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Ductal carcinoma in situ: knowledge of associated risks and prognosis among Latina and non-Latina white women

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Abstract

While not itself life-threatening, ductal carcinoma in situ (DCIS) can progress to invasive disease if untreated, and confers an increased risk of future breast cancer. We investigated knowledge of DCIS among a cohort of English- and Spanish-speaking Latina and English-speaking non-Latina

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white women previously treated for DCIS. We examined knowledge of DCIS with four true/false statements about risk of invasive disease, breast cancer recurrence, and prognosis. For each knowledge statement, we modeled the odds of a correct answer by language–ethnicity (English-speaking Latinas, Spanish-speaking Latinas, and English-speaking whites) adjusting for demographics, health history, and treatment factors. Of 710 participants, 52 % were English-speaking whites, 21 % English-speaking Latinas, and 27 % Spanish-speaking Latinas. Less than half (41 %) of participants were aware that DCIS is not life-threatening and only 32 % knew that surgical treatment choice does not impact mortality; whereas two-thirds (67 %) understood that DCIS confers increased risk of future breast cancer, and almost all (92 %) knew that DCIS, if untreated, could become invasive. Only three Spanish-speakers used professional interpreters during discussions with their physicians. In adjusted analyses, compared to English-speaking whites, both English- and Spanish-speaking Latinas had significantly lower odds of knowing that DCIS was not life-threatening (OR, 95 % CI 0.6, 0.4–0.9 and 0.5, 0.3–0.9, respectively). In contrast, Spanish-speaking Latinas had a twofold higher odds of knowing that DCIS increases risk of future breast cancer (OR, 95 % CI 2.6, 1.6–4.4), but English-speaking Latinas were no different from English-speaking whites. Our data suggest that physicians are more successful at conveying the risks conferred by DCIS than the nuances of DCIS as a non-life-threatening diagnosis. This uneven communication is most marked for Spanish-speaking Latinas. In addition to the use of professional interpreters, efforts to create culturally and linguistically standardized information could improve knowledge and engagement in informed decision making for all DCIS patients.

Keywords

Ductal carcinoma in situ; Latino/Hispanic; Breast cancer; Language barriers; Healthcare disparities; Patient; physician communication

Background

Since the advent of mammographic screening for breast cancer, ductal carcinoma in situ (DCIS) has become a common diagnosis, accounting for almost one-third of mammographically diagnosed breast cancers [1, 2]. Recent data from the California Cancer Registry indicate an increase in the incidence of DCIS among Latina women from 9.6/100,000 in 1990 to 19.5/100,000 in 2009 and an increase in incidence among non-Latina white women from 20.2/100,000 in 1990 to 35.1/100,000 in 2009 [3]. While DCIS is not life-threatening and is highly curable, it can progress to invasive disease if left untreated and does confer an increased risk of future breast cancer. Evidence suggests that up to 50 % of untreated DCIS may progress to invasive breast cancer over a women's lifetime [4].

The primary goal of DCIS treatment is to prevent invasive breast cancer [5]. Treatment options include mastectomy which is associated with a recurrence rate of only 1 % or breast-conserving surgery (BCS), with or without radiation therapy. BCS has comparable survival rates to mastectomy but has higher rates of local recurrence, particularly without radiation therapy [6–8]. Hormonal therapy may also be recommended for some DCIS patients [9]. Given the range of therapeutic options and the decisions required to determine the optimal treatment approach, patients need a clear understanding of the risk implications of a DCIS

diagnosis in order to make informed treatment decisions. However, communicating the risk implications of DCIS can be challenging due to their complexity [10].

One prior study demonstrated that although women with DCIS were satisfied with their care, there were significant gaps in women's knowledge about their diagnosis. These knowledge gaps were particularly notable with regard to the course and severity of the disease, and understanding of future breast cancer risk. Participants in this study were from a single clinical site and were almost all white [11]. Two more recent studies from Australia also demonstrated a knowledge gap about the lack of metastatic potential of DCIS, finding that women who thought DCIS could metastasize were more likely to be worried about dying from DCIS [12, 13].

This already-complex communication challenge is further complicated when there exists a need to communicate health information across culture and language. Less acculturated Latinas are more likely to be worried about their breast cancer diagnosis and worry is associated with a poorer understanding of information [14]. Additionally, language barriers may impede Spanish-speaking women from asking all of their questions at the time of breast cancer diagnosis [15]. There is limited information about the knowledge of DCIS particularly among Latina women. In a prior multi-ethnic, multilingual study examining women's knowledge of early-stage breast cancer, the authors found that only one-fifth of patients understood that there was a difference in recurrence rate between mastectomy and breast-conserving therapy and only half of patients knew that survival rates were equivalent across treatment strategies [16]. This study did not report results for women with DCIS separately from those with Stage I invasive breast cancer, nor did they report results separately for 8 % of the sample that was Latina.

Given the paucity of literature regarding the understanding of DCIS in Latina women, in the current study we sought to evaluate knowledge of DCIS among a cohort of English- and Spanish-speaking Latina and English-speaking non-Latina white women previously treated for DCIS. We hypothesized that due to a language barrier, Spanish-speaking Latinas would be least likely to know the risk implications of a DCIS diagnosis.

Methods

Study population and data collection

Data for this analysis were collected as part of an observational study designed to examine treatment decision-making, satisfaction, communication, and knowledge among Latina and non-Latina white women treated for DCIS. Details of participant recruitment and data collection have been published previously [17]. In brief, we identified potential participants through a statewide population-based cancer registry, the California Cancer Registry (CCR), representing 35 of 58 counties in California. Participants met the following inclusion criteria: (1) diagnosed with histologically confirmed DCIS in 2002–2005; (2) self-identified as Latina or non-Latina white; (3) English or Spanish-speaking; (4) 18 years of age or older; and (5) no subsequent diagnosis of invasive breast cancer. Study recruitment took place between January 2005 and September 2006. Within each region and county, all Latina women were sampled. Given the larger number of non-Latina white women, they were

selected randomly and matched to Latina cases by age (within 5-year increments), diagnosis period (within 6-month intervals), and county of diagnosis.

We conducted telephone interviews in English or Spanish according to the participant's preference, approximately 24 months after initial diagnosis. This 24-month period was necessary to receive and process complete information from the CCR and to reach participants for interviews. The UCSF Committee on Human Research approved all study procedures and informed consent was obtained from all participants. Verbal informed consent was obtained before initiating the telephone interview. Bilingual interviewers were trained by the project director through extensive role-playing and were provided with structured scripts. English and Spanish structured interview scripts were used indicating the purpose of the interview while informing the participant that the interview was voluntary and that they could elect to stop the interview at any point.

Measures

Primary predictor: ethnicity–language—Participants were sampled according to ethnicity in the CCR: Latina or non-Latina white. We confirmed their ethnicity by self-report at the time of enrollment. We additionally categorized Latinas as English-speaking or Spanish-speaking according to their preferred language of interview. Interview language, when compared for a subset of participants, was highly correlated with self-reported ability to speak English. Of the women who completed the interview in Spanish, 6.3 % reported that they spoke English well or very well.

Outcome: knowledge—We adapted a series of questions previously used to evaluate women's knowledge of DCIS to focus on risk of future breast cancer and mortality [11]. Embedded within a series of questions about breast cancer, the following four statements about future breast cancer risk and mortality risk were presented to the patients with the response options of true/false/unsure: “This type of breast cancer is not itself life-threatening,” “Women with this type of breast problem have more chances of developing breast cancer in the future,” “If untreated, this type of breast problem can become invasive cancer,” and “The chances of dying from the breast problem are the same for women who have a mastectomy and for those who have a lumpectomy with radiation.” The correct answer for each of these questions was “true.”

Demographic information

Women self-reported their educational attainment (less than high school/high school or vocational graduate/college or higher), current insurance status (public/private/no insurance/unknown), and age at the time of interview. Since in California women without insurance coverage would have qualified for Medicaid during their breast cancer treatment, and very few women ($n = 47$) reported no or unknown insurance, we combined those categories with public insurance. For descriptive and analytic purposes, we combined the 35 CCR regions into five geographic areas in California according to the counties covered (Bay Area, Central and Sacramento, Los Angeles and Tri-County, Riverside and San Bernardino, and San Diego).

Health history

DCIS treatment was documented in the CCR data and confirmed with women during their interview (mastectomy, lumpectomy without radiation, and lumpectomy with radiation). Three women who reported no treatment were not included in the analysis. We made this decision in order to be consistent with the methods in previous analyses of these data, and because our use of CCR data restricted us to reporting on groups of women. As only three women did not have treatment, this number did not represent a large enough group to report on separately. We asked women about their family history of breast cancer and categorized women as having an immediate relative (mother, sister, daughter, aunt, or grandmother), a distant relative, or no relative with breast cancer. As the number of women reporting a distant relative with breast cancer was small ($n = 49$), we combined those with a distant relative and those with no relative.

Diagnostic information

We asked women if they obtained a second opinion prior to their treatment for DCIS (yes/no). We additionally recorded the time from diagnosis to the time of interview to account for possible variation in recall.

Statistical analysis

We compared demographic, health history, diagnostic information, and knowledge outcome variables by language–ethnicity group (English-speaking Latinas, Spanish-speaking Latinas, and English-speaking whites). We used descriptive statistics to report overall proportions and means, and Chi square and *t*-tests to compare the groups. For the knowledge outcomes, we described the proportion in each group answering each of the four questions yes, no, or unsure.

In multivariate analysis, we modeled the odds of giving a correct answer for each question by ethnicity–language group and surgical treatment type (combining lumpectomy with and without radiation as very few Latinas reported no radiation). We further adjusted for family history of breast cancer, educational attainment, age, insurance, geographic region in California, time between diagnosis and interview, and having sought out a second opinion.

Results

Of the 1,231 women eligible for the study, attempts to contact them resulted in 319 refusals, 167 non-respondents, and 745 completed surveys. Whites had a higher completion rate than Latinas (67 % and 55 %, respectively) [17]. From this group of 745, a total of 710 patients answered the knowledge survey questions and were included in this study.

Sample characteristics

More than half of the sample was English-speaking whites (52 %), 21 % were English-speaking Latinas and 27 % were Spanish-speaking Latinas. The mean age of the sample overall was 57 (range 27–78), with balanced proportions of women less than age 50, age 50–64, and age 65 in all groups (Table 1).

Most of the white women reported having completed a college education, whereas most of the Spanish-speaking Latinas reported having completed less than a high school education. English-speaking Latinas reported a wider range of educational attainment. Most English-speaking whites and English-speaking Latinas were privately insured, compared to only half of Spanish-speakers. The distribution of surgery type was similar across groups, although fewer English-speaking whites underwent radiation therapy. Spanish-speakers were less likely than women in the other groups to have had an immediate relative with breast cancer or to have obtained a second opinion.

Of the 190 Spanish-speaking Latina participants, 64 % reported having someone present to interpret for them while with their breast cancer physician. Of these, 50 % had a family member or friend interpret for them, 44 % had non-interpreter clinic staff (e.g., a nurse or clerk) interpret, and 3 % had a professional interpreter. Four participants did not report who did the interpreting.

Knowledge of DCIS

Overall, less than half (41 %) of the women were aware that DCIS is not life-threatening and only a third (32 %) knew that mortality risk is the same for mastectomy and lumpectomy plus radiation. By contrast, two-thirds (67 %) were aware that DCIS confers increased risk of future breast cancer, and almost all (92 %) knew that it could become invasive if not treated (Table 2).

English-speaking whites were most likely to know that DCIS is not life-threatening. Spanish-speaking Latinas were most likely to correctly assess that women with DCIS have a higher chance of developing breast cancer in the future and that the mortality from DCIS after mastectomy was similar to that after lumpectomy with radiation.

These results persisted in multivariable-adjusted analysis for knowledge of the life-threatening nature of DCIS and risk of future breast cancer (Table 3). Compared with English-speaking whites, both English-speaking and Spanish-speaking Latinas had significantly lower odds of knowing that DCIS was not itself life-threatening (OR, 95 % CI 0.6, 0.4–0.9 and 0.5, 0.3–0.9 respectively). In contrast, Spanish-speaking Latinas had more than twofold higher odds of knowing that DCIS increases risk of future breast cancer (OR, 95 % CI 2.6, 1.6–4.4) while there was no difference in knowledge between English-speaking Latinas and English-speaking whites. Surgical treatment type was not independently associated with knowledge of any of the four items. None of the potential confounders except for age were associated with any of the knowledge outcomes. Age was associated with decreased odds of knowing the risk of future breast cancer (OR, 98 % CI 0.98, 0.96–1.00).

Discussion

This multi-ethnic, multilingual study design provided an ideal opportunity to investigate patient–provider exchange of information regarding DCIS, a complex and often poorly communicated diagnosis.

In this study of DCIS knowledge in a cohort of Latina and non-Latina white women, we hypothesized that Spanish-speaking Latinas would have poorer knowledge about the risks and prognosis related to DCIS than their English-speaking counterparts. However, our results reveal a more complicated scenario. Less than half of all women (41 %) demonstrated accurate knowledge about the long-term clinical impact of DCIS, even among those having attained a college education. While knowledge that DCIS is not itself life-threatening was low in our study overall, both Spanish- and English-speaking Latinas were less likely to correctly answer this question when compared to white women. In contrast, Spanish-speaking Latinas were more likely than their English-speaking counterparts—both Latinas and whites—to know that a diagnosis of DCIS confers an increased risk of a breast cancer diagnosis in the future. There was no difference among groups in knowledge of the risk of invasive cancer if DCIS is left untreated—the vast majority of women in all groups were aware of this risk. There was also no difference in the understanding of DCIS treatment and mortality. The majority of women in all groups lacked an understanding of this relationship, with less than one-third of all women indicating that there was no impact on mortality based on treatment choice. Overall, these findings suggest that overall knowledge of the prognosis and treatment implications for DCIS are poorly understood. Among Spanish-speaking women diagnosed with DCIS, there appears to be a clear message from their physicians about the risks, but perhaps not about the good prognosis of DCIS.

Our findings are consistent with prior studies of primarily white women who have found knowledge gaps in those diagnosed with either DCIS or invasive breast cancer [11–13, 16]. Importantly, these and other studies have indicated that less knowledge is associated with more anxiety and distress [10, 13, 18]. One qualitative study by members of our group found that Latinas tend to have more distress about their diagnosis than whites [19]. Thorough information exchange has the potential to build positive relationships between patients and their providers and furthermore may help women build a sense of mastery over their breast cancer [20]. The lack of such an exchange likely contributes to less knowledge and more worry. These results complement other research by our team where we asked breast surgeons and oncologists about challenges in communicating prognosis with patients across language barriers. More than half of the breast cancer physicians surveyed expressed experiencing difficulty discussing prognosis with their limited English proficient (LEP) patients and the majority worried that their LEP patients might not be asking all of their questions during these discussions [15]. Together with our current findings that Spanish-speaking women understand DCIS risks better than prognosis, it appears that physicians may focus on messages about the importance of treatment and follow-up in DCIS when communicating with LEP patients, rather than more positive and complex messages about the differences between DCIS and invasive cancer in terms of prognosis. Furthermore, Spanish-speaking Latina women may be less likely to ask questions to clarify their understanding, leading to poorer overall knowledge about their prognosis [21].

Importantly, we noted that despite the complexity of these discussions, only three Spanish-speaking women in our study reported having a professional interpreter present during visits with their cancer physicians. Professional interpreters have been shown to improve patient outcomes and patient and physician satisfaction with care for LEP patients across a spectrum of conditions and clinical settings [22]. The absence of professional interpreters and the use

of ad hoc family and clinic staff not trained to interpret may have contributed to a more reductionist approach to communicating about risk and prognosis associated with DCIS [23]. Physicians likely focused on a discussion of risk and the need for treatment to prevent invasive disease. Furthermore, patients may not have had sufficient opportunity to ask questions. Moreover, according to National Culturally and Linguistically Appropriate Services (CLAS) Standards in Health and Health Care, providers who received federal funding are mandated to provide language assistance to LEP patients [24]. The mandate requires that patients are made aware of language services and further suggests that the use of untrained interpreters should be avoided. The lack of provision of trained interpreters is not only of utmost importance to patient care, but is also a federal mandate.

This study has limitations, most notably the fact that women were interviewed on average two years after their diagnosis, which may have led to inaccurate recall of events that occurred around treatment. While answers to the knowledge questions may not accurately describe knowledge at the time of diagnosis and treatment, it has been shown in other longitudinal studies that perception of risks related to breast cancer does not change over time [18, 25]. An additional limitation of this survey-based study is that we were not able to observe actual discussions about risk and prognosis between participants and their physicians and had to rely on self-reported data. Another limitation is the fact that only 60 % of eligible women completed the survey which could make the findings less generalizable. However, women from all geographic areas of California, representing a wide range of socio-demographics did participate. Despite these limitations, our findings do provide insight into the overall poor understanding of DCIS among those having gone through treatment for the disease and indicates a clear need for improved communication around presenting treatment options and prognosis.

Conclusion

In this multi-ethnic, multilingual study of women with a recent history of DCIS diagnosis and treatment, participants had greater knowledge of the worrisome risks conferred by DCIS than the nuances of DCIS as a non-life-threatening disease with a good prognosis. This knowledge imbalance was most marked for Spanish-speaking Latina women, and may be a reflection of physicians' simplified communication with patients in the face of cultural and linguistic barriers. Culturally and linguistically appropriate standardized information about risks, treatment options, and prognosis would improve knowledge for all women diagnosed with DCIS. In particular, surgeons and oncologists treating LEP patients should be encouraged to use professionally trained interpreters to avoid overly simplified messages and promote more thorough information exchange.

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Table 1Description of the sample by language–ethnicity ($N = 710$)

	English-speaking whites ($N = 368$) N (%)	English-speaking Latinas ($N = 152$) N (%)	Spanish-speaking Latinas ($N = 190$) N (%)	p value
Demographic information				
Education				
Less than high school	10 (3)	21 (14)	113 (60)	< 0.0001
High school/vocational graduate	71 (19)	51 (34)	37 (20)	
College or higher	285 (78)	78 (52)	38 (20)	
Insurance				
Public	65 (18)	36 (24)	102 (54)	< 0.0001
Private	303 (82)	116 (76)	88 (46)	
Age				
< 50	105 (29)	42 (28)	64 (34)	0.50
50–64	173 (47)	70 (46)	89 (47)	
65	90 (24)	40 (26)	37 (19)	
California Cancer Registry region				
Bay area	103 (28)	39 (26)	34 (18)	0.13
Central and Sacramento	71 (19)	39 (26)	41 (22)	
L.A. and Tri-County	114 (31)	40 (26)	69 (36)	
Riverside and San Bernardino	48 (13)	25 (16)	27 (14)	
San Diego	32 (9)	9 (6)	19 (10)	
Health history				
Treatment type				
Lumpectomy with radiation	179 (49)	90 (59)	101 (53)	0.01
Lumpectomy, no radiation	72 (20)	14 (9)	22 (12)	
Mastectomy	117 (32)	48 (32)	67 (35)	
Family members with breast cancer				
Immediate relative	153 (42)	67 (44)	38 (20)	< 0.0001
Distant relative or none	215 (58)	85 (56)	152 (80)	
Diagnostic information				
Obtained second opinion				
Yes	167 (46)	63 (41)	39 (21)	< 0.0001
Time since diagnosis				
Months, mean \pm SD (range)	25 \pm 8 (8–49)	23 \pm 7 (9–43)	22 \pm 8 (7–51)	0.0002

Table 2DCIS knowledge by language–ethnicity ($N = 710$)

	English-speaking whites ($N = 368$) N (%)	English-speaking Latinas ($N = 152$) N (%)	Spanish-speaking Latinas ($N = 190$) N (%)	p value
This type of breast problem is not itself life-threatening				
True	178 (48)	52 (34)	60 (32)	0.0005
False	152 (41)	77 (51)	109 (57)	
Unsure	38 (10)	23 (15)	21 (11)	
Women with this type of breast problem have more chances of developing breast cancer in the future				
True	228 (62)	94 (62)	152 (80)	< 0.0001
False	46 (13)	22 (14)	5 (3)	
Unsure	94 (26)	36 (24)	33 (17)	
If untreated, this type of breast problem can become invasive cancer				
True	344 (93)	140 (92)	169 (89)	0.17
False	8 (2)	4 (3)	3 (2)	
Unsure	16 (4)	8 (5)	18 (9)	
The chances of dying from the breast problem are the same for women who have a mastectomy and for those who have a lumpectomy with radiation				
True	108 (29)	51 (34)	70 (37)	< 0.0001
False	124 (34)	35 (23)	29 (15)	
Unsure	136 (37)	66 (43)	91 (48)	

Percentages may add to greater than 100 % due to rounding error

Table 3Multivariable logistic regression: DCIS knowledge ($N = 710$)

	Not itself life-threatening OR (95 % CI)	More chances of future breast cancer OR (95 % CI)	If untreated, can become invasive OR (95 % CI)	Mortality the same for mastectomy and for lumpectomy + radiation OR (95 % CI)
Language–ethnicity				
English white	Reference	Reference	Reference	Reference
Latina English Latina	0.6 (0.4–0.9)	1.0 (0.6–1.4)	0.9 (0.4–1.8)	1.1 (0.7–1.7)
Latina Spanish Latina	0.5 (0.3–0.9)	2.6 (1.6–4.4)	0.7 (0.3–1.6)	1.2 (0.7–1.9)
Treatment type				
Mastectomy	Reference	Reference	Reference	Reference
Lumpectomy	1.2 (0.9–1.7)	1.0 (0.7–1.4)	0.9 (0.5–1.6)	1.0 (0.7–1.4)

All models also adjusted for family history of breast cancer, educational attainment, age, insurance, geographic region in California, time since diagnosis, and having sought out a second opinion