See page 183 for details about a podcast interview with the author of this article.

Survivor Loneliness of Women Following Breast Cancer

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In the years beyond diagnosis and acute treatment, the physical, emotional, and social effects of breast cancer may create ongoing challenges and crises that trigger the acute experience of loneliness. Women live with physical reminders (e.g., scars, sweats and hot flashes, fatigue, lymphedema, sexual difficulties), emotional sequelae (e.g., emotional upset and distress, alarm that any ache or pain signals recurrence, uncertainty about the future), and social challenges (e.g., pressure to get past the experience and "get back to normal," the burden of sustaining a heroic survivor narrative) (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Ganz, 2005; Gill et al., 2004; Hoybye, Johansen, & Tjornhoj-Thomsen, 2005; Landmark, Strandmark, & Wahl, 2001; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005; Sinding & Gray, 2005). The sheer volume and interplay of those factors may create ongoing challenges and crises that cause the experience of loneliness.

After the acute phase of breast cancer treatment, researchers have found that women continue to experience high levels of emotional distress (Aranda et al., 2005; Carlsson, Arman, Backman, & Hamrin, 2005; Cartwright-Alcarese, 2005; Knobf, 2007) as they seek a sense of personal meaning and growth from the experience (Hoybye et al., 2005; Landmark et al., 2001). Existential philosophy has characterized loneliness as emerging from the realization of one's mortality and the meaning this gives life, including the idea that inner growth often is preceded by suffering (Heidegger, 1927/1962; Kierkegaard, 1843/1985; Moustakas, 1972, 1989; Sartre, 1957; Tillich, 1963). The struggle to find meaning in a personal crisis, such as breast cancer, has been proposed to heighten people's consciousness of self, the world, and others and may be a precursor to loneliness (Mayers & Svarthberg, 2001; Portnoff, 1976). Loneliness may be among the psychosocial variables embedded in women's experiences following breast cancer (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Samarel, Tulman, & Fawcett, 2002). Despite the 2.4 million breast cancer survivors in the United States and millions more worldwide (American Cancer Society

Purpose/Objectives: To describe the experience of loneliness for women more than a year following breast cancer treatment.

Research Approach: Qualitative, phenomenologic.

Setting: Interviews conducted in women's setting of choice (e.g., home, library).

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

Methodologic Approach: Streubert's descriptive phenomenologic method based on Husserl's phenomenology.

Main Research Variables: Phenomenon of loneliness.

Findings: Women conveyed a unique description of loneliness that was termed *survivor loneliness*. They described how they felt alone in the awareness of mortality and were invalidated in the experience of ongoing symptom burden, a changed sense of identity and connection, and an altered threshold for distress that pervaded their long-term experiences. As they sought ways to lead more authentic lives, the women sometimes withheld truth or projected images they perceived as inauthentic, contributing to their loneliness. Paradoxically, as survivors perceived connections with others as more fragile, they also felt a strengthened vitality of connection, particularly with their children, and a deepened sense of empathy and connectedness to the suffering of others.

Conclusions: Findings shed light on the ongoing symptom experience of women and the isolation they experienced as they sought to work through an altered sense of self, connection, and identity as breast cancer survivors. Although survivor loneliness was experienced by all participants, findings suggest that some women may be more vulnerable to heightened psychological distress. Follow-up care should include giving recognition to survivors' experiences and normalizing the situation to allow for survivors' expressions of experience.

Interpretation: Through attentive and empathic assessment, clinicians need to be alert to the unmet needs of longer-term survivors, including the experience of survivor loneliness and the importance of identifying and assisting survivors who describe heightened distress. Prospective studies are needed to examine survivor loneliness and the factors that make some women more vulnerable to psychological distress. Grounded theory studies are needed to delineate the phases and challenges of breast cancer survivorship, including survivor loneliness.