Fostering meaning-making in grieving adults with intellectual and developmental disabilities

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Introduction

People with intellectual and developmental disabilities (IDDs) cite problems with service delivery as a key restricting factor for adequate care. They report that health care providers (HCPs) and other staff have inadequate skills to meet their needs. There is a lack of literature regarding the educational presentation and HCPs through an delivery as a key restricting factor for adequate needs. There is a lack of literature regarding the disenfranchisement, complicated grieving, and unhealthy mourning.

This project targeted staff and family at a day program in Springfield, MA through an educational presentation and HCPs through an article with recommendations for care.

Methods

A thorough literature review was completed.

- Interpersonal interaction
- Basic background in developmental models (Erikson’s Psychosocial Stages)
- Application to bereavement behavior
- Dual Model Process used for grief theory (Stroebe and Schut)
- Personal experience

Those involved with bereaved families may turn to bereavement journals

- Write article outlining current recommendations for grieving individuals with IDD.

Results

When working with this group, the focus is on adjusting developmental expectations for their functional age rather than their chronological age. Each individual should receive individualized support.

Expression may be complicated by verbal ability; but everyone experiences and feels loss despite functional ability. Lack of emotional expression does not reflect absence of care towards their family and loss.

Therapeutic strategies that are beneficial:

- Music therapy
- Art therapy
- Drawing
- Prompted grief journals/coloring books
- Bibliotherapy (stories, books)
- Journaling, letter writing
- Give space when needed
- Ask “how can I help you”
- Allow participation in grief rituals

Discussion suggestions

- Be present, listen
- Give ample time for processing of questions as well as the formation and delivery of a response
- Use literal language, no euphemisms
- Use familiar communication devices, such as tablets or images
- Provide privacy and a calm environment with few distractions
- Pose open-ended questions
- Consider what the family has told them
- Empower them to voice feelings; reassure that they will not be punished, and information will not be shared
- Reflect “why” questions back to the individual – what do they think?
- Don’t stifle emotional expression based on expected age and gender norms

Touch may be therapeutic to some but may make others uncomfortable. Always ask permission before initiating touch.

“Loss can be disempowering for anyone; but for people with an IDDD loss can be totally disempowering and overwhelming.”

-Sue Read, Supporting people with disabilities experience loss and bereavement

References


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