



At Banner Alzheimer's Institute, our Family & Community Services department sought to create an innovative program to better address grief and loss in dementia caregiving, assisting caregivers in identifying and coping with the "ambiguous loss" that occurs when a person with dementia is physically present, but psychologically changed or absent. Ambiguous loss is defined as a profound loss that is unclear, has no resolution and has no predictable ending or closure. This loss is rarely recognized by others, which can trigger stigma and intensify social isolation. This term was coined by Dr. Pauline Boss, who has written several books on this subject including, *Loving Someone Who Has Dementia*, in 2011.

The Steps to H.O.P.E. (Health, Optimism, Purpose, Endurance) program began in 2015 with the intention of introducing the concept of ambiguous loss in order to help family caregivers understand and name the unique grief that they experience in caring for their loved one with dementia; learn superior coping skills to enable more positive health and wellness; and stimulate greater success in caregiving. The program was delivered using a group therapy approach through instruction regarding Dr. Boss' ambiguous loss principles, counseling and training on concrete guidelines and strategies, bolstering the ability for participants to learn from each other, reduce isolation and develop longer-standing connections.

Our pilot included four groups offered to 38 caregivers, followed by monthly booster sessions. Each group demonstrated a statistically significant reduction in caregiver stress/burden on the Zarit Burden Scale and a reduction in ambiguity on the Boundary Ambiguity Scale over the course of each four week program.

In sum, through education, counseling and problem-solving activities in managing progressive loss and grief, family caregivers may begin to initiate self-care strategies, reduce ambiguity and promote inner resilience. We found that providing caregivers with the tools and resources necessary fosters vital self-care and in some cases, led to the caregiver's perception of a reduction in dependency for their care recipient as shown by the Dependence Scale.

These outcomes have gained significant traction nationally. In 2017, the results of this pilot project were recognized outside of BAI through an invitation for a workshop at the American Society on Aging Conference, in Chicago, IL; a poster session and ribbon award at the Annual NICHE Conference (Nurse's Improving Care for Health System Elders) in Austin, Texas and locally by a poster session at the Arizona Alzheimer's Consortium Scientific Conference in Phoenix, AZ. The most notable invitation was acceptance in the poster session at the Alzheimer's Association International Conference held recently in London, England. This project was published in the University of Arizona, College of Medicine Elder Care Journal, June, 2017 edition.

With the benefit of this Practice Change Leaders Award, the goal is to build on and leverage the positive results of the program and further develop its range to include additional caregivers at our Phoenix clinic. We also have plans to expand the program's scope to our sister site, Banner Sun Health Research Institute (BSHRI) located in Sun City, AZ to permit many other dyads within this retirement community to benefit. Increasing the number of family caregivers into this program will offer the chance to expand research and more widely disperse the results of the pilot trial, while establishing more dramatic outcomes. In addition, we plan to expand our target population to include a program track for people with early stage memory loss as our investigation reveals that those with insight into their illness often experience an analogous form of grief. Additionally, we believe it is critical to promote efforts to share Train the Trainer information with a larger number of community and rural professionals in order to ultimately impact a greater number of family caregivers.