

Perspectives on Self-Advocacy: Comparing Perceived Uses, Benefits, and Drawbacks Among Survivors and Providers

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All of the authors contributed to the conceptualization and design and provided the analysis. Hagan completed the data collection and provided statistical support. Hagan, Rosenzweig, van Londen, and Donovan contributed to the manuscript preparation.

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Purpose/Objectives: To describe and compare survivors' and providers' views of the uses of and perceived benefits and drawbacks of survivor self-advocacy.

Design: A cross-sectional, two-group, mixed-methods survey.

Setting: Survivors were recruited from local and national registries and advocacy organizations. Providers were recruited from the University of Pittsburgh Medical Center Cancer Center and a regional Oncology Nursing Society chapter.

Sample: 122 female cancer survivors and 39 providers involved in their direct care.

Methods: Quantitative survey data were summarized using descriptive statistics, including means and frequencies. Qualitative survey data were collected and analyzed using content analysis techniques, and main themes were counted and summarized.

Main Research Variables: Perceptions of the uses, benefits, and drawbacks of female cancer survivor self-advocacy.

Findings: Survivors and providers perceived similar but distinct uses of self-advocacy. Survivors and providers generally agreed on the potential benefits of self-advocacy but had different views of the potential drawbacks. Survivors were most concerned with finding and making sense of information, that their questions would not be answered, and having a worse relationship with their provider; providers were concerned with increases in clinic time and difficulties developing treatment plans.

Conclusions: Although survivors and providers recognized similar benefits to survivor self-advocacy, they had different views of the uses and drawbacks of female cancer survivor self-advocacy.

Implications for Nursing: Attempts to increase self-advocacy among female cancer survivors must address survivors' and providers' views and apprehensions about self-advocacy.

Self-advocacy, defined as a cancer survivor's ability to get his or her needs met in the face of a challenge, is a critical skill for those facing the overwhelming disease and psychological burdens of cancer (Hagan & Donovan, 2013a, 2013b). Self-advocacy consists of three main skills: (a) making informed decisions, (b) finding strength through connection with others, and (c) communicating effectively with the oncology care team. Survivors need to be equipped with these skills to ensure that they can engage in their care, make personally meaningful decisions, and voice their concerns, particularly when it is difficult or uncomfortable (Walsh-Burke & Marcusen, 1999). Survivors can use these skills throughout their cancer experience to face their ongoing symptom management and meet their health promotion needs.

Protecting survivors' rights to self-determination is upheld as a professional duty by all healthcare providers. Provision 3 of the American Nurses Association's