Exploring the Meaning of Caregiving During Life-Limiting Illness: Qualitative Results of the Caregiver Outlook Trial (FR467-C)

Karen Steinhauser, PhD, Duke University Medical Center and Durham VAMC, Durham, NC
Kimberly Johnson, MD MHS, Duke University Medical Center, Durham, NC
Annette Olsen, MDiv BSSW, Duke University Medical Center, Durham, NC
Daniel Grossoehme, DMin, Cincinnati Children’s Hospital Medical Center, Cincinnati, OH

Objectives

• Learn approach to addressing caregiver’s existential needs during serious illness.
• Learn context for study results within larger literature.

Original Research Background: Research suggests caregiver’s subjective sense of burden appears to be influenced by the meaning caregivers ascribe to their role.

Research Objectives: Identify the role-related meaning expressed by caregivers of those with life-limiting illness participating in an intervention, called Caregiver Outlook, to address caregiver’s existential needs.

Methods: The study was a one-arm pilot feasibility and acceptability trial of the Caregiver Outlook intervention, a standardized, chaplain-led intervention to address caregiver existential needs. Structured interviews allowed participants to respond as desired with follow-up probes based on caregiver’s responses. This presentation is a qualitative content analysis of the three intervention sessions, focused on relationship life review, forgiveness, and relational legacy. Content analyses included manifest coding as well as latent coding of caregiver’s narrative themes, expressing their individual stories and meaning of caregiving experience. Caregivers were recruited from outpatient palliative care and ALS clinics at an academic medical center; English speaking; and spouses, partners, or close family members of those with serious illness.

Results: Of the 36 trial participants, we selected a purposive subsample (n=13, 36 sessions), seeking maximum variation. Four participants cared for those with cancer and nine with ALS (matching sample proportions); six were male, seven female; two African American, nine white; and four adult children and nine spouses or partners. Caregiver main themes included caregiving challenges, motivation for caregiving, learning from caregiving, grief and loss, and spiritual journey. Each main theme included subthemes expressed across caregivers with detail varying particularly by subgroups (eg, motivation by gender or caregiver challenges by level of patient dependence).

Conclusions: Caregiver Outlook themes offer areas of potential needs and resources as caregivers explored meaning making to buffer caregiving demands.

Implications for Research, Policy, or Practice: Caregivers noted the opportunity to engage in such conversations assisted in gaining perspective in the midst of significant challenges and often isolation.