Quality of Life, Social Support, and Uncertainty Among Latina and Caucasian Breast Cancer Survivors: A Comparative Study

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he quality of life (QOL) of breast cancer survivors from diverse ethnic, cultural, and socioeconomic backgrounds is an emerging research priority (Ashing-Giwa et al., 2004); however, ethnic influence on the QOL of breast cancer survivors is a focus of research that has remained largely unexplored (Knobf, 2007). The existing knowledge base of the QOL of breast cancer survivors has been formulated from studies that mostly investigated middle- to upper-class Caucasian American women. QOL investigation of breast cancer survivors from ethnic minorities is sparse, as are comparative studies between Caucasian breast cancer survivors and those of ethnic minorities (Culver, Arena, Antoni, & Carver, 2002; Knobf; Leedham & Ganz, 1999).

Breast cancer is the most commonly occurring cancer within the Latina population (American Cancer Society [ACS], 2009), is diagnosed at a more advanced stage, and is the leading cause of cancer death (ACS; Hunter, 2000). Research studies that address how Latinas manage their breast cancer or its effect on QOL are particularly scarce (Knobf, 2007).

Social support and uncertainty have been identified as variables that influence the QOL of breast cancer survivors (Sammarco, 2001, 2003). Numerous studies have described the effect of social support and uncertainty on the QOL of predominantly Caucasian breast cancer survivors (Budin, 1998; Ferrans, 1994; Gil et al., 2004; Hoskins et al., 1996; Mast, 1998; Sammarco, 2001, 2003). As a result, the existing body of knowledge is limited in providing evidence that supports culturally competent healthcare delivery to Latina breast cancer survivors (Naranjo & Dirksen, 1998).

To address the paucity of QOL research that has been conducted among Latina breast cancer survivors, Sammarco and Konecny (2008) investigated the relationship among perceived social support, uncertainty, and QOL in this population. This article extends that inquiry. Latina and Caucasian cultural dynamics, sociodemographic differences, and behavioral characteristics create unique influences on breast cancer inci-

Purpose/Objectives: To examine the differences between Latina and Caucasian breast cancer survivors in perceived social support, uncertainty, and quality of life (QOL), and the differences between the cohorts in selected demographic variables.

Design: Descriptive, comparative study.

Setting: Selected private hospitals and American Cancer Society units in a metropolitan area of the northeastern United States.

Sample: 182 Caucasian and 98 Latina breast cancer survivors.

Methods: Participants completed a personal data sheet, the Social Support Questionnaire, the Mishel Uncertainty in Illness Scale–Community Form, and the Ferrans and Powers QOL Index–Cancer Version III at home and returned the questionnaires to the investigators via postage-paid envelope.

Main Research Variables: Perceived social support, uncertainty, and QOL.

Findings: Caucasians reported significantly higher levels of total perceived social support and QOL than Latinas.

Conclusions: Psychiatric illness comorbidity and lower level of education in Latinas were factors in the disparity of QOL.

Implications for Nursing: Nurses should be mindful of the essential association of perceived social support, uncertainty, and QOL in Latina breast cancer survivors and how Latinas differ from Caucasian breast cancer survivors. Factors such as cultural values, comorbidities, and education level likely influence perceived social support, uncertainty, and QOL.

dence, mortality, and survival (Sammarco & Konecny). Bringing the differences to light is important when formulating a culturally specific knowledge base to better meet the care requirements of Latina breast cancer survivors. Therefore, the purpose of this study was twofold: to examine the differences between Latina and Caucasian breast cancer survivors in perceived social support, uncertainty, and QOL; and to examine the differences between the cohorts in selected demographic variables.

Background

Hispanic, Latino, and Latina Population

The ethnic designations of Hispanic and Latina are used synonymously in the literature (Diaz, 2002). Latinas represent women from the heterogeneous communities of Mexico, Central America, the Caribbean, and South America living in the United States (Hulme et al., 2003). Variances in race, ethnicity, Spanish linguistics, socioeconomic status, and level of acculturation have been acknowledged among the subgroups. Nonetheless, subgroups share similarities in culture, language, social evolution, world view, and perceptions of health and well-being (Hulme et al.). For the purpose of this investigation, *Latinas* identifies the study population.

Perceived Social Support

Perceived social support is the awareness that leads to the belief that one is cared for, loved, esteemed, and valued and belongs to a network of communication and mutual obligation (Cobb, 1976). Social support, particularly perceived from close relationships with spouse and family, is a beneficial resource for the psychosocial adjustment of women with breast cancer (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007; Hoskins et al., 1996). The presence of breast cancer can disrupt women's emotional well-being, family life, and careers. Research has indicated that perceived social support can be instrumental in limiting the disruption of breast cancer (Alferi, Carver, Antoni, Weiss, & Durán, 2001). Among Latina breast cancer survivors, perceived social support has been associated with maintaining and predicting QOL (Alferi et al.; Sammarco & Konecny, 2008). However, women of color, those with lower levels of education, and those who lack private health insurance are less likely to perceive helpful social support (Arora et al.).

Uncertainty

Uncertainty is the inability of a person to determine the meaning of illness-related events such as their disease process, treatment, or hospitalization (Mishel, 1988). Uncertainty occurs because a person is unable to sufficiently understand or make sense of the illness event because the event is unexpected, unfamiliar, or highly complex or the individual lacks information (Gil et al., 2006; Mast, 1998). Uncertainty is a stressful and pervasive part of life for breast cancer survivors and strongly influences their adaptive behaviors (Mast, 1998). Breast cancer survivors often experience continuing uncertainty in response to fear of recurrence, decreased contact with healthcare delivery after treatment concludes, and long-term treatment related to side effects (Dirksen & Erickson, 2002; Mast, 1998).

Research suggests that increased uncertainty undermines the ability of Latina breast cancer survivors to sustain an acceptable QOL (Sammarco & Konecny, 2008) Social support has been recognized as an instrumental resource in reducing uncertainty in breast cancer survivors (Sammarco, 2001).

Quality of Life

QOL is a person's sense of well-being that stems from satisfaction or dissatisfaction with aspects of life that are important to them (Ferrans, 1990b). The dimensions of QOL include the domains of health and functioning, psychological and spiritual, socioeconomic, and family (Ferrans, 1996). Breast cancer presents multiple threats to the QOL of breast cancer survivors. Existential concerns, physical symptoms, uncertainty, distress, disruptions in social and family relationships, loss of control, changes in self-image, and concerns about finances and employment often persist well beyond the conclusion of treatment and throughout survivorship (Knobf, 2007). Research findings have consistently indicated that provision of adequate social support was important for maintaining or improving the QOL of breast cancer survivors (Alferi et al., 2001; Sammarco, 2001, 2003). Research also suggests that perceived social support and uncertainty are significant predictors of QOL in Latina breast cancer survivors (Sammarco & Konecny, 2008).

Theoretical Framework

The Mishel Uncertainty in Illness Theory (Mishel, 1988, 1990) and the Ferrans Conceptual Model of QOL (Ferrans, 1996) formed the theoretical framework of this study. The Mishel Uncertainty in Illness Theory maintains that uncertainty develops when an individual is unable to ascribe specific values to objects or events or is unable to predict outcomes from a lack of sufficient cues (Mishel, 1988). The Ferrans Conceptual Model of QOL contends that QOL is a multidimensional construct that entails four major underlying domains: health and functioning, socioeconomic, psychological and spiritual, and family. Social support decreases uncertainty in illness (Mishel, 1988) and is a key element in preserving the QOL of breast cancer survivors (Hoskins et al., 1996; Lee, 1997).

Research Questions

This research study endeavored to answer two research questions: What is the difference between Latina and Caucasian breast cancer survivors in perceived social support, uncertainty, and QOL; and what is the difference between Latina and Caucasian breast cancer survivors in selected demographic variables?

Methods

A descriptive, comparative design was used in this study. Permission to conduct the study was sought and obtained from institutional review boards affiliated with the investigators' academic institutions and sites participating in the study. To be considered for this study, participants had to be either Caucasian or Latina and be at least one year after diagnosis and treatment. A total of 1,023 breast cancer survivors who met inclusion criteria were identified through their records by the tumor registry of participating hospitals in the New York and New Jersey metropolitan area and through the patient records of participating ACS units in the New York area. The investigators supplied study packets to the registrars and staff of the ACS units. The study packets included an explanatory cover letter, study questionnaires, demographic survey, and stamped return envelopes. The registrars and staff members of ACS units addressed and mailed the study packets to potential participants. The identities of the potential participants were unknown to the investigators to protect their privacy. Recipients of the study packets were informed in the explanatory letter that they were anonymous to the investigators, and return of the completed questionnaires constituted implied consent.

With power set at 0.8, medium effect size (0.5) and significance criterion at 0.05, the minimum sample size sought for this study was 64 participants in each ethnic cohort (Cohen, 1988).

From the 1,023 study packets mailed to potential participants, 319 were returned, which resulted in an overall 31% response rate. After eliminating respondents who did not meet study inclusion criteria (12%), data from 182 Caucasian participants (57%) and 98 Latina participants (31%) were included in the analysis.

Instruments

Social Support Questionnaire

The Social Support Questionnaire (SSQ) (Northouse, 1988) is a self-administered measure of social support perceived by the study participant from five sources: spouse, family member, friend, nurse, and physician. A five-point Likert-type scale ranging from strongly disagree (1) to strongly agree (5) was used to rate eight items for each of the five sources of support, yielding a total of 40 items. A total score was obtained by summing the amount of support perceived from the five sources on each of the eight items. Possible scores ranged from 40–200. Higher scores indicated more perceived social support. Concurrent validity of the SSQ has been determined and internal consistency reliability has been reported as 0.9 from a sample of 50 breast cancer survivors (Northouse). Internal consistency reliability scores

obtained in this study were: total, 0.93; doctor, 0.9; family, 0.89; friend, 0.92; nurse, 0.96; and spouse, 0.97.

Mishel Uncertainty in Illness Scale-Community Form

The Mishel Uncertainty in Illness Scale—Community Form (MUIS-C) (Mishel, 1997) is a self-administered measure of uncertainty perceived in illness. The five-point Likert-type scale ranged from strongly disagree (1) to strongly agree (5). A 23-item one-factor version of the Mishel Uncertainty in Illness Scale was developed for non-hospitalized adults (Mishel, 1997). The total score was obtained by summing the point value of all selected items. Possible scores ranged from 23–115. Higher scores designate higher levels of uncertainty. Construct validity was determined and internal consistency reliability of the MUIS-C was reported to range from 0.74–0.92 (Mishel, 1997). Internal consistency reliability obtained in this study for the MUIS-C was 0.91.

Ferrans and Powers Quality of Life Index-Cancer Version III

The Ferrans and Powers QOL Index-Cancer Version III (QLI-CV) (Ferrans, 1990a) is a self-administered measure of QOL that consists of two 35-item sections: The first is satisfaction with various life domains, and the second is perceived importance of those domains, totaling 70 items. A six-point Likert-type scale ranges from very dissatisfied (1) to very satisfied (6) for section one items and from very unimportant (1) to very important (6) for section two items. The QLI-CV contains four subscales: health and functioning, socioeconomic, psychological and spiritual, and family. Possible scores ranged from 0-30 for total scores and each subscale score. Higher scores designate better-perceived QOL. Concurrent validity of the QLI-CV was established and internal consistency reliability was reported as 0.95 for the entire instrument (Ferrans, 1990a). Reliability for the subscales was reported as 0.66 for family, 0.9 for health and functioning, 0.93 for psychological and spiritual, and 0.84 for socioeconomic (Ferrans, 1990a). Internal consistency reliability scores for the QLI-CV and its subscales obtained in this study were: total, 0.94; family, 0.75; health and functioning, 0.87; psychological and spiritual, 0.89; and socioeconomic, 0.71.

Results

The total sample consisted of 280 breast cancer survivors, delineated as 65% Caucasian and 35% Latina, who had an average age of 57.05 years (SD = 13.81). Age ranged from 30–92 years. On average, the women had completed their breast cancer treatment 4.51 years prior (SD = 3.89) with a range of 1–35 years. The

majority of the sample was employed (56%, n = 157), was married (61%, n = 172), and had either a high school (41%, n = 115) or college education (53%, n = 144). The vast majority of the sample received a combination of surgery and adjuvant treatments (77%, n = 215). Fifteen women (two Caucasians, 13 Latinas) reported having been treated for a psychiatric illness, notably depression. Demographic data listed according to ethnic cohort are presented in Table 1.

Demographic Variable Differences

Chi square analyses were performed to check for significant associations between categorical demographic variables and ethnicity (Latina versus Caucasian). A significant association was found between ethnicity and marital status (χ^2 [5, n = 280] = 20.27, p = 0.01), with significantly more Latinas being divorced (16% versus 4%), separated (5% versus 1%), and significantly more

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Caucasians being married (69% versus 48%). No significant association was noted between cohorts regarding being widowed.

A significant association was found between education and ethnicity (χ^2 [3, n = 279]) = 24.62, p < 0.001). Subjects with only a grade school education were more likely to be Latina (17% of Latinas) than Caucasian (2% of Caucasians). At other levels of education, no association was noted.

A significant association was noted between ethnicity and the presence of psychiatric illness (χ^2 [1, n = 278] = 18.71, p < 0.001). Latinas reported more psychiatric illness (n = 13) than did Caucasians (n = 2).

A significant association with ethnicity also was found for type of treatment received for breast cancer (χ^2 [2, n = 278] 15.51, p < 0.001). Caucasians were more likely to receive only surgery (23% versus 6% of Latinas); Latinas were more likely to receive both surgery and

adjuvant treatment (91% versus 70% of Caucasians). However, Caucasians were more likely to have had a mastectomy (56%, n = 102) compared to the Latinas in this sample (52%, n = 50) (χ^2 [1, n = 279] = 0.51, p = 0.47).

No significant association was noted between ethnicity and employment category (χ^2 [7, n = 270] = 10.7, p = 0.15). Independent samples t tests were performed to determine whether differences existed between Latinas and Caucasians on continuous demographic variables. No significant differences were found in age (t [217.72] = -0.5, p = 0.62) or in time since treatment (t [263] = -1.62, p = 0.11).

Differences Between Latinas and Caucasians on Study Variables

Mean scores on the main study variables, along with SDs and ranges for the scales, are presented in Table 2. Independent samples t tests were performed to determine whether Latinas and Caucasians differed on measures of perceived social support, uncertainty, and QOL, with findings presented in Table 3. Findings indicate a significant difference between Caucasians and Latinas in perceived social support, with Caucasians reporting higher levels of total perceived social support than Latinas. However, on the various subscales within the SSQ measure, no significant differences were noted. Findings also reveal a significant difference in uncertainty. Latinas reported greater levels of uncertainty than Caucasians. Findings

Both

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^a Because of missing data, Caucasian participants do not equal 182.

^b Because of missing data, Latina participants do not equal 98.

^cOne Latina woman reported not receiving treatment and one Caucasian woman did not answer the question.

Table 2. Mean Scores Achieved by Subjects on Study Instruments

Scale	$\overline{\mathbf{x}}$	SD	Range	
MUIS-C	51.9	15.19	23-107	
QLI-CV family	23.99	5.48	6-30	
QLI-CV health	21.36	6.06	1-30	
QLI-CV psychological	21.58	6.41	3.43-30	
QLI-CV socioeconomic	22.56	4.72	6.63-30	
QLI-CV total	22.04	5.05	8.16-30	
SSQ doctor	30.11	6.45	0-40	
SSQ family	31.54	6.71	0-40	
SSQ friend	31.73	6.59	0-40	
SSQ nurse	27.85	9.24	0-40	
SSQ spouse ^a	25.26	12.73	0-40	
SSQ total	143.46	26.63	24–200	

N = 280

 $^{\mathrm{a}}$ N = 250 because of some of the sample was unmarried or unpartnered.

MUIS-C—Mishel Uncertainty in Illness Scale–Community Form; QLI–CV—Ferrans and Powers Quality of Life Index–Cancer Version III; SSQ—Social Support Questionnaire

also indicate a significant difference between Caucasians and Latinas in total QOL, with Caucasians scoring higher than Latinas. On the various subscales within the QOL measure, Caucasians reported significantly higher QOL in the health and functioning and socioeconomic domains.

Discussion

The findings of this study describe differences between Latina and Caucasian breast cancer survivors in perceived social support, uncertainty, QOL, and selected demographic variables. Among the Caucasian and Latina breast cancer survivors in this study, ethnicity likely had an influence on perceived social support, uncertainty, and QOL.

Perceived Social Support

The mean scores and ranges on the SSQ obtained by participants of this study indicate that the Caucasian cohort perceived significantly more social support than the Latina cohort. In the demographics of this study, significantly more Caucasians were married and Latinas reported significantly higher rates of divorce and separation. Prior studies of Caucasian breast cancer survivors have acknowledged spousal support as a key source of social support (Ashing-Giwa et al., 2004; Hoskins et al., 1996; Northouse, 1988; Northouse, Laten, & Reddy, 1995), which may explain why the Caucasian cohort in this study perceived more total social support than the Latinas. However, on closer examination of the mean scores of the SSQ subscales, Latinas in this study trended toward higher spousal support and slightly higher family sup-

port than their counterparts, which was an unexpected finding. This suggests that, although more spouses were present in the lives of the Caucasian cohort, having a spouse did not ensure that helpful or meaningful support was perceived from them (Neuling & Winefield, 1988; Pistrang & Barker, 1995). Within Latina culture, the strong family orientation known as *familialism* imparts Latinas with their main source of emotional, physical, and economic support in times of illness (Diaz, 2002). Therefore, despite the fact that more Latinas were without spouses than their counterparts, the support that the Latinas perceived from their spouses and families may have been more helpful and meaningful to them.

Uncertainty

Latinas in this study reported significantly higher levels of uncertainty than Caucasians. The presence of concurrent illness can place breast cancer survivors at increased risk of uncertainty and emotional distress. Additionally, uncertainty can be triggered by disease recurrence, presence of symptoms and comorbidities, side effects of treatments, fear of death and suffering, and financial concerns for health-related costs (Gil et al., 2004, Mast, 1995, 1998). Prior research revealed increased uncertainty among Latinas with less formal education (Sammarco & Konecny, 2008). In the current study, significantly more Latinas reported having only a grade school education, psychiatric illness, and more aggressive treatments than their Caucasian counterparts. These findings may have contributed to the higher levels of uncertainty in the Latina cohort. The Latina value of fatalismo, which is an acceptance of fate and of things that cannot be changed, may create a barrier to preventive care measures (Diaz, 2002) and add to Latinas' uncertainty about their breast cancer. The Latina value of paternalismo, whereby authority figures are perceived as interacting with subordinates as a father tending to his children (Diaz), could hamper Latinas from questioning treatment modalities and clarifying health information. The resultant lack of understanding about their disease and treatment may likely increase the degree of uncertainty Latinas experience (Mast, 1995).

Quality of Life

The Latina cohort in this study reported a significantly poorer total QOL than the Caucasian cohort. Closer examination of the subscales showed that Latinas reported significantly poorer health and functioning and socioeconomic QOL. Latinas, as an ethnic group, often are economically depressed, are medically underserved, and lack adequate health insurance and access to health care (Diaz, 2002; Huerta, 2003). To what extent these factors may have influenced the Latina cohort is unknown; however, psychiatric illness comorbidity (Knobf, 2007) and lower level of education (Aziz & Rowland, 2002)

Table 3. Differences Between Latinas and Caucasians on Quality of Life, Uncertainty, and Social Support

	Caucasians (N = 181)		Latinas (N = 98)				
Scale	$\overline{\mathbf{X}}$	SD	$\overline{\mathbf{X}}$	SD	t	df	р
MUIS-C	47.01	13.68	60.97	13.66	-8.14	278	< 0.001
QLI-CV family	24	5.52	23.96	5.43	0.06	276	0.95
QLI-CV health	22.32	4.87	19.58	7.51	3.26	142.18	0.001
QLI-CV psychological	21.84	6.03	21.09	7.07	0.89	172.15	0.38
QLI–CV socioeconomic	23.18	4.62	21.43	4.71	2.99	277	0.003
QLI-CV total	22.64	4.51	20.92	5.79	2.56	161.88	0.011
SSQ doctor	30.34	6.14	29.7	6.99	0.75	177.91	0.45
SSQ family	31.51	6.66	31.61	6.82	-0.12	277	0.9
SSQ friend	32.12	6.85	31	6.03	1.35	277	0.18
SSQ nurse	27.25	10.42	28.96	6.36	-1.69	271.98	0.09
SSQ spouse	24.68	13.29	26.82	11.02	-1.19	248	0.24
SSQ total	145.88	26.99	138.95	25.48	2.09	278	0.04

MUIS-C—Mishel Uncertainty in Illness Scale-Community Form; QLI-CV—Ferrans and Powers Quality of Life Index–Cancer Version III; SSQ—Social Support Questionnaire

in the Latina cohort of this study are factors to consider in explaining the disparity in QOL scores. Additional research is recommended to explore these issues. In the overall comparison of total QOL between Caucasian and Latina cohorts, the pattern of less perceived social support in the presence of increased uncertainty together likely influenced a poorer QOL in the Latina cohort. The findings underscore the patterns of prediction revealed in prior research, where perceived social support and uncertainty together influence the QOL of breast cancer survivors (Sammarco, 2001, 2003; Sammarco & Konecny, 2008).

Limitations

The Caucasian and Latina participants of this study were recruited by convenience sampling from private hospitals and ACS units in the New York and New Jersey metropolitan areas. The sample may not be representative of the study population throughout the United States. Therefore, study results should be viewed cautiously and not generalized beyond the study samples.

Implications for Practice

Nurses should be mindful of the essential association of perceived social support, uncertainty, and QOL in Latina breast cancer survivors and how Latinas differ from Caucasian breast cancer survivors. Factors such as cultural values, comorbidities, and education level likely influence perceived social support, uncertainty, and QOL. Nurses cognizant of Latina values such as familialism, paternalismo, and fatalismo are in position to augment social support and reduce uncertainty in Latina breast cancer survivors through culturally meaningful interventions that likely will enhance the health and functioning, socioeconomic, psychological

and spiritual, and family domains of QOL.

To address the value of familialism, efforts should be made to remove barriers that may impede family involvement in the care of Latina breast cancer survivors. Social support may be provided in a variety of tangible ways: through counseling, patient teaching, provision of spiritual care, moderating peer support groups, presence at the bedside, active listening, and public advocacy of breast cancer awareness. Because family is an integral domain of the QOL of Latina breast cancer survivors, con-

sideration should be given in supporting the needs of the family, particularly during times of screening, treatment regimens, follow-up care, and recurrence of breast cancer, when uncertainty is most likely to increase.

Paternalismo and fatalismo should be approached judiciously, because these values often influence personal beliefs and may create barriers that interfere with Latinas' understanding of their illness, treatments, and system of care (Diaz, 2002). Considerable reverence placed on the health practitioner through paternalismo may restrict Latinas' ability to question authority or clarify medical information (Diaz). In addition, nurses should be aware that fatalismo may adversely influence Latinas' understanding of their illness. Fatalismo may induce Latinas to reason their illness is a result of bad behavior, retribution for imprudent lifestyle, punishment from God, or an unpreventable life force (Diaz). Bilingual care providers, culturally competent patient teaching, Spanish-language patient education materials, assistance from Englishspeaking family and friends, and use of interpreters are suggested strategies to better meet the informational needs of Latina breast cancer survivors (Diaz).

Recommendations for Research

The lack of research that focuses on Latina breast cancer survivors indicates a need for continued research. Research is needed that focuses on Latina cultural values and how these values influence the QOL of Latina breast cancer survivors. Using Latina samples more representative of the medically underserved and lower socioeconomic strata also is suggested. Additional research to explore factors that explain the disparity in QOL that exists between Latinas and other ethnic groups is strongly suggested. Research to investigate culturally competent interventions that meet the QOL

needs of Latina breast cancer survivors will likely provide evidence toward improving QOL outcomes of Latina breast cancer survivors.

The authors gratefully acknowledge statistician Sarai Batchelder, PhD, for her invaluable assistance with data analysis in this study.

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Digital Object Identifier: 10.1188/10.ONF.93-99

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