

Ovarian Cancer Survivors' Experiences of Self-Advocacy: A Focus Group Study

Teresa L. Hagan, BSN, RN, BA, and Heidi S. Donovan, PhD, RN

Cancer survivors, defined as anyone with a history of a cancer diagnosis, are increasingly required to play an active role in their health care because of growing emphasis on patient-centered care, complex healthcare structures, and long-term survivorship (Hewitt, Greenfield, & Stovall, 2006; Johnson, 2011). Understanding how patients engage in and manage their care throughout all stages of cancer survivorship becomes crucially important in developing effective support programs for patients (Hibbard & Cunningham, 2008). One area of cancer survivorship, symptom management, requires significant work and input from survivors.

Self-advocacy is increasingly recognized by providers, researchers, and policymakers as a means of increasing the capacity for patient-centered care. As often as self-advocacy is quoted as a desirable patient characteristic, little definition or clarification is provided, leaving this concept dramatically oversimplified and misrepresented in clinical practice and research (Sinding, Miller, Hudak, Keller-Olaman, & Sussman, 2012). However, the idea of promoting self-advocacy has face validity for helping patients with cancer navigate their disease trajectory (Walsh-Burke & Marcusen, 1999) and has potential value for improving symptom management, healthcare use, and quality of life, as demonstrated in noncancer populations (Brashers, Haas, & Neidig, 1999). Because of self-advocacy's understudied but frequently referenced potential to improve the lives of cancer survivors, a thorough analysis of the concept from the perspective of the patient with cancer is necessary. Understanding how and why survivors advocate for themselves and the impact of self-advocacy on their ability to manage symptoms can influence how healthcare providers support survivors and facilitate patient engagement and empowerment. Female cancer survivors have distinctive experiences of self-advocacy because of their unique cancer-related symptoms and their gender-specific experiences of

Purpose/Objectives: To explore ovarian cancer survivors' experiences of self-advocacy in symptom management.

Research Approach: Descriptive, qualitative.

Setting: A public café in an urban setting.

Participants: 13 ovarian cancer survivors aged 26–69 years with a mean age of 51.31.

Methodologic Approach: Five focus groups were formed. Focus group discussions were audio recorded and transcribed verbatim. The content was analyzed using the constant comparison method with axial coding. In-depth interviews with 5 of the 13 participants occurred via telephone one to five months after each focus group meeting to clarify and expand on identified themes. Preliminary findings were shared with all participants for validation.

Findings: Two major themes emerged from the data: (a) knowing who I am and keeping my psyche intact, and (b) knowing what I need and fighting for it. Exemplar quotations illustrate the diverse dimensions of self-advocacy. In addition, a working female-centric definition of self-advocacy was attained.

Conclusions: Women have varying experiences with cancer- and treatment-related symptoms, but share a common process for recognizing and meeting their needs. Self-advocacy was defined as a process of learning one's needs and priorities as a cancer survivor and negotiating with healthcare teams, social supports, and other survivors to meet these needs.

Interpretation: This phenomenologic process identified key dimensions and a preliminary definition of self-advocacy that nurses can recognize and support when patients seek and receive care consistent with their own needs and preferences.

Knowledge Translation: Self-advocacy among female cancer survivors is a process of recognizing one's needs and priorities and fighting for them within their cancer care and life. Practitioners can support female cancer survivors through the process of self-advocacy by providing them with skills and resources in making informed choices for themselves.

health care (Greimel & Freidl, 2000; Miaskowski, 2004; Street, 2002). Patients with ovarian cancer, in particular, are in high need of advocacy regarding symptom