THE TRANSITION EXPERIENCE TO BREAST CANCER SURVIVORSHIP

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OBJECTIVES: *To provide an overview of the concerns and needs of breast cancer survivors and describe approaches to quality patient-centered breast cancer survivorship care.*

DATA SOURCES: *Review of the literature including research reports, review papers, and clinically based articles.*

CONCLUSION: *Breast cancer survivors report unmet needs and desire information and support to manage symptoms, cope with uncertainty and fears of recurrence, and guidelines for healthy lifestyle behaviors. Individualized and tailored survivorship care is required to meet the needs of those with varied risk profiles and recovery patterns.*

IMPLICATIONS FOR NURSING PRACTICE: *Nurses can be leaders in the assessment of needs after treatment, identification of those at higher risk for distress and ineffective coping, and in the delivery of high-quality care to breast cancer survivors.*

KEY WORDS: *Breast cancer survivors, needs, self-management, empowerment*

Breast cancer survivors (BCS) constitute 22% of the estimated 14.5 million cancer survivors,[1] and represent a population for which there is substantial research to provide evidence-based, high-quality patient-centered survivorship care. The transition from treatment to survivorship has been described as a conflicted experience where women try to balance feelings of gratitude or happiness for getting through treatment for breast cancer with the demands of persistent physical symptoms, uncertainty, anxiety, mood changes, and fears of recurrence.[2-8] Persistent symptoms can affect quality of life (QOL), family, and social roles, and challenge the recovery process.[2,7,9-12]

It has been nearly 8 years since the Institute of Medicine [2] published recommendations for cancer survivorship care and the Commission on Cancer expects that the new Standard for a Survivorship Care Plan (SCP) be operational in

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accredited cancer programs by 2015.[13] A SCP should include a summary of the treatment received, recommendations for surveillance and follow-up care, information on symptom management, monitoring for late effects, and health promotion.[2] Widespread adoption of the SCP has yet to occur,[14,15] with less than half of cancer survivors receiving a SCP.[16,17] Barriers identified include time, resources, institutional commitment, and financial support.[15-19] Survivorship clinics have emerged in cancer centers and community hospitals, but many offer a one-time visit and more narrowly focus on the treatment summary and follow-up surveillance,[20] falling short of the Institute of Medicine's recommendations to comprehensively address survivor needs.[19,21] The expectations for health care providers in survivorship care have been delineated, but to improve health and QOL outcomes for survivors, it is equally important to engage, inform, and support BCS in the transitional survivorship work in the context of their everyday lives.[22,23] The purpose of this article is to review reported concerns and needs of BCS in the transitional phase of survivorship, from curative intent therapy, and describe approaches to quality patient-centered BCS care.

BREAST CANCER SURVIVOR NEEDS

BCS report unmet physical, psychological, informational, and social support needs.[3,4,24] The most common physical symptoms are fatigue, cognitive changes, sleep difficulties, peripheral neuropathy, and menopausal symptoms, many of which reflect the effects of adjuvant therapies.[5,6,9,10,12] Fatigue is the most distressing symptom, strongly associated with radiotherapy and chemotherapy, but often worsened by the deconditioning that occurs because of decreased physical activity during therapy and negatively affects QOL.[10,25] There are also effects associated with surgery and radiotherapy that often receive less attention. Yet, reported symptoms of arm pain, decreased muscle strength, restricted range of motion and arm swelling[26] can result in emotional distress, poorer functional well-being, and interference with work performance.

Fear of recurrence, uncertainty, anxiety, mood changes, managing emotions, and integrating the experience into one's identity and life are dominant psychological responses.[4,12,22-24,27] Fear of recurrence represents existential concerns, uncertainty related to prognosis, and perceived morbidity associated with advanced disease. Anxiety is closely related to fear of recurrence and follow-up surveillance visits but lack of adequate knowledge to manage symptoms, uncertainty about the predicted recovery trajectory, and information and access to resources will increase a woman's anxiety levels.[28] Managing psychological responses are complex and embedded in the context of a woman's life. Communication with partners, family, and the health care providers, social support, age, stress and baseline psychosocial function can improve or impair a woman's ability to manage emotions.[27] BCS are often encouraged by family, friends, and the media associated with breast cancer to return to normal and celebrate being a survivor.[3] The vulnerability associated with diagnosis and effects of treatment[29] on a woman's physical, psychological, and personal perspective may contradict the expectation to return to normal for some women, resulting in conflict and distress.[27] BCS often state that family wants them to return to everyday life once treatment has ended and report that families are not interested in talking about ongoing psychological concerns and fears. This has been attributed, in part, to the family member's own challenges dealing with their respective emotional responses to their loved one's diagnosis. And, many women do not wish to engage in the celebratory survivorship expectations and identify as a BCS because of their struggle with uncertainty and fear of recurrence.[27]

Younger women have more overall needs than older women, specifically greater informational needs, worse symptoms, higher levels of emotional distress, and pragmatic concerns about work and managing everyday life.[10,12,30,31] Younger women are more likely to receive systemic adjuvant therapy, which explains the increased symptom profile,[32] and their developmental stage in life appears to contribute to greater everyday life stressors, resulting in poorer QOL outcomes.[11,33] Older women have less emotional distress but often poorer QOL related to limitations in physical function, more co-morbid illness, and the higher likelihood of non–cancer-related stressful life events.[11,27] BCS who are non-white and those with lower reported incomes have more unmet informational needs, greater challenges to access for quality care, and fewer resources for coping with and managing everyday life.[30,31]