

Racial and Ethnic Variation in Partner Perspectives About the Breast Cancer Treatment Decision-Making Experience

Sarah E. Lillie, PhD, MPH, Nancy K. Janz, PhD, Christopher R. Friese, PhD, RN, AOCN®, FAAN, John J. Graff, PhD, MS, Kendra Schwartz, MD, MSPH, Ann S. Hamilton, PhD, Brittany Bartol Gay, BA, Steven J. Katz, MD, MPH, and Sarah T. Hawley, PhD, MPH

A breast cancer diagnosis requires a series of complex treatment decisions related to type of treatment and side-effect profile. Research findings suggest that, for some women, these decisions are made with inadequate knowledge about the risks and benefits of treatment options (Fagerlin et al., 2006; Hawley, Fagerlin, Janz, & Katz, 2008; Janz et al., 2008). These decisions may be made in haste (Frosch & Elwyn, 2011) and can result in significant decision regret, distress, or remorse, which is true particularly for vulnerable patients such as racial and ethnic minorities (Brehaut et al., 2003; Hawley, Janz, et al., 2008; Sheehan, Sherman, Lam, & Boyages, 2007). The Institute of Medicine's (2001) definition of patient-centered care includes recognizing patients' medical needs while also incorporating their preferences and allowing them to guide decisions. This definition has been expanded to highlight the importance of significant others in medical decision making (Conway et al., 2006; Edgman-Levitan, 2003; Epstein & Street, 2011; Johnson et al., 2008; Shaller, 2007). However, little empirical research exists focusing on the contribution of significant others to the breast cancer treatment decision-making process.

Although women with breast cancer have reported valuing the opinions of others across the continuum of breast cancer treatment (Gilbar & Gilbar, 2009; Hawley et al., 2009; Öhlén, Balneaves, Bottorff, & Brazier, 2006; Stiggelbout et al., 2007), studies suggest that the involvement and influence of others may vary among different racial and ethnic groups. For instance, the research team previously found that Latina patients more often reported strong influences of family and friends in treatment decisions; however, Caucasian patients more often reported the strong influence of their spouses (Hawley et al., 2009). Maly, Umezawa, Leake, and Silliman (2004)

Purpose/Objectives: To characterize the perspectives of partners (husbands or significant others) of patients with breast cancer in the treatment decision-making process and to evaluate racial and ethnic differences in decision outcomes.

Design: A cross-sectional survey.

Setting: Los Angeles, CA, and Detroit, MI.

Sample: 517 partners of a population-based sample of patients with breast cancer four years post-treatment.

Methods: A self-administered mailed questionnaire. Chi-square tests and logistic regression were used to assess associations between race and ethnicity and decision outcomes.

Main Research Variables: Decision regret and three elements of the decision process: information received, actual involvement, and desired involvement.

Findings: Most partners reported receiving sufficient information (77%), being involved in treatment decisions (74%), and having sufficient involvement (73%). Less-aculturated Hispanic partners were more likely than their Caucasian counterparts to report high decision regret (45% versus 14%, $p < 0.001$). Factors significantly associated ($p < 0.05$) with high decision regret were insufficient receipt of treatment information, low involvement in decision making, and a desire for more involvement.

Conclusions: Partners were generally positive regarding their perspectives about participating in the breast cancer treatment decision-making process. However, less acculturated Hispanic partners were most vulnerable to decision regret. In addition, high decision regret was associated with modifiable elements of the decision-making process.

Implications for Nursing: Attention should be paid to ensuring racial and ethnic minority partners are sufficiently involved in breast cancer treatment decisions and receive decision support.

Key Words: decision making, family and caregivers, breast cancer