

# Psychological Distress, Fatigue, Burden of Care, and Quality of Life in Primary Caregivers of Patients With Breast Cancer Undergoing Autologous Bone Marrow Transplantation

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**Purpose/Objectives:** To determine the effects of sociodemographic variables, psychological distress, fatigue, and quality of life (QOL) on burden of care in primary caregivers of patients with breast cancer undergoing autologous bone marrow transplantation (BMT).

**Design:** Descriptive, correlational, predictive.

**Setting:** Urban National Cancer Institute-designated comprehensive cancer center in the eastern United States.

**Sample:** Convenience sample of 102 primary caregivers.

**Methods:** Participants completed the sociodemographic data form, Piper Fatigue Scale, Beck Depression Inventory, State-Trait Anxiety Inventory, QOL Index, and Measurement of Objective and Subjective Burden Scales prior to BMT during an oncology clinic visit.

**Main Research Variables:** Depression, anxiety, fatigue, QOL, and burden of care.

**Findings:** Mean fatigue scores were low. Primary caregivers experienced moderate state anxiety and low trait anxiety. Some experienced severe depression. The objective burden of care mean score was slightly higher than the subjective mean score. Mean QOL scores were low. All variables were significantly intercorrelated, except subjective burden and temporal and sensory fatigue. Significant correlations were found between age and subjective burden, and income with fatigue temporal subscale, and state and trait anxiety. Family subscale of QOL was a significant predictor of objective burden. Age and trait anxiety were significant predictors of subjective burden.

**Conclusions:** Primary caregivers of patients with breast cancer scheduled for BMT experience fatigue, anxiety, burden of care, and low QOL. These caregivers may have tried to meet their needs and the patients' needs simultaneously.

**Implications for Nursing:** Healthcare providers need to proactively assess primary caregivers of patients for fatigue, psychological distress, burden of care, and decreased QOL and provide nursing interventions tailored to individual needs.

## Key Points . . .

- ▶ Primary caregivers of patients with breast cancer scheduled for autologous bone marrow transplantation (BMT) following mastectomy and adjuvant chemotherapy may experience psychological distress, fatigue, burden of care, and decreased quality of life (QOL).
- ▶ Primary caregivers of these patients may need to fulfill multiple additional personal and household roles that may overwhelm existing coping strategies.
- ▶ Healthcare providers need to anticipate the often-stressful caregiver experience and begin assessment of psychological distress, fatigue, burden of care, and QOL during the pre-BMT time period.
- ▶ Nursing interventions need to be tailored to the individual needs of primary caregivers and delivered proactively.

A body of research exists describing the symptoms that patients with breast cancer experience, including fatigue, psychological distress, and quality of life (QOL) (Gaston-Johansson et al., 1999). Also described previously are stressors that patients experience following treatment related to the survivor role with new fears of recurrence (Gaston-Johansson et al., 2000; Zabora, 1998). Less literature exists regarding fatigue, psychological

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Patients with breast cancer who undergo autologous bone marrow transplantation (BMT) cope with a life-threatening treatment while also experiencing multiple interrelated symptoms, including pain, fatigue, psychological distress, and nausea (Gaston-Johansson, Fall-Dickson, Bakos, & Kennedy, 1999; Gaston-Johansson, Franco, & Zimmerman, 1992). These treatment-related stressors are experienced within a personal context, including a family support system. The primary caregiver, who the patient chooses as her main support person, is an integral part of this support system.

distress, QOL, and the burden of care experienced by primary caregivers of patients with breast cancer undergoing autologous BMT (Jassak, 1992; Rowland & Massie, 1996; Wochna, 1997). Although the importance of the pre-BMT time period for primary caregivers has been recognized (Foxall & Gaston-Johansson, 1996; Grimm, Zawacki, Mock, Krumm, & Frink, 2000; Siston et al., 2001), few studies have focused specifically on this time period. No studies were found that reported the impact of sociodemographic characteristics on primary caregivers' psychological distress and burden of care.

The purpose of this study was to determine the effects of sociodemographic variables, psychological distress, fatigue, and QOL on burden of care in primary caregivers of patients with breast cancer scheduled for BMT. Specific aims were to (a) describe the primary caregiver's experience of psychological distress, fatigue, QOL, and burden of care, (b) examine the relationships among these factors, (c) determine the influence of gender and marital status on these factors, and (d) determine to what degree sociodemographic variables, psychological distress, fatigue, and QOL were predictors of burden of care.

## Literature Review

### Family Cancer Experience

The literature related to the family's cancer journey may be categorized via four major dimensions: (a) developmental stage of the family, (b) cancer illness trajectory, (c) family responses to cancer, and (d) healthcare provider behaviors (Kristjanson & Ashcroft, 1994). Families may experience concerns and issues related to their developmental stage and age. For example, the developmental stage of the family experiencing breast cancer often includes middle-aged primary caregivers who are balancing multiple responsibilities to the patient, other family members, and themselves. Christ (1983) identified predominant transition points in the cancer experience as diagnosis, treatment initiation, treatment completion, cure, treatment failure, recurrence, decision to discontinue treatment, terminal illness, and death. Although no such clear demarcations exist for related transitional emotional stages (Lewis, 1993), family members may respond to cancer with concerns that vary with the time since diagnosis, disease status, and the patient's condition (Woods, Lewis, & Ellison, 1989).

### Primary Caregiver Experience

Caregiving is a multifaceted role, ranging from simple activities such as providing transportation to the complexities of providing physical care and recognizing reportable symptoms (Laizner, Yost, Barg, & McCorkle, 1993). Also included in this process is being present to share patients' feelings of mortality and uncertainty. Healthcare provider behaviors that primary caregivers have reported as being important include providing patient comfort, competent medical care, supportive communication, and honest information (Tringali, 1986). In a preliminary phenomenologic study of eight families of patients with diverse cancers, Thorne (1985) reported that family members felt a tremendous need to live as normally as possible, have faith in medical professionals, and maintain a positive attitude.

Other studies have focused on family caregivers of patients receiving BMT (Compton, McDonald, & Stetz, 1996; Foxall & Gaston-Johansson, 1996; Lesko, 1994; McDonald, Stetz, & Compton, 1996; Siston et al., 2001; Wochna, 1997). In a sample of 40 patients pre-allogeneic BMT and their 39 care-

givers, Siston et al. reported that caregivers experienced similar distress to that of patients. Grimm et al. (2000) reported in a longitudinal descriptive study of 43 caregivers of allogeneic or autologous BMT recipients that information needs pre-BMT included symptom management, financial matters, and ways to maintain a normal family life.

### Psychological Distress

The stresses of providing primary care to a woman with breast cancer are as complex as the distress that the patient feels. An exploratory study regarding the mental health (depression) symptoms and functional status of 49 patients with breast cancer and the mental health (depression) and reaction to care of their 49 caregivers revealed that psychological distress may be more marked in family members than in patients (Given & Given, 1992). Empiric evidence from 19 studies showed that families experience emotions paralleling the emotions experienced by women with breast cancer, including anxiety, depression, and mood swings (Northouse, 1995).

Autologous BMT raises issues of loss and arouses fears and death anxiety (Wochna, 1997), and sharing patients' existential concerns may be anxiety provoking for primary caregivers. In a descriptive study of 24 family caregivers of patients undergoing BMT, Foxall and Gaston-Johansson (1996) found that caregivers reported more anxiety and depression pre-BMT than on BMT days +5 and +20. Also, objective burden was found to relate significantly to depression and symptom distress on BMT day +5 and to anxiety and symptom distress on BMT day +20. Grimm et al. (2000) reported higher levels of anger, anxiety, confusion, depression, fatigue, and total mood disturbance in 43 caregivers pre-BMT than on day +21 and at discharge in both an inpatient and outpatient model ( $n = 17$ ) and an inpatient unit model ( $n = 26$ ). The outpatient model of care included an educational program for primary caregivers consisting of information about the BMT process, patient care skills, and signs and symptoms of potential physical and emotional difficulties. Outpatient primary caregivers appeared to have tolerated the experience better than their inpatient primary caregiver comparison group.

### Fatigue

Numerous caregiver responsibilities and responses to the patient's condition, such as hypervigilance and worry, may cause fatigue. Caregiver fatigue is significant when the care demands produce situations requiring constant, vigilant care (Anderson & Elfert, 1989; Jessop & Stein, 1985). In a descriptive study of 24 family caregivers of BMT recipients, Foxall and Gaston-Johansson (1996) found that among the most frequently reported areas of objective burden was "not [having] enough energy."

Contributing to caregiver fatigue may be the current shift from patients receiving autologous BMT in the inpatient setting to components of BMT treatment and care being delivered in the ambulatory setting. Patients are discharged from the hospital when they still may perceive themselves as being acutely ill (Laizner et al., 1993). This shift in treatment location further enmeshes the primary caregiver within the pre- and post-BMT process and may lead to increased fatigue.

### Burden of Care

Burden is the caregiver's response to the stressors engendered by caring for the patient with cancer that may result in negative

role perception (Bull, 1990). Burden may be conceptualized as a multidimensional concept with objective and subjective components (Bull; Montgomery, Gonyea, & Hooyman, 1985). Objective burden is defined as concrete events, happenings, and activities related to caregiving, such as financial problems and personal activity limitations (Hoenig & Hamilton, 1966). Subjective burden is defined as affective response to the caregiver experience, such as feelings and emotions related to fear, strain, or guilt (Montgomery et al.). The emotional strain of caregiving has been found to be more burdensome than activities related to providing care or disruptions in everyday family life (Bowers, 1987; Hoenig & Hamilton). Caregiver burden has been found to be highly predictive of depression in some caregivers (Baillie, Norbeck, & Barnes, 1988; Bull; Reinhard, 1994) but not in others (Robinson, 1983).

Nijboer et al. (1998), who reviewed the impact of caregiving on caregivers, reported that cancer progression led to care tasks that caregivers perceived as either negative (i.e., burden) or positive. Also noted was that the caregiver's health was affected by these negative or positive effects. Numerous sources of BMT patient caregiver burden exist, including uncertainty of treatment outcomes, negative sequelae of treatment or disease, invasive medical procedures, isolation, disruptions in the work or home environment, and existential concerns regarding mortality (Patenaude, 1990; Zabora, Smith, Baker, Wingard, & Curbow, 1992). Foxall and Gaston-Johansson (1996) reported in their study of 24 family caregivers of patients undergoing BMT that, with respect to subjective burden, caregivers stated that seeing their relatives suffer was painful and that they felt unappreciated pre-BMT.

## Quality of Life

QOL has been conceptualized to include four domains: health and functioning, socioeconomic, psychological/spiritual, and family (Ferrans & Powers, 1985). Loveys and Klaich (1991) reported 14 domains of illness demands that patients with breast cancer experience, all of which may affect the QOL of primary caregivers, including treatment issues, such as direct interaction with members of the healthcare community; changes in life context and perspective; acceptance of illness; social interaction and support; physical changes; reconstructing the self; uncertainty; loss; making comparisons; acquiring new knowledge; making choices; mortality issues; financial and occupational concerns; and making a contribution. Financial concerns have been echoed frequently in the literature (Blank, Clark, Longman, & Atwood, 1989; Jansen, Halliburton, Dibble, & Dodd, 1993). Increased family responsibilities, in addition to already challenging career expectations, may lead to changes in usual stress-reducing social interactions. Symptoms such as fatigue experienced by primary caregivers may compound the already challenging increased workload and lead to decreased QOL.

## Theoretical Framework

The Conceptual Model of Symptom Management, which was developed by the Center for Symptom Management in the School of Nursing at the University of California, San Francisco (Larson et al., 1994), provided the conceptual framework for this study. This model promotes a broad perspective regarding and a comprehensive approach to symptom management through inclusion of both symptom etiology and

the presenting symptoms themselves. The model has three interrelated dimensions: symptom experience, symptom management strategies, and symptom outcomes. This model guided the examination of interrelationships between primary caregivers' sociodemographic characteristics, fatigue, psychological distress, QOL, and burden of care.

## Methods

### Design

This study used a descriptive, correlational, predictive design.

### Sample and Setting

A convenience sample of 102 primary caregivers of women with stage II, III, or IV breast cancer who had undergone mastectomy, completed chemotherapy, and were scheduled for autologous BMT was recruited for the study. The sample of primary caregivers was determined by the number of women with breast cancer recruited to the study based on a power analysis. Caregivers were not approached to participate in the study if the patients with breast cancer declined to participate. All caregivers who were approached agreed to participate in the study. The time between chemotherapy completion and BMT varied, and no data regarding the length of this time were collected. The setting was an urban National Cancer Institute-designated comprehensive cancer center located in the eastern United States. The institutional review board approved the study prior to participant accrual. All participants were recruited directly either by the physician coinvestigator or the BMT clinical nurse specialist associate investigator, who also obtained written informed consent from each participant.

### Instruments

**Sociodemographic form:** This form was used to collect demographic and clinical data, including age, gender, race/ethnicity, marital status, educational level, religion, average yearly household income, occupation, and work status.

**Fatigue:** Fatigue was measured using the **Piper Fatigue Scale (PFS)** (Piper, 1997). The PFS was designed to measure fatigue as a multidimensional phenomenon. Subjective dimensions of this scale include perceptions regarding the temporal, sensory, affective, and severity components of fatigue. Piper stated that in this model of fatigue, "... subjective perception was believed to be key to understanding how fatigue might vary between healthy and ill individuals" (p. 485). The objective dimension includes signs of fatigue that can be validated by physiologic, biologic, and behavioral means. The scale consists of 41 horizontal visual analog scale (VAS) items measuring four dimensions of subjective fatigue: (a) temporal dimension (5 items relating to timing, frequency, pattern, and duration of fatigue), (b) intensity/severity dimension (12 items relating to severity, distress, and degrees of disruption in activities of daily living), (c) affective dimension (5 items relating to the emotional meaning of fatigue), and (d) sensory dimension (19 items relating to the physical, emotional, and mental symptoms of fatigue). Subjects respond to items in terms of how they feel at the time of assessment. Anchors on the VAS are item dependent. Individual subscale scores are calculated by measuring each VAS item with a 100 mm ruler from the left end to the subject's mark, summing all items

within the subscale, then dividing the sum by the number of items on the subscale to obtain a mean value. A total fatigue score is calculated by summing the four scores and dividing by four. The higher the fatigue score, the greater the intensity of fatigue. In a preliminary study by the principal investigator, Cronbach's alpha for the four subscales ranged from 0.83–0.98.

**Depression:** The **Beck Depression Inventory (BDI)** was used to measure depression in subjects (Beck & Steer, 1993). The BDI consists of 21 items that describe particular symptoms of depression. Subjects respond to a Likert-type scale by rating each item from 0 (no symptom) to 3 (severe or persistent presence of the symptom). Scores may range from 0–9 (normal), 10–15 (mild depression), 16–23 (moderate depression), and 24–63 (severe depression). The total possible score (range = 0–63) is obtained by summing the 21 responses. Internal consistency reliability studies have reported a correlation coefficient for the test items of 0.86, with a Spearman-Brown coefficient of 0.93 (Beck, 1970). Test-retest reliability in nonpsychiatric patients ranged from 0.60–0.90 (Beck & Steer, 1987). In a preliminary study, Gaston-Johansson et al. (1992) obtained a Cronbach's alpha of 0.84 in BMT recipients. Concurrent validity of the BDI has been established to range between 0.61–0.66 (Beck; Beck & Steer, 1984). Construct validity was demonstrated through correlation with the Minnesota Multiphasic Personality Inventory–Depression subscale (0.75) (Beck).

**Anxiety:** The **State-Trait Anxiety Inventory (STAI)** (Spielberger, Gorsuch, & Lushene, 1971) was used to measure anxiety. The STAI consists of two separate self-report scales. State anxiety is a transitory emotional response to a stressful situation. Trait anxiety reflects a stable predisposition to anxiety as determined by a personality pattern. Respondents rate themselves in relationship to a statement on a Likert scale ranging from 1–4. The total score is the sum of all 20 responses and ranges from a minimum score of 20–39 (low anxiety), 40–59 (moderate anxiety), to a maximum score of 60–80 (high anxiety). Scores are reported to be considerably higher under stress conditions than under normal conditions. Test-retest reliability coefficients of 0.73–0.86 and 0.86–0.92 for the trait subscale and coefficients of 0.16–0.54 and 0.83–0.92 for the state subscale have been reported (Spielberger et al.). Alpha coefficients estimating internal consistency reliability ranged from 0.83–0.92 for state anxiety, and from 0.86–0.92 for trait anxiety. Construct validity was demonstrated by comparing like subjects under stressful and nonstressful situations (Spielberger et al.).

**Burden of care:** Burden of care was assessed using the **Measurement of Objective Burden (MOB)** and the **Measurement of Subjective Burden (MSB)** scales developed by Montgomery et al. (1985). MOB is a nine-item, five-point scale ranging from 1–5 (1 = a lot more or better to 5 = a lot less or worse) designed to assess the extent to which caregiving behaviors have changed the caregivers' lives in nine areas: time for oneself, privacy, money, personal freedom, energy, recreational/social activities, vocational activities, relationships with other family members, and health. MSB is a 13-item, five-point scale ranging from 1–5 (1 = rarely or never to 5 = most of the time) designed to assess attitudes toward or emotional reactions to the caregiving experience. The lower the score, the lower the burden of care. Items for MSB were adapted from Zarit, Reever, and Bach-Peterson's (1980) 29-

item inventory relating to attitudes and feelings about caregiving. The reported alpha was 0.85 for the MOB scale and 0.86 for the MSB scale (Montgomery et al.). Cronbach's alphas for objective burden have been shown to range from 0.52–0.80, and for subjective burden from 0.86–0.97 in primary caregivers (Foxall & Gaston-Johansson, 1996).

**Quality of life:** QOL was measured by the **Quality of Life Index (QLI)**, which consists of 35 items that are categorized into the following subscales: health and functioning, socioeconomic, psychological/spiritual, and family (Ferrans & Powers, 1985). The tool uses six-point ordinal scales to measure both the satisfaction with and the importance placed on each item by the individual. Responses range from 1 (very dissatisfied/unimportant) to 6 (very satisfied/important). Possible final scores range from 0–30, with higher scores indicating greater QOL. The contrasted groups approach demonstrated construct validity. Support for convergent validity was provided by a strong correlation ( $r = 0.77$ ) between scores from the QLI and an assessment of life satisfaction (Ferrans & Powers, 1992). Internal consistency reliability was supported for the entire QLI ( $\alpha = 0.93$ ) and for the four subscales of health and functioning, socioeconomic, psychological/spiritual, and family ( $\alpha = 0.87, 0.82, 0.90, \text{ and } 0.77$ , respectively) (Ferrans & Powers, 1992).

## Data Collection

The subjects completed the questionnaires in a quiet, outpatient clinic room. The BMT clinical nurse specialist associate investigator provided the questionnaires, answered participants' questions, and retrieved the questionnaires after completion. Because subjects might experience increased caregiver burden as a result of answering many questionnaires, primary caregivers were informed that they could take a break at any time during the questionnaire completion, which took approximately one hour.

## Data Analysis

Measures of central tendency were used to describe the sample and responses to the instruments. Correlations among the multiple dimensions of fatigue and QOL, and depression, burden, and anxiety were analyzed using Pearson's product moment correlations and Spearman's Rho correlations as appropriate. T tests were performed to compare differences in fatigue, QOL, depression, burden of care, and anxiety between males and females and marital status. Hierarchical multiple linear regression techniques were used to determine the predictors of burden.

# Results

## Demographic Characteristics of the Sample

The 102 participants had a mean age of 47.59 years ( $SD = 10.76$ , range = 25–72). Of the primary caregivers, 75% were male, 90% were married to the patient, and 79% had some college education or were college graduates. Nineteen percent of the caregivers did not live with the patient. Most caregivers worked full-time in professional jobs with incomes greater than \$50,000 (see Table 1).

## Symptoms Experienced

**Fatigue:** Mean scores for the total fatigue and fatigue subscales were low, indicating a lower level of fatigue. Of the

**Table 1. Sociodemographic Characteristics of the Sample**

Characteristic	n	%
<b>Gender</b>		
Female	25	25
Male	77	75
<b>Race</b>		
White	89	87
African American	9	9
Hispanic	1	1
Asian	2	2
Other	1	1
<b>Marital status</b>		
Married	92	90
Single	9	9
Widowed	1	1
<b>Education completed</b>		
Grade school	2	2
High school	19	19
Some college	26	25
College graduate	36	35
Graduate degree	19	19
<b>Religion</b>		
Catholic	23	23
Protestant	47	45
Jewish	5	5
Other	16	16
None	9	9
Missing	2	2
<b>Patient lives with</b>		
Spouse	89	87
Significant other	3	3
Child	–	–
Parent	–	–
Self	9	9
Missing	1	1
<b>Average yearly income</b>		
< \$20,000	4	4
\$20,000–\$29,000	8	8
\$30,000–\$39,000	5	5
\$40,000–\$49,000	15	15
> \$50,000	65	63
Missing	5	5
<b>Occupation</b>		
Professional	62	60
Technical	13	13
Retired	12	12
Other	15	15
Missing	–	–
<b>Work status</b>		
Full-time	78	76
Part-time	7	7
Unemployed—resigned	5	5
Unemployed—disabled	2	2
Unemployed—retired	8	8
Missing	2	2

N = 102

fatigue subscales, temporal was the lowest ( $\bar{X} = 6.20$ , range 0–71.92) (see Table 2). The highest fatigue subscale score was sensory, with a mean of 36.04. The greatest maximum fatigue subscale scores were affective (90.60) and intensity/severity (90.50). These findings indicated a high level of fatigue.

**Psychological distress:** The caregivers experienced moderate state anxiety ( $\bar{X} = 40.28$ ) that ranged from a low of 22 to

a high of 64. The mean score for trait anxiety was low ( $\bar{X} = 37.40$ ), with a range of 24–58 (moderate). The mean depression score was normal (7.50), but the maximum score was 26, which was severe depression for some of the subjects.

**Burden of care and quality of life:** The objective burden mean score was slightly higher (32.50) than the mean subjective burden score (31.20). However, the maximum score was lower for the objective burden (42) compared to the subjective score (47).

The mean QOL scores on each of the subscales were low. The highest QOL mean score was on the health and functioning subscale, followed by family, spiritual/psychological, and, lastly, socioeconomic. The range for QOL scores was 0–30, except for health, which ranged from 1.50–23.90.

### Sociodemographic Influences on Study Variables

**Marital status:** Significantly more male caregivers were married than female caregivers. Subjects who were married had significantly more income and reported less sensory fatigue and state anxiety than caregivers who were not married. All of the other symptoms and subjective burden were less severe in married caregivers, although nonsignificant (see Table 3). No significant differences existed between married and nonmarried caregivers regarding socioeconomic, spiritual/psychological, and family QOL subscales.

**Difference between female and male caregivers:** The females were less educated and had lower incomes than the males. The females reported significantly more state and trait anxiety than the males. Although not statistically significant, the females experienced more depression than the males (see Table 4).

### Correlations Among Variables

Correlations among fatigue, QOL, psychological distress (anxiety, depression), and burden of care are presented in Table 5. Significant correlations were found among study variables and demographic characteristics of the sample. Age was

**Table 2. Means, Standard Deviations, and Ranges of Study Variables**

Variable	$\bar{X}$	SD	Minimum	Maximum
<b>Fatigue</b>				
Temporal	16.20	16.83	0.00	71.92
Intensity/severity	31.43	21.13	0.00	90.50
Affective	32.00	24.73	0.00	90.60
Sensory	36.04	20.72	0.00	76.58
Total fatigue	28.52	18.46	0.00	75.38
<b>Psychological distress</b>				
Depression	7.50	5.50	0.00	26.00
State anxiety	40.28	10.92	22.00	64.00
Trait anxiety	37.40	7.91	24.00	58.00
<b>Burden of care</b>				
Objective burden	32.50	3.90	23.00	42.00
Subjective burden	31.20	5.40	19.50	47.00
<b>Quality of life</b>				
Health and functioning	8.40	4.30	1.50	23.90
Socioeconomic	7.20	4.20	0.00	18.70
Spiritual/psychological	7.80	4.50	0.00	30.00
Family	8.10	5.50	0.00	24.00

**Table 3. Comparison of Selected Variables by Marital Status**

Variable	Married			Other			t	df	p
	Valid N	$\bar{X}$	SD	Valid N	$\bar{X}$	SD			
<b>Age</b>	92	48.21	10.19	10	41.90	14.43	1.780	100	0.078
<b>Fatigue</b>									
Intensity	92	15.85	16.75	10	19.41	18.15	-0.634	100	0.528
Temporal	92	30.40	20.93	10	40.86	21.68	-1.495	100	0.138
Affective	87	30.82	25.52	10	42.24	13.11	-1.389	95	0.168
Sensory	91	34.47	20.75	10	50.34	14.48	-2.351	99	0.021
Total	92	27.46	18.60	10	38.21	14.57	-1.766	100	0.080
<b>Depression</b>	92	7.23	5.50	10	10.22	4.86	-1.644	100	0.103
<b>Anxiety</b>									
State	91	39.35	10.65	10	48.77	10.04	-2.668	99	0.009
Trait	91	36.94	7.84	10	41.60	7.71	-1.787	99	0.077
<b>Quality of life</b>									
Health	91	8.74	6.22	10	8.77	7.16	-0.012	99	0.991
Socioeconomics	91	8.86	6.20	10	8.76	6.92	-0.047	99	0.962
Spiritual/psychological	91	8.77	6.27	10	8.71	7.28	-0.026	99	0.980
Family	91	8.18	6.90	9	7.01	7.21	-0.481	98	0.631
<b>Burden of care</b>									
Objective	92	32.69	3.96	10	30.63	3.23	1.591	100	0.115
Subjective	91	30.95	5.24	10	34.13	6.66	-1.768	99	0.080

significantly negatively correlated with subjective burden ( $r = -0.265$ ,  $p < 0.01$ ), income with the fatigue subscale temporal ( $r = -0.224$ ,  $p < 0.05$ ), state anxiety ( $r = -0.201$ ,  $p < 0.05$ ), and trait anxiety ( $r = -0.252$ ,  $p < 0.01$ ). All variables presented in Table 5 were significantly correlated to each other except for subjective burden and sensory fatigue. The highest correlation for subjective burden was with total QOL ( $r = -0.418$ ,  $p < 0.01$ ), and the highest correlation for objective burden was with the QOL health subscale ( $r = 0.484$ ,  $p < 0.001$ ), demonstrating high burden of care and low QOL.

### Predictors of Objective and Subjective Burden of Care

Multiple regression analysis was used for the statistical analysis with demographic variables (age, gender, and ethnicity) and all study variables included in the model. The results showed that family, a subscale of QOL, was a predictor of objective burden ( $\beta = 39$ ,  $[t = 3.07]$ ) and marriage ( $\beta = -0.30$ ,  $[t = -2.40]$ ),  $p < 0.01$ , adjusted  $R^2 = 27\%$ . No other significant predictors of objective burden existed among the variables of interest. Age ( $\beta = -0.242$ ,  $[t = -2.20]$ ,  $p < 0.05$ ) and trait anxiety ( $\beta = -0.345$ ,  $[t = 2.02]$ ,  $p < 0.05$ ), adjusted  $R^2 = 16\%$  were significant predictors of subjective burden.

## Discussion

Primary caregivers of patients with breast cancer who were treated with mastectomy and chemotherapy and scheduled for autologous BMT experienced low-grade fatigue, moderate anxiety, and high burden of care. The significant intercorrelations of all variables seen, except subjective burden and sensory fatigue, demonstrates the complexity of the primary caregiver symptom experience. Relationships among the perception, evaluation, and response components

of the symptom experience dimension of the Conceptual Model of Symptom Management were demonstrated, as well as between the symptom experience dimension and the symptom outcomes dimension components of burden of care and QOL (Larson et al., 1994). This model showed utility for capturing the complexity of the symptom experience for primary caregivers of patients scheduled for autologous BMT.

Although some primary caregivers experienced severe depression, in general, depression did not appear to be problematic during the time before patients are hospitalized for BMT. All QOL subscales (health, socioeconomic, spiritual/psychological, and family) were below 10, which may be viewed as troublesome because the highest possible score of these QOL subscales is 30. In addition, both objective and subjective burden of care are of concern. This is especially true for single female caregivers. All reported symptoms were more severe in females compared to males. Nine percent of the study sample was either single or widowed and lived alone, which may indicate that these primary caregivers are trying to accommodate the patients' needs as well as their own separate household needs.

Incorporating these findings into pre-BMT screening would promote early identification of primary caregivers of patients with breast cancer most at risk for burden of care and related symptomatology and allow for early counseling, treatment, or referral. For example, age and trait anxiety were found to be significant predictors of subjective burden, and the family subscale of QOL was a significant predictor of objective burden. Although mean fatigue scores were low in this sample, caregivers should be screened for fatigue in the pre-BMT period, with particular attention given to those caregivers who describe themselves as very burdened and exhausted, in agreement with Foxall and Gaston-Johansson (1996).

**Table 4. Comparison of Selected Variables Between Female and Male Caregivers**

Variable	Female (n = 25)		Male (n = 77)		t	df	p
	$\bar{X}$	SD	$\bar{X}$	SD			
<b>Age</b>	49.56	14.04	46.95	9.48	1.056	100	0.294
<b>Fatigue</b>							
Intensity	19.94	17.66	14.98	16.49	1.28	100	0.202
Temporal	36.14	19.17	29.90	21.62	1.29	100	0.201
Affective	32.40	19.57	31.86	26.41	0.09	95	0.925
Sensory	39.03	20.78	35.06	20.74	0.83	99	0.408
Total	31.88	16.61	27.43	19.00	1.05	100	0.298
<b>Depression</b>	9.32	5.43	6.94	5.42	1.90	100	0.060
<b>Anxiety</b>							
State	44.28	11.31	38.96	10.53	2.15	99	0.034
Trait	41.25	6.92	36.13	7.85	2.91	99	0.005
<b>Quality of life</b>							
Health	9.51	7.08	8.49	6.03	0.70	99	0.486
Socioeconomics	9.55	6.87	8.62	6.05	0.64	99	0.521
Spiritual/psychological	9.38	7.17	8.56	6.08	0.55	99	0.580
Family	8.77	7.62	7.86	6.69	0.56	98	0.576
<b>Burden of care</b>							
Objective	32.33	4.42	32.54	3.78	-0.23	100	0.819
Subjective	30.68	5.65	31.46	5.39	-0.62	99	0.534

The findings from this study complement previously identified needs of primary caregivers of patients with cancer who receive care in ambulatory and inpatient settings. An additional concern for primary caregivers of patients with breast cancer undergoing BMT is the rapid shift of treatment from the inpatient to the ambulatory care setting and home-care environment during the past decade. These negative sequelae of primary caregiver role expansion may be viewed within the context of the current study's findings showing that primary caregivers already suffer from high burden and low QOL pre-BMT.

## Limitations

This study was conducted at a single clinical site, using a primary caregiver sample that was composed mostly of Caucasian, Christian males who were well-educated professionals. Therefore, caution must be used when generalizing from this sample to other patient caregiver populations. The data were measured at one point in time, giving only a snapshot of this primary caregiver experience. Time since diagnosis may have had an impact on the variables that was not captured. In addition, preexisting depression, anxiety, QOL, and burden may have had an influence on the findings.

## Implications for Nursing Practice

Providing care for caregivers is challenging and requires planning, implementation, and evaluation in fast-paced inpatient and ambulatory treatment settings with often competing nursing priorities. Therefore, nurse-patient-caregiver interactions must be appropriate, adequate, effective, and efficient. Nursing interventions need to be tailored to the needs of primary caregivers and delivered proactively. Results of previous research should be used to provide anticipatory

guidance to caregivers functioning within the family cancer experience. For example, the expected morbidity of patients with breast cancer often corresponds to their BMT day, with patients experiencing the greatest pain and psychological distress on BMT day +5 (Gaston-Johansson et al., 1992). Waiting for primary caregivers to request information before any interventions are offered may lead to them exceeding their coping strategies and experiencing synergistic distresses. Therefore, the proactive use of research-based interventions to decrease negative sequelae of the primary caregiver's perception of the autologous BMT experience is critical. Effective interventions to reduce anxiety also include cognitive techniques (Anderson, 1992) and relaxation and imagery (Gagne & Toye, 1994). Healthcare providers need to include in their plan of care specific strategies to assist primary caregivers in coping with psychological distress, burden of care, and QOL issues. The results of this study may be useful in identifying primary caregivers who are more in need of immediate help.

A key healthcare provider behavior that reduces psychological distress, as viewed by the family with cancer, is the provision of accurate information in a timely fashion (Hilton, 1993; Kristjanson & Ashcroft, 1994; Tringali, 1986). Information seeking is considered to be a general coping strategy (Weisman, 1979) to decrease anxiety and increase a sense of control (Tringali). Difficulty inherent in family members acquiring information regarding treatment or patient status has been documented frequently in the literature (Stetz, McDonald, & Compton, 1996; Wright & Dyck, 1984). Healthcare professionals may enhance caring relationships with caregivers by acknowledging caregivers as individuals and providing clear expectations of the family caregiver role (Compton et al., 1996).

**Table 5. Correlations Among Study Variables**

Variable	Fatigue			Quality of Life				Depression		Burden of Care		Anxiety		
	Total	Temporal	Affective	Sensory	Intensity	Total	Family	Health	Spiritual	Socioecon.	Subjective	Objective	State	Trait
<b>Fatigue</b>														
Total	0.844**													
Temporal	0.892**	0.603**												
Affective	0.893**	0.648**	0.753**											
Sensory	0.876**	0.697**	0.702**	0.723**										
Intensity					-0.478*									
<b>Quality of life</b>														
Total	-0.547**	-0.413**	-0.477**	-0.547**	-0.478*	0.744**								
Family	0.341**	0.215*	0.382**	0.331**	0.269**	0.868**	0.446**							
Health	0.553**	0.483**	0.435**	0.517**	0.512**	0.870**	0.459**	0.753**						
Spiritual	0.493**	0.415**	0.379**	0.421**	0.421**	0.840**	0.427**	0.742**	0.701**					
Socioeconomic	0.429**	0.342**	0.335**	0.447**	0.385**	0.840**	0.427**	0.742**	0.619**	0.508**				
<b>Depression</b>	0.673**	0.576**	0.492**	0.639**	0.660**	-0.582**	0.278*	0.610**	0.619**	0.508**				
<b>Burden of care</b>														
Subjective	0.242*	0.198*	0.241*	0.174	0.236*	-0.418**	0.348**	0.336*	0.316**	0.368**	0.314*			
Objective	0.296**	0.211*	0.233*	0.268**	0.308**	-0.469**	0.385**	0.484**	0.361**	0.322**	0.403**	0.270*		
<b>Anxiety</b>														
State	0.541**	0.324**	0.492**	0.603**	0.491**	-0.558**	0.384**	0.509**	0.509**	0.492**	0.659**	0.301*	0.344**	
Trait	0.500**	0.405**	0.383**	0.456**	0.546**	-0.649**	0.374**	0.520**	0.546**	0.489**	0.679**	0.357**	0.309**	0.669**

\* p = 0.05; \*\* p = 0.01; \*\*\* p = 0.001

## Implications for Future Research

This study adds to the growing body of clinical research literature examining the stressors inherent in the role of primary caregiver to patients with cancer. Future research is needed to examine the outcomes of interventions targeted at specific primary caregiver symptomatology and burden of care. Also, previous research conducted with patients with breast cancer undergoing autologous BMT, as well as other populations of patients with cancer, primarily has used small, select, and single-site samples similar to this study. These high-income, primarily Caucasian samples, while representative of the U.S. population of patients with cancer undergoing autologous BMT, do not yield information regarding outcomes of patients from diverse cultures, ethnicities, and socioeconomic statuses. Inherent in this research that is targeted at primary caregivers of patients with breast cancer are investigations of economic, cultural, and related barriers for these patients to receive BMT when clinically appropriate.

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## References

Anderson, B.L. (1992). Psychological interventions for cancer patients to enhance the quality of life. *Journal of Consulting Clinical Psychology, 60*, 552–568.

Anderson, J.M., & Elfert, H. (1989). Managing chronic illness in the family: Women as caretakers. *Journal of Advanced Nursing, 14*, 735–743.

Baillie, V., Norbeck, J.S., & Barnes, L.E. (1988). Stress, social support, and psychological distress of family caregivers of the elderly. *Nursing Research, 37*, 217–222.

Beck, A.T. (1970). *Depression: Causes and treatment*. Philadelphia: University of Philadelphia Press.

Beck, A.T., & Steer, R.A. (1984). Internal consistencies of the original and revised Beck Depression Inventory. *Journal of Clinical Psychology, 46*, 1365–1367.

Beck, A.T., & Steer, R.A. (1987). *Beck Depression Inventory manual*. San Antonio, TX: The Psychological Corporation, Harcourt Brace Jovanovich.

Beck, A.T., & Steer, R.A. (1993). *Beck Depression Inventory manual*. San Antonio, TX: The Psychological Corporation, Harcourt Brace & Company.

Blank, J.J., Clark, L., Longman, A.J., & Atwood, J.R. (1989). Perceived home care needs of cancer patients and their caregivers. *Cancer Nursing, 12*, 78–84.

Bowers, B.J. (1987). Intergenerational caregiving: Adult caregivers and their aging parents. *Advances in Nursing Science, 9*, 20–31.

Bull, M.J. (1990). Factors influencing family caregiver burden and health. *Western Journal of Nursing Research, 12*, 758–770.

Christ, G.H. (1983). A psychosocial assessment framework for cancer patients and their families. *Health and Social Work, 8*, 57–64.

Compton, K., McDonald, J.C., & Stetz, K.M. (1996). Understanding the caring relationship during marrow transplantation: Family caregivers and healthcare professionals. *Oncology Nursing Forum, 23*, 1428–1439.

Ferrans, C.E., & Powers, M.J. (1985). Quality of Life Index: Development and psychometric properties. *Advances in Nursing Science, 8*, 15–24.

Ferrans, C.E., & Powers, M.J. (1992). Psychometric assessment of the Quality of Life Index. *Research in Nursing and Health, 15*, 29–38.

Foxall, M.J., & Gaston-Johansson, F. (1996). Burden and health outcomes of family caregivers of hospitalized bone marrow transplant patients. *Journal of Advanced Nursing, 24*, 915–923.

Gagne, D., & Toye, R.C. (1994). The effects of therapeutic touch and relaxation therapy in reducing anxiety. *Archives of Psychiatric Nursing, 8*, 184–189.



- Gaston-Johansson, F., Fall-Dickson, J.M., Bakos, A.B., & Kennedy, M.J. (1999). Fatigue, pain, and depression in pre-autotransplant breast cancer patients. *Cancer Practice*, 7, 240–247.
- Gaston-Johansson, F., Fall-Dickson, J.M., Nanda, J., Ohly, K.V., Stillman, S., Krumm, S., et al. (2000). The effectiveness of the Comprehensive Coping Strategy Program on clinical outcomes in breast cancer autologous bone marrow transplantation. *Cancer Nursing*, 23, 277–285.
- Gaston-Johansson, F., Franco, T., & Zimmerman, L. (1992). Pain and psychological distress in patients undergoing autologous bone marrow transplantation. *Oncology Nursing Forum*, 19, 41–48.
- Given, B., & Given, C.W. (1992). Patient and family caregiver reaction to new and recurrent breast cancer. *Journal of the American Medical Women's Association*, 47, 201–206.
- Grimm, P.M., Zawacki, K.L., Mock, V., Krumm, S., & Frink, B.B. (2000). Caregiver responses and needs. An ambulatory bone marrow transplant model. *Cancer Practice*, 8, 120–128.
- Hilton, B.A. (1993). Issues, problems, and challenges for families coping with breast cancer. *Seminars in Oncology Nursing*, 9, 88–100.
- Hoinig, J., & Hamilton, M. (1966). *The desecration of the mentally ill*. London: Routledge and Kegan Paul.
- Jansen, C., Halliburton, P., Dibble, S., & Dodd, M.J. (1993). Family problems during cancer chemotherapy. *Oncology Nursing Forum*, 20, 689–696.
- Jassak, P.F. (1992). Families: An essential element in the care of the patient with cancer. *Oncology Nursing Forum*, 19, 871–876.
- Jessop, D.J., & Stein, R.E. (1985). Uncertainty and its relation to the psychological and social correlates of chronic illness in children. *Social Science and Medicine*, 20, 993–999.
- Kristjanson, L.J., & Ashcroft, T. (1994). The family's cancer journey: A literature review. *Cancer Nursing*, 17, 1–17.
- Laizner, A.M., Yost, L.M., Barg, F.K., & McCorkle, R. (1993). Needs of family caregivers of persons with cancer: A review. *Seminars in Oncology Nursing*, 9, 114–120.
- Larson, P.J., Carrieri-Kohlman, V., Dodd, M.J., Douglas, M., Faucett, J., Froelicher, E.S., et al. (1994). A model for symptom management. *Image: Journal of Nursing Scholarship*, 26, 272–276.
- Lesko, L.M. (1994). Bone marrow transplantation: Support of the patient and his/her family. *Supportive Care in Cancer*, 2, 35–49.
- Lewis, F.M. (1993). Psychosocial transitions and the family's work in adjusting to cancer. *Seminars in Oncology Nursing*, 9, 127–129.
- Loveys, B.J., & Klaich, K. (1991). Breast cancer: Demands of illness. *Oncology Nursing Forum*, 18, 75–80.
- McDonald, J.C., Stetz, K.M., & Compton, K. (1996). Educational interventions for family caregivers during marrow transplantation. *Oncology Nursing Forum*, 23, 1432–1439.
- Montgomery, R.J., Gonyea, J.G., & Hooyman, N.R. (1985). Caregiving and the experience of subjective and objective burden. *Family Relations*, 34, 19–26.
- Nijboer, C., Tempelaar, R., Sanderman, R., Triemstra, M., Struijt, R.J., & van den Bos, G.A. (1998). Cancer and caregiving: The impact on the caregiver's health. *Psycho-Oncology*, 7, 3–13.
- Northouse, L.L. (1995). The impact of cancer in women on the family. *Cancer Practice*, 3, 134–142.
- Patenaude, A.F. (1990). Psychological impact of bone marrow transplantation: Current perspectives. *Yale Journal of Biology and Medicine*, 63, 515–519.
- Piper, B.F. (1997). Measuring fatigue. In M. Frank-Stromborg & S.J. Olsen (Eds.), *Instruments for clinical health-care research* (2nd ed., pp. 482–496). Sudbury, MA: Jones and Bartlett.
- Reinhard, S.C. (1994). Living with mental illness. Effects of professional support and personal control on caregiver burden. *Research in Nursing and Health*, 17, 79–88.
- Robinson, B.C. (1983). Validation of a caregiver strain index. *Journal of Gerontology*, 38, 344–348.
- Rowland, J.H., & Massie, M.J. (1996). Patient rehabilitation and support. In J.R. Harris, M.E. Lippman, M. Morrow, & S. Hellman (Eds.), *Diseases of the breast* (pp. 919–938). Philadelphia: Lippincott-Raven.
- Siston, A.K., List, M.A., Daugherty, C.K., Banik, D.M., Menke, C., Cornetta, K., et al. (2001). Psychosocial adjustment of patients and caregivers prior to allogeneic bone marrow transplantation. *Bone Marrow Transplantation*, 27, 1181–1188.
- Spielberger, C.G., Gorsuch, F., & Lushene, R. (1971). *STAI Manual for the S-T-A-I ("Self-evaluation questionnaire")*. Palo Alto, CA: Consulting Psychologist Press.
- Stetz, K.M., McDonald, J.C., & Compton, K. (1996). Needs and experiences of family caregivers during marrow transplantation. *Oncology Nursing Forum*, 23, 1422–1427.
- Thorne, S. (1985). The family cancer experience. *Cancer Nursing*, 8, 285–291.
- Tringali, C.A. (1986). The needs of family members of cancer patients. *Oncology Nursing Forum*, 13, 65–70.
- Weisman, A.D. (1979). *Coping with cancer*. New York: McGraw-Hill.
- Wochna, V. (1997). Anxiety, needs, and coping in family members of the bone marrow transplant patient. *Cancer Nursing*, 20, 244–250.
- Woods, N.F., Lewis, F.M., & Ellison, E.S. (1989). Living with cancer: Family experiences. *Cancer Nursing*, 12, 28–33.
- Wright, K., & Dyck, S. (1984). Expressed concerns of adult cancer patients' family members. *Cancer Nursing*, 7, 371–374.
- Zabora, J.R. (1998). The psychological consequences of breast cancer. In K.I. Bland & E.M. Copeland (Eds.), *The breast: Comprehensive management of benign and malignant diseases, volume 2* (2nd ed., pp. 1539–1547). Philadelphia: Saunders.
- Zabora, J.R., Smith, E.D., Baker, F., Wingard, J.R., & Curbow, B. (1992). The family: The other side of bone marrow transplantation. *Journal of Psychosocial Oncology*, 10, 35–46.
- Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, 20, 649–655.

## For more information . . .

- ▶ CancerSymptoms.org: Fatigue  
[www.cancersymptoms.org/symptoms/fatigue](http://www.cancersymptoms.org/symptoms/fatigue)
- ▶ Quality of Life and Management of Living Resources  
[www.cordis.lu/life](http://www.cordis.lu/life)
- ▶ Y-Me National Breast Cancer Organization  
[www.y-me.org](http://www.y-me.org)

Links can be found at [www.ons.org](http://www.ons.org).