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Caregiver burden: Empowering caregivers with shared decision-making strategies and skills to improve patient quality of life and outcomes.

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Abstract Disclosures

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Background:

Data from the National Cancer Institute's Surveillance, Epidemiology & End Results (SEER 2016) program estimates there are 15.5 million cancer survivors in the United States who rely on cancer caregivers every day. Caregivers play an essential role throughout the care continuum greatly impacting a patient's quality of survivorship.

Methods:

August 2019–March 2020 the Raymond Foundation hosted nationwide caregiver focus groups and an online survey. Primary goals were reaching caregivers and the patients they serve in rural, urban, and community oncology settings to gain perspective from diverse populations. Focus groups were held in person and online via video conferencing.

Results:

1012 caregivers and the patients they care for (41% male, 59% female) participated in our focus groups and online survey: 92% reported a lack of educational resources necessary to participate in shared decision making regarding treatment protocol; 90% reported they lacked communication strategies required to

effectively communicate with their healthcare team; 87% reported they would like to learn more about clinical trials but did not know where to start; 85% reported they did not feel comfortable reporting treatment adverse effects; 94% reported working toward a patient-centered, advocate based care approach would lead to enhanced quality of life and improved outcomes.

Conclusions:

Cancer caregivers and the patients they assist understand the importance of shared decision-making and patient centered care. Based on our focus groups and survey findings, our call to action includes developing the Cancer Caregiver Advocacy Plan. This unique educational resource will provide key information to address educational gaps and empower caregivers to become informed healthcare advocates. The Cancer Caregiver Advocacy Plan will be a companion resource to the Raymond Foundation's 2018 Cancer Caregiver Action Plan as we continue to expand our education and outreach to minimize cancer burdens for patients and caregivers.

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