

The Breast Cancer Treatment Response Inventory: Development, Psychometric Testing, and Refinement for Use in Practice

Wendy C. Budin, PhD, RN-BC, Frances Cartwright-Alcares, PhD, RN, AOCN®, and Carol Noll Hoskins, PhD, RN, FAAN

Purpose/Objectives: To describe the development, testing, and utility of the Breast Cancer Treatment Response Inventory (BCTRI), an instrument that captures the symptom experience of women with breast cancer.

Data Sources: Journal articles and results of research studies used to establish BCTRI psychometric properties.

Data Synthesis: The tool is a valid and reliable method to determine and monitor numbers of symptoms, the severity of those symptoms, and the amount of distress experienced by patients. It is an easily and quickly employed assessment tool to guide and evaluate interventions.

Conclusions: The BCTRI has strong psychometric properties and is a valid and reliable instrument to measure symptom experience among populations of breast cancer survivors.

Implications for Nursing: Data collected using the BCTRI provide information that healthcare providers can use to target interventions toward symptoms that are most troublesome or distressful. The BCTRI can be used at meaningful points in treatment, recovery, and ongoing survivorship to explore the emerging concept of symptom experience in samples that reflect socioeconomically and ethnically diverse populations.

Key Points . . .

- ▶ Women with breast cancer report continued distress resulting from ongoing symptoms associated with the diagnosis of breast cancer in the physical, psychological, social, and spiritual domains.
- ▶ In addition to emerging research methodologies that test the effects of interventions on nursing-sensitive outcomes, multi-dimensional instruments that conceptualize and operationalize the breast cancer symptom experience are needed.
- ▶ The Breast Cancer Treatment Response Inventory demonstrated strong psychometric properties in testing among women with breast cancer and has potential to be a valuable tool to examine symptom experience so that nursing interventions can be aimed at sources of distress.

Approximately 2,356,795 women in the United States have a history of breast cancer (Ries et al., n.d.); most of them continue to experience distress related to the physical, psychological, social, and spiritual aspects of the breast cancer experience (Budin, 1998; Byar, Berger, Bakken, & Cetak, 2006; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997, 1998; Meraviglia, 2006). Despite improvements in surgery and radiation therapy, long-term localized symptoms persist (Armer, Radina, Porock, & Culbertson, 2003; Carpenter et al., 1999; Erickson, Pearson, Ganz, Adams, & Kahn, 2001; Oncology Nursing Society [ONS], n.d.), and chemotherapy regimens produce symptoms that may continue for five or more years after therapy (Byar et al.; Ganz et al., 2002; Knobf, 2006; Longman, Braden, & Mishel, 1999). Treatment recommendations for women with hormonally responsive breast cancer extend beyond five years, thus adding to their symptom experience (National Comprehensive Cancer Network [NCCN], 2007a).

Symptom experience must be consistently defined conceptually and operationally (Armstrong, 2003; Dodd, Janson, et al., 2001; Goodell & Nail, 2005; Ropka & Spencer-Cisek,

2001) so that healthcare professionals can evaluate and address what survivors perceive as important and requiring attention. Armstrong wrote about a need to understand the meaning that the symptom experience has on life so that interventions can be targeted to provide survivors with needed adjustment and coping strategies. With that information, healthcare professionals can respond more adequately to the needs of breast cancer survivors (Armstrong; Dodd, Miaskowski, & Lee, 2004; Goodell & Nail). Until resources are targeted toward breast cancer survivors' specific needs and concerns, many women will continue to resume their lives with inadequate resources and support. This article discusses the conceptualization of symptom experience followed by

Wendy C. Budin, PhD, RN-BC, is the director of nursing research at New York University (NYU) Hospitals Center, research professor of nursing in the School of Medicine at NYU, and clinical professor in the College of Nursing at NYU; Frances Cartwright-Alcares, PhD, RN, AOCN®, is the director of nursing, oncology services, at NYU Medical Center; and Carol Noll Hoskins, PhD, RN, FAAN, is a senior research scientist in the College of Nursing at NYU. (Submitted November 2006. Accepted for publication June 21, 2007.)

Digital Object Identifier: 10.1188/08.ONF.209-215

a description of the development, psychometric properties, and utility of the Breast Cancer Treatment Response Inventory (BCTRI) (Budin & Hoskins, 2000; Cartwright-Alcares, 2005), an instrument designed to measure the relationships among the dimensions of symptom experience from treatment through ongoing recovery.

Literature Review

A breast cancer survivor's symptom experience is more than a list of symptoms. Symptom experience has been conceptualized to include the number of symptoms, severity of symptoms, and amount of distress experienced (Armstrong, 2003; Goodell & Nail, 2005). Symptom clusters, as well as the effects of numerous concurrent symptoms on outcomes, are important dimensions of symptom experience and require further exploration (Armstrong; Dodd, Miaskowski, & Paul, 2001; Fox & Lyon, 2006; Goodell & Nail; Miaskowski, Dodd, & Lee, 2004; Miaskowski et al., 2006).

Dodd et al. (2004) defined a symptom cluster as "three or more symptoms that . . . occur together and are related to each other" (p. 77) and suggested that further exploration was needed to determine whether the definition could be modified to include two or more symptoms. Kim, McGuire, Tulman, and Barsevick (2005) analyzed studies regarding symptom clusters in the psychology and psychiatry, general medicine, and nursing literature and provided a discussion that reveals that the concept is well developed in the psychology and psychiatry literature. Kim et al. concurred that the concept of symptom clusters is early in its evolution in the nursing literature. They concluded from the literature review that the number of symptoms in a cluster is not important but that the major antecedent of a symptom cluster is two or more symptoms. The authors pointed out that the clinical utility of the symptom cluster is an important factor, as well as the testing of interventions that may affect outcome.

Symptoms in a cluster can have different causes (Dodd, Miaskowski, et al., 2001; Kim et al., 2005). For example, symptoms associated with fatigue may include pain, sleep disruption, and emotional disruption, but pain may be from the surgical procedure (e.g., chronic postmastectomy pain), sleep disruption from the abrupt onset of menopausal symptoms, and emotional distress from existential concerns (e.g., fear of recurrence). The literature suggests that symptom clusters and their possible synergistic effects may help to explain the effect of symptom experience on quality-of-life outcomes (Dodd et al., 2004).

Multiple symptoms are associated with breast cancer and its treatment. Reiner and Lacasse (2006) reviewed the literature to explore correlates of symptoms in individuals with cancer who were aged 55 years or older; they found that multiple symptoms result in decreased physical functioning and that pain and fatigue are predictors for an increase in the number of symptoms. To examine the occurrence of concurrent, numerous symptoms and their possible multiplicative effects, data must be collected with a tool that includes a comprehensive list of symptoms relevant to women with breast cancer throughout the treatment and recovery period (Armstrong, 2003; Dodd, Janson, et al., 2001; Dodd et al., 2004; Goodell & Nail, 2005; Ropka & Spencer-Cisek, 2001). As more information becomes available about the

relationships among the various dimensions of the symptom experience, resources and support can be identified and provided to women according to their specific needs and priorities.

NCCN (2007b) defines symptom distress as "a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment." Healthcare providers must measure not only severity of symptoms but also patients' responses to their symptoms (i.e., perceived level of distress) to determine how they will cope and seek resources (Armstrong, 2003; Goodell & Nail, 2005; Lazarus, 1993; Lazarus & Folkman, 1984; Rhodes, McDaniel, Homan, Johnson, & Madsen, 2000). Some symptoms are more distressing than others, and a patient's values influence the relationship among number of symptoms, severity of symptoms, and amount of distress experienced. Demographic variability (including age, ethnicity, marital status, education, and employment status) may influence the meaning the symptom experience has on a breast cancer survivor's individual life and, subsequently, may influence distress (Goodell & Nail).

A breast cancer survivor may perceive a symptom as distressful despite low severity. For example, two breast cancer survivors, a professional singer and a violinist, may perceive the severity of peripheral neuropathy as moderate; however, the professional singer may experience the symptom as a reminder that she has "beaten the disease," whereas the violinist may find her peripheral neuropathy to be severely distressful because she does not have the needed sensitivity in her fingers to perform optimally. Thus, associated distress is an important indicator to determine appropriate problem-focused or emotion-focused strategies to help women minimize or cope with negative meanings of symptoms.

When nothing can be done to relieve the severity of a symptom, measures to decrease the associated distress may be an option. Badger, Braden, and Mishel (2001) demonstrated that when they examined the effects of self-help interventions on quality of life among 169 women with breast cancer as compared to a control group (standard care). The investigators noted that even when women reported continued high severity of symptoms, the associated distress frequently was decreased from intervention effects. Thus, associated distress can be used as a "red flag" indicating the need to ascertain the personal meaning of symptoms so that targeted interventions can be identified.

Nursing research on symptom experience is in its infancy, but the conceptualization provided by Armstrong (2003), Goodell and Nail (2005), Dodd et al. (2004), and Kim et al. (2005) provides a standardized definition that lends itself to measurement and analysis. An instrument that measures symptom experience must include a comprehensive list of symptoms relevant to breast cancer survivors to fully explore symptom experience (Armstrong; Dodd, Janson, et al., 2001; Goodell & Nail).

As recommended in the assessment phase of ONS's Priority Symptom Management Project (Ropka & Spencer-Cisek, 2001), a tool is needed to comprehensively screen for symptoms related to breast cancer, treatment, and ongoing survivorship, making further exploration of the symptom

experience possible. This includes the various relationships among number of symptoms, severity of symptoms, amount of distress experienced, and the possible synergistic effects of symptom clusters and concurrent symptoms and multiplicative effects on specific outcomes. This, in turn, would help researchers identify management strategies (Ropka & Spencer-Cisek).

Development, Refinement, and Psychometric Properties of the Breast Cancer Treatment Response Inventory

The Breast Cancer Treatment Response Inventory (BCTRI) (Budin & Hoskins, 2000; Cartwright-Alcares, 2005) is a tool that captures the myriad symptoms common to breast cancer survivors and facilitates further exploration regarding the relationships among dimensions of symptom experience, number, severity, and related distress. The BCTRI was adapted and refined from an earlier version of an instrument called the Treatment Response Inventory (TRI), developed for use in a longitudinal study that examined patterns of adjustment among patients with breast cancer and their partners (Hoskins, Baker, et al., 1996; Hoskins, Budin, & Maislin, 1996). The TRI consisted of a yes/no checklist of 20 side effects or symptoms associated with breast cancer treatments that were identified in the literature and then validated by an oncology clinical nurse specialist. The original 20 side effects and symptoms included on the TRI were fatigue, difficulty sleeping, shoulder or arm discomfort, pain, emotional upset, difficulty concentrating, nausea and vomiting, bowel problems, sexual problems, swelling of arm or breast, referred sensations, fluid at surgical site, radiation skin effects, temperature fluctuation, decrease in appetite, hair loss or thinning, mouth sores, poor wound healing, infection, and bleeding at surgical site. The TRI also included a section for investigators to fill in information about treatment options, including primary surgical procedures and reconstruction, as well as diagnostic indicators such as node status, stage of disease, and types of adjuvant therapy received (e.g., radiation, chemotherapy, hormone therapy). The TRI was designed to be completed by an investigator using information gathered from an interview with a patient and taking approximately five minutes.

Hoskins (1997) recognized that because many of the symptoms listed on the TRI were subjective, a patient's response would be more meaningful than a clinician's assessment. In addition, despite the fact that the TRI had a single item identifying the presence of emotional distress, the investigator recommended a revision to the instrument to include an evaluation of distress associated with each symptom reported and a factor analysis conducted to clarify the structure of the TRI further.

Budin and Hoskins (2000) revised the TRI to be a self-report measure of a patient's side effects and associated distress, renamed the BCTRI. Using the same list of symptoms as the TRI, the BCTRI allows patients not only to check off any of the 20 side effects or symptoms they are experiencing but also to rate the severity and distress associated with each on a Likert scale of 0 (absence of severity or distress associated with the symptom) to 3 (greatest amount of severity or

distress associated with the symptom). To establish validity and reliability, Budin and Hoskins used the revised BCTRI to collect data from 105 women with breast cancer (Sample 1) from the time of surgery through ongoing recovery.

Sample 1

Characteristics: Participant ages ranged from 36–79 years, with a mean age of 51.0 years ($SD = 12.1$). More than half were college educated and employed in diverse professional and semiprofessional occupations. At the time of diagnosis, nearly one-third ($n = 37$, 35%) had stage 0 or stage 1 disease, 47% had stage II, and 18% had stage III disease. Types of surgical treatment included lumpectomy ($n = 51$, 49%), modified radical mastectomy ($n = 54$, 51%), and reconstructive surgery ($n = 37$, 69% of those who had mastectomy). At the time the participants completed the BCTRI, approximately one-third were undergoing radiation therapy, one-third receiving chemotherapy, and nearly one-half receiving hormone therapy (see Table 1).

Findings: Total number of symptoms, severity of symptoms, and total amount of distress experienced were calculated

Table 1. Demographic and Medical Variables

Variable	Sample 1 (N = 105)			Sample 2 (N = 131)		
	\bar{X}	SD	Range	\bar{X}	SD	Range
Age (years)	51.0	12.1	36–79	51.5	12.1	31–84
Variable	n	%		n	%	
Level of education						
Some high school	6	6		3	2	
High school graduate	18	17		18	14	
Partial college	28	27		27	21	
College graduate	34	32		29	22	
Graduate degree	15	14		47	36	
Postgraduate degree	4	4		6	5	
Missing	–	–		1	1	
Stage of disease						
0	2	2		6	5	
I	35	33		64	49	
II	49	47		41	31	
III	19	18		13	10	
IV	–	–		7	5	
Surgical procedure						
Breast conserving	51	49		39	30	
Modified radical mastectomy	54	51		92	70	
With reconstruction	37	69		66	72	
Without reconstruction	17	32		26	28	
Had radiation therapy						
Yes	38	36		58	44	
No	67	64		73	56	
Currently receiving chemotherapy						
Yes	36	34		3	2	
No	69	66		128	98	
Currently receiving hormone therapy						
Yes	48	46		82	63	
No	57	54		49	37	

(see Table 2). The most frequently occurring and distressful symptoms were fatigue, difficulty sleeping, shoulder or arm discomfort, pain, emotional upset, difficulty concentrating, nausea and vomiting, and bowel problems (see Table 3). To determine discriminate validity, the researchers compared total distress between those who were receiving chemotherapy ($\bar{X} = 10.03$, $SD = 6.1$) and those who were not ($\bar{X} = 4.96$, $SD = 4.6$). Women receiving chemotherapy reported significantly more distress than those not receiving chemotherapy ($t = 4.4$, $p < 0.001$), thus supporting the ability of the BCTRI to discriminate between two groups expected to report different levels of symptom distress (i.e., contrasting or known groups).

In addition to completing the BCTRI, the 105 women in Sample 1 completed the Symptom Distress Scale (SDS) (McCorkle & Young, 1978), a widely used and well-validated tool that measures symptom distress. Distress scores measured by the BCTRI were correlated with total scores from the SDS, thus providing support for criterion validity or convergence ($r = 0.86$, $p < 0.001$). The factor structure of the BCTRI was evaluated with a principal components factor analysis with varimax rotation. A five-factor solution accounted for 68% of the variance. The first factor consisted of nine items with loadings ranging from 0.45–0.75. The items related to adjuvant therapy (i.e., nausea and vomiting, hair loss, bowel problems, mouth sores, skin problems, decrease in appetite, fatigue, emotional upset, and difficulty concentrating). The second factor consisted of six items with factor loadings ranging from 0.42–0.78. The items were associated with surgical interventions (i.e., pain, referred sensation, swelling, shoulder or arm discomfort, sleep disturbance, and sexual problems). The third, fourth, and fifth factors each contained only one item each with a factor loading above 0.5 (fluid collection at surgical site, temperature fluctuation, and infection). Two items (poor wound healing and bleeding at the surgical site) did not load on any factors because the symptoms were not experienced by any women in the sample.

Frequency distributions for all items for Sample 1 were calculated. Scores were calculated for the number of symptoms, severity of symptoms, and amount of distress. Reliability for the three dimensions of the symptom experience was evident in Cronbach alpha coefficients of 0.64, 0.77, and 0.72, respectively, indicating that the dimensions were homogenous (i.e., the dimensions were internally consistent).

Table 2. Symptoms Reported, Severity of Symptoms, and Amount of Distress Experienced

Variable	Possible Range	Actual Range	\bar{X}	SD
Sample 1 (N = 105)				
Number of symptoms	1–21	1–12	6.0	2.62
Severity of symptoms	1–63	1–23	8.9	4.86
Amount of distress experienced	0–63	0–26	6.5	5.66
Sample 2 (N = 131)				
Number of symptoms	0–23	0–19	6.6	4.04
Severity of symptoms	0–69	0–40	10.9	8.40
Amount of distress experienced	0–69	0–41	10.4	8.92

Sample 2

BCTRI instrument refinement: Cartwright-Alcares (2005) used the BCTRI to collect data regarding the symptom experience of women with breast cancer in ongoing recovery (Sample 2). With permission from Budin and Hoskins (2000), the researcher modified the BCTRI to include seven additional symptoms associated with ongoing recovery—sweats (hot flashes), vaginal dryness, vaginal discharge, vaginal bleeding, facial swelling, numbness and tingling, and increase in appetite—resulting in a total of 27 items (see Table 3).

Investigators who explored the effects of breast cancer treatment (Graydon et al., 1997) and examined the outcomes of clinical breast cancer trials (Thurlimann et al., 2005) reported that the symptoms are relevant to the recovery phase of breast cancer. Because the purpose of Cartwright-Alcares’s (2005) study was to explore side effects relevant to ongoing recovery, three items (fluid collection at the site of surgery, bleeding at the surgical site, and poor wound healing) that were directly related to the immediate postsurgical period were not included in the data collection.

Also with permission from Budin and Hoskins (2000), Cartwright-Alcares (2005) further modified the BCTRI to include a more comprehensive list of specific surgical treatment options, hormonal therapies, and chemotherapy regimens relevant to breast cancer treatment so that participants could easily check off the treatments they received. In addition, all types of breast cancer surgery and radiation therapy treatment, as well as stage of disease, were listed for participants. Participants were encouraged to validate the treatment options with their healthcare providers.

Characteristics: Sample 2 consisted of 131 breast cancer survivors in ongoing recovery from one month to five years after completion of primary therapy (Cartwright-Alcares, 2005). Participant ages ranged from 31–84 years, with a mean age of 51.5 years ($SD = 12.1$). More than half were college educated and employed in diverse professional and semiprofessional occupations. At the time of diagnosis, nearly half (54%) had stage 0–I disease, 41% had stage II–III disease, and 5% had stage IV disease. Types of surgical treatment included modified radical mastectomy ($n = 92$, 70%), lumpectomy ($n = 39$, 30%), and reconstructive surgery ($n = 66$, 71% of those who had mastectomy). At the time the participants completed the BCTRI, only 2% were receiving chemotherapy and 63% were receiving hormone therapy; 44% had received radiation therapy (see Table 1).

Findings: Table 2 lists the mean scores for severity of symptoms and amount of distress experienced for women in the ongoing recovery phase of breast cancer. Symptoms reported as most distressful were sweats and hot flashes, difficulty sleeping, fatigue, emotional upset, vaginal dryness, shoulder or arm discomfort, difficulty concentrating, and sexual problems (see Table 3).

Reliability for the three subscales or dimensions of symptom experience measured by the BCTRI was demonstrated by Cronbach alpha coefficients of 0.72, 0.82, and 0.84, respectively, indicating that the dimensions were homogeneous and internally consistent (Talbot, 1995; Waltz, Strickland, & Lenz, 1991). The reliability coefficients are similar to those reported by Budin and Hoskins (2000).

Table 3. Severity of Symptoms and Amount of Distress

Symptom ^a	Severity of Symptoms		Amount of Distress	
	Sample 1	Sample 2	Sample 1	Sample 2
Sample 1				
Fatigue	1.32	0.95	0.91	0.92
Difficulty sleeping	1.14	1.11	0.79	1.01
Shoulder/arm discomfort	0.95	0.69	0.76	0.63
Pain	0.76	0.50	0.48	0.50
Emotional upset	0.77	0.98	0.67	0.96
Difficulty concentrating	0.46	0.69	0.43	0.72
Nausea/vomiting	0.58	0.12	0.39	0.11
Bowel problems	0.37	0.36	0.32	0.34
Sexual problems	0.43	0.68	0.23	0.68
Swelling of arm or breast	0.32	0.25	0.20	0.24
Referred sensations	0.34	0.30	0.14	0.24
Fluid at surgical site	0.28	—	0.19	—
Radiation skin effects	0.21	—	0.21	—
Temperature fluctuation	0.22	0.50	0.13	0.47
Decrease in appetite	—	—	—	—
Hair loss/thinning	0.23	0.14	0.25	0.11
Mouth sores	0.22	0.46	0.25	0.41
Poor wound healing	0.74	0.06	0.06	0.05
Infection	—	—	—	—
Bleeding at surgical site	—	0.05	—	0.05
Sample 2—symptoms added				
Sweats/hot flashes	—	1.12	—	0.99
Vaginal dryness	—	0.85	—	0.79
Vaginal discharge	—	0.15	—	0.13
Vaginal bleeding	—	0.06	—	0.09
Facial swelling (moonface)	—	0.08	—	0.10
Numbness and tingling	—	0.49	—	0.50
Increase in appetite	—	0.33	—	0.35

N = 105 for sample 1; N = 131 for sample 2

^a Symptoms are listed in order of frequency of occurrence.

Utility of the Breast Cancer Treatment Response Inventory to Evaluate Symptom Experience

Concurrent Symptoms: Multiplicative Effect

Dodd et al. (2004) differentiated symptom clusters from concurrent symptoms. Concurrent symptoms are a number of symptoms occurring simultaneously and may be used as predictors of patient outcomes. For example, cognitive changes in breast cancer survivors are reported frequently (Ahles et al., 2002; Cartwright-Alcares, 2005; Ganz et al., 2002; Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Jansen, Miaskowski, Dodd, & Dowling, 2005; Knopf, 2001; Samarel et al., 1996; Fan et al., 2005). Nail (2006) indicated that cognitive changes can result “from the disease, the treatment, complications of treatment, comorbid conditions, the adverse effects of drugs, other symptoms, aging, and psychological responses to the cancer diagnosis” (p. 48), thus suggesting that the number of symptoms may have a multiplicative effect on cognitive changes. The following is an example of how the BCTRI is a useful tool to empirically screen for symptom clusters or to note when a multiplicative effect results from an increase in number of symptoms that

may, in turn, influence overall distress or another specific outcome.

Nail (2006) cautioned that few studies have examined the pattern of change in concentration throughout the breast cancer treatment and recovery period. Thus, to test the multiplicative effect of number of symptoms on difficulty concentrating, using the previously described data (Cartwright-Alcares, 2005), a Pearson correlation matrix was calculated. The Pearson correlation coefficients show that the number of symptoms is moderately correlated to difficulty concentrating ($r = 0.631$, $p = 0.000$), indicating that approximately 40% of difficulty concentrating can be explained by increased number of symptoms, suggesting a multiplicative effect (i.e., as the number of symptoms increase, difficulty concentrating becomes more severe).

Although this suggests that decreasing the number of symptoms would improve concentration, no empirical evidence supports the hypothesis. The clinical relevance of the correlation will become meaningful only when investigators test interventions targeted toward the number of symptoms, specific symptoms, or symptom clusters that demonstrate improvement in specific outcomes, in this case difficulty concentrating.

Symptom Clusters

Dodd et al. (2004) noted that many symptom clusters may be “buried in the text of articles and ‘yet to be analyzed’ large symptom data sets, making retrieval and estimates of prevalence difficult to derive” (p. 76). Recently, in the cancer nursing literature, investigators have examined data exploring the occurrence of symptom clusters and have included pain, fatigue, depression, and sleep disruption as dimensions of the clusters (Beck, Dudley, & Barsevick, 2005; Bender, Ergyn, Rosenzweig, Cohen, & Sereika, 2005; Dodd, Miaskowski, et al., 2001; Fox & Lyon, 2006; Miaskowski et al., 2004; National Institutes of Health State-of-Science Panel, 2004). Dodd et al. (2004) conducted a review of the literature and reported that the strength of the intercorrelations among pain, fatigue, and sleep disruption varied in different cancer populations. Higher and significant correlations were found among women with breast cancer. Therefore, for the purpose of demonstrating the BCTRI’s utility in testing for symptom clusters, the symptom cluster that includes pain, fatigue, and sleep disruption was tested in a sample of 131 women with breast cancer previously described in this article (Cartwright-Alcares, 2005). A Pearson correlation matrix was calculated for sleep disturbance, fatigue, and pain. The correlations, although statistically significant ($p < 0.001$), ranged from 0.301–0.357, indicating low to moderate relationship strength (Munro, 2001). The symptoms frequently are associated with varying types of emotional upset (Bower et al., 2000; Reiner & Lacasse, 2006).

To test the symptom cluster for synergistic effect on emotional upset, the dependent variable of emotional distress was included in the correlation matrix, resulting in significant correlations ($p < 0.001$) ranging from 0.353–0.558, suggesting that in that sample, the symptoms in the cluster could explain as much as 61% of the variance in emotional upset. The clinical relevance of the statistical findings would be determined by targeting interventions toward specific clusters or concurrent symptoms to determine whether the distress or another outcome is influenced.

Implications for Nursing Practice and Further Research

Increasing the scope of knowledge regarding symptom experience is a national priority recognized by the National Cancer Institute, ONS (2003), and the Institute of Medicine (Berger et al., 2005; Ferrell, Virani, Smith, & Juarez, 2003; Hampton, 2005; Ropka & Spencer-Cisek, 2001). Reliable and valid tools are needed that can be used consistently in research and practice settings (Byar et al., 2006). Oncology nurses are in a pivotal position to partner with breast cancer survivors to identify aspects of symptom experience that are most troublesome so that nursing interventions can be developed to help patients adjust and cope with the challenges. Oncology nurses can make a key contribution to improving patient outcomes by linking interventions to dimensions of symptom experience that have been identified as most distressful and by demonstrating how the interventions influence specific nursing-sensitive patient outcomes.

Investigators should conduct additional studies with longitudinal designs using the BCTRI (Budin & Hoskins, 2000; Cartwright-Alcares, 2005) at specific meaningful time points in treatment, recovery (one to five years), and ongoing survivorship (more than five years) to further explore the emerging concept of symptom experience, which includes the number of symptoms, the severity of symptoms, and the amount of distress experienced, as well as multiplicative effects of numerous concurrent symptoms and the synergistic

effects of symptom clusters on specific outcomes. Such studies would permit further exploration of the dimensions of symptom experience described in this article. The findings can be used to determine survivors' symptom-related needs and to examine how the relationships among the variables change at different time points in the treatment-recovery trajectory.

Samples that reflect more socioeconomically and ethnically diverse populations should be included to examine a more heterogeneous symptom experience. The BCTRI also would be a useful assessment tool during breast cancer treatment and in the recovery period to ensure that oncology nurses are aware of patients' perceptions of distress related to symptom experience so that care can be focused to meet patients' needs.

Included among the six priority areas in ONS's research agenda (ONS, 2004) are cancer symptoms and side effects, as well as the late effects of cancer treatment and long-term survivorship issues. The BCTRI as a standardized data collection tool will provide oncology nurses with a means to identify the comprehensive list of breast cancer symptoms that women experience. The data then can be analyzed and lead to a better understanding of the complex relationships among symptoms, symptom clusters, and the effects the variables have on distress and other outcomes so that care and interventions can be symptom focused.

Author Contact: Wendy C. Budin, PhD, RN-BC, can be reached at wendy.budin@nyc.edu, with copy to editor at ONFEditor@ons.org.

References

- Ahles, T.A., Saykin, A.J., Furstenberg, C.T., Cole, B., Mott, L.A., & Skalla, K. (2002). Neuropsychologic impact of standard-dose systemic chemotherapy in long-term survivors of breast cancer and lymphoma. *Journal of Clinical Oncology*, 20, 485-493.
- Armer, J.M., Radina, M.E., Porock, D., & Culbertson, S.D. (2003). Predicting breast cancer-related lymphedema using self-reported symptoms. *Nursing Research*, 52(6), 370-379.
- Armstrong, T.S. (2003). Symptoms experience: A concept analysis. *Oncology Nursing Forum*, 30(4), 601-606.
- Badger, T.A., Braden, C.J., & Mishel, M.H. (2001). Depression burden, self-help interventions, and side effect experience in women receiving treatment for breast cancer. *Oncology Nursing Forum*, 28(3), 567-574.
- Beck, S.L., Dudley, W.N., & Barsevick, A. (2005). Pain, sleep disturbance, and fatigue in patients with cancer: Using a mediation model to test a symptom cluster [Online exclusive]. *Oncology Nursing Forum*, 32(3), E48-E55. Retrieved February 6, 2008, from <http://www.ons.org/Publications/journals/ONF/Volume32/Issue3/3203542.asp>
- Bender, C.M., Ergyn, F.S., Rosenzweig, M.Q., Cohen, S.M., & Sereika, S.M. (2005). Symptom clusters in breast cancer across three phases of the disease. *Cancer Nursing*, 28(3), 219-225.
- Berger, A.M., Berry, D.L., Christopher, K.A., Greene, A.L., Maliski, S., Swenson, K.K., et al. (2005). Oncology Nursing Society Year 2004 Research Priorities Survey. *Oncology Nursing Forum*, 32(2), 281-290.
- Bower, J., Ganz, P.A., Desmond, K.A., Rowland, J.H., Meyerowitz, B.E., & Belin, T. (2000). Fatigue in breast cancer survivors: Occurrence, correlates, and impact on quality of life. *Journal of Clinical Oncology*, 18(4), 743-753.
- Budin, W., & Hoskins, C.N. (2000). [Revision and validation of the breast cancer treatment response inventory]. Unpublished raw data. New York.
- Budin, W.C. (1998). Psychosocial adjustment to breast cancer in unmarried women. *Research in Nursing and Health*, 21(2), 155-166.
- Byar, K.L., Berger, A.M., Bakken, S.L., & Cetak, M.A. (2006). Impact of adjuvant breast cancer chemotherapy on fatigue, other symptoms, and quality of life [Online exclusive]. *Oncology Nursing Forum*, 33(1), E18-E26. Retrieved February 6, 2008, from <http://www.ons.org/publications/journals/ONF/volume33/issue1/330139.asp>
- Carpenter, J.S., Sloan, P., Andrykowski, M.A., McGrath, P., Sloan, D., Rexford, T., et al. (1999). Risk factors for pain after mastectomy/lumpectomy. *Cancer Practice*, 7(2), 66-70.
- Cartwright-Alcares, F. (2005). Information needs of women with breast cancer in recovery. *Dissertation Abstracts International*, 65(11), 5631. (UMI No. 072699).
- Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E.S., Humphreys, J., et al. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, 33(5), 668-676.
- Dodd, M.J., Miaskowski, C., & Lee, K.A. (2004). Occurrence of symptom clusters. *Journal of National Cancer Institute Monographs*, 32, 76-78.
- Dodd, M.J., Miaskowski, C., & Paul, S.M. (2001). Symptom clusters and their effect on the functional status of patients with cancer. *Oncology Nursing Forum*, 28(3), 465-470.
- Erickson, V.S., Pearson, M.L., Ganz, P.A., Adams, J., & Kahn, K.L. (2001). Arm edema in breast cancer patients. *Journal of the National Cancer Institute*, 93(2), 96-111.
- Fan, H.G., Houede-Tchen, N., Yi, Q.L., Chemernsky, I., Downie, F.P., Sabate, K., et al. (2005). Fatigue, menopausal symptoms, and cognitive function in women after adjuvant chemotherapy for breast cancer: 1- and 2-year follow-up of a prospective controlled study. *Journal of Clinical Oncology*, 23(31), 8025-8032.
- Ferrell, B.R., Grant, M., Funk, B., Otis-Green, S., & Garcia, N. (1997). Quality of life in breast cancer. Part I: Physical and social well-being. *Cancer Nursing*, 20(6), 398-408.
- Ferrell, B.R., Grant, M., Funk, B., Otis-Green, S., & Garcia, N. (1998). Quality of life in breast cancer. Part II: Psychological and spiritual well-being. *Cancer Nursing*, 21(1), 1-9.
- Ferrell, B.R., Virani, R., Smith, S., & Juarez, G. (2003). The role of oncology nursing to ensure quality care for cancer survivors: A report commissioned by the National Cancer Policy Board and Institute of Medicine [Online

- exclusive]. *Oncology Nursing Forum*, 30(1), E1–E11. Retrieved February 6, 2008, from <http://ons.metapress.com/content/3k31602727q874h5/?p=b474fb14dc345659353782355f62c83&pi=0>
- Fox, S.W., & Lyon, D.E. (2006). Symptom clusters and quality of life in survivors of lung cancer. *Oncology Nursing Forum*, 33(5), 931–936.
- Ganz, P.A., Desmond, K.A., Leedham, B., Rowland, J.H., Meyerowitz, B.E., & Belin, T.R. (2002). Quality of life in long-term, disease-free survivors of breast cancer: A follow-up study. *Journal of the National Cancer Institute*, 94(1), 39–49.
- 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(22), 4184–4193.
- Goodell, T.T., & Nail, L.M. (2005). Operationalizing symptom distress in adults with cancer: A literature synthesis [Online exclusive]. *Oncology Nursing Forum*, 32(2), E42–E47. Retrieved February 6, 2008, from <http://www.ons.org/publications/journals/ONF/Volume32/Issue2/320242.asp>
- Graydon, J., Galloway, S., Palmer-Wickham, S., Harrison, D., Rich-van der Bij, L., West, P., et al. (1997). Information needs of women during early treatment for breast cancer. *Journal of Advanced Nursing*, 26(1), 59–64.
- Hampton, T. (2005). Cancer survivors need better care: New report makes recommendations. *JAMA*, 294(23), 2959–2960.
- Hoskins, C.N. (1997). Breast cancer treatment-related patterns in side effects, psychological distress, and perceived health status. *Oncology Nursing Forum*, 24(9), 1575–1583.
- Hoskins, C.N., Baker, S., Sherman, D., Bohlander, J., Bookbinder, M., Budin, W., et al. (1996). Social support and patterns of adjustment to breast cancer. *Scholarly Inquiry for Nursing Practice*, 10(2), 99–123.
- Hoskins, C.N., Budin, W., & Maislin, G. (1996). Medical factors and patterns of adjustment to breast cancer. *Psycho-Oncology*, 5, 31–44.
- Jansen, C.E., Miaskowski, C., Dodd, M., & Dowling, G. (2005). Chemotherapy-induced cognitive impairment in women with breast cancer: A critique of the literature. *Oncology Nursing Forum*, 32(2), 329–342.
- Kim, H.J., McGuire, D.B., Tulman, L., & Barsevick, A.M. (2005). Symptom clusters: Concept analysis and clinical implications for cancer nursing. *Cancer Nursing*, 28(4), 270–282.
- Knobf, M.T. (2001). The menopausal symptom experience in young mid-life women with breast cancer. *Cancer Nursing*, 24(3), 201–210.
- Knobf, M.T. (2006). Reproductive and hormonal sequelae of chemotherapy in women. *American Journal of Nursing*, 106(3, Suppl.), 60–65.
- Lazarus, R.S. (1993). Coping theory and research: Past, present, and future. *Psychosomatic Medicine*, 55(3), 234–247.
- Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Longman, A.J., Braden, C.J., & Mishel, M.H. (1999). Side-effects burden, psychological adjustment, and life quality in women with breast cancer: Pattern of association over time. *Oncology Nursing Forum*, 26(5), 909–915.
- McCorkle, R., & Young, K. (1978). Development of a symptom distress scale. *Cancer Nursing*, 1(5), 373–378.
- Meraviglia, M. (2006). Effects of spirituality in breast cancer survivors [Online exclusive]. *Oncology Nursing Forum*, 33(1), E1–E7. Retrieved February 6, 2008, <http://ons.metapress.com/content/45726u6551g05213/?p=78dac26c037d406c82026271702e51c6&pi=0>
- Miaskowski, C., Cooper, B.A., Paul, S.M., Dodd, M., Lee, K., Aouizerat, B.E., et al. (2006). Subgroups of patients with cancer with different symptom experiences and quality-of-life outcomes: A cluster analysis [Online exclusive]. *Oncology Nursing Forum*, 33(5), E79–E89. Retrieved February 6, 2008, from <http://www.ons.org/publications/journals/onf/Volume33/Issue5/pdf/3305887.pdf>
- Miaskowski, C., Dodd, M., & Lee, K. (2004). Symptom clusters: The new frontier in symptom management research [Monograph]. *Journal of the National Cancer Institute*, 32, 17–21.
- Munro, B.H. (2001). *Statistical methods for health care research*. New York: Lippincott.
- Nail, L.M. (2006). Cognitive changes in cancer survivors. *American Journal of Nursing*, 106(3, Suppl.), 48–54.
- National Comprehensive Cancer Network. (2007a). *NCCN clinical practice guidelines in oncology: Breast cancer* [v.2.2007]. Retrieved June 17, 2007, from http://www.nccn.org/professionals/physician_gls/PDF/breast.pdf
- National Comprehensive Cancer Network. (2007b). *NCCN clinical practice guidelines in oncology: Distress management* [v.1.2007]. Retrieved June 17, 2007, from http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf
- National Institutes of Health State-of-the-Science Panel. (2004). National Institutes of Health State-of-the-Science Conference Statement: Symptom management in cancer: Pain, depression, and fatigue, July 15–17, 2002. *Journal of the National Cancer Institute Monographs*, 32, 9–16.
- Oncology Nursing Society. (n.d.). *Oncology Nursing Society outcomes resource area*. Retrieved August 22, 2006, from <http://onsopcontent.ons.org/toolkits/evidence/Clinical/index.shtml>
- Oncology Nursing Society. (2003). Oncology Nursing Society position: Patients' bill of rights for quality cancer care. *Oncology Nursing Forum*, 30(1), 13–14.
- Oncology Nursing Society. (2004). *Oncology Nursing Society research agenda 2005–2009*. Retrieved June 17, 2007, from <http://www.ons.org/research/information/documents/pdfs/agenda05.pdf>
- Reiner, A., & Lacasse, C. (2006). Symptom correlates in the gero-oncology population. *Seminars in Oncology Nursing*, 22(1), 20–30.
- Rhodes, V.A., McDaniel, R.W., Homan, S.S., Johnson, M., & Madsen, R. (2000). An instrument to measure symptom experience: Symptom occurrence and symptom distress. *Cancer Nursing*, 23(1), 49–54.
- Ries, L.A.G., Harkins, D., Krapcho, M., Mariotto, M., Miller, B.A., Feuer, E.J., et al. (Eds.). (n.d.). *SEER cancer statistics review, 1975–2003*. Bethesda, MD: National Cancer Institute. Retrieved June 23, 2006, from http://seer.cancer.gov/csr/1975_2003/
- Ropka, M.E., & Spencer-Cisek, P. (2001). PRISM: Priority Symptom Management Project. Phase I: Assessment. *Oncology Nursing Forum*, 28(10), 1585–1594.
- Samarel, N., Leddy, S.K., Grecco, K., Cooley, M.E., Torres, S.C., Tulman, L., et al. (1996). Development and testing of the Symptom Experience Scale. *Journal of Pain and Symptom Management*, 12(4), 221–228.
- Talbot, L.A. (1995). *Principles and practice of nursing research*. St. Louis, MO: Mosby-Yearbook.
- Thurlimann, B., Keshaviah, A., Coates, A.S., Mouridsen, H., Mauriac, L., Forbes, J.F., et al. (2005). A comparison of letrozole and tamoxifen in postmenopausal women with early breast cancer: The Breast International Group (BIG) 1–98 Collaborative Group. *New England Journal of Medicine*, 353(26), 2747–2757.
- Waltz, C.F., Strickland, O.L., & Lenz, E.R. (1991). *Measurement in nursing research* (2nd ed.). Philadelphia: F.A. Davis.