Loss and grief within intellectual disability.

Owen Doody

Introduction

One of the most significant trends seen in recent years has been the increasing longevity of people with intellectual disability (Doody et al., 2013). Advances in medical and neonatal care along with deinstitutionalisation have increased life expectancy for most individuals with intellectual disability. In today's society individuals with intellectual disability live with family members, in special assisted living facilities, community group-homes or on their own. Just like anyone else people with intellectual disability have created and developed attachments to various persons be it family members, fellow residents, staff members, co-workers, members of their communities, and other friends. With such attachments comes the experience of loss, where staff members leave, other residents relocate or die and the death of a parent, caregiver or family member may occur. Thereby loss and grief are a natural part life however; individuals with intellectual disability may experience significant secondary losses such as the loss of a parent or caregiver may necessitate a change in residence leading to a cascade of losses that may include friends, neighbors and employment. In addition some higher functioning individuals may experience a sense of grief and loss over their disability where they experience a persistent sense of loss over the fact that they are perceived as different from others.

Grief reactions in people with intellectual disabilities

Since cognitive processes are impaired, individuals with intellectual disability may have difficulty in comprehending death. However, ability to understand death is not dependent on IQ but rather chronological age suggesting the critical importance of experiential learning (Fabian et al. 2011). Often the grief of individuals with intellectual disability is often disenfranchised (Doka, 2002; Read and Elliott, 2007). Disenfranchised grief occurs when an individual experience a loss but that loss is not openly acknowledged, socially supported, or openly mourned. Thereby the person experiences a loss, but has no socially sanctioned right to grieve. Disenfranchised grief may occur as caregivers may feel inadequate in addressing grief in individuals with intellectual disability and hence ignore their needs. There may be a sense of over-protectiveness that creates a reluctance to upset individuals with intellectual disability that results in attempts to limit exposure or discussion of death, loss, and grief. However just because an individuals grief may not be understood by other; it does not mean that the individual does not understand and experience the loss. There is no timetable for grief, over time an individual's painful cognitive and emotional reactions lesson and return to their former levels of functioning. In truth, for some individual's their loss can create an opportunity to learn new skills and gain insight. Over time individuals may experience surges of grief especially at holiday or anniversary times or at events in which the presence of the deceased is deeply missed. There is no particular sequence or stages within the grieving process and Worden (2008) sees grief as a series of very individual processes. What needs to be considered is that individuals with intellectual disability often have limited or distorted emotional

expressions such as giggling when anxious or positive bias where they report they are happy (Dodd et al. 2005). These may mask the deep feelings of anxiety, dependency, and ambivalence about the dependency, and abandonment that may be generated by the loss (Kaufman, 2005).

Grief is common to all people thereby; individuals with intellectual disability generally grieve in the same ways as others who experience a loss. However, every individual's experience of grief is unique, based upon the characteristics of the person and the relationship to the person they have lost. Grief manifestations include physical, cognitive, emotional, behavioral, and spiritual. On a physical level grief may be converted into physical reactions such as nausea, headaches, or other bodily aches or pains. Moreover physical symptoms result in care, concern and support from others at a painful time. Often emotional manifestations are also converted and interpreted as physical symptoms for example anxiety is often expressed as stomach pains. Thereby it is crucial to frequently assess physical health. At an emotional level there is a range of responses to loss including; anger, guilt, jealousy, anxiety, sadness, or regret. It is not uncommon that displaced anger is directed towards other residents or staff members and guilt can be a common reaction due to limited understanding of causality. At a cognitive level in the initial phases of grief shock, disbelief, and denial may occur. Throughout the grieving process an individuals concentration or attention span can be affected, their ability to process information less effectively and may experience impaired judgment. Behaviors may be influenced and an individual may seem lethargic or hyperactive and sleeping or eating pattern may change. Generally angry, lashing out at others, or becoming withdrawn is common and may become quite resistant to any changes in routine. Resistance to changes may result in compulsive behaviors where an individual becomes rigid in trying to maintain stability.

Acknowledging other mourners

Within grief support it is important to acknowledge other mourners; family members particularly may need support. Often, the death of an individual with intellectual disability can be disenfranchised by others, where the loss of an adult child with intellectual disability may not always be acknowledged by others (Doka, 2002). Memorial services at group homes or residences and sheltered workshops can have much value. As they can bring a community of mourners together that includes family, staff, friends, fellow housemates and co-workers. Such remembrances reaffirm the worth of the deceased and the inherent value of the deceased's life. This is particularly important when the wider community may view such a loss more ambivalently. Family members also may be invited to participate in memorials. In addition, it may be effective education to encourage the deceased's fellow housemates, co-workers, and residents to acknowledge the loss to the family through cards, drawings, or video tributes as families often treasure such items.

Grief support should also be extended to staff members as staff members can create strong bonds with individuals with intellectual disability that can last over years. Moreover, the deaths of clients can result in a secondary loss for staff where contact with family members is likely to cease once a resident dies. Moreover the loss of a resident

may raise concerns for staff around the ethical decisions that have were made or they may feel that end-of-life care was inappropriate to the nature of the individual's disability. Without grief support for staff it is unrealistic to expect staff to develop close bonds with clients, and support other individuals with intellectual disability at the time of the loss if their own needs for grief support are not met. The result of such unrealistic expectations is that staff members are either likely to experience a sense of occupational stress or burnout, or become wary of bonding to residents as closely in the future (Papadatou, 2000). Effective grief support generally involves individual strategies of self-care. These include acknowledging and validating loss, finding effective methods of respite that allow one to manage stress, and developing a personal and spiritual stance that allows a staff member to find an overarching framework for attributing meaning to life and death as well as finding satisfaction in one's own work (Doka, 2006). However, research also has emphasized that organisations play a large role in effecting support. Effective organisations require formal policies and informal procedures that validate loss that include time off to attend funerals or debriefings after death. These policies /procedures create an environment where supervisors and employees can be both validating and supportive of grief. In addition effective organisations offer both ongoing education and rituals that marked significant deaths (Gilrane-McGarry Taggart, 2007; Blackman, 2008). However it is important to also acknowledge that not all losses involve death, such as when residents or staff members leave also can engender feelings of grief and ought to be marked by ritual.

Conclusion

Like other populations, individuals with intellectual disabilities as they age will inevitably have to cope with loss and grief. While one cannot protect individuals from such loss, one can prepare and support individuals and support should begin even before the illness experience or loss occurs. In supporting the person we should provide opportunities to grieve and consider any change in behaviour with a high degree of suspicion. Within the grief process we need to consider the people left behind and when a person with intellectual disability passes away this will mean providing support to family, staff, housemates, co-workers and friends.

References (can be on request if you wish to cut content)

Blackman, N. (2008). The development of an assessment tool for the bereavement needs of people with learning disabilities. British Journal of Learning Disabilities, 36(3), 165-170.

Doka, K.J. (2002) Disenfranchised grief: New directions, challenges, and strategies for practice. Champaign, Il: Research Press.

Doka, K.J. (2006) Caring for the carer: The lessons of research: Grief Matters, The Australian Journal of Grief and Bereavement, 9, 4-7.

Dodd, P., Dowling, S. and Hollins, P. (2005) A review of the emotional, psychiatric and behavioural responses to bereavement in people with intellectual disabilities. Journal of Intellectual Disability Research, 49 (7), 537–543.

Doody, C.M., Markey, K. and Doody, O. (2013) Future need of ageing people with an intellectual disability in the Republic of Ireland: lessons learned from the literature. British Journal of Learning Disabilities, 41, 13-21.

Fabian, J.M., Thompson, W.W. and Lazarus, J.B. (2011) Life, Death, and IQ: It's Much More than Just a Score: Understanding and Utilizing Forensic Psychological and Neuropsychological Evaluations in Atkins Intellectual Disability/Mental Retardation Cases, 59 Clev. St. L. Rev. 399-430. available at http://engagedscholarship.csuohio.edu/clevstlrev/vol59/iss3/7

Gilrane-McGarry, U., & Taggart, L. (2007). An exploration of the support received by people with intellectual disabilities who have been bereaved. Journal of Research in Nursing, 12(2), 129-144.

Kauffman, J. (2005) Guidebook on helping persons with mental retardation mourn. Amityville, NY: Baywood Publishing.

Papadatou, D. (2000) A proposed model of health professionals' grieving process. Omega: Journal of Death and Dying, 41, 59-77.

Read S. and Elliott, D. (2007) Exploring a continuum of support for bereaved people with intellectual disabilities: A strategic approach. Journal of Intellectual Disabilities, 11 (2), 167-181.

Worden, J.W. (2008) Grief counseling and grief therapy, 4th Ed, New York: Springer.