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Editorial

Centering patients with advanced cancer includes supporting their caregivers

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A diagnosis of advanced cancer ripples outward from patients, hitting their caregivers: partners, family members, and friends who step in to provide support. The social network around the patient absorbs the impact of cancer. Effects from both cancer and its treatment create a need for support that the health-care delivery system is unequipped to handle without the support of caregivers. Fortunately, increased attention to patient-centeredness has illuminated just how impactful cancer can be for caregivers. Unfortunately, the health-care system is not routinely set up to recognize, assess, or support caregivers. A resultant surge in supportive care interventions to improve quality of life in caregivers demonstrates the willingness of enterprising behavioral scientists to address this systemic gap. Understanding the state of the science of interventions for cancer caregivers, particularly of patients with the most severe disease, is needed to guide future iterations of this work.

In this issue of the Journal, Chow and colleagues (1) provide a systematic review and meta-analysis of interventions to improve health outcomes among caregivers of patients with advanced cancer. The review focused on trials that delivered psychoeducational content, skills training, counseling, or team-based interventions with peer support and/or coping skills content. Interventions included those that could be administered to caregivers only, the patient-caregiver dyad, or the whole family. The authors closely adhered to systematic review best practices in accordance with Cochrane and Preferred Reporting Items for Systematic Review and Meta-Analyses (2,3).

Out of over 12 000 identified references, 56 articles covering 49 unique trials were identified and reviewed. Interventions were primarily targeted at patient-caregiver dyads (39%), but 33% targeted caregivers and 29% targeted patients and their whole families. Most of the studies (69%) were conducted with caregivers of patients with mixed cancer types. Pooled intervention effects were estimated 1-3 months post intervention. For mental health outcomes, the pooled effects yielded standardized mean differences of 0.24 on caregiver quality of life, 0.14 on mental well-being, 0.27 on anxiety, and 0.34 on depression compared with standard care (attentional or active controls). On the contrary, the meta-analysis suggested very small effects of the interventions examined on physical well-being. The intervention effects on quality of life and mental health included in the meta-analysis are promising, particularly given the high prevalence of depression and anxiety that many caregivers of patients with advanced cancer experience.

Limitations reported on in the review included low numbers of trial participants (most <100) and high risk of bias. Missing data rates across intervention outcomes were high. Though the number of trials has increased, diversity of trial participants remains low. Most caregivers (>70%) included in these trials are White, a finding that has been noted in other systematic reviews of cancer caregiving interventions (4-7). In addition, measures used to capture caregiver experiences and outcomes have seldom been validated in caregivers with advanced cancer, rendering results of individual trials difficult to interpret. Finally, consistent, thorough documentation of elements critical for evaluation and improvement of caregiver interventions—adherence, cost, implementation outcomes—are needed (8).

Despite the inability to recommend specific interventions for implementation, Chow and colleagues (1) do conclude that the benefits evident in the review uphold the notion that cancer centers should make supportive interventions available and that oncologists should routinely assess caregiver well-being. The ability to implement caregiver supports in practice, however, depends on the capacity of the health-care system to identify, document, and assess caregivers for unmet needs or distress. Previously, despite calls for implementing caregiver distress screening, very few cancer centers and oncology practices have standardized these practices (9), likely due to limited operational guidelines and absent reimbursement for such services. Many oncology caregivers are, in fact, distressed and in need of services. A recent nationwide cross-sectional survey of caregivers of older adult cancer patients (aged >70 years) found that 44% (n = 414) screened positive for distress (10).

Though caregiver distress screening remains rare, one example in the pediatric oncology setting shows promise. The authors of a study of 2013 pediatric oncology caregivers demonstrated the feasibility of implementing distress screening (96% of total) for caregivers followed by appropriate referral to services for those reporting high distress (96% of 493) (11). Examples in the adult setting are more limited (12).

The recognition for policy reform to enable standardization is increasing. The 2018 passage of the US RAISE (Recognize, Assist, Include, Support, Engage) Act (13) laid the groundwork for a 2022 national strategy for supporting family caregivers to include

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expanding support services for caregivers with high unmet needs and furthering integration of caregivers into the medical team (14). In addition, the US CARE (Caregiver, Advise, Record, Enable) Act, currently passed in 45 states, requires that anyone being hospitalized be asked if they have a caregiver and have that person's identity be recorded for further follow-up and discharge planning (15). A recent difference-in-difference analysis of hospitals in states that had passed vs not passed the CARE Act found improvements in several patient experience measures following the act's passage, suggesting potential for improving care quality (16). Taken together, it appears that more of the components necessary for widespread caregiver support are emerging.

The quality of future supportive interventions for caregivers and the overall evidence base will benefit from the reviews of Chow et al. (1) and others. In the future, we should expect increased rigor in interventions, including better reporting of adherence and intervention fidelity. Intervention efficacy is necessary but insufficient for implementation; we need better capture and reporting of factors critical for implementation. Interventionists need to include outcomes responsive to the demands and pressures of health-care administrators and policymakers with the hope of demonstrating how investments in caregiver and family support can improve quality of overall care to patients and create a care system more in line with patient values and preferences. We should also expect more interventions to be designed for specific caregiver populations and/or culturally tailored to meet specific needs. Underserved cancer caregiver populations include Black, Latino/a, and Native American patient-caregiver groups as well as LGBTQ+, rural and geographically remote, low-income, youth, and young adult caregivers (17). Arguably the best way forward is to cultivate more partnerships with community and advocacy organizations, including the rising number of local coalitions and task forces focused on improving family caregiving supports.

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