# Women With Breast Cancer: Self-Reported Distress in Early Survivorship

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## Abstract

**Purpose/Objectives—**To identify and compare levels of distress and sources of problems among patients with breast cancer in early survivorship.

**Design—**Descriptive, cross-sectional.

**Setting—**A National Cancer Institute–designated comprehensive cancer center.

**Sample—**100 breast cancer survivors were selected to represent four time points in the cancer trajectory.

**Methods—**Distress was self-reported using the Distress Thermometer and its 38-item problem list. Analysis of variance and chi-square analyses were performed as appropriate.

**Main Research Variables—**Distress scores, problem reports, and time groups.

**Findings—**Participants scored in range of the cutoff of more than 4 (range = 4.1–5.1) from treatment through three months post-treatment. At six months post-treatment, distress levels were significantly lower. Significant differences were found between groups on the total problem list score (p = 0.007) and emotional (p = 0.01) and physical subscale scores (p = 0.003).

**Conclusions—**Comparison of groups at different points in the cancer trajectory found similar elevated levels from diagnosis through three months. Distress remained elevated in early survivorship but significantly decreased at six months post-treatment.

**Implications for Nursing—**Interventions to reduce or prevent distress may improve outcomes in early survivorship.

## Keywords

distress; breast cancer; survivorship; screening

Distress is the sixth vital sign in patients with cancer and designates patient-reported psychosocial or physical suffering (Holland et al., 2013). Distress is prevalent in women with breast cancer, with reports of multiple physical, psychological, and social needs and a trajectory of worry, stress, and loss (Head et al., 2012). Newly diagnosed patients with breast cancer (stages I–IV) reported a mean distress score of 4.87 (SD = 3.2) (Head et al., 2012); a score of 4 or more indicates moderate to severe distress (National Comprehensive Cancer Network [NCCN], 2014). Distress screening can be difficult to integrate into routine care (Holland, Kelly, & Weinberger, 2010). Oncologists have reported barriers to psychosocial communication with patients secondary to insufficient consultation time, lack of resources for identified problems, and lack of methods to evaluate psychosocial health (Fagerlind, Kettis, Glimelius, & Ring, 2013). The concordance of patient-reported and clinician ratings of cancer-related distress were reported as very low (kappa values of less than 0.1), signifying the importance of distress screening and professional education (Werner, Stenner, & Schüz, 2011).

Since the 1990s, the breast cancer population has been heavily studied compared to other cancer types (Moorey, 2013; Valdes-Stauber, Vietz, & Kilian, 2013). The relationship between the level and source of distress and time periods in the cancer survivorship trajectory has been understudied, particularly in controlled homogenous samples. Using reliable and valid instruments is important, and researchers should consider using instruments that will provide comparative data.

## Background

To test for time points for supportive care interventions during early treatment and follow-up, the authors proposed to examine reports of distress in newly diagnosed (stages I, II, and III) breast cancer survivors representing four time points in early survivorship, starting at active treatment to six months post-treatment. Distress screenings can be quickly and inexpensively performed using the validated Distress Thermometer (Hollingworth et al., 2013; NCCN, 2014).

The diagnostic, treatment, and early follow-up periods in the cancer trajectory are times of increased distress (Agarwal et al., 2013; Head et al., 2012; Knobf, Major-Campos, Chagpar, Seigerman, & McCorkle, 2014; Luutonen, Vahlberg, Eloranta, Hyväri, Salminen, 2011). Distress is highest in the diagnostic phase of the breast cancer trajectory (Agarwal et al., 2013; Head et al., 2012; Knobf et al., 2013) and is also associated with down regulation of immunity (Andersen et al., 1998). Distress is also associated with trait anxiety (Ando et al., 2011; Iwatani, Matsuda, Kawabata, Miura, & Matsushima, 2013) and lack of confidence in support systems (Harding, 2014).

In women facing primary breast cancer surgery, poor body image was a factor in elevated distress in younger women (Miller, Schnur, Weinberger-Litman, & Montgomery, 2013). Postoperatively, higher levels of distress occurred in women who underwent multimodality therapy (e.g., chemotherapy with radiation therapy) and concomitantly suffered from decreased cognitive function and fatigue (Ploos van Amstel et al., 2013). Distress remained high in patients with breast cancer during chemotherapy despite multiple group and one-to-one interventions prior to and after the first dose of chemotherapy (Aranda et al., 2012). Distress was increased during postoperative radiation therapy in 28% of patients with breast cancer; independent factors included age and negative hormone receptor status (Luutonen et al., 2011). Distress and emotional upset prior to radiation therapy included feelings of pessimism, cancer stage, and mastectomy (Sohl et al., 2012). However, post-traumatic growth was shown to coexist with distress and dysfunction in women undergoing chemotherapy or radiation therapy (Silva, Moreira, & Canavarro, 2012).

Following the completion of all adjuvant therapies, the level of distress decreased in patients in supportive relationships but remained elevated in women who avoided social sharing and lacked social support (Boinon et al., 2013). Distress levels in the first eight months after surgery predicted six-year psychological outcomes (Lam, Shing, Bonanno, Mancini, & Fielding, 2012). Women with chronic distress experienced more long-term psychological and cancer-related distress and poorer social adjustment compared to women who initially reported low distress levels (Lam et al., 2012).

Given the long-term cancer trajectory in breast cancer survivors, healthcare providers should consider psychological and physical care across the cancer continuum. The number of psychological comorbidities and the survivor's time point in the cancer trajectory may determine her level of distress and should inform the timing and type of intervention (Rissanen, Arving, Ahlgren, Cernvall, & Nordin, 2014). Adjustment disorders, anxiety, grief, and mood swings were common causes of psychological distress in survivors (Mitchell et al., 2011). Distress levels remained elevated in the first two years after breast cancer surgery in women with decreased physical fitness and muscle strength and increased fatigue (Ploos van Amstel et al., 2013).

The purpose of this study was to identify and compare the levels and sources of distress among groups of patients with breast cancer from four time periods. The four time periods included during treatment, at the end of treatment, three months post-treatment, and six months post-treatment. The authors predicted an effect of time period and anticipated that the level and sources of distress among the four groups would decline significantly from the

initial treatment group score to the final six months post-treatment group score. In addition, the authors anticipated that the greatest change in distress levels would be observed between the end of treatment and three months post-treatment.

## Methods

A cross-sectional design compared the level and sources of distress from patients with breast cancer (N = 100) sampled and represented the time periods of during treatment (n = 25), after treatment (n = 25), three months post-treatment (n = 25), and six months post-treatment (n = 25).

Women were accrued for the study from September 2011 to December 2011 in surgical and medical oncology clinics in a free-standing comprehensive breast center at a large, university-based, National Cancer Institute–designated comprehensive cancer center. The study was approved by the institutional review board at the Ohio State University in Columbus.

Inclusion criteria were female patients aged 18 years or older with stage I, II, or III primary breast cancer including ductal carcinoma in situ (stage 0). Exclusion criteria were inflammatory or stage IV breast cancer and any condition impairing cognition. Nurses and research staff reviewed patient logs daily to identify potential participants. Using convenience sampling, 102 eligible patients were approached. One-hundred patients completed the consent process; two people declined participation. Participants completed questionnaires in the waiting area prior to an appointment. The questionnaires took 7–10 minutes for completion. The research team was available for questions and collected completed instruments from participants.

### Measures

The Distress Thermometer and its 38-item problem list (Bogaarts et al., 2011; NCCN, 2014) were used to measure the participants' self-reported distress level and sources of distress over the past week, including the day of completion. The Distress Thermometer is a vertical thermometer figure with ratings from 0 (no distress) to 10 (extreme distress). Scores of 4 or greater suggest moderate to severe distress (Bogaarts et al., 2011). The instrument's 38-item problem list includes potential sources of distress, with responses of yes or no for each. Scores can range from 0–38, comprised of five item groupings (practical [6 items], family [4 items], emotional [6 items], physical [21 items], and spiritual/religious [1 item]). In a pooled study (N = 1,477) the combined sensitivity of the Distress Thermometer to measure distress was 77%, and combined specificity was 66% (Mitchell, 2007). The instrument's positive predictive value for the measurement of distress was 55.6 and negative predictive value was 80.1 (Mitchell, 2007).

Descriptive data included the participant's age, race, ethnicity, marital status, education level, employment status, insurance status, and perceived health status. Electronic chart reviews were performed by the research team for information regarding stage of disease, pathology type, and cancer-related treatment.

### Data Analysis

The sample size was determined by planned tests of differences in average distress scores across four time periods. Data were assumed to arise from a binomial distribution on the integers 0–10. For simplicity of testing, a two-sample t-test was planned with a 5% significance level. A Monte Carlo simulation found that a difference of 0.7 between two time points could be detected with 90% power using a sample size of 25 participants for each time period. Therefore, a sample of 100 participants with four cohorts of 25 participants each was obtained.

Descriptive statistics were used to summarize data with frequencies and percentages; when appropriate, means and standard deviations were calculated. Relationships between time periods and continuous variables were tested with analysis of variance (ANOVA). For significant findings, Tukey post hoc tests were applied to reveal if relationships existed between variables and specific pairs of time periods. For categorical variables, chi-square tests were used. Post hoc tests with a Bonferonni adjustment were applied to significant findings to identify relationships to specific time periods. In cells with less than five endorsements, p values were calculated with Fisher's exact test with a Monte Carlo approximation to the true p value.

## Results

### Participants

Participants ($N = 100$) had a mean age of 56 years (SD = 11.8; range = 31–88) (see Table 1). The sample was predominantly Caucasian (89%), non-Hispanic (100%), and partnered (75%). The majority of women were newly diagnosed with stage I (39%) and stage II (41%) breast cancers. Participants had an average of 14.8 (SD = 1.2) years of education. About half of participants were currently employed (49%) on a full-time (34%) or part-time (15%) basis; 57% were retired, 16% were medically disabled, 8% were unemployed, and 20% were in volunteer positions. Perceived health status was rated on a scale of one to four, with one being poor and four being excellent. Participant self-reports of perceived health status were excellent (18%), good (55%), fair (23%), or poor (4%), with a mean response of 2.9 (SD = 0.8). ANOVA or chi-square comparisons of the groups on the demographic, disease and treatment, and perceived health status variables revealed no significant differences (p  0.08 for all).

### Group Comparisons

The authors examined the relationships between the four time periods and scores for the Distress Thermometer and its problem list with five subscales (i.e., practical, family, emotional, physical, and spiritual). Breast cancer survivors reported an overall mean score of 4.3 (SD = 3.1, range 0–10). The one-way ANOVA was significant across time groups ($F[3, 96] = 5.3$, $p = 0.002$) (see Table 2). Tukey post hoc tests revealed no significant differences between the time groups during treatment, at the end of treatment, and three months post-treatment. However, the scores of the group at six months post-treatment showed significantly lower distress compared to the prior time groups ($p < 0.01$ for all).

The total problem score as well as the subscale scores were examined for group differences with multiple comparisons for significant ANOVA results. Significant findings existed for the total problem score (F[3, 96] = 4.2, p = 0.007). Follow-up multiple comparisons showed the number of endorsements for the groups during treatment, at the end of treatment, and three months post-treatment to be equivalent (averages ranged from 7.88–10.68 with a possible range of 0–38) and significantly higher than the number of endorsements reported by group at six months post-treatment ($\bar{X}$ = 5.2, p < 0.01). Significant group differences on the emotional (F[3, 96] = 3.7, p = 0.01) and physical (F[3, 96] = 4.9, p = 0.003) subscales. Follow-up multiple comparisons revealed the same pattern of findings as for the total score (i.e., equivalent and higher numbers of items endorsed for the groups during treatment, at the end of treatment, and three months post-treatment with a significant decline in emotional and physical item endorsements from the group six months post-treatment). No significant group differences were found on the practical, family, or spirituality subscale scores (p > 0.53 for all).

The authors of the current study also examined relationships between the four time periods of the study, demographic variables, and items on the Distress Thermometer's 38-item problem list. Breast cancer survivors self-reported their specific needs by positive endorsements of items on the five subscales. The emotional and physical subscales had the highest number of endorsements ($\bar{X}$ = 2, SD = 2 and $\bar{X}$ = 4, SD = 3, respectively) compared to the practical, family, and spiritual subscales (averages ranged from 0.3–0.8 with a possible range of 1–6). The highest number of endorsed items on each subscale included practical subscale– finances (28%); family subscale–concerns about family health (26%); emotional subscale–depression (27%), fears (34%), nervousness (48%), sadness (35%), and worry (55%); physical subscale–appearance (33%), fatigue (56%), feeling swollen (25%), memory and concentration (32%), pain 36%, skin dryness 34%, and sleep 52%; and spiritual subscale (1%). An average of 8 (SD = 6) sources of distress were noted at any one time on the problem list. The number of endorsed items was highest during treatment ($\bar{X}$ = 9, SD = 6) and gradually decreased by six months post-treatment ($\bar{X}$ = 6, SD = 5).

Significant relationships (p < 0.01) between items on the problem list and linked pairs of time periods were noted for work schedules, fears, nervousness, fatigue, nasal congestion, and sleep. Trending but nonsignificant relationships (p = 0.06) included depression, appearance, difficulty in bathing or dressing, fevers, and mouth sores. Post hoc tests of significant relationships did not identify significant differences (p > 0.05) among pairs of time periods.

## Discussion

The current study was successful in identifying self-reported levels and sources of distress in breast cancer survivors with stage 0 (e.g., noninvasive ductal carcinoma in situ), I, II, or III (e.g., invasive breast cancer) in early survivorship. A cross-sectional design was used to illustrate the distribution and significance of distressing items during four time periods in the cancer trajectory. The components of distress were identified using the Distress Thermometer and its 38-item problem list.

## Level of Distress and Time Periods

Women with breast cancer reported an overall mean distress score of 4.3 (SD = 3.1) across time periods; this moderate to severe distress level is congruent with previous studies (Bogaarts et al., 2011; Head et al., 2013). The authors' prediction that distress levels would change, with a decline in distress levels from during treatment to six months post-treatment, proved correct, which is consistent with findings in previous studies of distress in women with breast cancer (Boinon et al., 2014; Harding, 2014; Head et al., 2012; Ploos van Amstel, 2013).

The authors also predicted that the greatest change in distress levels would occur between the time points of after treatment and three months post-treatment. Instead, the greatest difference in mean distress scores was noted between three months post-treatment and six months post-treatment. Distress was statistically equivalent through three months post-treatment. These findings align with previous findings (Carlson, Waller, Groff, Giese-Davis, & Bultz, 2013) that breast cancer survivors can experience sustained distress in early survivorship. An explanation for these findings includes the prolonged timelines between the groups during treatment, after treatment, and three months post-treatment. The treatment stage can include surgery, chemotherapy, and radiation therapy. In women who have extended postoperative complications or recovery (e.g., persistent seroma, infection) after bilateral mastectomies, extensive immediate reconstructive procedures, extensive and extended chemotherapy, or the addition of radiation therapy, the time period from the treatment stage to after treatment could represent 26–52 weeks or longer. The longest time interval from diagnosis to end of radiation therapy in the current study was 19.1 months, and the shortest was 5.2 months.

The time periods are dependent on a patient's rate of surgical healing, the type of surgical procedure (e.g., repeated surgical procedures with or without reconstruction), side effects from chemotherapy and radiation therapy, and stage of disease. Therefore, healthcare providers must understand that some women may experience prolonged levels of distress (e.g., during treatment to three months post-treatment) that may span a year or longer. These considerations are important to the planning and administration of supportive or survivorship care, which has been advocated at the end of treatment or within three months post-treatment. Undue distress or even increasing distress may be allowed if healthcare providers delay the identification of problems and the creation of a care plan intended to prevent or ameliorate distress (Rissanen et al., 2014).

## Sources of Distress

The sources of distress were fairly consistent with other published studies (Agarwal et al., 2013; Andreu et al., 2012; Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010; Iwatani et al., 2013; Liao et al., 2013) in their type and frequency of occurrence. A cluster of symptoms (e.g., fatigue, worry, sleep, nervousness) were identified in 48%–56% of breast cancer survivors in this study. The results demonstrated significant levels of physical change as a result of breast cancer diagnosis and treatment with sustained negative side effects.

The findings in this study further demonstrated that the level and source of distress do not differ between stages of disease. Women with stage 0 or I breast cancer had similar levels of distress as those with stage III disease, which imparts the need to screen all people without relation to stage of disease.

### Strengths and Limitations

The strengths of this study included a broad range of ages, representative stages of disease with similar treatment regimens, a quasilongitudinal design, multiple distress measures, distress associated with time periods, and a study powered for accurate outcome measures. Because this study concentrated on one cancer diagnosis and a specific time period in the disease trajectory, it provided a homogenous view of distress in early survivorship for breast cancer survivors. The sample (N = 100) represented 67 cities or towns located in 45 counties; 98% of the sample lived in Ohio and 2% lived in West Virginia.

Limitations of this study included its use of only one institution in the midwestern United States, which may reduce the ability to generalize the data. Future studies may provide more robust data if the study started at the time of diagnosis and included longitudinal measures for each participant.

## Implications for Practice

Distress is common in women diagnosed with breast cancer. Screening patients for distress early in the treatment phase is important to identify sources of distress and to provide follow-up with appropriate assessment, interventions, and referrals. Data on specific diagnoses and specific time periods are needed to define what happens when on the cancer trajectory. With empirical data that include homogenous samples, specific time periods, and validated and comparable instruments, healthcare providers can further develop survivorship care and accompanying guidelines for symptom prevention or management.

## Conclusion

This study is consistent with other published studies of breast cancer survivors that document high levels of distress in early survivorship and sources of distress that may be challenging over time. The authors found that women with a new breast cancer diagnosis experienced moderate to severe distress throughout early survivorship. Their level of distress did not significantly vary until six months post-treatment, a time period that could represent 12 months or more after the initial diagnosis.

The potential of this sustained distress requires further study and investigation of effective interventions. In addition, the timing of survivorship care plans may require modification to incorporate distress management at earlier time periods than at the end of treatment. The identification of persistent symptoms provides opportunities to target interventions for survivors and improve their outcomes. Knowledge of the level and source of distress during treatment and short-term follow-up are important to future intervention studies.

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**Knowledge Translation**

Distress occurs in response to breast cancer and treatment side effects.

The Distress Thermometer and its problem list can detect the level and source of distress.

Highest levels of distress occur early in treatment and significantly decrease by six months post-treatment, which identifies important time points for interventions.

**Table 1**

**Participant Demographics for Each Time Period (N = 100)**

| Variable | Total | | During Treatment (n = 25) | | After Treatment (n = 25) | | Three Months Post-Treatment (n = 25) | | Six Months Post-Treatment (n = 25) | |
|---|---|---|---|---|---|---|---|---|---|---|
| | $\bar{X}$ | SD | $\bar{X}$ | SD | $\bar{X}$ | SD | $\bar{X}$ | SD | $\bar{X}$ | SD |
| Age (years) | 56.1 | 11.8 | 54 | 11 | 59.9 | 11 | 58.4 | 11 | 53.3 | 11.8 |
| Education (years) | 14.8 | 1.2 | 14.4 | 1.3 | 14 | 1.1 | 16 | 1.1 | 14 | 1.2 |
| Perceived health status[a] | 2.9 | 0.8 | 3.1 | 0.7 | 2.8 | 0.9 | 2.8 | 0.6 | 2.9 | 0.8 |
| **Variable** | **n** | | **n** | | **n** | | **n** | | **n** | |
| **Ethnicity** | | | | | | | | | | |
| Caucasian | 89 | | 21 | | 23 | | 22 | | 23 | |
| Other | 11 | | 4 | | 2 | | 3 | | 2 | |
| **Marriage status** | | | | | | | | | | |
| Partnered | 75 | | 18 | | 17 | | 19 | | 21 | |
| **Employment status** | | | | | | | | | | |
| Full-time | 34 | | 5 | | 10 | | 11 | | 8 | |
| Part-time | 15 | | 6 | | 4 | | 1 | | 4 | |
| Unemployed | 51 | | 14 | | 11 | | 13 | | 13 | |
| **Cancer stage** | | | | | | | | | | |
| 0 | 14 | | – | | 4 | | 5 | | 5 | |
| I | 39 | | 10 | | 11 | | 9 | | 9 | |
| II | 41 | | 15 | | 7 | | 8 | | 11 | |
| III | 5 | | – | | 3 | | 2 | | – | |

[a] Measured on a scale of one to four, with one being poor and four being excellent

**Table 2**

**Mean Scores on the Distress Thermometer and Subscales Across Groups**

| Variable | Range | During Treatment (n = 25) | | After Treatment (n = 25) | | Three Months Post-Treatment (n = 25) | | Six Months Post-Treatment (n = 25) | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | $\bar{X}$ | SD | $\bar{X}$ | SD | $\bar{X}$ | SD | $\bar{X}$ | SD | p |
| Distress | 0–10 | 5.08* | 3.3* | 4.1* | 2.9* | 4.2* | 2.9* | 3.6** | 3.2* | 0.002 |
| Practical | 0–6 | 0.96* | 1.2* | 0.8* | 0.83* | 0.56* | 0.95* | 0.76* | 0.64* | 0.54 |
| Family | 0–4 | 0.6* | 0.6* | 0.6* | 1.04* | 0.64* | 0.82* | 0.4* | 0.8* | 0.73 |
| Emotional | 0–6 | 2.88* | 2* | 2.16* | 2.1* | 2.44* | 1.9* | 1.2** | 1.71* | 0.01 |
| Physical | 0–21 | 6.12* | 3.2* | 4.24* | 3.5* | 4.52* | 3.3* | 2.76** | 3.1* | 0.003 |
| Spiritual | 0–1 | 0.04* | 0.2* | 0.04* | 0.2* | 0.04* | 0.2* | 0* | 0* | 0.8 |
| Total | 0–38 | 10.68* | 5.8* | 7.88* | 6.5* | 8.16* | 5.5* | 5.12** | 5.2* | 0.007 |

* No significant differences were found.

** Significant differences (p ≤ 0.05) were found.