

Describing Self-Advocacy in Underrepresented Women With Advanced Cancer

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PURPOSE: To describe the self-advocacy experiences of women from underrepresented groups who have advanced breast or gynecologic cancer.

PARTICIPANTS & SETTING: To be eligible for the study, participants had to self-identify as vulnerable, which was defined as a member of a group considered at risk for poor cancer outcomes and underrepresented in clinical research.

METHODOLOGIC APPROACH: This descriptive, longitudinal, qualitative study consisted of one-on-one interviews of women within three months of an advanced breast or gynecologic cancer diagnosis.

FINDINGS: 10 participants completed 25 interviews. The average age of participants was 60.2 years (range = 38–75 years). Three major themes emerged: (a) speaking up and speaking out, (b) interacting with the healthcare team, and (c) relying on support from others.

IMPLICATIONS FOR NURSING: Women with advanced cancer who are from underrepresented groups self-advocated in unique ways, learning over time the importance of how to communicate their needs and manage their healthcare team. Future research should incorporate these findings into tailored self-advocacy interventions.

KEYWORDS self-advocacy; underrepresented group; breast cancer; gynecologic cancer

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Self-advocacy is the ability of a patient to have their needs met when faced with a challenge. Self-advocacy behaviors include navigating complex medical systems, communicating with the healthcare team, collaborating in decision-making regarding treatment, having input regarding the impact of disease and its treatment on quality of life, and using social networks for support (Thomas et al., 2021). Self-advocating is important for individuals with advanced cancer because of their ongoing need for treatment and the common side effects and complications of cancer and treatment. Research has found that, across sociodemographic groups, women with advanced gynecologic or breast cancer who practice self-advocacy behaviors have higher quality-of-life scores on several symptom scales (Thomas et al., 2023).

Women from groups that are historically underrepresented in cancer clinical trials are often also at increased risk for poor cancer outcomes (Shariff-Marco et al., 2015; Taylor et al., 2022). These groups include women of non-White race and Latina ethnicity, with a high school education or lower, an annual household income of 200% of the federal poverty level or less, and nonheterosexual sexual orientation.

Often, women from groups historically underrepresented in clinical research experience more challenges and obstacles to high-quality cancer care (Patel, Lopez, et al., 2020). Area deprivation, which is determined based on indicators such as employment, housing quality, poverty, and neighborhood-level measures of education, produces a direct negative effect on overall survival, progression-free survival, and cancer-specific survival (Unger, Moseley, et al., 2021). These findings suggest that underrepresented populations could benefit from self-advocating because of the additional challenges they experience in receiving cancer care (Gonzalez et al., 2022;