Oncology Nurses’ Knowledge, Confidence, and Practice in Addressing Caregiver Strain and Burden

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OBJECTIVES: To describe nurses’ practices, confidence, and knowledge of evidence-based interventions for cancer caregiver strain and burden and to identify factors that contribute to these aspects.

SAMPLE & SETTING: 2,055 Oncology Nursing Society members completed an emailed survey.

METHODS & VARIABLES: Pooled analysis of survey results. Variables included the baseline nursing assessment, intervention, confidence, knowledge, strategies used, and barriers encountered.

RESULTS: Nurses tend to overestimate the strength of evidence for interventions not shown to be effective and have moderate confidence in assessing and intervening with caregivers. Having been an informal caregiver and having received care from an informal caregiver were associated with higher reported practice and confidence. Major strategies used were referral to social workers and others. Barriers reported were financial, caregiver emotional responses, and distance.

IMPLICATIONS FOR NURSING: An opportunity exists to increase nurses’ knowledge and confidence in assessment and intervention with caregivers. Greater use of technology may help nurses overcome some barriers to working with caregivers. Findings can be used to plan continuing education, develop clinical processes, and identify resources nurses need to address strain and burden among informal caregivers.

KEYWORDS caregiver strain and burden; confidence; barriers; caregiving

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Family caregivers are long-term care providers for people with cancer and an important extension of the cancer care workforce. Caregivers communicate with healthcare providers about patients’ health, monitor the severity of their condition, provide hands-on care, and advocate on behalf of patients. Research has indicated that caregiving is an intense experience that can be physically and emotionally demanding, and the proportion of cancer caregivers who report high levels of stress is higher than that of non-cancer caregivers (National Alliance for Caregiving, 2016). Although family caregivers play a central role in helping patients, demands on caregivers that exceed their resources can lead to strain and burden (Honea et al., 2008). Caregiver strain and burden is a construct that “encompasses difficulties assuming and functioning in the caregiver role as well as associated alterations in the caregiver’s emotional and physical health that can occur when care demands exceed resources” (Oncology Nursing Society [ONS], 2017, para. 1). According to a national survey by the National Alliance for Caregiving (2016), 62% of caregivers of patients with cancer reported high burden situations, averaging 33 hours of care per week, and 43% of caregivers provided complex medical or nursing tasks for which they had no preparation (National Alliance for Caregiving, 2016). High caregiver burden needs to be addressed because it can have detrimental effects on caregivers’ health (National Alliance for Caregiving, 2016; Stenberg, Ruland, & Miaskowski, 2010), hinder caregivers’ ability to help patients (HAVYR, van Ryn, Wilson, & Griffin, 2017), and negatively affect patients’ mental and physical health (Boele et al., 2017; Kershaw et al., 2015).

The caregiver’s need for help is often overlooked. According to the National Alliance for Caregiving (2016), 40% of the caregivers wanted more help.