

Symptom Burden and Self-Advocacy

Exploring the relationship among female cancer survivors

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BACKGROUND: Although patient self-advocacy is a critical component of patient-centered care, the association between symptom burden and self-advocacy has received little attention.

OBJECTIVES: This analysis evaluates the degree to which self-advocacy is associated with symptom burden among women with a history of cancer.

METHODS: Participants completed online or paper questionnaires. Descriptive statistics and ordinary least squares regression models were used to analyze the association between the three dimensions of self-advocacy and two dimensions of symptom burden: symptom severity and interference.

FINDINGS: Participants reported moderate levels of symptom burden. Fatigue, disturbed sleep, and memory problems were most common. Informed decision making was positively associated with symptom burden and participants' burden across the three most severe symptoms. Effective communication was negatively associated with total symptom burden and the degree to which symptoms interfered with daily life.

KEYWORDS

self-advocacy; symptom burden; effective communication; decision making

DIGITAL OBJECT IDENTIFIER

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HEALTHCARE ORGANIZATIONS HAVE PLACED INCREASING EMPHASIS on promoting patients' ability to advocate for their healthcare needs and priorities, and cancer care is no exception (Shapiro et al., 2009). Self-advocacy, generally defined as the ability to ensure that one's needs are met in the face of a challenge, is a foundational skill that can help an individual achieve improved health outcomes and quality of life (Walsh-Burke & Marcusen, 1999). As patient advocates and experts in symptom management (Oncology Nursing Society, 2016), oncology nurses must understand how the ability of patients to self-advocate relates to their ability to manage their cancer- and treatment-related symptoms. Although the concept of self-advocacy originated in populations with HIV and AIDS (Brashers, Haas, Neidig, & Rintamaki, 2002; Test, Fowler, Wood, Brewer, & Eddy, 2005), the language of self-advocacy was broadly accepted by the oncology community, although without a unique conceptualization (Hermansen-Kobulnick, 2008). To provide conceptual clarity to what self-advocacy means for patients with cancer, the current authors conducted a content analysis and discovered that self-advocacy is a behavioral skill that equips individuals with the ability to actively engage in behaviors that support their autonomy and improve their quality of life (Hagan, Cohen, Stone, & Donovan, 2016). In this study, the research team defined the unique ways in which women with cancer advocate for themselves when faced with a challenging situation (Hagan et al., 2016). Self-advocacy for female cancer survivors consists of three primary ways in which they can have their needs met in the face of a challenge: making informed decisions, balancing personal needs with others' needs, and effectively communicating with members of the healthcare team (Hagan et al., 2016).

Adult women with cancer experience high levels of symptom burden during and after treatment for cancer (Cheng, Wong, & Koh, 2016; Cheung, Le, Gagliese, & Zimmermann, 2011; Falk et al., 2016). Cancer-related symptoms can persist years after treatment has ended and affect an individual's functional ability and quality of life (Huang et al., 2016; Ness et al., 2013). A recent review article of cancer survivors by Wu and Harden (2015) revealed that one-third of cancer survivors continue to experience symptoms after their treatment has ended, with little reduction in severity. Symptom burden is a key area in which women with cancer can self-advocate, and