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The Time is Now: Assessing and Addressing the Needs of Cancer Caregivers

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In 2007, the IOM issued a report outlining the components of effective cancer care, which included addressing the psychosocial needs of informal caregivers of cancer patients [1]. This aspirational goal is a challenge given the growing population of cancer survivors and the associated number of informal caregivers. In 2013, it was estimated that there were four million informal caregivers for adult cancer patients in the U.S. [2], although this was almost certainly an underestimate given the 14.5 million cancer survivors in the U.S. at the beginning of 2014 [3]. The extent of care provided by these informal caregivers is significant, far exceeding the care provided by professional caregivers - averaging 8.8 hours/day over more than four years [4,5]. As cancer treatment has become more complicated and more often delivered in the outpatient setting, the care and wellbeing of cancer patients has become increasingly dependent on informal caregivers. These shifts in cancer treatment have occurred at the same time that informal caregivers have become increasingly likely to be employed outside the home, and thus juggling the demands of work and caregiving.

There is clear evidence that caregivers have psychosocial needs. As described in the article accompanying this editorial, Sklenarova et al surveyed cancer caregiver and patient dyads about their unmet needs, distress, anxiety and depression [6]. Their results indicated that the caregivers were more distressed and more anxious than the cancer patients. This result is consistent with a large and growing body of literature that documents the significant distress experienced by caregivers of patients with cancer. Indeed, caregivers experience a range of psychological complications (e.g., 8), including significant mood disturbance. While some studies have reported rates of anxiety and depression for caregivers that are comparable to those of the patients for whom they provide care (e.g., 9,11), others have reported rates for caregivers that surpass those of patients (e.g., 9,12,13). For example, rates of depression between 12 and 59% and anxiety between 30 and 50% [14,15] have been reported in samples of family caregivers, in comparison to rates of depression between 10 and 25% [16] and rates of anxiety between 19 and 34% [17] in patient samples. Higher rates of depressive and anxious symptomatology are found among caregivers of cancer patients receiving active treatment [18], survivors post-treatment [19], and patients with advanced cancers [12], in

comparison with the rates for the patients for whom they provide care. Therefore, across all points in the caregiving trajectory, cancer caregivers represent a population at significant risk for psychiatric morbidity and potentially in need of psychosocial services.

Sklenarova et al found that 43.6% of caregivers reported more than 10 unmet needs and only 14.4% reported no unmet needs [6]. In comparison, Soothill et al reported that 13.8% of the caregivers they surveyed had 10 or more unmet needs and 57.4% indicated no unmet needs [20]. The latter study documented that caregivers reported more unmet needs than patients, and while Sklenarova et al also surveyed patients about their unmet needs, unfortunately they did not report this data in their paper. The most common needs identified in the Sklenarova article concern fears about the patient's deterioration and risk for recurrence and feelings about death and dying [6]. Other needs included information about alternative therapies, benefits and side effects of treatment, and patient's prognosis. The needs identified in the Soothill study were more likely to be practical and emotional in nature [20]. These differences may be related to the different assessment measures used in these two studies, the different cultures assessed, or some other undetermined difference. Unfortunately, as is often the case in psychosocial oncology research, there is no consensus about the best tool to use in assessing caregivers' needs.

An interesting aspect of the Sklenarova study is the aim to identify predictors of caregivers' needs. Consistent with the results of others (e.g. 21), demographic and clinical variables did not predict caregivers' needs. While Sklenarova found that the extent of patients' needs was the only predictor of caregivers' needs, other studies have found that the number of hours spent providing care is associated with caregivers' informational [22] and psychosocial needs [21]. These results suggest that it is difficult, if not impossible, to categorically identify particular types of caregivers who would benefit most from support and that further assessment is required to identify those caregivers at highest risk for the psychiatric and medical sequelae of caregiver burden.

A particular strength of the Sklenarova investigation is its broad sample, which included a wide representation of caregivers of patients with a variety of sites and stages of cancer, receiving both curative and palliative treatment. Additionally, close to one third of caregivers enrolled were male, a group often underrepresented in psychosocial research and particularly in research on caregivers. As such, the results may be generalized across the caregiving trajectory and to various groups of caregivers, underscoring the clear demand for supportive care services for this vulnerable population. An additional strength of the current study is the near perfect response rate of participants; attrition from psychosocial research generally – and psycho-oncology specifically – is typically high, yet nearly the entire participant sample of patient-caregiver dyads in the current study completed questionnaires. Not surprisingly, the results indicated that the magnitude of unmet needs among caregivers was associated with that of patients, regardless of the patients' site or stage of cancer. Together, these data point to the need for adequate distress screening of caregivers, particularly for those providing care for patients with extensive needs.

The Sklenarova study makes an important contribution to the field of psycho-oncology and the growing body of literature documenting distress among caregivers. Understanding the

supportive care needs of cancer caregivers is a critical next step for our field, particularly given their importance in cancer care as currently delivered. The accumulating data on caregivers for cancer patients clearly indicates that this is a population vulnerable to distress and in need of support for their caregiving role. The Sklenarova study adds to this body of research, contributing additional data that the psychosocial distress and the unmet needs of cancer caregivers are significant and greater than that experienced by the patients for whom they provide care. Identifying the needs of informal caregivers of cancer patients is a necessary step in developing empirically supported treatments that address the unique experience of this population. Future research is needed to adapt and evaluate the efficacy of currently available empirically supported interventions for anxiety and depression for cancer caregivers, as well as interventions to address specific areas of unmet need highlighted here, such as fear of recurrence and concerns about death and dying. The state of the science of empirically supported interventions for cancer caregivers remains in its infancy [23] and the time is ripe for this area of focus to become a priority for future research in psycho-oncology.

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