Background

According to the Alzheimer’s Association (2017), over 5 million Americans are living with Alzheimer’s disease and related dementias, which are considered terminal conditions. Family caregivers may experience loss and grief, leading to ambiguity in their caregiving role. Palliative care interventions are necessary to help family members cope with the progressive and unanswerable grief experienced with these terminal conditions.

The Steps to H.O.P.E. program was created to offer professional guidance, education, and support for family caregivers in understanding and managing ambiguous loss, to maximize resilience and to promote individual self-care.

Aim

1. Caregivers of persons with dementia who participate in the Steps to H.O.P.E. program will experience improved mood and behaviors of caregiver stress, anxiety, compromised coping and the inability to manage progressive loss and grief.
2. Care recipients will experience improved mood and behaviors of dependency upon others was meaning that the caregiver’s perception of a reduction in dependency for the care recipient was significant.

Theoretical Framework

Boundary Ambiguity and Ambiguous Loss Theories are the guiding theoretical frameworks for Steps to H.O.P.E. Ambiguous loss, which happens when a person with dementia is progressively physically present but sometimes psychologically absent, may contribute to caregiver stress, anxiety, compromised coping and the inability to initiate self-care strategies necessary for successful caregiving.

Varied resources are helpful for dementia care professionals and caregivers to learn management strategies for ambiguous loss (Alzheimer’s Society, 2013; Boss, 2006 & 2011).

Seven Guidelines for Managing Ambiguous Loss (Boss, 2011)
1. Find Meaning
2. Balance Control with Acceptance
3. Broaden Your Identity
4. Manage Your Mixed Emotions/Reduce Ambivalence
5. Hold On and Let Go
6. Imagine New Hopes & Dreams
7. Take Time to Mind Yourself: Caregiver Self-care

Sample and Setting

- Four pilot groups of 8 to 10 caregivers of persons with dementia who are experienced with these terminal conditions.
- Caregivers participate in focused discussion and program education and professional guidance, use of the book “Steps to Hope While Coping with Stress and Grief” by Carol O. Long, PhD, RN, FPCN, FAAN and Michael Malek-Ahmadi, MPhPh,Jan Dougherty, MS, RN, FAAN, “Steps to Hope While Coping with Stress and Grief” by Carol O. Long, PhD, RN, FPCN, FAAN and Michael Malek-Ahmadi, MPhPh,Jan Dougherty, MS, RN, FAAN

Method

- Participant Demographics
- Patient Health Questionnaire-2 (PHQ-2) (Kroenke et al., 2003) and one general health question
- Boundary Ambiguity Scale #6 (Boss, 1990)
- Zarit Burden Interview Short Form (Bedard et al., 2001)
- The Dependence Scale (Yaakov, 2002)
- Mood & Behaviors Scale (Cummings et al., 1994; Cummings, 1997).

Intervention

Targeted training and coaching interventions were used in weekly sessions over four weeks for each of the four pilot groups and monthly booster sessions. Study participants read “Steps to Hope While Coping with Stress and Grief” by Carol O. Long, PhD, RN, FPCN, FAAN and Michael Malek-Ahmadi, MPhPh,Jan Dougherty, MS, RN, FAAN

Analysis

- The analysis for this study consisted of descriptive statistics, paired t-tests, and repeated measures ANOVA.
- Qualitative Findings
- Numerous self-care strategies and program tools were reported as helpful to caregivers including: physical exercise, self-talk, asking for help and taking breaks throughout the day.

Demographic Characteristics

- The total sample (N=37) included 32 females and 5 males with a mean age of 68 years. Most (86%) reported being the primary caregiver; the average length of time of caregiving was 57.3±47.13 months and 81% of the care recipients had Alzheimer’s disease.

Caregiver Stress and Burden

- The findings revealed that there was a reduction in caregiver stress and burden; the Zarit Burden Interview Short Form (F=26.88, p<0.001).
- There was a reduction in ambiguity noted on the Boundary Ambiguity Scale (F=44.82, p<0.001).
- There was a significant reduction in ambiguity, stress and burden for caregivers who participated in the Steps to H.O.P.E. program and a reduction in dependency for the care recipient.

Discussion

- There was a significant reduction in ambiguity, stress and burden for caregivers who participated in the Steps to H.O.P.E. program and a reduction in dependency for the care recipient.
- Self-care reported strategies used by caregivers suggest that program education and professional guidance, use of the book and Seven Guidelines may be helpful for caregivers in managing progressive loss and grief.

Conclusions

- Through education and problem-solving activities in managing loss and grief, family caregivers may begin to initiate self-care strategies, reduce ambiguity and promote inner resilience.
- Providing caregivers with the tools and resources necessary to reduce ambiguity, promote resilience and foster self-care are vital.
- Understanding the relationship between the Steps to H.O.P.E. program interventions and outcomes and the caregiver perception of decreased dependency and decline in the person with dementia requires further investigation.

Selected References


Contact Information

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- For information about the research study, contact Dr. Carol Long at carolonghgd@gmail.com

Conclusion

There was a significant reduction in ambiguity, stress and burden for caregivers who participated in the Steps to H.O.P.E. program and a reduction in dependency for the care recipient.

Self-care reported strategies used by caregivers suggest that program education and professional guidance, use of the book and Seven Guidelines may be helpful for caregivers in managing progressive loss and grief.