics

Among the 160 parent respondents there were 47 Spanish-speaking Hispanics, 44 English speaking Hispanics, and 69 English speaking non-Hispanics (Table 1). Parents' ages ranged from 34 to 69 years old and they were predominately female (89.3%). Spanish-speaking Hispanics had lower income and were less likely to have health care coverage compared to English-speaking Hispanic and non-Hispanic parent groups. Significant differences were observed for parents' level of education, with 79% of Spanish-speaking Hispanics reporting less than a high school degree, compared to 33% of English-speaking Hispanics and 6% of non-Hispanic parents ($p < 0.001$).

About two-thirds of Spanish-speaking and English-speaking Hispanic parents reported that they accessed health information about their child's cancer from hospital resources, compared to 33% of non-Hispanic parents ($p = 0.002$). A greater proportion of English-speaking Hispanic and non-Hispanic parents reported that they accessed health information about their child's cancer from social media and the internet compared to Spanish only speaking Hispanics (43% and 41% vs 21%; $p = 0.0485$).

Prevalence of parental communication and satisfaction with child's health care provider

Notably, across the three groups we found that there were significant differences in communication about follow-up care ($p < 0.001$). In our multiple comparisons test, Spanish-speaking parents more often talked to their child often about his/her needs for cancer related follow-up care, compared to English-speaking non-Hispanic parents (57% vs 20%; $p < 0.001$). Furthermore, English-speaking Hispanic parents were also more likely to talk

to their child about needs for cancer related follow-up care than the English-speaking non-Hispanic parents (45% vs 20%, $p=0.005$). Overall, our results showed that there are differences in parent report of CCS having a regular doctor based on ethnicity and language preference ($p=0.0425$). In our multiple comparisons test, we found that this was driven by Spanish-speaking Hispanic parents who reported a lower proportion of their child had a regular doctor compared to English-speaking Hispanic (66% vs 86%; $p=0.0132$).

There were no differences in parental communication with their child's doctors, parent satisfaction with their child's health care provider, or in receiving a survivorship care plan by parents' race/ethnicity and language. However, Spanish-speaking Hispanic parents were more likely than English-speaking Hispanics (46% vs 26%; $p=0.0486$) and non-Hispanic parents (46% vs 13%; $p=0.001$) to report difficulties in understanding doctors due to language barriers.

Factors related to communication outcome measures

After adjusting for covariates, Spanish-speaking parents were five times more likely than English-speaking non-Hispanic parents to report talking to their child about follow-up care (OR=5.58 [95% confidence intervals 1.22, 25.62]; Table 3). In the adjusted models, ethnicity/language preference was no longer related to having difficulties in communication with medical providers. Subsequently, we performed sensitivity analysis by including whether CCS had regular doctor as a covariate and our results were consistent for both models.

DISCUSSION

We found that Spanish-speaking parents were much more likely to talk to their CCS about cancer related follow-up care than either the English-speaking Hispanic parents or the non-Hispanic parents. However, if the CCS had a regular doctor, levels of satisfaction with care received by their CCS did not differ by parent's ethnicity or language. Patterns differed regarding sources for receiving health information, with Hispanics (both Spanish and English speaking) relying more on hospital sources for information about their child's cancer than non-Hispanics, who utilized the internet and social media.

While few studies have assessed characteristics of health information provided among Hispanic parents and childhood cancer survivors, Miller et al. (2018) found that Hispanic young adult CCS, like we found for their parents, most frequently reported receiving cancer-related information from hospital sources. Our results showed that Hispanic parents (regardless of preferred language) relied more on hospital sources for cancer-related information and that the Spanish-speaking Hispanic parents were the least likely to use the internet or social media to look for information. This might suggest that these are difference levels of comfort or access in seeking cancer information online among Hispanic parents.

These finding support previous studies which have shown that Spanish-speaking Hispanics report greater difficulties accessing cancer information (Vanderpool, Kornfeld, Rutten, & Squiers, 2009) and Hispanics who are not comfortable speaking English have lower trust in health information from the internet (Clayman, Manganello, Viswanath, Hesse, & Arora,

2010). Previous findings have shown that both U.S. born, and foreign-born Hispanics do not use the internet or access health information online at the same rate as non-Hispanic whites (Gonzalez, Sanders-Jackson, & Wright, 2019). Furthermore, considering that there were differences in parents' level of education among Hispanics, this might also be a result of health literacy, as it is known that individuals that report lower levels of education also have lower levels of health literacy (Kutner, Greenburg, Jin, & Paulsen, 2006), and English fluency might be barrier to internet use. There are also differences among Hispanic demographic subgroups in the use of mobile phones or tablets as a form of internet, where Hispanic adults with less than high school education and with a family income of less than \$30,000 are less likely to access the internet via a mobile device (Anna Brown, 2016). Among Central and South American Latino subgroups previous findings have also shown that they have lower odds of using a patient portal to email health care providers than non-Hispanic whites (Gonzalez et al., 2019), however, family and friends assistance facilitated their gathering of information from the Internet (Selsky et al., 2013).

In contrast to the internet sources, hospitals were most important source of information for Hispanics, and especially Spanish-speaking families, to learn and communicate about medical history and future risks with medical providers. Future studies should assess whether the information that these families are receiving in the hospital are in a format that is culturally congruent to ensure that health communication is maximized (Schim & Doorenbos, 2010). Likewise, more information on what other groups are receiving through the internet should be evaluated.

We found no racial/ethnic difference in parent satisfaction with their child's medical provider among those who reported having a regular doctor. Our results differed from a recent study of caregivers of pediatric cancer patients which found that Spanish-speaking caregivers reported higher satisfaction with care compared to English-speaking caregivers (Zamora et al., 2016). In our study Hispanics and non-Hispanic parents all rated their child's medical provider very highly. This is an important finding because greater satisfaction with cancer care has been found to be associated with an increase in confidence in managing communication with provider and health related quality of life among Hispanic adults who are cancer survivors (Moreno et al., 2018). Future research is needed with larger sample size and with heterogenous group of Hispanic samples.

There were differences in communication patterns based on parents' language preference. Spanish-speaking parents reported more frequent communication regarding follow-up care with their child. One explanation for this finding, is that greater communication between Hispanic parent-child compared to non-Hispanics may be reflective of *familismo*, a fundamental cultural value for Hispanics that expresses strong loyalty, reciprocity, and solidarity among family members (Organista et al., 2018). While this finding supports the broader application of patient and family-centered care and the value of health information sharing (Clay & Parsh, 2016), it may also indicate that among Spanish-speaking Hispanic parents of CCS (where the vast majority of children speak English), CCS become language brokers, where the child is responsible for gathering and sharing medical information for the parent (Kam, 2011). Research is needed to determine the extent to which CCS from Spanish-speaking homes act as language brokers and whether this positively or negatively

impacts communication throughout the cancer experience. This is particularly important because federal guidelines indicate that non-professional interpreters (including family members) should not be utilized in healthcare settings (VanderWielen et al., 2014), and medical practitioners have raised concerns regarding children acting as language brokers because of fidelity of the translation and the complexity of information being disclosed (Mier-Chairez et al., 2019; Vikki, 2014). Despite efforts to improve communication through the availability of translators and interpreters (Hadler et al., 2012), language services are underutilized and there is a continued use of non-professionals interpreters (including family members, commonly known as language brokering) (Hadler et al., 2012; Mier-Chairez et al., 2019; Taira et al., 2019).

Strengths and Limitations

Our study had several strengths including its unique sample of underrepresented Hispanic parents of childhood cancer survivors who were linguistically diverse. To our knowledge, no existing studies have assessed the relationship between health communication, Hispanic ethnicity and language between parents, CCS, and their medical providers in the United States. Due to this being a cross-sectional study, causal conclusions cannot be drawn. The sample of Hispanic parents was mostly from Mexico or Central America so findings may not generalize to other US Hispanic populations. In addition, choice of language to take survey was only offered to those Hispanic-sounding surnames. Furthermore, the majority of participants in our study were mothers, which limits examination of gender-related cultural differences. Although our sample size of Hispanic parents is large compared with other studies of this group it is still small sample size when comparing subgroups, thus, power to detect differences may be low. Due to sample size and the exploratory nature of this study, we did not adjust for multiple inferential tests. In addition, Hispanics parents were less likely to respond compared to non-Hispanic white parents, and those of older CCS were also less likely to respond, thus this limits generalizability. Other limitations include, there was no information collected on the language spoken by the provider, the language of the health information they received and the child survivorship care plan, or an assessment on literacy and numeracy among participants. Lastly, there was no assessment on whether CCS acted as language brokers for their parents in the medical setting.

Implications

These findings point to the potential importance of ethnicity and language to parent-child and parent-provider communication, and it also suggests that assessing more direct aspects of cultural values and health literacy may be useful to determine the best strategies to meet the needs of parents. Awareness of factors associated with parent and CCS communication behaviors may enable recognition of areas for improvement. Our results also highlight the need to assess the information being received from different sources to ensure that parents are understanding and communicating health information accurately. In future studies, the role of parent-child and parent-provider communication on health outcomes should be examined and differences by language and ethnicity should be explored.

ACKNOWLEDGEMENTS

This work was supported by the Whittier Foundation, grant R01MD007801 from the National Institute on Minority Health and Health Disparities of the National Institutes of Health and P30CA014089 and T32CA009492 from the National Cancer Institute of the National Institutes of Health. The collection of cancer incidence data used in this study was supported by the California Department of Public Health pursuant to California Health and Safety Code Section 103885; Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries, under cooperative agreement 5NU58DP003862-04/DP003862; the National Cancer Institute's Surveillance, Epidemiology and End Results Program under contract HHSN261201000140C awarded to the Cancer Prevention Institute of California, contract HHSN261201000035C awarded to the University of Southern California, and contract HHSN261201000034C awarded to the Public Health Institute. USC Norris Comprehensive Cancer Center NIH P30CA014089. The ideas and opinions expressed herein are those of the author(s) and endorsement by the State of California Department of Public Health.

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Table 1.

Parent participants' socio-demographic, clinical, and sources of information characteristics by Hispanic ethnicity and language (n=160)

	Hispanic Spanish (n=47)	Hispanics English (n=44)	Non-Hispanic English (n=69)	P-Value
Parent characteristics				
Age (mean/SD)	47.13 (6.48)	45.97 (5.39)	51.58 (6.57)	<0.0001
<45	17 (38%)	14 (36%)	11 (17%)	0.0021
45–54	20 (46%)	23 (59%)	30 (48%)	
55+	7 (16%)	2 (5%)	22 (35%)	
Gender				
Male	3 (6%)	5 (11%)	10 (15%)	0.41
Female	44 (94%)	39 (89%)	58 (85%)	
Education Level				
<12 years	37 (79%)	14 (33%)	4 (6%)	<0.0001
High school/GED (12 years)	7 (15%)	8 (19%)	6 (9%)	
>12 years	3 (6%)	21 (49%)	58 (85%)	
Income				
<\$20,000	21 (62%)	12 (33%)	11 (18%)	<0.0001
\$20,000– 59,999	13 (38%)	15 (42%)	10 (16%)	
> \$60,000	0 (0%)	9 (25%)	40 (66%)	
Hispanic subgroup				
Mexico	36 (77%)	19 (70%)	--	0.21
Other-Central/South America	11 (23%)	8 (30%)	--	
Marital Status				
Single	5 (11%)	7 (16%)	12 (18%)	0.81
Married/Marriage-like	35 (74%)	28 (65%)	45 (67%)	
Widowed/Divorced/Separated	7 (15%)	8 (19%)	10 (15%)	
Health Care Coverage				
No	22 (50%)	11 (26%)	4 (6%)	<0.0001
Yes	22 (50%)	31 (74%)	64 (92%)	
Type of Health Care Coverage				
None	22 (50%)	11 (26%)	4 (6%)	<0.0001
Public (such as Medicaid)	9 (20%)	8 (19%)	8 (12%)	
Private	2 (5%)	20 (48%)	52 (76%)	
Other	11 (25%)	3 (7%)	4 (6%)	
Sources of Information Seeking ^a				
Hospital	30 (64%)	25 (57%)	23 (33%)	0.002
Social media/internet	10 (21%)	19 (43%)	28 (41%)	0.0485
Other survivors	11 (23%)	8 (18%)	16 (23%)	0.78
Family members	4 (9%)	7 (16%)	9 (13%)	0.59

	Hispanic Spanish (n=47)	Hispanics English (n=44)	Non-Hispanic English (n=69)	P-Value
Childhood cancer survivor characteristics				
Age at survey (mean/SD)	20.38(2.70)	19.89 (2.63)	20.59 (3.08)	0.44
Gender				
Male	24 (51%)	22 (50%)	33 (48%)	0.94
Female	23 (49%)	22 (50%)	36 (52%)	
Health care coverage				
No	22 (48%)	10 (23%)	12 (18%)	<0.001
Yes	24 (52%)	33 (77%)	56 (82%)	
Time since diagnosis Treatment intensity	7.51 (2.38)	7.14 (1.97)	7.57 (2.03)	0.54
1	5 (11%)	3 (7%)	8 (12%)	0.24
2	13 (28%)	19 (43%)	20 (29%)	
3	25 (53%)	15 (34%)	36 (53%)	
4	4 (9%)	7 (16%)	4 (6%)	

Note: n varies based on missing responses; percentages are based on valid percent;

^aPercent of participants that received information from these domains.

Table 2.

Percent Distribution of Parental communication and satisfaction with child's health care provider by ethnicity/ language preference

<i>Outcomes</i>	Hispanics Spanish (n=47)	Hispanics English (n=44)	Non-Hispanics English (n=69)	P-Value
Frequent P-C^a communication about cancer experience				
Never/Occasionally	34 (72%)	33 (77%)	58 (84%)	0.30
Often	13 (28%)	10 (23%)	11 (16%)	
Frequent P-C^a communication about follow-up care				
Never/Occasionally	20 (43%)	23 (55%)	55 (80%)	<0.001
Often	27 (57%)	19 (45%)	14 (20%)	
Frequent P-C^a communication about health insurance				
Never/Occasionally	27 (59%)	35 (81%)	51 (74%)	0.05
Often	19 (41%)	8 (19%)	18 (26%)	
Endorsed P-P^b communication about future health care				
Yes	30 (64%)	30 (68%)	51 (74%)	0.50
No/Not sure	17 (36%)	14 (32%)	18 (26%)	
Endorsed problems understanding				
Yes	25 (53%)	20 (48%)	28 (41%)	0.44
No	22 (47%)	22 (52%)	40 (59%)	
Endorsed difficulties due to language				
Yes	21(46%)	11 (26%)	9 (13%)	<0.001
No	25 (54%)	32 (74%)	59 (87%)	
Received survivorship care plan				
Yes	27 (59%)	21 (48%)	29 (43%)	0.24
No/Not Sure	19 (41%)	23 (52%)	39 (57%)	
Reported CCS regular doctor				
Yes	31 (66%)	32 (73%)	59 (86%)	0.0425
No/Not Sure	16 (34%)	12 (27%)	10 (14%)	
Parent Satisfaction with Child HCP^c (mean/SD)	16.72 (3.76)	16.88 (4.00)	17.39 (3.06)	0.63

^a; P-C= Parent-Child;

^bP-P = Parent-Provider;

^cHCP= health care provider, only among those who said yes to child having a regular doctor.

Table 3.

Adjusted odds ratio for factors related to communication outcome measures

	Frequent P-C Communication: Follow-up care (n=122) AOR (95% CI)	Endorsed P-P Communication: Difficulties due to language (n=121) AOR (95% CI)
<i>Ethnicity/Language</i> (ref=Non-Hispanic English)	1.0	1.0
Hispanic English	1.85 [0.57, 5.99]	0.69 [0.14, 3.33]
Hispanic Spanish	5.58 [1.22, 25.62] *	1.39 [0.26, 7.40]
<i>Covariates</i>		
Parent age ^a	0.94 [0.87, 1.02]	1.05 [0.96, 1.14]
CCS age at survey ^a	0.93 [0.78, 1.12]	1.10 [0.89, 1.35]
Income (ref: <\$20,000)	1.0	1.0
\$20,000– 59,999	1.82 [0.61, 5.45]	0.91 [0.28, 2.92]
> \$60,000	0.92 [0.23, 3.63]	0.18 [0.03, 1.07]
Parent education (ref: 12 years)	1.0	1.0
<12 years	1.72 [0.44, 6.70]	2.33 [0.53, 10.29]
High school/GED (12 years)	0.99 [0.23, 4.21]	0.83 [0.13, 5.35]
Treatment intensity ^a	1.77 [0.97, 3.21]	0.86 [0.45, 1.66]
Time since diagnosis ^a	0.90 [0.73, 1.11]	1.03 [0.82, 1.30]
CCS gender (ref: Female)		
Male	1.00 [0.41, 2.47]	0.93 [0.32, 2.76]
CCS health insurance (ref: Yes)		
No	0.83 [0.30, 2.34]	2.40 [0.79, 7.28]

Abbreviations: CI = confidence interval; AOR =adjusted odds ration; P-C = Parent-Child communication; P-P = Patient-Provider communication.

^aContinuous variable

* P<0.05