Deconstructing Decisions to Initiate, Maintain, or Discontinue Adjuvant Endocrine Therapy in Breast Cancer Survivors: A Mixed-Methods Study

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Bluethmann and Mollica were supported through the Cancer Prevention Fellowship at the National Cancer Institute. Bluethmann also received funding through the Cancer Education and Career Development Program at the School of Public Health, University of Texas Health Science Center at Houston (R25CA57712). The findings and conclusions are those of the authors and do not necessarily represent the official positions of the National Cancer Institute/National Institutes of Health. Mention of specific products and opinions related to those products do not indicate or imply endorsement by the Oncology Nursing Society.

Bluethmann, Murphy, Tiro, and Bartholomew contributed to the conceptualization and design. Bluethmann, Murphy, and Tiro led analysis and interpretation of data. Murphy provided statistical support. All of the authors approved final analysis and contributed to the manuscript preparation.

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Submitted May 2016. Accepted for publication August 24, 2016.

Keywords: breast cancer survivors; side effects; adjuvant endocrine therapy; survivorship care; symptoms

ONF, 44(3), E101–E110.

doi: 10.1188/17.ONF.E101-E110

Purpose/Objectives: Adjuvant endocrine therapy (AET) has been shown to improve survival in hormone receptor–positive breast cancer survivors, but as many as half do not complete recommended treatment. Management of medication-related side effects and engagement with providers are two potentially modifiable factors, but their associations with adherence are not well understood. The aims were to build on survey results to qualitatively explore survivors' experiences with prescribed AET to (a) describe appraisal and management of AET side effects and (b) deconstruct decisions to initiate, discontinue, or maintain AET.

Research Approach: The authors used a mixed-methods explanatory sequence research design with a qualitative emphasis.

Setting: Survivors were recruited from a clinical cancer registry maintained at the University of Texas Southwestern Medical Center, which includes the Harold C. Simmons Comprehensive Cancer Center (National Cancer Institute–designated), in Dallas.

Participants: 452 survivors completed a survey, and 30 took part in telephone interviews.

Methodologic Approach: Qualitative methods were used in which the authors recorded and transcribed interviews for analysis and used open coding to reduce data into themes.

Findings: Among adherent survivors, the themes of tolerance of side effects and perseverance were strong. Nonadherent survivors expressed more difficulty managing side effects and perceived fewer benefits when side effects were bothersome. The most common side effects mentioned by all survivors were menopausal symptoms and joint pain; less common side effects were cognitive decline and cardiac distress. Some sought advice from their oncology team. Nonadherent survivors appeared initially motivated to maintain AET but identified a tolerance limit for side effects after which a provider's recommendation was less influential in their decision to maintain or discontinue AET.

Interpretation: This study elucidated adherence as a complex continuum of behaviors, appraisals, and decision points. These insights may be particularly useful in counseling survivors taking AET and promoting timely delivery of clinical interventions to enhance adherence.

Implications for Nursing: Nurses should be involved in the planning and implementation of clinical interventions to manage side effects and other barriers to AET adherence.

Adjuvant endocrine therapy (AET) (including tamoxifen [Nolvadex®] and aromatase inhibitors [AIs]) is widely recognized as a critical component of breast cancer treatment for women with hormone receptor–positive disease (Chlebowski & Geller, 2006; Chlebowski, Kim, & Haque, 2014). Several randomized, controlled trials have demonstrated significant reductions for recurrence risk and mortality in women treated with tamoxifen (Early Breast Cancer Trialists' Collaborative Group, 2005, 2011), and similar results have been found with AIs (Dowsett et al., 2010). Clinical guidelines have historically recommended AET to women with hormone receptor–positive disease for five years following primary treatment (Burstein et al., 2010). Updated guidelines now recommend as many as 10 years of continuous therapy (Burstein