

Triggers of Uncertainty About Recurrence and Long-Term Treatment Side Effects in Older African American and Caucasian Breast Cancer Survivors

Karen M. Gil, PhD, Merle H. Mishel, RN, PhD, Michael Belyea, PhD,
Barbara Germino, RN, PhD, Laura S. Porter, PhD,
Iris Carlton LaNey, PhD, and Janet Stewart, BSN, MN, PhD

Purpose/Objectives: To examine the sources of uncertainty in older African American and Caucasian long-term breast cancer survivors by focusing on frequency of triggers of uncertainty about cancer recurrence and physical symptoms linked to long-term treatment side effects.

Design: In the context of a larger randomized, controlled treatment-outcome study, data were gathered from 10 monthly follow-up telephone calls by nurses.

Setting: Rural and urban regions of North Carolina.

Sample: 244 older women (\bar{X} age = 64 years); 73 African American women and 171 Caucasian women who were five to nine years after breast cancer diagnosis.

Findings: The most frequent triggers were hearing about someone else's cancer and new aches and pains. The most frequent symptoms were fatigue, joint stiffness, and pain. Although no ethnic differences occurred in the experience of symptoms, Caucasian women were more likely than African American women to report that their fears of recurrence were triggered by hearing about someone else's cancer, environmental triggers, and information or controversy about breast cancer discussed in the media.

Conclusions: Illness uncertainty persisted long after cancer diagnosis and treatment, with most women experiencing multiple triggers of uncertainty about recurrence and a range of symptoms and treatment side effects.

Implications for Nursing: Nurses can help cancer survivors to identify, monitor, and manage illness uncertainty and emotional distress.

Key Points . . .

- Illness uncertainty persists long after cancer diagnosis and treatment.
- Older long-term breast cancer survivors experience multiple triggers of uncertainty about recurrence and a range of symptoms and treatment side effects.
- Healthcare providers need to identify, monitor, and assist breast cancer survivors who are at risk for illness uncertainty and emotional distress.

tied to both threat of recurrence and physical symptoms of long-term residual effects of treatment. Survivors express this uncertainty as not knowing what will happen, when to be concerned about bodily changes, or how to discern normal changes of aging from signs of disease progression (Gray et al., 1998).

Specific areas of uncertainty during breast cancer survivorship have been identified. Recurrence is the major fear of women five years after treatment, and that fear continues in the years that follow (Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Fredette, 1995; Mahon & Casperson, 1997). Beyond five years, the likelihood of recurrence decreases

Advances in early detection and medical treatment of breast cancer have improved the survival of women such that they are living beyond diagnosis and treatment to an older age (Andersen & Urban, 1999). According to recent statistics, 97% of women diagnosed with localized breast cancer and 78% of those with regional disease are expected to be alive five years later (American Cancer Society, 2003a). Although five-year survival is promoted as a milestone for recovery, many women will continue to experience uncertainty about how to interpret and manage long-term treatment-related side effects such as arm swelling, cosmetic changes, fatigue, and other effects from axillary dissection and radiation, along with the continuing uncertainty about recurrence and secondary cancer (Dow, 1995; Pelusi, 1997). Uncertainty has been targeted as a major experience of breast cancer survivors and is predictive of emotional distress and a poorer quality of life (Mast, 1998; Nelson, 1996; Sammarco, 2001). The uncertainty of breast cancer survivors is

Karen M. Gil, PhD, is a professor in the Department of Psychology at the University of North Carolina at Chapel Hill; Merle H. Mishel, RN, PhD, is a Kenan professor, Michael Belyea, PhD, is a research associate professor, and Barbara Germino, RN, PhD, is a Beerstecher Blackwell professor, all in the School of Nursing at the University of North Carolina at Chapel Hill; Laura S. Porter, PhD, is an assistant clinical professor in the Department of Psychiatry and Behavioral Sciences at Duke University Medical Center in Durham, NC; Iris Carlton LaNey, PhD, is a professor in the School of Social Work at the University of North Carolina at Chapel Hill; and Janet Stewart, BSN, MN, PhD, is an assistant professor in the School of Nursing at the University of Pittsburgh in Pennsylvania. This research was supported by a grant from the National Institutes of Health National Cancer Institute (1R01 CA78955, M. Mishel, principal investigator). (Submitted March 2003. Accepted for publication July 30, 2003.)

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slowly through year 12, with a mean likelihood of recurrence from years 5–12 of 4.3% (Saphner, Tormey, & Gray, 1996). However, postmenopausal women have a higher rate of recurrence (e.g., from years 5–6, the rate of recurrence for postmenopausal women is 5% versus 3.9% for premenopausal women; from years 7–8, the rate of recurrence for postmenopausal women is 6.4% versus 3.8% for premenopausal women [Saphner et al.]).

Uncertainty about recurrence and secondary cancer varies but has been reported to reappear with its original intensity after specific triggers (Cordova et al., 1995), including new bodily or functional changes, general medical situations such as checkups, media events about breast cancer, or news of another survivor having disease extension (Ganz et al., 1996; Gray et al., 1998; Leigh, 1992; Polinsky, 1994; Wyatt, Kurtz, & Liken, 1993). Without specific indicators to identify recurrence or second malignancy, women report self-monitoring of ambiguous physical symptoms to find some causal explanation and reduce their fear (Loescher, Clark, Atwood, Leigh, & Lamb, 1990; Smith & Lesko, 1988). Uncertainty about recurrence or secondary cancer brings persistent anxiety (Ferrell et al., 1995; Pelusi, 1997). Cordova et al. reported that among women who had survived breast cancer for six months to five years, 44% said they were “super alert” or on guard, and some noted that they had difficulty sleeping.

Survival from cancer brings not only enduring uncertainty about the possibility of recurrence, but also late-emerging treatment side effects (Dow, 1995; Fredette, 1995). Women have been poorly informed about late-emerging treatment side effects and often are uncertain about whether a symptom reflects a treatment side effect (Gray et al., 1998). Lymphedema, probably the most debilitating late effect from treatment for breast cancer, is estimated to affect 2%–62% of breast cancer survivors (Carter, 1997; Farncombe, Daniels, & Cross, 1994). Time of onset varies; lymphedema can occur at any time after treatment, even 30 years after surgery (Brennan & Weitz, 1992), and it can be aggravated by concomitant conditions often found in the elderly, such as diabetes, cardiac failure, and obesity (Foldi, Foldi, & Clodius, 1989). Other long-term effects cited in the literature include surgery- and radiation-induced pain, numbness, pins and needles, skin sensitivity, and swelling in the breast, arm, underarm, and area of the scar (Ganz et al., 1996; Tasmuth, von Smitten, Hietanen, Kataja, & Kalso, 1995). For many older survivors, such symptoms have persisted or emerged years later. For example, scar pain can remain constant for more than six years after treatment (Kroner, Knudsen, Lundby, & Hvid, 1992), and skin firmness, thickness, and tenderness in a radiated area can exist five years after treatment (Olivotto et al., 1996).

Although the triggers of uncertainty about recurrence and long-term treatment side effects have been identified in the literature, most investigators have focused on young women during the early years after treatment. Indeed, most of the information available about the psychosocial and health concerns of breast cancer survivors is based on samples of women who were young (\bar{X} age < 50 years) or who were one to three years after diagnosis (e.g., Bleiker, Pouwer, van der Ploeg, Leer, & Ader, 2000; Sammarco, 2001; Stanton, Danoff-Burg, & Huggins, 2002). Only recently have researchers begun to describe the health and psychosocial con-

cerns of long-term survivors and those older than 50 (Ganz et al., 2002; Holzner et al., 2001; Pedro, 2001; Saleeba, Weitzner, & Meyers, 1996; Stewart et al., 2001; Tomich & Helgeson, 2002; Utley, 1999). Because the incidence of breast cancer increases with age and the five-year survival rate is so high, long-term survivors are predominantly women older than 60. Yet specific information about the types and frequency of these triggers or fears of recurrence and the long-term symptoms of older, long-term survivors (i.e., beyond five to seven years postdiagnosis) remain understudied.

Furthermore, a lack of attention has been paid to the psychosocial and health concerns of African American women who have survived cancer, and little to no effort has been made to contrast their experiences with those of other women (Ashing-Giwa, Ganz, & Petersen, 1999; Meyerowitz, Richardson, Hudson, & Leedham, 1998). Recent studies of African American women with breast cancer indicate that these women experience treatment-related side effects of energy loss and pain along with pervasive fear and uncertainty (Farmer & Smith, 2002; Northouse et al., 1999). Investigators have not addressed survivorship from an ethnic or cultural perspective. In part, this may be caused by difficulties recruiting and retaining African American women into cancer control studies (Ashing-Giwa & Ganz, 2000) and the perception, even among African American women themselves, that breast cancer is a “white woman’s disease” (Moore, 2001). Studying African American women is extremely important for several reasons (Jones & Chilton, 2002). African American women are less likely than Caucasian women to survive for five years (American Cancer Society, 2001, 2003b), partially because of later stage at detection, tumors that are more aggressive and less responsive to treatment, and higher incidence of coexisting illnesses. Economic barriers to healthcare access, as well as cultural, social, and personal variables, also may play significant roles (Bibb, 2001). Furthermore, a perceived lack of social support and understanding about the unique life experiences of African American women exists (Moore).

The current study examined the frequency of triggers of uncertainty and physical symptoms linked to long-term treatment side effects in older, long-term survivors of breast cancer. The aims of this article are to describe patterns and frequencies of triggers and symptoms and to compare patterns and frequencies between African American and Caucasian women.

Methods

Overview

Women in this study were participating in a larger study of women surviving beyond breast cancer treatment (National Institutes of Health National Cancer Institute 1R01 CA78955, M. Mishel, principal investigator). The purpose of the larger study was to test the efficacy of an uncertainty-management intervention that combines training in cognitive-behavioral skills for dealing with uncertainty about recurrence with standardized information for the management of treatment side effects provided in a manual. The intervention was self-administered and delivered via audiotapes and an educational manual. Research nurses guided participants through the intervention during four weekly, structured telephone calls. During each of the four telephone calls, women practiced one of four skills:

relaxation, pleasant imagery, calming self-talk, and distraction. During the third and fourth calls, women also were guided in the use of the manual, which contained educational material about long-term treatment side effects, including lymphedema, pain, stiffness, and other health concerns. Women were encouraged to use the manual as a self-help guide, that is, to read the relevant manual sections and refer to the manual in the future as questions and issues about symptoms arose. After the fourth telephone call, when the intervention was completed, monthly follow-up calls continued for 10 months to document the experiences of triggers and symptoms.

To be eligible in the larger study, women had to be about 50 years or older, be about five to nine years after breast cancer diagnosis, have no other cancers or breast cancer recurrence, be African American or Caucasian, speak English, have access to a telephone, and be willing to receive monthly telephone calls. Women were excluded if they scored 13 or lower on the short form (Koenig, 1996) of the Mini-Mental Status Examination (Folstein, Folstein, & McHugh, 1975), which was delivered during the recruitment phone call.

Participants and Recruitment Strategy

The majority of women in the study were identified and contacted via cancer registries at 15 hospitals and medical centers throughout North Carolina. After the study was approved by institutional review boards at each participating center, an introductory letter was mailed from the cancer registries to women meeting study eligibility criteria. Women were given an opportunity to refuse further contact by returning an enclosed postcard to the cancer registry or by contacting the study office directly. After two or three weeks, study personnel called women who did not return the postcard to ascertain their willingness to participate, explain the study further, and determine their eligibility. The cancer registry mechanism was supplemented by community-based recruitment, consisting of radio and newspaper advertisements, posters placed in locations likely to be frequented by women with breast cancer, and local networking via community volunteers, particularly in the African American community. Women who learned of the study via these mechanisms called the study office and were screened for eligibility. These additional strategies were used to maximize the numbers of African American women in the study and, therefore, permit meaningful statistical comparisons with Caucasian women. Other investigators have employed modified recruitment strategies to obtain adequate numbers of African American respondents (e.g., Ashing-Giwa et al., 1999).

A total of 2,114 women (528 African American and 1,586 Caucasian) were identified as potentially eligible for the study. About 50% of the women who initially were identified either could not be contacted (72%) or did not meet eligibility criteria (28%). Of the 1,055 women remaining, 577 (55%) agreed to participate in the study. Women who chose not to participate cited lack of interest (50%), not enough time (26%), other health problems (10%), not wanting to be reminded of their breast cancer experience (5%), other reasons (3%), or no reason (6%). To date, 65 women (24 African American and 41 Caucasian) have dropped or were dropped from the study, with the primary reasons being cancer recurrence or new primary tumor, too busy to continue in the intervention, or unreachable by phone. The resulting sample of 512 women included 362 Caucasian and 150 African Ameri-

can women. The sample for the present analysis consisted of the 244 women enrolled in the intervention arm of the study who completed all of the monthly follow-up calls (\bar{X} number of calls = 8).

Monthly Telephone Protocol

Each month during follow-up, one of the research nurses (three with baccalaureate degrees in nursing, one with a master's degree in nursing) called each participant and followed a standard telephone protocol for gathering data on triggers and symptoms. Telephone calls lasted about 15–30 minutes and started with some brief opening comments to establish rapport.

Triggers of uncertainty: Triggers were defined as “places, events, or surroundings that bring back (or trigger) memories, feelings, or concerns about breast cancer.” The most common triggers referred to in the literature are annual reminders such as mammograms and follow-up doctor visits. These events or cues can trigger emotional responses, usually anxiety, if the events are appraised as stressful. However, uncertainty also may arise if the meaning of an event is unfamiliar, incomplete, or nonspecific, or the cue is vague and difficult to interpret (Mast, 1998; Mishel, 1988). For this study, the specific triggers were identified from three focus groups with older long-term survivors of breast cancer (5–12 women per focus group; 5–20 years postdiagnosis). The audiotapes of the focus groups were transcribed verbatim. A content analysis process was used to identify the most common (frequently mentioned) triggers across focus groups. A list of 10 potential triggers was identified and included new aches, pain, or physical symptoms; annual mammogram; and anniversary day of diagnosis. During a telephone interview, the nurse read each trigger to the survivor and asked her whether she had experienced that trigger in the prior month.

Symptoms: Following the section on triggers, the nurse read a list of six potential symptoms and asked the survivor whether she had experienced the symptom or concerns about the symptom in that month. Women were asked specifically whether they experienced these symptoms secondary to their cancer. For example, for stiffness, women were asked whether they had experienced stiffness in their shoulders, arms, or hand on the operative side. The six symptoms were identified from the literature and the focus groups in the same manner as described previously.

Data Analysis

The occurrence and frequency of each of the 10 triggers and six symptoms were determined using descriptive statistics. Chi square analyses and t tests were performed to examine ethnic differences. Pearson correlations were calculated to examine associations between demographic and disease variables and frequency of triggers and symptoms.

Results

Sample

The 244 women included 171 Caucasian women and 73 African American women with a mean age of 64.3 years ($SD = 8.3$ years, range = 49–87 years). The average educational level was 13.9 years of formal education ($SD = 2.8$ years, range = 4–22 years). For the study sample, 58% of the women were married, 21% widowed, 14% divorced or separated, and 7% never married. Thirty-four percent of the women in the sample

lived alone, whereas 66% were living with one or more people. Table 1 reports the demographic information by ethnic group. Significant differences by ethnicity existed for level of education, with Caucasian women having a higher level ($t [242] = 2.61, p < 0.01$); for marital status, with Caucasian women more likely to be married ($\chi^2 = 24.04, p < 0.0001$); and for income, with a higher proportion of Caucasian women in higher income brackets ($\chi^2 = 29.29, p < 0.0001$). African American women were more likely to live alone ($\chi^2 = 9.6, p < 0.05$).

The women had an average time since diagnosis of 6.8 years ($SD = 1.2$ years, range = 4.8–11.7 years). Most women had stage I (49%) or stage II (35%) breast cancer at diagnosis. Women identified a mean of about four health problems on the Co-Morbidity Index, a list of 25 medical conditions adapted by Satariano, Ragheb, and Dupuis (1989) from those used by the Human Population Laboratory in the Alameda County (CA) Survey (Berkman & Breslow, 1983). The most common comorbid health problems reported were arthritis and rheumatism (61% of the women), blood pressure (47%), constipation (28%), and cataracts (25%). Table 1 includes medical and staging data by ethnicity. No significant differences existed in time since diagnosis, disease staging, or overall number of health problems. However, significant differences existed for certain health problems, with African American women having significantly more blood pressure problems (68% versus 37%, $p < 0.0001$), diabetes (38% women versus 9%, $p < 0.0001$), and glaucoma (12% versus 5%, $p < 0.05$). This higher prevalence of certain coexisting conditions for African American women in this study was anticipated given overall patterns of comorbid illnesses for African American women with cancer (American Cancer Society, 2003b).

Triggers of Uncertainty

For the overall study sample, the average number of triggers was 1.8 per month ($SD = 1.0$). For Caucasian women, the

mean was 1.9 triggers per month ($SD = 1.0$); for African American women, the mean was 1.6 triggers per month ($SD = 0.94$). A t test indicated that this difference was not significant.

Table 2 summarizes the occurrence and frequency of each type of trigger for the total sample and by ethnic group. The most frequent trigger was “hearing about someone else’s cancer,” reported during 37% of the phone interviews; 82% of women reported this trigger at least once during the study period. Other common and frequent triggers were new aches, pains, or physical symptoms; environmental triggers (e.g., sights, sounds, and smells associated with the breast cancer experience); information from television, radio, the Internet, or magazines; and doctor’s appointments for annual check-ups. Four triggers were significantly different in frequency of occurrence by ethnic group: (a) hearing about someone else’s cancer or worsening disease, (b) environmental triggers, (c) information from television and radio, and (d) controversy in the media. The order of frequency of triggers also differed by ethnic group. The most frequent trigger for African American women was new symptoms; for Caucasian women, it was hearing about someone with cancer. However, the ethnic groups were very similar in the frequency of occurrence for 6 of the 10 triggers.

To determine whether any of the demographic or disease variables were related to the frequency of triggers, Pearson correlations were calculated. Older women in the sample reported significantly fewer triggers ($r = -0.16, p < 0.01$), and women with higher education reported more triggers ($r = 0.21, p < 0.001$), although the strength of these correlations was rather weak. Time since diagnosis and number of health problems were not significantly related to the average number of triggers per month.

Symptoms and Treatment Side Effects

For the overall sample, the average number of symptoms was 1.4 per month ($SD = 0.90$), with equivalent numbers of symptoms (1.4 per month) for both Caucasian women ($SD = 0.92$) and African American women ($SD = 0.86$). Table 3 summarizes the occurrence and frequency of each of the symptoms for the total sample and by ethnic group. The most common and frequent symptom reported by the women was fatigue, with 83% of the women reporting fatigue at least once during the study period. Other common symptoms were joint stiffness (reported by 82%) and pain (reported by 76%). The symptoms occurring with greatest frequency included those listed previously, plus lymphedema. No significant ethnic differences existed in the occurrence and frequency of symptoms.

Pearson correlations were calculated to determine whether demographic variables were related to the frequency of symptoms, and no significant associations existed. Regarding the medical data, time since diagnosis was not significantly related to the average number of symptoms per month; however, a weak positive association was found between “other” health problems and symptoms ($r = 0.34, p < 0.0001$).

Discussion

The results of this study, taken together with other recent studies (Ashing-Giwa et al., 1999; Mast, 1998), add to the growing body of knowledge regarding the factors affecting the quality of life of long-term breast cancer survivors and verify that illness uncertainty persists long after cancer diag-

Table 1. Demographic and Medical Data by Ethnicity

Variable	Caucasian (n = 171)		African American (n = 73)	
	\bar{X}	SD	\bar{X}	SD
Age (years)	64.3	8.3	64.4	8.3
Education (years)*	14.2	2.7	13.2	3.0
Time since diagnosis (years)	6.7	1.1	7.0	1.3
Health problems	3.7	2.5	4.3	2.5
	%		%	
Marital status (% married)*	67		37	
Living alone*	29		45	
Monthly income* (% below \$2,000 per month)	28		64	
Disease staging				
In situ	6		10	
Stage I*	53		41	
Stage II*	32		42	
Stage III	9		7	

* $p < 0.05$

Table 2. Occurrence and Frequency of Triggers for the Total Sample and by Ethnic Group

Trigger	Number of Women Experiencing the Trigger			Frequency of Triggers Across Telephone Interviews		
	Total (N = 244) n (%)	Caucasian (n = 171) n (%)	African American (n = 73) n (%)	Total (N = 1,949) n (%)	Caucasian (n = 1,363) n (%)	African American (n = 586) n (%)
New aches, pain, or physical symptoms	214 (88)	153 (89)	61 (84)	637 (32)	441 (32)	196 (33)
Hearing about someone else's cancer or worsening disease	200 (82)	144 (84)	56 (77)	722 (37)	555 (41)	167 (29)*
Environmental triggers	159 (65)	121 (71)	38 (52)*	380 (19)	297 (22)	83 (14)*
Information from television, radio, the Internet, and magazines	153 (63)	109 (64)	44 (60)	383 (20)	286 (21)	97 (17)*
Doctor's appointment for annual checkup	147 (60)	105 (51)	42 (58)	278 (14)	199 (15)	79 (13)
Controversy about breast cancer discussed in media	119 (49)	98 (57)	21 (29)*	225 (12)	193 (14)	32 (5)*
Annual mammogram	114 (47)	78 (46)	36 (49)	171 (9)	116 (9)	55 (9)
Late-emerging treatment side effect	103 (42)	71 (42)	32 (44)	248 (13)	184 (13)	64 (11)
Anniversary of diagnosis	87 (36)	62 (36)	25 (34)	119 (6)	85 (6)	34 (6)
Healthcare provider pays attention to a symptom	76 (31)	50 (29)	26 (36)	100 (5)	64 (5)	36 (6)

* $p < 0.05$

Note. Each of the 244 women received a mean of about eight telephone calls, for a total of 1,949 calls. Percentages reflect the proportion of times that the women reported the occurrence of the trigger divided by the total number of calls. For example, during 32% of the interviews, women reported experiencing new aches, pain, or physical symptoms. Women usually reported multiple triggers during a typical telephone call; therefore, percentages do not total 100.

nosis and treatment. In general, older long-term breast cancer survivors in this study reported experiencing multiple triggers of uncertainty about recurrence and a range of symptoms and treatment side effects. Importantly, time since diagnosis was unrelated to the frequency of either triggers or symptoms, indicating that these experiences do not significantly diminish over time even in this older group of women who had survived five to nine years after diagnosis. The most commonly reported triggers were hearing about someone else's cancer or worsening disease; new aches and pains; environmental triggers such as sights, sounds, and smells; and information seen in the media. These triggers occurred on a regular basis, with women reporting an average of about two triggers per month. The most common physical symptoms reported by women in this study were fatigue, joint

stiffness, and pain. The prevalence of these symptoms was high: More than 75% of the women in the study reported having these symptoms at some point during the 10-month study period. In addition, more than 50% of the women reported symptoms of lymphedema, and about 50% reported skin changes and hormonal or sexual problems. Most women reported at least one symptom per month. The results of this study are consistent with those of previous studies that also found a high prevalence of pain, fatigue, and sexual changes in breast cancer survivors (Holzner et al., 2001; Mast). However, few previous studies have included significant numbers of older women or African American participants. Findings from the current study indicate that the pattern and frequency of symptoms are similar in African American and Caucasian survivors.

Table 3. Occurrence and Frequency of Symptoms for the Total Sample and by Ethnic Group

Symptom	Number of Women Experiencing the Symptom			Frequency of Symptoms Across Telephone Interviews		
	Total (N = 244) n (%)	Caucasian (n = 171) n (%)	African American (n = 73) n (%)	Total (N = 1,949) n (%)	Caucasian (n = 1,363) n (%)	African American (n = 586) n (%)
Fatigue	203 (83)	143 (84)	60 (82)	689 (35)	491 (36)	198 (34)
Joint stiffness	200 (82)	139 (81)	61 (84)	687 (35)	467 (34)	220 (38)
Pain	185 (76)	128 (75)	57 (78)	512 (26)	353 (26)	159 (27)
Lymphedema	136 (56)	96 (56)	40 (55)	409 (21)	287 (21)	122 (21)
Skin changes	121 (50)	87 (51)	34 (47)	225 (12)	170 (12)	55 (9)
Hormonal or sexual changes	103 (42)	74 (43)	29 (40)	193 (10)	134 (10)	59 (10)

Note. Percentages reflect the proportion of times that the women reported the occurrence of the symptoms divided by the total number of calls. Women usually reported multiple symptoms during a typical telephone call; therefore, percentages do not total 100.

Although no ethnic differences were found in the experience of symptoms, Caucasian women were more likely than African American women to report their fears of recurrence being triggered by hearing about someone else's cancer, environmental factors, and information or controversy about breast cancer discussed in the media. The differences in these patterns may be because African American women tend to identify with a smaller reference group and because the African American community has a more negative view of cancer (Bourjolly, 1998; Wilmoth & Sanders, 2001). African American women frequently keep their diagnosis to themselves and may not seek social support to help them deal with it (Phillips, Cohen, & Moses, 1999; Wilmoth & Sanders). Whereas Caucasian women may more readily talk to others about their cancer, African American women have been reported to be less willing to share such information. Regarding the media, information and controversies in the media might have less impact among African American women because typical media coverage often ignores the experiences of African American women.

This study has several issues and possible limitations that should be mentioned. First, the study did not include a comparison group of older women who did not have cancer. This limitation is mostly a concern for the analyses related to physical symptoms because triggers of uncertainty are largely specific to cancer survivors. Whether women can distinguish the effects secondary to cancer from those caused by aging or comorbidities is unclear (Gotay & Muraoka, 1998). However, in this study, symptoms such as joint stiffness, skin changes, pain, and lymphedema were reported as occurring on the same side as the breast cancer, thus likely to be residuals of treatment. Although fatigue is a part of aging, breast cancer survivors describe it differently, as a "bone tiredness" that interferes with every aspect of their lives (Ferrell, Grant, Dean, Funk, & Ly, 1996). Hormonal and sexual changes are more questionable as solely related to breast cancer treatment. The findings with regard to lymphedema are of particular interest because more than half of the women reported this symptom, and lymphedema is specific to cancer survivors. Furthermore, regardless of the source of symptoms, the meaning of symptoms may be different for cancer survivors than for other individuals because they can themselves act as triggers of uncertainty. For example, vague physical discomfort can be difficult to interpret (Wong & Bramwell, 1992).

A second potential limitation is that the current study relied on retrospective reports of triggers and symptoms occurring in the preceding month. Investigators may consider using daily diary methodologies in the future to lessen biases associated with retrospective recall and to study the temporal dynamics among symptoms, triggers, and outcomes such as mood and daily functioning. Finally, women in this study were part of an ongoing intervention study. Their report of symptoms and triggers of uncertainty could have been influenced by participation in the intervention either by heightening their awareness of

symptoms or triggers or by leading to improvements that could have diminished actual frequencies of symptoms and triggers.

Conclusions and Recommendations for Practice

The findings of this study may have important clinical implications for the management of the physical and emotional sequelae of breast cancer. Nurses, health psychologists, medical social workers, and other healthcare providers need to identify, monitor, and assist breast cancer survivors who are at risk for illness uncertainty and emotional distress (Mast, 1998). New or ongoing symptoms can be highly anxiety-provoking because many women may not know which symptoms are common for survivors of breast cancer. Thus, healthcare providers should offer specific information during follow-up care about the range of typical long-term symptoms and late-emerging treatment side effects to reduce or prevent unnecessary distress (Leedham & Ganz, 1999). This information may be especially important for older women and African American women who may have higher rates of comorbid illnesses.

In addition to health-related events, other common daily occurrences may remind women about their cancer diagnosis and treatments, leading to feelings of uncertainty. Through education and counseling, healthcare providers can help survivors more effectively manage these encounters, thereby reducing distress and increasing a sense of control. For example, a woman who knows that going for an annual mammogram or medical checkup might lead to uncertainty can be advised to prepare for the event by bringing a supportive friend or distracting activity such as something to read while in the waiting room. An African American woman who relies heavily on her religion to deal with life stresses (Bourjolly, 1998) might be encouraged to use prayer to prepare for situations that trigger uncertainty.

In conclusion, the findings of this study may have important implications for healthcare providers of older breast cancer survivors. Many survivors complain that they are not taken seriously when they express concerns about recurrence or symptoms such as fatigue (Ferrell et al., 1996). As the number of breast cancer survivors grows, addressing their concerns will be a challenge for healthcare professionals. Healthcare providers will need to deal more effectively with survivors by acknowledging their ongoing issues with recurrence and long-term treatment side effects.

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Author Contact: Karen M. Gil, PhD, can be reached at kgil@email.unc.edu, with copy to editor at rose_mary@earthlink.net.

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