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Quality of cancer follow-up care: a focus on Latina breast cancer survivors

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Abstract

Introduction—Receiving quality cancer follow-up care influences survivorship outcomes.

Among Latinas, breast cancer is the number one cause of cancer death; yet Latinas do not receive adequate follow-up care. This study examined quality of cancer follow-up care among Latina breast cancer survivors (BCS) and whether it differs by participant language and healthcare system variables (provider specialty, and medical setting).

Methods—Two hundred thirty-two (95 English-speaking Latina and 137 Spanish-speaking) Latina BCS were recruited from the California Cancer Registry, hospital cancer registries, and community agencies.

Results—English-speaking Latina BCS were more likely to report receiving cancer follow-up care at a doctor's office ($p<0.001$). BCS without a regular place for cancer follow-up care were more likely to report not seeing a primary care provider ($p<0.05$) or cancer specialist ($p<0.001$) in the past 12 months. English-speaking Latina BCS ($p<0.001$), BCS who saw a cancer specialist in the past 12 months ($p<0.001$), and received follow-up care at a doctor's office ($p<0.05$) reported higher quality of care. Speaking English, having seen a cancer specialist, and receiving follow-up care at a doctor's office were independently associated with higher quality of care, explaining 44 % of the variance.

Conclusions—Our study findings suggest that examining the influence of ethnic and linguistic factors on quality of cancer follow-up care is necessary to address health disparities. Improved access to cancer follow-up care for Spanish-speaking Latina BCS is of particular concern.

Implication of Cancer Survivors—Identifying follow-up care needs of Latina BCS may contribute to providing high-quality care and improved survivorship outcomes.

Keywords

Breast cancer survivor; Follow-up care; Quality of care; Provider specialty; Latina

Introduction

Post-acute follow-up breast cancer care is critically important to improving survival and survivorship outcomes [1, 2]. Existing recommendations for breast cancer follow-up care (e.g., American Society of Clinical Oncology; National Comprehensive Cancer Network) include physical examination, full oncology reevaluation, regularly scheduled mammograms, and pelvic examinations [3, 4]. These follow-up care recommendations also include early recognition and treatment of a potential recurrence and secondary breast cancer, and screening for therapy-related complications [5].

Despite ongoing efforts to improve cancer care and outcomes for all, breast cancer disparities by ethnic group persist. Access and adherence to breast cancer follow-up care recommendations are particularly critical for Latinas who are likely to be diagnosed at a younger age, at advanced stages, have larger tumors and lower 5-year survival rates [6–8], and present with endocrine distinct breast cancer subtypes (estrogen- or progesterone-) [9–11]. Unfortunately, Latina women diagnosed with breast cancer commonly experience delays in diagnostic and therapeutic care [12–14], are less likely to receive recommended posttreatment cancer follow-up care [7, 12, 14–17], and have inadequate knowledge of and access to cancer follow-up care [14, 18]. Thus, they warrant closer medical monitoring and management due to their increased risk of recurrence, new cancers, and subsequent chronic conditions.

Furthermore, Latinas may be more likely to fall through the net of care and receive lower quality cancer follow-up care services. Latinas report poorer provider communication, trust, and greater treatment dissatisfaction [19–21], as well as lower quality care ratings compared to non-Latina White women [19, 22, 23]. Research indicates that good patient-provider relationship and quality of care may enhance patients' medical outcomes [20, 24]. Also, Latinas attribute their lower quality of cancer care to their ethnic group membership, low income, immigration status, and limited English language proficiency [19]. Despite these documented disparities in cancer care, Latinas are underrepresented in cancer research [25, 26]. Including Latina breast cancer survivors (BCS) in cancer research is necessary for understanding and addressing barriers to receiving optimal and high-quality cancer follow-up care.

Thus, the aim of this study was to examine the quality of cancer follow-up care among English-speaking and Spanish-speaking Latina BCS. Specifically, we examined the effects

of participant's language, provider specialty, and medical setting on the quality of cancer follow-up care.

Methods

Participants and study design

This study includes baseline data from a health-related quality of life psycho-educational intervention study conducted during 2005 through 2010. The parent study aimed to test the effectiveness of a telephonic-based intervention to relieve distress; intervention outcomes will be presented elsewhere. Participants were women who were (1) 18+ years of age, (2) self-identified as Latina, (3) within 1–6 years of a breast cancer diagnosis, and (4) diagnosed with stage 0–III breast cancer. BCS were recruited from the California Cancer Registry, City of Hope and UCLA Institutional Cancer Registries, and BCS support groups. BCS who voluntarily agreed to participate were mailed a study package containing consent forms and self-administered assessments in their language of preference (English or Spanish). Institutional review board approval from participating entities was obtained and all participants in the study signed the informed consent form for study participation.

Measures

Participants completed a self-administered comprehensive questionnaire that included standard measures and new measures informed by previous research with multiethnic BCS [27, 28]. The specific measures utilized for this investigation are listed below.

Demographic and cancer medical characteristics—Participant age, household income, educational attainment, marital and employment status, and health insurance status (i.e., no insurance, HMO or PPO, and Medi-Cal coverage) were assessed. Language was measured using the participant's preferred language for completing the study survey. Cancer-related medical characteristics included breast cancer stage, type of surgery (e.g., lumpectomy), and adjuvant therapy received (e.g., chemotherapy, radiation).

Medical setting for cancer follow-up care—Participants were asked to indicate the type of medical place or facility they went to for obtaining their breast cancer follow-up care from the following list: no place, clinic or health center, doctor's office, or HMO. Seeking care at a doctor's office was considered as having a regular place of care. Receiving care at a clinic or health center was not considered a regular place of care because this care may be transient, with BCS seeking care only when they deem it necessary and not as recommended by a doctor whom they see on a regular basis.

Follow-up care provider specialty—Participants were presented with a list of providers and asked (yes/no) if in the past 12 months they had seen any of the following health care providers for their cancer follow-up care: primary care provider, gynecologist, or cancer specialist. The type of provider seen was not mutually exclusive, thus BCS could report seeing more than one type of provider.

Outcome: quality of care—This measure is adapted from the Interpersonal Aspects of Care subscale from the Adherence Determinants Questionnaire [29]. This seven-item measure focuses on the quality of care received (sample items: “The doctors and healthcare professionals listen carefully to what I have to say”; “The doctors and healthcare professionals answer all of my questions”). These items are rated on a five-point Likert scale (1 strongly disagree to 5 strongly agree) with higher scores indicating higher quality of care (possible range 7 to 35). The measure has been used with English- and Spanish-speaking Latinas diagnosed with breast cancer and demonstrated good reliability ($\alpha=0.80$) [28, 30]. In this study, the measure demonstrated good reliability ($\alpha=0.72$) with observed scores ranging from 14 to 35.

Data analysis

Differences in demographic and cancer-related medical characteristics and medical setting for cancer follow-up care (no place, clinic/health center, doctor’s office/HMO) were examined by language group with chi-squares. A *t* test was conducted to examine differences in mean ratings of quality of care by language group. Additionally, *t* tests were conducted to examine differences in mean ratings of quality of care by provider specialty (separate *t* tests were conducted for each provider specialty: primary care provider, gynecologist, cancer specialist). Levene’s test for equality of variances was used to test whether the variance was equal across groups and the appropriate test statistic is presented for each *t* test analysis. Analysis of variance was used to examine differences in quality of care across medical setting for cancer follow-up care. Tukey post hoc comparisons were conducted to examine group differences across medical setting. Lastly, hierarchical regression analysis was performed to determine the independent influence of variables of interest on quality of care. Specifically, demographic variables were entered in model 1 and cancer-related medical factors in model 2. Provider specialty variables were entered in model 3 and medical setting for cancer follow-up care was entered in model 4. The order in which the variables were entered allowed the investigators to evaluate the contributions of the demographic and cancer-related medical factors prior to testing the influence of provider specialty and medical setting for cancer follow-up care. Preliminary analyses were conducted to rule out multicollinearity by examining the associations among independent variables, and the tolerance and VIF values for determining the presence of multicollinearity. Analyses were conducted using SPSS 21. All hypotheses were tested with a $p<0.05$ criterion of significance for a two-sided test.

Results

Demographic and cancer-related medical characteristics

A total of 232 Latina BCS participated in this study, of which 137 were Spanish-speaking and 95 were English-speaking. The majority of BCS were Mexican (73 %) and the remaining were Central-American (13 %), South-American (9 %), and US-born Latinas (5 %). On average, participants were 53(SD=10.5)years old, with the majority in the 50–64 year range (Table 1). Most participants reported having less than a high school education (47 %), being born outside the US (74 %), being low income (54 %), unemployed (61 %), being partnered (61 %), and having HMO or PPO (48 %) as their health insurance coverage. The

bivariate analyses showed that Spanish-speaking Latina BCS were more likely to have lower educational attainment (72 vs. 13 %, $p<0.001$), be foreign born (97 vs. 40 %, $p<0.001$), and report lower household income (70 vs. 31 %, $p<0.001$) compared to English-speaking Latina BCS. English-speaking Latina BCS were more likely to report being employed (60 vs. 25 %, $p<0.001$) and having HMO or PPO as their health insurance coverage (72 vs. 32 %, $p<0.001$).

In terms of medical characteristics (Table 2), a majority of BCS were diagnosed with early stage breast cancer (83 %); 54 % reported receiving a lumpectomy, and 41 % reported receiving a mastectomy. Among all BCS, 70 % reported receiving chemotherapy and radiation therapy, while 66 % reported receiving hormonal therapy. Spanish-speaking Latinas were more likely to report having a mastectomy (47 vs. 32 %, $p<0.05$) but less likely to report breast reconstruction (7 vs. 17 %, $p<0.05$) compared to English-speaking Latina BCS.

Follow-up care

Overall, half of Latina BCS (51 %) received their follow-up care at a doctor's office/HMO (Table 2). Spanish-speaking Latina BCS were more likely to report receiving their cancer follow-up care at a clinic/health center (25 vs. 5 %, $p<0.001$) compared to English-speaking Latina BCS. Furthermore, English-speaking Latina BCS were more likely to report getting their cancer follow-up care at a doctor's office/HMO (57 vs. 48 %, $p<0.001$) compared to Spanish-speaking Latina BCS. In the past 12 months, about 70 % of Latina BCS reported seeing a primary care provider, gynecologist, and cancer specialist. However, Latina BCS who reported not having a regular place to obtain their cancer follow-up care were more likely to report not seeing a primary care provider (46 vs. 12 vs. 42 %, $p<0.05$) or cancer specialist (83 vs. 8 vs. 9 %, $p<0.001$) in the past 12 months compared to Latina BCS who reported receiving care at a clinic or doctor's office.

Quality of care

In bivariate analyses participant language group, type of provider and medical setting for follow-up care were associated significantly with quality of care (Table 3). Notably, Spanish-speaking Latina BCS reported lower quality of care ($M=24.7$, $SD=3.9$) compared to English-speaking Latina BCS ($M=27.2$, $SD=6.2$), ($p<0.001$). Latina BCS who reported seeing a cancer specialist in the past 12 months reported higher quality of care ($M=27.3$, $SD=4.7$) than BCS who had not seen a cancer specialist ($M=21.7$, $SD=3.8$), ($p<0.001$). The analyses also revealed a statistically significant difference in quality of care by the medical setting where cancer follow-up care was received, $F(2,227)=50.1$, $p<0.001$. Post hoc comparisons indicated that BCS who received follow-up care at a doctor's office/HMO ($M=28.3$, $SD=4.3$; 95 % CI 27.5–29.1) reported higher quality of care than BCS who received care at a clinic/health center ($M=25.1$, $SD=4.1$; 95 % CI 23.7–26.3), and BCS who did not have a regular place of care ($M=21.9$, $SD=4.3$; 95%CI 20.9–23.1), $p<0.05$.

Multivariate analyses

Hierarchical regression analyses identified factors influencing quality of care (Table 4). Demographic variables (model 1) explained 13 % of the variance of quality of care

($R^2=0.135$; $F(11, 206)=2.91$; $p<0.01$). This model indicates that women 50–64 years of age reported experiencing lower quality of care than women aged 65 and older. When cancer-related medical factors were added in model 2, the model was statistically significant; however, the additional variance explained was not statistically significant (R^2 change=0.038, $F(6, 200)=1.53$; $p>0.05$). Adding provider specialty (model 3) significantly improved the model (R^2 change=0.191, $F(3, 197)=19.71$; $p<0.001$), explaining an additional 19 % of the variability, with patients who saw a cancer specialist reporting higher quality of care than the other provider types. Adding medical setting for cancer follow-up care in model 4 significantly improved the model (R^2 change=0.80, $F(2, 195)=13.93$; $p<0.001$), explaining an additional 8 % of the variability in quality of care. The final model, incorporating all factors explained 44% of the variability in quality of care. Overall, Latina BCS who were English-speaking and who reported seeing a cancer specialist in the past 12 months reported higher quality of care than their counterparts. Furthermore, Latina BCS who did not have a regular medical setting for cancer follow-up care or who received follow-up care at a clinic/health center reported lower quality of care than BCS who received care at a doctor's office/HMO.

Discussion

The continued growth of the ethnic minority breast cancer survivor population calls for investigations of their initial and follow-up care experiences and outcomes in order to address disparities in quality of care and survival. Our study is innovative as it begins to address important gaps in scientific knowledge regarding differences in provider specialty, medical setting, and quality of cancer follow-up care among English- and Spanish-speaking Latina BCS.

While we found that half of Latina BCS reported having a regular place for follow-up care, our study findings show that BCS who did not have a regular place to obtain cancer follow-up care had not seen a primary care provider or a cancer specialist in the past year. We also observed language differences with Spanish-speaking Latina BCS being less likely to have a regular place of care compared to English-speaking Latina BCS. Our study supports previous findings indicating that limited English language proficiency and lack of culturally and linguistically appropriate services [17, 31, 32] are associated with disparities in access to care.

Our data revealed that Spanish-speaking Latina BCS and Latina BCS who did not have a regular place for cancer follow-up care or who received follow-up cancer care at a general clinic/health center reported poorer quality of care than those who spoke English or were seen at a doctor's office. These findings support the existing literature indicating that Latinas report treatment dissatisfaction and lower quality of care ratings [19, 22]. Furthermore, our findings concur with the limited literature reporting that Latina BCS [19], and Latinos in general [33], perceive receiving lower quality of care due to their limited English language proficiency. Limited English language proficiency may interplay with communication and socioeconomic issues, which in turn can affect perceptions of the quality of care received. Spanish-speaking Latina BCS in our study may have experienced poor communication with their healthcare providers or may not have had access to interpreters during their visits. Our

results indicate the need for increased attention to the quality of cancer follow-up care if we are to improve cancer outcomes among this vulnerable population.

Caution should be taken when interpreting these findings. Study limitations include that the sample was not representative of all Latina BCS since participants reported being of Mexican descent, primarily. Also, the data were cross-sectional, and thus the causality of quality of care cannot be determined. Analyses were not corrected for multiple comparisons; however, this is acceptable given the exploratory nature of this study. In addition, Latina BCS are underrepresented in research, hence less restricted exploratory analyses allows for discovery that can generate new research questions and hypotheses for further and future investigations. Additionally, the inclusion criteria limited participation to women diagnosed with stages 0–III and thus excluded women with more advanced stages. Furthermore, the data are self-reported and retrospective in nature, thus recall bias may have influenced the findings. A further limitation is that the present analyses did not account for immigration status, which may also influence quality of care. However, despite these limitations, this study contributes to the small body of research on cancer follow-up care and quality of care among English- and Spanish-speaking Latina BCS. To our knowledge, ours is the first study to examine how Latina BCS rate the quality of follow-up care they receive from cancer specialists and primary care providers.

Our findings point to the need for future research aimed at examining the delivery of care and quality of care received by Spanish-speaking Latinas once they complete active treatment. These types of studies should focus on identifying specific strategies that may improve patient-provider communication and interactions with medical staff. Examining determinants of disparities in quality of care ratings across language groups will suggest interventions in addition to professional medical interpretation that may address disparities in outcomes of cancer care. Additionally, future research should examine the interplay of cultural values (e.g., trust, respect) during delivery of care for both Spanish-speaking and English-speaking Latinos, and their potential associations with quality of care. Associations between patient-doctor communication processes and patient outcomes such as adherence to follow-up care recommendations and quality of care should also be explored in future investigations.

Furthermore, given the importance of receiving adequate cancer follow-up care [34], limited or no access to care needs to be addressed, especially for Latinas who are at increased risk for poor outcomes [7]. Receipt of follow-up care that is patient-centered hinges on care coordination between specialists and primary care physicians, effective patient-doctor communication, and continuity of care. The limited research examining provision of cancer follow-up care by different healthcare providers indicates that Latina BCS who report receiving care from both primary care providers and cancer specialists are more likely to adhere to recommended care [35, 36]. Future research should explore the quality of follow-up care, how care is coordinated across primary care providers and cancer specialists, and what this means in terms of patient-reported quality care and long-term survival. Current breast cancer follow-up care recommendations include screenings and exams (e.g., physical exams, mammograms) that are provided by different healthcare providers. Additionally, these follow-up care recommendations form part of the treatment summary and survivorship

care plans, which will be required to be provided to all cancer survivors by 2015 [37]. Also, proponents and advocates of these comprehensive plans recommend the participation of primary care providers in managing and providing cancer follow-up care [38]. However, optimum methods of cancer follow-up across provider specialties are unknown.

Overall, we need to ensure that our research efforts address the needs of ethnic minority and underserved cancer survivors. Thus, we need programs of care, health care services, and resources that are culturally and linguistically responsive. As the ethnic minority breast cancer survivor population continues to grow, understanding the experience of Latina BCS in navigating the complex healthcare system for their follow-up care, the healthcare providers they see, and the quality of care received is essential. Assessing quality of care may help uncover unknown care needs of Latina BCS that in turn can contribute to providing high-quality care and improved survivorship outcomes and quality of life.

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Table 1

Demographic sample characteristics by language, $N=232$ Southern California Latina women with breast cancer, 2005–2010

	Total sample	Spanis-speaking	English-speaking	Chi-square
	Total (%)	Total (%)	Total (%)	
Age				
<50	92 (40)	48 (35)	44 (46)	3.53
50–64	104 (45)	68 (50)	36 (38)	
65+	36 (15)	21 (15)	15 (16)	
Education				
<High school	109 (47)	97 (72)	12 (13)	91.2***
High school	33 (14)	19 (14)	14 (15)	
>High school	88 (38)	19 (14)	69 (72)	
Birth place				
US	61 (26)	4 (3)	57 (60)	94.9***
Outside US	169 (74)	132 (97)	37 (40)	
Income				
<25 K	125 (54)	96 (70)	29 (31)	67.7***
\$25–45K	47 (20)	32 (23)	15 (16)	
>\$45–75K	25 (11)	7 (5)	18 (19)	
>\$75K	34 (15)	2 (2)	32 (34)	
Currently employed				
No	140 (61)	102 (75)	38 (40)	27.1***
Yes	91 (39)	35 (25)	56 (60)	
Marital status				
Partnered	140 (61)	84 (62)	56 (59)	0.186
Unpartnered	91 (39)	52 (38)	39 (41)	
Insurance status				
No insurance	51 (22)	44 (32)	7 (7)	37.8***
HMO/PPO	110 (48)	43 (32)	67 (72)	
Medi-Cal	69 (30)	49 (36)	20 (21)	

 $p<0.001$

Table 2

Cancer-related medical characteristics and follow-up care by language

	Total sample Total (%)	Spanish- speaking Total (%)	English- speaking Total (%)	Chi-square
BC stage				
0/1	96 (42)	56 (42)	40 (42)	0.448
2	95 (41)	54 (40)	41 (43)	
3	38 (17)	24 (18)	14 (15)	
Lumpectomy				
No	107 (46)	68 (50)	39 (41)	1.66
Yes	125 (54)	69 (50)	56 (59)	
Mastectomy				
No	137 (59)	72 (53)	65 (68)	5.84*
Yes	95 (41)	65 (47)	30 (32)	
Immediate reconstruction				
No	207 (89)	128 (93)	79 (83)	6.15*
Yes	25 (11)	9 (7)	16 (17)	
Radiation therapy				
No	69 (30)	36 (26)	33 (35)	1.92
Yes	163 (70)	101 (74)	62 (65)	
Chemotherapy				
No	70 (30)	41 (30)	29 (31)	0.010
Yes	162 (70)	96 (70)	66 (69)	
Hormonal therapy				
No	78 (34)	47 (34)	31 (33)	0.071
Yes	154 (66)	90 (66)	64 (67)	
Cancer follow-up care				
Medical setting for follow-up care				
No place	73 (32)	37 (27)	36 (38)	15.9***
Clinic or health center	39 (17)	34 (25)	5 (5)	
Doctor office/HMO	118 (51)	64 (48)	54 (57)	
Primary care provider				
No	61 (27)	39 (30)	22 (24)	1.02
Yes	163 (73)	92 (70)	71 (76)	
Gynecologist				
No	65 (29)	41 (32)	24 (26)	0.932
Yes	157 (71)	88 (68)	69 (74)	
Cancer specialist				
No	63 (28)	35 (26)	28 (30)	0.314
Yes	166 (72)	99 (73)	67 (70)	

*
 $p < 0.05$;

 $p < 0.001$

Table 3

Quality of care by language, provider specialty, and medical setting

	M (SD)	T test
Language		-3.42**
Spanish-speaking	24.7 (3.9)	
English-speaking	27.2 (6.2)	
Primary care provider		-1.51
No	24.9 (5.6)	
Yes	26.1 (4.9)	
Gynecologist		1.10
No	26.4 (5.1)	
Yes	25.6 (5.2)	
Cancer specialist		-9.17***
No	21.7 (3.8)	
Yes	27.3 (4.7)	
	M (SD)	F test
Medical setting for follow-up care		50.1***
No place	21.9 (4.3) ^{b c}	
Clinic or health center	25.1 (4.1) ^b	
Doctor's office/HMO	28.3 (4.3) ^{a b}	

^{abc} Post hoc tests: significant group differences at $p < 0.05$

^a No Place

^b Clinic/health center

^c Doctor's office/HMO

** $p < 0.01$;

*** $p < 0.001$

Table 4

Predictive model of quality of care

	Unstandardized b coefficients			
	Model 1 R ² =0.135 F=2.91**	Model 2 R ² =0.173 F=2.45**	Model 3 R ² =0.364 F=5.63***	Model 4 R ² =0.443 F=7.06***
Demographic characteristics				
Age (ref: 65+)				
<50	-1.94	-2.24*	-2.24*	-1.17
50–64	-2.93**	-3.03**	-3.03**	-1.61
Education level (ref: >high school)				
<high school	0.321	0.402	0.699	0.593
High school	0.417	0.229	0.470	-0.296
Language (ref: Spanish-speaking)				
English-speaking	1.50	1.71*	2.35**	2.51**
Household income (ref: >\$75k)				
<\$25k	-1.97	-2.61*	-1.39	-1.23
\$25–45k	-0.658	-1.13	-0.677	0.068
>\$45–75k	-1.10	-1.74	-0.955	-0.775
Employed (ref: unemployed)				
Employed	0.146	0.086	0.124	0.161
Insurance status (ref: none)				
HMO/PPO	0.263	0.063	0.353	-0.013
Medi-Cal	-1.50	-2.08*	-1.51	-1.41
Cancer-related medical information				
Cancer stage		0.094	-0.007	0.134
Type of surgery				
Lumpectomy		-1.14	-0.467	-0.993
Mastectomy		0.178	0.163	-0.331
Treatment type				
Radiation		2.17*	1.56*	1.30
Chemotherapy		0.842	0.288	0.434
Hormonal therapy		0.146	0.429	0.399
Provider specialty				
Primary care provider			0.036	-0.323
Gynecologist			-1.01	-0.463
Cancer specialist			5.12***	2.24*
Cancer follow-up care				
Place for follow-up care (ref: doctor's office/HMO)				
No place				-4.59***
Clinic or health center				-1.90*

*
 $p < 0.05$;

**
 $p < 0.01$;

 $p < 0.001$