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Confronting the Unexpected: Temporal, Situational, and Attributive Dimensions of Distressing Symptom Experience for Breast Cancer Survivors

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According to the World Health Organization ([WHO], 2005), more than a million people will be diagnosed with breast cancer each year worldwide. Despite the worldwide epidemic, improvements in treatment have substantially increased survival rates, resulting in more than 2.4 million breast cancer survivors in the United States (National Cancer Institute [NCI], 2008) and millions more worldwide. As the number of people living after cancer exponentially rises, discussions about the global burden of disease increasingly focus on cancer (WHO) and how breast cancer and its treatment affect the quality of life of breast cancer survivors (Knobf, 2007; Paim, de Paula Lima, Fu, de Paula Lima, & Casali, 2008). NCI (2006) specifically identifies the need for research with cancer survivors to examine chronic and late effects of cancer and its treatment. The effects of cancer are influenced by women's responses to the traumatic event of cancer, including how they make meaning of cancer and how they perceive ongoing symptoms (Antoni et al., 2001). The ways women perceive and respond to their symptom experiences are vitally important in understanding the long-term effects of breast cancer on survivors (Armstrong, 2003; Budin, Cartwright-Alcares, & Hoskins, 2008).

Uncertainty, feelings of vulnerability, and high levels of emotional distress have been reported in breast cancer survivors in the years after active treatment (Aranda et al., 2005; Budin et al., 2008; Paim et al., 2008). A review of breast cancer survivorship (Knobf, 2007) found that survivors experienced increased psychological distress and worsened health outcomes when they felt unprepared about what to expect in survivorship. That finding was supported by this article's first author's original study, in which all participants described a sense of survivor loneliness and a subset of women described heightened distress (Rosedale, 2009). Although researchers have reported significant prevalence of ongoing symptom experience by

Purpose/Objectives: To describe women's unexpected and distressing symptom experiences after breast cancer treatment.

Research Approach: Qualitative and descriptive.

Setting: Depending upon their preference, participants were interviewed in their homes or in a private office space in a nearby library.

Participants: Purposive sample of 13 women 1–18 years after breast cancer treatment.

Methodologic Approach: Secondary analysis of phenomenologic data (constant comparative method).

Main Research Variables: Breast cancer symptom distress, ongoing symptoms, and unexpected experiences.

Findings: Women described experiences of unexpected and distressing symptoms in the years following breast cancer treatment. Symptoms included pain, loss of energy, impaired limb movement, cognitive disturbance, changed sexual experience, and lymphedema. Four central themes were derived: living with lingering symptoms, confronting unexpected situations, losing precancer being, and feeling like a has-been. Distress intensified when women expected symptoms to disappear but symptoms persisted instead. Increased distress also was associated with sudden and unexpected situations or when symptoms elicited feelings of loss about precancer being and feelings of being a has-been. Findings suggest that symptom distress has temporal, situational, and attributive dimensions.

Conclusions: Breast cancer survivors' perceptions of ongoing and unexpected symptoms have important influences on quality of life. Understanding temporal, situational, and attributive dimensions of symptom distress empowers nurses and healthcare professionals to help breast cancer survivors prepare for subsequent ongoing or unexpected experiences in the years after breast cancer treatment.

Interpretation: Follow-up care for breast cancer survivors should foster dialogue about ways that symptoms might emerge and that unexpected situations might occur. Prospective studies are needed to examine symptom distress in terms of temporal, situational, and attributive dimensions and explore the relationship between symptom distress and psychological distress after breast cancer treatment.