

# Ambiguous Loss and Its Disenfranchisement: The Need for Social Work Intervention

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## Abstract

Ambiguous grief results from a nondeath loss and has received minimal attention in the social work literature. This type of loss occurs in situations like missing persons, incarceration, military deployment, adoption, and foster care and chronic conditions like dementia. The reactions of loved ones faced with these situations rarely have been understood as a form of grief. The lack of recognition of ambiguous loss means that it is more likely to be disenfranchised, which undermines bereaved individuals' resilience and ability to move on with their lives. The authors discuss the nature of ambiguous loss and its disenfranchisement. Based upon theory and research, implications for micro-, mezzo-, and macropractice are presented. Case examples illustrate key points and challenges.

## Keywords

grief, ambiguous loss, disenfranchised grief, grief counseling

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A wealth of practice and research literature is readily available to guide social workers engaged in grief work (see, for example, Neimeyer, 2012; Winokuer & Harris, 2015). In recent years, this literature has expanded to include ethical and cultural considerations and factors that promote resilience and adversarial growth (Bonanno & Lilienfeld, 2008; Gamino & Ritter, 2012; Neimeyer & Currier, 2009). The nature of and interventions for complicated grief—defined as reactions to loss that are prolonged and not easily resolved and that result in significant social, psychological, and emotional impairment—also have received increased attention (Wittouck, Van Autreve, De Jaegere, Portzky, & van Heeringen, 2011).

Grief and grief counseling almost always are discussed in the context of death of a loved one. The loved one is presumed to be a person, but loss associated with pets has

received some attention. However, individuals also experience grief in response to non-death losses and face unique challenges in their attempts to mourn their loss. Nondeath loss is rarely socially acknowledged, and it is this lack of social acknowledgement that compromises bereaved individuals' ability to cope and move beyond their grief (Howarth, 2011).

Social workers are uniquely positioned to assist those experiencing grief in response to a nondeath loss at the micro-, mezzo-, and macro-levels. In this article, the authors focus on a

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common nondeath loss—ambiguous loss—that is encountered but rarely addressed in social work practice. The authors discuss the nature of ambiguous loss, citing available practice and research literature. Case examples illustrate challenges associated with clients experiencing nondeath loss. The authors then suggest practice interventions that provide clients the opportunity to grieve and that promote resilience and social recognition of ambiguous loss.

## **Ambiguous Loss**

Ambiguous loss is defined as “a situation of unclear loss that remains unverified and thus without resolution” (Boss, 2016, p. 270). Ambiguous losses are confusing and typically defy closure. The lack of resolution places the bereaved in limbo, unable to move forward, and isolated, since the normal rituals of support that accompany death loss do not apply and therefore are unavailable. Ambiguous loss is viewed as a “relational disorder” (Boss, 2010), since it involves grief in response to the changed nature and circumstances of a significant relationship. Affective reactions that accompany ambiguous loss have at times been framed as “anticipatory grief,” and there also are some similarities between ambiguous loss and complicated grief. But anticipatory and complicated grief are associated with death loss. Ambiguous loss may precede a death-related one. But its defining characteristic is the uncertainty that the bereaved face as they attempt to reconcile, accept, and move beyond the loss.

Individuals’ reactions to ambiguous loss—when they are even acknowledged—are framed as pathological because of their chronicity. However, “the source of pathology lies in the type of loss and not in the type of grief” (Boss, 2016, p. 271). Boss (2010) identified two broad types of ambiguous loss: physical absence with psychological presence and physical presence with psychological absence. Each reflects a different manifestation of the paradox associated with the simultaneous presence and absence of a loved one.

## ***Physical Absence With Psychological Presence***

Child welfare is one of the few practice contexts in which ambiguous loss has been studied. Biological parents who permanently lose custody of their children and foster parents whose foster children are removed not only mourn the immediate loss of their children, but also wonder and worry about their current and future well-being (Mitchell, 2016). Foster children who lose contact with their foster or biological parents and siblings also may experience ambiguous loss (Hebert, Kulkin, & McLean, 2013; Mitchell, 2017). In each case, it is the grief associated with not knowing the fate and future of valued loved ones that creates challenges for the bereaved. The child or parent may no longer be physically accessible, but they remain powerfully present in the memories and therefore the lives of their loved ones.

There is some indication that foster parents’ ambiguous grief may contribute to burnout, results in a reluctance to take children in the future, and undermine their ability to bond with their foster children (Hebert & Kulkin, 2016). Further, research suggests that adopted and foster children’s ability to form attachments may be undermined by the ambiguous loss associated with removal from biological and/or foster homes. Therefore, what have heretofore been viewed as behavioral and emotional problems of children in the child welfare system may in fact be indicators of unrecognized and unresolved grief (Hebert & Kulkin, 2016; Mitchell, 2017).

Deployment of service members is another common practice setting in which ambiguous loss occurs. The negative impact that deployment (and the return home) has on service members and their families has been recognized but not in the context of grief and loss (Crow, Myers, Ellor, Dolan, & Morrisette, 2016). Supportive services offered to military families focus on the void created by the absence of the deployed family member, paying far less attention to the grief that the absence generates. Services also tend to be

offered to immediate family members rather than extended family and friends who might also experience loss.

Limited evidence suggests that it is the ambiguity of the service member's absence, and the feelings of loss that are generated, that lead to emotional and behavioral problems in children and stress and anxiety among adult loved ones (Crow et al., 2016; Jensen, Martin, & Watanabe, 1996; Sofer, Kacen, & Shochat, 1993). Further, the ways in which loved ones manage feelings of loss—typically through avoidance and denial—during deployment undermine the service member's transition back into family life once the deployment ends (Shalev & Ben-Asher, 2011).

Another ambiguous loss associated with physical absence, but psychological presence, occurs when a loved one is incarcerated. Limited research suggests that what has been interpreted to be signs of trauma in children separated from their incarcerated parents may, in fact, reflect grief associated with ambiguous loss (Bockneck, Sanderson, & Britner, 2009). Younger children, particularly, are unlikely to understand why their caregiver is no longer present, making their physical absence but also their psychological presence even more difficult.

Finally, ambiguous loss is experienced by individuals whose loved one has gone missing due to kidnapping, war, or a natural or human-made disaster. In other instances, an individual may simply disappear for reasons unknown. The experience of "being left behind" and being caught "between life and death" brings with it both despair and hope (Wayland, Maple, McKay, & Glassock, 2016). Because of the significant distress that this form of loss generates, Robins (2016) observes the ways in which "disappearing" individuals are intentionally used to achieve political ends. "Disappearance has emerged as an explicit tactic of states and other armed actors because of the power it has to induce collective anguish that can be exploited for social and political ends" (Robins, 2016, p. 308). Ambiguous loss among loved ones of missing persons has not been widely studied. However, one study found that, when compared

to relatives of murdered individuals, those whose loved one went missing without explanation were much more likely to report being "stuck" and unable to move past their grief (Lenferink, vanDenderen, deKeijser, Wessel, & Boelen, 2017).

### *Physical Presence With Psychological Absence*

If physical absence is framed as "gone but not for sure," physical presence with psychological absence means "here but not here" (Boss, 2016, p. 270). This type of ambiguous loss is best exemplified by the grief experienced by caregivers of individuals with a progressive or permanent medical illness, disability, or disorder. This ambiguous loss has received some attention in the literature but generally has been understood as the anticipatory grief associated with the eventual death of the loved one. The emphasis in counseling has been on alleviating the burden and stress associated with caregiving (Dugleby et al., 2013). In fact, the bereaved are faced with loss of the psychological presence of their loved ones, which includes companionship, normalcy, and hope (Cheung & Hocking, 2004; Scholte op Reimer, deHaan, Rijinders, Limburg, & van den Bos, 1998). Limited research indicates that the severity of the loss is influenced by how physically "absent" the loved one is or becomes (Guarino, Prunas, Della Fontana, & Chiambretto, 2012).

More recently, attention has turned to the ambiguous loss experienced by loved ones of transgendered individuals. Emerging evidence suggests that even when loved ones, particularly parents, are supportive of a family member's gender transition, feelings of loss are common (Coolhart, Ritenour, & Grodzinski, 2017; Norwood, 2012). "The trans person is not exactly absent in mind *or* body (barring estrangement) and yet something is lost" (Norwood, 2013, p. 26). In one of the only studies of its kind, Coolhart et al.'s (2017) investigation of the experiences of parents of transgendered individuals revealed that they grieved the loss of dreams, aspirations, intimate familiarity, and rites of passage associated

with the child they knew, which the researchers characterized as a “living death.” Parents’ struggle was intensified by the ambiguity associated with their child still being physically present (though often in an altered way) but psychologically different.

In many cases, the individual’s transition is met with scorn and hostility; this complicates efforts to transition as well as family members’ efforts to adapt (Wahlig, 2015). In those instances where family members are unable to accept their loved ones’ transition, resulting in alienation and/or breaking off the relationship, ambiguous loss on the parts of both family members and the transgender individual is likely to be exacerbated (Norwood, 2013).

## The Disenfranchisement of Ambiguous Loss

Since the grief associated with ambiguous loss is not socially recognized, this leads to further pathologizing what is in fact an expected and understandable reaction to an already untenable loss. Social norms dictate “who, when, where, how, how long, and for *whom* [italics added for emphasis] people should grieve” (Doka, 1989, p. 4). Social norms also determine under what circumstances an individual has a “right” to grieve (Attig, 2004). Disenfranchisement results because of the socially constructed nature of grief.

Research into the disenfranchisement of grief has focused on death losses that occurred under stigmatized circumstances, such as a suicide or drug overdose (Mitchell, 2017; Valentine, Bauld, & Walter, 2016). Professional attention expanded to include loss in response to the death of a pet (Packman et al., 2014). However, until relatively recently, disenfranchisement was understood only in the context of a death loss.

Since ambiguous loss does not result from death, it is likely to be disenfranchised (Bordere, 2017). Disenfranchisement is evidenced in and reinforced by individuals’ social networks, societal institutions, and organizational policies (Attig, 2004; Mitchell, 2017). Funeral homes, cemeteries, and church ser-

vices legitimize death losses and provide mourners with opportunities to grieve. Many companies allow employees compassionate leave, and cultural and religious traditions like sitting Shiva, holding a wake, and memorial services validate mourners’ grief when a loved one dies. These opportunities and experiences are unavailable for individuals grieving an ambiguous loss.

Instead, grief in response to ambiguous loss is mistaken for mental health problems including posttraumatic stress, anxiety, and depression (Kendler & Aggen, 2014; Leach, Burgess, & Holmwood, 2008; Malone, Pomeroy, & Jones, 2011; Mitchell, 2017). Further, factors that protect individuals and promote resilience—most notably social and professional support—are limited or nonexistent, which increases the intensity and longevity of the grieving process (Bordere, 2017; Hermann, 2011; Memarnia, Nolte, Norris, & Harborne, 2015; Radosh & Simkin, 2016). Individuals grieving an ambiguous loss become “frozen or stuck in a state of chronic mourning” (Zhang, El-Jawahri, & Prigerson, 2006, p. 1192).

Early conceptualizations of disenfranchised grief reflected a binary view: Grief either was or was not disenfranchised. More recently, theory and research suggest that it is more appropriate to view disenfranchisement on a continuum, with some losses being more socially recognized than others and others being dismissed altogether (Robson & Walter, 2013). Six factors contribute to disenfranchisement.

First, the loss is ignored, minimized, or not acknowledged. Second, feelings in response to the loss are ignored, dismissed, criticized, or misunderstood. Third, the bereaved receive minimal or no support. Fourth, opportunities to grieve are absent or discouraged. Fifth, reactions of others to the bereaved convey disbelief, reproach, or condemnation. Finally, the loss and/or the individual’s grief reactions occur in a context of stigma. For example, the stigma associated with having children taken away further complicates grieving for biological parents who lose custody (Memarnia et al., 2015). Similarly, researchers found that partners

of individuals who were no longer able to perform sexually grieved the loss of sexual intimacy but were reluctant to discuss this with a professional due to embarrassment (Pillai-Friedman & Ashline, 2014; Radosh & Simkin, 2016).

All six factors need not be present for disenfranchisement to occur. However, the concept of a continuum suggests that the more the individual encounters these experiences, the more disenfranchised the grief (Robson & Walter, 2013).

### Case Examples

In many instances, the disenfranchisement of ambiguous loss is the result of “benign neglect.” In the case that follows, the client’s grief is not so much ignored as it is misinterpreted and misunderstood.

*The ambiguous loss of “here but not here.”* A student was placed in an outpatient health and wellness clinic for aged individuals. Many clients were diagnosed with dementia. In response to caregivers’ distress, social work services were available to provide them with support and help them manage the challenges associated with caring for their loved one. In class, the student, Hannah, expressed confusion regarding how she could be helpful to Mr. Reynolds, age 85, who was the primary caregiver for his wife, Alice, who was diagnosed 1 year ago with dementia. Hannah described her most recent session with Mr. Reynolds, in which she felt “helpless” and unable to alleviate his distress:

Mr. Reynolds: Alice had a good week. She recognized our daughter and grandson and was even able to carry on a conversation with them. For a moment or two, I had my old Alice back [starts to cry].

Hannah: I’m so very sorry, Mr. Reynolds. It must be very hard. Sometimes Alice is “your” Alice and other times she isn’t.

Mr. Reynolds: [Crying] I never know who I am going to wake up with in the morning. I worry constantly that she [Alice] is going to wander away, burn herself on the oven and forget to turn off the

stove. I am doing my best, but it’s just so hard and nothing I do changes that she is leaving me.

Hannah: I feel terrible that that you are losing her.

Mr. Reynolds: [Continues to cry].[Silence]

Hannah: Perhaps we need to provide you with more in-home services to ease the burden on you of caring for Alice?

Hannah explained in class that at this point in the interview with Mr. Reynolds, she did not know what to say. “We talk about the same thing every time I see him. We just aren’t getting anywhere. How do I help someone who’s stuck in such a terrible situation?” Hannah understood Mr. Reynolds’ reactions only in the context of the stress associated with caring for his wife, which explained her offer of additional services. From the perspective of ambiguous loss, his reactions reflected the grief he was experiencing because Alice was no longer “his” Alice. Hannah recognized that Mr. Reynolds’ situation was continuing, which exacerbates his grief. However, her comment that her client “is losing his wife” does not accurately characterize his loss. From his perspective, he *already has* lost Alice but must deal with the ambiguity associated with her continued physical presence.

*The ambiguous loss of “gone but not for sure.”* The ambiguous loss experienced by loved ones of incarcerated individuals epitomizes disenfranchisement. The social isolation family members encounter and the stigma associated with the reason for their loss often result in a devaluing or complete dismissal of their grief (Turanovic, Rodriguez, & Pratt, 2012). Research suggests that the more heinous and socially unacceptable the offense, particularly if it involves crimes against children, the greater the stigma for loved ones and therefore the more disenfranchised their grief (Bailey, 2017).

The following example occurred in a shelter for homeless families. A weekly group afforded parents the chance to support one another as they attempted to find themselves

affordable housing and address the many other challenges they faced. In one session, members' loss and grief became apparent after one member described her reactions to her son's lengthy incarceration:

Johnetta: LaShawn [her son] has been in jail for 3 years now. He's 19 and I only seen him twice. He's becoming a man, and I ain't been part of his life. He's being taught how to be a man by gang bangers and thugs. He ain't getting out for another 20 years! I ain't saying he didn't deserve it, but I worry I won't even be around when he gets out. He is gonna be 40 years old when he is released!

Monique: Gerald [the father of two of her children] has been gone for 6 years. I'm starting to forget what he looks like, what he smells like. I only seen him a couple of times. I got no way to get out there to the prison. His kids don't even know their own daddy [starts to cry]. I think of him every day, talk about him to my children, but I don't know how he's getting on, what he's doing, nothing.

Tamara: My daddy be in jail since I was a baby. My mama would tell us all about him, but he wasn't real to me. I saw him a few times, but he was a picture in our living room. And now Romeo [her son] is going down the same path. He be gone for 10 years.

Residents of the shelter—all of whom were extremely disadvantaged and marginalized—struggled with multiple losses. While the group was not specifically focused on grief and loss, these reactions surfaced regularly. Members' loved ones remained a constant presence in their lives, even though they were physically absent. The lack of transportation and limited means of communication served to compound the ambiguity. Members' struggles to find affordable housing, daycare, and employment that pays a living wage were exacerbated by multiple losses for which there had been no acknowledgment, validation, and therefore, resolution.

It was beyond the purpose of this group—and social worker's role at the shelter—to examine members' grief in-depth. Nonetheless, the worker likened their reactions to what individuals feel when someone they love dies: "In many ways what you all are talking about is grief. Tamara's father didn't die, but symbolically he might as well have. He was just an image. And now some of you are mourning the loss of your children. There's nothing worse than losing your child. They are alive, very much present to you, but also in many ways gone, sometimes for good."

This comment was met with tears but also with a sense of relief and self-understanding. *All* members in this session realized that they had experienced grief in response to the ambiguous nature of their loved ones' status. They had not viewed their reactions this way, nor had they ever really discussed them. This session assisted them in having a name and reason for what they had been experiencing, which in turn made it just a bit easier for them to manage.

## Practice Implications

The social work profession is ideally situated to help clients cope with ambiguous loss as well as its disenfranchisement. This requires intervention at the micro-, mezzo-, and macrolevels.

### *Direct Practice Interventions*

While many of the clients seen by social workers are likely to experience ambiguous loss, little attention has been devoted to identifying appropriate practice interventions due to its disenfranchisement. The lack of practice guidelines is complicated by the fact that clients rarely seek assistance for ambiguous loss, since they—and their workers—are unaware of its existence. At minimum, social workers must be sensitive to and look for signs of ambiguous loss when working with clients who have encountered the types of experiences we have identified in this article.

Ideally, however, social workers are prepared to provide counseling to clients grieving an

ambiguous loss that is tailored to their unique needs and challenges. Efforts have been directed towards minimizing and/or addressing ambiguous loss experienced by children and families in child welfare settings. Research findings in this arena provide guidance for social workers in other practice settings.

When foster and biological parents are offered individual or group treatment to address the grief associated with the loss of their child, their loss is normalized and validated. Grief-oriented intervention has been found to be associated with higher rates of foster parent retention, increased cooperation between biological parents and child welfare professionals, and enhanced likelihood of reunification with biological parents (Hebert & Kulkin, 2016; Hebert et al., 2013; Hojer, 2011; Schofield et al., 2011). Similarly, assisting children and adolescents in understanding and expressing their grief and, when appropriate, providing them with opportunities to stay connected to loved ones has been found to be associated with lower rates of replacement, fewer emotional and behavioral problems, increased likelihood of a permanent plan, and reduced risk of long-term behavioral, social, and emotional problems (Fineran, 2012; Mitchell, 2017).

The nature and source of ambiguous loss suggests that the stage models of grief and recovery in response to death loss may be of limited utility (Boss, 2010). Grief work in cases of death loss typically involves assisting clients in achieving closure and acceptance of the loss (Neimeyer & Currier, 2009). However, closure is not possible with many ambiguous losses (Duggleby et al., 2013). In these instances, closure may be a “myth” and unattainable (Boss, 2010). Therefore, the worker must help clients “to hold a paradox ... that someone [they] love can be both absent and present at the same time” (Boss, 2010, p. 141).

As the previous case illustrations reveal, clients’ grief may be ongoing. The goal in these cases is to promote resilience by helping clients to tolerate ambiguity rather than achieve closure. Boss (2010) identifies strategies that

assist individuals in managing ambiguous loss. Depending upon the nature of the loss, Boss (2010) suggests that workers will need to help clients:

1. find meaning: “Sometimes, if the loss is so incomprehensible, people will say it will never make sense. ... I tell them that it is also a meaning—it will never make sense” (p. 141);
2. regain control through adopting a “both/and” mind set: “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’)” (p. 142);
3. construct a new identity for the self and the loved one;
4. normalize and validate ambivalence;
5. revise attachments to loved ones: “Revision means being able to celebrate what of the person is still available and grieving the connections that are no longer available” (p. 144); and
6. discover hope through “thinking less of ourselves and more about larger purposes—hopeful ones” (p. 144).

Since the experience of ambiguous loss is likely to be unending, social work services must be readily available to accommodate clients’ ongoing and evolving needs. As noted, findings from child welfare settings suggest that providing opportunities for clients to stay connected to “lost” loved ones, when appropriate, may reduce grief and promote resilience (Fineran, 2012; Mitchell, 2017). In another relevant study, researchers found that when children were provided ongoing opportunities to visit with and stay connected to incarcerated parents, their emotional and behavioral problems were reduced (Bockneck et al., 2009).

While limited, research findings from child welfare also suggest that the group modality may be particularly beneficial to clients experiencing ambiguous loss (Cheung & Hocking,

2004; Duggleby et al., 2013; Hebert et al., 2013; Pillai-Friedman & Ashline, 2014). As noted, groups formed to help biological or foster parents grieve the loss of their children normalized and validated their loss and were associated with several positive benefits. Presumably, groups formed for clients experiencing other types of ambiguous loss would, almost by definition, reduce isolation and stigma and provide much-needed social acknowledgement since all members are “in the same boat.”

### ***Mezzo- and Macropractice Interventions***

Disenfranchised grief exists because the loss is not socially sanctioned or recognized (Attig, 2004). Examples of the disenfranchisement of ambiguous loss that require macrointervention abound. Organizational policies may allow employees to take leave time when a loved one dies, but such opportunities are rarely—if ever—available in response to a nondeath loss, particularly if it is ambiguous and ongoing. Public and private funding to study grief is almost exclusively focused on death loss (Mitchell, 2017). An important first step is for social workers to educate the public about the existence of ambiguous loss and promote organizational and public policies and services that promote grieving and resilience for those who have experienced it. This includes insisting that funds be made available for its study.

Agencies and programs that serve clients who are likely to experience ambiguous loss typically do not address it or even acknowledge its existence (Denby & Gomez, 2016; Leach et al., 2008; Mitchell, 2017; Valentine et al., 2016). Social workers have an obligation to ensure that agency policies and services do not inadvertently create situations that lead to or exacerbate ambiguous loss. We also must advocate that services be made available that specifically respond to the unique needs of challenges faced by those faced with ambiguous loss. The provision of such services is in and of itself an important

first step in reducing its disenfranchisement. It is particularly important that we work to minimize ambiguous loss and its impact in those settings in which it is most likely to occur, such as child welfare, forensics, and medical and health. Individuals facing ambiguous loss have the right to grieve (Attig, 2004). This means advocating that services are both readily available and continuing to those struggling with ambiguous loss.

Social workers should be in the forefront of advocating that the same rights accorded to those grieving a death loss be provided to those grieving an ambiguous one. This is consistent with the profession’s commitment to social justice. We should be building upon, learning from, and expanding the initiatives that have been established in child welfare settings to promote the more equitable treatment of other populations at risk of experiencing ambiguous loss including offenders, transgendered individuals, deployed military personnel, and their families.

### **Conclusion**

The concept of ambiguous loss has much relevance for the challenges faced by many of the clients social workers encounter in their practice. Since its existence has only begun to be recognized, the needs of clients experiencing ambiguous loss have been largely overlooked, misunderstood, or minimized. As professionals committed to social justice, social workers have an obligation to develop the same expertise in helping clients with ambiguous loss that guides us in our work with clients faced with death loss.

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