

Title

Towards an Understanding of the Influence of Significant Others on Breast Cancer Patients' Treatment Journeys

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Abstract

Over the past 40 years, breast cancer in the public consciousness has transformed from an illness fraught with shame and stigma to one where a global breast cancer movement of organizations and industry encourage women to “*Think Pink*”, support research for a cure and vigilantly screen for the disease. [1]. As one of the most publicized cancers in the United States, with the greatest resource allocation from public and private sources, information about breast cancer, whether grounded in evidence based medicine or layperson accounts, is abundantly available in the print and electronic media [2]. At the same time, advances in oncology care are rapidly changing the landscape of breast cancer treatment options. In addition, a patient centered care model, incorporating patient participation, preferences and shared decision-making is increasingly encouraged in clinical practice. Yet, little is known about how these patients work through their choices, cope with the subsequent effects, and in particular who or what influences the decisions they must make. Such struggles and decisions form the basis of what many breast cancer survivors often refer to as the “journey” through breast cancer treatment and recovery. Separately, extensive research has been published about the role of family members, spouses and significant others (S.O.'s) in the cancer patient's journey. The literature documents well the emotional distress breast cancer creates for patients and their S.O.'s and further, how its manifestations (i.e. coping, anxiety, other psychosocial distress) can potentially impact the patient's clinical outcomes. How S.O.'s involvement facilitates, influences or hinders decision making merits more rigorous scientific investigation. The specific aims of this ethnographic study are to:

1. Describe the influence and impact the significant others may have on patient's clinical decision making, including identifying who significant others are, in what ways they become involved in breast cancer patient's decision making processes, and how their influence impacts the patient's treatment journey.
2. Describe how breast cancer patients and their significant others deliberate about the various treatment options, their associated benefits/and drawbacks and any other factors that are considered when making treatment decisions.
3. Develop a taxonomy describing under what circumstances and how significant others influence patient's treatment decision making.

In order to comprehensively describe the patient journey, the proposed study employs qualitative and quantitative methods for data collection and analysis. In Phase I Key Informant interviews (n=20) will be conducted. In Phase II, the Patient Ethnography (n=60) will be conducted and includes 1) in-depth interviews with newly diagnosed patients and questionnaires at four time points throughout the treatment journey; 2) internet Journals and 3) electronic Health Records Review.