
GUEST EDITORIAL

Survival of the fittest . . . caregiver?

If you enter the word “caregiver” into your Google search engine, three keywords continue to repeat in the first 50 or so pages of entries: “burden,” “support,” and “survival.” The first two are just as prominent if you enter “caregiver” into the PubMed search engine. “Survival,” however, is surprising rarely addressed in the scientific literature on caregivers. On Google, you will see numerous entries for “the caregiving survival guide,” “survival tips for caregivers,” and “surviving caregiving.” But systematic scientific study appears to be lagging, and we clearly do not as of yet have a one-size-fits-all recipe for survival as a caregiver. It was 1864 when Herbert Spencer coined the phrase “survival of the fittest,” after reading Charles Darwin’s *On the Origin of Species*, drawing parallels between his economic theories and Darwin’s biological suppositions. While the authors of these entries in Google were likely not referencing natural selection, what is likely implied by both the scientific and lay communities is the fact that caregivers do bring a set of predisposing—genetic, attitudinal, personality, and environmental—factors that promote (or hinder) resilience (and survival) during caregiving. Identifying these factors—identifying caregivers who may be naturally able to face the demands of the role without significant and negative outcomes, and importantly, those who will require active support to protect against these outcomes—is a critical mission for our field.

The hopeful news is that progress is indeed happening and we have entered into a rich era of scientific attention focused on addressing the needs of caregivers. Over the past year, our journal has seen a significant increase in the number of articles that examine the needs of caregivers of patients with chronic and/or life-limiting illnesses—a notable shift from just a few years ago, when only a handful of studies included caregiver participants or discussed their needs. Our first Special Issue on Caregivers was published in June of 2015, just a month after the National Cancer Institute and the National Institute of Nursing Research convened a landmark meeting canvassing the state of the science of cancer

caregiving. The meeting brought together more than 75 experts, including researchers, clinicians, advocates, and representatives from national funding agencies. The meeting’s findings highlighted, among other things, the wide variety of measures used to assess caregiving tasks, burden, and health outcomes (Kent et al., 2016). This limitation, along with the fact that the majority of studies discussed had been conducted at major cancer centers solely among well-educated non-Hispanic white caregivers, made it nearly impossible to generalize the findings. Just a year later, the AARP and the National Alliance for Caregiving published their updated report, “Cancer Caregiving in the U.S.: An Intense, Episodic, and Challenging Care Experience” (AARP, 2016). This report emphasized that the majority of caregivers do not have conversations with healthcare providers about their needs (a mere 29% of respondents acknowledged discussing self-care at all with a professional) and the need to examine the patient–caregiver–provider dynamics that promote and/or hinder caregiver well-being and discussion about palliative and end-of-life-care. The report also underscored the need for improved screening and assessment processes to identify distressed caregivers in need of support, which would ideally lead to appropriate referrals and optimal use of our already-burdened healthcare system. So the message is clear: in order to advance the state of the science of caregiving and meet the needs of hundreds of thousands of caregivers across the country and across the world, we need a cohesive approach for assessing and communicating these needs. Moreover, we must recognize how our healthcare system and healthcare policies contribute to the challenges currently faced by caregivers.

The majority of the articles in the present Special Issue of *Palliative & Supportive Care* address the important theme of screening, highlighted by the abovementioned reports. Olivier-d’Avignon et al. describe the validation of a needs assessment for siblings of severely ill children, which in practice will help to identify a “silent” group of caregivers, often

unrecognized as being in need of services. When put into practice, this measure will help to promote a family-centered approach to care. Aoun et al. present the feasibility and relevance of a needs assessment tool for caregivers of patients with motor neuron disease, a group with unique needs and who remain underrepresented in the palliative care literature. Roberts et al. describe the development of a self-report bereavement risk screening tool that will facilitate more effective identification of family members in need of psychosocial support before and after a cancer loss. Importantly, many caregivers disengage from potential supportive services at perhaps one of the most difficult moments in the caregiving trajectory—when patients transition to hospice care. Identifying those at risk for poor bereavement outcomes earlier on in the trajectory will assist with engaging or maintaining such caregivers in care and protect them as they move through transitions in care. Tanco et al. provide a systematic review summarizing the availability of instruments to assess various dimensions of distress among caregivers, including burden, needs, satisfaction with care, and quality of life. As has previously been found in the psychosocial oncology literature, their review highlights discrepancies in how many of these constructs are operationalized, and hence evaluated, and points to the need for more consistent assessment processes.

Several articles also address what can perhaps be classified lightly as “precision medicine” for caregivers. Wittenberg et al. provide the first evidence-based validation for a family caregiver communication typology and its relationship to caregiver outcomes; and Ho et al. examine the impact of patient and caregiver characteristics on completion of advanced directives. These studies suggest that caregiver characteristics ranging from age and race to communication style may significantly impact such caregivers’ experience of the role and should be considered when engaging in treatment planning. Importantly, their results also emphasize the need to increase efforts dedicated to counseling patients and caregivers from underrepresented groups to promote more open patient–caregiver–physician communication and thus the completion of advanced directives. Finally, Bakitas et al. evaluate a decision aid for patients and caregivers to facilitate end-of-life care. In practice, such an aid will allow families to take more control over their medical care earlier on in the illness

trajectory, which will have a tremendous impact on families’ experience of illness and eventually, bereavement outcomes among caregivers, who are at high risk for trauma and prolonged grief disorder when required to make decisions on behalf of patients in the absence of previously held open communication.

In the opening to our first Special Issue on Caregivers, I noted that the state of the science of empirically supported interventions was in its infancy and that caregivers remained “isolated, invisible, and in-need” (Applebaum, 2015). Since that time, there has been a burgeoning of research focusing on screening and supporting caregivers across the care trajectory, and in this short time we are indeed working to prevent caregivers from isolation and unnecessary burden. Over this time, we have also seen several funding opportunity announcements from the National Cancer Institute and the National Institute of Nursing Research specifically focused on addressing the needs of caregivers through screening, assessment and intervention, and examining these needs from the individual through the systems-level perspectives. As increased attention, funding, and support and targeted research efforts as described in this issue further evolve, perhaps PubMed will catch up with Google and we may truly assist in the survival of all caregivers, not just those selectively advantaged for the role.

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