

# Triggers of Uncertainty About Recurrence and Long-Term Treatment Side Effects in Older African American and Caucasian Breast Cancer Survivors

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**Purpose/Objectives:** To examine the sources of uncertainty in older African American and Caucasian long-term breast cancer survivors by focusing on frequency of triggers of uncertainty about cancer recurrence and physical symptoms linked to long-term treatment side effects.

**Design:** In the context of a larger randomized, controlled treatment-outcome study, data were gathered from 10 monthly follow-up telephone calls by nurses.

**Setting:** Rural and urban regions of North Carolina.

**Sample:** 244 older women ( $\bar{X}$  age = 64 years); 73 African American women and 171 Caucasian women who were five to nine years after breast cancer diagnosis.

**Findings:** The most frequent triggers were hearing about someone else's cancer and new aches and pains. The most frequent symptoms were fatigue, joint stiffness, and pain. Although no ethnic differences occurred in the experience of symptoms, Caucasian women were more likely than African American women to report that their fears of recurrence were triggered by hearing about someone else's cancer, environmental triggers, and information or controversy about breast cancer discussed in the media.

**Conclusions:** Illness uncertainty persisted long after cancer diagnosis and treatment, with most women experiencing multiple triggers of uncertainty about recurrence and a range of symptoms and treatment side effects.

**Implications for Nursing:** Nurses can help cancer survivors to identify, monitor, and manage illness uncertainty and emotional distress.

## Key Points . . .

- Illness uncertainty persists long after cancer diagnosis and treatment.
- Older long-term breast cancer survivors experience multiple triggers of uncertainty about recurrence and a range of symptoms and treatment side effects.
- Healthcare providers need to identify, monitor, and assist breast cancer survivors who are at risk for illness uncertainty and emotional distress.

tied to both threat of recurrence and physical symptoms of long-term residual effects of treatment. Survivors express this uncertainty as not knowing what will happen, when to be concerned about bodily changes, or how to discern normal changes of aging from signs of disease progression (Gray et al., 1998).

Specific areas of uncertainty during breast cancer survivorship have been identified. Recurrence is the major fear of women five years after treatment, and that fear continues in the years that follow (Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Fredette, 1995; Mahon & Casperson, 1997). Beyond five years, the likelihood of recurrence decreases

Advances in early detection and medical treatment of breast cancer have improved the survival of women such that they are living beyond diagnosis and treatment to an older age (Andersen & Urban, 1999). According to recent statistics, 97% of women diagnosed with localized breast cancer and 78% of those with regional disease are expected to be alive five years later (American Cancer Society, 2003a). Although five-year survival is promoted as a milestone for recovery, many women will continue to experience uncertainty about how to interpret and manage long-term treatment-related side effects such as arm swelling, cosmetic changes, fatigue, and other effects from axillary dissection and radiation, along with the continuing uncertainty about recurrence and secondary cancer (Dow, 1995; Pelusi, 1997). Uncertainty has been targeted as a major experience of breast cancer survivors and is predictive of emotional distress and a poorer quality of life (Mast, 1998; Nelson, 1996; Sammarco, 2001). The uncertainty of breast cancer survivors is

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