

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 unsurmountable 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 a reduction in ambiguous loss, stress and burden, and identify self-care measures to improve overall health and well-being.
2. Care recipients will experience improved mood and behaviors and decreased dependence on caregivers.

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 caregiver 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

Method

Sample and Setting

- Four pilot groups of 8 to 10 caregivers of persons with dementia were recruited to participate in focused discussion and professional guidance about ambiguous loss. A convenience sample of thirty-seven (37) caregivers participated in this pilot study.
- Inclusion criteria: Each participant self-verified that 1) they either live with the person with dementia or have in-person contact at least four hours a week 2) were 18 years of age or older, 3) their family member had a dementia diagnosis and 4) they could read, write, and understand English.
- The Steps to H.O.P.E. program was launched at Banner Alzheimer's Institute (BAI), an out-patient center of excellence, located in Phoenix, Arizona.

Design

A comparative experimental design with repeated measures was used for this research. Approval for the study was obtained from the Institutional Review Board at Banner Health.

Measures

1. Participant Demographics
2. Patient Health Questionnaire-2 (PHQ-2) (Kroenke et al., 2003) and one general health question
3. Boundary Ambiguity Scale #6 (Boss, 1990)
4. Zarit Burden Interview Short Form (Bedard et al., 2001)
5. The Dependence Scale (Yaakov, 2002)
6. 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 *Loving Someone Who Has Dementia* (Boss, 2011) and reviewed the Seven Guidelines for Managing Ambiguous Loss.

Analysis

The analysis for this study consisted of descriptive statistics, paired t-tests, and repeated measures ANOVA.

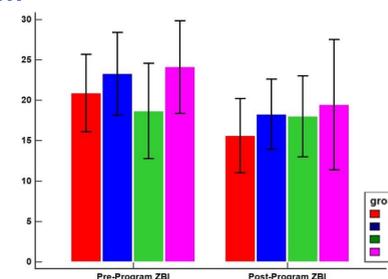
Results

Demographic Characteristics

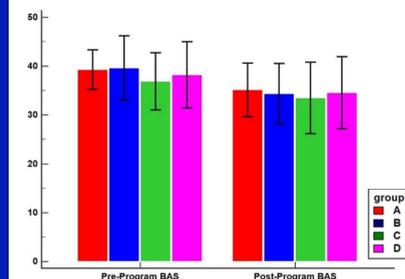
The total sample (N=37) included 32 females and 5 males with a mean age of 68 years. Most (89%) reported being the primary caregiver; the average length of time of caregiving was 57.31±47.13 months and 81% of the care recipients had Alzheimer's disease.

Caregiver Stress and Burden

The findings revealed that there was a reduction in caregiver stress and burden on the Zarit Burden Interview Short Form ($F=26.88, p<0.001$)



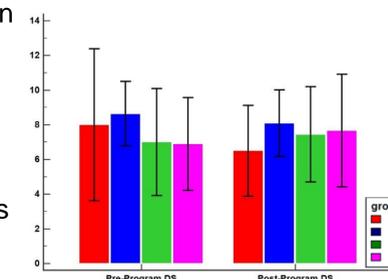
Boundary Ambiguity



There was a reduction in ambiguity noted on the Boundary Ambiguity Scale ($F=44.82, p<0.001$).

Dependence

There was a group interaction effect for The Dependence Scale ($F=3.16, p=.037$) meaning that the caregiver's perception of a reduction in the person with dementia's dependency upon others was related to their pilot group affiliation.



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.

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

- Alzheimer's Society. (2013). *Ambiguous loss and grief in dementia. A resource for healthcare providers.* Available from <http://www.alzheimer.ca>
- Boss, P. (2006). *Loss, trauma, and resilience. Therapeutic work with ambiguous loss.* New York: W. W. Norton & Company.
- Boss, P. (2011). *Loving someone who has dementia. How to find hope while coping with stress and grief.* San Francisco, CA: Jossey-Bass.

Contact Information

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