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# An Individualized Representational Intervention to Improve Symptom Management (IRIS) in Older Breast Cancer Survivors: Three Pilot Studies

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**M**ore than a decade ago, the Oncology Nursing Society (ONS) recognized that oncology nurses will be caring for a growing number of older (aged 65 years or older) adults with cancer and that nursing care must meet the unique cancer-specific needs of this population (Boyle, 1992). The sentiment was revisited in 2007 in ONS's joint position with the Geriatric Oncology Consortium on cancer care for older adults. For older breast cancer survivors, the impact of a cancer diagnosis and cancer treatment combined with the physical and health changes commonly associated with aging result in unique survivorship issues (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006; Deimling, Sterns, Bowman, & Kahana, 2005; Keating, Norredam, Landrum, Huskamp, & Meara, 2005; Yancik et al., 2001). One such issue is the experience of numerous, often chronic, symptoms that can be caused by cancer diagnosis and treatment, comorbid chronic health problems, and aging in general. These symptoms affect quality of life (QOL), including physical function, emotional well-being, and existential concerns. In clinical practice, healthcare providers are faced with trying to assist older breast cancer survivors in managing these symptoms. Yet, with a few exceptions (Sherwood et al., 2005), research has focused on testing symptom interventions that address a single symptom (Dodd et al., 2001).

Nursing interventions are needed to address the symptoms faced by older breast cancer survivors. To this end, an individualized representational intervention to improve symptom management (IRIS) was developed. The underlying hypothesis guiding the IRIS was that it would improve symptom management behaviors, resulting in decreased distress from symptoms. Lower symptom distress would, in turn, improve

**Purpose/Objectives:** To test the feasibility and acceptability of an individualized representational intervention to improve symptom management (IRIS) in older breast cancer survivors and test the short-term effects of an IRIS on symptom distress.

**Design:** Two small randomized clinical trials and one pre-experimental study.

**Setting:** Oncology clinic and community.

**Sample:** 41 women with breast cancer (aged 65 years and older) in pilot study 1, 20 in pilot study 2, and 21 in pilot study 3.

**Methods:** In pilot study 1, women were randomized to the IRIS or usual care control. In pilot study 2, women were randomized to the IRIS or delayed IRIS (wait list) control. In pilot study 3, all women received the IRIS by telephone. Measures were collected at baseline, postintervention, and follow-up (up to four months).

**Main Research Variables:** Feasibility, acceptability, symptom distress, symptom management behaviors, symptom management barriers, and quality of life.

**Findings:** Across three pilot studies, 76% of eligible women participated, 95% completed the study, 88% reported the study was helpful, and 91% were satisfied with the study. Some measures of symptom distress decreased significantly after the IRIS, but quality of life was stable. Women in the IRIS group changed their symptom management behaviors more than controls.

**Conclusions:** Preliminary evidence supports the need for and feasibility of an IRIS.

**Implications for Nursing:** Nurses may help older breast cancer survivors manage their numerous chronic symptoms more effectively by assessing women's beliefs about their symptoms and their current symptom management strategies.

QOL. Three pilot studies were carried out to test the feasibility and acceptability of an IRIS in older (aged 65 years or older) breast cancer survivors and to test the short-term effects of an IRIS on symptom distress.

Secondary aims were to explore the effect of an IRIS on symptom management behaviors and QOL and to explore barriers to symptom management.

## Background

Breast cancer is an age-related disease. Sixty-five percent of breast cancers occur in women older than 64 years (Ries et al., 2008). Breast cancer is considered a chronic disease in old age (Byrne, Smart, Chu, & Hartmann, 1994; Peer, Verbeek, Mravunac, Hendriks, & Holland, 1996), and older breast cancer survivors typically are coping with an average of four additional chronic health problems (Deimling et al., 2005; Heidrich, Egan, Hengudomsub, & Randolph, 2006). These multiple chronic health conditions are accompanied by symptoms that can have a negative impact on QOL, particularly when they interfere with the ability to carry out desired activities (Heidrich, 1996; Heidrich et al., 2006; Heidrich, Forsthoef, & Ward, 1994).

For cancer survivors, any symptom can lead to questions about whether to seek care for that symptom as well as worry that the symptom is a sign of a cancer recurrence (Clayton, Mishel, & Belyea, 2006). In preliminary studies of older breast cancer survivors, the average number of symptoms reported was 16, and many women were unsure of the possible cause of their symptoms (e.g., breast cancer, chronic health problems, aging). Uncertainty about the cause of symptoms was related to lower levels of QOL (Heidrich et al., 2006). For older cancer survivors, sorting out symptoms can be especially difficult; however, few studies have examined the symptom experience of older cancer survivors or interventions to improve symptom management.

## Theoretical Basis of the Intervention

The IRIS in these studies is based on Donovan and Ward's (2001) (Donovan et al., 2007) Representational Approach to Patient Education, which was formulated as a theoretical model to guide psychoeducational nursing interventions. This model was derived from Leventhal and Diefenbach's Common Sense Model (1991) and theories of conceptual change (Hewson & Thorley, 1989; Posner, Strike, Hewson, & Gertzog, 1982). According to the Common Sense Model, people have common sense beliefs or representations about their health problems that guide coping behaviors. A symptom representation is the set of beliefs (whether medically sound or unsubstantiated) that a person has about that symptom and consists of five dimensions: identity (how one describes the symptom), cause (individuals' beliefs about the origin of the symptom), timeline (the acute, chronic, or cyclic nature of the symptom), consequences (ideas about the short- and long-term outcomes of the symptom), and

cure/control (beliefs about the extent to which one can control or cure a symptom). However, representations are resistant to change, which is one explanation for why simply delivering information does not reliably lead to behavior change. Posner et al. (1982) proposed that conceptual change is most likely to occur when a person is dissatisfied with an existing conception, an intelligible and plausible alternative is offered, and the new conception clearly will be beneficial. Change also is facilitated when individuals are given the opportunity to monitor and comment on their own ideas (Hewson & Thorley).

Assessing an individual's representations of symptoms can facilitate conceptual change about beliefs embedded in that representation in two ways. First, through a detailed discussion of beliefs about symptoms, individuals have an opportunity to examine these beliefs and become aware of beliefs that interfere with symptom management. Second, when an individual's symptom representation has been elicited, educational information can be presented in a highly individualized manner such that the new information will be seen as suitable for guiding new behavioral strategies. Ultimately, a new representation is formed that has the benefit of encouraging better symptom management. Initial evidence shows that the representational approach not only is well liked by patients but also is efficacious (Donovan & Ward, 2001; Donovan et al., 2007; Song, Kirchhoff, Douglas, Ward, & Hammes, 2005; Ward et al., 2008).

The IRIS is a patient-centered, highly individualized approach in which women choose the symptom(s) for intervention, develop their goals for symptom management, and choose the strategies they will use to achieve those goals. The three pilot studies reported in this article were tests of the feasibility and acceptability of the IRIS for older breast cancer survivors and the short-term effects of IRIS on symptom distress. Secondary aims were to examine the effects of IRIS on symptom management behaviors and QOL. In addition, beliefs and attitudes that may be barriers to symptom management were explored.

## Pilot Study 1

### Design

In a randomized clinical trial, women were randomized to the IRIS or usual care control. Measures were taken at baseline, 6 weeks (post-test), and 10 weeks (follow-up).

### Participants

Women were eligible if they were aged 65 years or older, at least one year postdiagnosis of nonmetastatic breast cancer (by self-report), at least one month post-treatment for breast cancer (except hormonal therapies), and could read and write English. Women were excluded

if they reported metastatic disease, a breast cancer recurrence, or other cancer diagnosis (other than skin). The intervention and control groups had no demographic differences (see Table 1).

### Measures

**Demographics and health history:** Women were asked about their age, education, marital status, living arrangements, ethnicity, and income. They also were asked their date of breast cancer diagnosis, treatments, and dates of treatment. Health problems at baseline were assessed with a 16-item **Older Americans Resources Service** schedule of illnesses, an instrument widely used to assess health status in community-dwelling samples of middle-aged and older adults (Duke University Center for the Study of Aging and Human Development, 1978). The total number of health problems was computed.

**Feasibility and acceptability:** Feasibility was assessed by examining participation rates and dropout rates and by noting women's spontaneous comments about being in the study. Acceptability was assessed with eight questions about women's perceptions about being a participant in the study and the helpfulness of the intervention.

**Symptom distress:** Symptom distress was measured in two ways on the **Symptom Bother-Revised Scale (SB-R)** (Heidrich et al., 2006). The SB-R consists of 34 symptoms common to aging, age-related chronic conditions, and breast cancer and its treatment. Respondents are asked if they have each symptom and how much they are bothered by it on a 0 (do not have), 1 (have, but not at all bothered) to 5 (extremely bothered) scale. The SB-R scale has demonstrated reliability ( $\alpha = 0.89$ ) and validity (significant correlations with health

problems and QOL) in older adults with cancer. The total number of symptoms (0–34 possible) and mean degree of bother were computed.

In the experimental group only, symptom distress was measured with a single item called **Target Symptom Distress**. For each of the symptoms women chose for intervention (target symptom), women were asked to rate their level of distress on a 1 (not at all) to 10 (worst I can imagine) scale.

Symptom management behaviors were measured by asking women whether or not they had engaged in five self-care behaviors during the study (e.g., communicated with healthcare provider, changed self-care of symptom) and whether the behavior was helpful or not (yes or no). The frequency and helpfulness of each behavior was tallied.

**Quality of life:** QOL was conceptualized broadly to include physical, emotional, and existential dimensions. Outcome measures were chosen to reflect each of these.

**Medical Outcomes Study SF-36<sup>®</sup>** (Ware & Sherbourne, 1992) is a 36-item scale that includes two subscales that measure QOL related to physical and mental health. This scale is valid for use with older adults and other patients with cancer, has demonstrated validity and reliability, and has published age- and disease-specific norms (Ware, 2000). Standardized scores are computed, and higher scores indicate better QOL.

The **Purpose in Life scale (PIL)** (Ryff & Keyes, 1995) measures dimensions related to spirituality and to finding meaning and purpose in life, both of which have demonstrated important relationships with adaptation to breast cancer. The PIL is a 14-item scale that has been used in cross-sectional, longitudinal, and cross-cultural

**Table 1. Demographic and Health History Characteristics of Participants by Pilot Study**

Characteristic	Pilot 1 (N = 41)		Pilot 2 (N = 20)		Pilot 3 (N = 21)	
	$\bar{X}$	Range	$\bar{X}$	Range	$\bar{X}$	Range
Age (years)	72	65–86	69.7	65–82	67.9	65–73
Education (years)	15	–	15	–	15	–
Years since breast cancer diagnosis	9	1–35	2.7	1–7	3.6	1–15
Other health problems	3.5	0–7	5.2	2–9	5.2	2–11
Number of symptoms	17	5–30	16.4	6–30	16	6–29
Number of medications	–	–	7.6	2–13	7.3	2–10
Characteristic	n	%	n	%	n	%
White	40	97	19	95	21	100
Married	24	59	15	75	14	67
Income less than \$30,000	14	39	2	19	3	17
Lives alone	14	34	4	20	5	23
Mastectomy	24	59	6	32	9	43
Lumpectomy	18	44	13	68	13	62
Chemotherapy	9	23	4	21	9	43
Radiation treatment	20	49	14	74	13	62
Hormonal treatment	14	34	15	79	14	67



studies; is reliable (alphas range from 0.86–0.93); test-retest reliability more than six weeks ranges from 0.81–0.88; and is related to other indices of well-being (i.e., affect balance, life satisfaction, self-esteem, morale, depression, and internal locus of control) (Ryff & Keyes). Participants respond to items on a six-point scale (1 = strongly agree; 6 = strongly disagree). Higher scores indicate higher levels of purpose in life.

**Mood:** Depressive symptoms were assessed with a shortened 10-item version of the **Center for Epidemiologic Studies–Depression Scale (CES-D)**. The short version has been tested and validated in a number of studies of older adults (Irwin, Artin, & Oxman, 1999; Kohout, Berkman, Evans, & Cornoni-Huntley, 1993). The short version, using a cut-off score of 4 for clinical depression, has a sensitivity of 97%, specificity of 84%, and positive predictive value of 85% in older adults. The 10-item scale is a dichotomous scale of mood and symptoms over the prior week (none or much of the time). Higher scores indicate more depressive symptoms.

The **STAI-State Anxiety Scale** is a 20-item inventory that is used widely in health and social-psychological research and in community and patient populations (Spielberger, Gorsuch, & Lushene, 1970). Extensive psychometric testing has been reported for reliability (internal consistency = 0.83–0.92) and validity (convergent and discriminant). Respondents rate on a 1 (not at all) to 4 (very much) scale how they feel “right now” for 20 mood items. Higher scores indicate higher anxiety.

**Barriers to symptom management:** Three scales to measure barriers to symptom management were developed and tested in a pilot study (Yeom & Heidrich, 2006). The **Symptom Management Beliefs Questionnaire (SMBQ)** assesses the extent to which people hold negative beliefs or ageist stereotypes about experiencing or managing symptoms. The SMBQ is a 13-item scale developed by adapting some items from Ward’s Barriers Questionnaire (Gunnarsdottir, Donovan, Serlin, Voge, & Ward, 2002; Ward et al., 1993) and by adding specific items reflecting negative stereotypes about aging. Items are scored from 0 (do not agree) to 5 (completely agree); higher scores indicate more negative beliefs about symptom management.

**Communication Attitudes (CommA)** is a seven-item scale that assesses the extent to which patients experience negative stereotypes about aging from their healthcare providers. **Communication Difficulties (CommD)** is a six-item scale that assesses difficulties patients have in communicating with healthcare providers about symptoms. Responses to both scales are dichotomous (yes or no). Higher scores indicate experiencing more negative attitudes from healthcare providers or more difficulty communicating about symptoms.

The three scales were tested for reliability and validity in 140 adults recruited from senior centers and internal medicine clinics. Evidence for construct validity of the

new scales was indicated by significant correlations ( $p < 0.05$ ) between the SMBQ and CommA ( $r = 0.38$ ) and CommD ( $r = 0.23$ ). CommA and CommD were significantly related to each other ( $r = 0.47$ ). Those with less education reported significantly ( $p < 0.05$ ) more negative beliefs about symptom management ( $r = -0.38$ ) and more difficulty communicating with healthcare providers ( $r = 0.47$ ). Alpha coefficients for the SMBQ, CommA, and CommD were 0.83, 0.91, and 0.94, respectively.

## Procedure

All of the studies reported in this article were approved by an institutional review board. Women were recruited from the oncology clinics of a large comprehensive cancer center located in the midwestern United States and from the community using advertising. Interested women called the research office, the study was explained, and eligibility determined. If interested, women were sent an informed consent form, and an appointment was made for the baseline interview. At the interview (in the participant’s home or setting of choice), written informed consent was obtained, and women were randomly assigned to the IRIS or usual care control group. Women in both groups completed baseline measures, and women in the IRIS group participated in the IRIS interview. At four weeks, women in the IRIS group were phoned to review their symptom management plan and revised the plan if needed. At 6 weeks (post-test) and 10 weeks (follow-up), measures were sent to both groups and returned by mail.

**Intervention protocol:** IRIS is a counseling interview conducted by advanced practice nurses. The length of the intervention varies (30–75 minutes) and is determined by the number of beliefs and strategies raised by the participant. Therefore, the “dose” of the intervention is individualized in that the length of the session is driven by the individual’s needs.

The intervention begins with an assessment of an individual’s representation of symptoms. The woman is encouraged to describe her beliefs about her most bothersome or serious symptoms along the five dimensions of representation. Any beliefs about symptom control that arise during this discussion are explored in terms of how the person came to have the belief.

Next, the participant is asked to discuss her beliefs embedded in the representation and how her beliefs affect how she copes with the symptom and her ability to adequately manage the symptom and to enjoy life. The nurse then summarizes the beliefs that have been elicited and the consequences of those beliefs to create conditions for conceptual change. The participant then is engaged in a discussion of symptom management strategies and information to replace existing beliefs that are functioning as barriers to symptom management. The symptom management strategies and information are based on best clinical practices information. The

nurse outlines the ways in which the new information could facilitate better symptom management strategies, thereby improving QOL outcomes.

The session ends with the nurse and the participant creating a symptom management plan in which the participant identifies goals and strategies that will help reach those goals. The participant keeps a copy of the written plan. Session two of the intervention was carried out over the phone. During the phone interview, the nurse and participant review the symptom management plan to analyze progress toward goals, determine which strategies have been most useful, determine if any barriers are impeding progress, and revise the plan as needed. A sample of the intervention sessions were audiotaped and reviewed for fidelity with the protocol.

## Data Analysis

Descriptive statistics were used to describe the sample and to answer questions about the feasibility of the study. The short-term effects of the IRIS were examined using Chi-square and t tests (to examine group differences) and generalized linear model (GLM) (to test for significant changes over time).

## Results

The demographics and health history for pilot study 1 are reported in Table 1. No significant differences were observed between group 1 and the subsequent groups at baseline on any of these variables.

**Feasibility and acceptability:** 56 women were screened and 41 were recruited (73% participation). The most common reason for refusal, when it could be assessed, was lack of time ( $n = 11$ ). Two women dropped out. More than 90% of the women in the intervention and control groups reported that the study addressed important issues and topics, addressed relevant concerns, was worthwhile and positive, and gave them a chance to express their opinions. All of the women in the intervention group reported that the study was helpful, and 95% were satisfied with what they learned. As expected, 72% of the control reported that the study was helpful, and 68% were satisfied.

**Effects on symptom distress:** Women in the experimental group chose a total of 40 target symptoms to address (range = 1–5). The most common were sleep problems ( $n = 8$ ), pain ( $n = 6$ ), weight gain ( $n = 4$ ), shortness of breath ( $n = 3$ ), lymphedema ( $n = 2$ ), depression ( $n = 2$ ), stomach problems ( $n = 2$ ), and fatigue ( $n = 2$ ). Because the number of women choosing more than one symptom was small, only data for the first target symptom were used in analyses. In the intervention group, symptom distress ratings were compared over time using GLM procedures. Only women with ratings at all three times were included in the analyses. Distress

decreased significantly from baseline ( $\bar{X} = 3.94$ ,  $SD = 0.67$ ) to follow-up ( $\bar{X} = 2.65$ ,  $SD = 1.06$ , multivariate  $F[2, 15] = 16.50$ ,  $p < 0.0001$ ).

Because target symptom ratings for women in the control group were not available, a symptom distress rating from the SB-R scale for a control group woman was matched (on a random basis) with a corresponding SB-R rating corresponding to a target symptom in the experimental group. For each symptom, change scores from baseline to post-test were computed. Higher change scores reflect decreased distress. Change scores were available for 14 experimental and 15 control group women. A t test was not significant,  $t(27) = 1.52$ ,  $p = 0.13$ , but the results were in the hypothesized direction ( $\bar{X}_{\text{experimental}} = 1.21$ ,  $SD = 0.57$ ;  $\bar{X}_{\text{control}} = 0.73$ ,  $SD = 1.03$ ).

**Symptom management behaviors:** IRIS and control groups' reports of symptom management behaviors at 10 weeks (follow-up) ( $N = 39$ ) were compared with Chi-square tests (see Table 2). Significantly ( $p < 0.05$ ), more women in the experimental group reported changing self-care of symptoms. Although not significant, more women in the experimental group reported talking with their healthcare provider, beginning a new treatment, talking with family and friends, and using other sources of information.

Women in the experimental group were asked how many symptom management strategies from their symptom management plan they had tried. The mean number of strategies attempted was 3.4 (range = 1–10), which was 96% of the strategies planned. Of these, 96% were perceived as useful.

**Quality of life:** No significant differences were observed on any of the QOL outcomes by group.

**Symptom management barriers:** At baseline, the mean SMBQ score was 1.78 ( $SD = 0.80$ ), indicating a low level of barriers. The items with the highest agreement ratings were "Many symptoms are just a normal part of getting older" ( $\bar{X} = 3.90$ ,  $SD = 1.04$ ), "It is easier to put up with pain than with the side effects of some medications" ( $\bar{X} = 2.82$ ,  $SD = 1.47$ ), and "The cure for symptoms is often worse than the disease" ( $\bar{X} = 2.40$ ,  $SD = 1.71$ ). Responses to the CommA and CommD scales are in Table 3. Items on the CommA scale were endorsed by 5%–13% of women, indicating few negative attitudes from healthcare providers. Items on the CommD scale were endorsed by 8%–28% of women, suggesting some difficulty in communicating with healthcare providers about symptoms.

Results of pilot study 1 indicated that the IRIS was feasible and well liked by women aged 65 years and older. However, a number of shortcomings were evident. More appropriate and sensitive outcome measures of symptom distress had to be developed. In addition, women in the intervention group said they needed more time to carry out symptom management plans and strategies, and they asked for more contact time with the nurse. Women in the control group were less satisfied.

**Table 2. Symptom Management Behaviors by Group at Follow-Up**

Variable	Pilot 1 (N = 41)				Pilot 2 (N = 20)				Pilot 3 (N = 21)	
	IRIS		Control		IRIS		Control		IRIS	
	n	%	n	%	n	%	n	%	n	%
Discussed symptom with healthcare provider	16	80	13	68	9	100*	5	56	19	95
Began new medical treatment	12	60	6	32	8	89*	3	33	11	55
Improved with new treatment	8	57	6	100	7	100*	1	50	11	100
Changed self-care of symptom	15	75**	5	26	9	100**	1	11	17	85
• Found it helpful	14	93*	3	60	7	88	0	0	17	100
Talked with family and friends about symptom	15	75	10	53	5	56	5	56	15	75
• Found it helpful	1	87	8	57	5	100	4	80	15	100
Used other sources of information	9	45	6	32	4	44	3	33	12	60
• Found it helpful	—	—	—	—	4	100	2	67	12	100

\*p < 0.05; \*\* p<0.01

IRIS—individualized representational intervention to improve symptom management

Note. Follow-up measures at 10 weeks (pilot 1) or 16 weeks (pilots 2 and 3)

Note. Percentages were computed based on valid cases for each group.

## Pilot Study 2

Pilot study 2 was designed to address the shortcomings in pilot study 1. Symptom distress outcomes measures were changed and the dose of the IRIS was increased by providing additional contacts with the nurse. To improve recruitment, retention, and satisfaction with the study, the control condition was changed to a delayed IRIS condition. The aims of pilot study 2 were the same as pilot study 1.

## Design and Procedure

Eligibility was the same in study 2 as in study 1. Women were randomized to the IRIS or a delayed IRIS control group. Measures were taken at baseline, 2, 4, 6, 8, and 16 weeks. Delayed intervention group participants could receive the intervention after the 16-week assessment if desired. The IRIS protocol was the same as in study 1 except for the addition of four biweekly telephone reinforcement sessions beginning two weeks after the baseline interview. For these sessions, women in the IRIS group were asked about their symptom distress, their symptom management plan was reviewed, and any changes to the plan were made. Women in the delayed IRIS control group were asked about their symptom distress ratings.

## Measures

Measures were the same as in study 1 except for the following changes. To assess the primary outcome of symptom distress, three measures were added. Symptom duration was measured with a single item that assesses the amount of time during the prior week the participant had spent with a target symptom rating of moderate to

severe (Einhorn, 1994). Responses are on a 1 (never) to 5 (always) scale. In pain studies, symptom duration was moderately correlated with symptom severity scales, with patient satisfaction with symptom management, and with barriers to symptom management (Gordon et al., 2002; Gunnarsdottir et al., 2002).

Symptom severity was measured with three items from the **Brief Pain Inventory (BPI)** (Cleeland & Syrjala, 1992; Daut, Cleeland, & Flanery, 1983) and substituting each woman's target symptom for the word "pain." The BPI severity items have been used widely in cancer research and have demonstrated reliability, validity, and sensitivity to change (Cleeland & Syrjala; Serlin, Mendoza, Nakamura, Edwards, & Cleeland, 1995). Women rated their target symptom rating at its worst during the prior week, least during the prior week, and now, on a 0 (no symptom) to 10 (as bad as you can imagine) scale. Mean scores were computed.

Symptom interference was assessed with seven symptom interference items from the BPI, substituting each woman's target symptom in the instructions (Cleeland & Syrjala, 1992; Daut et al., 1983). This scale has been used extensively in pain research and has shown excellent internal consistency and construct validity (Serlin et al., 1995; Ward, Donovan, Owen, Grosen, & Serlin, 2000). Women were asked how much their target symptom interfered with seven life domains on a 0 (does not interfere) to 10 (completely interferes) scale; a mean score was computed. Higher scores indicate more interference.

To measure QOL, the **Medical Outcomes Study Short Form-12 (SF-12)** was used instead of the SF-36 to reduce subject burden. The SF-12 includes two subscales that measure physical and mental health. As with the SF-36, this scale is valid for use with older adults and patients

with cancer, has demonstrated validity and reliability, and has published norms (Ware, 2000). Standardized scores were computed; higher scores indicate better QOL.

Positive relations with others was added as a QOL outcome because of the importance of relationships to existential and emotional QOL. The 14-item purpose **Positive Relations Scale** developed by Ryff (1989) was used. The scale measures dimensions of emotional support and supportive relationships, has been used in many studies of older adults, and is reliable and valid (Ryff & Keyes, 1995). Participants responded to items on a six-point (strongly agree to strongly disagree) scale. Higher scores indicate higher levels of positive relation.

### Results

Demographics and health history of subjects in study 2 are reported in Table 1.

**Feasibility and acceptability:** 26 women were screened and 20 were recruited (81% participation). One woman dropped out. One hundred percent of women reported that the intervention addressed important issues, was relevant, important, worthwhile, positive, and gave them a chance to express their opinions. Eighty-eight percent of women in both groups reported that the study was helpful and they were satisfied with what they learned.

**Symptom distress:** Women chose a total of 49 target symptoms, ranging from 1–3 per woman. The most common symptoms chosen in the intervention group were pain ( $n = 8$ ), fatigue ( $n = 4$ ), sleep problems ( $n = 2$ ), and urinary incontinence ( $n = 2$ ). Seventy-two percent of women reported that they previously had discussed their target symptom with a healthcare provider.

Because of the small sample size and skewed distribution of some variables, nonparametric tests (Mann-

Whitney-U) were used to examine group differences for three symptom distress measures at 8 and 16 weeks with change scores. At eight weeks, the IRIS group ( $\bar{X} = 2.20$ ,  $SD = 1.23$ ) reported significantly less symptom duration compared to the control group ( $\bar{X} = 2.67$ ,  $SD = 1.12$ ) ( $p < 0.01$ ). No other significant differences were found.

**Symptom management behaviors:** At 16 weeks, women in the IRIS group were significantly more likely to have talked to their healthcare provider, begun new medical treatment for their symptoms, and changed self-care of their symptom ( $p < 0.05$ ) (see Table 2). Women in the delayed IRIS group also were asked about the perceived effectiveness of their individual symptom management strategies. Of 47 strategies tried, 35 (74%) were rated as effective.

**Quality of life:** No significant differences were observed on any of the QOL outcomes by group.

**Symptom management barriers:** The mean SMBQ score at baseline was 1.24 ( $SD = 0.69$ ). The highest rated items were the same as in pilot study 1. Negative attitudes from healthcare providers were reported by 5%–20% of women and communication difficulties were reported by 5%–45% of women (see Table 3).

Results from pilot study 2 indicated that the IRIS is feasible and well-liked by older women. One-half of the women in the control group elected to receive the IRIS at the end of the study, and women in the control group were satisfied with being in the study. The measures of symptom distress were easy for women to respond to and the measures appear valid and sensitive to change. Women were able to institute their symptom management plans and carry out most of their strategies in the eight-week period. However, the in-person baseline interviews were time-consuming and expensive in terms of nurse time.

**Table 3. Communication Problems Reported at Baseline**

Communication	Pilot 1 (N = 41)		Pilot 2 (N = 20)		Pilot 3 (N = 21)	
	n	%	n	%	n	%
<b>Attitude</b>						
After all this time, you shouldn't be so concerned, worried, or anxious about your health problems.	5	13	2	10	2	9
You are better off than a lot of people who have your health problems.	4	10	4	20	2	9
You should be thankful you have lived as long as you have.	2	5	2	10	1	5
A lot of people with your health problems are worse off than you.	3	8	4	20	2	9
Compared to other people with your health problems, your concerns are minor.	3	8	4	20	2	9
It is not necessary for you to know the details about your condition.	5	13	1	5	1	5
You are worrying too much.	4	10	1	5	–	–
<b>Difficulty</b>						
Not knowing which doctor to talk to	8	21	9	45	8	36
Not sure if doctors are communicating	8	21	6	30	7	32
Not sure which symptoms to report	11	28	5	25	5	23
Worry I am ignoring serious symptoms	7	18	3	15	4	18
Do not want to be a "complainer"	7	18	2	10	3	14
Worry about being "labeled"	3	8	1	5	1	5



## Pilot Study 3

Pilot study 3 was conducted to determine whether IRIS could be delivered by telephone. Even if the face-to-face intervention was efficacious, it would be difficult to incorporate into clinical practice because of scheduling face-to-face contacts. Telephone-conducted interventions have been successful in other self-management venues (Ludman et al., 2007).

In pilot study 3, an additional symptom distress outcome, mood resulting from symptoms, was included for exploratory purposes. This was based on the observation that women in the previous studies often commented on the negative effects of symptoms on their mood.

### Design

Pilot study 3 used a pre-experimental design (the IRIS group only) to determine the feasibility of conducting the IRIS by telephone. Time of measurements was the same as in pilot study 2.

### Participants

Eligibility was the same as the previous pilot studies. Demographic characteristics are reported in Table 1.

### Measures

Measures were the same as in pilot study 2 except for the following changes. Mood disturbance from symptoms was added as a measure of symptom distress using five subscales from the **Profile of Mood States-Short Form (POMS)** (Shacham, 1983): tension, depression, anger, fatigue, and confusion. The POMS has been validated in older adults in a number of studies, has been used in most studies of interventions in women with breast cancer, and is sensitive to change over time (Gibson, 1997). Participants were asked to respond according to how their target symptom made them feel. Responses were on a 0 (not at all) to 4 (extremely) scale, with higher scores indicating more negative mood. Total and subscale mean scores were computed.

The SF-36 (the measure used in pilot study 1) was used rather than the SF-12 (used in pilot study 2) because the SF-36 provides a more complex picture of QOL. In addition, the authors wanted to further assess whether women would complete the longer measure.

### Data Analysis and Results

**Feasibility and acceptability:** 31 women were screened and 21 were recruited (68% participation). One woman dropped out. One hundred percent of women reported that the study addressed important issues, was relevant, important, worthwhile, positive, and gave them a chance to express their opinions. One hundred percent reported

that they were satisfied with what they learned, and 90% reported that the study was helpful.

**Symptom distress:** Women chose a total of 22 target symptoms. The most frequent symptoms were musculoskeletal aches and pains ( $n = 8$ ), breast pain ( $n = 2$ ), and lymphedema ( $n = 2$ ).

Wilcoxin paired-sample tests were used to examine changes from baseline to 8 weeks and baseline to 16 weeks in symptom distress. From baseline to eight weeks, symptom interference decreased significantly ( $z = -2.26$ ,  $p < 0.05$ ) and negative mood from symptoms (total POMS:  $z = -2.90$ ,  $p < 0.01$ ; anger:  $z = -2.64$ ,  $p < 0.05$ ; fatigue:  $z = -2.08$ ,  $p < 0.05$ ). From baseline to 16 weeks, symptom duration ( $z = -2.84$ ,  $p < 0.01$ ), symptom interference ( $z = -2.56$ ,  $p < 0.05$ ), and negative mood from symptoms (overall mood state:  $z = -3.22$ ,  $p < 0.01$ ; tension:  $z = -2.88$ ,  $p < 0.01$ ; depression:  $z = -2.47$ ,  $p < 0.05$ ; anger:  $z = -3.15$ ,  $p < 0.05$ ; fatigue:  $z = -2.75$ ,  $p < 0.01$ ; and confusion:  $z = -1.98$ ,  $p < 0.05$ ) decreased significantly.

**Symptom management behaviors:** Consistent with findings in the previous pilot studies, changes in symptom management behaviors were reported by most women (see Table 2). Sixty-six percent of strategies tried were perceived as effective.

**Quality of life:** No significant changes in quality of life were observed.

**Symptom management barriers:** The mean SMBQ score was 1.33 ( $SD = 0.64$ ) and the items with the highest means were the same as in pilot studies 1 and 2. Negative attitudes were reported by 0%–9% of women, but communication difficulties were reported by 5%–36% of women (see Table 3).

Results of pilot study 3 indicated that the IRIS can be successfully delivered by telephone. Women were able to engage in the representational interview and develop goals and strategies by telephone. Women stayed in the study for more than the 16 weeks and perceived the study as helpful and satisfactory.

## Discussion

Although the number of women is small, the findings reveal that a symptom management intervention for older breast cancer survivors is needed, a randomized clinical trial is feasible, the symptom distress outcomes are sensitive to change, and preliminary support exists for the efficacy of an IRIS in changing women's symptom management behaviors and reducing symptom distress. The authors' studies to date support the theory-based approach to symptom management and provide compelling data about the extent of symptoms and symptom distress in older breast cancer survivors. The pilot data are encouraging regarding the efficacy of an IRIS.

An IRIS differs from most behavioral or psycho-educational interventions in that it is highly individualized. Philosophically, then, an IRIS is highly



patient-centered; women were able to choose whatever symptom they wished to work on and choose, with the assistance of the nurse who provided symptom management information, the strategies they wanted to employ. The strategies (and the women's goals) were shaped and formed by their changing symptom representations. Women reported a high degree of satisfaction with the IRIS that the authors believe is the result of the highly individualized approach. Although not reported here, many of the strategies women worked on involved learning more effective ways to communicate with healthcare providers about symptoms, many of which were chronic in nature (Yeom & Heidrich, 2006). Methodologically, highly individualized interventions are difficult because the outcome measures also must be individualized in some way. This issue was addressed by instructing women to respond to the same measurement items but in reference to women's unique symptoms. The approach has promise and is amenable to analytic strategies such as growth curve modeling that provide information about individual trajectories of change.

Women in these studies reported an average of 16–17 symptoms, and the symptoms chosen for intervention were quite variable. However, the symptoms reported by women in all three pilot studies were similar even though the women differed in terms of time since diagnosis and treatments for their breast cancer. The list of chosen target symptoms indicates that many distressing symptoms in older breast cancer survivors may not be related to their cancer but reflect common symptoms in older adults and older adults with chronic conditions. The problem this creates for older cancer survivors is reflected in responses to the Communication Difficulties Scale in that the most commonly reported difficulties included knowing which doctor to talk to about a symptom and knowing which symptom to report. Many target symptoms also were worrisome because they may or may not have been cancer-related. This ambiguity about symptoms in old age may be an important barrier to effective self-care and symptom management and deserves further attention.

The most significant findings in these studies were the reports of changes in symptom management behaviors. In pilot studies 1 and 2, women in the intervention group were more likely to change their own behavior or were able to accomplish a change in medical treatment compared to women in the control group. Some of the differences were quite striking. However, differences in symptom distress measures between the two groups were small and not always significant. These discrepancies have numerous explanations. Many of the self-care or medical treatment changes women initiated over the course of 8 weeks might not have been in place long enough by the 8- or 16-week assessment for changes in distress to take place. Strategies were changed over time and some strategies took many

weeks to implement. Life events sometimes delayed the implementation of new strategies. In addition, although most women rated the new strategies as effective, these were subjective, rather than objective, measures. A longer follow-up and a more direct assessment of individual strategies using technologies such as Ecological Momentary Assessment (Stone et al., 1998) would help clarify these issues.

No QOL differences were observed between the intervention and control groups. Theoretically, a decrease in distress from symptoms would increase QOL; however, most QOL measures address constructs such as satisfaction with life and positive mood that, in older adults, may be quite stable. Furthermore, overall ratings of QOL are likely influenced by a broad array of factors, not just one's own health but what is happening with one's family, friends, and communities. In addition, older breast cancer survivors do not report changes in QOL after their diagnosis and treatment (Clough-Gorr, Ganz, & Silliman, 2007). These factors likely override the impact of a few distressing symptoms on overall QOL and suggest that more proximal measures (such as symptom distress) are the most salient outcomes to measure.

The theoretical model also suggests that barriers to symptom management mediate the influence of an IRIS on symptom distress and that an IRIS should reduce barriers to symptom management. Mediating effects in these small pilot studies could not be examined; however, a number of communication barriers were described and many of the strategies women chose were communication-enhancement strategies. Further work is needed to determine whether other salient barriers to self-care of symptoms in older cancer survivors exist.

The pilot studies were designed to test the feasibility and acceptability of an IRIS. The results clearly should be viewed with caution given the small sample sizes. Furthermore, the samples of older women were homogeneous in terms of race and ethnicity, although not in terms of sociodemographic or health variables. However, an IRIS is an intervention most likely to be effective across diverse groups. This needs to be demonstrated in further research.

The authors currently are testing the IRIS telephone intervention in a large, randomized trial of older breast cancer survivors. If efficacious, it will be important to examine if the IRIS can effectively be delivered in a clinical practice setting. The results from the pilot studies suggest that a highly individualized intervention is feasible, well liked by patients, and could be easily adapted for use with other patient populations.

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