

Decentering on Self-Management of Stress and End of Life Planning in Caregivers of Cancer Patients

Sara L. Douglas, PI

Over 500,000 patients in the US are living with cancer (National Consensus Project for Quality Palliative Care). Significant advances in early diagnosis and treatment have transformed cancer from an acute and invariably fatal disease into a chronic illness, with cure possible for some and long periods of remission for many. Caregivers of patients with advanced cancer (when cure is not possible) not only serve in traditional caregiving roles with resulting poor physical and psychological outcomes but also deal with additional concerns related to end of life (EOL) planning and coping with the potential loss of their loved one. When EOL plans are discussed and put into place, caregivers have higher satisfaction with EOL care and less decision regret than when plans are not made. The need to facilitate and improve EOL planning has been well identified and the IOM and NINR have incorporated EOL into their priorities. For these caregivers, self-monitoring includes ongoing assessment of their own EOL values and goals of care for the patient's treatment; self-awareness involves recognition of their own symptoms of distress and anxiety; and self-regulation includes engaging in EOL planning discussions, documentation of patient wishes, and communication with providers regarding EOL plans. Self-management, then, can help these caregivers by increasing decisional control, increasing the concordance between EOL values and the goals of care for treatment of their loved one and reducing anxiety and distress.

For this study, we will compare the effectiveness of a theoretically based intervention with two key components (called EOL_M): (a) EOL planning activities for caregivers delivered online, and (b) daily meditation (Stop, Breathe & Think™) delivered using a smartphone application to an intervention with only the daily meditation component (M_Only). The intervention will consist of daily meditation using a tested application that they will tailor to meet their individual needs. Participants will also have 3 coaching sessions with an Advanced Practice Nurse (each 10 minutes long) to discuss key aspects of EOL planning. We will conduct a randomized trial pilot study to examine two arms of the intervention among 20 caregivers of patients with advanced cancer. We will collect mixed methods data at baseline and 1 month after subject enrollment to describe changes in outcomes. We aim to:

1. Evaluate the effects of the EOL_M and M_Only interventions on stress reduction and EOL planning behaviors and determine if there are different effects between EOL_M and M_Only interventions.
2. Evaluate the effects of the intervention on health status, psychological status (distress, anxiety), decisional control, concordance between EOL values and goals of care for treatment, decisional regret, satisfaction with EOL care and cost.
3. Evaluate the impact of decentering on the association between the interventions, self-management behaviors (stress reduction and EOL planning behaviors) and distress, anxiety, concordance between EOL values and goals of care for treatment, decisional regret and satisfaction with EOL care.
4. Describe the neural activity processes that are associated with increased self-management activities.