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