



June 2017

ELDER CARE

A Resource for Interprofessional Providers

Ambiguous Loss in Dementia Caregiving

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Professional and informal caregivers of persons with dementia face numerous challenges in their roles, frequently resulting in stress and burden. At times, caregiver stress and burden may be misunderstood. Perhaps the real culprit responsible for these feelings is ambiguous loss.

What is Ambiguous Loss

Pauline Boss, PhD originated the Theory of Ambiguous Loss as a way to explain losses that are related to presence and absence. Ambiguous loss is a loss that is unclear; it has no resolution and no predictable ending or closure. It occurs in two situations. The first, not relevant to dementia, is when the physical body is absent but psychologically the person is still present to family and others. The second type of ambiguous loss is when the body is physically present, but the person is changed from how they once were, as is the case in dementia. For caregivers, the grief that is experienced with ambiguous loss in dementia is confusing and unlike other types of grief.

Ambiguous loss in dementia is a powerful stressor that leads to anxiety and ongoing strain and tension that can block the caregiver's ability to cope when engaging in the necessary and important tasks of caring for the person and for themselves. Ambiguous loss is a relational phenomenon that obscures relationships, creating role confusion. Family members may experience ongoing stress and grief that leads to depression, anxiety, family discord and subsequently dysfunctional relationships. Over time, ongoing dissonance can erode once-positive interactions, leading to isolation for caregivers.

The Importance of Understanding Ambiguous Loss

Understanding this unique loss can help the caregiver develop methods to cope more effectively and live successfully with the uncertainty of dementia. The challenge for caregivers is to learn how to become more comfortable

with ambiguity and to learn new ways of relating to the person with dementia. Since the progression and effects of dementia cannot be controlled, how caregivers perceive and manage these losses promotes resilience in their daily lives. Naming the problem, deriving meaning from the experience during times of great sadness, and normalizing feelings can help with coping. As caregiver stress and burden are better managed, the person with dementia may also benefit.

Professionals can help caregivers achieve comfort with ambiguity by explaining ambiguous loss and supporting everyday strategies to manage this ambiguity. Key concepts that professionals can use to achieve this goal include the following:

Call it what it is: Ambiguous Loss Explaining the concept of ambiguous loss to caregivers can be a powerful way to help them cope by providing meaning to their own personal experience. Coach caregivers to use the term "ambiguous loss," thereby dispelling the notion that the problem is them, when, in fact, the problem is the situation. This allows caregivers to take the first step in proactively managing ambiguous loss.

Accept what is "Good Enough" This principle requires caregivers to learn that less than perfect solutions are both acceptable and attainable. Coach caregivers to avoid absolute thinking and the need for certainty, but instead to find the middle ground. Emphasize that although the relationship has changed, it is still important. Encourage caregivers to create new rituals as a way to cope and thrive day-to-day. When feasible, caregivers should continue with family celebrations and traditions, with adaptations as needed (e.g., birthdays, holidays, etc.).

TIPS FOR MANAGING AMBIGUOUS LOSS IN DEMENTIA CAREGIVING

- Dementia creates ambiguity. What was will never be again. Guide caregivers to change their perceptions and to re-frame the experience.
- Dementia can't take everything away. Daily joy and resilience is possible from learning ways to change perceptions and manage ambiguous loss.
- While much is lost, much can be gained. Incorporating new skills into each day will boost resilience and coping abilities.

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Engage in “Dual Thinking” Dual or paradoxical thinking allows the caregiver to accept the presence and absence found in ambiguity. Using “both/and” thinking as opposed to “either/or” holds two contradictory ideas, both of which are true at the same time. Help caregivers to reframe their perceptions of a situation and diagnosis that cannot be changed through revised thinking strategies. The following statement is an example of dual thinking: “My husband is here and needs help, *and* I need opportunities to enjoy my life.”

Make Peace with Ambiguity Accepting ambiguity requires the caregiver to be ok with unanswered questions and problems that cannot be fixed, as they are not in control. Guide caregivers to find meaning in a relationship that has changed as a pathway to greater resilience. Coach caregivers to live each day as it comes; to stay present and in the moment. Help them recognize that closure is impossible with ambiguous loss. Encourage them to see the positive side of ambiguity with newly learned skills but also to acknowledge sadness and to grieve along the way.

Revise Self-Identity Ambiguity evolves from the lack of clarity and identity in the caregiving role. Interpersonal and family relationships are challenged by the ambiguity created by dementia. Assist caregivers to revise and broaden their self-identity to fit the ambiguity as a way to lower their stress and reduce role confusion. Encourage dual thinking to help. For example, “I am both a caregiver and a wife.”

Reduce Ambivalence It is normal to have ambivalent feelings or mixed emotions when caring for someone with dementia. Anger, guilt, or wishing that it were over are normal feelings. However, unrecognized ambivalence can fuel negative relationships and destroy caregiver resilience. Guide caregivers to share ambivalent feelings with supportive friends, a support group, or healthcare professionals as needed. Seek professional help for caregivers who express extreme distress, hopelessness,

helplessness, are depressed, or unable to function.

Restructure Attachments Personal attachments change in ambiguous loss. While the caregiver is “attached” or connected to the person with dementia, the relationship becomes one-sided and may lead to anxiety, stress and role confusion. Dr. Boss refers to this concept as “holding on and letting go.” Professionals can guide caregivers to create and verbalize new goals: 1) to revise the attachment and learn to live with the ambiguity of the loss and 2) accept a less than perfect relationship, still important, but now changed.

Build a Psychological Family Human connections keep one healthy and are vital during times of stress, loss, and the continuing challenges of caregiving. Encourage caregivers to seek new or strengthen current connections to a psychological family (e.g., friends, neighbors, and support systems) to help manage the stress of caregiving. This may require caregivers to ask for additional hands-on assistance and/or for emotional support. Be prepared to share local community resources with caregivers, including professional counselors, support groups, and respite care.

Take Control of Self-Care While the current situation cannot be fixed, the approach to living each day can. Thus, self-preservation is necessary. Provide practical strategies for caregivers to regularly engage in self-care (e.g., exercise, hobbies, respite care), to secure extra help as needed and to build connections with a psychological family. As Boss writes, “minding yourself is not selfish. Do it for the person you love who now needs you to stay healthy and strong.”

In summary, resolve can emerge from recognizing and making peace with ambiguity and by learning new skills. Coach caregivers to let go of the past, which can no longer be relived, and to create hopes and dreams for a future of realistic possibilities.

“Life with dementia can be less than ideal and still be pretty good. That perceptual shift is under your control.”
- Pauline Boss, 2011, p. 171

References and Resources

- Alzheimer’s Society. Ambiguous loss and grief in dementia. A resource for individuals and families. 2013. http://www.alzheimer.ca/~media/Files/national/Core-lit-brochures/ambiguous_loss_family_e.pdf
- Alzheimer’s Society. Ambiguous loss and grief in dementia. A resource for healthcare providers. 2013. <http://www.alzheimer.ca/en/We-can-help/Resources/For-health-care-professionals/grief>
- Boss P. Loss, trauma, and resilience. Therapeutic work with ambiguous loss. 2006. New York: WW Norton & Company.
- Boss P. Loving Someone Who Has Dementia. How to Find Hope While Coping with Stress and Grief. 2011, San Francisco, CA: Jossey-Bass.

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Supported by: Donald W. Reynolds Foundation, Arizona Geriatrics Workforce Enhancement Program and the University of Arizona Center on Aging

This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U1QHP28721, Arizona Geriatrics Workforce Enhancement Program. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.