Caregiving Through Uncertain Times:

Finding Meaning and New Hope in Ambiguous Loss

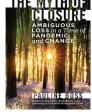
Dr. Pauline Boss Professor Emeritus University of Minnesota

Mid-America Institute on Aging and Wellness August 12, 2022

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Presentation Based On



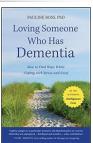


Harvard University Press, 2000

W. W. Norton, 2022



W. W. Norton, 2006



Jossey-Bass, 2011



What is Ambiguous Loss?

- A loss that remains unclear and without resolution.
- A loss that has no official or social verification; thus can't be clarified, cured, or fixed.
- A rupture in a close relationship.
- Thus, an ambiguous loss implies there was attachment to the person or object that has gone missing

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Two Types of Ambiguous Loss

- I. <u>Physical absence with psychological presence catastrophic:</u> MIA soldiers, Holocaust victims, forced separations, refugees, missing bodies, kidnapped, imprisoned; <u>more common</u>: unable to be with loved ones during pandemic; breakups; family alienation; divorce; adoption; immigration, migration; military deployment; transitioning gender; loved one leaving home for institutional care.
- II. Psychological absence with physical presence catastrophic: Alzheimer's disease and the over 80 other illnesses/conditions that cause dementia, brain injury, addiction, serious mental illnesses; more common. preoccupation with work, our devices, gaming, etc.

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Note:

<u>Both types</u> of ambiguous loss can occur simultaneously in *one family:* caregiver's husband, suffering with dementia, must leave home to go to institutional care (physical AL)—while daughter, living at home, is suffering with severe depression (psychological AL).

Again, an ambiguous loss implies attachment to the missing person.



Personal Ambiguous Loss

- Physical: loss of a limb, loss of reproductive organs, loss of sight or hearing, etc.
- Psychological: loss of one's memory and cognitive skills.
- <u>Both types</u> of ambiguous loss can occur simultaneously in *one person*: e.g., the simultaneous loss of physical and psychological functions (being unable to walk plus loss of cognitive functioning).

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Ambiguous Losses Due to COVID-19 (hard to quantify)

- Loss of certainty about safety and health for yourself as caregiver and for the person you care for.
- Loss of routines that give meaning to the caregiving day.
- Loss of caregiver's support systems and social contacts.
- Loss of caregiver's ability to be with loved one who is hospitalized, in nursing home, or in hospice, dying.
- Loss of traditional rituals of mourning and burial, not knowing where the body of a loved one is.
- Loss of trust in the world as a safe place.

(See Boss, 2022, for more.)

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Clear Losses (easy to quantify)

- Validated deaths of family, friends, colleagues
- Loss of job or business and thus income
- Loss of retirement savings
- Loss of one's home or apartment
- Other

(Boss, 2022)



What Ambiguous Loss is Not

(*with caveats)

- Not death* (yet this depends on beliefs)
- Not a grief disorder* (yet akin to complicated grief; prolonged grief disorder)
- Not PTSD* (yet traumatic)
- Not ambivalence

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Unlike Death . . .

- AL has no official verification that a loss has occurred.
- With the <u>physically</u> missing: "She is gone from our home now, but still present in my heart and mind."
- With the <u>psychologically</u> missing: "She is both here at home with me, and also gone."
- Thus, ambiguous loss is a <u>paradoxical</u> kind of loss: <u>both gone and here; both here and gone</u>. Caregivers feel this. Name it, so they can begin coping.

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Unlike Complicated Grief . . .

- With AL, chronic grief is a normal reaction to an abnormal social situation; a relational loss. The source of pathology lies externally in the <u>type</u> of loss, ambiguous—not in a caregiver's psyche.
- Yet, because AL is a complicated <u>loss</u>, it has been linked to complicated <u>grief</u> disorder: on-going state of grief, problems accepting death/loss, lack of trust in others, bitterness about the loss, etc. (Shear et al., 2011; Mayo Clinic, n.d.)
- Such symptoms understandably experienced by families of the lost, physically or psychologically.

Unlike DSM 5+ Prolonged Grief Disorder . . .



- Most people/caregivers with ambiguous loss should not be labeled as sick or having a disorder; instead, the pathology lies in their <u>social context</u> of "ambiguity and its uncertainty."
- Yet, they may manifest symptoms akin to the recent "Prolonged Grief Disorder": unresolved loss and grief, preoccupation with lost person, difficulty finding meaning, putting life on hold, chronic sadness, not accepting their absence/death.
- Such criteria pathologizes typical reactions to having someone you love go missing—in mind or body.
- Therapeutic goal: Externalize the blame to the context; it's not the fault of those left behind (e.g., dementia, leaving home for care, pandemic, war, natural disasters, etc.).

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Can Death Also be an Ambiguous Loss?



- An officially validated or witnessed death is <u>not</u> an ambiguous loss.
- But there is often a degree of ambiguity after a death due to unanswered questions.
- Some deaths have more ambiguity than others; they count as ambiguous losses because they may never make sense, lack meaning:

Suicide, murder, friendly fire Death of an infant or child Miscarriage, stillborn Execution of innocents: the Holocaust, genocide, unjust police killings

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Individual Effects of Ambiguous Loss

Caregiver Symptoms of Depression

- Anxiety
- Hopelessness (no meaning); brain does not like ambiguity
- Helplessness (no mastery without facts)
- Confused identity (Who am I now?)
- Increased ambivalence: social, not psychiatric
- Anxious attachment (insecure, searching)
- Frozen grief (sadness vs. depression)



Sadness vs. Depression

- Sadness: mildly grieving and unhappy, but still functioning; oscillation. <u>Intervention:</u> human connection, peer groups, social support and activities.
- Depression: sadness so deep one cannot function; cannot care for self or others.
- <u>Intervention</u>: professional psychotherapy, family therapy, perhaps medication.

(Adapted from Boss, 2011, pp. 26 & 130)

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Family/Couple Systemic Effects

- Family conflict: cutoffs, rifts, alienation
- Family rituals/celebrations: canceled
- Roles: confused; who does what?
- Family/couple boundaries: who is in, who is out? Not clear.
- Family decision making: process frozen

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What Does AL Teach Us About Closure?

The Myth of Closure, Boss (2022)

- Define closure: an act of closing—like the closing of a door, a gate, a road, or business deal.
- Popular meaning: the completion of grief. The mourner can now move on without further grief or sadness.
 They (and we) are "over it."
- Closure implies there is a finite ending to grief; prolonged grief is pathological (DSM 5+).

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The Myth of Closure (cont.)

- Or is it a misnomer? Does a caregiver have closure when the care recipient dies?
- Will we have closure on our pandemic losses?
- <u>Current research</u>: We can live with grief if we find some meaning and purpose in it; no need for closure. (See Victor Frankl and other references at end of ppt.)

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Where Did the Idea of Closure Come From?

- Societal impatience with grief and suffering, thus needing people to "get over it" fast.
- Our fear and denial of death (Becker, The Denial of Death, 1973).
- Our cultural discomfort with ambiguity and its uncertainty.

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The Culture of Closure

A culture that values mastery and control will demand closure;

A culture that denies death will demand closure;

A culture that assumes we can solve any problem will demand closure;

And our own anxiety about death demands closure (Boss, 2011).

Denial of historical or present loss is false closure (Boss, 2022).



Cultural Meanings of Loss and Grief

Mastery over Nature (more Western view)

- One can master anything if you try hard enough.
 Loss and grief are things to "get over."
 We can cure, fix, solve anything.

- Successful people don't suffer; judgement.
 Illness is failure and something to be ashamed of.

Harmony with Nature (more Eastern view)

- Suffering is part of life.
- Thinking that suffering can be avoided is ego
- wanting its own way.

 It is possible to have a good life while living with the suffering of loss.

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Cultural Beliefs About Closure After Death

- More Eastern Views Desire to stay in touch with ancestors who often perform a symbolic role; e.g., they watch over the missing family members. (Fukushima, Native Americans)
- More Western Views
 Need for closure, need to be productive again, "need to get
 over it," discomfort with others who are suffering; judgement.
- East and West: Rituals of comfort provided for families after a death but often withheld from families suffering with ambiguous loss. (9/11 and 3/11)
- Values: Community support vs. individual self-reliance. Both?

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Conflicting Ideas: The Personal vs. the Professional

Although grief experts have historically promoted the idea of closure and finishing the work of grieving, they, surprisingly, tell a very different story when referring to their own losses.

When a patient asked Freud about his beloved daughter who died from the 1918 flu, he touched a tiny locket that he wore fastened to his watch chain, and said, "She is here." Peter Gay, Freud: A Life for Our Time, 2006, p. 392

Freud reflects this view of "no closure" in his personal writings more than in his professional writings. (See Boss, 2022.)



More Conflicted Messages

- Freud's letter to Binswanger after he lost his son. (See Boss, 2022, p 97.)
- Freud: "... although mourning involves grave departures from the normal attitude toward life, it never occurs to us to regard it as a pathological condition and to refer it to a medical treatment" (Shear et al., 2011, p. 243).
- <u>Kübler-Ross'</u> last writings after she was suffering from strokes. (See Boss, 2022, pp. 98-99.)

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Elisabeth Kübler-Ross

"The process of dying when it is prolonged like mine is a nightmare. I have struggled with the constant pain and paralysis. After many years of total independence, it is a difficult state of being. It has been a long nine years since my stroke, and I am anxious to die—graduate as I call it. I now know that the purpose of my life is more than these stages. . . . It is not just about knowing the stages. It is not just about life lost but also the life lived. . . . I am so much more than five stages. And so are you."

(Kübler-Ross & Kessler, 2005, p. 216)

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Instead of Closure:



Continuing Bonds Silverman & Klass, 1996

- In the 1996 Continuing Bonds, Phyllis Silverman and Dennis Klass state their thesis of continuing bonds:
 - "The focus on facilitating mourning needs to be on how to change connections, to hold the relationship separate" (Silverman & Klass, 1996, p. 20).
- Also, Viktor Frankl's personal words are congruent with his professional writings. (See Boss, 2022, pp. 100-101.)



Treatment & Interventions for Ambiguous Loss

- Assessment
- Resilience
- Paradoxical Thinking
- Therapy and Interventions
- Guidelines for Meaning and New Hope

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ASSESSMENT: Family Roles, Rules, & Rituals

Roles

• Who does what in the family now that someone is missing?

Rules

• Who is in charge or is power shared?

Rituals

What family and community celebrations, holiday events, and religious rituals did you observe before your losses, clear or ambiguous? How do you and your family adapt now given your loss?

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RESILIENCE

Our best hope with ambiguous loss and other stressors that have no solution is <u>resilience</u>. (E.g., dementia, terminal illness, natural disasters, etc.).



The Many Definitions of Resilience

- Family resilience is the path the family follows as it adapts and prospers in the face of stress in the present and over time (paraphrased, Hawley & DeHaan, 1996).
- Strengths forged through adversity (Walsh, 2012).
- Individual resilience: Ordinary magic (Masten, 2001).
- With ambiguous loss, resilience is having a high tolerance for ambiguity (Boss, 2006, 2022).

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Update on Resilience

(Boss, 2006; Boss, Bryant, & Mancini, 2017)

- Resilience is more than recovery.
- · Resilience is more common than we thought.
- There are often uncommon pathways to resilience: e.g., family, community, culture, spiritual beliefs, etc. (See Boss, 2006, Ch. 3.)
- Family Stress Management: A Contextual Approach (3rd edition) update (Boss, Bryant, & Mancini, 2017).
- Cautions today about being resilient.

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Cautions About Resilience

- Resilience is not always desirable (injustice, abuse).
 Change and agency needed, not resilience.
- The process of resilience contributes to "allostatic load and weathering" for "Black Americans who persevered and thrived in the face of pervasive adversity" leading to "significant health challenges" (Bryant, Anderson, & Notice, 2022).



New Ways of Thinking to Find Meaning in Our Ambiguous Loss

The test of a first-rate intelligence is the ability to hold two opposed ideas in mind at the same time, and still retain the ability to function.

--F. Scott Fitzgerald *The Crack-Up,* 1945, p. 69

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Both/And Thinking for Finding Meaning in Ambiguous Loss

- She is both gone—and still here. (e.g., "Far-Away Maggie" in The Ferryman).
- I must find a way to both let go—and hold on.
- I am both sad about my lost hopes and dreams—and happy about some new ones.
- Yours?

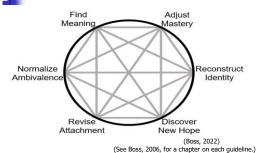
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. . . As Opposed to Absolute/Binary Thinking

- Nothing is wrong: Nothing has changed. Dad is only forgetful because he is aging. Let him drive.
- Premature closure: Person is alive, but extruded from the family. He is dead to me. She no longer knows me, so I no longer visit her.
- Binary thinking: She is either alive or dead; present or absent; there is nothing in between.

Six Guidelines for Living with Ambiguous Loss and its Unresolved and Prolonged Grief



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How to Use the Guidelines

- Nonlinear
- No stages or phases
- No prescribed order
- No timeline
- Flexible process

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Find Meaning

Find Meaning: How can I make sense of my loss?

What Helps? Giving the problem a name: "ambiguous loss;" talking with others; using both/and thinking; finding spirituality/ambiguity; continuing, but adapting family rituals and celebrations.

Essential question for professionals to ask someone experiencing ambiguous loss: $\underline{What\ does\ this\ situation\ mean\ to\ you?}$



Adjust Mastery

Adjust Mastery: Recognizing you can't control everything

What Helps? Recognizing the world is not always fair; decreasing self blame; externalizing blame; mastering one's internal self (meditation, prayer, mindfulness); believing that bad things can happen to good people; knowing that sometimes, there are problems that have no solution.

e.g., East Timor vs. NYC

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Reconstruct Identity

Reconstruct Identity: Who am I now?

What Helps? Imagining new roles and experiences; finding a psychological family (peer group); redefining your relationship boundaries: who's in, who's out, who plays what roles. Ask yourself: Who am I now? What community or group do I belong to now? Am I married or single?

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Normalize Ambivalence

Normalize Ambivalence: Mixed emotions

What Helps? Normalizing anger and guilt, but not harmful actions; seeing conflicted feelings about caregiving as normal, but talk about them with a peer group or mental health professional.

Consider the difference between guilt and shame.



Revise Attachment

Revise Attachment: Letting go while remembering

<u>What Helps?</u> Recognizing that your loved one is *both* here *and* gone; grieving what you've lost, celebrating what you still have; finding new human connections; not expecting closure.

- --Loved ones remain part of our lives after loss, clear or ambiguous, but symbolically, in a new way.
- --After loss, it's normal to remember someone or something to whom we have been attached.

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Discover New Hope

Discover New Hope

What Helps? Becoming more comfortable with ambiguity (a kind of spirituality), being able to laugh at absurdity, redefine justice, imagine new hopes and dreams, and feel some control over your life—even if the ambiguity persists and things don't always go your way.

--Know there is no meaning without hope nor hope without meaning. They are linked. (Based on Frankl, 2006, original publication, 1959)

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Our Personal/Professional Challenge

- Give up on perfectionism in human relationships.
- Temper our need for mastery and control.
- Increase our tolerance for ambiguity, not closure.
- But in situations where we are controlled by an outside force (e.g., COVID, illness), find something we can control, even if small.
- View anxiety as normal in abnormal times. (See Boss,
- Practice having fun with ambiguity (Carl Whitaker: "Let's go and get lost.")



Ending. . . .

Questions and Comments?

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AL Online Training

The University of Minnesota's Department of Family Social Science now offers an online noncredit professional development certificate program led by Dr. Pauline Boss, professor emeritus and the groundbreaking family therapy theorist known as the pioneer in the interdisciplinary study of ambiguous loss. Human relationships are often traumatized by ambiguous loss; however, this unique kind of loss is just beginning to be discussed in professional texts and training courses. Understanding the difference between ambiguous loss and other kinds of loss will help you serve students, clients, and patients more effectively.

Cost: Multiple options. \$100 for just the introductory module, or \$500 for entire program. You will earn a professional development Certificate of Completion and 15 CEUs from the University of Minnesota.

Learn more:

http://www.cehd.umn.edu/fsos/programs/continuing_ed/AL_index.html_or www.ambiquousloss.com.

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Appendix Update on Loss and Grief

A. Focus: Finishing the Work of Grief

- Grief as Repressed or Delayed (Lindemann, 1944)
- Grief in Five Stages (Kübler-Ross, 1969) (denial, anger, bargaining, Grief in Tive Sages (Kubier-Noss, 1909) (Jenial, Jangel, Jangelining, depression, acceptance)
 Four Tasks of Mourning (Worden, 2018)
 Focus: More Nuanced Types of Grief
 Disenfranchised Grief (Doka, 1989); Complicated Grief (Shear et al., 2011)

- Chronic Sorrow (Harris, 2010; Olshansky, 1962; Roos, 2002)
- Grief as normal oscillations instead of closure (Bonanno, 2009; Kissane,

2003; Kissane & Hooghe, 2011). C. Focus on Living With Grief; No Need to "Get Over It;" No Timeline

- Becvar, 2001 Frankl, 1959 Neimeyer et al., 2011 Kissane & Hooghe, 2011 O'Connor, 2022
- Boss, 2006-2022
- Boss & Carnes, 2012 Kissane & Parnes, 2014 Boss & Ishii, 2015 Klass et al., 1996



Appendix (cont.)

- D. Focus on Types of Loss (Context)
 Ambiguous Loss (Boss 1999/2000, 2006, 2011, 2012a, 2022)
- Traumatic Loss (Huppertz, 2019; van der Kolk, 2014)
 E. Focus on Resilience Instead of Closure
 Becvar, 2001 Masten, 2001, 2016

- Boss, 2006, 2012b, 2022 Hawley & DeHaan, 1996 Film: Wind River, etc.
- McCubbin & McCubbin, 1993 Walsh, 1998, 2012

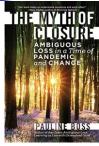
F. Focus on Family/Community After Loss

- Kissane & Parnes, 2014 Landau, 2007 Robins, 2013 Saul, 2013 Boss, 1988/2002, 1999/2000, 2006 Boss, Beaulieu, Wieling, Turner,
- & LaCruz, 2003

Kissane, 2003 Kissane & Hooghe, 2011

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- Also, see www.ambiguousloss.com.



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