



TBI-BH ECHO

Traumatic Brain Injury - Behavioral Health ECHO
UW Medicine | Psychiatry and Behavioral Sciences

Sitting with Grief in TBI

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UW Palliative Care & Rehab Medicine



Speaker disclosures

We have no conflicts of interests to disclose.

The following series planners have no conflicts of interest:

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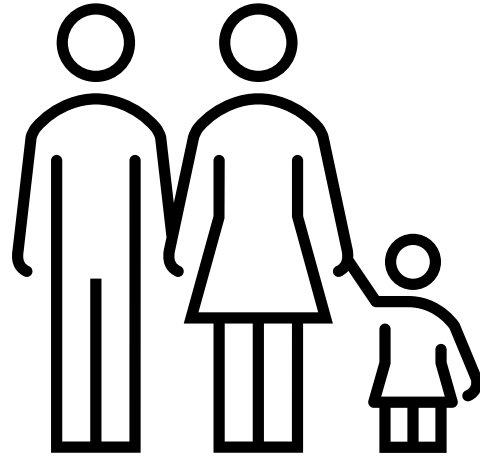


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Objectives

1. Review types of grief and loss and general theories pertaining to grief
2. Explore unique aspects of grief relevant to survivors of TBI and their loved ones
3. Discuss approaches to recognize and engage with grief



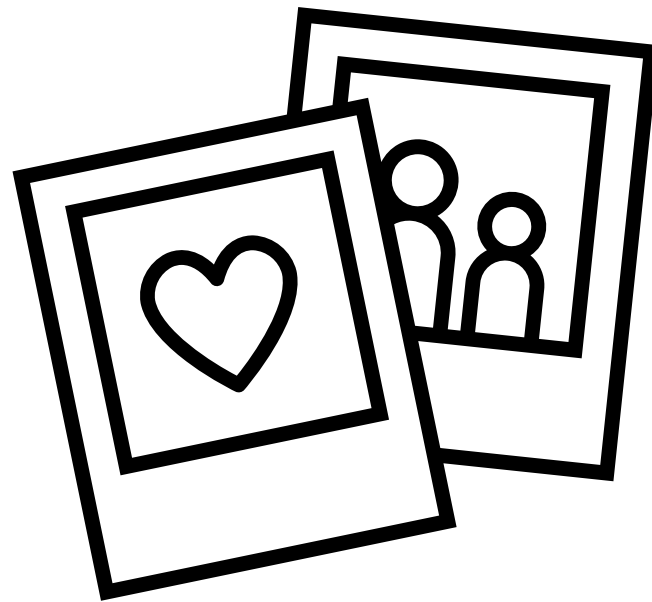


A case

Jennifer is a 53 yo woman with a history of traumatic brain injury 8 months prior resulting in hydrocephalus s/p VPS and minimally conscious state. She presents to the emergency department from a skilled nursing facility with concern for worsening hydrocephalus...



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Grief and Loss



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Grief

- ▶ A natural, expected response to a significant loss
 - ▶ Typically conceptualized as a death-related reaction
 - ▶ Also experienced in response to the profound changes inherent to other losses, such as loss of a job, a friend moving away or another type of medical event
 - ▶ a traumatic brain injury (TBI)
- ▶ Unique to the individual and their circumstances
- ▶ Grief is not inherently pathological!



Common Grief Theories

- ▶ Five Stages of Grief (Kubler-Ross)
 - ▶ Denial
 - ▶ Anger
 - ▶ Bargaining
 - ▶ Depression
 - ▶ Acceptance
- ▶ Nonlinear

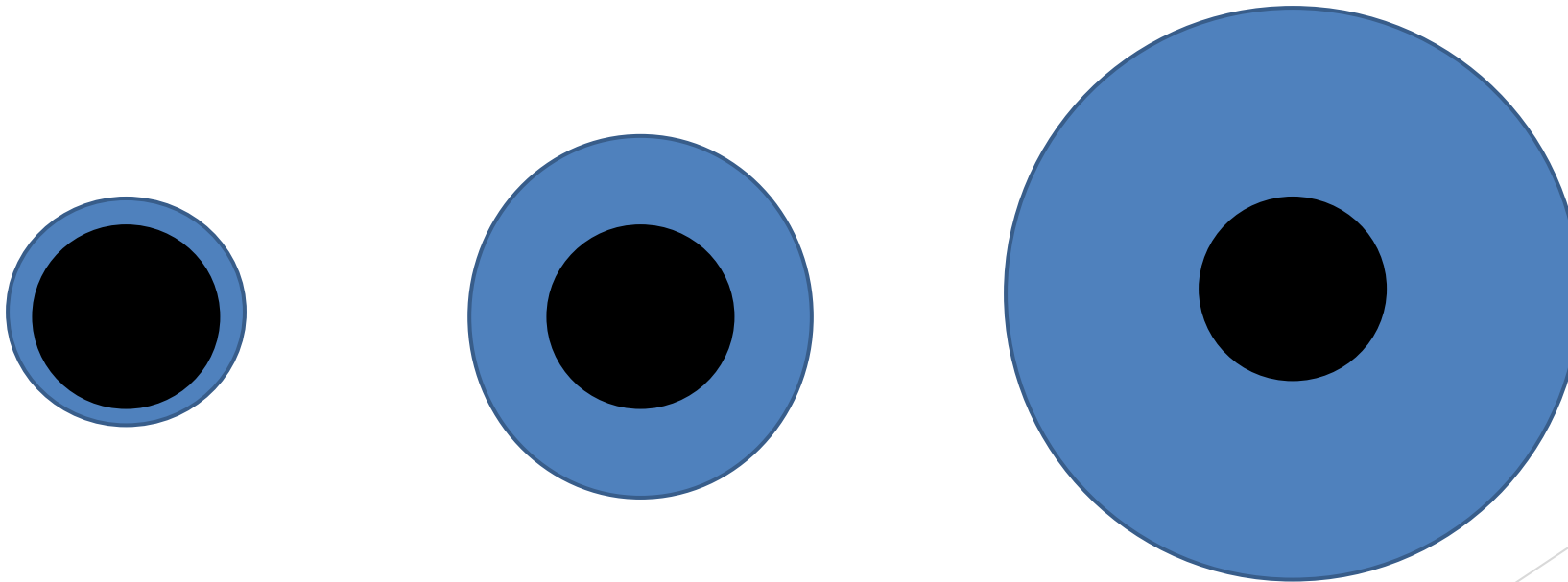
Kubler-Ross E. On Death and Dying. New York, NY: Simon and Schuster; 1997



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Theories (continued)

- ▶ Growing Around Grief (Tonkin)
 - ▶ Over time, your grief stays the same but your life grows around it.



Tonkin, L. (1996). Growing around grief—another way of looking at grief and recovery. *Bereavement Care*, 15(1), 10.



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Grief Theory (continued)

- ▶ Continuing Bonds Theory (Klass, Silverman, Nickman)
 - ▶ Grief that does not resolve by detaching from the loss of a loved one, but rather creating a new relationship with the new person

Klass, D., Silverman, P. R., & Nickman, S. L. (Eds.).
(1996). *Continuing bonds: New understandings of grief*. Taylor & Francis.



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Types of Grief and Loss

- ▶ Sudden Loss

- ▶ Grief that is experienced after a sudden loss, such as an unexpected death or traumatic accident

- ▶ Anticipatory Grief

- ▶ Though the loved one is still here, the process of mourning begins as people anticipate the impending loss. It's a normal process that allows one to prepare for the reality of the loss



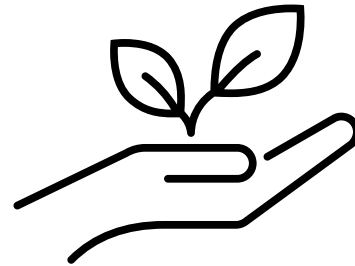
Types of Grief (continued)

- ▶ **Complicated Grief**
 - ▶ Symptoms of grief remain strong, dramatically interferes with everyday functioning
 - ▶ May have concern for prolonged grief disorder, which can be comorbid with depression and anxiety as well
- ▶ **Traumatic Grief**
 - ▶ Grief that is related to a Trauma
 - ▶ Can be particularly complex when related to homicide/suicide/community trauma
- ▶ **Disenfranchised/Ambiguous Grief**
 - ▶ Grief that is not always recognized by society (loss of pet, miscarriage, dementia, addiction, etc.)
 - ▶ In TBI, this may manifest from profound change in identity, roles, and relationships & loss of future as expected



Grief in TBI

- ▶ It may surprise you - there is not a large body of research explicitly on grief in TBI
- ▶ Research is largely qualitative



Experiences of loss and grief in adults with acquired brain injury (ABI): A systematic review and meta synthesis of qualitative studies (Conaill et al 2025)

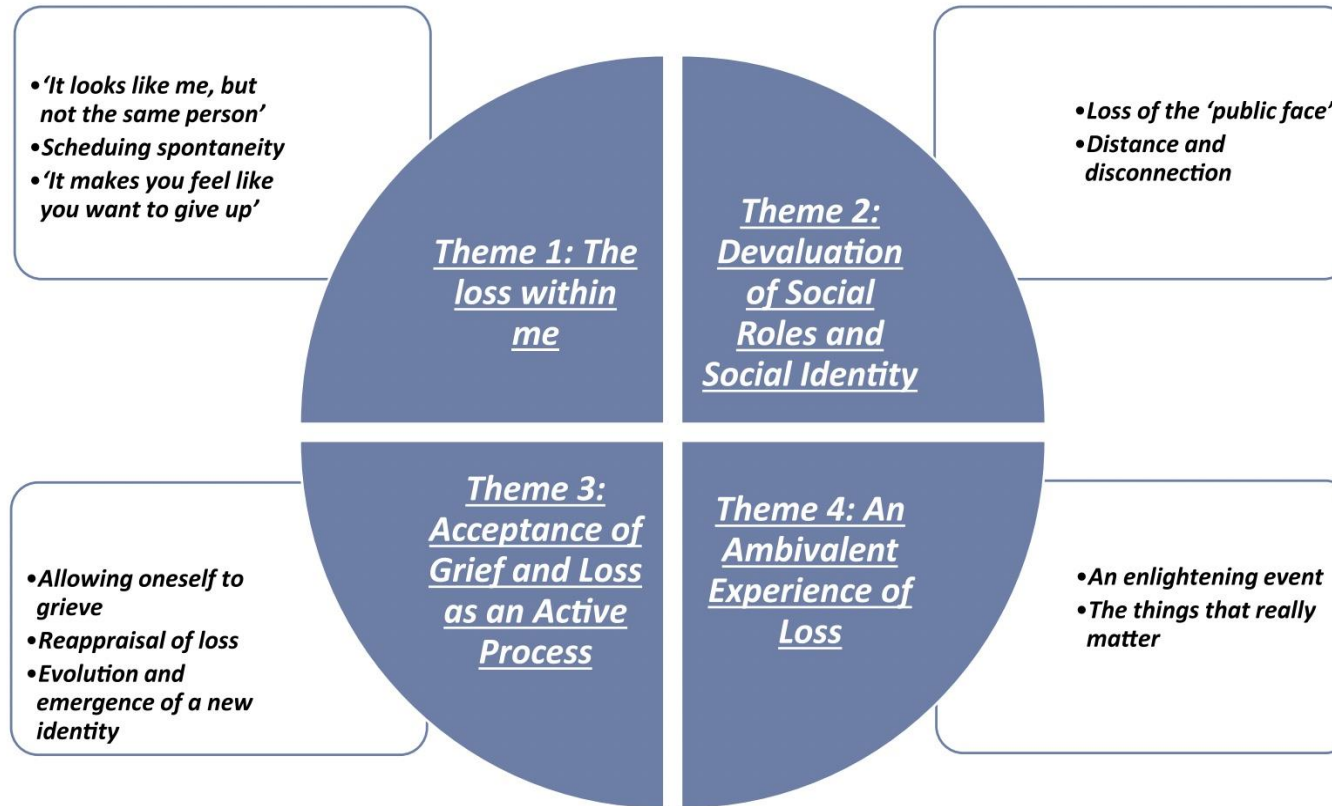


Figure 2. Themes/subthemes.



“

: “I really felt about it was that it’s like a death, while no one has died I appreciate, but the old you is gone, you’re going through a grieving process whether you know it or not, but grieving alone” (Lowe et al., 2021, p. 451).

”



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A qualitative study involving spouses and parents...

Loss of expected future

- ▶ *What makes it worse is that you are constantly remembering the person they used to be. I tend to cry a lot over that...he still had his whole life ahead of him...and it was just like so tragic.*

-Mother

Loss of relationship/identity

- ▶ *When you're husband and wife and you have a shared relationship and you have intimacy, and you do things together, and you share decision making and then that person is not there...*

-Spouse

Katz et al, 2017



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“

I guess life has changed...Now it's like oh well, you know, nothing really matters anymore. You know like nothing is that important anymore. Before it was important to get a new car, it was important to do something else...Now it's like, it's important that we're all healthy, that we're all here.

”

-Father

Grief theory, growing around grief, adjustment

Katz et al, 2017



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Recognizing and Supporting Grief



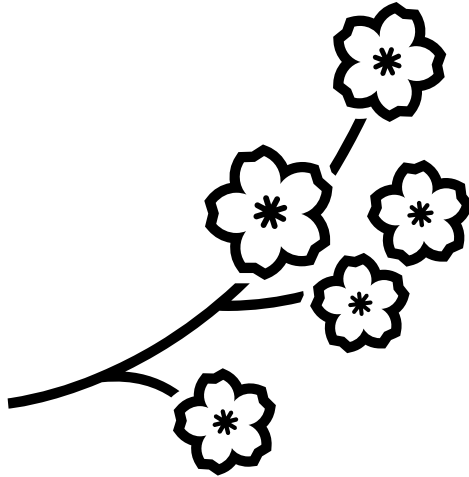
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Common Grief Reactions/Recognizing Grief

- ▶ Sadness
- ▶ Fear
- ▶ Relief
- ▶ Shock
- ▶ Guilt
- ▶ Confusion
- ▶ Anger



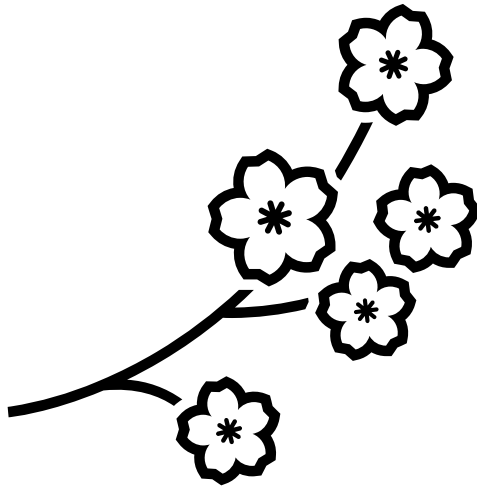
Skills and Tools for Engaging with Grief



- ▶ Basic Needs
- ▶ Time
 - ▶ Recognizing when people are too overwhelmed to make decisions
- ▶ Presence & Connection



Skills and Tools for Engaging with Grief



- ▶ Presence & Connection
 - ▶ Presence/bearing witness
 - ▶ Holding space
 - ▶ Normalizing
 - ▶ Narrative medicine/narrative approach
 - ▶ Non-Abandonment
 - ▶ Conflict resolution



Trauma Informed Care



Substance Abuse and Mental Health
Services Administration

Six Principles of a TIA

- 1 Safety** Safety in physical settings and interpersonal interactions
- 2 Trustworthiness and Transparency** Operations are conducted and decisions are made with transparency, consistency, respect, and fairness so as to build and maintain trust
- 3 Peer Support** Support from those with lived experiences of trauma or, in case of children with history of trauma, their family members
- 4 Collaboration and Mutuality** Partnering, leveling of power differences between and among staff and clients
- 5 Empowerment** Individuals' strengths and experiences are recognized and built upon
- 6 Cultural, Historical, and Gender Issues** Organization moves beyond the cultural stereotypes and biases

<https://library.samhsa.gov/sites/default/files/pep23-06-05-005.pdf>

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How about our grief?



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This Work

Exhilarating and exhausting
Drives me up a wall and opens doors I never imagined
Lays bare a wide range of emotions yet leaves me feeling numb beyond belief
Provides tremendous satisfaction and leaves me feeling profoundly helpless
Evokes genuine empathy and provokes a fearsome intolerance within me
Puts me in touch with deep suffering and points me toward greater
wholeness
Brings me face to face with many poverties and enriches me encounter by
encounter
Renews my hope and leaves me grasping for faith
Enables me to envision a future but with no ability to control it
Leaves me wounded and heals me.

-Ken Kraybill, MSW

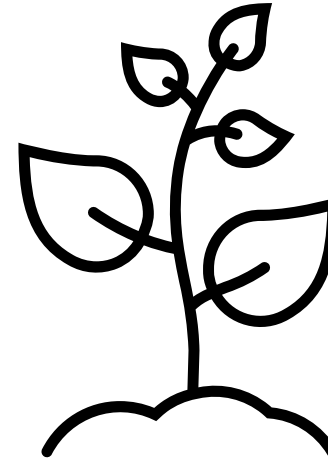
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How about our grief?

- ▶ Individual
 - ▶ Maintaining compassion for ourselves
 - ▶ Implementing a practice/ritual
 - ▶ Snack/rest/connection
- ▶ Team/Institution
 - ▶ Remembrances practices
 - ▶ Schwartz Rounds
 - ▶ Interdisciplinary support (SW, Spiritual Care, Wellness/Resilience Committees)



Back to our case...



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Key Points

- ▶ Grief is a human reaction to loss. While grief is typically thought of in the context of death, grief occurs in the context of many types of loss and is especially relevant to TBI
- ▶ Grief is non-linear and has a variety of dynamic feelings and manifestations
- ▶ Ambiguous/disenfranchised grief and grief related to trauma may be of particular relevance in TBI
- ▶ In general, grief is not *pathologic*, but a process that we can support through acknowledgement and presence



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