Psychospiritual Well-Being and Symptom Distress in Women With Breast Cancer

Juanita K. Manning-Walsh, PhD, RN

Purpose/Objectives: To examine the relationship between symptom distress and psychospiritual well-being in women with breast cancer.

Design: Descriptive, cross-sectional, correlational study.


Sample: 100 women were invited to participate in the study after posting an entry in the Web site guest book. Most had stage I or II breast cancer, were nearly 46 years old, and were 10.25 months post-diagnosis.

Methods: Mailed questionnaires. Women were required to meet the following inclusion criteria: a confirmed breast cancer diagnosis, first cancer experience, fewer than two years postsurgery for breast cancer, 18 years of age or older, and the ability to read and write in English. Symptom distress was measured using the Symptom Distress Scale. Psychospiritual well-being was measured by combining scores from the psychological subscale of the breast-cancer specific version of the Functional Assessment of Cancer Therapy Scale and the Functional Assessment of Chronic Illness Therapy (Spiritual) Measurement System 12 for a composite score.

Main Research Variables: Symptom distress, psychospiritual well-being.

Findings: Symptom distress and psychospiritual well-being were inversely related. No relationship was found between age and symptom distress; however, age was inversely related to psychospiritual well-being. Age and symptom distress accounted for 23.1% of the variance in psychospiritual well-being.

Conclusions: Participants experienced a small amount of symptom distress, which was inversely related to psychospiritual well-being. Although their symptom distress was similar to other patients, patients in this study reported lower psychospiritual well-being than participants in other studies.

Implications for Nursing: Psychospiritual well-being is an important concept for nurses seeking a holistic approach to practice because it connects the mind and spirit with the body.

A breast cancer diagnosis is a highly stressful experience associated with a myriad of symptoms that cause distress (Cimprich, 1999; McCorkle, 1987). These symptoms can begin as early as the time of diagnosis (Cimprich), last for two years or longer after completion of adjuvant therapy (Glanz & Lerman, 1992), and often disrupt a patient’s quality of life (QOL), specifically its psychological and spiritual aspects (Lin & Bauer-Wu, 2003). QOL has many dimensions, including physical, functional, social, psychological, and spiritual well-being (Brady et al., 1997; Brady, Peterman, Fitchett, Mo, & Cell, 1999; Cella et al., 1993; Lin & Bauer-Wu). Numerous studies have examined the effects of symptom distress on various psychological outcomes, such as anger, depression, and hope (McCorkle, Cooley, & Shea, n.d.), in participants with a variety of disease conditions, but very few have examined the effects of symptom distress on spiritual outcomes (Taylor, 1993).

Little effort has been directed toward the elucidation of spiritual responses as they relate to symptom distress (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998; Lin & Bauer-Wu, 2003); consequently, little is known about the effect of symptom distress on psychospiritual well-being, a composite of the psychological and spiritual well-being dimensions of QOL (Lin & Bauer-Wu). The purpose of this descriptive, cross-sectional, and correlational study, which was a secondary analysis of data collected in 2000, was to examine the relationship between symptom distress and psychospiritual well-being. The original study (Manning, 2000) examined the effects of a mediation model in a group of women with breast cancer. A conceptual framework of stress and coping (Lazarus & Folkman, 1984) guided the literature review.

Juanita K. Manning-Walsh, PhD, RN, is an assistant professor in the Bronson School of Nursing at Western Michigan University in Kalamazoo. (Submitted June 2004. Accepted for publication November 1, 2004.)

Digital Object Identifier: 10.1188/05.ONF.E56-E62
Literature Review

Symptom Distress

Symptoms are subjective phenomena indicating a condition departing from normal function, sensation, or appearance (McCorkle & Young, 1978). They result in physical and mental suffering, are often unpleasant or unusual, and interfere with comfort and productivity (Giardino & Wolf, 1993). Attempts to measure or quantify symptom distress usually are made through the evaluation of the subjective reports of individuals experiencing the symptom(s) (McCorkle, 1987).

Individual responses to symptoms associated with the diagnosis and treatment of breast cancer vary widely (Munkres, Oberst, & Hughes, 1992; McCorkle, 1987), with symptoms such as emotional distress, fatigue, and insomnia beginning as early as the time of diagnosis (Cimprich, 1999; Cimprich & Ronis, 2003). Glanz and Lerman (1992) found that symptoms persist for up to two years after adjuvant therapy is complete in 20%–30% of women with breast cancer.

Some symptoms may be more problematic and distressing than others. Among the most common symptoms experienced by women receiving adjuvant therapy for breast cancer are fatigue (Cohen, Kahn, & Steeves, 1998; Longman, Braden, & Mishel, 1999), difficulty concentrating (Cimprich, 1999; Longman et al.), pain, skin irritation, depression, and anxiety (Longman et al.), with fatigue being the most problematic over time.

Symptom distress may be a critical variable in predicting or explaining patient outcomes and concerns (McCorkle, 1987). A number of studies have demonstrated relationships between symptom distress and psychological well-being (Kurtz, Kurtz, Given, & Given, 1995; Molassiotis, Van Den Akker, Milligan, Goldman, & Boughton, 1996; Sarna, 1998; Taylor, Baird, Malone, & McCorkle, 1993), and symptom distress has been shown to be inversely related to psychological well-being in women with recurrent breast cancer receiving chemotherapy (Northouse, Dorris, & Charron-Moore, 1995). In a longitudinal study measuring patients’ symptom distress for six months following a breast cancer diagnosis, Longman et al. (1999) reported that the number of symptoms experienced was inversely related to overall QOL, but the researchers did not address psychological or spiritual well-being specifically.

Some evidence shows that certain demographic variables, such as age (Budin, 1998; Degner & Sloan, 1995) and marital status (Northouse et al., 1995), have an impact on the relationship between symptom distress and psychological well-being. Younger women and those who are single tend to experience more symptom distress and disruption in psychological well-being than older or married women.

Little is known about the relationship between symptom distress and spiritual well-being. Only one study has been published in which the effect of symptom distress on spiritual well-being was examined. In a study of 74 participants with recurrent cancers of various types, symptom distress was inversely related to spiritual well-being, which was expressed through the creation of a sense of meaning and purpose for the experience despite facing a life-threatening illness (Taylor, 1993).

In this study, participants reported on their symptom distress, defined as the degree of perceived discomfort in relation to a symptom. Symptoms of interest were nausea, changes in mood, decreased appetite, insomnia, pain, decreased mobility, fatigue, altered bowel patterns, decreased ability to concentrate, and dissatisfaction with physical appearance (McCorkle & Young, 1978). Although symptom distress has been investigated in relation to psychological and spiritual well-being, it has not been evaluated in relation to psychospiritual well-being as one construct.

Psychospiritual Well-Being

Spiritual well-being arises from the human spiritual dimension. This spiritual dimension has no voice or unique means of expression, thus making scientific measurement difficult (Bash, 2004). Therefore, spiritual well-being must be expressed through other human dimensions. Frequently, the psychological dimension is the conduit through which spiritual well-being is expressed (Ellison & Smith, 1991). Although studies examining the interconnectedness of the psychological and spiritual dimensions offer little support for the combination of psychological well-being and spiritual well-being into one construct (i.e., psychospiritual well-being), psychological and spiritual well-being have been examined as one construct (Taylor, 1993).

Along with other life-threatening conditions, a breast cancer diagnosis changes a woman’s perception of her life (Swenson, Fuller, & Clements, 1993) and puts her at risk for altered psychospiritual well-being because of changes in health, symptoms associated with the disease and treatment, and the abrupt need to face her own mortality, any of which may be related to increased fear and anxiety and decreased psychological well-being (Utley, 1999). Study findings indicate that spiritual well-being is inversely related to depression in caregivers of disabled older adults (Chang, Noonan, & Tennstedt, 1998; Fehring, Miller, & Shaw, 1997), anxiety in older women with a chronic illness (Koenig, 2002), and loneliness (Miller, 1985) and uncertainty in adults with chronic illness (Landis, 1996). Spiritual well-being is positively correlated to hope in patients with cancer (Fehring et al.) and community-dwelling older women (Zorn & Johnson, 1997), caring behaviors in nurses working with patients with AIDS (Sherman, 1996), and life satisfaction among African Americans (Levin, Chatters, & Taylor, 1995). Notably, few studies reporting interconnectedness between psychological and spiritual well-being have examined patients with cancer, and none have evaluated women with breast cancer.

In an integrative literature review of 43 studies investigating either psychological or spiritual well-being in patients with advanced cancer, Lin and Bauer-Wu (2003) concluded that “psychospiritual well-being is a subjective experience that incorporates emotional health and meaning-in-life concerns” (p. 70). Psychospiritual well-being includes such attributes as optimism and peacefulness (Miller, Manne, Taylor, Keates, & Dougherty, 1996); meaning and purpose in life (Ferrell et al., 1998; McSherry, 1998; Walton, 1999); connectedness with self, others, nature, and a higher power (McSherry; Walton); comfort in faith or beliefs (Hill & Pargament, 2003); and the lack of negative emotions, such as nervousness, worry about the future, sadness, and hopelessness (Ballard, Green, McCaa, & Logsdon, 1997; Benzein, Norberg, & Saveman, 2001; Flemming, 1997). Psychospiritual well-being refers to people’s experiences and the effects their experiences have on them (Bash, 2004). For this study, psychospiritual well-being was defined as a subjective experience that incorporates psychological well-being and meaning in life, or spiritual well-being.

Although a wide body of evidence does not exist, studies have examined demographic (e.g., age, marital status, household income) and illness-related (e.g., type of surgery, time since...
diagnosis) variables in relation to symptom distress and QOL. Budin (1998) found that younger participants experienced more symptom distress than older ones. Wyatt and Friedman (1996) found that age was inversely related to QOL in female cancer survivors, whereas Riley et al. (1998) found no relationship between age and QOL in patients with chronic illness, including breast cancer survivors. Married women reported easier adjustment to breast cancer diagnosis and higher QOL than single women (Northouse et al., 1999). Higher household income was predictive of better QOL in patients with chronic renal or cardiac diseases (Ferrans & Powers, 1992; Lukkarinen & Hentinen, 1998). Hughes (1993) found that psychological well-being was disrupted most at the time of breast cancer diagnosis and improved over time, whereas Northouse et al. (1999) found no relationship among the time since breast cancer diagnosis, type of surgery, and QOL.

Research Questions

This study explored three research questions: (a) What is the relationship between symptom distress and psychospiritual well-being in women with breast cancer? (b) What are the relationships among demographic variables, illness-related variables, symptom distress, and psychospiritual well-being in women with breast cancer? and (c) How much of the variance in psychospiritual well-being is explained by symptom distress and demographic and illness-related variables in women with breast cancer?

Methods

Design

This research was part of a larger study that examined a model of stress and coping in women with breast cancer and was an exploratory secondary analysis of data collected from a convenience sample obtained through Internet recruitment. Although cross-sectional sampling does not allow for determination of time order as a test of causality (Polit & Beck, 2003), using this design for an initial exploration of the relationships in question is appropriate because of the limited existing research examining the effect of symptom distress on psychospiritual well-being.

Sample and Setting

University institutional review board approval was obtained in 2000 for the original study and in 2004 for this secondary analysis. A convenience sample of 100 participants was recruited from the Breast Cancer Support Web site at http://pages.prodigy.net/replyasap/bc in the spring of 2000. A woman could participate in the study if she met the inclusion criteria, which were a confirmed diagnosis of breast cancer, first cancer experience, fewer than two years postsurgery for breast cancer, 18 years of age or older, and the ability to read and write in English. Although breast cancer in men and women who are pregnant has been reported, these two groups were excluded because treatment options, associated symptoms, and psychological and spiritual responses vary among them.

Instruments

The variables in this study were measured using three instruments. Demographic data (i.e., age, marital status, level of education, household income, and race) and illness-related data (i.e., time since diagnosis, stage of cancer, type of surgery, adjuvant therapy, and whether adjuvant therapy was completed) also were collected because they could influence the amount of symptom distress (Degner & Sloan, 1995) and psychospiritual well-being (Hill & Pargament, 2003; Koenig, 2002) a woman with breast cancer was experiencing.

Symptom distress was measured using the 10-item version of the Symptom Distress Scale (SDS) (McCorkle & Young, 1978). The SDS measures symptom distress in relation to the following common symptoms: nausea, loss of appetite, insomnia, pain, mobility, bowel pattern, fatigue, loss of concentration, changes in appearance, and mood state. The scale has well-established content and construct validity according to the current user’s manual (McCorkle et al., n.d.). Each symptom is assessed using a Likert-type scale with two anchor statements, reflecting a maximum or minimum amount of distress. For example, insomnia can be scored from 1 (no distress at all) to 5 (maximum amount of distress); a score of 5 indicates that the symptom “couldn’t have been worse,” and a score of 1 reflects “a perfect night last night.” The 10 response scores are summed to provide a symptom distress score. In this study, the possible score range was 10–50, with higher scores indicating more distress. Internal consistency using Cronbach’s alpha reliability for the SDS in other studies has ranged from 0.70 (when used with participants with various types of cancer) to 0.92 (when used with participants with HIV or AIDS). Most studies that use the SDS report Cronbach’s alpha levels greater than 0.80. In this study, Cronbach’s alpha reliability coefficient was 0.81, similar to the 0.83 reported by Cimprich (1999) when the 10-item version of the instrument was used in a study of women with newly diagnosed breast cancer.

Psychospiritual well-being was measured using two instruments that were combined to create one composite score: the psychological subscale of the breast cancer-specific version of the Functional Assessment of Cancer Therapy Scale-Breast (FACT-B) (Cella et al., 1993) and the Functional Assessment of Chronic Illness Therapy (Spiritual) Measurement System 12 (FACIT-Sp-12) (Fitchett, Peterman, & Cella, 1996), which measures spiritual well-being. The FACT-B is a 36-item instrument with five subscales that measures general QOL. The psychological subscale has six items and measures psychological well-being. The FACT-B has well-established content and construct validity, as does the psychological well-being subscale, which was constructed to perform well as a unidimensional indicator (Brady et al., 1997). The FACT-Sp-12 is a 12-item scale that was developed by the researchers who developed the FACT-B and measures spiritual well-being. The FACT-Sp-12 has well-established content and construct validity (Brady et al., 1999). The psychological well-being subscale and the FACT-Sp-12 had construct validity when combined into one measure of psychospiritual well-being (K. Webster, personal communication, January 3, 2000). Both are Likert-type scales, with items scored from 0 (not at all) to 4 (very much). Higher total scores reflected better psychological and spiritual well-being. Reliability has been reported to be 0.82 for the psychological subscale (Cella et al.) and 0.87 for the FACT-Sp-12 (Fitchett et al.). In this study sample, Cronbach’s alpha reliability coefficient was 0.84 for the psychological subscale and 0.87 for the FACT-Sp-12. The scores from the psychological well-being subscale and FACT-Sp-12 were summed to produce one composite score measuring psychospiritual well-being. Because no published studies were found in which the psychological subscale of FACT-B and FACIT-Sp-12 were combined and a Cronbach’s alpha reliability coefficient was computed, no
comparative data exist for the alpha of 0.91 derived for the measure in this study.

Procedure

For the original study (Manning, 2000), a minimum sample size of 84 was determined by power analysis using Cohen’s Table (Cohen, 1988), which would have a power of 0.80 to detect a small or medium effect size ($f^2 = 0.15$) at a 95% confidence level when using regression analysis. A notice was posted on the Breast Cancer Support Web site guest book, and personal invitations were e-mailed to women with guest book entries. The notice and e-mails briefly described the study and invited participation. Women who responded were mailed questionnaire packets. The women were informed that consent to participate in the study was implied by their return of the completed questionnaire. Of the 126 questionnaires mailed, 110 (87%) were returned. Ten questionnaires were not included in the data analysis because the respondents did not meet the inclusion criteria, leaving a total sample of 100 women.

Data Analysis

Demographic and illness-related characteristics of the sample were examined using frequency distributions. All data were inspected for normalcy (Munro, 2002). Relationships among study variables were examined using Pearson product-moment correlations and multiple regression analysis. An acceptable significance level for all data analysis was set at $p \leq 0.05$. SPSS® 10.0 (SPSS Inc., Chicago, IL) was used to analyze data.

Results

Demographic and illness-related characteristics of the sample ($N = 100$) are presented in Table 1. In general, the women were well educated: 98% had graduated from high school, 43% had graduated from college, and 30% had a graduate-level education. Most were married or had a partner (74%) and Caucasian (93%). The average age was nearly 46 years (SD = 8.85), and 65% had an annual household income of more than $50,000. Wide variation existed within the sample regarding combination of adjuvant therapy (i.e., chemotherapy, radiation, and hormone therapy).

Mean symptom distress, psychological well-being, and spiritual well-being scores are listed in Table 2. Using Pearson product-moment correlation, a moderate statistically significant inverse relationship was found between symptom distress and psychological well-being ($r = -0.42$, $p = 0.01$), symptom distress and spiritual well-being ($r = -0.38$, $p = 0.01$), and symptom distress and psychospiritual well-being ($r = -0.45$, $p = 0.01$).

After frequency distributions of the data were examined, age was collapsed into two groups—women younger than 48 years and women 48 years and older. This split was based on the age at which a woman might anticipate menopause (i.e., 48 years) and provided for groups of similar sizes. Bivariate correlations were examined to identify significant relationships among demographic and illness-related variables, symptom distress, and psychospiritual well-being. No relationship between age and symptom distress was found; however, age was significantly related to psychospiritual well-being ($r = 0.21$, $p < 0.05$). Using analysis of variance, the researcher determined that younger women ($n = 51$) reported significantly lower psychospiritual well-being ($\bar{X} = 4.87$, SD = 1.20) than older women ($n = 49$, $\bar{X} = 5.41$, SD = 1.32, $F = 4.42$, df = 1, $p < 0.05$). No other demographic or illness-related characteristics were significantly related to either symptom distress or psychospiritual well-being.

Because age was significantly related to psychospiritual well-being, it was entered into the regression equation along with symptom distress to determine the amount of variance in psychospiritual well-being that could be explained by both. Age and symptom distress accounted for 23% of the variance in psychospiritual well-being; however, age alone did not maintain significance in the model (Multiple $R = 0.48$, $R^2 = 0.231$, $F = 14.53$, $p < 0.001$) (see Table 3).

Using one-sample $t$ tests, additional analysis was done to compare the mean symptom distress and psychospiritual well-being scores of this sample with other samples reported in the literature. Participants in this study had levels of symptom distress that were similar to those of a group of women with breast cancer who recently completed radiation therapy (Graydon, 1994); however, the current sample had significantly lower psychological ($t = -10.65$, df = 99, $p < 0.001$) (Brady et al., 1997) and spiritual well-being ($t = -6.82$, df = 99, $p < 0.001$) (Brady et al., 1999) scores than were reported previously.
was reported between participants receiving adjuvant therapy and those whose therapy was complete. Women who had completed adjuvant therapy reported slightly higher insomnia (X = 2.69, SD = 1.13 versus X = 2.32, SD = 1.11) and more difficulty concentrating (X = 2.21, SD = 1.01 versus X = 2.08, SD = 1.01) than those still in therapy, although neither of these findings was statistically significant. Participants not currently in adjuvant therapy were experiencing symptom distress, which is consistent with the findings of Cimprich (1999) and Berger (2003), who reported that women began experiencing fatigue, insomnia, and loss of concentration shortly after diagnosis of breast cancer and even before surgical intervention and adjuvant therapy. In addition, Glanz and Lerman (1992) found that symptoms persisted for as many as two years after adjuvant therapy was complete. Many of the women in the current study added comments to their questionnaires regarding feelings of uncertainty about the future and that their lives had been turned “upside down” after learning that they had breast cancer. The findings of this study, along with those of Cimprich, Berger, and Glanz and Lerman, underscore the lingering relationship between symptom distress and psychospiritual well-being associated with diagnosis and treatment of breast cancer.

Breast cancer is known to be a highly stressful experience associated with psychological and spiritual difficulties (Lin & Bauer-Wu, 2003). Psychospiritual well-being is a subjective experience that incorporates psychological health and spiritual concerns and was inversely related to symptom distress in this study. Although numerous studies have demonstrated links between symptom distress and psychological well-being (Berger, 2003; Cimprich, 1999; Kurtz et al., 1995; Northouse et al., 1995), fewer studies have demonstrated a relationship between symptom distress and spiritual well-being (Narayanasamy, 2004; Taylor, 1993; Taylor et al., 1993), both of which are elements of psychospiritual well-being. Nurses play a vital role in assisting clients with enhancing their psychospiritual well-being. Because nursing espouses holistic care as a central tenet, nurses are well positioned to recognize evidence of decreased psychospiritual well-being in patients, which is evidence of symptom distress and would prompt the need for psychological or spiritual care (Taylor, 2003). Nurses must assist clients in finding meaning and purpose in their breast cancer experience and provide an environment in which the spirit can find repose. This may include allowing space and privacy so women may commune with their higher power or providing opportunities
for communication with others, time and space for spiritual ceremonies, a quiet space for communing with the self through music, spiritual reading, meditation, or journaling (Acton & Miller, 2003), or becoming immersed in nature (Cimprich & Ronis, 2003). Women with breast cancer may benefit from nursing interventions that are sensitive, supportive, and responsive to psychospiritual needs (Narayanasamy).

The findings of this study related to symptom distress have implications for nursing practice. When symptom distress is present during assessment or reported by a woman with breast cancer, decreased psychospiritual well-being should be anticipated and evaluation should occur. Nurses are important resources for helping patients to recognize, prevent, and manage their symptoms. Women newly diagnosed with breast cancer or those in the treatment phase of the cancer trajectory frequently have contact with healthcare professionals, which provides them the opportunity to report symptom distress and seek assistance with treatment and relief. Women who have completed adjuvant therapy are less likely to be in regular, frequent contact with healthcare professionals but still are likely to experience symptoms. Nurses should assess patients for continued symptoms near the end of adjuvant therapy and include teaching and interventions to alleviate symptoms in patients’ long-term plan of care. Nurses also should follow up periodically with clients after treatment is completed to determine whether the need exists for further intervention or teaching in response to continued symptom distress.

Limitations

Although this study had statistically significant findings, the relationships were modest. Future studies with larger samples may yield greater effect sizes. Because of the convenience sample and cross-sectional design, these findings may not be generalizable beyond the current sample. Sampling bias is a possibility because the participants selected themselves for the study via Internet recruitment. The cross-sectional design does not allow for an examination of symptom distress and psychospiritual well-being over time. Longitudinal studies could provide understanding about how these concepts relate to each other and whether symptom distress and psychospiritual well-being change over time as women become further removed from their breast cancer diagnoses and treatments.

The women in this study, who were Internet users, were well educated when compared to the U.S. national average for women aged 25 years and older (U.S. Census Bureau, 2000). The participants were predominantly Caucasian. Future studies are needed that examine symptom distress and psychospiritual well-being in diverse samples. Purposeful recruitment of minority populations, such as African American, Latino, or Native American women with breast cancer, is warranted because other racial and ethnic groups may experience psychospiritual well-being differently. Eighty-nine percent of the participants had stage I or II cancer. Women at more advanced stages may experience more or varied symptom distress.

Numerous studies have measured psychological and spiritual well-being, but none has measured psychospiritual well-being. Although the psychological well-being subscale of FACT-B and FACT-Sp-12 have well-established reliability and validity on their own, further research is needed to support the reliability and validity of the two when combined to create a single measure of psychospiritual well-being and to support further the findings of this study.

Conclusions

Despite the limitations of this study, the findings suggest potential implications for nursing practice. For nurses seeking to adopt a holistic approach to their practice, psychospiritual well-being is an important concept (Lin & Bauer-Wu, 2003) within the context of breast cancer because it integrates the mind and spirit in a way that allows for the effects of physical symptoms on them to be examined, hence supporting a mind-body-spirit connection.

The women in this study experienced a small amount of symptom distress. Their psychological and spiritual well-being were lower than participants in other studies examining women with breast cancer or patients with a variety of cancers. This study addressed a gap in the literature regarding psychospiritual well-being. Future studies should include larger samples of women with breast cancer and participants with health concerns other than breast cancer, as well as examine psychospiritual well-being. When nurses have more knowledge about psychospiritual well-being, they will be equipped better to assist women with breast cancer with managing their symptoms and understanding their psychospiritual well-being.

Author Contact: Juanita K. Manning-Walsh, PhD, RN, can be reached at Juanita.Manning@wmich.edu, with copy to editor at rose_mary@earthlink.net.

References


