Empowering Lung Cancer Survivors in Post-Treatment Survivorship Care Using Participatory Action Research

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PURPOSE: To explore the experiences of lung cancer survivors (LCSs) and their informal and professional caregivers with post-treatment care and to empower them to implement action-based study findings.

PARTICIPANTS & SETTING: Participants were recruited using purposeful and snowball sampling from patients at a National Cancer Institute–designated cancer center in the northeastern United States.

METHODOLOGIC APPROACH: This study used a participatory action research (PAR) four-phase design. Phase 1 was a focused ethnography; phase 2 consisted of a core group of participants deciding on an action, which was implemented in phase 3; and phase 4 consisted of an evaluation of the action.

FINDINGS: The study found 28 categories, eight patterns, and three themes. The themes were the need for resources and education, involvement in mentoring and advocacy, and the value of living versus surviving. The action was creating two flyers focused on resources and advocacy for post-treatment support for LCSs. All participants agreed with the themes and action. Tobacco management and smoking-related stigma for LCSs were the only topics of dissent.

IMPLICATIONS FOR NURSING: Oncology nurses can use PAR to empower survivors in their post-treatment care. Future PAR cycles should focus on creating support groups and alleviating stigma for LCSs and their caregivers.

KEYWORDS lung cancer; survivorship; participatory action research; post-treatment care
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In 2022, 236,740 people were estimated to have been diagnosed with lung cancer, making it the second most common cancer in the United States (Siegel et al., 2022). Improvements in lung cancer survival rates reflect several factors, including diagnostic and surgical procedures, targeted therapy, immunotherapy, improved access to care related to the Affordable Care Act, and expansion of eligibility for lung cancer screening (Siegel et al., 2022). Because of these improvements, this survivor group, which has needs not previously identified or addressed by care teams, is expected to grow (Giuliani et al., 2016; Swisher et al., 2020).

Because lung cancer survivors (LCSs) represent a small proportion of cancer survivors, research specific to their needs is not as robust as that for other cancer types. A focus on symptom management versus holistic post-treatment care may compel LCSs to seek information about healthy behaviors, smoking cessation, and social issues (McDonnell et al., 2020; Rohan et al., 2016). For these reasons, developing care models and resources specific to LCSs is vital for health systems to address any care gaps that may result in poor cancer and noncancer health outcomes.

Cancer survivorship and post-treatment care have been studied for the past three decades; however, care models remain elusive, and innovations are needed. Healthcare systems' goals should include promoting patient-centered care, finding methods to reduce disparities, and providing coordinated survivorship care (Alcaraz et al., 2020; Yabroff et al., 2019). This study leveraged these goals by empowering LCSs, as an underrepresented survivor group, to engage in and implement immediate changes to post-treatment care. A previously published integrative review (Filchner et al., 2022) revealed the need for additional research into engagement of survivors in their own care as well as research into the interplay