

Hidden Sorrows: Bereavement in I/DD Population

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Educational Objectives

- Identify symptoms that commonly present in grieving individuals with I/DD.
- Identify assessment tools and interventions for supporting individuals with I/DD through the grieving process.
- Learn how to utilize interventions that are specific to individuals with I/DD.

Myths about grief in I/DD population

- Don't understand
- Should not be included in grieving rituals (or even informed when a loved one dies)
- Death is the only form of loss



Findings from Research

- People with I/DD *do* grieve
- Enhanced, individualized support needed

McRitchie, et. al (2014)

Findings from Research

- Enhanced Supports
 - Concrete information and explanations.
- *Cumulative loss*: participants who did not feel informed or included in rituals felt added loss.

McRitchie, et. al (2014)

Findings from Research

- Important things to consider:
 - Intrapersonal/Interpersonal experiences
 - Core beliefs about life and death
 - Level of inclusion
 - Continuing relationship with the deceased

McRitchie, et. al (2014)

Findings from Research

- Staff reported a lack of confidence and knowledge of how to support their clients with bereavement issues
- Wanted supervisors to recognize the emotional impact that supporting bereaved individuals can have on the staff
- Need for staff training on bereavement and supports

McEvoy, et. al (2010)

“What happens a lot within the organization ... is that you might have a staff working in an area for a long time and they move out and weeks later they might move back ... and I am sure they don’t know the difference a lot of the time between death and people having moved on or retired.”

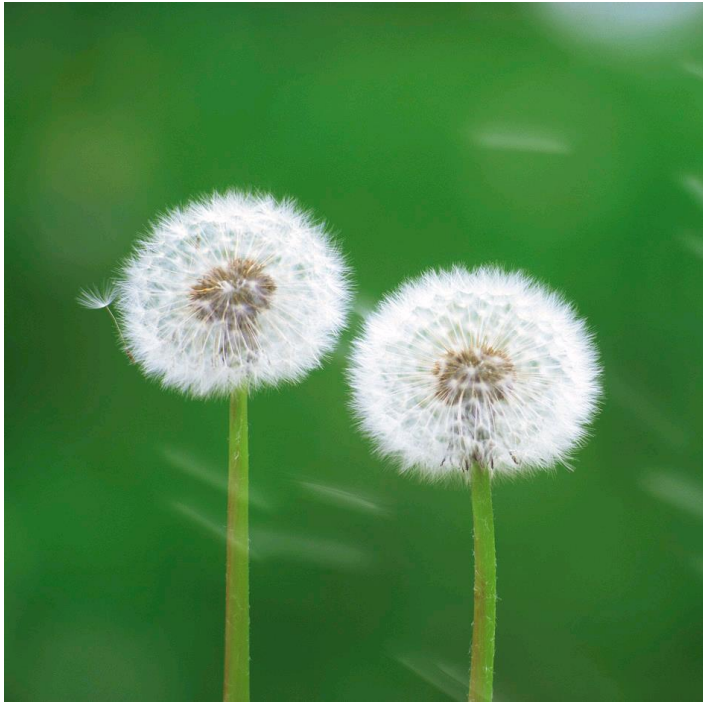
- Quote from participant in McEvoy study

Findings from Research

- Paid caregivers participated in 6-hour training course:
 - Theories of bereavement
 - Symptoms of bereavement
 - Treatment interventions
- Not one participant had received any similar training prior to the study

Watters, McKenzie, & Wright (2011)

Sources of Loss



- Increased life expectancy → more exposure to loss
- Within the last 20 years, individuals with I/DD are outliving their parents on average (Clute 2010).

Sources of Loss

➤ *TRANSITION*

- New caregivers or staff
- Move to new home/apartment
- Death of a caregiver

- Perceptions of others (feeling less valued)
- Reduced independence
- Loss of employment

COVID-19 Impact

- Mourning the loss of what was once “normal.”
- Anxiety & Depression
- Loss of independence
- Staffing crisis

Getting back to normal...

- Anxiety about re-entering community?
- Lost social skills?

Assessment

Things to consider:



- Individual differences in the grieving process
- How is grief expression impacted by the clients disabilities/diagnoses (verbal, non-verbal, level of functioning e.g., mild, moderate severe)

Assessment cont'd

- Amount and types of loss experienced:
 - Recent Deaths (parents, siblings)
 - Frequent changes in staff
 - Separation from caregivers (e.g., divorce, death of caregiver, or move from home into group home or supported living site).

Assessment Cont'd

- Input and observations from family and staff
- Change Inventory questionnaire (Positive Identity development) helps identify amount of staff turnover, deaths experienced by client and transitions.
- <https://thenadd.org/materials-for-positive-identity-development/>

Assessment Cont'd



- I. *Behavior changes* (e.g., Social withdrawal)
 - Aggression, self-injurious behavior (especially when verbal communication is limited)
 - Has work productivity changed?

Assessment Cont'd

Behavior changes

- Is this person withdrawing from social activities?
- Has their personality changed?
- Changes in mood (See emotional/affective)
- Increased crying, hyperactivity, inappropriate speech
- Challenging behavior/mental health problems such as depression, mania and psychosis.

Assessment Cont'd

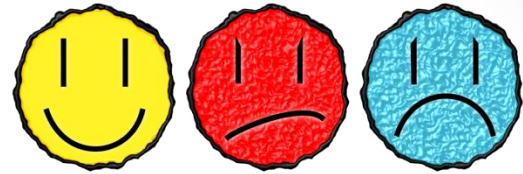


II. Cognitive (e.g., confusion and helplessness).

Cognitive abilities vary greatly from person to person. This can make it difficult to assess those diagnosed with profound or severe intellectual disabilities. Although most are diagnosed with mild to moderate intellectual disabilities.

- ❖ Severity of disability impacts understanding and expression of grief (McEvoy et. al 2011).

Assessment Cont'd



III. Emotional/affective (e.g., anger, sadness)

Emotional/affective states may not be expressed in a manner others think of as “typical”. Look for indicators of their true feelings, such as behavior and use non verbal means to help express emotions.

Assessment Cont'd

Emotional/Affective

- Anxiety
- Hyperactivity
- Agitation
- Depression
- Sadness
- Distress



Assessment Cont'd

IV. Physiological (e.g., sleep disturbance, loss of appetite)

- Have sleeping patterns changed?
- Having eating habits changed?
- Has there been an increase in complaints of pain or illness?

Assessment Cont'd

Physiological

- Headaches
- Stomachaches
- Dreams



Assessment Cont'd

- Six factors to take into account during assessment:
 1. Ego strength: Clients understanding about who they are and what there capabilities are.
 2. Age: Some examples of age appropriate guidelines
<https://www.counseling.org/docs/trauma-disaster/fact-sheet-12---grief-reactions-over-the-life-span.pdf?sfvrsn=2>
 3. Degree of dependency

Assessment Cont'd

Six Factors Cont'd:

4. Emotional closeness
5. Circumstances of the death (sudden vs. expected); and
6. Capacity to cope with stress

Interventions

- Once we have assessed the client's symptoms and level of need, we can coordinate services and provide effective interventions.
- Important to be proactive with interventions/strategies as well.
- Work with the team (Behavior clinician, direct support staff, guardians, therapists, psychiatrist) to provide the best level of care for the client.

Interventions

➤ **Death Education Groups:**

- These can be adapted to client's needs.
- Focus on educating client about death, grief and loss.

➤ **Grief Support Groups:**

- Much overlooked but much needed resource for those diagnosed with I/DD.
- Group to support loss clients experienced.

Interventions Cont'd

➤ **Individual grief counseling:**

- Gives client individual space to process grief.
- Good option when groups are unavailable

➤ **Social stories to teach, educate, and guide grief process:**

- These can be completed and added as a supplement to the behavior plan and tailored to the individual clients needs.

Interventions Cont'd

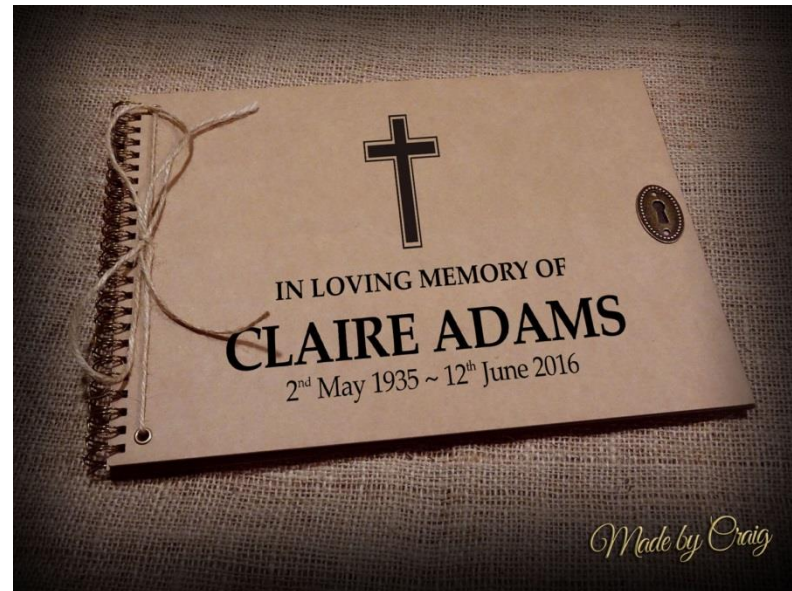
- Examples of Social Stories:
- See Handout Social Story Example: Supporting People with Disabilities coping with Grief & Loss
- <https://www.andnextcomesl.com/2018/09/free-social-stories-about-death-and-funerals.html>
- <https://www.pathfindersforautism.org/docs/social-story-about-death.pdf>

Interventions Cont'd

- Proactively teaching and training staff to assess for and handle grief processes
- Involve them in the process as much as possible and tell them what to expect during rituals: open casket, funeral services, people crying, burial, etc.
- Use pictures if needed for clients who are non-verbal.

Interventions Cont'd

Photos and mementos can be helpful such as memory scrapbooks or blankets



Interventions Cont'd

Memory Gardens, planting a tree in memory of a loved one or picture collages



Interventions Cont'd

Memory Bracelets or balloon releases to honor/memory of the loved one.



Interventions Cont'd

- Use natural community supports (Pastors/church, therapy) when available and desired by client.
- Review helpful insights on Listening to the bereaved (P.T. Clements article pg. 806-807).
 - Provides examples of what not listening looks like for staff/caregivers
 - Provides examples of what listening truly is for staff/caregivers.

Interventions Cont'd

- Develop interventions to add to the behavior plan based on assessments.
 - May include strengthening coping skills
 - Expression of feelings in an appropriate manner
 - Can use templates to help guide

- May also add supplements to the behavior plan, such as social stories.

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Questions/Comments?