



Grief and Loss in Individuals with Intellectual and Developmental Disabilities

Overview

Loss is something that all individuals experience. Grief is an emotion that someone may experience following a loss, especially if the two people are particularly close. People with intellectual and developmental disabilities (I/DD) have to deal with loss and grief just like anyone else. Their experience of these events, however, may differ depending on their understanding of the circumstances. People with I/DD may have to deal with the death of a loved one or close friend, but grief can happen even in the absence of death. For example, people with I/DD may develop close bonds with their caregivers and experience grief when they move or change their placements if in a group home or residential facility.⁴

There are five recognized stages of grief: denial, anger, bargaining, depression, and acceptance. Someone experiencing grief may experience all, or only some, of these stages and also may not experience them in order.⁶ People with I/DD may have a hard time expressing their own emotions related to grief and may have an exceptionally difficult time adjusting to changes after they experience a loss.⁴

There are four different tasks that an individual must navigate in order to come to terms with a loss. These include: accept the reality of the loss, experience the pain of grief, adjust to an environment without the loved one, and withdraw emotional energy to invest in another relationship.⁶ Those with I/DD can also complete these tasks, however their process may look different from someone who is neurotypical.⁴

Challenges and Considerations

It is important to consider several aspects of someone's functioning when helping them deal with grief and loss.⁴ First, their level of cognitive functioning may affect their understanding of death

or permanent loss (e.g., a move). Notably, however, they still feel the emotional burden of grief and loss, even if they do not cognitively understand what death is. The majority of individuals with I/DD typically have mild to moderate cognitive impairments and are very capable of understanding the permanence of death or a significant loss.^{3, 4} It is important to not underestimate someone's ability and level of understanding.

Second, providers must also take into account the person's level of speech and language ability. Consider how someone's level of both receptive and expressive language may impact their ability to understand how loss is communicated. Use a congruent level of language when relaying that someone has died. Providers should not assume that a non-verbal individual cannot understand or process their grief. In these instances, use augmented communication devices and check for behavior changes to assess how an individual may be feeling. Notable behavior changes include increased or decreased sleep, changes in appetite, increased self-injurious behaviors, increased agitation, or increased aggression.⁴ Another study found increases in lethargy, hyperactivity, and irritability among bereaved individuals with I/DD.²

Third, providers should consider how a person with I/DD typically responds to emotional situations. Does the person tend to respond positively no matter the question? Do they tend to have a diminished expression of emotions? The grief process takes time for anyone and grief in individuals with I/DD may be compounded by multiple moves or changes in caregiver. It is necessary to remind the individual that you are there to support them and to provide continuity of care. Furthermore, it is possible that the individual needs lifelong support for their disabilities and loss or the death of a loved may lead to increased anxiety related to their future.⁴

Implications for Practice

First and foremost, agencies should offer training and professional development related to supporting individuals experiencing grief. This helps to demystify the grieving process and provide staff with strategies for helping their patients.¹ More specifically, in order to facilitate and aid in the grieving process, the person who delivers the news to the individual with I/DD should be a trusted, familiar adult.⁴ Deliver the news in a way that ensures understanding. The person may need to repeat the story back for understanding, so be patient if they attempt to retell the story or re-enact it in some way (e.g., drawing). As with anyone who may be grieving, allow them space to express their feelings and ask questions, but do not force them to talk about the loss.^{4, 6} Additionally, as much as is possible, involve the individual in any memorials or funerals so they may share in their grief with any relatives or friends.⁵ Many individuals with I/DD may feel as though their lives are not within their own control, therefore, allow them to choose a way to memorialize or pay tribute to someone they have lost (e.g., through artwork, letters, collages). Participation in these rituals facilitate the stages of grief and allow the individual to work through the tasks of grief.^{5, 6}

Contributors

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References

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