

Identifying Barriers to Advocacy Among Patients With Lung Cancer: The Role of Stigma-Related Interpersonal Constraint

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OBJECTIVES: To examine whether aspects of disease-specific stigma are barriers to advocacy among individuals with lung cancer.

SAMPLE & SETTING: 266 patients with lung cancer treated at two National Cancer Institute–designated comprehensive cancer centers in the United States.

METHODS & VARIABLES: Patients completed a cross-sectional survey. Demographic, clinical, and stigma-related correlates of advocacy were also explored.

RESULTS: In multivariable analyses, lower levels of patient advocacy were reported by older patients and those with higher levels of constrained disclosure (i.e., avoidance of or discomfort in disclosing one's lung cancer status).

IMPLICATIONS FOR NURSING: Avoidance of discussing lung cancer (constrained disclosure) may be a barrier to patient involvement in advocacy. Additional research is needed to examine this relationship, reduce stigma, and promote inclusivity for individuals with lung cancer.

KEYWORDS lung cancer; stigma; smoking; patient advocacy; constrained disclosure

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Patient advocates are crucial voices in advancing health care, research, and policy decisions. Patient advocacy can take many forms, such as supporting a cause, idea, or policy through knowledge acquisition and sharing, personal contact, or organized activities, and is essential for achieving support to make progress against the disease. Although advocacy is a broad term used to describe varied efforts, a growing body of research suggests that various forms of advocacy—from informal individual efforts to acquire and share knowledge to more organized participation in groups to promote awareness and influence policy—can help to facilitate patient benefits, including patient self-efficacy, empowerment, and social support (Brashers et al., 2002; Hagan, Cohen, et al., 2018; Molina et al., 2016; Peterson et al., 2012).

For example, patient advocates have led the way in promoting treatment advances, adequate funding, greater visibility, and increased compassion for individuals with HIV/AIDS (Dresser, 2008). These efforts have been seen in other patient advocacy movements focused on conditions such as breast cancer and Alzheimer disease (Antone et al., 2021; Dresser, 2008; Hollister et al., 2021; Osuch et al., 2012). Disease-specific organizations have emerged as important forums for patient narratives, education, fundraising, and coordinated lobbying efforts (Best, 2019). Smaller-scale self-advocacy efforts have also been shown qualitatively and quantitatively to promote better outcomes for students with disabilities and female cancer survivors by having their needs recognized and met (Hagan, Gilbertson-White, et al., 2018; Test et al., 2005).