



## Formative research in the development of a care transition intervention in breast cancer survivors



Elizabeth A. Kvale<sup>a, b, \*</sup>, Karen Meneses<sup>b</sup>, Wendy Demark-Wahnefried<sup>b</sup>, Marie Bakitas<sup>b, c</sup>, Christine Ritchie<sup>d</sup>

<sup>a</sup> The Birmingham VA Medical Center, 700 S. 19th Street, Birmingham, AL, USA

<sup>b</sup> The University of Alabama at Birmingham (UAB) Comprehensive Cancer Center, 1720 2nd Ave South, Birmingham, AL 35294, USA

<sup>c</sup> The University of Alabama at Birmingham (UAB) School of Nursing, USA

<sup>d</sup> The San Francisco VA Medical Center and the University of California, San Francisco, 3333 California St, Suite 380, San Francisco, CA 94143, USA

### A B S T R A C T

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**Purpose:** The purpose of this qualitative study was to evaluate breast cancer survivors' (BCS) responses to a self-management survivorship care transition intervention in the formative development of such an intervention. The experience of BCS is marked by uncertainty and anxiety about subsequent care, and a desire for more information about future care needs and late effects of treatment. Self-management strategies have demonstrated improved outcomes in chronic illness, and may address the unmet needs of breast cancer survivors.

**Methods and Sample:** Five focus and discussion groups each were conducted at a single site in the Southeastern United States with a total of twenty breast cancer survivors. BCS were presented with a description of a survivorship transition intervention that encouraged self-management. Groups were led by a trained moderator using a semi-structured guide with 7 open-ended questions about their care transition experience and response to the proposed intervention. A theoretically-derived, concept-guided coding strategy was developed after review of transcripts. Iterative constant comparative methods were used to ensure that transcripts were reviewed exhaustively for emerging codes and relationships.

**Key results:** Three dominant themes emerged around readiness for self-management: 1) the breast cancer experience as a catalyst for self-management; 2) fear of recurrence as a catalyst for self-management; and 3) the impact of the meaning of breast cancer on individual readiness for self-management.

**Conclusions:** These findings contribute to further development of a conceptual model and interventions built on BCS self-management to improve the survivorship experience.

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### Introduction

Because of improved survival and the aging worldwide population, the number of breast cancer survivors will increase in coming years (Jemal et al., 2004). It is estimated that almost 3 million women in the United States alone have a personal history of breast cancer or carcinoma in situ, and a similar growth in survivorship populations is observed in Western Europe (American

Cancer Society, 2011). BCS are also likely to be managing comorbid health conditions (Hewitt et al., 2003; Jordan et al., 2014), thereby increasing the complexity of survivorship care (Garman et al., 2003). A number of interventions have demonstrated promise in improving quality of life and function in survivorship (Demark-Wahnefried et al., 2006, 2003; Galway et al., 2012; Meneses et al., 2009), but few interventions have focused on the transition from active treatment to survivorship and even fewer have taken into account the complexity of managing comorbidity (Meneses et al., 2007). Therefore, women with breast cancer are likely to experience the completion of active cancer treatment and the transition into survivorship as a time of uncertainty, marked by fragmented care, unaddressed psychosocial concerns, unaddressed

\* Corresponding author. CH19 Room 219R, Birmingham, AL 35294, USA. Tel.: +1 205 901 0460.

E-mail address: [ekvale@uabmc.edu](mailto:ekvale@uabmc.edu) (E.A. Kvale).

symptom burden, and unanswered questions (Ganz et al., 1996, 2002; Hewitt et al., 2005; Takahashi, 2014). There is a pressing need for more focused support in the survivorship transition period, especially since breast cancer survivors are more likely to report symptom burden, impaired quality of life, and functional impairment than peers without a personal history of cancer even years after treatment (Ganz et al., 2002; Hewitt et al., 2003; Mehnert and Koch, 2008).

The completion of active cancer treatment is a critical care transition from a period of provider-directed disease management to self-management of survivorship (McCorkle et al., 2011; Wagner et al., 2010). While effective strategies to improve survivorship outcomes in care transition are lacking, evidence exists that self-management and patient activation strategies have demonstrated a positive impact in chronic illness transitional care, and may have significant potential to address the symptom burden, fragmented care, and functional impairment observed in cancer survivors (Bodenheimer et al., 2002; McCorkle et al., 2011). Survivor self-management can be defined as the agency and self-determination that survivors incorporate to engage with health-promoting or disease management activities during the survivorship period. These activities may include adhering to follow-up, surveillance schedules, and medication recommendations, recognizing late effects of cancer treatment, and for some the additional challenges of managing other comorbidities.

Informed by existing literature and relevant behavioral theories including the Health Belief Model (Bandura, 1977) and Social Cognitive Theory (Bandura, 2004), the authors identified constructs and a framework of factors that could influence the uptake of self-management strategies in breast cancer survivorship (Fig. 1). As

depicted in Fig. 1, facilitators of readiness for self-management may include prior experience with self-management and problem solving skills. Other elements, such as environmental and social factors or the individual's experience with the health system might serve to either facilitate or inhibit readiness for self-management. Other psychosocial factors that may influence an individual's readiness for self-management include constructs such as outcome expectations and self-efficacy. In addition, personal illness models may impact the way that patients cognitively understand their illness, such as the language that individuals use to describe their illness and symptoms, their sense of the timeline of their illness or symptoms, and beliefs related to causation, consequences, and controllability of their illness. The purpose of this qualitative study was to utilize this framework to evaluate BCS's responses to a proposed self-management survivorship care transition intervention as an element of the formative development of such an intervention. We sought to evaluate whether elements identified a priori as likely to influence readiness for uptake of self-management activities were reflected in survivor's description of their experiences.

**Methods**

This was a qualitative interview study using a descriptive method (Sandelowski, 2010), conducted at the University of Alabama at Birmingham (UAB) Comprehensive Cancer Center and approved by the UAB Institutional Review Board (protocol #F110614016). A convenience sample of English-speaking women who responded to recruitment flyers placed in regional breast cancer treatment centers, announcements on social media, and announcements through regional breast cancer resources and

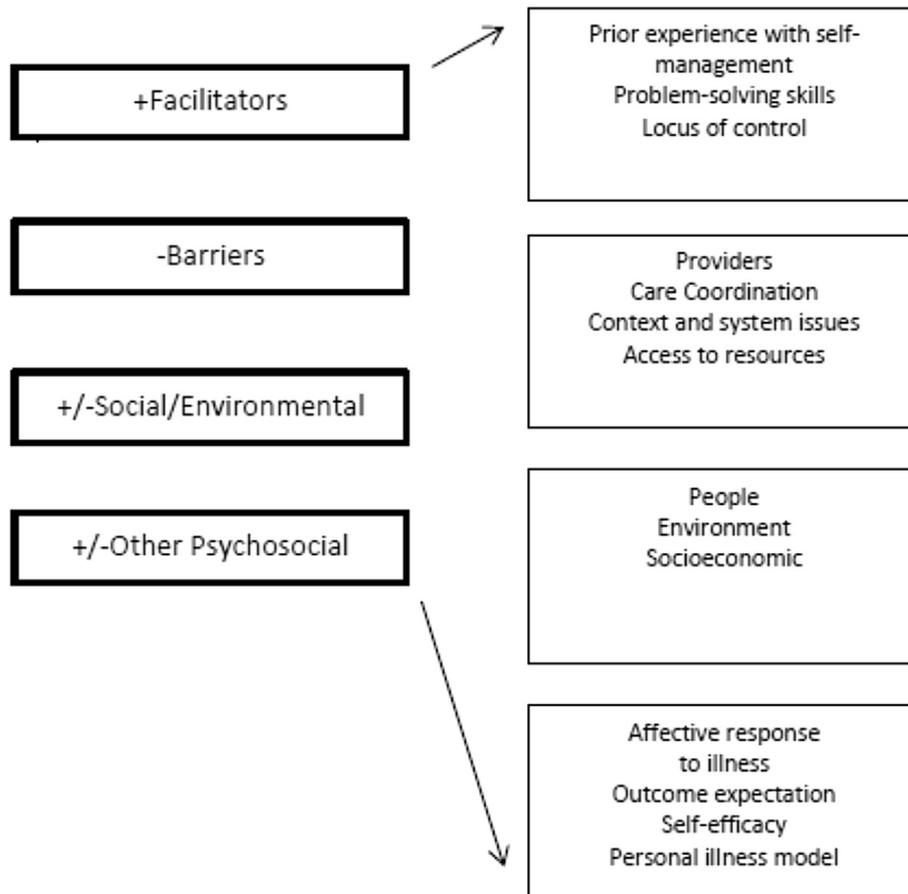


Fig. 1. Theoretical framework for factors influencing readiness for self-management in breast cancer survivors.

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