

The Trauma and Complicated Grief of Ambiguous Loss

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Published online: 11 November 2009
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Abstract Ambiguous loss is a newly identified type of loss that occurs when a loved one is physically present, but psychologically absent. Dementia is just one example. Because the lost person is here, but not here, grief is frozen, life is put on hold, and people are traumatized. With no official verification of death, no possibility of closure, and no rituals for support, there is no resolution of grief (Boss 1999). Clergy, especially pastoral counselors, can witness and provide comfort for such uncanny loss because people rely on them for support, not just from the clear loss of death, but from the ambiguous losses, catastrophic and ordinary, that inevitably will occur across the life course.

Keywords Ambiguous loss · Traumatic loss · Complicated grief · Resilience · Self-reflection

In the world of unresolved grief, there is a unique kind of loss that complicates grief, confuses relationships, and prevents closure. I call it *ambiguous loss*. It lies at the root of much depression, anxiety, and family conflict. While religious communities traditionally have comforted those who lose a loved one from death—a clear loss—less attention is paid to ambiguous loss. This is understandable as there is no official notice or ritual for such unclear loss. Yet, the trauma devastates people. Traditional therapies are insufficient because closure, the usual goal in grief therapy, is impossible. With faith communities so often the central support system for people who are suffering, knowing about this more nuanced and complicated loss is important.¹

I begin with the story of Jan. She was sad and anxious, not able to concentrate, and feeling guilty about her role as wife of her beloved husband. She did not know what to do

¹While the ambiguous loss theory is useful as well for understanding and intervening with distressed communities (congregations, for example, where a pastor is incapacitated), I limit my focus here to the couple and family levels. For details, see Boss (1999, 2006) and www.ambiguousloss.com.

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or where to turn. When I saw her, she apologized for needing therapy, as she was proud of her self-sufficiency. But she was desperate. Her husband of 49 years was, as she said, “no longer himself.” I asked her what she meant. She said he forgot things, was getting lost even out in the yard, and at times became angry and coarse in his speech and actions, something he never did before. The doctor diagnosed frontal lobe dementia. She knew he was fading away but couldn’t grieve because he was still alive. She was depressed—and stuck.

I told Jan that she was experiencing ambiguous loss, the most difficult kind of loss because it was so confusing and without closure. The trauma she felt was from the immobilizing ambiguity surrounding the psychological loss of her husband—and not knowing what would disappear next. The roller coaster experience of his being lost, with occasional flashes of return, only added to her confusion. It encouraged false hopes that he might recover, and that immobilized her even more.

I did not see Jan for long. Once she understood that the real culprit was the ambiguity and not her husband, she knew how to proceed. To ease her ambivalence and guilt about what she thought was premature grief, I encouraged her to take time to grieve the little losses from the illness as they occurred instead of only seeing grieving as something one does after the finality of death. Her resilience was back in play. It was still not easy, but she could cope now that she knew what the problem was and that she had the power to shape its meaning. Her problem was not a recalcitrant husband nor even a terrible disease, but rather, learning how to live with an irresolvable quandary—ambiguous loss.

How do people do this? First, they need someone—clergy, counselors, medical professionals—to witness and validate their uncanny experience. They need a name. I begin simply with, “What you are experiencing is an ambiguous loss, the most difficult kind of loss because there is no closure.” I do not pathologize. Depression is, of course, a symptom that needs treatment, but its cause is not always a weak psyche. In the case of ambiguous loss, the cause lies in the external environment. It is important for people suffering from this kind of traumatic loss to know that it is not their fault (See Boss 2006.)

What is ambiguous loss?

- * Ambiguous loss is unclear loss.
- * Ambiguous loss is traumatic loss.
- * Ambiguous loss is a relational disorder.
- * Ambiguous loss is externally caused (e.g., illness, war), not by individual pathology.
- * Ambiguous loss is an uncanny loss—confusing and incomprehensible.²

There are two types of ambiguous loss. *The first is physical absence with psychological presence.* A loved one is missing physically—lost, kidnapped, disappeared, but kept present psychologically because they might reappear. Examples can be catastrophic (e.g., lost at sea with no body to bury) or more common (divorce, adoption, migration, immigration).

The second type of ambiguous loss—the focus of this paper—is physical presence with psychological absence. A loved one is physically present, but missing psychologically. Catastrophic examples are Alzheimer’s disease, Pick’s disease and others that lead to dementia, traumatic brain injury, stroke, coma, chronic mental illness, depression, autism,

² For research and development of ambiguous loss theory and its clinical application, see Blieszner et al. 2007; Boss, 1999, 2002, 2004, 2006, 2007a, b; and Boss and Greenberg, 1984.

and addiction. More common examples include an excessive preoccupation with work or obsessions with computer games, some other activity, or person. While both types of ambiguous loss can occur simultaneously in one person or family, this discussion is limited to the second type of ambiguous loss—specifically, cognitive impairment from disease or brain injury.

When a loved one loses their memory and personality, caregivers often become anxious and depressed. Symptoms resemble melancholia or complicated grief, but no death has occurred. We begin to pathologize. But even seasoned professionals are stymied by ambiguous loss. A veteran therapist whose husband had an accident and was severely brain injured asks passionately, “How is it possible to lose half a person? Half is dead, half remains alive . . . the uncanny story violates the observer’s trust in reality. Life may then deceive by promising substance and delivering ghosts. The doppelganger sits at the dinner table” (Feilgeson 1993, p. 335). Another experienced therapist felt the same uncanniness about a doppelganger at the dinner table, but this time he was drunk (Boss 2006).

Professionals too experience ambiguous loss, and before we can help others, we need to understand our own. Self-reflection and training are essential before we can comfort or counsel others. Indeed, to live more comfortably with ambiguity and uncertainty, we must first find our own peace with not having all the answers. This may be difficult for absolute thinkers with more fundamental beliefs.

Living with ambiguous loss requires a spiritual tolerance—no, spiritual comfort—with ambiguity. Simply put, it requires faith. Not all professionals are trained to accept this way of thinking, but pastors and people of spirituality have a head start.

However we come to find more comfort with the unknown and unsolvable—and temper our needs for control and mastery—that transformative growth will paradoxically increase our effectiveness to ease the suffering of others who must, through no fault of their own, continue to live with the pain of ambiguous loss.

Is ambiguous loss traumatic?

Yes, ambiguous loss is traumatic because it is painful, immobilizing, and incomprehensible so that coping is blocked. It is akin to the trauma that causes posttraumatic stress disorder (PTSD) in that it is a painful experience far beyond normal human expectations. But unlike PTSD, it remains in the present; that is, the traumatizing experience (the ambiguity) often continues for years, a lifetime, or even across generations as with slavery or the Holocaust. Because there is no social or religious ritual to deal with such losses, people are stuck alone in a limbo of not knowing, with none of the usual supports for grieving and moving forward with their lives.

I think of Mary whose husband has Alzheimer’s disease. She knows now that it is not a one-time trauma. The diagnosis was just the first of many shocks. Many others followed. She listed her cascade of losses: the loss of being able to travel together, the loss of being able to walk together, the loss of his memory, the loss of his continence, the loss of her husband knowing who she was, and, most recently, the loss of his being able to swallow food. Each loss paralyzes her as she does not know what to do about the latest deficit. She has some difficult decisions to make now.

Mary said that the caregiver group at her church was invaluable. Connecting with others who were “in the same boat” helped her regain her resiliency after each shock. Psychoeducational talks by experts gave her the information she needed to make the ever more difficult decisions. Spiritual support gave her the strength to carry on.

Indeed, faith communities play a major role in sponsoring or supporting such peer groups. Importantly, they should not be called “grief groups,” but rather, groups for people like Mary who must live with the inability to grieve. (For more on frozen grief, see Boss 1999.)

Is ambiguous loss different from ordinary loss and grief?

Yes, ambiguous loss is qualitatively different from ordinary loss (death) in that the person is still here, but not all here. Part is gone, part remains. As a result, there is no possibility of resolution or closure.

When a loss is complicated by ambiguity, the grief process is frozen (Boss 1999). The person is immobilized and isolated from the usual supports, which makes matters worse. Unlike death, with ambiguous loss (e.g., dementia or brain injury), the process of bereavement is blocked by an external situation beyond the control of the sufferers. Even the strongest people are immobilized in such situations. Grief therapies are understandably resisted. Bystanders often show impatience and question such resistance by asking, “Why aren’t they over it yet?” Or the other naïve query: “Why didn’t he cry at his wife’s funeral?” People may not realize that all the grieving was done along the way of a very long illness. Death, with its clarity, can actually bring relief.

Knowing the difference between ordinary loss and ambiguous loss helps clergy and congregants to be more empathetic and patient with parishioners whose grief lingers on and on: the woman whose husband is here, but not as he used to be; a father whose son is addicted and no longer himself; a daughter who now mothers her own mother; a person whose mate is having an affair. While death is acknowledged in every religious tradition, ambiguous loss often goes unnoticed, perhaps because it is ubiquitous.

To be sure, some of what we know about traditional grief therapy is still applicable during the downward trajectory of dementia. Family members and friends need validation for their feelings of helplessness and sadness. They need new rituals for each small loss along the way (e.g., sending a paper crane out to sea or a balloon into the air—or lighting a candle) when there is yet another loss in a loved one’s presence. Family, friends, congregants should join in to witness the loss. When loved ones no longer remember our names, it calls for ritual and congregational support even if no death has occurred.

When Esther and her husband moved into a new community, the welcome person brought a basket and then said, “Have a nice life!” It was no wonder that after her father-in-law died, there was little congregational support. They were on their own. Despite urbanization and large congregations, we must return to the old idea of community, of being there for one another in joy and in sadness, and of comforting each other after any kind of loss in the family.

While complicated *loss* causes symptoms that resemble complicated *grief*, the mention of such loss does not exist in our diagnostic manuals now. They do, however, mention the importance of environmental context in grief and loss. That’s a start. While we know that symptoms must be treated, a broader and more inclusive lens is needed to help people live more comfortably with the contextual ambiguity that envelops the cognitively impaired and their families. One such lens is ambiguous loss theory (Boss 1999, 2002, 2004, 2006; Boss et al. 2003). It provides a new way to think about loss and its lack of resolution. Complicated grief is often not the result of emotional weakness; it results from forces outside the individual. How do people cope? They begin by giving up on the idea of closure.

Is closure a myth?

Yes, with ambiguous loss, closure is a myth. Instead of a clear ending, there is a gradual slipping away that is full of confusion. In a can-do society, not being able to find closure is, however, criticized as malingering. Even with dementia—unfinished, unending, and impenetrable—society has little patience. It makes people feel as if the inability to resolve loss is failure. Of course, it is not. Yet, in a society that places a high value on solutions, mourners and caregivers alike are expected to shut the door, get over it, and do so rather quickly. People tell me that is why they stop visiting loved ones with dementia; their discomfort with the ambiguity forces them to consider the person totally gone.

Instead of seeking closure, we should help the people we serve (and ourselves) to become more tolerant of the still-open door. Learning to hold a paradox helps—that someone we love can be both absent and present at the same time.

In cultures where people are socialized to triumph over adversity, however, paradox, compromise, and adaptation are devalued. Yet, adapt we must when an illness takes away the mind. Scientists will soon find a cure for such illnesses, but meanwhile we learn from those who out of necessity have discovered how to adapt.

Rather than stages, or even patterns, I propose guidelines—guidelines for resiliency and how to adapt without harming one's health. Because research shows that caregiving is dangerous to one's health, the goal is caregiver well-being. Applying ambiguous loss theory, six guidelines resulted from three decades of research and therapy with the people who stayed healthy and resilient despite some kind of ambiguous loss. They are not linear, but rather occur in a more chaotic and dialectical pattern of up-and-down, back-and-forth. In addition, individual differences and cultural diversity abound, especially about religious rituals and meaning, so a normative structure on how people were expected to grieve is rejected. Thus we have guidelines (not prescriptions) for resiliency (not normalcy) in the face of complicated loss: (1) finding meaning, (2) tempering mastery, (3) reconstructing identity, (4) normalizing ambivalence, (5) revising attachment, and (6) discovering hope.

Finding meaning

Finding meaning, or being able to make sense out of what is happening is especially difficult with ambiguous loss.³ Viktor Frankl (1963) believed that there is no meaning without hope and no hope without meaning. If hopelessness then leads to depression, it is important for us to help people find some meaning in their loss, in this case, with dementia and brain injury.

The process to find meaning is dialectal, not linear. Rather than focusing on stages of grief, we stimulate a recursive process of both/and thinking. This works best in peer groups. During this process, we discuss cultural attitudes, beliefs, or values that reflect resiliency as well as those that block resiliency and change. Surprisingly, resistance to change often emerges from family narratives and traditions that frankly are rigid. “We stick to our guns.” “We never give up.” “We can find a cure if we look hard enough.” Loss and change are resisted at all costs. Whether family or religious traditions or simply weekly customs of

³ Sometimes, if the loss is so incomprehensible, people say it never will make sense (e.g., a suicide without a note). I tell them that this is also a meaning—it will never make sense! That bring us back to the nonsensical and how people still find new hope. See Boss (2006).

meals together (or the lack thereof, e.g., eating alone or standing up, out of the fridge), traditions can make or break one's resiliency. Flexibility is key. While traditions mean continuity, they must allow for change so that people can bend under the pressure of illnesses that have no cure and losses that have no closure—and emerge stronger for it.

With dementia, the tendency to cancel rituals and traditions may be another form of rigidity. Cancellation represents an absolute decision rooted in resistance to change; "If we can't have the dinner the way we always had it, we cancel it." Not good. Rather, there should be a rethinking of the celebration and where it takes place. The father of the bride had a heart attack and is hospitalized so the wedding is moved to the hospital. Thanksgiving dinner is shifted to a nursing home. Birthdays are celebrated, but simplified. These examples illustrate adaptability and flexibility that make possible the continuity of celebration and ritual.

In both Christian and Jewish faith traditions, it is family rituals, holidays, and celebrations that help us find meaning after loss. What we must guard against are rituals and customs that block resiliency. I was, for example, surprised when a group of older caregiving women said they could no longer attend religious services even though they wanted to. I asked them why not. They replied that they could attend if they were widows but could not while their husbands were still at home. I found their assumptions bizarre but soon realized they had some validity. Whether or not a congregation has such implicit rules, the topic must be addressed openly so that no caregiver feels they must stay home. Because of its authority, the leadership of clergy is essential in asking for volunteers who can fill in for caregivers, female as well as male, so they can still worship with their religious community.

Tempering mastery

To counteract helplessness and regain control, it helps to think of two possible answers to ambiguous loss: "He is both here and not here." "She is both absent and present." Out of necessity, we move to a both/and mind set: "He is both my father and someone who no longer knows who I am." "I am both a daughter and the parent to my parent." "I feel both married and not married." "He is both my husband and a stranger in the house." Thinking in this way is difficult at first because it requires tempering mastery and our need for certainty, but it is possible with mindfulness and practice. Learning to hold two opposing ideas at the same time allows for a synthesis between: (1) insisting on the status quo ("Nothing is wrong with Dad"), and (2) yearning for closure ("Mom is dead to me."). Neither extreme promotes resilience. The goal instead is to become more comfortable with the ambiguity (Boss 1999).

People do, however, need some mastery and control over their lives if they are to remain healthy. The trick is to balance one's need for control with acceptance of an irresolvable loss. Echoing the Serenity Prayer, we talk with others about what can be controlled and what cannot. We accept the ambiguity because there is nothing else we can do. We recognize the world is not always fair—that things don't always go our way and that we can externalize the blame (ambiguity as the culprit). We make choices and decisions where possible and find things we can control, such as reconstructing family gatherings and rituals so they can continue. When we can't master the external environment, we master our internal selves through prayer, meditation, yoga, listening to music, reading poetry, painting, playing the piano, among others. We balance the tyranny of dementia's ambiguity with the ability to master our internal self.

Reconstructing identity

Once a person has memory loss, the people who care about them are forced into changing who they are. Consider these questions: Who am I now that the dementia has made my parent or partner more like a child? Who am I now that my loved one no longer knows who I am? The situation forces us to become more flexible about gender and generational roles. We become more aware of our uniqueness and cultural identity, especially if forced to change what we have been doing before we became a caregiver. We gradually broaden our roles and routines to become a decision maker, problem solver, and head of household. In reconstructing one's identity, we uncover assumptions about our own as well as the community's identity. Stigma and discrimination may block change in identity, even if that means one cannot do the work needed now that there is illness in the family. Increasingly, males are caregiving, but the statistics show that 59–75% of caregivers are wives, adult daughters, daughters-in-law, or sisters (Family Caregiver Alliance 2003).

Hanging on to absolute identities does not serve us well, especially in an aging society. Sons and daughters may now have to tend fathers or mothers. Indeed, who one is expands with ambiguous loss, but with that flexibility, our humanity also grows.

Normalizing ambivalence

Ambiguous loss leads to ambivalence, not psychiatric ambivalence, but what is called sociological ambivalence (Boss 2006; Kaplan and Boss 1999; Merton and Barber 1963; Weigert 1991). Something in the relational environment leads to a person's conflicted feelings and emotions. In the case of having a loved one with some cognitive impairment, the conflicted emotions are a normal reaction to an abnormal loss. In such cases, there is always some ambivalence: joy and anger, a wish for continued life and a wish for the pain to be over.⁴

If discussed in a nonjudgmental setting, people begin to share their negative emotions and feelings. Once acknowledged and brought into the open, they are better able to minimize and manage their ambivalence. It helps to find someone (clergy, friend, counselor) to talk with, especially about the negative feelings. In the case of dementia with its inherent ambiguity, one's ambivalence is understandably high. To manage this tension, we must be mindful of our negative thoughts and feelings and talk about them with someone so as not to act on them unconsciously. As we talk with others, we can bring guilt, shame, and anger out into the open, learn how to manage them, and increase resiliency for this kind of tension by seeing some humor in it. Family caregivers tell me they put this at the top of their list.

Revising attachment

John Bowlby (1973, 1980) wrote about the pain of loss in the context of attachment—the complexities of ambivalence in lost attachments and the stress that motivates despair and

⁴ There are times when ambivalence leads to ambiguity such as when someone is conflicted about having a test for cancer, let's say, and then discovers it is too late to be treated for it; or when the young man whose father has Lou Gehrig's disease prefers to live with the ambiguity rather than risking the knowledge that he has the same fate as his father.

letting go. He did not, however, refer to losses that were ambiguous. Nor did Sigmund Freud (1917). These giants in the loss literature never addressed partial death. With even mild cognitive impairment, attachment is no longer balanced or reciprocal as it once was. The relationship is disturbed. The ill partner increasingly depends on the other for essential care and nurturance. Yet, despite altered affection and communication, strong attachment often remains. Kübler-Ross (1969) tells us that the natural persistence of attachment is so great that she recommends telling a dying mate that it is all right to leave.

In this regard, I saw a sixty-year-old woman whose husband had frontal lobe dementia. Over the months, her ability to care for both her husband and herself demonstrated resiliency, but now he was becoming more confused and distant. I told her it might be good to say good-bye while he was still aware. She was surprised. “He may live for another year according to the doctor.” I told her that while that was true, it would be best to say good-bye when both partners were *there*. She would know when the right time came. Months later, after he died, she said that this was the most helpful thing I said to her, and she thanked me for suggesting what she thought was a crazy idea at the time. They had said their good-byes during a lucid period, and in the months that came after, he was calmer as was she.

Revising attachment means accepting rather than resisting the ambiguity that surrounds a relationship when one person has dementia. Revision means being able to celebrate what of that person is still available and grieving the connections that are no longer possible. Among the losses people have told me about are traveling together, sexual intimacy, dancing, hearing his or her voice, having eye contact, and being recognized. What many say is still there is touch, even if one has to lift the ill person’s hand to get that. The goal is not to disconnect, but rather to balance new human connections and social activities with the attachment to someone who is fading away. It is both/and, not either/or.

Discovering hope

To stay strong, people need hope despite ambiguous loss. Hope lies in discovering that suffering is more than an assault on our personal comfort. Becoming more spiritual helps. We discover patience, even forgiveness. We understand that “bad things happen to good people” (Kushner 1981). We see suffering as part of life. We begin to think less of ourselves and more about larger purposes—hopeful ones.

Of course, people discover hope in diverse ways—through religion, prayer, worship, meditation, nature, exercise, and the arts (music, theater, poetry, play, dance). But in all cases, it is more easily found in the company of others. Meaningful human community helps both to imagine new hope and to discover its grace. We may no longer hope for a loved one’s recovery, but we realize that life can continue in a new way. No matter one’s age, resilience requires a combination of continuity and change.

Conclusion

Ambiguous loss is a relational disorder that occurs when a loved one is physically present but psychologically absent. The theory proposes that this uncanny kind of loss is the most stressful and traumatizing loss since there is no verification, no closure, no rituals for support, and thus no resolution of grief (Boss 1999). Clergypersons are in a position to witness and provide comfort for such loss. Because of existing relationships of trust, they are major referral sources or may do the counseling themselves if trained and certified as

pastoral counselors.⁵ Indeed, I encourage training and certification. It is, after all, in faith communities that people find support after loss, not just from death, but from the myriad of losses, clear and ambiguous, catastrophic and ordinary, that inevitably occur across the life course.

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⁵ This article should not be viewed as training, but rather as information about a new kind of loss that is common in congregations. I refer you to Boss (2006) for more details. For further information about training as a certified pastoral counselor, see www.aapc.org.