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ORIGINAL ARTICLE

Supportive care priorities of low-income Latina breast cancer survivors

Alix G. Sleight[1] · **Kathleen Doyle Lyons**[2,3] · **Cheryl Vigen**[1] · **Heather Macdonald**[4] · **Florence Clark**[1]

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Abstract

Purpose This study investigated the supportive care needs of a sample of low-income Latina breast cancer survivors.

Methods Ninety-nine Spanish-speaking breast cancer survivors who self-identified as Latina and reported an income below the US Census Bureau low-income threshold were recruited from the oncology clinic of a major public safety net hospital. Eligible participants completed the supportive care needs survey (SCNS-SF34) and a demographic questionnaire.

Results Ninety-three percent of respondents had unmet needs. The majority of frequently reported unmet needs involved (1) access to and delivery of health-related information and (2) physical function. These findings appear to contrast with those of other studies of supportive care needs in heterogeneous cancer survivors, most of which describe psychological concerns as most urgent.

Conclusions Participants espoused information-related needs with a higher frequency than many other samples of cancer survivors. This study population may also require a particularly high level of assistance with overcoming participation restrictions. Further research is needed to understand these discrepancies and to address unmet needs across all domains.

Keywords Hispanic Americans · Breast cancer · Needs assessment · Socioeconomic factors

Introduction

Among Latina women in the USA, breast cancer is the most common cancer type, with an estimated 19,800 new cases of breast cancer occurring annually [1]. However, Latinas tend to receive a lower quality of health care than non-Hispanic whites [2], and Latino cancer survivors in the USA report significantly higher levels of distress and lower health-related quality of life than non-Hispanic white cancer survivors [3]. In addition, socioeconomic and gender disparities contribute to decreased quality of life and poorer quality health care in Latina cancer survivors [4, 5]. Low-income Latina breast cancer survivors are therefore particularly at risk for poor health outcomes.

Supportive care is defined as any service that facilitates coping with cancer and its physical and psychosocial sequelae [6]. Robust, culturally tailored supportive care interventions that address physical, psychosocial, and informational needs while being responsive to differences in language, health literacy, and cultural values have been associated with improved health outcomes for Latina breast cancer survivors [7]. In contrast, unmet supportive care needs are associated with

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✉ Alix G. Sleight
sleight@usc.edu

Kathleen Doyle Lyons
kathleen.d.lyons@dartmouth.edu

Cheryl Vigen
vigen@usc.edu

Heather Macdonald
hmacdona@med.usc.edu

Florence Clark
fclark@usc.edu

[1] Mrs. T.H. Chan Division of Occupational Science and Occupational Therapy, University of Southern California, Los Angeles, CA, USA

[2] Norris Cotton Cancer Center, Dartmouth-Hitchcock Medical Center, Lebanon, NH, USA

[3] Geisel School of Medicine at Dartmouth, Hanover, NH, USA

[4] Keck School of Medicine, University of Southern California, Los Angeles, CA, USA

decreased quality of life and psychological distress in ethnically diverse breast cancer survivors [8, 9]. Strong supportive care services are therefore crucial to maximizing well-being and minimizing during cancer survivorship [8, 9]. Despite the critical importance of supportive care and the risk for poor health outcomes in racial/ethnic minority populations, very little research has been conducted to date regarding the specific needs and experiences of culturally diverse breast cancer survivors [10]. As a result, not enough is currently known about the unique supportive care needs of low-income Latina breast cancer survivors in order to design appropriately tailored supportive care services.

Given that the number of low-income Latina women with breast cancer in the USA continues to increase [7, 11], it is imperative to identify the unique supportive care needs of this population so they may be adequately addressed to optimize health outcomes. This study investigates the supportive care needs of a sample of low-income Latina breast cancer survivors with the aim of improving care for this population.

Methods

After obtaining ethnical approval from the study site and the university where the first author is affiliated, recruitment took place using flyers in the waiting room of the Los Angeles County + USC Medical Center (LAC+USC) Oncology Clinic. LAC+USC is a 600-bed public hospital and the largest single provider of health care in Los Angeles County. In order to maximize the number of eligible participants accrued during each session, individuals were recruited from the clinic on days specifically reserved for breast cancer follow-up appointments. Inclusion criteria for study respondents were (1) adults 18 years or older; (2) self-identifying as Latina; (3) self-reported income falling below the low-income threshold, defined as < 200% of the federal poverty level, determined on a sliding scale for each family size [12, 13]; (4) receiving ongoing care at LAC+USC; (5) diagnosis of breast cancer; (6) completed primary surgical treatment, chemotherapy, and radiation; (7) ability to understand English and/or Spanish; and (8) willingness to sign a written informed consent. Individuals currently undergoing hormone therapy or reconstructive surgery or were considered eligible for this study, while women with metastatic cancer and those still undergoing chemotherapy or radiation were excluded.

Three Spanish-speaking research assistants circulated flyers, screened patients, and administered questionnaires with clinic visitors who preferred to speak Spanish. The first author completed all recruitment, screening, and study administration tasks with clinic visitors who preferred to speak English. All eligible patients were escorted to a private room inside the LAC+USC Oncology Clinic. Informed consent was obtained from all individual participants included in the study. After obtaining informed consent, participants were asked to complete four unique questionnaires in their language of choice (Spanish or English) that asked about (1) demographics, (2) unmet supportive care needs, (3) health-related quality of life, and (4) health behaviors and logistical challenges. The current analysis focuses on the unmet supportive care needs questionnaire. All participants who completed the questionnaires were compensated for their time with a $5.00 gift card.

Measures

Supportive care needs survey (SCNS-SF34)

The SCNS-SF34 is a standardized, 34-item, condensed version of the 59-item Supportive Care Needs Survey, the most commonly used tool currently available to capture the supportive care needs of cancer survivors. Its psychometric properties have been well documented [14], and it has demonstrated validity and reliability for utilization across various cancer types, including breast cancer [15]. The survey has been employed widely in over 50 published studies of supportive care need during cancer survivorship, and its Spanish-language version has demonstrated reliability and validity with Spanish-speaking Latino cancer survivors [16], making it appropriate for the primarily Latino patient population at LAC+USC.

The SCNS-SF34 measures satisfaction with health care in the following domains: (1) Psychological, (2) Health System and Information, (3) Physical and Daily Living, (4) Patient Care and Support, and (5) Sexuality. Each survey item is preceded with the stem question, “In the last month, what was your level of need for help with…?” The responses, displayed as a five-point scale, include (1) “no need, not applicable”; (2) “no need, satisfied”; (3) “low need”; (4) “moderate need”; or (5) “high need.” In accordance with the purpose of this study, the SCNS was used as a checklist, with the scores dichotomized into two categories: “no need” or “some need.” As such, all items marked “not applicable” or “satisfied” were designated no need. Items marked “low,” “moderate,” or “high” need were designated some need. In accordance with recommendations from the SCNS Spanish-language validation study [16], all participants with a Spanish-language preference were provided with verbal assistance from a bilingual guide to complete the survey.

Demographics

A standard demographic questionnaire was used to collect basic information relevant to the current study, including age, race/ethnicity, income level, educational attainment, and

Table 1 Participant characteristics ($n = 99$)

Age (years)	Mean (SD): 54.0 (8.6)
	30–39: 5
	40–49: 27
	50–59: 38
	60–69: 26
	70–79: 2
Years elapsed since cancer diagnosis, mean (SD)	4.52 (2.61)
Number of comorbidities, mean (SD)	1.45 (1.42)
	0: 28
	1: 32
	2: 17
	3: 16
	4: 3
	5: 2
	6: 0
	7: 0
	8: 1
Treatments completed	Surgery, radiation, and chemo: 49
	Surgery and radiation: 19
	Surgery and chemo: 13
	Surgery: 13
	Radiation: 4
	Chemo: 1
Education	8th grade or less: 57
	Some high school: 10
	High school graduate: 11
	Some university: 8
	Bachelor’s degree or higher: 5
	Technical/vocational training: 7
	Unknown: 1
Annual household income	< $10,000: 58
	10,000–14,999: 20
	15,000–24,999: 13
	25,000–49,999: 3
	≥ 50,000: 2
	Unknown: 3
Marriage status	Single: 37
	Married: 45
	Widowed: 4
	Divorced: 4
	Separated: 6
	Unknown: 3
Number of children	1: 15
	2: 24
	3: 23
	4: 16
	5+: 6
	0: 9
	Unknown: 6
Stage of cancer	Stage 1: 29
	Stage 2: 19
	Stage 3: 2
	Stage 4: 1
	Unknown: 29

cancer stage/laterality, among other variables (see Table 1). The questionnaire was translated into Spanish by a certified translation service and piloted with two Spanish-speaking breast cancer survivors. Bilingual research assistants read demographic questionnaire items out loud to participants to mitigate reading comprehension issues.

Data analysis

Basic descriptive statistics (means, modes, standard deviations) were obtained from the demographic questionnaire. Number of total unmet needs per participant (all responses falling into the some need category) were counted and averaged for the sample. Spearman correlation coefficients were calculated to analyze the relationship between unmet needs and all demographic variables that were hypothesized to be related (stage of cancer, income, education, number of comorbidities, age, and years since diagnosis). Unmet supportive care needs prevalence was determined using the proportion of patients reporting some need for each of the SCNS-SF34 items and then listing these items by descending frequency and grouping them by domain. Mean total scores and standard deviations were also calculated for each of the five SCNS-SF34 domains by calculating each participant’s raw score for each domain and then averaging those scores. These mean scores were then transformed into proportions of possible points per domain to rank each domain’s relative importance to study participants. Data analyses were conducted using the SAS software for Windows, version 9.4 (SAS, Cary, NC).

Results

Sample description

One-hundred-two participants met eligibility criteria and completed the surveys. Ninety-nine participants completed the surveys in Spanish with the assistance of a bilingual Spanish/English-speaking research assistant, while three completed the surveys in English. In the interest of consistency, the three English speakers were excluded from these analyses with no substantial change in results. See Table 1 for a full description of characteristics. The average age of all participants was 54 (range 35–78), and the average amount of time elapsed since diagnosis was 4.52 years (range 6 months–12 years). Seventy-nine percent of participants disclosed an annual income of $15,000 or less. A majority (68%) of participants reported completing less than a high school education. Comorbidities were commonly reported, with 72% of participants indicated having at least one comorbidity. Nearly a third (31%) of participants reporting having diabetes. The other most commonly reported comorbidities were hypertension (29%), arthritis (20%), overweight/obesity (13%), and depression (12%).

Overview of unmet supportive care needs

Respondents reported, on average, 14 unmet supportive care needs (range 0–33). Ninety-three percent of participants reported at least one unmet need. A higher score on the

SCNS-SF34 was significantly correlated with a higher number of comorbidities ($r = 0.20$, $p = 0.05$) in study participants. Correlations between unmet needs and other demographic and treatment-related variables noted above were all $r < 0.18$ and not statistically significant.

All 34 individual survey items are ranked by frequency in descending order in Table 2. The top 10 most frequently endorsed items are highlighted.

Of the 10 highest-need items, 7 were related to the Health System and Information needs domain. Two were related to the Psychological domain, 1 was related to the Physical and Daily Living domain, and 1 was related to the Patient Care and Support domain. No unmet needs from the Sexuality domain appeared in the top 10 items.

The proportion of survivors experiencing an unmet need ranged from a low of 19% (for the item "To be given information about sexual relationships") to a high of 57% (for the item "Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment, and follow-up"). Items from the Health System and Information domain were endorsed with the highest frequency (see Table 3 for a ranked list of all domains by total score). Questions from the Sexuality domain were the least frequently endorsed, with no single item reported as requiring additional support by more than 26% percent of respondents.

Top 10 unmet needs

Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment, and follow-up, from the Health System and Information domain, was the most frequently reported need across all domains and was endorsed by 58% of participants. The second most highly endorsed item in the Health System and Information domain was "Having access to professional counseling if you, family, or friends need it" (51% of respondents). Four other top 10 items in the Health Systems and Information domain pertained to the provision of adequate information: (1) "Being given information about aspects of managing your illness and side effects at home" (51% of respondents), (2) "Being informed about things you can do to help yourself to get well" (47% of respondents), (3) "Being given explanations of those tests for which you would like explanations" (46% of respondents), and (4) "Being given written information about the important aspects of your care" (44% of respondents). Two items from the top 10 fell within the Psychological domain: (1) "Concerns about the worries of those close to you" (53% of respondents) and (2) "Fears about the cancer spreading" (48% of respondents). One top 10 item, "Hospital staff attending promptly to your physical needs" (47% of participants), belonged in the Patient Care and Support domain. The last top 10 item, from the Health System and Information domain, was "Being treated like a person not just another case" (45% of respondents).

Participants citing no unmet needs

Seven participants reported having no unmet supportive care needs. These individuals did not differ substantially from the larger study sample across demographic variables, with the only notable difference being a longer time elapsed since diagnosis in participants reporting no unmet needs (5.2 vs. 4.4 years in the greater study population). One of these participants with no unmet needs had marked no need, not applicable for every item on the survey, an answer choice defined on the survey instructions as "this was not a problem for me as a result of having cancer." The other six respondents reported a mixture of both no need, not applicable and no need, satisfied responses across all survey items.

Discussion

The low-income Latina breast cancer survivors in this study reported a wide range of supportive care needs, with 93% reporting at least one unmet need. A greater number of unmet needs was significantly correlated with a higher number of comorbidities, reflecting the negative impact of the presence of comorbidities on quality of life for breast cancer survivors [4, 17].

The majority of frequently endorsed unmet supportive care needs in this population belonged in the Health System and Information domain, with 7 of the top 10 unmet needs falling within this category. The importance of the Health System and Information domain in this population contrasts with other studies using the SCNS. In most studies of supportive care needs in groups of heterogeneous cancer survivors across all cancer stages, the Psychological domain contains the most frequently endorsed items. Almost universally, Fears about the cancer spreading appears as the most commonly reported item across previous studies using the SCNS [e.g., 9, 18–22]. This commonality also extends to many SCNS studies focusing on breast cancer survivors. In a systematic review including 10 studies using the SCNS to measure unmet supportive care needs in breast cancer survivors [23], Fears about the cancer spreading was reported as the single most prevalent unmet need. While Fears about the cancer spreading appeared within the top 10 most prevalent needs in the present study, it was only the fifth most commonly endorsed. This discrepancy is not explainable by any substantial difference in time since diagnosis between samples, as participants in the current study population reported a similar range and average time since diagnosis as those in most previous SCNS research. Rather, the prioritization of Fears about the cancer spreading within other study populations may be partially attributable to the

Table 2 SCNS-SF34 items ranked by prevalence with top 10 needs highlighted ($n = 99$)

Rank	Item	Percent of sample reporting some needs, *n* (%)	Domain
1	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment, and follow-up	57 (57)	Health System and Information
2	Concerns about the worries of those close to you	52 (52)	Psychological
3	Having access to professional counseling (e.g., psychologist, social worker, counselor, nurse specialist) if you, family, or friends need it	51 (51)	Health System and Information
4	Being given information (written, diagrams, drawings) about aspects of managing your illness and side effects at home	50 (50)	Health System and Information
5	Not being able to do the things you used to do	48 (58)	Physical and Daily Living
5	Fears about the cancer spreading	48 (49)	Psychological
7	Hospital staff attending promptly to your physical needs	47 (47)	Patient Care and Support
7	Being informed about things you can do to help yourself to get well	47 (46)	Health System and Information
9	Being given explanations of those tests for which you would like explanations	45 (45)	Health System and Information
10	Being given written information about the important aspects of your care	44 (44)	Health System and Information
10	Being treated like a person not just another case	44 (44)	Health System and Information
12	Being adequately informed about the benefits and side effects of treatments before you choose to have them	43 (43)	Health System and Information
12	Being informed about your test results as soon as feasible	43 (43)	Health System and Information
12	Reassurance by medical staff that the way you feel is normal	43 (43)	Patient Care and Support
15	Being treated in a hospital of clinic that is as physically pleasant as possible	42 (42)	Health System and Information
15	Work around the home	42 (41)	Physical and Daily Living
17	Being informed about cancer which is under control or diminishing (that is, remission)	41 (41)	Health System and Information
17	Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	41 (40)	Patient Care and Support
17	Pain	41 (41)	Physical and Daily Living
20	Uncertainty about the future	40 (40)	Psychological
21	Lack of energy/tiredness	39 (37)	Physical and Daily Living
22	Feelings about death and dying	38 (39)	Psychological
22	Feeling down or depressed	38 (38)	Psychological
22	Feeling unwell a lot of the time	38 (37)	Physical and Daily Living
25	Feelings of sadness	37 (37)	Psychological
25	Keeping a positive outlook	37 (37)	Psychological
25	More choice about which cancer specialists you see	37 (37)	Patient Care and Support
28	Anxiety	33 (33)	Psychological
28	Learning to feel in control of your situation	33 (33)	Psychological
30	Worry that the results of treatment are beyond your control	32 (32)	Psychological
31	Changes in sexual feelings	26 (25)	Sexuality
32	More choice about which hospital you attend	23 (24)	Patient Care and Support
33	Changes in your sexual relationships	19 (19)	Sexuality
34	To be given information about sexual relationships	19 (19)	Sexuality

inclusion of participants with metastatic cancer and those undergoing active treatment, both of whom were excluded from the present study. These individuals are often more uncertain about their prognoses and, accordingly, experience more psychological needs than those with less advanced cancer and those who are finished with treatment [24–26]. Cultural differences and variations in health care models between populations likely also contributed to the disparate results between the current study and previous studies using the SCNS. To illustrate this point, Fielding et al. [27] compared three studies that employed the SCNS to measure unmet supportive care needs in three ethnic groups from three countries with different health care systems. After adjusting for clinical factors, they found that that treatment status and disease stage

Table 3 Mean scores for each domain of the SCNS-SF34

Domain	Number of items	Minimum score	Maximum score	Mean Score (SD)	Mean score as percentage of possible points
Health System and Information	11	11	55	28.4 (14.8)	52
Physical and Daily Living	5	5	25	11.5 (6.2)	46
Psychological	10	10	50	22.1 (10.5)	44
Patient Care and Support	5	5	25	11.1 (5.8)	44
Sexuality	3	3	15	5.1 (3.3)	34

accounted for the *least* variance in SCNS domain scores, while sample origin accounted for the most variance. Therefore, health service and cultural factors should not be discounted in future efforts to isolate determinants of supportive care needs in diverse populations.

Previous research indicates that breast cancer survivors across all ethnic groups receive more treatment-related information than survivorship-related information [28]. However, women in this study strongly endorsed survey items pertaining to treatment *and* survivorship-related information throughout the entire spectrum of care, from basic explanations of cancer treatments to instructions about health self-management and follow-up care. Given the demographic characteristics of the study participants, two characteristics may have influenced a higher proportion of unmet needs in the Health System and Information domain: (1) Spanish-language preference and (2) lower health literacy. Research suggests that Latinos with a Spanish-language preference have significantly worse health status than English-speaking Latinos [29, 30]. Often, communication problems in non-English-speaking patients are addressed through the implementation of translation services [31]. However, some research has suggested that public safety net hospitals may lack skilled translators who can provide not only literal translation but also culturally resonant interpretation and accurate depiction of emotional content [32]. Health literacy, defined as the capacity to obtain, process, and understand basic health information [33], may also have influenced information needs. Older age, racial/ethnic minority status, less education, lower income, and less time spent living in the USA have been shown to predict lower health literacy [34]. In turn, limited health literacy has been shown to predict higher unmet information needs [35]. Experts suggest that in working with populations with lower health literacy, it may be useful to offer in-depth patient counseling with health educators in a less intimidating environment. Two emerging models of care may therefore be helpful in future efforts to meet information-related needs in this population: (1) patient navigation and (2) the *Promatora de Salud*/Lay health worker model.

Patient navigators are lay people selected from the community who are often bilingual and familiar with the cultures of the patients they serve [36, 37]. These individuals may therefore help racial/ethnic minorities and low-income survivors better access and understand health-related information [38]. Patient navigators are also able to help underserved patients circumvent financial and logistical barriers to accessing treatment and supportive care [38], which are commonly experienced among minority populations [39]. *Promotoras de Salud*, who are trained, bilingual, lay health promoters from the community, have also been shown to be efficacious in relaying important information regarding breast cancer prevention and treatment to Latina women [40]. Promotoras may therefore be used in health care settings to facilitate access to information and services as well as to provide support and a cultural context for discussing issues surrounding cancer [41]. When widely integrated into models of cancer care, patient navigators and promotoras may contribute to meeting the commonly cited need in the current study for a single individual with which to discuss all aspects of health, cancer treatment, and follow-up.

Notably, items from the Physical and Daily Living domain were the second most frequently endorsed in the current study population. “Not being able to do the things you used to do” was the most pressing issue in this category, ranked at #5. This finding is not surprising given that cancer survivors often experience modest to moderate degrees of functional deficit [42], and commonly require additional supportive care for physical impairments [43] and psychological and emotional sequelae [1], all of which can lead to participation restrictions. “Not being able to do the things you used to do” was more commonly endorsed in the current study than in numerous previous studies of breast cancer survivors using the SCNS [e.g., 9, 24, 44–48], indicating an unusually prevalent need for help with participation limitations in this population.

In order to better meet function and participation-related needs, health care providers may consider two approaches: (1) anticipate and prevent cancer treatment-related impairments through a prehabilitation process and (2) streamline referrals to a multidisciplinary rehabilitation team. Prehabilitation is the process of intervening to improve physical and psychological health *prior* to acute cancer treatment [49], which has been shown to enhance function and reduce future impairments during survivorship [50]. Examples of prehabilitation approaches may include nutritional optimization, stress reduction/psychological support, smoking cessation, and exercise regimens [51]. Breast cancer survivors in particular may be able to avoid functional deficits stemming from upper extremity limitations with a prehabilitation approach [52].

Multidisciplinary rehabilitation services have been shown to improve function and participation in many populations [53], but little evidence exists to support the efficacy of most rehabilitation interventions for cancer survivors [54]. Furthermore, most current models of cancer care lack a standardized procedure for identifying and addressing rehabilitation needs, potentially contributing to the high prevalence of untreated function-related problems during survivorship [55, 56]. For example, one study of 163 breast cancer survivors found that 92% required a physical rehabilitation intervention. However, despite the high level of need, fewer than 30% of these individuals ultimately received rehabilitation [43]. Efforts to better help cancer survivors "do the things they used to do" should therefore include (1) an emphasis on prehabilitation in combination with traditional rehabilitation, (2) further research on the efficacy of rehabilitation interventions during cancer survivorship, and (3) the development and testing of standardized mechanisms of referral from oncology to rehabilitation [57].

Limitations

This study measured the supportive care needs of a modest sample size from a single setting at one point in time, and therefore, its findings may not be generalizable and do not reflect how needs evolve over time. Another notable limitation is that the SCNS-SF34 anchors the need for help within a specific time period (1 month prior to survey completion). Since an inclusion criterion for this study was having completed all cancer treatment, the women in this study had been diagnosed, on average, nearly 5 years prior to completing the survey. Therefore, selected questions may not have been relevant to their recent experience within the past month (e.g., "being adequately informed about the benefits and side effects of treatments before you choose to have them"). This may have produced an underestimation of the supportive care needs of the general population of low-income Latina breast cancer survivors as the current study only reflects the needs of those in the recovery phase. Finally, the reading level of the SCNS-SF34, as calculated using the Flesch-Kincaid grade level score, is seventh to eighth grade [16]. Research assistants orally administered the survey to compensate for any reading comprehension difficulties. Nonetheless, the reading level of the SCNS may have hindered understanding of survey questions for some participants.

Conclusion

The most critical unmet supportive care needs of this population of low-income Latina breast cancer survivors involved access to and delivery of information. Participants also strongly endorsed a need for assistance with participation in everyday activities. These results appear to contrast with the findings of many other studies of supportive care needs in heterogeneous cancer survivors, most of which indicate a high prevalence of psychological concerns. The exclusion of participants with metastases and those undergoing active treatment in the current study may have influenced this discrepancy. However, sociocultural factors and attributes of the health care system likely also played a role in determining the prevalence of specific unmet needs in this population. Therefore, future research should further explore the needs of diverse populations of cancer survivors while homing in on the clinical factors, systemic issues, and sociocultural differences that predict specific unmet supportive care needs in each unique group. Ultimately, a better understanding of the unmet supportive care needs of low-income Latina breast cancer survivors will allow health care professionals working with this population to focus care on the issues considered most salient by their patients.

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Compliance with ethical standards

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

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