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PALLIATIVE AND SUPPORTIVE CARE

The cancer caregiver lived experience: Supporting and advocating for patients with cancer throughout the care continuum.



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Abstract

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ABSTRACT

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Background: Data from the National Cancer Institute's Surveillance, Epidemiology & End Results Program (SEER 2022) estimates there are currently over 18.1 million cancer survivors in the United States who rely on family and friends to provide caregiver support. Family and volunteer caregivers fulfill a vital and essential role for cancer patients throughout the care continuum and are at the forefront of advocating and navigating the health care system for the patients under their care. Recognizing the caregiver's lived experience and the demands and obstacles caregivers endure has a direct impact on understanding the challenges cancer patients face daily.

Methods: November 2022 – April 2023 the Raymond Foundation hosted nationwide cancer caregiver focus groups, personal interviews, advisory boards, and online surveys. Primary goals included reaching a diverse range of caregivers in medically underserved communities, rural, urban and community oncology settings. In addition, researchers were interested to learn how the cancer caregiver experience and burden had evolved since our nationwide cancer caregiver published studies in 2018 and 2020. **Results:** 1214 caregivers (48% identified as male; 52% identified as female) participated

COMPANION ARTICLES

No companion articles

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during the six-month research period. 96% stated they provide direct patient care, such as: overseeing and ensuring adherence of oral chemotherapy or immunotherapy; communicating with clinicians to coordinate medications for adverse effects; surgical and treatment-related wound and drain care; colostomy, ileostomy, urostomy, and percutaneous endoscopic gastrostomy (PEG or G) support; 94% of caregivers reported they are included in all medical and treatment decisions; 91% reported they felt ill-equipped to navigate complex medical terminology including precision medicine information, biomarker, genetic and hereditary testing and navigating clinical trial options; 87% reported respite care, additional support and educational services would enable them to become a more empowered caregiver and patient advocate; 78% reported their overall quality of life had diminished since becoming a caregiver with feelings of depression, anxiety, financial insecurity, burn-out, loneliness and fear. **Conclusions:** Cancer caregivers experience significant challenges as they care for their loved one facing a cancer diagnosis. Caregivers are trusted partners in treatment decision making, but too often caregivers do not receive the tools they need to help make informed decisions. Additional caregiver education and support services are essential, so caregivers can provide the best possible support for patients throughout the care continuum.

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