

# Outcomes of an Uncertainty Management Intervention in Younger African American and Caucasian Breast Cancer Survivors

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**R**elated to an increased use of targeted, aggressive treatment, younger women (aged 50 years or younger) are surviving breast cancer in greater numbers as incidence rates are stable and death rates are declining (American Cancer Society [ACS], 2012). According to ACS (2012), the five-year relative survival rate for female patients with breast cancer improved from 63% in the early 1960s to the current 90% mark. However, particularly during the first five years after completing treatment, many of these women are not prepared nor do they have the resources to manage ongoing and often distressing uncertainties of survivorship, including the threat of recurrence and major changes to their bodies (Bloom, Stewart, D'Onofrio, Luce, & Banks, 2008; Kornblith et al., 2007).

## Theoretical Framework

The experience of living with uncertainty is one of the most common challenges facing younger breast cancer survivors (BCSs). The intervention tested in this current study is based on Mishel's (1981, 1988, 1999) and Mishel and Fleury's (1997) theory of uncertainty in illness. That theory provides a framework for selecting interventions to improve psychological and behavioral outcomes under conditions of uncertainty. According to the theory, uncertainty is generated when components of illness, treatment-related stimuli, and illness-related events have the characteristics of complexity, inconsistency, randomness, unpredictability, and a lack of information in situations that are important to the person (Mishel, 1981, 1988). For BCSs, uncertainty is present in fear of recurrence, sexual dysfunction, body changes and symptoms related to the impact of treatment, and psychological issues (Friedlander & Thewes, 2003). Uncertainty and its management are part of the enduring physical and

**Purpose/Objectives:** To determine whether breast cancer survivors (BCSs) who received an uncertainty management intervention, compared to an attention control condition, would have less uncertainty, better uncertainty management, fewer breast cancer-specific concerns, and more positive psychological outcomes.

**Design:** A 2 x 2 randomized block, repeated-measures design, with data collected at baseline and two other points postintervention, as well as a few days before or after either a mammogram or oncologist visit.

**Setting:** Rural and urban clinical and community settings.

**Sample:** 313 female BCSs aged 50 or younger; 117 African Americans and 196 Caucasians.

**Methods:** Participants were blocked on ethnicity and randomly assigned to intervention or control. The intervention, consisting of a scripted CD and a guide booklet, was supplemented by four scripted, 20-minute weekly training calls conducted by nurse interventionists. The control group received the four scripted, 20-minute weekly training calls.

**Main Research Variables:** Uncertainty in illness, uncertainty management, breast cancer-specific concerns, and positive psychological outcomes.

**Findings:** BCSs who received the intervention reported reductions in uncertainty and significant improvements in behavioral and cognitive coping strategies to manage uncertainty, self-efficacy, and sexual dysfunction.

**Conclusions:** The intervention was effective as delivered in managing uncertainties related to being a younger BCS.

**Implications for Nursing:** The intervention can realistically be applied in practice because of its efficient and cost-effective nature requiring minimal direct caregiver involvement. The intervention allows survivors who are having a particular survival issue at any given point in time to access information, resources, and management strategies.

**Knowledge Translation:** Materials tested in CD and guide booklet format could be translated into online format for survivors to access as issues arise during increasingly lengthy survivorship periods. Materials could be downloaded to a variety of electronic devices, fitting with the information needs and management styles of younger BCSs.

social issues that impact quality of life (Bloom et al., 2008; Kornblith et al., 2007).

## Breast Cancer Survivorship for Younger Women

Because breast cancer is more common in older women, younger BCSs lack peer groups of fellow survivors who are available to older women. This also limits access to advice and knowledge about the management of long-term treatment side effects, such as premature menopause (e.g., sexual dysfunction, fatigue, insomnia), as well as resources containing credible information (Knobf, 2001; Thewes, Butow, Girgis, & Pendlebury, 2004). In addition, younger BCSs often are hesitant to disclose concerns to intimate others (Baucom, Porter, Kirby, Gremore, & Keefe, 2005).

Younger BCSs often report higher levels of distress than older BCSs, affecting their psychological state and emotional and social function, causing sexual problems, and leading to unmet needs (Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Kornblith et al., 2007; Sammarco, 2009). This may be from experiencing breast cancer at a time when they have multiple, varying demands in their lives that are then complicated by the diagnosis and treatment of a potentially life-threatening illness. Demands on women of younger age may include caring for children, parents, or grandparents; work responsibilities; and/or completing education while they are trying to develop or nurture intimate relationships and planning for future children. The uncertainties and resulting distress reported by younger BCSs may relate to the unknown and fears of cancer recurrence, which are out of synch with developmental norms and peer experiences (Rosen, Rodriguez-Wallberg, & Rosenzweig, 2009). Their uncertainties and fears can be linked to intrusive thoughts, fear of progression, and future uncertainty surrounding the welfare of their children (Baucom et al., 2005; Mehnert, Berg, Henrich, & Herschbach, 2009). Because the uncertainties in their lives are so varied and complex, younger BCSs require interventions directed specifically to their concerns that are provided through a medium that fits into their lives.

Of the existing studies of younger BCSs, few include African American survivors or other ethnic minorities in numbers adequate for comparison (or the studies are theory-based). The strategies tested and reported to be effective have varied greatly (Meneses, McNeese, Azuero, & Jukkala, 2010; Mishel et al., 2005), as have the targeted outcomes (Antoni et al., 2006; Marcus et al., 2010; Meneses et al., 2010; Mishel et al., 2005; Savard, Simard, Ivers, & Morin, 2005). Samples for published psychosocial intervention trials have generally lacked ethnic diversity, and the few studies that have included

younger African American BCSs indicated that this population benefits from targeted interventions focused on their concerns (Aziz & Rowland, 2002; Germino et al., 2011; Mishel et al., 2005).

## Ethnic Variation

Some existing evidence suggests that African American BCSs have more difficult survivor experiences than Caucasians and that they may have concerns that are less prevalent among Caucasian BCSs (Kantsiper et al., 2009; Russell, Von Ah, Giesler, Storniolo, & Haase, 2008). However, many of the studies that have been conducted on younger BCSs have inadequate samples of African Americans or other minority populations and, therefore, whether the knowledge about younger survivors' issues is applicable beyond the majority Caucasian population cannot be determined. To address this concern in the current study, the authors recruited an ethnically diverse sample so that findings could be generalized to both Caucasian and African American women. In addition, previous studies have included samples of survivors of various types of cancers (Aziz & Rowland, 2002) or samples of women of all ages, but the authors of the current study limited their sample to BCSs aged 50 years or younger.

In this article, the authors report the results of a randomized trial of the Younger Breast Cancer Survivor Uncertainty Management Intervention (YS-UMI), conducted with Caucasian and African American BCSs aged 50 years or younger. The key goal of the YS-UMI was to teach strategies to younger BCSs for managing uncertainty in survivorship. In addition, the YS-UMI addresses specific areas of concern to younger women during the one- to four-year period after treatment. The YS-UMI was largely self-delivered so that it could realistically be adapted to fit into these women's lives. The authors tested the hypothesis that women who received the YS-UMI, in comparison to an attention control condition, would have (a) less uncertainty, (b) better uncertainty management (more knowledge of long-term side effects, better cognitive reframing and problem solving, more self-disclosure, and more use of cognitive and behavioral coping strategies), (c) more sources for information and increased helpfulness of that information, (d) fewer breast cancer-specific concerns (less fear of recurrence, fewer intrusive thoughts, and reductions in treatment-related symptoms including sexual dysfunction, fatigue, and sleep disturbance), and (e) more positive psychological outcomes (greater personal growth, greater self-efficacy, and more positive and less negative affect). The authors also examined the impact of the intervention on common episodic acute stress events for BCSs (e.g., during a mammogram or oncologist visit) to determine whether the relationship between uncertainty as a stressor would result in

emotional distress, as has been supported in reviews of studies on uncertainty in illness (Mast, 1995; Mishel, 1999; Mishel & Fleury, 1997).

## Methods

### Design

The YS-UMI was tested using a 2 x 2 randomized block, repeated-measures design. Participants were randomly assigned, using a table of random numbers, to either YS-UMI or the attention control condition group after being blocked on ethnicity (Caucasian and African American). Outcome data were collected in women's homes at baseline (T1), 4–6 months after baseline (T2), and 8–10 months after baseline (T3). Basic demographic data were collected at T1. All other measures described in Table 1 were administered at T1, T2, and T3. To determine whether the YS-UMI could alter response to a cancer-related stress event (i.e., a mammogram or oncologist visit), data on positive and negative affect (measured with the Positive and Negative Affect Scale [PANAS]) were collected.

### Sample

The authors recruited and randomized 313 female BCSs ( $\bar{X}$  age = 44 years) consisting of 117 African American and 196 Caucasian women. Details of the multiple strategies for recruitment and the nature of recruitment sites have been reported elsewhere (Germino et al., 2011). The only significant demographic differences between intervention and control participants were that members of the control group had more years of education and were more likely to be privately insured than the intervention group.

### Intervention

The YS-UMI consists of two components. The first component is a scripted, professionally acted and produced CD that provided specific cognitive and behavioral strategies to control uncertainty and to promote self-efficacy for dealing with thoughts of recurrence, to improve disclosure of cancer-related concerns to others, and to make positive life changes. Specific strategies on the CD, with examples and vignettes, include calming self-talk to address triggers of uncertainty and intrusive thoughts, breathing relaxation and distraction to deal with emotional reactions to triggers of uncertainty, communication strategies to assist women in more effectively disclosing their concerns to those important to them, and skills for considering positive life changes by altering their appraisal of uncertainty to an opportunity rather than a threat.

The second component of the intervention was an investigator-developed guide that addresses selected uncertainties related to long-term breast cancer treatment side effects and life issues. The topics were chosen

based on the literature on uncertainties of younger BCSs and the authors' pilot study findings and included (a) hormonal changes that result in premature menopause with hot flashes, sexual problems, fertility issues, weight gain, loss of bone density, and mood alterations (Friedlander & Thewes, 2003; Maxwell & Viale, 2005); (b) disturbances in body and self-image (Avis, Crawford, & Manuel, 2005; Pinto & Trunzo, 2004; Spencer et al., 1999); (c) fatigue and sleep disturbances (Schwartz, 2000); and (d) prelymphedema symptoms as well as lymphedema (Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002; Harris, Hugi, Olivotto, Levine, & the Steering Committee for Clinical Practice Guidelines for the Care and Treatment of Breast Cancer, 2001). For sensory changes, cognitive changes, and future employment concerns, few research-based strategies are available, but the variety of resources that do exist for women with these problems were provided to participants. The guide included specific behavioral strategies, common medical approaches, and resources to help empower younger BCSs to manage their uncertainty-related concerns. Resources included the intervention CD along with a listing of organizations, Web sites, books, and pamphlets, as well as noted resources in a participant's community, including support groups designed specifically for younger women and for African American women.

The intervention was tailored to the uncertainties of younger survivors living busy, active lives, and was designed to be easily used by women at any time that concerns related to their survivorship arose. The CD could be played at home, at work, or while traveling; the provided guide has organized, tabbed sections on each topic of potential concern.

The intervention materials were delivered to intervention participants in their homes by the data collectors at the first data collection (T1). The materials were supplemented by four 20-minute weekly training calls conducted by trained nurse interventionists (NIs) using a scripted protocol and planned appointment times. On the telephone, the NIs reviewed and reinforced practice with the previous week's skills, focused on the rationale for new skills, and rehearsed new skills. Importantly, the NIs helped the women apply the skills to their particular uncertainties and integrate them into their lives. NIs also referred the women to the guide and worked through a topic of interest. All telephone calls were audio recorded with the participant's consent. Recording also allowed the investigators to review all calls to ensure intervention fidelity. All information from the calls was entered into an interactive database.

### Control Condition

The attention control condition was designed to control for the time and attention that women in the

**Table 1. Constructs and Measures Used in the Intervention Trial**

Construct	Measure	Study	Subscale Used	Total Items	Item Format	Current Study Reliability
<b>Uncertainty Management</b>						
Cognitive reframing and problem solving	Self-Control Schedule	Rosenbaum, 1983	Cognitive reframing and problem solving	20	Each statement about strategy use is rated on a 10-point scale indicating its truth for the participant.	Cronbach alpha = 0.82 for cognitive reframing and 0.81 for problem solving
Knowledge	Cancer Survivor Knowledge Scale	Investigator-developed	Total score	21	True or false statements about long-term and late-treatment effects	–
Self-disclosure	Disclosure Scale	Pistrang & Barker, 1992	Disclosing and holding back	10	Each item is rated on two six-point Likert-type scales indicating level of disclosure about the item to significant other and degree of holding back from talking about the item to significant other.	Cronbach alpha = 0.91 for disclosing and 0.9 for holding back
Sources for and helpfulness of information	Sources of Information Checklist	Investigator-developed	Number of sources and overall helpfulness	25	Two parts: whether received information (yes or no) and, if so, helpfulness of information on a four-point Likert-type scale	Cronbach alpha = 0.73–0.79
Uncertainty	Mishel Uncertainty in Illness Scale–Survivor Version	Mishel, 1983, 1984	Total score	22	Five-point Likert-type scale	Cronbach alpha = 0.84
<b>Breast Cancer–Specific Concerns</b>						
Fears of recurrence	Concerns About Recurrence Scale	Vickberg, 2003	Total score	4	Six-point scale indicating the degree of thought, upset, worry, and fear of recurrence	Alpha = 0.87 [32] Cronbach alpha = 0.89
Intrusive thoughts	Impact of Events	Horowitz et al., 1979	Intrusion	7	Four-point Likert-type scale indicating how frequently participants experience intrusive thoughts	Cronbach alpha = 0.88
Symptoms	Insomnia Severity Index	Bastien et al., 2001; Morin, 1993	Total severity score	7	Likert-type scale from 0 (not at all) to 4 (very much) for severity of insomnia during the previous two weeks	Alpha = 0.74 [34] Cronbach alpha = 0.89
Symptoms	Medical Outcomes Study–Sexual Functioning	Ware & Sherbourne, 1992	Total score	4	Six-point Likert-type scale rating how much of a problem each item was during the prior four weeks	Cronbach alpha = 0.92
Symptoms	Piper Fatigue Scale	Piper et al., 1998	Total score	22	11-point scale indicating the degree that fatigue interferes in the participant's life	Cronbach alpha at least 0.91 for all subscales, 0.96 for entire scale
<b>Positive Psychological Outcomes</b>						
Affect	Positive and Negative Affect Scale	Watson et al., 1988	Positive and negative affect	20	Five-point Likert-type scale measuring level of identification with words describing affect	Cronbach alpha = 0.89 for positive affect, 0.9 for negative affect

*(Continued on the next page)*

**Table 1. Constructs and Measures Used in the Intervention Trial (Continued)**

Construct	Measure	Study	Subscale Used	Total Items	Item Format	Current Study Reliability
<b>Positive Psychological Outcomes (Continued)</b>						
Personal growth	Growth Through Uncertainty Scale	Mishel & Fleury, 1997	New view, approach, growth, absence of fear and uncertainty, and total score	39	Six-point Likert-type scale measuring personal growth as a result of illness	Cronbach alpha = 0.71–0.93 for the four subscales and total score
Self-efficacy	Self-Efficacy for Breast Cancer	Lorig et al., 1989	Total score	16	11-point rating of how confident the participant is about her ability to manage common symptoms	Cronbach alpha = 0.92

intervention group received from the NIs. BCSs randomized to this condition received four 20-minute telephone calls from psychology graduate students that focused on inviting the survivor to describe the cancer experience related to her diagnosis, treatment, and survivorship. The graduate students also were trained to listen to the participant and not to offer any information or commentary. All calls were recorded and reviewed by an investigator to ensure that guidelines for duration, content, and caller role were being followed. At the end of the study, the control participants were sent the intervention CD and guide.

### Statistical Analysis

The effect of the intervention on the outcomes was assessed using linear mixed models in SAS® (PROC MIXED), version 9.2. Previous studies have suggested that ethnicity may moderate the intervention effect (Mishel et al., 2005; Mishel & Fleury, 1997); therefore, the interaction between ethnicity and intervention was included in the model where significant, allowing the estimation of separate treatment effects for African Americans and Caucasians. In an intent-to-treat analysis, a group test of intervention versus control differences at all follow-up times was used to detect evidence of an intervention effect, either separately by ethnicity (if the interaction was significant) or for the entire group. The main effect of ethnicity was included in all models.

Because tests were based on intervention versus control differences at follow-up, modifications to the analysis were necessary to control for variables that differed between intervention and control groups at baseline. To control for baseline differences when examining intervention effects on these variables, the authors considered changes from baseline in each group rather than comparison of the intervention versus control

at a follow-up visit. At baseline, the intervention and control groups had a trend toward significant differences on three study outcomes: knowledge of long-term side effects ( $p = 0.006$ ), use of behavioral activities as a cognitive coping strategy ( $p = 0.05$ ), and negative affect ( $p = 0.03$  in African Americans). Specifically, the intervention group began the study with less knowledge of long-term side effects and lower reported use of behavioral activities, and African Americans in the intervention group began with higher negative affect than control participants.

Because the groups were randomized, results controlling for the demographics that differed between the groups (education and health insurance status) are not reported. The authors did, however, fit the mixed models controlling for these variables, and all the statistically significant intervention effects remained significant.

## Results

### Uncertainty and Uncertainty Management

The intervention group experienced a decrease in uncertainty that was significantly larger than in the control group ( $F[3,528] = 3.6, p = 0.01$ ). The intervention also positively impacted knowledge of long-term side effects. Although the control group was higher at baseline than the intervention group, knowledge of long-term side effects increased significantly more from baseline ( $F[3,528] = 3.29, p = 0.02$ ) in the intervention group, surpassing that of the control group. In addition, the intervention group reported a greater increase in the number of sources of information ( $F[3,526] = 44.8, p < 0.001$ ) and the helpfulness of the sources they used ( $F[3,522] = 10.61, p < 0.001$ ).

Survivors in the intervention group, compared to those in the control group, displayed enhanced use

of cognitive coping strategies, specifically diverting attention ( $F[3,527] = 6.01, p < 0.001$ ) and behavioral activities ( $F[3,527] = 4.62, p = 0.003$ ). The increase in use of coping self-statements was marginally significant ( $F[3,527] = 2.51, p = 0.06$ ). None of the other cognitive coping strategies (catastrophizing, praying or hoping, and ignoring sensations) was significantly impacted by the intervention. However, cognitive reframing and problem solving both increased in the intervention group more than the control group ( $F[3,528] = 4.81, p = 0.003$  and  $F[3,528] = 2.82, p = 0.04$ , respectively).

### Breast Cancer–Specific Concerns

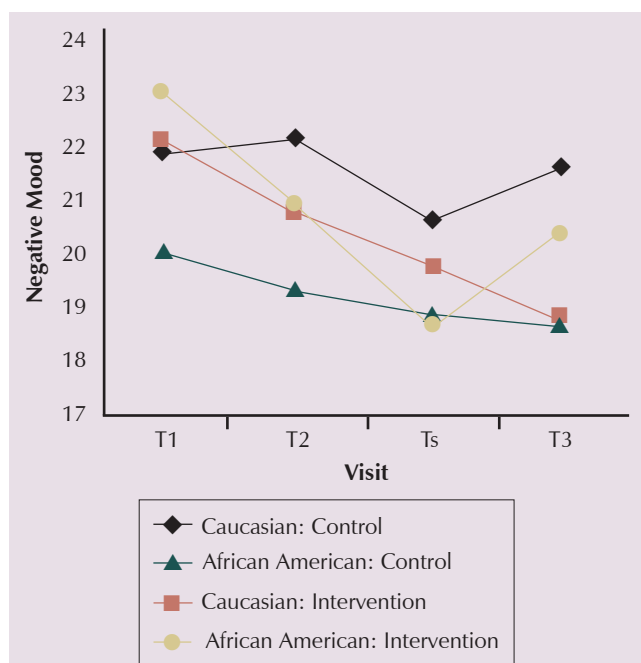
Although intrusive thoughts are a major issue for younger BCSs, no significant intervention effect was noted on this variable ( $F[3,528] = 0.64, p = 0.59$ ). However, those in the intervention group had a larger decrease in fear of recurrence than the control condition, although the difference was not quite statistically significant ( $F[3,528] = 2.31, p = 0.08$ ). At T2, sexual dysfunction was lower in the intervention group ( $F[3,525] = 2.93, p = 0.033$ ), implying that women dealing with sexual dysfunction used the interventions in the guide and found them useful. For the other symptoms, the uncertainty management intervention had no effect on insomnia ( $F[3,527] = 1.41, p = 0.24$ ), fatigue ( $F[3,433] = 1.06, p = 0.37$ ), or menopausal symptoms ( $F[3,514] = 1.31, p = 0.27$ ).

### Positive Psychological Outcomes

Participants in the intervention group experienced a larger increase in cancer-related self-efficacy than those in the control group ( $F[3,528] = 4.79, p = 0.003$ ). Regarding personal growth, no significant effect was noted on the Growth Through Uncertainty Scale (GTUS) total score or on three of the subscales (new view, approach, and growth). However, a significant effect was detected on the absence of fear and uncertainty subscale ( $F[3, 528] = 3.07, p = 0.03$ ), an important finding because, while changes in the GTUS refer to current events, change in the absence of fear and uncertainty subscale refer to future events. This indicates that the influence of the intervention significantly improved over time.

The impact of the intervention on positive and negative affect (measured by PANAS) was examined with an added focus on intervention effects at a stress event. No significant effect was noted from the intervention on positive affect, but significant ethnicity moderation of the intervention effect on negative affect was found ( $F[4,761] = 3.68, p = 0.006$ ) (see Figure 1). Although the intervention did not have a statistically significant impact on negative affect in Caucasians ( $F[4,760] = 1.96, p = 0.12$ ), evidence of differences from baseline in African Americans was detected ( $F[1,758] = 4.81, p = 0.03$ ); therefore, the authors used the mixed model to test the change from baseline to each follow-up. The YS-UMI was found to significantly decrease the amount of negative affect in African American survivors at the time of the stress event ( $F[1,758] = 10.7, p = 0.001$ ). The means and standard deviations (by treatment group and times) for outcomes significantly affected by the intervention can be found in Table 2.

In summary, the intervention group experienced significant decreases in uncertainty and sexual dysfunction and, in comparison to controls, a larger (although not significant) decrease in fears of recurrence. Women who received the intervention reported improved knowledge of long-term treatment side effects, a greater number of sources of information, more helpfulness of information, more frequent use of cognitive coping strategies such as diverting attention and behavioral activities, more use of cognitive reframing and problem solving, and an improvement in cancer-related self-efficacy. African American intervention participants in this study experienced a significant decrease in negative affect at the time of a cancer-related stress event.



Note. T1 was baseline, T2 was 4–6 months after baseline, T<sub>s</sub> was a stress event, and T3 was 8–10 months after baseline.

**Figure 1. Average Negative Mood by Intervention Group and Ethnicity Over Time**

### Discussion

A number of features distinguish this study from prior intervention studies with BCSs. First, the current study targeted a population of both Caucasian and African American BCSs aged 50 years and younger who

**Table 2. Means and Standard Deviations for Outcomes Significantly Impacted by the Intervention Over Time (N = 313)**

Variable	Control (n = 146)						Intervention (n = 167)					
	T1		T2		T3		T1		T2		T3	
	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD
Knowledge of long-term side effects	17.2	2.6	17.7	2.5	18.2	2.4	16.3	2.9	18.1	2.4	18.4	2.3
Number of sources of information	13.2	7.7	14.4	7.4	15.8	7.6	13.2	7.8	21.3	5.6	23.3	5.9
Helpfulness of sources of information	3.03	0.44	3.08	0.4	3.05	0.42	2.98	0.51	3.3	0.44	3.26	0.42
Diverting attention	3.8	1.24	3.71	1.24	3.94	1.22	3.58	1.19	4.19	0.93	4.23	1.13
Behavioral activities	3.6	1.24	3.53	1.14	3.63	1.16	3.34	1.13	3.9	0.88	3.83	1.12
Cognitive reframing	7.42	1.28	7.5	1.3	7.62	1.07	7.22	1.44	7.91	1.16	7.97	1.15
Problem solving	7.54	1.22	7.57	1.25	7.65	1.11	7.48	1.35	7.89	1.05	7.95	1.19
Cancer-related self-efficacy	70.1	16.2	73.1	13.6	73.9	14.1	68.4	17.5	76.3	14.7	79.8	12.8
Negative mood (African Americans) <sup>a</sup>	20	7.6	19.1	7	18.4	6.7	23	9	20.9	7.5	20.6	8.1
Absence of fear and uncertainty	4.15	1.18	4.29	1.25	4.42	1.1	4.09	1.3	4.63	1	4.69	1.02
Sexual dysfunction	2.29	1.1	2.3	1.11	2.18	1.06	2.1	1.02	1.98	1.01	2.03	1.06

<sup>a</sup> The mean stress event for negative mood was 18.5 (SD = 7.3) in the control group and 18.4 (SD = 6.3) in the intervention group. Note. T1 was baseline, T2 was 4–6 months after baseline, and T3 was 8–10 months after baseline.

have been underrepresented in intervention research that has usually included samples across a broad age range. Second, the intervention was based on uncertainty theory and required minimal therapist contact. Third, the inclusion of an adequate number of African American survivors enabled the authors to examine potential ethnic differences in response to the intervention. Fourth, the study included an assessment at the time of an acute cancer-related stress event. Finally, the longitudinal study design and inclusion of an attention control condition strengthened the design, improving confidence in the findings.

Compared to those in the attention control condition, BCSs who received the YS-UMI reported significant benefits in a number of areas. As hypothesized, the intervention led to reductions in the subjective survivorship experience of uncertainty for both Caucasian and African American women. Consistent with uncertainty theory, the information and support provided by the guidebook and NIs likely clarified BCSs' concerns, therefore weakening the experience of uncertainty (Baucom et al., 2005; Sammarco, 2009). These findings build on those of several prior studies testing uncer-

tainty management interventions with older BCSs (Mishel et al., 2005), as well as survivors of prostate cancer (Mishel et al., 2003).

In addition to reductions in uncertainty, women who received the intervention reported improvements in the absence of fear and uncertainty subscale of the GTUS ( $r = -0.29$ ,  $p > 0.001$ ). As mentioned previously, because the uncertainty scale refers to the present and the GTUS absence of fear and uncertainty subscale refers to the future, the effects of the intervention included reductions in fear of the future, as well as the present experience of uncertainty.

Women who received the YS-UMI also reported improvements in a variety of domains of uncertainty management. Both Caucasian and African American survivors reported increases in cancer knowledge and use of information about breast cancer—primary resources for managing uncertainty. Information can clarify illness-related events, thus reducing uncertainty. That may be particularly important for younger BCSs who may be less likely than older BCSs to receive health information in a timely manner or usable format or with a focus on managing psychosocial sequelae (Avis et

al., 2005; Jukkala, Azuero, McNees, Bates, & Meneses, 2010). The findings suggest that the information in the intervention was appropriate for this sample, addressing their concerns and meeting ongoing needs for information on physical symptoms (Thewes et al., 2004). This also is consistent with a prior intervention study with younger BCSs (Bloom et al., 2008), extending findings to a multiethnic sample.

The YS-UMI also led to improvements in coping for Caucasian and African American survivors, including behavioral coping strategies (problem solving and use of behavioral activities) and cognitive strategies (cognitive reframing and diverting attention). Behavioral activities are effective for coping with some stressors of survivorship such as finding and using information about managing physical symptoms. However, cognitive strategies may be more effective for coping with other stressors, such as fear of recurrence. The ability to cognitively reframe threatening events into more manageable events has been found to benefit older BCSs, as well as men with prostate cancer (Mishel et al., 2002, 2005), and the authors expected that it would benefit younger BCSs, too. The significant findings related to coping and cancer knowledge are consistent with those obtained with a similar intervention targeted toward older, long-term BCSs (Mishel et al., 2005). The benefit found for these strategies among a younger multiethnic sample of BCSs supports their generalizability across age groups regardless of differences in the specific content areas and issues between the two age groups.

Although one component of the intervention was devoted to disclosure of cancer-related concerns to significant others and included a discussion of the difficulties BCSs face in talking about their cancer-related concerns, the potential benefits of talking openly about these concerns, and training in effective communication strategies, the intervention did not lead to improvement in this area. This intervention was targeted to the individual BCS and improvement in disclosure might require an intervention that focuses on dyadic communication. Findings from couple-based intervention studies that focused on improving communication between patients with cancer and their partners provide evidence that these interventions can lead to improvements in relationship functioning (Baucom et al., 2009; Porter et al., 2009), suggesting that outcomes such as disclosure are more effectively addressed in interventions that include both members of a dyad.

In the area of survivors' self-efficacy, outcomes from the intervention were consistent with the findings of several other intervention studies targeting self-efficacy in patients with cancer (Lev et al., 2001; Stiegelis et al., 2004). The findings in the current study extend results to younger African American BCSs. Components of

the intervention that were likely to lead to improvements in self-efficacy include providing information addressing cancer-related concerns, as well as inclusion of techniques based on self-efficacy theory (Bandura, 1997). The authors found a strong negative relationship between self-efficacy and uncertainty ( $r = -0.58$ ). In future studies, investigators may want to examine whether the increase in self-efficacy that occurs with a brief intervention leads to more durable effects in reducing uncertainty.

Of the breast cancer-related symptoms, sexual dysfunction was improved by the intervention. Sexual dysfunction is particularly salient for younger women, negatively impacts their quality of life, and has been recommended as a target for intervention (Avis et al., 2005; Baucom et al., 2005; Ganz et al., 2003). Sexual dysfunction may continue because of a lack of information (Jukkala et al., 2010), as well as from uncertainty that can affect the ability to register information (Rosen et al., 2009). This intervention provided women with sufficient information and strategies to reduce uncertainty, which may have allowed them to seek additional information.

The lack of intervention effect on fatigue, insomnia, and menopausal symptoms was somewhat surprising given that the guidebook offered a number of evidence-based management strategies for these symptoms. Although the strategies included in the guide were based on the most current literature at the time, women may not have used the guide consistently, widely, or for an adequate period of time. In particular, interventions to address insomnia and sleep disturbances require persistent, prolonged practice. Strategies described may not have been successful for some of the women who tried them. For instance, some menopausal symptoms such as hot flashes and vaginal dryness may be particularly difficult to successfully manage.

Although pilot participants had indicated that they preferred content about symptom management in booklet form, this format did not have the portability and ease of access found with the CD. The authors know that many women in the study listened to the CD in their car on the way to and from work or other destinations, and a few even listened to it at work.

The ethnic difference found was that the intervention led to a significant decrease in negative affect at the time of the stress event among African Americans. The authors could find this difference because of a sufficiently large sample of minority women in this study. With the inclusion of a larger sample of African American women, some evidence now exists that younger African American BCSs may respond more positively to this type of intervention than their Caucasian counterparts and may then have had more positive outcomes. These women may have been able to apply the strategies from the intervention when faced with



a potentially distressing cancer-related event such as a mammogram or follow-up oncology appointment.

## Limitations

The sample included only Caucasian and African American women, limiting the ability to generalize findings to other ethnic groups. Future investigators should consider how they can best capture the ethnic diversity in their communities to ensure minority representation. The study follow-up was limited to 8–10 months following the intervention. This may have precluded the authors' ability to detect improvements in some outcomes that might take longer to change.

## Clinical Implications

Despite the few limitations, the efficacy of the YS-UMI for younger, long-term Caucasian and African American BCSs is highly promising for clinical application because it can realistically be delivered in a clinical context. The YS-UMI is efficient and cost-effective because intervention materials, inexpensive to reproduce, can be given to survivors on clinical visits and used as the need arises. The materials are designed to be accessed by specific topic after a brief introduction so that the BCS can focus on those problems or the issues most salient and concerning to her at any given time, thus using the intervention materials to meet her particular needs in an efficient manner. CD tracks are clearly designated, as are the problems with which they are useful. Any cognitive behavioral strategy that is of interest to the woman or fits with ongoing approaches to coping can be identified and learned by itself. In the guide, each topic covered includes additional resources so the woman can easily explore the problem and possible management strategies in some depth. Follow-up to ascertain that patients fully understand the intervention and can integrate it into their daily lives has been demonstrated to be effectively delivered in brief telephone contacts and also could be done via e-mail.

## Research Implications

The efficacy and efficiency of this intervention have been demonstrated in this clinical trial that includes an

adequate number of African American participants to indicate its effectiveness for both ethnic groups of BCSs aged 50 years and younger. Future trials are needed that include adequate numbers of younger BCSs of additional ethnicities to be sure that the intervention is effective for a diverse population.

In this trial, participants' mean age was 44 years. The subsample of survivors aged 30 years and younger was too small to examine separately. Women at the youngest end of the age spectrum of premenopausal BCSs, those aged 18–35 years, could be a group that has additional needs specific to their age and developmental stage. This subgroup is likely to be developing serious relationships and considering childbearing, issues that remain to be examined in planning for clinical intervention designed to help that population.

Because the authors were targeting younger women, the use of current technology to deliver the intervention is vital. Many younger women use smartphones and tablet devices to manage the information in their lives. The authors are currently adapting this intervention for online and mobile device use and will be testing it through a national online survivor group. With portability and convenient access of information being a strong value among younger people with busy and complex lives, the study of current technology for intervention delivery is an important area for future research.

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## References

- American Cancer Society. (2012). *Cancer facts and figures, 2012*. Atlanta, GA: Author.
- Antoni, M.H., Lechner, S.C., Kazi, A., Wimberly, S.R., Sifre, T., Urcuyo, K.R., . . . Carver, C.S. (2006). How stress management improves quality of life after treatment for breast cancer. *Journal of Consulting and Clinical Psychology, 74*, 1143–1152.
- Avis, N.E., Crawford, S., & Manuel, J. (2005). Quality of life among younger women with breast cancer. *Journal of Clinical Oncology, 23*, 3322–3330.
- Aziz, N.M., & Rowland, J.H. (2002). Cancer survivorship research among ethnic minority and medically underserved groups. *Oncology Nursing Forum, 29*, 789–801. doi:10.1188/02.ONF.789-801
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York, NY: W.H. Freeman.
- Bastien, C.H., Vallieres, A., & Morin, C.M. (2001). Validation of the insomnia severity index as an outcome measure for insomnia research. *Sleep Medicine, 2*, 297–307.

- Baucom, D.H., Porter, L.S., Kirby, J.S., Gremore, T.M., & Keefe, F.J. (2005). Psychosocial issues confronting young women with breast cancer. *Breast Diseases, 23*, 103–113.
- Baucom, D.H., Porter, L.S., Kirby, J.S., Gremore, T.M., Wiesenthal, N., Aldridge, W., . . . Keefe, F.J. (2009). A couple-based intervention for female breast cancer. *Psycho-Oncology, 18*, 276–283. doi:10.1002/pon.1395
- Bloom, J.R., Stewart, S.L., D'Onofrio, C.N., Luce, J., & Banks, P.J. (2008). Addressing the needs of young breast cancer survivors at the five-year milestone: Can a short-term, low-intensity intervention produce change? *Journal of Cancer Survivorship, 2*, 190–204. doi:10.1007/s11764-008-0058-x
- Box, R.C., Reul-Hirche, H.M., Bullock-Saxton, J.E., & Furnival, C.M. (2002). Shoulder movement after breast cancer surgery: Results of a randomized controlled study of postoperative physiotherapy. *Breast Cancer Research and Treatment, 75*, 35–50.
- Friedlander, M., & Thewes, B. (2003). Counting the costs of treatment: The reproductive and gynaecological consequences of adjuvant therapy in young women with breast cancer. *Internal Medicine Journal, 33*, 372–379.
- Ganz, P.A., Greendale, G.A., Petersen, L., Kahn, B., & Bower, J.E. (2003). Breast cancer in younger women: Reproductive and late health effects of treatment. *Journal of Clinical Oncology, 21*, 4184–4193. doi:10.1200/JCO.2003.04.196
- Germino, B.B., Mishel, M.H., Alexander, A.R., Jenerette, C., Blyler, D., Baker, C., . . . Long, D.C. (2011). Engaging African American breast cancer survivors in an intervention trial: Culture, responsiveness, and community. *Journal of Cancer Survivorship, 5*, 82–91. doi:10.1007/s11764-010-0150-1
- Harris, S.R., Hugi, M.R., Olivotto, I.A., Levine, M., & the Steering Committee for Clinical Practice Guidelines for the Care and Treatment of Breast Cancer. (2001). Clinical practice guidelines for the care and treatment of breast cancer: 11. Lymphedema. *Canadian Medical Association Journal, 164*, 191–199.
- Horowitz, M., Wilner, N., & Alvarez, W. (1979). Impact of Events scale: A measure of subjective stress. *Psychosomatic Medicine, 41*, 209–218.
- Jukkala, A.M., Azuero, A., McNees, P., Bates, G.W., & Meneses, K. (2010). Self-assessed knowledge of treatment and fertility preservation in young women with breast cancer. *Fertility and Sterility, 3*, 43. doi:10.1016/j.fertnstert.2010.03.043
- Kantsiper, M., McDonald, E.L., Geller, G., Shockney, L., Snyder, C., & Wolff, A.C. (2009). Transitioning to breast cancer survivorship: Perspectives of patients, cancer specialists, and primary care providers. *Journal of General Internal Medicine, 24*(Suppl. 2), S459–S466. doi:10.1007/s11606-009-1000-2
- Knobf, M.T. (2001). The menopausal symptom experience in young mid-life women with breast cancer. *Cancer Nursing, 24*, 201–210.
- Kornblith, A.B., Powell, M., Regan, M.M., Bennett, S., Krasner, C., May, B., . . . Winer, E. (2007). Long-term psychosocial adjustment of older versus younger survivors of breast and endometrial cancer. *Psycho-Oncology, 16*, 895–903. doi:10.1002/pon.1146
- Lev, E.L., Daley, K.M., Conner, N.E., Reith, M., Fernandez, C., & Owen, S.V. (2001). An intervention to increase quality of life and self-care self-efficacy and decrease symptoms in breast cancer patients. *Scholarly Inquiry in Nursing Practice, 15*, 277–294.
- Lorig, K., Chastain, R.L., Ung, E., Shoor, S., & Holman, H.R. (1989). Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. *Arthritis and Rheumatism, 32*, 37–44.
- Marcus, A.C., Garrett, K.M., Cella, D., Wenzel, L., Brady, M.J., Fairclough, D., . . . Flynn, P.J. (2010). Can telephone counseling post-treatment improve psychosocial outcomes among early stage breast cancer survivors? *Psycho-Oncology, 19*, 923–932. doi:10.1002/pon.1653
- Maat, M. (1995). Survivors of breast cancer: Illness uncertainty, positive reappraisal, and emotional distress. *Oncology Nursing Forum, 25*, 555–562.
- Maxwell, C., & Viale, P.H. (2005). Cancer treatment-induced bone loss in patients with breast or prostate cancer. *Oncology Nursing Forum, 32*, 589–603. doi:10.1188/05.ONF.589-603
- Mehnert, A., Berg, P., Henrich, G., & Herschbach, P. (2009). Fear of cancer progression and cancer-related intrusive cognitions in breast cancer survivors. *Psycho-Oncology, 18*, 1273–1280. doi:10.1002/pon.1481
- Meneses, K., McNees, P., Azuero, A., & Jukkala, A. (2010). Evaluation of the fertility and cancer project (FCP) among young breast cancer survivors. *Psycho-Oncology, 19*, 1112–1115. doi:10.1002/pon.1648
- Mishel, M.H. (1981). The measurement of uncertainty in illness. *Nursing Research, 30*, 258–263.
- Mishel, M.H. (1983). Adjusting the fit: Development of uncertainty scales for specific clinical populations. *Western Journal of Nursing Research, 5*, 355–370.
- Mishel, M.H. (1984). Perceived uncertainty and stress in illness. *Research in Nursing and Health, 7*, 163–171.
- Mishel, M.H. (1988). Uncertainty in illness. *Image: Journal of Nursing Scholarship, 20*, 225–232.
- Mishel, M.H. (1999). Uncertainty in chronic illness. *Annual Review of Nursing Research, 17*, 269–294.
- Mishel, M.H., Belyea, M., Germino, B.B., Stewart, J.L., Bailey, D.E., Robertson, C., & Mohler, J.L. (2002). Helping patients with localized prostate carcinoma manage uncertainty and treatment side effects: Nurse-delivered psychoeducational intervention over the telephone. *Cancer, 94*, 1854–1866.
- Mishel, M.H., & Fleury, J. (1997). The growth through uncertainty scale. Unpublished manuscript.
- Mishel, M.H., Germino, B.B., Belyea, M., Stewart, J.L., Bailey, D.E., Mohler, J., & Robertson, C. (2003). Moderators of an uncertainty management intervention: For men with localized prostate cancer. *Nursing Research, 5*, 89–97.
- Mishel, M.H., Germino, B.B., Gil, K.M., Belyea, M., LeNay, I.C., Stewart, J., . . . Clayton, M.F. (2005). Benefits from an uncertainty management intervention for African American and Caucasian older long-term breast cancer survivors. *Psycho-Oncology, 14*, 962–978. doi:10.1002/pon.909
- Morin, C.M. (1993). *Insomnia: Psychological assessment and management*. New York, NY: Guilford Press.
- Pinto, B.M., & Trunzo, J.J. (2004). Body esteem and mood among sedentary and active breast cancer survivors. *Mayo Clinic Proceedings, 79*, 181–186.
- Piper, B.F., Dibble, S.L., Dodd, M.J., Weiss, M.C., Slaughter, R.E., & Paul, S.M. (1998). The revised Piper Fatigue Scale: Psychometric evaluation in women with breast cancer. *Oncology Nursing Forum, 25*, 677–684.
- Pistrang, N., & Barker, C. (1992). Disclosure of concerns in breast cancer. *Psycho-Oncology, 1*, 183–192. doi:10.1002/pon.2960010307
- Porter, L.S., Keefe, F.J., Baucom, D.H., Hurwitz, H., Moser, B., Patterson, E., & Kim, H.J. (2009). Partner-assisted emotional disclosure for patients with gastrointestinal cancer: Results from a randomized controlled trial. *Cancer, 115*, 4326–4338. doi:10.1002/cncr.24578
- Rosen, A., Rodriguez-Wallberg, K.A., & Rosenzweig, L. (2009). Psychosocial distress in young cancer survivors. *Seminars in Oncology Nursing, 25*, 268–277. doi:10.1016/j.soncn.2009.08.004
- Rosenbaum, M. (1983). Learned resourcefulness as a behavioral repertoire for the self-regulation of maternal events: Issues and speculations. In M. Rosenbaum, C.M. Frands, & Y. Jaffe (Eds.), *Perspectives on behavior therapy in the Eighties* (pp. 54–73). New York, NY: Springer.
- Russell, K.M., Von Ah, D.M., Giesler, R.B., Storniolo, A.M., & Haase, J.E. (2008). Quality of life of African American breast cancer survivors: How much do we know? *Cancer Nursing, 31*, E36–E45. doi:10.1097/01.NCC.0000339254.68324.d7
- Sammarco, A. (2009). Quality of life of breast cancer survivors: A comparative study of age cohorts. *Cancer Nursing, 32*, 347–356. doi:10.1097/NCC.0b013e31819e23b7
- Savard, J., Simard, S., Ivers, H., & Morin, C.M. (2005). Randomized study on the efficacy of cognitive-behavioral therapy for insomnia secondary to breast cancer. Part II: Immunologic effects. *Journal of Clinical Oncology, 23*, 6097–6106. doi:10.1200/JCO.2005.12.513
- Schwartz, A.L. (2000). Daily fatigue patterns and effect of exercise in women with breast cancer. *Cancer Practice, 8*, 16–24.
- Spencer, S.M., Lehman, J.M., Wynings, C., Arena, P., Carver, C.S.,

- Antoni, M.H., . . . Love, N. (1999). Concerns about breast cancer and relations to psychosocial well-being in a multiethnic sample of early-stage patients. *Health Psychology, 18*, 159–168.
- Stiegelis, H.E., Hagedoorn, M., Sanderman, R., Bennenbroek, G.T., Buunk, B.P., van den Bergh, A.C., . . . Ranchor, A.V. (2004). The impact of an informational self-management intervention on the association between control and illness uncertainty before and psychological distress after radiotherapy. *Psycho-Oncology, 13*, 248–259. doi:10.1002/pon.738
- Thewes, B., Butow, P., Girgis, A., & Pendlebury, S. (2004). The psychosocial needs of breast cancer survivors: A qualitative study of the shared and unique needs of younger versus older survivors. *Psycho-Oncology, 13*, 177–189. doi:10.1002/pon.710
- Vickberg, S.M. (2003). The Concerns About Recurrence Scale (CARS): A systematic measure of women's fears about the possibility of breast cancer recurrence. *Annals of Behavioral Medicine, 25*, 16–24.
- Ware, J.E., Jr., & Sherbourne, C.D. (1992). The MOS 36-item short-form health survey (SF-36). 1. Conceptual framework and item selection. *Medical Care, 30*, 473–483.
- Watson, D., Clark, L.A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scale. *Journal of Personality and Social Psychology, 54*, 1063–1070.

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1. The authors of this study suggest that African American women with breast cancer experience differences in affect and after the intervention showed a greater improvement than their Caucasian counterparts. What is the reason for this and what role does ethnicity or culture play in the experience of women with breast cancer?
2. The intervention had no effect on insomnia, fatigue, or menopausal symptoms but did improve sexual functioning. What might be the reasons for this and is this a surprising finding for you?
3. The intervention did not improve communication for these women with their significant others. The authors suggest that communication needs to be dealt with within the couple dyad. Do you agree with this and how would you try to help women in this regard?

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Germino is a research professor in the School of Nursing at the University of North Carolina at Chapel Hill. Her previous research has focused on the uncertainty that cancer survivors experience, particularly African American and Caucasian female populations.

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