

# 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.