

NAPCRG 52nd Annual Meeting — Abstracts of Completed Research 2024.

Submission Id: 7064

Title

Patient Advocacy Group Leaders' Perceptions on Primary Care's Role in Caring for Patients with a History of Breast Cancer

Priority 1 (Research Category)

Healthcare Services, Delivery, and Financing

Presenters

Kacie Barry, Sarah Fadem, PhD, Jennifer Hemler, PhD, Jenna Howard, PhD, Lisa Mikesell, PhD, Denalee O'Malley, PhD, Shawna Hudson, PhD, Benjamin Crabtree, PhD

Abstract

Context: Patient advocacy groups engage patients, families, and caregivers in navigating the cancer landscape, focusing on early detection/screening, as well as psychosocial and financial support during treatment. As these groups have grown, they have major influences over their communities, funding, and policy. Objective: To understand perceptions of advocacy group leaders on primary care's role in breast cancer survivorship care, given a documented lack of primary care engagement despite being endorsed as a receptor site by the National Cancer Institute (NCI). Study design: As part of a larger NCI-funded study, we used snowball and purposive sampling to select diverse patient advocacy group leaders with knowledge in breast cancer survivorship for depth interviews that were recorded, professionally transcribed, and analyzed using an immersion-crystallization process to identify themes and patterns. Setting: Depth interviews conducted on Zoom. Population studied: Diverse leaders of cancer-focused patient advocacy groups. Intervention: Depth interviews. Outcome measures: Perceptions of primary care's role in breast cancer survivorship care. Results: Participants (n=9) included leaders from two local advocacy groups, three regional groups, and four national groups. Advocacy groups were responsive to patients' experiences and needs before diagnosis and during treatment but generally not actively engaged in long-term survivorship. We identified four consistent themes. Participants reported that transitions away from oncology are difficult for the patient but did not recognize primary care as a solution. Instead, participants emphasized a need for patients with a history of breast cancer to advocate for themselves. Participants described the ideal role of primary care as listening to patients and referring them to appropriate specialists. Nevertheless, they perceived patients with a history of breast cancer to have unique and complex needs that are different from the standard

of care within a primary care setting. Conclusions: Advocacy groups emerged due to perceptions of inadequate support and care for cancer patients; however, they do not identify primary care as a key player in survivorship. Patient advocacy groups have significant opportunity to shape the conversation about survivorship in primary care. Improved collaboration between primary care and advocacy groups is needed to better articulate and address primary care's involvement in survivorship care.

Downloaded from the Annals of Family Medicine website at www.AnnFamMed.org. Copyright © 2024 Annals of Family Medicine, Inc. For the private, noncommercial use of one individual user of the Web site. All other rights reserved. Contact copyrights@aafp.org for copyright questions and/or permission requests.