Understanding Stress Variances Among Hospice Caregivers: Validation of the ACT Theoretical Framework

Elaine Wittenberg-Lyles, PhD1, 2, George Demiris, PhD, Debra Parker Oliver, MSW, PhD, 3 Karla Washington, MSW, PhD, 4 Stephanie Burt, MS, 5 Sara Shaunfield, MS 1 Markey Cancer Center & 1 Department of Communication, University of Kentucky, University of Washington, 4 University of Missouri, 3 University of Louisville, 4 University of North Texas

Introduction

Care interventions are not routinely provided for hospice family caregivers, despite widespread documentation of the burden and toll of the caregiving experience. Assessing caregivers for team interventions (ACT) is a theoretical framework proposing that holistic patient and family care includes ongoing caregiver needs assessment of primary, secondary, and intrapsychic stressors. The goal of this study was to describe the variance in stressors for caregivers as further evidence supporting the ACT theoretical framework.

Methods

Using secondary interview data from a large randomized controlled trial, hospice caregiver discussions about caregiving concerns were analyzed for stressors and then thematized. Data analysis explored digitally recorded discussions between hospice caregivers and interventionists where caregivers were asked to identify and describe the most pressing problems or concerns they face.

Theoretical Framework

A theoretical framework called ACT: Assessing Caregivers for Team interventions (Parker Oliver, Demiris, & Porock, 2010) depicts the hospice interdisciplinary team (physician, nurse, social worker, and chaplain) as an external mediator within the caregiving experience. The model calls for ongoing assessment of the caregiver’s background along with primary, secondary, and intrapsychic stressors, and ultimately the outcomes of caregiving in order to design and deliver appropriate customized interventions by the hospice team. As the degree of anxiety occurs as a consequence of caregiving, it is counterbalanced by positive experiences gained through support and information from hospice staff. However, limited personal resources and coping strategies can cause psychological complications, triggering anxiety appraisal and coping which can be reduced through the provision of support and information.

Summary

Digital recordings of 84 intervention discussions were captured and analyzed. Primary stressors emanated from performing caregiving tasks. Caregivers reported task-related primary stress from witnessing the patient’s decline, experiencing conflict over care with the patient, second-guessing pain management, and unsolicited evaluation from outsiders. Secondary stressors resulted from the impact of providing primary care and were considered by caregivers to be more personal in nature, centering around the impact of the caregiving role on their personal lives and routines. This included family stress related to providing care, fatigue, finances, and guilt. Intrapsychic stressors represented the caregiver’s awareness and thoughts about the role of caregiving. This stressor was characterized by self-imposed role expectations, role mastery related to hospice acceptance, the tendency to neglect emotions, and anticipatory grief during caregiving.

Conclusions

The findings in this study confirm that hospice family caregivers are “second order patients” with their own unique care needs. Variances in stress suggest that caregiver interventions should range from knowledge and skill building to cognitive-behavioral interventions that aid in coping. The data in this study allude to a shift from negative to positive between primary and secondary stressors and intrapsychic stressors. This shift suggests that coping occurs as caregivers learn more about their role.

Implications

Family members who assume the role of primary caregiver for a dying loved one should be routinely assessed by hospice providers for customized interventions. For example:

• Caregivers should be assessed for “caring for experience” so that interdisciplinary team members in the clinical disciplines (physician, nurse) can provide appropriate training on pain management practices, ranging from assessment to medication provision.
• Caregivers should be assessed to determine the social support networks available.
• Caregiver assessment should take into consideration the family system, and future intervention research should consider a family-based approach as opposed to a sole focus on the primary caregiver.

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Aging is associated with stress intolerance and an impaired ability to regulate inflammation. Systemic inflammatory response syndrome (SIRS), caused by sepsis or trauma, is a serious clinical condition characterized by whole-body inflammation which is particularly threatening to elderly patients who suffer much higher mortality rates than the young. SIRS can lead to an array of organ dysfunction that is associated with increased morbidity and mortality. Histone H4 release is one of the major pathological consequences of SIRS and acute lung injury (ALI). We previously reported age-dependent severity of hypothermia 12 h after LPS injection was compared. (D) APC levels during SIRS.

**Figure 2.** Age-dependent mortality and difference in plasma APC levels between young and aged mice. Young and aged mice were injected with LPS (2.5 mg/kg; n 4 in each group). Starr et al (2010) Blood 115 (22) 4880-4885.

**Figure 3.** Schematic of APC-mediated cytoprotection during SIRS/sepsis. Histones, normally thought of as necessary components of the DNA packaging proteins, were recently shown to be lymphocytes in endothelial cells and macrophages associated with key transduction pathways implicated in inflammation. Histone H4 release is one of the major pathological consequences of SIRS and acute lung injury (ALI). APC, activated protein C; Cytoprotection, protection against cell death by activated protein C (aPC).

**Figure 4.** A model depicting the potential protective role of aPC in aged mice. The presence of histone H4 increased during SIRS and mimic sepsis-associated complications upon release from dying cells. Our data demonstrated that aPC protects aged mice by stimulating the expression of an anti-apoptotic factor, thymoquinone, high levels of activating factors, in combination with low levels of aPC protein, and cytoprotection in aged mice.  

**Figure 5.** Proteomic analysis identifies age-associated increase of Histone H4 during endotoxemia. A linear spectrometer identified spot 1521 showing age-dependent increase during SIRS in aged mice with a low dose (2.5 mg/kg; n 4 in each group) versus young mice with a high dose (20 mg/kg) versus Control. (A) Total lung proteins from young and aged mice were used to produce 2D gel electrophoresis. (B) One-dimensional gel electrophoresis. Histone Injection. Aged mice are more sensitive to LPS-induced hypothermia than young mice. Histones thus inactivating them and improving sepsis related complications upon release from dying cells [Xu et al. (2009) Nature Medicine]. APC, activated protein C receptor; EPCR: endothelial protein C receptor. Western Blot Analysis. Proteins were electrophoretically transferred to nitrocellulose or polyvinylidene fluoride membranes and Western blot analysis performed. 

**Figure 6.** Western Blot Analysis. Proteins were electrophoretically transferred to nitrocellulose or polyvinylidene fluoride membranes and Western blot analysis performed. 

**Figure 7.** Schematic of APC-mediated cytoprotection during SIRS/sepsis. Histones, normally thought of as necessary components of the DNA packaging proteins, were recently shown to be lymphocytes in endothelial cells and macrophages associated with key transduction pathways implicated in inflammation. Histone H4 release is one of the major pathological consequences of SIRS and acute lung injury (ALI). APC, activated protein C; Cytoprotection, protection against cell death by activated protein C (aPC).

**Figure 8.** Aged mice are more sensitive to LPS-induced hypothermia than young mice. Histones thus inactivating them and improving sepsis related complications upon release from dying cells [Xu et al. (2009) Nature Medicine]. APC, activated protein C receptor; EPCR: endothelial protein C receptor. Western Blot Analysis. Proteins were electrophoretically transferred to nitrocellulose or polyvinylidene fluoride membranes and Western blot analysis performed. 

**Figure 9.** Aged mice are more sensitive to LPS-induced hypothermia than young mice. Histones thus inactivating them and improving sepsis related complications upon release from dying cells [Xu et al. (2009) Nature Medicine]. APC, activated protein C receptor; EPCR: endothelial protein C receptor. Western Blot Analysis. Proteins were electrophoretically transferred to nitrocellulose or polyvinylidene fluoride membranes and Western blot analysis performed. 

**Figure 10.** Aged mice are more sensitive to LPS-induced hypothermia than young mice. Histones thus inactivating them and improving sepsis related complications upon release from dying cells [Xu et al. (2009) Nature Medicine]. APC, activated protein C receptor; EPCR: endothelial protein C receptor. Western Blot Analysis. Proteins were electrophoretically transferred to nitrocellulose or polyvinylidene fluoride membranes and Western blot analysis performed.