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Reclaiming Life on One's Own Terms: A Grounded Theory Study of the Process of Breast Cancer Survivorship

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Breast cancer survivors comprise about 25% of all cancer survivors in the United States (American Cancer Society [ACS], 2012). An estimated 226,870 women are diagnosed with invasive breast cancer and an additional 63,300 women are diagnosed with in situ breast cancer in the United States annually (ACS, 2012). With the incidence rate continuing to rise but the overall five-year survival rate having improved for all stages, an increasing number of women with breast cancer are living longer than ever. For many, effective screening and treatment have transformed breast cancer into a chronic illness.

For women who have completed treatment, the literature suggests that symptoms of physical and psychological distress pervade the longer-term experience (Cartwright-Alcares, 2004; Fu & Rosedale, 2009; Knobf, 2002; Rosedale & Fu, 2010; Samarel, Tulman, & Fawcett, 2002; Schmidt & Andrykowski, 2004; Thomas-MacLean, 2005; Tulman & Fawcett, 2002), and long-term survivors of breast cancer have continued informational and emotional needs (Vivar & McQueen, 2005). For years following breast cancer diagnosis, many women continue to experience pain (Gil et al., 2004; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005), fatigue (Gil et al., 2004), symptoms associated with premature menopause (e.g., sweats, hot flashes, sexual difficulties, fertility issues) (Ganz et al., 2002; Thomas-MacLean, 2005), changes in body image (Thomas-MacLean, 2005), and lymphedema-related symptoms (Fu & Rosedale, 2009). On an emotional level, many breast cancer survivors still express uncertainty (Dirksen, 2000; Sammarco, 2001; Tomich & Helgeson, 2002), emotional distress (Aranda et al., 2005; Carlsson, Arman, Backman, & Hamrin, 2005;

Purpose/Objectives: To develop a substantive theory of the process of breast cancer survivorship.

Research Approach: Grounded theory.

Setting: A LISTSERV announcement posted on the SHARE Web site and purposeful recruitment of women known to be diagnosed and treated for breast cancer.

Participants: 15 women diagnosed with early-stage breast cancer.

Methodologic Approach: Constant comparative analysis.

Main Research Variables: Breast cancer survivorship.

Findings: The core variable identified was Reclaiming Life on One's Own Terms. The perceptions and experiences of the participants revealed overall that the diagnosis of breast cancer was a turning point in life and the stimulus for change. That was followed by the recognition of breast cancer as now being a part of life, leading to the necessity of learning to live with breast cancer, and finally, creating a new life after breast cancer. Participants revealed that breast cancer survivorship is a process marked and shaped by time, the perception of support, and coming to terms with the trauma of a cancer diagnosis and the aftermath of treatment. The process of survivorship continues by assuming an active role in self-healing, gaining a new perspective and reconciling paradoxes, creating a new mindset and moving to a new normal, developing a new way of being in the world on one's own terms, and experiencing growth through adversity beyond survivorship.

Conclusions: The process of survivorship for women with breast cancer is an evolutionary journey with short- and long-term challenges.

Interpretation: This study shows the development of an empirically testable theory of survivorship that describes and predicts women's experiences following breast cancer treatment from the initial phase of recovery and beyond. The theory also informs interventions that not only reduce negative outcomes, but promote ongoing healing, adjustment, and resilience over time.