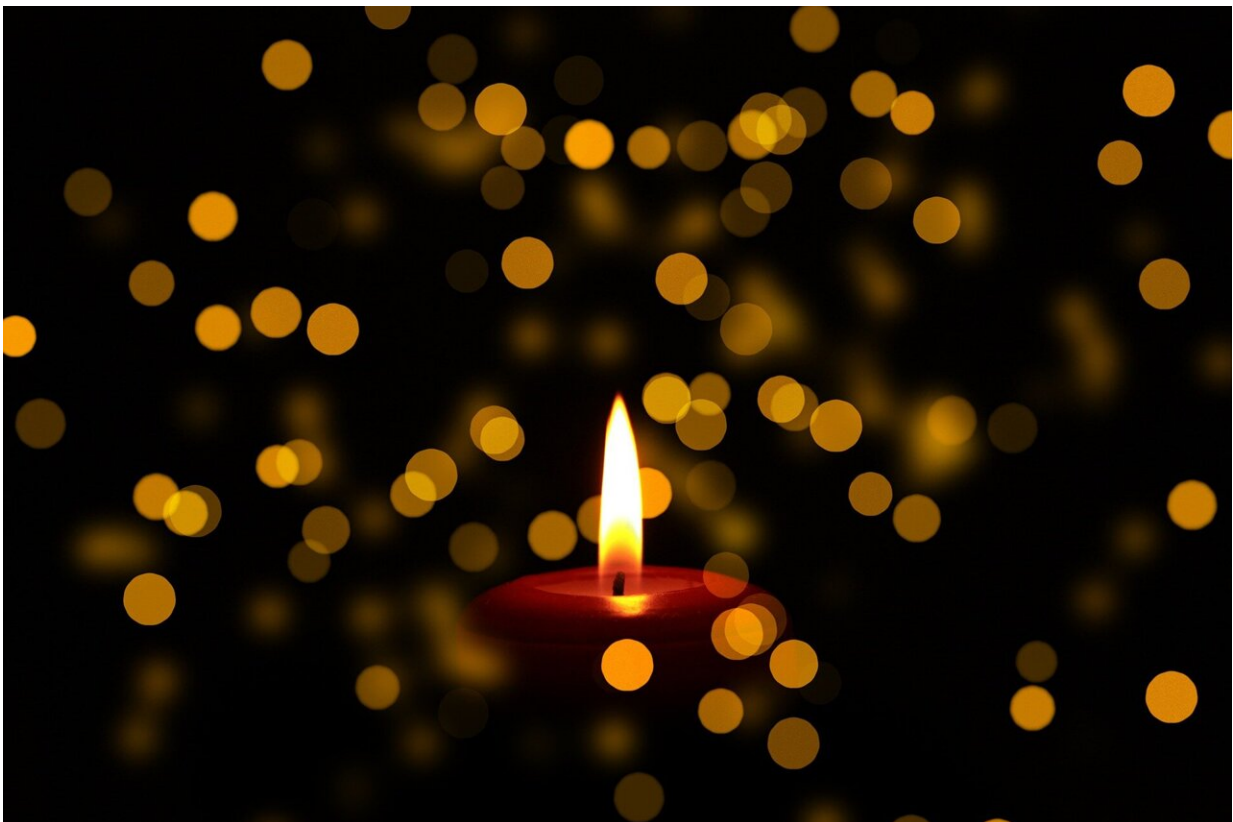


Processing and grieving an ongoing loss does not fit neatly into traditional models of grief, says researcher

June 23 2023, by Brad Phillips



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Traditional loss is [typically considered a five-stage process](#), linear and time-bound, where a person moves from denial to acceptance.

Generally, traditional loss is linked to death—such as the death of a loved one, or a miscarriage. It is permanent, often abrupt, occurring when someone or something once present is suddenly absent.

But loss is complex. Other kinds of loss do not follow the one-size-fits-all archetype, and many experts now [criticize the five stages of grief model](#).

[As a nursing professor](#) who researches the impact of childhood illness on family well-being, one of my main areas of study is how people navigate another type of loss—ambiguous loss, or loss without closure.

Coping with absence, letting go

Ambiguous loss is [something that's ongoing, recurring or unresolved](#). The loved one is still alive but different from who they once were.

For over a decade, I have worked with hundreds of [parents](#) who became caregivers to once-healthy children who sustained a devastating injury or illness. Perhaps the child has a [traumatic brain injury](#), resulting from a car accident or a near drowning. Or they were born with progressive disabilities resulting in the need for specialized, [long-term care](#).

In these instances, the caregiver is not only coping with the absence of what was but letting go of what could have been.

As one parent said to me: "You have all these dreams for your child. Sometimes with disabilities those things will never happen. Reevaluating expectations is challenging and a little sad."

Because of the ambiguity of these types of experiences, nothing—no model, no set number of stages—can fully prepare parents to navigate this type of loss.

But although ambiguous loss differs from traditional loss, researchers still lump the two together. That is why studies on ambiguous loss are scarce, and there is no formula to help [the caregivers manage their grief](#).

Until researchers abandon their traditional view of loss, we won't fully understand how to help those experiencing ambiguous loss.

Finding meaning in loss

During the 1960s, psychiatrist Viktor Frankl [developed the concept of "Will to Meaning,"](#) based on his experience as a Holocaust survivor in Nazi concentration camps during World War II.

Frankl saw some prisoners in the camp keep a positive attitude and wondered how they did it in such a treacherous environment. He came to understand that humans have the ability to choose how they perceive their experiences. Finding [meaning](#), he learned, [helps people persevere through their suffering](#).

In the 1980s, Frankl's concepts were adapted into the "[theory of meaning](#)"—[essentially a guide for nurses](#) on how to help patients find meaning and purpose after an unprecedented loss. Nurses discovered that an individual's active, personal decisions could alter that person's perception of these traumatic experiences.

That theory of meaning proved to be a beacon of hope for people in difficult situations. For decades, nurses throughout the world have used this concept to [reach out to countless numbers of patients](#), particularly those who have cancer, [spinal cord injuries](#), drug or alcohol addictions, or those in [hospice care](#).

But I believe my work is the first of its kind to use the theory of meaning to interact [with parents experiencing ambiguous loss](#). I interviewed eight

parents of children with an acquired disability—mostly traumatic brain injuries—to better understand whether they were able to find meaning in their loss.

I found that parents were experiencing profound suffering because they were on edge, worried about lifelong care for their child and unaware of the consequences of loss. This suffering reached every family member and led to strained marital relationships, depression, anxiety, anger, sleep deprivation and fear of the unknown.

However, parents overcame these challenges by providing care to their child and creating a space to connect to family, friends and other parents undergoing similar experiences. They found joy in their child's smallest success. The result was deeper relationships within their family and a hopeful outlook for the future.

One parent told me: "There's nothing that's ever been harder ... but caring for (my child) is the most rewarding thing I've ever done with my life." Another said, "He has overcome so much, and our family has grown because of what we've experienced."

It's clear these parents didn't just move through the traditional stages of denial, anger, bargaining, depression and acceptance. Surely these broad emotions and feelings were likely present, probably even all at once. But they were able to choose how they perceived their experiences—to find purpose in their caregiving regardless of the disability.

These parents didn't simply accept their loss as the traditional model describes, but transformed it into something meaningful to help them persevere through their experiences.

How to help

What these parents often [lack is community-based support](#), such as respite care, transportation, financial aid and support groups. This helps parents meet basic needs so they can take care of themselves, reflect on their experiences more clearly and find meaning to push them forward.

During a time of ambiguous loss, parents say their lives have turned upside down; they are trying to navigate a new normal. They feel isolated, lonely, misunderstood and judged.

If you know someone experiencing ambiguous loss, it helps to simply ask them how they're doing. You might offer to bring them dinner, include them in activities or just sit with them and listen. These simple acts of kindness may help them feel better understood—and reinvigorate their purpose to face another day.

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