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Editorial

The collective voice of the authors published in this edition of *Grief Matters* articulate the disenfranchised nature of the grief and bereavement experience of those with cognitive impairment, either as a result of intellectual disability or as a result of an acquired brain injury. While description of the issues and impacts of these impairments has increasingly appeared in the literature, the applied clinical practice implications have been slower to make their presence felt. This edition takes a particular focus on frameworks that can guide appropriate and sensitive responses to individuals, families and those who provide care.

The paper by Luchterhand explores the bereavement experience for adults with an intellectual disability. She makes the powerful argument for the provision of death education and grief support for persons with an intellectual disability. She emphasises the need for collaboration between persons with an intellectual disability, grief and bereavement professionals, disabilities staff, health care practitioners and academics as a means of developing creative responses to the needs of this population.

Riches articulates how grief among people with an intellectual disability is both unrecognised and unsupported. She believes that this lack of response can have significant long-term effects on quality of life, health and well-being. Frequently the lack of information, exclusion from rituals, isolation from family, communication limitations and lack of support can result in complex grief reactions, which are frequently misunderstood by others.

The paper by Read explores the loss and bereavement experiences of people with an intellectual disability from a counselling and support perspective. She describes a continuum of support, which serves as a framework for the development of bereavement counselling and support services.

Harms and Keating consider the unique challenges of living with an acquired brain injury and consider both traumatic loss and traumatic growth as critical components of the experience of loss and adaptation.

The final paper by Charles and Butera-Prinzi also considers acquired brain injury with a particular focus on the grief of family members. The paper draws upon the experience of families affected by brain injury who have attended counselling at a family therapy centre. The authors explore grief frameworks, which have been incorporated within a broader systemic and meaning-focused framework, which guides their work with families.

Our understanding of the nature of grief and disability has made rapid advances in the past decade. One significant contributor to this developing understanding was the Melbourne based psychologist and researcher Dr. Elizabeth Bruce, who died in August of this year. Liz, along with her colleague Cynthia Schultz, published widely on the experience of non-finite loss for parents who have a child with a disability. Her books (Bruce & Schultz, 1999; 2004), journal articles, conference presentations, clinical work and teaching in the area of loss and grief stand as a lasting and important legacy. This edition of *Grief Matters: The Australian Journal of Grief and Bereavement* is dedicated to her memory.

References

- Bruce, E. J., & Schultz, C. L. (1999). *Nonfinite loss and grief: A psychoeducational approach*. Baltimore: Brookes.
Bruce, E. J., & Schultz, C. L. (2004). *Through loss*. Melbourne. Australian Council for Educational Research.

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Death Education and Grief Support for Individuals with Intellectual Disabilities: A Hidden Need

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Abstract

Within the past 20 years, there has been increased service provision focusing on the needs of older adults with intellectual disabilities in health care, residential support, and vocational/retirement options. Some families and professionals have also recognised the need to address the issue of death and grief. Awareness of this issue, along with appropriate support and intervention, however, may remain dependent upon the compassion, knowledge, and creativity of individual family members and professionals, rather than well-developed practice. The author describes ways in which grief and bereavement affect adults with intellectual disabilities and offers suggestions to prevent or reverse the hopelessness that some individuals with intellectual disabilities feel after a death or other loss and to empower others to provide assistance.

Introduction

"It's like having a pie and then a big piece is taken out, and my pie will never be whole again. My life will never be the same again." A young man with intellectual disabilities movingly spoke these words years ago during a session on grief at a national convention in the United States. He was describing his life after the death of his father. Henry's* words transport all of us who have experienced similar losses to that time and place when we actually comprehended the depth of our loss and wondered how life would go on. In a heartbeat we know that despite his intellectual disability (ID), Henry shares the same reactions and emotions as we all do when someone special to us dies.

Henry was a success story. He had achieved significant life goals and lived independently in his own apartment. Conducting himself with quiet dignity, he not only understood the concept of emotions but also had the ability to articulate his feelings to others. Henry was a tribute to his own perseverance and courage, and the time, care, and energy of his family, teachers, and mentors. Despite his successes, his quality of life was diminished. Henry described physical isolation and reduced interaction with remaining family members. He could not identify activities that might help him cope with his loss and feel better. Worst of all was the hopelessness that his speech and demeanour conveyed. Time had elapsed since his father's death, yet life was not getting better. He did not expect that his life would ever be pleasurable again. Years later, Henry's poignant description serves as a catalyst, compelling me to reach across time and distance to share a message on behalf of others.

Background

Henry appeared depressed. When one is familiar with literature on grief and mourning and knows that the antecedent for Henry's depressed state was the death of his father, a more complete picture emerges. Worden (2002) conceptualised four tasks inherent in grief work as the bereaved adapt to loss: 1) to accept the reality of the loss, 2) to work through the pain of grief, 3)

to adjust to an environment in which the deceased is missing, and 4) to emotionally relocate the deceased and move on with life. Henry had started to move through the grief process as he acknowledged his great loss and felt the pain of separation from his father. One hopes that Henry adjusted to life without his father and eventually found meaning and pleasure through work, leisure activities, and relationships with other people – that he retained fond, loving memories, but also looked forward to the future. The degree to which Henry accomplished the remaining grief tasks may be related to the assistance and support he received from others.

Many people in the general population also have difficulty coping with the deaths of loved ones (Rando, 1993). Guided by decades of cultural norms as well as basic human compassion, clergy, family members, friends, neighbours, even acquaintances offer supportive gestures and participate in rituals surrounding death. Grief support groups and professional counsellors can be readily located. Bookstores allot shelves to self-help publications on the topic of grief.

We do not have the same rich history in supporting bereaved individuals with an ID. For some groups, such as adults with Down syndrome, life expectancy historically suggested they would not outlive their siblings or parents (Eyman, Call, & White, 1991). The need for grief support arises as life expectancy has increased. In the past, many individuals with disabilities lived out their lives in institutions, and their needs were hidden from public view (Factor, 1993). Even the grief reactions of those with disabilities living in the community have often been misinterpreted, and deemed inexplicable (Emerson, 1977).

Individuals with an ID may have even greater need for grief support than do their peers in the general population. Adults with an ID may have been sheltered from the concept of death and when a loved one dies, lack basic knowledge (such as the inevitability, irreversibility, and universality of death and experience with grief rituals) that the general population usually accumulates throughout their developmental years (Hollins, 1995; Lavin, 2002). Those with disabilities are likely to face multiple losses when a caregiver dies such as changes in living arrangements, daily routines, availability of support and attention, and finances. "These additional losses and changes produce a snowballing effect, overwhelming the person already coping with grief" (Kloepfel & Hollins, 1989, p. 36). Among the factors contributing to complicated mourning described by Rando (1993) are a pre-morbid relationship with the deceased that was markedly dependent and the bereaved individual's perceived lack of social support, two situations that characterise the lives of many individuals with an ID. She also noted that a lack of open communication about loss, dying, and death (a common experience for many adults with intellectual disabilities) increases the likelihood of negative outcomes regarding adjustment following a death loss.

*Anecdotes in this article are from the author's professional experience. Names and identifying information have been changed to preserve anonymity.

Doka (1989; 2002), Lavin (2002), and Rando (1993) have called attention to the concept of *disenfranchised grief*, or grief experienced when a loss is not or cannot be openly acknowledged, publicly mourned or socially supported. This concept recognises the importance of cultural norms and the social aspect of grief.

When individuals are denied access to their culture's mourning rituals, and the social support given to others in society is withheld, emotional reactions can become intensified, and mourning can be more complicated. "Situations where the mourner is invalidated occur frequently when the mourner is an elder or a child, or has a mental disability" (Rando, 1993, p. 11). These groups are often not identified as capable of grief; therefore, their loss and need to mourn are not acknowledged. Problems are exacerbated when a bereaved individual recognises that support could be available, but it is withheld for some reason (Rando, 1993). The grieving person must then deal with this secondary loss and accompanying feelings of anger, hurt or resentment in addition to grief.

Another issue specific to most adults with intellectual disabilities is the smaller size and different composition of their social circles compared with those of the general population. As they age, their relationships may become less intimate as grandparents, parents and siblings die and those losses are not mitigated by the development of relationships with a spouse, children, or grandchildren of their own. As such, the most intimate and rewarding social relationships may occur when they are young, and the memories of these relationships may be crucial to future equanimity. The views of more recent grief theorists (Klass, Silverman, & Nickman, 1996; Walter, 1999) who acknowledge the continuing bond between the deceased and bereaved may shed new light on how to assist this population with their grief.

Recognising and Addressing Needs

Within the past 20 years there has been increased recognition and service provision to address the needs of older adults with IDs in the major arenas of their lives: health care, residential support, and vocational/retirement options (Janicki & Ansello, 2000). A number of families and professionals have identified the need to address the issue of death and grief as well. The literature includes descriptions of supportive family actions, death education programs, staff education approaches, grief counselling and other supportive techniques (e.g., Moise, 1978; Luchterhand & Murphy, 1998; Botsford, 2000; Blackman, 2002; Van Dyke, 2003; Kauffman, 2004; Dowling, Hubert, White, & Hollins, 2006).

Not surprisingly, wide variability exists among families and agencies in regard to teaching about death and dying, recognising grief, and providing support following a death or other loss. Some adults with IDs receive such excellent information and support that they in turn provide emotional support for others following a death (Luchterhand & Murphy, 1998). Some parents have normalised the experience of death for their children by addressing the topic and the accompanying emotions as various events involving illness and death unfold around them (Moise, 1978).

There are other positive examples. A residential provider used a journal to document what a young woman with significant disabilities saw, heard, and felt throughout the time of her father's failing health and eventual death. She used the woman's own words whenever possible and included positive aspects of her

life, such as names of people who remained active in her life and lists of activities and events she enjoyed. Staff have organised informal memorial services or encouraged lighting candles as a way to acknowledge anniversary dates of deaths. Some individuals have been invited and prepared to be pallbearers. Others have been encouraged to share anecdotes about the deceased that could be incorporated into a funeral or memorial service.

Individuals with an ID, even those with significant disabilities, have responded to grief support, when it has been tailored to their specific needs. A man with physical disabilities whose parents were deceased found comfort in placing a framed photograph of his family in his bedroom where he could see it immediately upon awakening and before he slept. It seemed to serve as a visual reminder that he was a member of a close, loving family. A musically gifted man with Down syndrome identified songs he liked to play when he thought of his deceased father. A serene woman with a beautiful smile painstakingly created a picture of a church when asked what had helped her following her mother's death. Several individuals requested items that had belonged to the deceased, which had special meaning to them: jewellery, clothes, or a particular chair. Workers at a vocational centre requested that a tree or shrub be planted on the grounds in memory of their deceased family members. The garden containing memorial placards became a source of comfort and pride for the workers. Some individuals have initiated visits to the cemeteries where the bodies of their loved ones were interred. After multiple attempts at communicating with various support staff, a man with limited verbal abilities eventually succeeded in telling a caring staff member that he wanted to place flowers on his mother's grave for Mothers' Day.

It is notable that individuals with IDs themselves initiated some of these activities. They knew what could help them adjust to their losses. It is also noteworthy that some people with IDs are prevented from engaging in common grief rituals that help the general public cope.

Grief Continues to be Under-Addressed

Funding for special projects such as death education and grief support end, experienced staff leave, new families face losses, research requires time. While there appear to be cultural differences in supporting people with an ID in their grief (Dodd, McEvoy, Guerin, McGovern, Smith, & Hillery, 2005), literature from multiple countries (Clute, 2007; MacHale & Carey, 2002; Read & Elliott, 2007) indicates that more work is needed in this area. Education about death, recognition of grief in this population and appropriate support and intervention may remain dependent upon the compassion, knowledge and creativity of individual family members and professionals, rather than well developed practice. Common, heart-wrenching themes emerge as individuals with disabilities, their families, and service providers struggle to deal with the issue.

The topic of death is avoided as long as possible; some adults with disabilities grow up never learning about the universality, inevitability, and irreversibility of death, until they abruptly are faced with the loss of a loved one (Crick, 1988).

Carrie understood that grandparents die, but when her father was diagnosed with a terminal illness, she was shocked to learn that parents die too. Her behaviour proved challenging at times.*

With a misguided desire to protect the person from reality or not feeling up to the task of disclosing this reality, some families and professionals may avoid telling individuals with an ID about the deaths of loved ones (Blackman, 2002).

Tom read about the death of his favourite aunt in the newspaper. He knew his mother had attended her funeral. No one mentioned the death in his presence. Crying every night when alone in his bedroom, he embraced the opportunity to talk when finally given the chance.*

Families struggle to cope with their own emotions and often do not know how to provide emotional support to their relatives with disabilities.

Mr. Thompson's wife of 50 years died before they made long-term plans for their daughter, by then in her 40s. Grief-stricken and over-whelmed, he asked the bereavement counsellor not to return when he heard his daughter crying after their first visit together.*

Many direct care providers are young and have had little experience with death and grief. They may not recognise symptoms of grief, especially if the symptoms are delayed, or they may not know how to provide support as the grief process unfolds. Tears are misinterpreted as a loss of control, a behavioural problem, or as sadness to be redirected, rather than as emotion benefiting from expression.

Following the death of Sadie's mother, residential staff would direct Sadie to change stations rather than listen to her favourite radio program. She always seemed to cry when her favourite station played hymns.*

Consequences related to the lack of grief support vary from person to person. Depression and a diminished quality of life can result, as they did for Henry. The time and energy of family members and staff are often taxed as well. For those with lesser intellectual capabilities, behavioural change may be the first indication that they are reacting to a death loss. The behavioural change can be striking: verbal or physical aggression or extreme withdrawal. Emerson (1977), a consultant on challenging behaviours, reported that the death or loss of someone close preceded the onset of symptoms for 50% of her clientele.

Individuals with an ID usually need lifelong support. A temporary loss of skills and change in emotions related to a death or other loss, when incorrectly attributed to the ID, can result in inappropriate future planning and a loss of opportunities, with the decisions made being difficult to reverse (Hollins, 1995). Bereaved individuals often have a need to repeat the story of the loss and the details surrounding it. "This compulsion to repeat is an attempt to understand and make the event real on a mental and emotional level" (Weizmann & Kamm, 1985, p. 38). For those with an ID, medication or behavioural interventions may be used unnecessarily and inappropriately if this phenomenon of *retelling* is mistaken for perseveration or if the antecedents for challenging behaviours are not accurately identified and addressed (Harper & Wadsworth, 1993; Luchterhand, 1998). Insensitive practices by well-meaning caregivers may lead to irreversible behavioural regression and chronic psychiatric disturbances (Wadsworth & Harper, 1991).

Who Can Help?

Many people will be part of the solution. Various collaborations – between persons with IDs, families, clergy, grief professionals, disabilities staff, health care practitioners, and academics – will be especially helpful through sharing information, pooling knowledge, and identifying creative responses to the need, which is often hidden.

National and international conferences will draw diverse groups together for discussion. Locally, inter-agency work groups and training workshops can bring disabilities staff together with grief professionals to learn from each other.

Primary care practitioners and nurses may help through increased awareness of the issue. Information that these healthcare professionals learn from other family members or disabilities staff can give them insight to understand when presenting health symptoms may be related to grief.

Grief and bereavement specialists and clergy can reach out to this population and their caregivers. Persons with an ID can be included in grief support groups for the general public when feasible; separate support groups for this population can be developed when warranted. They can look to literature on helping techniques (e.g., Deutsch, 1985; McDaniel, 1989; Rothenberg, 1994; Hollins & Sireling, 1989; 1994; Luchterhand, 1998; Luchterhand & Murphy, 1998; Blackman, 2002; Van Dyke, 2003; Dowling et al., 2006) and continue to use their creativity to develop novel approaches.

Staff who work in the ID field can continue to use and adapt death education curricula developed for persons with IDs (Hedger & Dyer Smith, 1993; Yanok & Beifus 1993; Sterns et al., 1999). They can encourage ageing parents, who may not have expected to outlive their children with disabilities, to use day-to-day opportunities as they arise to teach these children about death. Helping individuals with IDs develop and maintain friendships with, and connections to others, takes on even more significance when we consider that they are likely to outlive parents and other ageing relatives.

At the university level, content on grief and ID can be incorporated into coursework in the psychosocial and health sciences. New funding mechanisms need to be created, and research continued. Harper and Wadsworth (1993, p. 328) suggest: "Research that clarifies what to do when and for whom would seem to be a profitable direction in trying to understand and assist adults with mental retardation who are also grieving."

In our quest to inform ourselves completely, however, we must not overlook or deny the reality that each individual is unique. Research will provide general guidance, yet individual needs for support will vary as greatly as do those of adults in the general population. We must afford individuals with IDs the right to learn about death and then interact compassionately with them on a personal level when they are grieving, attending to behaviour as well as words.

Conclusion

Henry and his peers present a challenge to those of us who live with, work with, or otherwise are called upon to provide support to adults with IDs. Just as he compared his life to a pie with a piece missing, support for persons with an ID may have a missing component – death education and grief support – and the need for that support may be hidden from view. The consequences of this missing component can have a significant, long-term impact on quality of life. Many individuals with IDs demonstrate courage and perseverance in their daily lives – courage to try something new that seems difficult and perseverance to stick with the task. May we learn from them. May we have the courage to try to help when we might not know how to do so, and may we resolve to "keep at it". Many of us can be part of the solution.

References

- Blackman, N. J. (2002). Grief and intellectual disability: A systemic approach. *Journal of Gerontological Social Work, 38*(1/2), 253–262.
- Botsford, A. (2000). Integrating end-of-life care into services for people with an intellectual disability. *Social Work in Health Care, 31*(1), 35–48.
- Clute, M. A. (2007). A grounded theory study of the bereavement experience for adults with developmental disabilities following the death of a parent or loved one: Perceptions of bereavement counselors. *Dissertation Abstracts International, 67*(10-A), 3979.
- Crick, L. (1988). Facing grief. *Nursing Times, 84* (28), 61–63.
- Deutsch, H. (1985). Grief counseling with the mentally retarded clients. *Psychiatric Aspects of Mental Retardation Reviews, 4*(5), 17–20.
- Dodd, P., McEvoy, J., Guerin, S., McGovern, E., Smith, E., & Hillery, J. (2005). Attitudes to bereavement and intellectual disabilities in an Irish context. *Journal of Applied Research in Intellectual Disabilities, 18*, 237–243.
- Doka, K. (Ed.). (1989). *Disenfranchised grief: Recognizing hidden sorrow*. Lexington, MA: Lexington Books.
- Doka, K. (Ed.). (2002). *Disenfranchised grief: New directions, challenges, and strategies for practice*. Champaign, IL: Research Press.
- Dowling, S., Hubert, J., White, S., & Hollins, S. (2006). Bereaved adults with intellectual disabilities: A combined randomised controlled trial and qualitative study of two community-based interventions. *Journal of Intellectual Disability Research, 50*(4), 277–287.
- Emerson, P. (1977). Covert grief reactions in mentally retarded clients. *Mental Retardation, 15*(6), 46–47.
- Eyman, R. K., Call, T. L., & White, J. F. (1991). Life expectancy of persons with Down syndrome. *American Journal on Mental Retardation, 95*, 603–612.
- Factor, A. R. (1993). Translating policy into practice. In E. Sutton, A. R. Factor, B. A. Hawkins, T. Heller, & G. B. Seltzer (Eds.), *Older adults with developmental disabilities: Optimizing choice and change*. Baltimore: Paul H. Brookes Publishing Company.
- Harper, D. C., & Wadsworth, J. S. (1993). Grief in adults with mental retardation: Preliminary findings. *Research in Developmental Disabilities, 14*, 313–330.
- Hedger, C. J., & Dyer Smith, M. J. (1993). Death education for older adults with developmental disabilities: A life cycle therapeutic recreation approach. *Activities, Adaptation & Aging, 18*(1), 29–36.
- Hollins, S. (1995). Managing grief better: People with developmental disabilities. *The Habilitative Mental Healthcare Newsletter, 14*(3), 50–52.
- Hollins, S., & Sireling, L. (Eds.). (1994). *When dad died*. (2nd ed.). London: St. George's Hospital Medical School, St. George's Mental Health Library.
- Hollins, S., & Sireling, L. (Eds.). (1989). *When mum died*. (2nd ed.). London: St. George's Hospital Medical School, St. George's Mental Health Library.
- Janicki, M. P., & Ansello, E. F. (Eds.). (2000). *Community supports for aging adults with lifelong disabilities*. Baltimore: Paul H. Brookes Publishing Company.
- Kauffman, J. (2004). *Guidebook on helping persons with mental retardation mourn*. Amityville, NY: Baywood Publishing Inc.
- Klass, D., Silverman, P. R., & Nickman, S. L. (1996). *Continuing bonds: New understandings of grief*. Washington, DC: Taylor & Francis.
- Kloppel, D. A., & Hollins, S. (1989). Double handicap: Mental retardation and death in the family. *Death Studies, 13*, 31–38.
- Lavin, C. (2002). Disenfranchised grief and individuals with developmental disabilities. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice*. Champaign, IL: Research Press.
- Luchterhand, C. (1998). *Mental retardation and grief following a death loss: Information for families and other caregivers*. Arlington, TX: The Arc of the United States.
- Luchterhand, C. M., & Murphy, N. E. (1998). *Helping adults with mental retardation grieve a death loss*. Bristol, PA: Accelerated Development.
- MacHale, R., & Carey, S. (2002). An investigation of the effects of bereavement on mental health and challenging behaviour in adults with learning disability. *British Journal of Learning Disabilities, 30*, 113–117.
- McDaniel, B. A. (1989). A group work experience with mentally retarded adults on the issues of death and dying. *Journal of Gerontological Social Work, 13*(3/4), 187–191.
- Moise, L. E. (1978). In sickness and in death. *Mental Retardation, 16*(6), 397–398.
- Rando, T. A. (1993). *Treatment of complicated mourning*. Champaign, IL: Research Press.
- Read, S., & 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.
- Rothenberg, E. D. (1994). Bereavement intervention with vulnerable populations: A case report on group work with the developmentally disabled. *Social Work with Groups, 17*(3), 61–75.
- Sterns, H. L., Kennedy, E. A., & Sed, C. M. (2000). *Person-centered planning for later life: Death and dying – A curriculum for adults with mental retardation*. Chicago/Akron, OH: Clearinghouse on Aging and Developmental Disabilities, Rehabilitation Research and Training Center on Aging with Mental Retardation, Institute on Disabilities and Human Development, University of Illinois at Chicago; and Institute for Life-Span Development and Gerontology, University of Akron.
- Van Dyke, L. (2003). *Lessons in grief and death: Supporting people with developmental disabilities in the healing process*. Homewood, IL: High Tide Press.
- Wadsworth, J. S., & Harper, D. C. (1991). Grief and bereavement in mental retardation: A need for a new understanding. *Death Studies, 15*, 281–292.
- Walter, T. (1999). *On bereavement: The culture of grief*. Buckingham, UK: Open University Press.
- Weizman, S. G., & Kamm, P. (1985). *About mourning: Support and guidance for the bereaved*. New York: Human Sciences Press.
- Worden, J. W. (2002). *Grief counseling and grief therapy: A handbook for the mental health practitioner* (3rd ed.). New York: Springer Publishing Co.
- Yanok, J., & Beifus, J. A. (1993). Communicating about loss and mourning: Death education for individuals with mental retardation. *Mental Retardation, 31*(3), 144–147.



Unrecognised and Unsupported: Grief Among People with Intellectual Disability

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Abstract

People with intellectual disabilities grieve too. Research indicates that many of their loss and grief experiences have not been adequately recognised, nor have these individuals been well supported. This can have significant long-term effects on quality of life, health and wellbeing. Frequently encountered types of loss are discussed and highlighted by several cases. Recognition of grief reactions in people with intellectual disabilities can be difficult, and atypical and prolonged grief has frequently been misinterpreted as challenging behaviour or psychopathology. Evidence now emerging about the benefits of intervention and the types of support necessary is also presented.

Introduction

Until recently, the impact of loss and grief on people with an intellectual disability (ID) was not recognised, or was ignored or minimised by family members, caregivers and specialist disability services alike (Allen, 1996; Bonnell-Pascual et al., 1999; Huline-Dickens, Hollins, Esterhuyzen, Sedgewick, Abdelnoor, & Hubert, 1999; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; Kloepfel & Hollins, 1989; Murray, McKenzie, & Quigley, 2000). However, a number of studies have demonstrated that people with an ID do grieve and require bereavement counselling and support, and that failure to recognise and provide appropriate supports can result in significant long term distress affecting quality of life, health and wellbeing (Allen, 1996; Bonnell-Pascual et al., 1999; Hollins & Esterhuyzen, 1997; Wadsworth & Harper, 1991).

Intellectual disability is a heterogeneous condition defined by significantly sub-average intellectual and adaptive functioning and onset before age 18 years (American Association on Mental Retardation [AAMR], 2002; American Psychiatric Association [AMA], 1994). Its prevalence is estimated to be about 1–2% of the population, and about 85% of these individuals have IQs within the mild ID range (AACAP, 1999; Xingyan, 1997).

The diagnosis of an intellectual disability is, for most families, associated with shock and grief responses that can be accompanied by chronic sorrow. Olshansky (1962) described chronic sorrow as a parent's natural and pervasive psychological reaction in response to living with a child with a disability. Chronic sorrow is a process that occurs in phases of denial, developing awareness and restitution with adaptive and/or maladaptive coping, marked by such defining characteristics as periodic, inescapable recurrences of pain and sadness; roller-coaster cycles of elation and depression fuelled by denial; grief at the loss of the idealised "normal" child; and varying intensities of grieving from time to time and from situation to situation (Bolst, 1990; Copley & Bodensteiner, 1987; Featherstone, 1980; Solnit & Stark, 1961; Winkler, Wasow, & Hatfield, 1983; Young, 1977).

This process was poignantly described by Perl Kingsley (1987) in her classic analogy *Welcome to Holland*.

Disability in some cultures is still perceived as a divine punishment or an inherited evil that can result in public disgrace for the family; neglect or isolation of the child; and failure to seek assistance, even when families migrate to western nations (Grocé & Zola, 1993). In contrast, Kearney & Griffin (2001) report that the presence of a child with a disability is not necessarily a tragedy or a burden on society, and that Australian parents tend to manage with optimism and resourcefulness, despite the pain and challenges presented to them. Indeed, many families learn to celebrate each small step and victory. Nevertheless, parents do journey through bereavement, although this may stimulate personal and spiritual growth. Writing as both a parent and a psychologist raising a child with autism and severe ID in the US, Naseef concluded that his experience enriched him as a person and that "there were many gifts derived from the suffering" (Naseef, 2002, p. 85).

Loss and Grief Experienced by Those with an Intellectual Disability

But what of the person who has an intellectual disability? Many children grow up aware they are somehow "different" to their siblings and peers, and there can be an ill-defined sense of loss and disappointment about their disability and a heightened sense of rejection resulting in aggression, irritability or sullenness. Seldom are these grief responses ever acknowledged or addressed. This was found to be the case in an investigation undertaken by Riches (1998) using a critical-case, purposeful sampling strategy (McMillan & Schumacher, 1989; Yin, 1994) that explored anger and aggression among young adults who had an intellectual disability and anger problems.

Three males and five females, aged from 18 to 26 years participated in the study. All had a mild or moderate ID. All had attended specialist schools or classes and were supported by disability agencies at the time of the study. Baseline assessments using Spielberger's STAXI scales of state and trait anger and anger expression revealed significant anger patterns for each individual, reaching critical levels above the 75th percentile. At this level, Spielberger (1988, p. 4) reports difficulties can be expected to occur in interpersonal relationships or in the disposition to develop psychological or physical disorders. Each of these participants was found to suffer from low self-esteem that was fuelled by ongoing negative evaluations from self and others relating to lack of competence and feelings of inadequacy and rejection, often directly related to their disability. An unexpected result was that additional previous loss and grief situations also contributed significantly to unresolved

anger banks for seven of the eight individuals, involving death of school friends, siblings and grandparents; death of pets; loss of valued friendships and relationships; grief over separation from family through placement in supported living arrangements; and in one case, loss of a kidney resulting in ongoing health concerns and fear of death.

William had a history of behaviour problems from age 8. During the investigation, William was encouraged to share specific details of incidents where he had reacted with aggression, as well as his thoughts and feelings about these incidents and provocations. William's perception of himself was very negative. He described himself as "a failure", "lazy," a "no hoper" and "scum". He believed other people, particularly significant others such as his father and grandparents, saw him like this. Not surprisingly, William had a large anger bank. During one session William disclosed that two younger siblings had died, one two years previously of cancer and the other following his referral to the anger study and two weeks prior to his participation. Neither the investigator nor the referring agency knew this had occurred. William expressed shock, confusion and guilt over both deaths. He said he had not talked about his grief with anyone, and no one had talked to him. He stated he had tried to cope by cutting himself off from family interaction. He would go to his room and try to sleep, not think at all, or he tried to think about pleasant things, but this only worked for a short time. He said he felt angry and upset at both deaths.²

As well as participants working through unresolved past issues, an analysis was undertaken of self-reported anger and aggressive incidents that occurred for each individual during the course of the study (on average 10 weeks per person), which is reported in Table 1. Similar themes were evident, with provocations involving a number of threats to self-esteem (58%), fear of rejection or actual rejection (10%) and specific loss and grief situations (8%). There had been no previous recognition of loss or support for any of these young people, and addressing these themes and problems was an important part of the intervention that resulted in significantly reduced anger and aggression and improved quality of life for each (Riches, 1998).

Table 1

Provocations for anger and aggressive incidents (N = 8 participants)

Provocations/sources of anger	Number	%
Threat to self-esteem/shame	89	58.2
Conflicting goals	32	20.9
Rejection/failure to be included socially	15	9.8
Loss and grief	12	7.8
Other e.g. frustration with a task or object	5	3.3
Total	153	100.0

This pattern has been replicated during counselling provided to a number of adults with IDs in private practice over the past decade. Furthermore, some of these individuals, particularly males, have reported a preference for feeling angry rather than sad, as feelings of sadness and grief made them feel even more powerless and out of control.

Multiple bereavement is also frequently seen in this population and can complicate grief further (Hollins & Esterhuyzen, 1997; Klopper & Hollins, 1989; MacHale & Carey, 2002; Stoddart, Burke, & Temple, 2002). When the primary caregiver dies, this can mean not only loss of the parent, but also loss of the caregiver who provided instrumental and emotional support. A number of people with IDs are also forced to leave the family home and are placed in residential care, such as in an institution, nursing home or group home. This in turn means the loss of everything familiar, including existing friends and peers, neighbourhood and community, regular routines, and so on. Two studies from the UK report the rate of such relocation at around 40% (Hollins & Esterhuyzen, 1997; Klopper & Hollins, 1989). Australian figures are not available, but clinical experience suggests these rates would be comparable.

Tom was a 19-year-old male with Down syndrome who was referred to the author for grief counselling due to behavioural problems following the death of both parents. One parent was killed in a car accident; the other had died two weeks later from cancer. The teenager was not allowed to attend either funeral. Relatives were unable to cope or care for him, and he was placed in supported accommodation. Within weeks he lost his parents, his home, his siblings, his school and school friends, his community and his familiar routines. He presented as very angry and blamed himself for his father's death. He disclosed they had argued just prior to the accident. Tom became best friends with another young man in the supported living arrangement, but this friend developed leukemia and died the following year. Tom clearly stated he would rather be angry than sad.

Advances in technology, medical care and community supports have enabled many who once would have died before reaching late adulthood to have a life expectancy that approximates that of the general population. Inclusive practices also mean that many adults with IDs now live at home with ageing parents, so the number of adults with an ID who suffer multiple losses of parent, carer and home environment is likely to rise rather than decrease in the coming years.

When families cannot cope and children or adults with IDs are placed "in care" in a hospital or a supported living arrangement, there is generally little or no recognition of loss and grief through separation from the family and all that was familiar. Moreover, a move to supported living means individuals are placed in an environment not of their choosing, with people they do not know and may not like, with no choice or control over the staff who are employed to support them. Attachments that are formed with staff members are often disapproved of, and frequently broken as staff inevitably change jobs or relocate. The compounding loss and grief experienced is rarely recognised or addressed. In fact, these are forms of disenfranchised grief (Doka, 1989).

² All case studies come from the author's clinical experience

Lesley has a moderate ID, is aged 26, and lives in a hostel with 17 other adults with disabilities. Lesley goes home once a month, but sometimes she chooses not to go home. She is often more upset by home visits than not. According to staff, Lesley was “not the favoured one in the family”, and was treated as “second best”. Records show Lesley had been placed in the residential institution on Christmas Eve when she was seven years old. Lesley admitted there had been lots of problems in her family home and she often had tantrums there, both in the past and presently. Just talking about home results in tears and distress, such that it is impossible to understand what Lesley is trying to verbalise. Lesley craves staff attention and her deep needs for affection and attention are not being met by frequently changing staff in the institutional environment. Asked to draw a “person-house-tree”, (See Figure 1) Lesley uses only the colour blue. She draws herself as a stick figure on one side of the house, considerably isolated from the rest of the family. The tree has a cut across it, which may be a sign of unresolved grief (Glassock, 1993). All other family members are represented by circles placed in a line near the tree on the other side of the house.

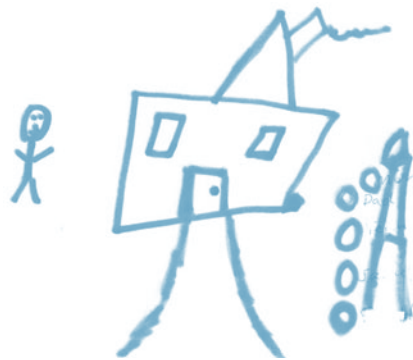


Figure 1
Person-house-tree

People with IDs are frequently viewed as not experiencing grief nor needing protection from grief. For individuals separated from family and living in supported accommodation, news of the death of parents or family has sometimes been withheld for weeks, months or even forever (Bicknell, 1983; Oswin, 1991). Even when an individual is informed – as Tom was – it has been common practice for the person with an ID to be denied the opportunity to take part in the funeral. Yet it is well known that participation in the cultural rituals surrounding the death, including the funeral service itself, can have a direct role in aiding the mourning process.

Recognising Grief Responses Among People with an Intellectual Disability

Many individuals with an ID respond to loss in similar ways to other individuals and grieve at the time of bereavement (Dodd, Dowling, & Hollins, 2005; Reynolds, Guerin, McEvoy, & Dodd, 2008; Stoddart et al., 2002). However, chronic grief or delayed or inhibited grief reactions can occur due to lack of information, dependence on others, exclusion from rituals, over-protectiveness, lack of personal supports and isolation from family (Stoddart et al., 2002; Stoddart & McDonnell, 1999).

Recognition of grief reactions in people with IDs can be difficult because of communication limitations (Delorme, 1999; Stoddart et al., 2002). For example, Hollins & Sireling (1991) reported that some who were unable to express themselves verbally were treated as though they experienced no feelings, while in other cases, the one person who had been able to understand what may be a very individual means of communication was the one who had died, thus further complicating the loss.

Moreover, there has also been a general failure of staff and carers to attribute increased behavioural problems to bereavement. This is a form of diagnostic overshadowing, whereby challenging behaviour or symptoms of mental illness are attributed to the person's lifelong disability (Prosser et al., 1998; Reiss, 1990; Reiss, Levitan, & Szyszko, 1982). Even when cases have been referred to a mental health professional for advice regarding disturbed behaviour, this tends to occur without recognition of the nature of the link between grief and behaviour (Kloepfel & Hollins, 1989). Interestingly, Day (1985) reported half the admissions of patients with intellectual delay to a psychiatric ward were precipitated by a death or serious illness of a relative or caregiver. It is clear that atypical and prolonged grief following the death of a family member or close friend has frequently been misinterpreted as challenging behaviour or psychopathology (Bonnell-Pascual et al., 1999; Dodd et al., 2005; Dowling et al., 2006; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; MacHale & Carey, 2002; Wadsworth & Harper, 1991).

Hollins and Esterhuyzen (1997) found highly significant differences between a sample of 50 parent-bereaved people with IDs in the UK and a matched control group of 50 non-bereaved people. The bereaved group showed a significant increase in aberrant behaviours (irritability, lethargy, hyperactivity, stereotypic, inappropriate speech) and an increase in psychopathology, with 51% meeting criteria for an affective, anxiety or adjustment disorder. None of this behaviour was recognised by staff or carers as related to bereavement, despite their knowledge of the bereavement. A follow up of 41 of the parent-bereaved sample, 6–8 years after bereavement, showed there had been a small increase on each of the behaviour subscales, a reduction in anxiety and adjustment disorder symptoms, but no statistically significant change in measures of psychopathology. Generally, where behaviour got worse, so did psychopathology. Only a quarter of the participants received any recognised bereavement support, either formal or informal, and for most a continuing sense of loss was evident, demonstrated through tearfulness, crying out for the deceased parent, mood swings and physical symptoms. The authors concluded that intellectual disability is a predictor of pathological grief, that the long-term effects of bereavement should be taken into account in the management of challenging behaviour, and that the onset of symptoms for this population is often delayed, and the duration prolonged. Importantly, participants adapted more easily when basic emotional needs were constructively met by carers (Bonnell-Pascual et al., 1999).

Support and Intervention

Evidence is emerging about the benefits of intervention and the types of support necessary. In Ireland, many of the traditional rituals associated with bereavement are still practiced and Dodd claims that people with an ID have benefited when they have been supported to attend these (Dodd et al., 2005). Baxter (2001) also found that for many people with an ID, accompanying the person to a private individual body-viewing farewell was even more meaningful than attending the funeral. This process can assist the bereaved to better understand what has happened, to connect to their feelings associated with the loss and to have the opportunity to say goodbye.

The time that we spent was amazing, it demonstrated to me that regardless of a person's disability there is, within us all, an intrinsic sense that lets us know as human beings that another person is dead, that they're not asleep, they are actually dead. David went from absolute pain and agony during the first few minutes of exposure to his Mum to acceptance that she was dead. Perhaps he finally realised the meaning of all the pictures that had been pushed under his nose during the days before. (Baxter, 2001, p. 7)

A randomised controlled trial of two interventions reported that significant improvements occurred amongst a group of adults with IDs who had received counselling by trained volunteer bereavement counsellors, according to quantitative and qualitative data regarding mental health and behaviour. Improvements were particularly evident in the areas of irritability, angry behaviour, isolating and withdrawn behaviour and reluctance to talk about the person who had died. Improvements in sociability and relationships, quality of life and emotional wellbeing were also found. These positive results were in stark contrast to an alternative approach that attempted to provide support from a combination of family/carers and day centre staff. This approach proved ineffective and in some cases exacerbated problems, as many family/carers still had to come to terms with their own losses and support from day centre staff tended to be haphazard. The authors concluded that volunteer bereavement counsellors could, with relatively little additional training, adapt their skills for use with people with IDs, and that bereavement counselling could achieve significant improvements in mental health, regardless of degree of ID or length of time since bereavement. They also identified the need for professionals working in the field to share knowledge and information with other counsellors about how to work and communicate with people with IDs, and to share resources (Dowling et al., 2005).

In another study, Stoddart et al. (2002) reported that bereavement interventions resulted in lower depression scores, particularly for those with dual diagnosis (ID and mental illness) although no reduction was evident in anxiety or increase shown in knowledge and understanding of the bereavement process in this group. The need for a comprehensive assessment of the bereaved person's characteristics

and issues arising from the way services are run that may exacerbate or perpetuate chronic grief responses was also identified (Stoddart et al., 2002).

When a person with an ID is known to have suffered loss, particularly death of a family member or regular carer, clearly care plans should include bereavement support needs and the long term effects of bereavement should be taken into account in the management of challenging behaviour.

Support can involve provision of explanations, help to attend the funeral, opportunities to talk about the loss, share photos and mementos, visit the grave or celebrate in some way, ensure opportunities for family and peer group involvement, as well as individual or group counselling (Allen, 1996; Hollins, 1995). The importance of the caring relationship is well recognised in general counselling, particularly qualities such as warmth, caring, acceptance, genuineness and encouragement (Hubble, Duncan & Miller, 1999; Morawetz, 2007; Rogers, 1951). These characteristics and types of support are helpful for people with and without intellectual disability.

Additionally, Hollins & Sireling (1991) have stressed the importance of using non-verbal methods of communication, and the need for repeated attempts to explain new experiences, ensure understanding and avoid behavioural disturbance. Fortunately, there are many different strategies that can be utilised for those with limited verbal communication, such as alternative forms of communication including symbols (Aguirre, 2000), art therapy, music (Bright, 1996) and drama therapy; and making life-story books, memory boxes and picture books (e.g., *The Memory Book*, Knoderer & Miele, 1995; *When Dad Died* series, Hollins & Sireling, 1994).

Specialist training for caregivers and professionals has been identified as crucial (McHale & Carey, 2002; Murray et al., 2000, Reynolds et al., 2008). Even when staff knowledge of, and attitudes towards the grieving process in this population is good, many still appear to lack confidence – but bereavement training has proven effective in changing this (Reynolds et al., 2008).

Research has highlighted the devastating consequences that can occur for people with an ID who do not receive appropriate recognition and support when they are grieving. Far too many fall into this category. Yet people with IDs have the same need to understand loss, death and bereavement, to be able to grieve and commemorate, and to receive timely and relevant support and counselling, as others do. What is now needed is further research concerning what people with IDs themselves want, and how to provide this effectively without being patronising or intrusive. The outcomes of such support and grief therapy for this population will also need to be examined.

References

- Aguirre, H. (2000). Grief therapy with non-verbal adults who have profound and multiple learning disabilities: A case study. *Journal of Intellectual Disability Research, 44*(3/4), 191.
- Allen, D. (1996). Coming to terms with grief. *Nursing Standard, 11*(6), 22–24.
- American Academy of Child and Adolescent Psychiatry. (1999). Practice parameters for the assessment and treatment of children, adolescents, and adults with mental retardation and co-morbid mental disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*(12) (Supplement), December 1999, 5S–31S.
- American Association on Mental Retardation (AAMR) (2002). *Mental retardation: Diagnosis, classification and systems of support* (10th ed.). Washington, DC: Author.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.
- Baxter, V. J. (2001). Seeing is believing: Bereavement support in practice. Paper presented at the Australasian Society for Study of Intellectual Disability (ASSID) National Conference, Melbourne, November.
- Bicknell, J. (1983). The psychopathology of handicap. *British Journal of Medical Psychology, 56*, 167–178.
- Bolst, A. (1990). Grief, loss and disability: Parent and students perceptions and experiences. Paper presented at the Australian Association of Special Education Conference, Canberra, September.
- Bonell-Pascual, E., Huline-Dickens, S., Hollins, S., Esterhuyzen, A., Sedgwick, P., Abdelnoor, A., et al. (1999). Bereavement and grief in adults with learning disabilities: A follow-up study. *The British Journal of Psychiatry, 175*, 348–350.
- Bright, R. (1996). *Grief and powerlessness: Helping people regain control of their lives*. London: Jessica Kingsley Publishers.
- Lansdall-Welfare, R., Andrews, C., Clegg, J., & Thurman, S. (2000). Setting standards in bereavement management for clients with learning disabilities using grounded theory. *Journal of Intellectual Disability Research, 44*(3 & 4), 359.
- Copley, M. F., & Bodensteiner, J. B. (1987). Chronic sorrow in families of disabled children. *Journal of Child Neurology, 2*, January, 67–70.
- Day, K. (1985). Psychiatric disorder in the middle-aged and elderly mentally handicapped. *British Journal of Psychiatry, 147*, 660–667.
- Delorme, A. (1999). Aging and people with developmental disabilities. In I. Brown & M. Percy (Eds.), *Developmental Disabilities in Ontario* (pp. 189–195). Toronto: Front Porch Publishing.
- Dodd, P., McEvoy, J., Guerin, S., McGovern, E., Smith, E., & Hillery, J. (2005). Attitudes to bereavement and intellectual disabilities in an Irish context. *Journal of Applied Research in Intellectual Disabilities, 18*, 237–243.
- Dowling, S., Hubert, J., White, S., & Hollins, S. (2006). Bereaved adults with intellectual disabilities: A combined randomised controlled trial and qualitative study of two community-based interventions. *Journal of Intellectual Disability Research, 50*, 277–287.
- Doka, K. J. (Ed.). (1989). *Disenfranchised grief: Recognizing hidden sorrow*. New York: Lexington Books.
- Featherstone, H. (1980). *A difference in the family: Living with a disabled child*. Middlesex: Penguin.
- Glasscock, G. (1993). *Counselling grieving children and their families, Grief counselling seminar* (Cassette Recording). Health Care in Christ, Sydney, September 4, 1993.
- Groce, N. E., & Zola, I. K. (1993). Raising children with disabling conditions in a culturally diverse world: Multiculturalism, chronic illness and disability. *American Academy of Pediatrics, 91*(5) (Suppl. 2), 1048–1055.
- Harper, D. C., & Wadsworth, J. S. (1993). Grief in adults with mental retardation: Preliminary findings. *Research in Developmental Disabilities, 14*, 313–330.
- Hollins, S. (1995). Managing grief better: People with developmental disabilities. *The Habilitative Mental Healthcare Newsletter, 14*(3), 1–5.
- Hollins, S., & Esterhuyzen, A. (1997). Bereavement and grief in adults with learning disabilities. *The British Journal of Psychiatry, 170*(6), 497–501.
- Hollins, S., & Sireling, L. (1991). *Working through loss with people who have a learning disability*. Windsor: NFER-Nelson.
- Hollins, S., & Sireling, L. (1994). *When dad died. Books beyond words series*. London: Gaskell Press and St George's Hospital Medical School.
- Hubble, M. A., Duncan, B. L., & Miller, S. D. (1999). *The heart and soul of change: What works in therapy*. Washington DC: American Psychological Association Press.
- James, I. (1995). Helping people with a learning disability to cope with bereavement. *British Journal of Learning Disabilities, 23*, 74–78.
- Kearney, P., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing, 34*(5), 582–592.
- Klopper, D., & Hollins, S. (1989). Double handicap: Mental retardation and death in the family. *Death Studies, 13*, 31–38.
- Knoderer, K., & Miele, B. (1995). *Memory book: A special way to remember someone you love*. Warminster, PA: MAR-CO Products, Inc.
- McHale, R., & Carey, S. (2002). An investigation of the effects of bereavement on mental health and challenging behaviour in adults with learning difficulty. *British Journal of Learning Disabilities, 30*, 113–117.
- McMillan, J. H., & Schumacher, S. (1989). *Research in education: A conceptual introduction*. (2nd ed.). Glenview, Ill: Scott, Foresman and Company.

- Miles, M. (1984). Helping adults mourn the death of a child. In H. Wass & C. A. Corr (Eds.), *Childhood and death*. Washington DC: Hemisphere Publishing Corporation.
- Moddia, B., & Chung, M. C. (1995). Grief reactions and learning disabilities. *Nursing Standard*, 33, 38–39.
- Morawetz, D. (2007). What works in grief counselling? US evidence and Australian experience. *Grief Matters: The Australian Journal of Grief and Bereavement* 10(3), 56–59.
- Murray, G. C., McKenzie, K., & Quigley, A. (2000). An examination of the knowledge and understanding of health and social care staff about the grieving process in individuals with a learning disability. *Journal of Learning Disabilities*, 4, 77–90.
- Naseef, R. (2002) When the bough breaks: A father's story. *Journal of Religion, Disability & Health*, 6(1), 75–87.
- Olshansky S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework*, 43, 190–193.
- Oswin, M. (1991). *Am I allowed to cry? A study of bereavement among people who have learning difficulties*. London: Human Horizons.
- Parkes, C. M. (1972). *Bereavement: Studies of grief in adult life*. London: Human Horizons.
- Perl Kingsley, E. (1987). *Welcome to Holland*. Retrieved July 14, 2008, from <http://www.ndscenter.org/resources/package1.php>
- Prosser, H., Moss, S., Costello, H., Simpson, N., Patel, P., & Rowe, S. (1998). Reliability and validity of the Mini PAS-ADD for assessing psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research*, 42(4), 264–272.
- Reiss S. (1990). Prevalence of dual diagnosis in community-based programs in the Chicago metropolitan area. *American Journal on Mental Retardation*, 94, 578–85.
- Reiss, S., Levitan, G. W., & Szyszko, J. (1982). Emotional disturbance and mental retardation: Diagnostic overshadowing. *American Journal of Mental Deficiency*, 86, 567–574.
- Reynolds, S., Guerin, S., McEvoy, J., & Dodd, P. (2008). Evaluation of a bereavement training program for staff in an intellectual disabilities service. *Journal of Policy and Practice in Intellectual Disabilities* 5(1), 1–5.
- Riches, V. C. (1998). *Guns or roses: Anger among young adults with intellectual disabilities*. Unpublished doctoral dissertation, Macquarie University, Sydney.
- Rogers, C. R. (1951 and 1970). Client-centered therapy: Its current practice, implications and theory. (1st and 2nd eds.). Boston: Houghton Mifflin.
- Solnit, A. J. & Stark, M. H. (1961). Mourning the birth of a defective child. In A. J. Solnit, (Ed.), (1977) *An anthology of the psychoanalytic study of the child: Physical illness and handicap in childhood*, (pp. 181–194). Newhaven: Yale University Press.
- Spielberger, C. D. (1988). *State-trait anger expression inventory*. Orlando, FL: Psychological Assessment Resources, Inc.
- Stoddart, K. P., Burke, L., & Temple, V. (2002). Outcome evaluation of bereavement for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 28–35.
- Stoddart, K. P., & McDonnell, J. (1999). Addressing grief and loss in adults with developmental delays. *Journal of Developmental Disabilities*, 6, 51–65.
- Wadsworth, J. S., & Harper, D. C. (1991). Grief and bereavement in mental retardation: A need for a new understanding. *Death Studies*, 15, 281–292.
- Xingyan, W. (1997). *The definition and prevalence of intellectual disability in Australia*. Canberra: Australian Institute of Health and Welfare.
- Winkler, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Parent vs professional depiction of the adjustment of parents of mentally retarded children. *American Journal of Orthopsychiatry*, 51(1), 63–70.
- Winkler, L., Wasow, M., & Hatfield, E. (1983). Seeking strength in families of developmentally disabled children. *Social Work* 28, 313–315.
- Yin, R. K. (1994). *Case study research. Applied social research methods series, Vol. 5*. (2nd ed.). Thousand Oaks, California: Sage.
- Young, R. K. (1977). Chronic sorrow: Parent's response to the birth of a child with a defect. *MCN: The American Journal of Maternal Child Nursing*, 2, 38–42.



Loss, Bereavement, Counselling and Support: An Intellectual Disability Perspective

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Abstract

The social context in which death occurs may affect both the nature and quality of the death itself and those bereaved survivors. Disadvantaged, marginalised populations often struggle to have their grief needs acknowledged and supported, perhaps because of their social circumstances, associated health challenges or the beliefs, values and attitudes of those around them. This positional paper explores the loss and bereavement experiences of people with an intellectual disability, from a counselling and support perspective. It defines the population, introduces a range of challenges that may impact on effective bereavement counselling and support, explores the concept of disenfranchised grief and, finally, offers a “continuum of support” model that acts as a framework for the development of bereavement counselling and support for this population.

Introduction

Death never occurs in a vacuum, but from within a social context, and varied social contexts can often impact greatly upon the nature and circumstances surrounding the death itself (Olivière & Monroe, 2004) and the subsequent effects upon those survivors left behind. Much has been both researched and written about cultural diversity from a loss, death and bereavement perspective, (e.g., Parkes et al., 1997), yet for many people, death remains a mystery, and is often misunderstood (Kellehear, 2005). This is particularly the case for those individuals who are perceived as belonging to a marginalised group, a group that has historically been viewed as “different” from the rest of society. Individuals in this situation may lack the voice to be heard and are often overlooked when psychosocial/emotional support needs are concerned. They may be ignored when issues around loss, dying, death and grief arise. Such groups include people with mental health challenges, children, older people, people diagnosed with HIV and AIDS and people with intellectual disabilities, who may struggle to have their grief needs either acknowledged or responded to in a constructive way.

People with Intellectual Disabilities

In the United Kingdom, the Department of Health (DH, 2001) describes people with a learning disability (LD) as having a reduced ability to understand new or complex information, or to learn new skills (impaired intelligence) with a reduced ability to cope independently (impaired social functioning) that started before adulthood and which had a lasting effect on development (DH, 2001). Clearly this definition describes individuals who may have a whole range of different presenting competencies in communication, social skills, social functioning and/or behaviour. Mencap (a United Kingdom [UK] national charity)

identifies that there are around 1.5 million people with a LD in the UK alone, yet “people with learning disabilit[ies] are amongst the most socially excluded and vulnerable groups in Britain today” (Department of Health, 2001, p. 14), particularly when it comes to loss, death and bereavement, for a variety of reasons. The current term used in the UK is learning disability, but intellectual disability (ID) has become a more universal term from an international perspective, and will be used hereon in this article.

Loss, Bereavement and ID

Loss is universal and can have a profound impact on individuals throughout life, as “it sometimes seems as if all our lives we are trying to cope with loss – either the fear of it, or the memory of it or its raw immediate presence” (Oswin, 1991, p. 15). For some, loss is omnipresent. People with IDs do experience grief (Oswin, 2000; Hollins & Esterhuzen, 1997), but the impact of grief is varied and often complex (Conboy-Hill, 1992; Hollins & Esterhuzen, 1997; MacHale & Carey, 2002). Whilst “response to bereavement by adults [with intellectual disabilities] is similar in type, though not in expression, to that of the general population” (Bonell-Pascual et al., 1999), often people with IDs are neither encouraged, nor expected to grieve or express their grief in any way. People with intellectual disabilities are also prone to multiple and successive losses (Oswin 1991; Elliott, 2003). For example, if a sole or main carer dies, the individual with an ID is usually admitted to respite care, and suddenly the raw realities of living and the associated losses (not knowing where they might sleep, or whom they might live with or when they may find a permanent home) can temporarily overtake the sadness of death and grief work may be delayed, sometimes indefinitely, as the person is exposed to other losses.

People with an ID are vulnerable, as many have an external locus of control, remaining reliant on so many people (often professional carers) for so much, and they are actively excluded from responding to death and dying (Read & Elliott, 2003). There appears to be an increasing factorial affect: with people with IDs that precludes active involvement in the sad business of death, where the more complex the needs (such as having communication impairment or challenging behaviours), the less likelihood they have of being involved (Read & Elliott, 2003). Additionally, people with IDs usually experience sudden as opposed to anticipatory grief (O’Nians, 1993), which reduces any opportunity for caregivers, staff or counsellors to work towards the death with the dying person, thus minimising any opportunity to say their goodbyes in any meaningful fashion.

The emotional needs of people with an ID are often neglected (Arthur, 2003), perhaps because of varied perceptions of their ability to grieve (McLoughlin, 1986; Elliot, 1995; Read, 1996), over protectiveness by carers (Deutsch, 1985), or carers' feelings of fear, inadequacy and uncertainty (Emerson, 1976; Thurm, 1989; Oswin, 1991). Conboy-Hill recognised the role of carers as she argued that: "Failure to recognise the impact of loss on people with learning disabilities arises from our need to see such people as lacking in effective emotional apparatus ... this conveniently feeds our own need to avoid discussion of pain and grief and so the cycle of ignorance and inaction has been perpetuated" (Conboy-Hill, 1992, p. 151).

Challenges to Bereavement Support

In addition to the cultural and societal taboos that exist generally around death and disability (Oswin, 1991), and the varied rituals associated with cultural differences in bereavement support (Dodd et al., 2005), supporting a bereaved person with an intellectual disability can be difficult. Emphatically bad attitudes (Oswin, 1991; 2001) have meant that many carers have failed to recognise the importance of grief work for this population. Parents and professional carers have tended to focus upon the symptoms resulting from the reactions of loss (i.e., changes in behaviour) rather than addressing the cause of loss itself (Crick, 1988), meaning that there is always the possibility that grief reactions will return.

More than 50% of people with an intellectual disability may have some form of communication impairment (Kerr et al., 1996), and many lack the appropriate verbal repertoire to express their inner feelings in an articulate, meaningful way. Supporting the person may not be easy, as there may be uncertainty concerning exactly what has been absorbed or indeed understood. Since bereavement counselling is perceived as a "talking therapy", the combination of limited cognitive ability, attention span and emotional vocabulary (Conboy-Hill, 1982) may make counselling support difficult for some people with an ID, and carers may believe such an intervention is inappropriate. Such a range of issues potentially makes grief support complicated or hard to access, many people with an intellectual disability may not receive the support they need following bereavement, and thus may experience disenfranchised grief (Doka, 1989; 2002).

Disenfranchised Grief

Disenfranchised grief is described as "the grief that persons experience when they incur a loss that cannot be openly acknowledged, publicly mourned, or socially supported" (Doka, 1989; 2002). Disenfranchised grief usually means that:

- The relationship between the deceased and the bereaved person is not recognised
- The loss is not recognised
- The griever is not recognised.

(Doka, 1989)

Factors affecting this also include the circumstances surrounding the death and the ways that individuals grieve or how they have previously learned to cope with loss, or failed to cope in some situations. (Doka, 2002.) Those experiencing disenfranchised grief may have intensified emotional responses to loss (feelings of anger, guilt or powerlessness); they may experience ambivalent relationships and concurrent life crises, which can complicate grief, or the factors that facilitate mourning may be missing (e.g., grief rituals). Ultimately, the very nature of disenfranchised grief precludes social support, at the time when such support is seen as crucial (Doka, 2002).

Responding to Disenfranchised Grief

Doka (2002) highlighted the various ways of responding to disenfranchised grief (Table 1), and suggested that acknowledging and legitimising the loss itself is important if the loss is to be ultimately accommodated (Worden, 2001).

Table 1

Responding to disenfranchised grief (Doka, 2002)
<ul style="list-style-type: none"> • Acknowledging/legitimising the loss • Active listening • Empathy • Meaning making • Constructive use of ritual • Sharing of fears and anxieties • Spiritual support • Mutual support (group work) • Counselling

According to Doka the constructive use of rituals is a powerful therapeutic tool. The use of ritual might include the funeral itself, rituals of continuity (such as lighting candles on certain days), rituals of transition (marking the change or transition stage), rituals of reconciliation (which allow the person to offer or accept forgiveness or to complete some degree of unfinished business) and rituals of affirmation (which allow individuals to affirm the loss and recognise any good things that have come out of the loss experience). Doka also recognised the importance of various therapeutic interventions including the sharing of fears and anxieties, the usefulness of spiritual support, the ability to access support groups and bereavement counselling.

Bereavement Counselling and Support

Whilst "access to ordinary counselling services would be ideal ... as yet, the practitioners within these services are not geared to our clients' needs and the services themselves are not free" (Conboy-Hill, 1992, p. 168), bereavement counselling for this group remains at best inconsistent, and at worse, non-existent (Read & Elliott, 2007, pp. 167-181). Bereavement counselling for the person with an ID has been described as "the skilled facilitation of the individual's response to loss through purposeful

communication within a caring relationship forged upon trust and mutual regard The core conditions are seen as central to this reciprocal relationship". (Read, 2007, pp. 27-28) This skilled facilitation may involve a range of activities in addition to the spoken word, such as the development of memory books and life story work (Read & Bowler, 2007), artwork, and photographs. Such creative approaches enable the counsellor to access the individual's thoughts, feelings and dynamic inner world in an effort to engage with their sadness, understand their pain, help the person to explore their feelings (Read, 1999; 2007) and accommodate the deceased in the life of the living. However, not all bereaved individuals require counselling – some may simply require information and knowledge and facilitating healthy grief responses for people with IDs is multifaceted.

A Model to Facilitate Healthy Grief Work (after Read, 2005; Read & Elliott, 2007)

Not all bereaved people need specialist interventions, as many may learn to cope with their loss with the help of relatives and friends in their own social context, in keeping with the majority of society. Read (2005) advocated that bereaved people with IDs can learn to develop healthy coping strategies that will help them to deal with grief but only if:

- They are treated as adults
- Their losses are acknowledged
- Their grief is anticipated and expected
- They are given accurate and truthful information
- People communicate with them in a meaningful way
- They are actively encouraged to participate in grief and the associated grief rituals
- They are offered continuing and appropriate support
- Carers have the knowledge, skill and understanding to appreciate their sadness and know when to seek additional, specific help from others
- There is proactive policy and guidance
- Training is integrated into all aspects of intellectual disability health care.

A continuum of support involves a broad range of strategies that are available at many different levels. These strategies range from general preparation *before* loss or death has occurred (education) to portraying loss and death as *natural life events* (participation) or providing consistent support *after* the death has occurred (facilitation) and identifying of the need for *specific help* (therapeutic interventions). This continuum of support is diagrammatically illustrated in Figure 1 and each section will now be briefly described.

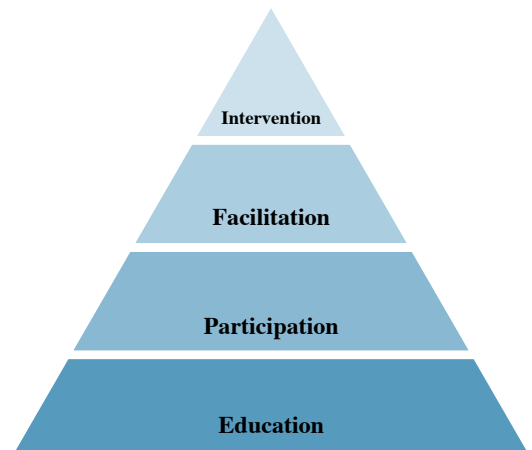


Figure 1

A model offering a continuum of bereavement support (Read, 2005; reproduced by kind permission of the Royal College of Nursing, 2005).

Education involves helping people to understand loss, change, grief and death, and this includes:

- Educational opportunities to explore how the individuals themselves, and others, respond to loss, for example using group work as an educational vehicle (Read et al., 2000; Read & Papakosta-Harvey, 2004)
- Openly sharing feelings and responses to loss
- Helping individuals to record life events using (for example) life story approaches, in a visual and concrete way.

Participation involves nurturing a healthy response to loss, which can be achieved by proactive support incorporating:

- Using everyday, natural opportunities to talk, explore and express feelings in a broader context, rather than relying on a reactive approach
- Developing and using a range of resources (e.g. North Staffordshire bereavement leaflets, 2007; Hollins and Sireling, 2004) as discussed below
- Utilising a variety of mediums to communicate effectively, including pictures, books, videos and DVDs, television and radio.

The North Staffordshire bereavement leaflets (developed by the Bereavement Support for people with Learning Disabilities group) are a series of three, free leaflets (BSLD, 2007a, 2007b, 2007c) developed in pictorial format to address bereavement and loss from an individual, personal carer and professional carer perspective (Read & Spall, 2006). An example of these leaflets is presented in Figure 2:



Figure 2

Bereavement leaflet for a person with an intellectual disability: When someone you know has died (BSLD, 2007a).

Facilitation includes reactive support following a loss or death, and means that the support person has to be able to:

- Assess individual needs
- Actively listen
- Communicate in a meaningful way
- Give factual information
- Offer consistent support
- Educate the person to learn about grief responses
- Encourage grief responses
- Have appropriate perception and observation skills
- Encourage individuals to participate in grief rituals surrounding the death (Raj & Hollins, 2003)
- Normalise the grief experience
- Know when and how to refer on when appropriate
- Keep accurate and accessible records about who has died, where they are buried, and so on.

Finally, *Therapeutic interventions* involve the need to refer someone for specialist counselling and support which may necessitate:

- Assessment of need (knowing when to refer on)
- Counselling
- Psychotherapy
- Guided mourning interventions.

If people with an ID are actively involved and are helped to understand the complexities of death and dying before the loss occurs (education), and this is expressed in simple easy to understand language where individuals are regularly encouraged to share their own experiences with others in a naturalistic settings (participation) and if they receive appropriate support at the point of need (facilitation), then the need for more specific help such as counselling (therapeutic interventions) should be reduced. Nurses, personal carers and other professionals will have a pivotal role within this continuum of support.

Such a model has much to offer as a framework to developing grief counselling, support and educational approaches to people with an ID, on a micro, macro and meso level (Read & Elliot, 2007).

Conclusion

Loss is an important feature of everyone's lives, including people with IDs. Whilst "the bereaved only discover that the dead continue to enrich their lives 'in here' after they have spotted the desperate search for them 'out there'" (Parkes et al., 1997, p. 215), for some populations coming to this conclusion may be difficult. Having an ID means that they may be treated differently, and not expected to grieve for the loss of their loved ones in the way(s) that others express their grief. However, research indicates that such populations do grieve, but the attitudes of others towards them, and the challenges associated with their disability, may preclude effective bereavement support.

Simple practice issues include record keeping about who died, when, where they are buried etc, so that important information can be accessed months or years after the event. Developing an evidenced-based, skilled approach to breaking bad news to people with an ID would encourage carers to talk about difficult and sensitive topics in a more confident manner. Involving people in grief rituals (Raji & Hollins, 2003) will help to affirm and legitimise the death, and give the person the opportunity to share their grief and experience the social mourning rituals and customs. It will also give them the opportunity to develop constructive coping mechanisms when experiencing loss. Reinforcing the normality of grief (James, 1995) and actively looking for grief responses (Kitching, 1987) means adopting a proactive approach to loss, where carers are trained, confident, skilled, knowledgeable and where they, above all, feel comfortable in their approach. Explicit guidelines and directions will ensure a consistency of approach. Inherent within this is the need for more empirical research, education and training.

Marginalised groups (such as people with IDs) often experience disenfranchised grief, and as such may need extra support to express their grief in a meaningful fashion. Education is the basis for effective support, in order for people with an intellectual disability to prepare themselves for loss, and for carers to help them in their support role. Since “people with learning disabilities are a part of us, rather than being apart from us” (Todd, 2006, p. 23), a range of professional carers need to be able to positively respond to the grief needs of this population from many different angles. The Continuum of Support Model (Read, 2005) provides a useful framework to help practitioners, service developers, bereavement counsellors, therapists and others to develop meaningful approaches from a variety of different perspectives. People with IDs have more similarities *to us* than differences *from us*, particularly when loss, death and bereavement occurs, so professionals need to build on these similarities and not become constrained by the differences, when offering bereavement counselling and support.

References

- Arthur, A. R. (2003). The emotional lives of people with learning disability. *British Journal of Learning Disabilities*, 31, 25–30.
- Bereavement Support for People with Learning Disabilities (2007a). *When someone you know has died* (2nd ed.) [Leaflet]. England: Author.
- Bereavement Support for People with Learning Disabilities (2007b). *When someone you know has died ... A guide for carers offering support* (2nd ed.) [Leaflet]. England: Author.
- Bereavement Support for People with Learning Disabilities (2007c). *When someone you know has died ... A guide for professionals offering bereavement support* (2nd ed.) [Leaflet]. England: Author.

- Bonell-Pascual, E., Huline-Dickens, S., Hollins, S., Esterhuyzen, A., Sedwick P., Abdelnoor, A., et al. (1999). Bereavement and grief in adults with learning disabilities. *British Journal of Psychiatry*, 175, 348–350.
- Conboy-Hill, S. (1992). Grief, loss and people with learning disabilities. In A. Waitman, & S. Conboy-Hill (Eds.), *Psychotherapy and mental handicap* (pp. 150–170). London: Sage Publications.
- Crick, L. (1988). Facing grief. *Nursing Times*, 84 (28), 61–62.
- Dodd, P., McEvoy, J., McGovern, & E., Hillary, J. (2005). Bereavement and learning disability: An Irish context. *Journal of Applied Research in Intellectual Disabilities*, 18, 237–243.
- Department of Health (2001). *Valuing people: A new strategy for learning disability for the 21st century*. London: Department of Health.
- Doka, K. J. (1989). *Disenfranchised grief: Recognizing hidden sorrow*. Toronto, Canada: Lexington Books.
- Doka, K. J. (Ed.). (2002). *Disenfranchised grief: New directions, challenges and strategies for practice*. Illinois: Research Press.
- Elliott, D. (2003). Loss and bereavement. In M. Jukes, & M. Bollard (Eds.), *Contemporary learning disability practice* (pp. 124–134). Wiltshire: Quay Books.
- Elliott, D. (1995). Helping people with learning disabilities to handle grief. *Nursing Times*, 91(43), 27–29.
- Emerson, P. (1976). Covert grief reactions in mentally retarded clients. *Mental Retardation*, 15(6), 27–29.
- Hollins, S., & Sireling, L. (2004). *When dad died* (2nd ed.). London: St. George’s Hospital Medical School.
- Hollins, S., & Esterhuyzen, A. (1997) Bereavement and grief in adults with learning disabilities. *British Journal of Psychiatry*, 170, 497–501.
- James, I. A. (1995). Helping people with learning disabilities to cope with bereavement. *British Journal of Learning Disabilities*, 23, 74–78.
- Kellehear, A. (2005). *Compassionate cities: public health and end of life care*. London: Routledge.
- Kerr, M., Fraser, W., & Felce, D. (1996). Primary healthcare for people with a learning disability. *British Journal of Learning Disabilities*, 24(1), 2–8.
- Kitching, N. (1987). Helping people with mental handicaps cope with bereavement: A case study with discussion. *Mental Handicap*, 15, 61–63.
- MacHale, R., & Carey, S. (2002). An investigation into the effects of bereavement on mental health and challenging behaviour in adults with learning disability. *British Journal of Learning Disabilities*, 30, 113–117.
- McLoughlin, I. J. (1986). Care of the dying: Bereavement in the mentally handicapped. *British Journal of Hospital Medicine*, October, 256–260.

- Olivière, D., & Monroe, B. (2004). *Death, dying and social difference*. Oxford: Oxford University Press.
- Oswin, M. (1991). *Am I allowed to cry?* London: Souvenir Press.
- Oswin, M. (2000). *Am I allowed to cry?* (2nd ed.). London: Souvenir Press.
- Parkes, C. M., Laungani, P., & Young, B. (1997). *Death and bereavement across cultures*. London: Routledge.
- Raji, O., & Hollins, S. (2003). How far are people with learning disabilities involved in funeral rites? *British Journal of Learning Disabilities*, 31, 42–45.
- Read, S., (1999). Creative ways of working when exploring the bereavement counselling process. In N. Blackman (Ed.), *Living with loss: Helping people with learning disabilities cope with loss and bereavement* (pp. 9–13). Brighton: Pavilion Publications.
- Read S. (2005). Loss, bereavement and learning disability: Providing a continuum of support. *Learning Disability Practice*, 8(1), 31–37
- Read, S. (2007). *Bereavement counselling for people with a learning disability: A manual to develop practice*. London: Quay Books.
- Read, S., & Bowler, C. (2007). Life story work and bereavement: Shared reflections on its usefulness. *Learning Disability Practice*, 10(4), 10–15.
- Read, S., & Elliott, D. (2003). Death and learning disability: A vulnerability perspective. *Journal of Adult Protection*, 5(1), 5–14.
- Read, S., & Elliott, D. (2007) Exploring a continuum of support for bereaved people with intellectual disabilities. *Journal of Learning Disabilities*, 11(2), 167–181.
- Read, S., & Papakosta-Harvey, V. (2004). Using workshops on loss for adults with learning disabilities: A second study. *Journal of Learning Disabilities*, 8(2), 191–208.
- Read, S., & Spall, B. (2006). Bereavement and people with a learning disability: A practice initiative in response to a local need. *Learning Disability Practice*, 9(2), 8–15.
- Read, S., Papakosta-Harvey, V., & Bower, S. (2001). Using workshops on loss for adults with learning disabilities. *Groupwork*, 12(2), 6–26.
- Sheldon, F. (1998). ABC of palliative care: Bereavement. *British Medical Journal*, 316, 456–458.
- Thurm, A. (1989). I've lost a good friend. *Nursing Times*, 85(32), 66–68.
- Todd, S. (2006). A troubled past and present – A history of death and disability. In S. Read (Ed.), *Palliative care learning disability* (pp. 13–25). London: Quay Books.
- Worden, J. W. (2001). *Grief and grief therapy: A handbook for mental health practitioners* (3rd ed.). London: Routledge.



Traumatic Loss and Growth: The Unique Challenges of Living with Acquired Brain Injury

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Abstract

Survivor and family adaptation following an Acquired Brain Injury (ABI) is typically a long-term, challenging process. In this article, consideration is given to the ways in which understanding some of the *traumatic loss* and *traumatic growth* experiences of survivors and their families might contribute to the grief, stress and burden understandings that have dominated in research and practice. These two themes emerged as the available literature was analysed by the authors for the purposes of considering a family adaptation study. Through acknowledging traumatic loss experiences, a focus on the “acquired” nature of the injury and disability, the role of denial and the complexities of notions of “a new reality” emerges. In addition, survivor and family resilience and strengths can be emphasised in listening for traumatic growth experiences.

The Unique Challenges of Living with Acquired Brain Injury

Using the definition of the Australian Institute of Health and Welfare (AIHW), Acquired Brain Injury (ABI) is “a term used to describe disability arising from any damage to the brain acquired after birth, regardless of cause” (2007, p. 2), while TBI refers to traumatic brain injury: an “acquired brain injury caused by a traumatic event such as a traffic accident or a blow to the head” (AIHW, 2007, p. 2). The definition of TBI – the brain injury that is the particular focus of this article – highlights the fact that two dimensions are present in each survivor’s and family’s experience: the unique events leading to the acquisition of an injury and the injury’s significant aftermath.

The limited research available on living with an ABI focuses on some key experiences for survivors and their families: the grief and adaptation experiences (Niemeier & Burnett, 2001; Marwit & Kaye, 2006), posttraumatic stress disorder (McMillan, Williams, & Bryant, 2003), other psychosocial (Watts & Perlesz, 2007) and psychiatric sequelae (van Reekum, Cohen, & Wong, 2000) and, to a lesser extent, some aspects of the subjective experience of living with ABI (Chamberlain, 2006). This research highlights the many challenges survivors and families face, particularly in relation to adapting to a person whose personality, cognitive functioning and behaviour has changed.

Loss Perspectives

The losses associated with ABI experiences are well noted – the loss of the former self of the survivor psychologically, intellectually and behaviourally (Wade et al., 2001), the loss of friendships, of intimacy and the familiar; and the loss of current and anticipated roles. Many survivors report a

loss of freedom and independence. Over time, the survivor can display unpredictable changes in behaviour and emotions, bringing challenges in the present and emphasising the loss of the person as they were (Ergh et al., 2002, p. 156; Carnes & Quinn, 2005, pp. 199–200). Dreams and hopes about their future can also be lost, both by the survivor and their family. Grief and acquired disability have typically been understood through the original lens of families living with *chronic sorrow* (Olshansky, 1962), moving on to understandings of *episodic grief* (Hewson, 1997) and more recently to the *notion of non-finite grief* (Bruce & Schultz, 2001). Stroebe and Schut’s (1999) Dual Process Model, highlighting the need to oscillate between loss and restoration orientations in accommodating the new experiences, also has salience. The restoration tasks, however, are complicated for survivors and family members by the ongoing regaining of function that so characterises the first year or two following an ABI. Within grief literature, one of the major tasks identified in the restoration or recovery process has been the establishment of a new reality. As Worden states, “the first task of grieving is to come full face with the reality that the person is dead, that the person is gone and will not return” (2003, p. 27).

Worden argues that coming to terms with this new reality “takes time since it involves not only an intellectual acceptance but also an emotional one” (2003, p. 29). Coming to terms with a new reality, however, also assumes that there is one broad reality of the loss. One of the major challenges for both survivors and families living with an ABI is that there is no immediate “reality”.

Unlike bereavement experiences, where the new reality is the absence and inaccessibility of the person who has died, familiar aspects of the personality, intellectual and behavioural characteristics of the person with an ABI may have “died” but the person themselves has not. To complicate this “reality” is the paradox that on the one hand, survivors and families are told that it will be at least a year, if not years, before an injury stabilises and its aftermath will become more apparent, while on the other, families, in particular, are expected by many of those around them to come to terms with the “new reality”. Thus, survivors and their families are dealing, and grappling, with multiple, constantly shifting realities. The complexities of these new realities are sometimes minimised in the family adaptation studies in particular.

Families, in facing these shifting realities, are sometimes perceived to be “in denial”: that is “failing” to come to terms with the nature and consequences of the injury. This notion first came into the published

literature in 1974 when Romano wrote about the “protracted persistence of denial of disability”, manifest in “common fantasies about patient recovery” (Romano, 1974, p. 1). More than thirty years later, the complex dance of denial and hope that families and survivors must negotiate in order to cope still seems to be underestimated.

The family has the task of maintaining hope and optimism in relation to potentially positive outcomes as well as the task of coming to terms with the “new reality”. There is new knowledge now about the human brain’s capacity to repair and recover function (see, for example, Shonkoff & Phillips, 2000). The shifting realities of the first few years of recovery, in particular, mean that this is a process of oscillation between certainty and uncertainty, hope and despair. It is unlike a bereavement or other traumatic experience. It can be a time of continuing traumatic loss.

Traumatic Loss Perspectives

Surviving a brain injury involves not only the trauma of the incident that brought about the injury, but also a gradual process, often years long, of dealing with the losses, changes and growth that arises for individuals and families. In this sense, it is not *traumatic bereavement* where a traumatic death marks the transition point to a new reality. It is also unlike other traumatic events, where there is a single event or incident and survival, after which there is a gradual reworking of a sense of coherence and meaning. What ABI is characterised by then is this concept of “acquired”, the injury marking a distinction between one reality and continually unfolding new ones. By using the term *traumatic loss*, a new emphasis emerges in relation to both the acquired and traumatic nature of the injury experience, for survivors *and* their families, one which recognises the loss that can continually unfold over the years that follow the injury, for both the survivors and their families.

The trauma research literature adds to some of the understandings of the unique ways in which ABIs can be experienced. By definition, TBI occurs as a result of a sudden and unexpected external event. These events include road trauma, other accidents, and, as is less commonly identified, through interpersonal violence. In each of these instances, a unique story of responsibility, preventability, blame and/or regret, unlike many other illness and disability experiences, may unfold. Each ABI typically also carries an interpersonal component concerning causation. Phrases like “what if” and “if only” can characterise many discussions, and themes of control and prevention can be pervasive, even if unspoken. Many dimensions of people’s experiences connect with a very common risk factor for posttraumatic stress disorder (PTSD) (American Psychiatric Association, 2000).

This risk factor relates to how the trauma occurred in the first instance and any residual blame, guilt or anger. When trauma is perceived to be interpersonally caused (McMillen, Smith, & Fisher, 1997) as distinct from arising from natural disasters, the distress outcomes seem to be more profound. Many traumatic events resulting in an ABI are preventable, occurring as a result of human error, intention or recklessness. This leaves many survivors and families with issues of

guilt, anger and blame, which may be directed towards themselves or others.

Researchers have examined the impact of perceived responsibility, and therefore perceived control, for the trauma on recovery outcomes in relation to road trauma recovery (Delahanty et al., 1997), rape (Frazier & Schauben, 1994) and other trauma experiences. One study found that those who blamed themselves for a motor vehicle accident and fulfilled criteria for PTSD were “less symptomatic initially” and that they recovered “more rapidly in the first six months than those with PTSD who blame another party for the accident” (Hickling et al., 1999, p. 345). Researchers have also examined the ways in which characterological and behavioural self-blame influence outcomes from trauma (Frazier & Schauben, 1994). Some found that behavioural self-blame may be protective, enabling the individual to feel confident and in control of how they act in the future. Discourses of acquisition are important.

For many years, the possibility that a patient with an ABI could experience PTSD was dismissed. Current research refutes this earlier belief (McMillan et al., 2003). Yet no research focuses on the trauma experienced by family members, and the possibility that they too may be experiencing trauma and loss. In part, this relates to the fact that survival is initially so celebrated, irrespective of disability outcomes, and rehabilitation becomes the focus for survivors, families and health professionals. Yet leaving trauma out of the equation may mean that some of the initial distress of survivors and families is not understood.

This is not unique to the experience of ABI. One study of family members’ adaptations following a patient’s admission to, and discharge from, an Intensive Care Unit, identified significant levels of posttraumatic stress symptoms at 6 weeks following the injury or illness experience (Muir et al., 2006). More than two-thirds of the participants (n=29) were experiencing significant traumatic distress. Yet much of the research into family experience focuses more on stress, chronic stress and grief reactions in the early phase of adaptation to injury, overlooking the traumatic dimensions of the experience. With the exception of Watts and Perlesz’s (2007) study of families living with an ABI, very little Australian research explores the lived experiences of survivors and their networks of support at all.

In working with people who have survived a traumatic bereavement, the emphasis is on listening to the unique dimensions and experiences of the traumatic event first and foremost before the longer term grief tasks can be engaged with (Raphael & Meldrum, 1994). Translating this framework into the present discussion, listening and working with trauma is crucial to then being able to also listen and work with people’s loss and grief reactions.

Traumatic Growth Perspectives: A Focus on Resilience

To focus on loss only, however, negates the fact that many families cope well with extraordinarily challenging and changed circumstances. A small literature base is emerging where the possibility of experiencing posttraumatic growth following an

ABI has been explored. Despite the many losses, and often traumas, associated with an ABI and its aftermath, 21 survivors identified growth in key areas, as measured by the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996). In descending order of importance, these related to appreciation of life, relating to others, personal strength, new possibilities and spiritual change (McGrath & Linley, 2006). No studies have been undertaken with families of ABI survivors, leaving a significant gap in understandings of protective factors and resilience possibilities. Some generalisations might be drawn from other survivor groups, with a study of 79 road trauma survivors (excluding those with ABIs) found that at three to four years postinjury, 99% reported posttraumatic growth experiences, in amongst significant ongoing distress and stress (Harms & Talbot, 2007).

Christine Durham, a TBI survivor, tells her story of recovery and adaptation in her autobiography *Doing Up Buttons*. Her story provides a rare glimpse into the private, demanding experiences for both survivors and their families in the aftermath of an ABI. At the same time, it captures the hope and growth that simultaneously lies at the core of so many families' experiences. Her words stand as a testament to that resilience:

I have learnt to enjoy the present because happiness is not a date in the future, nor is the present only a way to get to the future. I have learnt to live and enjoy each moment rather than thinking ahead all the time. (Durham, 1997, p. 173)

Conclusion

For health professionals, we propose that traumatic loss and growth perspectives open up other ways of listening to where ABI survivors and their families are in their processes of recovery and adaptation. Listening to these many complex dimensions of the experience enables a focus on understanding risk and vulnerability, but also reveals the resilience that characterises the lives of survivors and their families. Research has gone some way in identifying this complex interaction of risk and protective factors. Questions remain, however, as to how survivors and families engage with these traumatic loss and growth experiences in their daily lives over time and as the new realities and challenges emerge.

References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed.) Text revision. Washington: Author.
- Australian Institute of Health and Welfare. (2007). Disability in Australia: Acquired brain injury. *Bulletin*, 55, December. Canberra: Author.
- Bruce, E., & Schultz, C. (2001). *Nonfinite loss and grief: A psychoeducational approach*. Eastgardens: MacLennan & Petty.
- Carnes, S., & Quinn, W. (2005). Family adaptation to brain injury: Coping and psychological distress. *Families, Systems and Health*, 23(2), 186–203.
- Chamberlain, D. (2006). The experience of surviving traumatic brain injury. *Journal of Advanced Nursing*, 54(4), 407–417.
- Charles, N., Butera-Prinzi, F., & Perlesz, A. (2007). Families living with acquired brain injury: A multiple family group experience. *NeuroRehabilitation*, 22, 61–76.
- Delahanty, D., Herberman, H., Craig, K., Hayward, M., Fullerton, C., Ursano, R., et al. (1997). Acute and chronic distress and posttraumatic stress disorder as a function of responsibility for serious motor vehicle accidents. *Journal of Consulting and Clinical Psychology*, 65(4), 560–567.
- Durham, C. (1997). *Doing up buttons: A deeply personal yet practical account of understanding head injury*. Ringwood: Penguin Books.
- Ergil, T., Rapport, L., Coleman, R., & Hanks, R. (2002). Predictors of caregiver and family functioning following traumatic brain injury: Social support moderates caregiver distress. *Journal of Head Trauma Rehabilitation*, 17(2), April, 155–174.
- Frazier, P., & Schauben, L. (1994). Causal attributions and recovery from rape and other stressful life events. *Journal of Social and Clinical Psychology*, 13(1), 1–14.
- Harms, L. (2007). *Working with people: Communication skills for reflective practice*. South Melbourne: Oxford University Press.
- Harms, L., & Talbot, M. (2007). The aftermath of road trauma: Survivors' perceptions of trauma and growth. *Health and Social Work*, 32(2), 129–137.
- Hewson, D. (1997). Coping with loss of ability: "Good grief" or episodic stress responses? *Social Science and Medicine*, 44(8), 1129–1139.
- Hickling, E., Blanchard, E., Buckley, T., & Taylor, A. (1999). Effects of attribution of responsibility for motor vehicle accidents on severity of PTSD: Ways of coping and recovery over six months. *Journal of Traumatic Stress*, 12(2), 345–353.
- Marwit, S., & Kaye, P. (2006). Measuring grief in caregivers of persons with acquired brain injury. *Brain Injury*, 20(13-14), 1419–1429.
- Mateer, C., Sira, C., & O'Connell, M. (2005). Putting Humpty Dumpty together again: The importance of integrating cognitive and emotional interventions. *Journal of Head Trauma Rehabilitation*, 20(1), 62–75.
- Mayou, R., Bryant, R., & Duthie, R. (1993). Psychiatric consequences of road traffic accidents. *British Medical Journal*, 307, 647–651.
- McGrath, J., & Linley, P. (2006). Post-traumatic growth in acquired brain injury: A preliminary small scale study. *Brain Injury*, 20(7), 767–773.
- McMillan, T., Williams, W., & Bryant, R. (2003). Posttraumatic stress disorder and traumatic brain injury: A review of causal mechanisms, assessment, and treatment. *Neuropsychological Rehabilitation*, 13, 149–164.
- McMillen, J., Smith, E., & Fisher, R. (1997). Perceived benefit and mental health after three types of disaster. *Journal of Consulting and Clinical Psychology*, 65(5), 733–739.

- Muir, K., Barnes, L., Du Plooy, L., Harms, L., Rowe, C., & Wellington-Boyd, A. (2006). Rights, reticence and resilience: Reflections on a hospital study, Paper presented at the *Fifth International Conference on Health and Mental Health*, Hong Kong, December 10–14.
- Niemeier, J., & Burnett, D. (2001). No such thing as “uncomplicated bereavement” for patients in rehabilitation. *Disability and Rehabilitation*, *23*(15), 645–653.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework: The Journal of Contemporary Social Work*, *43*, 190–193.
- Perlesz, A., Kinsella, G., & Crowe, S. (2000). Psychological distress and family satisfaction following traumatic brain injury: Injured individuals and their primary, secondary and tertiary carers. *Journal of Head Trauma Rehabilitation*, *15*(3), 909–929.
- Raphael, B., & Meldrum, L. (1994). Helping people cope with trauma. In R. Watts & D. Horne (Eds.), *Coping with trauma: The victim and the helper* (pp. 1–19). Brisbane: Australian Academic Press.
- Romano, M. (1974). Family response to traumatic head injury. *Scandinavian Journal of Rehabilitation Medicine*, *6*, 1–4.
- Shonkoff, J., & Phillips, D. (2000). *From neurons to neighborhoods: The science of early childhood development*. Washington: National Academy Press.
- Simpson, G., Simons, M., & McFadyen, M. (2002). The challenges of a hidden disability: Social work practice in the field of traumatic brain injury. *Australian Social Work*, *55*(1), 24–37.
- Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies*, *23*(3), 197–224.
- Tedeschi, R., & Calhoun, L. (1996). The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress*, *9*(3), 455–471.
- van Reekum, R., Cohen, T., & Wong, J. (2000). Can traumatic brain injury cause psychiatric disorders? *Neuropsychiatry & Clinical Neuroscience*, *12*, 316–327.
- Wade, S., Drotar, D., Taylor, H., & Stancin, T. (1995). Assessing the effects of traumatic brain injury on family functioning: Conceptual and methodological issues. *Journal of Pediatric Psychology*, *20*(6), 737–752.
- Wade, S., Yeates, K., Borawski, E., Taylor, H., Drotar, D., & Stancin, T. (2001). The relationship of caregiver coping to family outcomes during the initial year following pediatric traumatic injury. *Journal of Consulting and Clinical Psychology*, *69*(3), 406–415.
- Watts, R., & Perlesz, A. (1999). Psychosocial outcome risk indicator: Predicting psychosocial outcome following traumatic brain injury. *Brain Injury*, *13*(2), 113–124.
- Worden, J. (2003). *Grief counselling and grief therapy: A handbook for the mental health practitioner*. London: Routledge.



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Acquired Brain Injury: Reconstructing Meaning Following Traumatic Grief

Abstract

Acquired Brain Injury (ABI) is a catastrophic life event that changes life forever both for the person with the injury and their family members. Varying degrees of recovery are possible, with moderate to severe injuries typically resulting in changes in multiple areas of functioning. While this can include physical impairment, often there are no outward signs. It is the “invisible” changes associated with cognition, emotions and behaviour that cause the greatest difficulties and distress. The grief for family members and the person with the injury can be overwhelming. Grieving is often put in abeyance while family members struggle to integrate the functional changes into their daily lives. For families facing challenging behaviours that involve unpredictability, mood swings, verbal and physical aggression, grieving is complicated by ongoing relational trauma, leading to disintegration in relationships. Grief mixed with trauma can manifest in family members as persistent heightened distress, hypervigilance, depression, anxiety, anger and physical ill health. While the stress and burden on family members is well recognised in the literature, less attention has been given to the experience of grief complicated by trauma and its impact on family relationships. This article draws on the experiences of families living with ABIs who have attended counselling at The Bouverie Centre. It describes grief frameworks that have enhanced our understanding of the complexities and ongoing nature of grief following an ABI, including the nature of “ambiguous” and “non-finite” loss, the effects of trauma on grief and the need to “embrace paradox”. These ideas are incorporated within a broader systemic and meaning-focused framework, the Family Tasks Model, (Perlesz et al., 1992; Perlesz, 1999), that guides our work with families.

Brain Injury in Australia

ABI is an injury to the brain occurring after birth that results in deterioration in cognitive (memory, concentration, planning, organisational skills), physical, emotional or independent functioning. ABIs can occur as a result of “traumatic brain injury” (e.g. accidents, falls or assault), hypoxia (lack of oxygen resulting from heart attack, near-drowning or suicide attempts), infection, tumor, substance abuse (alcohol or drugs), stroke or degenerative neurological diseases (such as Multiple Sclerosis or Parkinson’s disease: DHS, 2001). An estimated 432,700 people or approximately 2.2% of the total population of Australia live with “traumatic brain injuries” and require varying degrees of supervision or personal assistance. Traumatic brain injury disproportionately affects young people under the age of 25, who can expect to live with the effects

of the injury for many decades (Brain Injury Australia Queensland [BIAQ], 2006). Complex support needs are a feature, with families primarily bearing the burden of care and support over a lifetime (BIAQ, 2006). Emotional recovery is complicated by high rates of psychiatric disorder and/or substance abuse.

Complex Nature of Grief Following ABI

Family responses over time

The grieving process following an ABI is complex due to the prolonged and uncertain nature of recovery. Families experience a range of emotions over time, beginning with relief and elation that the person has survived. The weeks or months in rehabilitation can be marked with emotional highs as the individual directs extraordinary efforts toward recovery and dire predictions are proven wrong – the person learns to walk again, speech is regained; recovery in some areas can be rapid. An overriding hope exists that with time and continued effort, full recovery will be possible. Following an initial “honeymoon” period after the person returns home, the reality of the changes begin to emerge as the person confronts the demands and challenges of family life or returns to work. Hope for a full recovery gives way to grief as the individual and family struggle with the emerging implications of the injury. Grieving is put in abeyance for prolonged periods, often years, until the reality of what has been lost becomes clear. Active grieving allows families to re-organise their lives to accommodate the injury. Although these are common responses in families, these responses are not universal or time-limited (Lezak, 1989) and are shaped by the course of recovery and prognosis (Rolland, 1998).

Unique aspects of grief following ABI

Grief following an ABI is most often experienced as “recurrent” or “ongoing” with adjustment being life-long (Kendall et al., 1998; Collings 2007; Simpson et al., 2002). Grief and hope can re-emerge in alternating patterns over time (Davis 1987; Ingram & Perlesz, 2007) or coexist as each new experience is confronted and the individual and family gradually reconstruct the “schemas” or beliefs, with which they understood themselves and their experiences (Neimeyer, 2002). While the loss reaction may lessen with time, “positive adaptation” or “adjustment” to brain injury do not require the grieving to end and should not be associated with achieving expected end-states such as “acceptance” or “resolution” (Murray, 2001; Collings, 2007). The cultural pressures to deny ongoing grief are particularly strong following brain injury as families are expected to “move on” with life, with gratitude that the person is still alive (Rycroft & Perlesz, 2001; Davis, 1987).

The Bouverie Acquired Brain Injury Team (ABI Team) was formed in the 1980s and provides a counselling service to families affected by ABIs (inclusive of the person with the injury), training and secondary consultation to workers in “family sensitive practice” across Victoria, Australia.

Grief is non-finite and incremental

Non-finite loss has a continuing presence. As described by Bruce and Schults (2004), its presence can be “blatantly obvious or shadowy, but always there – above or below the surface”. The following quotations and examples are from our own practice. The father of a young man now in his 20s who suffered an ABI from uncontrolled seizures in childhood, reflects on the ongoing nature of his grief:

I accepted a long time ago that Craig wasn't going to have the life most young men his age have and yet, paradoxically, I'm more angry today than I ever was. It's the day to day stuff. He can't go out nightclubbing like his brothers do; he can't do an enormous amount of things that most “normal” young people can do and yet he is so close to “normal” it's not funny. He has very few friends his own age. You don't get over it. The loss is there everyday.

The young man's mother describes the unpredictable nature of the grief, which can hit at unexpected times:

The grief hits you in different ways. A period of intense grief might not even be triggered by anything in particular. It might hit you in the shower or in the middle of the night, it just rolls on and on. You don't want to burden your friends because it is too hard, those lovely friends who continue to ask. But it is a huge burden.

Grief following an ABI can also be “incremental” or “additive” in nature. That is, one loss can trigger another, resulting in a magnification of grief with each added loss (Cook & Oltjenbruns, 1989), as described by this mother:

I remember going through this dreadful vacuum where he was rejected even by the disability employment agency; he was rejected by sporting clubs; he was rejected by every social group he wanted to get into ... and with all the good intentions in the world, his world was closing in on him.

Grief is due to psychological loss and is disenfranchised

Grief following an ABI involves “psychological loss” and can be as devastating as physical loss. Psychological loss is especially painful because it is associated with the loss of intimacy and reciprocity in relationships (Rolland, 1990).

Psychological loss is also disenfranchised in that it cannot be openly acknowledged, publicly mourned or socially supported (Doka, 1989; Rycroft & Perlesz, 2001). How does one grieve in the presence of someone who is still alive? The process is even more difficult when changes result in challenging behaviour. When loss remains unnamed, it remains unreal (Young, Bailey, & Rycroft, 2004) and families are left in an emotional bind, vacillating from feelings of guilt and shame to despair and anger.

Here, the partner of a man who suffered a stroke in his 40s, describes the loneliness that can accompany an unacknowledged loss:

I weep for the woman, who, not yet 43, finds herself alone. I cry with loneliness. I cry for the loss of intimacy – the shared looks over a child's head, the hugs and squeezes and touches that don't come anymore, the shared silences, the thud of his heartbeat as we snuggle up in bed, my head on his chest. Sometimes I would give all I own for a hug.

The father of a child who was injured in a bicycle accident describes the memories of his child pre-injury, which are difficult to talk about in the context of the continuing presence of his child:

He was such an easygoing kid, a funny kid. We would laugh together. Now he takes everything so seriously and I can't joke around with him. I miss the boy I had.

This father's grief manifested as intolerance and emotional distancing from his child. Naming and validating the underlying grief became an important part of him making sense of his own emotions and reconnecting with his son.

Loss involves grieving a postinjury identity and life

Unlike congenital or developmental disabilities, an acquired disability involves grieving a pre-injury identity and life. These memories are most vividly held by family members. It can be difficult for practitioners to appreciate the depth of grief in families or the difficulty families experience in accepting the person as they are now. This mother describes her devastating sadness for her son nearly 12 years post-injury:

My grief is through Stephen's loss ... seeing him like he is and seeing what he has to struggle with, what he can't do that he used to be able to do. It's devastatingly sad and I don't know how I will ever get over it. It's for his sake that you are sad.

The losses are ambiguous

Many people with ABIs retain their intelligence and prior knowledge but experience difficulties with new learning, memory and reduced control over thinking and emotions, making the losses “ambiguous” (Boss, 1999). Ambiguous losses are difficult to grieve because there is no closure or certainty. It is only with time and repeated experiences that clarity begins to emerge about the skills that remain, those that can be re-learned and those that need to be compensated for with strategies or environment restructuring. The ambiguous nature of the loss makes ABI an inherently confusing experience, as described by this spouse:

At times, I forget that Andrew has an ABI as he appears normal on the outside. This causes a lot of frustration inside me, when I develop expectations of what Andrew can do, and then when he can't, I get annoyed. Especially his memory, it appears very random; one day he remembers something, the next he doesn't. It seems like he is playing with my mind, and it really spins my head.

While the absence of certainty complicates the grief, paradoxically, it leaves room for hope for further recovery (Boss, 1999).

Embracing the paradox of mixed emotions

“Embracing the paradox” (Larson, 1998) involves embracing both sides of the emotional experience of brain injury – the joy and the grief, the hope and the despair, the seeking of solutions and the surrender to helplessness, the overwhelming anxiety and the courage. Rather than trying to “resolve” mixed emotions or seeing “ambivalence” as problematic, giving families permission to experience both can be enormously freeing, as described by this mother of a disabled child:

While I grieve, I also hold deep love and joy for Jessica, knowing she is perfect just the way she is. It is such a paradox. I am finally learning to embrace this paradox of joy and grief that I will always hold, rather than telling myself that I shouldn't feel this way. It is just the way it is. But tonight I will cry my sad tears. Then tomorrow I will continue on. (Marsh, in Larson, 1998, p. 127).

We hear in our practice, similar expressions of mixed emotions, such as described by this spouse:

I often blame him for getting on that bike and putting us through this hell. I swing from resentment and rage to profound compassion and grief.

Rather than deepening despair, which can be a fear for practitioners, hearing and bearing witness to profound distress supports the movement towards adjustment over time (Perlesz, 1999; Larson, 1998). Importantly, the oscillation between hope and despair enables the gradual accommodation of the reality of the disability in a “dose” that can be managed emotionally (Stroebe & Schut, 1999). Or as Davis (1987) describes, “therapeutic expressions of despair” can have the opposite effect, of permitting “a return to optimism that is not based on denial” (p. 356).

When Grief is Complicated by Trauma

In brain injury, the grieving process is further complicated by trauma.²

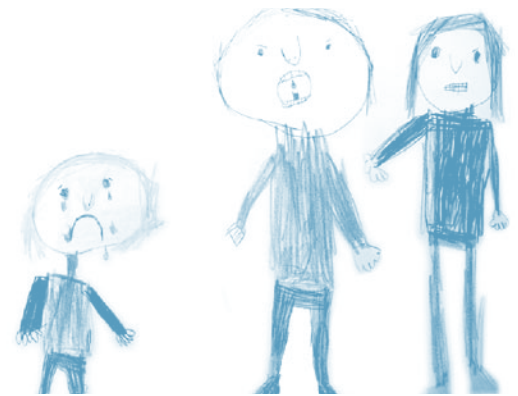
Trauma can be both *acute*, associated with the initial injury and *ongoing* resulting from behavioural changes that emerge in later stages of recovery. Behavioural changes associated with unpredictability, aggression or violence can become the source of “relational trauma”, leading to disintegration in family relationships.

Acute trauma: the initial injury

Trauma can result from witnessing, being directly involved or associated with the injury or from the events that follow (DSM-IV-TR). Receiving that fateful phone call, confronting the near death of a loved one, the bedside vigil while a person's life hangs in the balance in a state of coma, are all such events. The days or weeks following the gradual awakening from a coma (referred to as posttraumatic amnesia, [PTA]) can be particularly harrowing for families. People with PTA can be afraid, grossly dis-inhibited, agitated and aggressive. While the injured person often has no memory of the injury or period in PTA, family members carry the imprint of these distressing memories. Recovery from trauma requires a return to equilibrium through the restoration of safety, predictability and control (Herman, 1992). Trauma recovery can be complicated by the circumstances surrounding the injury, which can have long-lasting impacts on feelings of blame, responsibility and guilt.

Relational trauma: Trauma that disrupts relationships

When brain injury results in behavioural changes marked by unpredictability, aggression or violence, families can find themselves locked into patterns of heightened distress. The initial trauma is further exacerbated by “relational trauma”, which causes disruptions to the quality of relationships, sense of safety, openness and security within the family (Sheinberg & Fraenkl, 2001). Children of parents with brain injuries are particularly at risk of relational trauma if they experience their parent as frightening, unpredictable, inconsistent or non-nurturing. The distress of the non-injured spouse can further exacerbate the trauma for children, as described by this 5-year-old child:



This is my family. Dad's brain doesn't work and he's getting yelled at by mum and then he yells. I feel like I'm being blown away. When my mum yells I cry even more. It hurts my feelings. I feel it in my heart. My heart is breaking and I shake all over. I get scared and run away.



This is my house with the trees, chooks and the birds and dog. I like being outside.

While the outdoors appears safe and fun, the house is depicted as fiery and scary.

Unable to self-regulate his responses, this child's father often lost control and terrorised his son with verbal aggression and physical intimidation, behaviour he felt deeply ashamed of. His son became frightened to be left alone with his father and suffered from psychosomatic symptoms such as stomach-aches and night terrors.

Physiological arousal from ongoing trauma can continue unabated from many years and manifest in family members as frustration, intolerance, irritability, quick startle response, emotional reactivity, over-protectiveness, general anxiety or specific fears (Herman, 1992). Without an understanding of emotional trauma, these reactions can be misinterpreted by practitioners as apparent lack of compassion, intolerance, “sabotage” or “over-reaction”. Family members can suffer in silence with unrecognised trauma for many years, with significant consequences for family relationships generally and for children in particular, who are developmentally vulnerable.

How trauma interferes with the grieving process

While both grief and trauma cause intense emotional responses, the two states are very different in how they are experienced and require different responses from practitioners. Grief is a normal reaction to loss and, while ongoing or recurrent in brain injury, its intensity tends to diminish over time. Trauma, on the other hand, can become a disabling condition, that can block the grieving process and leave family members emotionally vulnerable. While trauma incorporates grief reactions associated with the loss suffered, grief can exist without trauma (National Institute of Trauma and Loss in Children [TLC]).

The table below distinguishes trauma driven responses from grief responses (adapted from TLC):

Table 1

The Effects Of Grief	The Effects Of Trauma
Sadness is the predominant emotion	Terror or fear is the dominant emotion
Grief feels real	Trauma feels unreal
Talking about grief can help	Talking about trauma is difficult or impossible
Pain is related to the loss of the person	Pain involves not just loss, but terror, helplessness and fear of danger
Guilt involves unfinished business relating to the injured person	Guilt involves self-blame for what happened to the injured person
Memories of the pre-injury person or pre-injury life appear in dreams	Themes of danger and fear appear in dreams
Symptoms lessen naturally over time	Untreated symptoms may get worse

Assessment of the presence of trauma related to the circumstances of the injury and subsequent relational trauma is critical in brain injury. The presence of aggression and violence requires sensitive but direct questioning from practitioners, as families rarely volunteer this information due to loyalty, fear or shame (Butera-Prinzi & Perlesz, 2004). Relational trauma is reduced by re-establishing caring, nurturing and safe relationships in families.

Meaning-finding and the social context of disability

Grieving following brain injury involves re-learning how to be in the world and to live meaningfully again. This meaning-finding process (Attig, 2001) is shaped by the social context of disability, including systemic influences which ultimately determine quality of life for people with disabilities.

Integrating disability and impairment into one’s identity is a profoundly difficult process, made all the more painful in the context of stigma and misunderstanding of brain injury in the community. Individuals are at risk of seeing themselves as diminished and devalued, a source of great suffering for individuals and their families (Kendall et al., 1998). The challenge in reconstructing identity can be ongoing for many years as it involves understanding the limitations of the disability but not being totally defined by it, enabling the appreciation of qualities and strengths alongside the limitations (Williams & Kay, 1991). This reconstruction process is recurrent and incremental as new schemas are revised, modified or completely restructured in the context of adapting to life with a brain injury (Neimeyer, 1999; Kendall et al., 1998). Families and individuals can experience enhanced meaning or personal growth through surviving adversity, involving such qualities as deepened compassion for others, re-establishing values and priorities in life, the learning of new skills, providing service to others or deepened spirituality (Adams, 1996; Perlesz, 1999; Rycroft & Perlesz, 2001).

Fully engaging with hope

Positive outcomes are possible and a growing number of people identify with an emerging “disability culture” which actively rejects stigma-based views of disability, instead adopting identities of pride and advocating the right to be viewed as being of equal value and worth as non-disabled people (Swain & French, 2000).

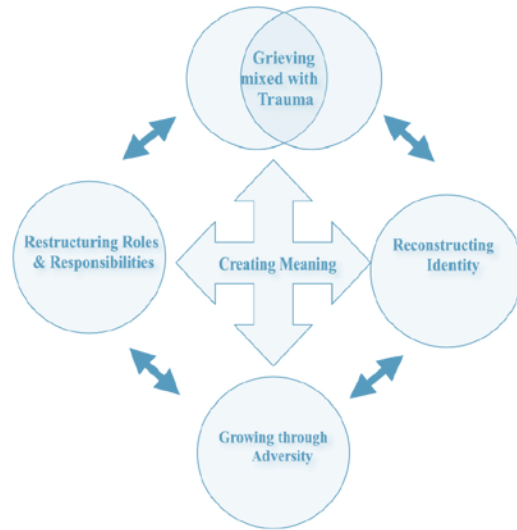
Bringing families together who have shared similar experiences and developing a supportive community of people affected by brain injury is vitally important for the restoration of hope and pride (Charles et al., 2007). The families and individuals we work with are a continuing source of inspiration. We have had the privilege of seeing many families create meaningful lives from profound grief and trauma. Living with meaning and purpose with an ABI includes living with grief and hope as an ongoing part of the experience. As Perlesz states (1999), “recovery following TBI involves the experience of despair at the magnitude of the tragedy along with hope for the positives that can emerge through suffering” (p. 14).

The mother of a young man with an ABI expressed this sentiment beautifully in a discussion with other families at The Bouverie Centre:

There is a huge richness [pause]. You are forced to look at life in a very different way. That whole idea of living in the moment ... valuing the present and valuing the good times. I guess you experience things in a more intense way. And because Craig is such a beautiful person underneath it all, it forces you to look at the essence of the person ... and it’s hard to look at the essence of the person past the brain isn’t it? ... It’s a huge challenge to dig beneath the brain into the soul of the person. It’s a wonderful thing to have to do ... sometimes.

**A family-sensitive model of practice:
The Family Tasks Model**

The Family Tasks Model (Perlesz et al., 1992) (see below) incorporates the key tasks for families and individuals following an ABI. These tasks are ongoing and recursive. This article has highlighted the traumatic grief experienced by families and individuals confronted with an acquired brain injury.



Family Tasks Model

Key Practice Guidelines in Brain Injury

- Legitimate grief and trauma
- Resource families with information about brain injury and compensatory strategies to reduce challenging behaviours
- Address the fundamental trauma and impacts on relationships within the family, especially children, not just the impact on the individual
- Create opportunities for meaning-finding through participation in meaningful activities, valued roles and finding a valued purpose in life
- Advocate for social policies that support the dignity and rights of people with disability for participation and inclusion in the community
- Provide supports and services intermittently, over the life cycle in recognition of the complex and changing needs of individuals and their families.

¹ Nearly a third of traumatic injuries are sustained below the age of 15, another third between the ages of 15 and 24; one fifth between 25 and 44 and only one tenth above that age (BIAQ, 2006).

² “Trauma” is used here to refer to psychological or emotional trauma from brain injury as distinct from the medical terms “traumatic and non-traumatic brain injury” which describe subsets of acquired brain injuries according to cause.

³ Most causes of brain injury involve a sudden and unexpected threat to life and result in serious injury to a family member, resulting in feelings of intense fear, helplessness or horror which are the cardinal feature of trauma as defined by DSM-IV-TR.

⁴ This concept, initially developed in relation to intra-familial sexual abuse, has been extended to other forms of trauma including disaster-based traumas.

⁵ High levels of unmet needs exist among people living with brain injury (BIAQ, 2006) across a spectrum of issues including meaningful employment, educational support, housing options and access to formal supports. The issue of young people in nursing homes is just one example of how systemic issues influence quality of life and prolong and deepen family grief.

References

Adams, N. (1996). Positive outcomes in families following traumatic brain injury. *Australian and New Zealand Journal of Family Therapy*, 12(2), 75–84.

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.) Text revision. Washington, DC: Author.

Attig, T. (2001). Relearning the world: Making and finding meanings. In R. Neimeyer. (Ed.), *Meaning reconstruction and the experience of loss* (pp. 33–54). Washington, DC: American Psychological Association.

BIAQ. (2006). Brain Injury Australia Queensland: Australian statistics on brain injury. Retrieved April 19, 2008, from <http://www.braininjury.org.au>

Boss, P. (1999). *Ambiguous loss. Learning to live with unresolved grief*. London: Harvard University Press.

Bruce, E., & Schultz, C. (2004). *Through grief*. Melbourne: ACER Press.

Butera-Prinzi, F., & Perlesz, A. (2004). Children’s experience of living with a parent with a head injury. *Brain Injury*, 18(1), 83–101.

Charles, N., Butera-Prinzi, F., & Perlesz, A. (2007). Families living with acquired brain injury: A multiple family group experience. *NeuroRehabilitation* 22(1), 61–67.

Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5, 168–195.

Collings, C. (2007). That’s not my child anymore! Parental grief after acquired brain Injury (ABI): Incidence, nature and longevity, *British Journal of Social Work* (in press). doi: 10.1093/bjsw/bcm055. Can be accessed: <http://bjsw.oxfordjournals.org/cgi/reprint/bcm055?ijkey=rdK8Lg9AxO9sLQd&keytype=ref>

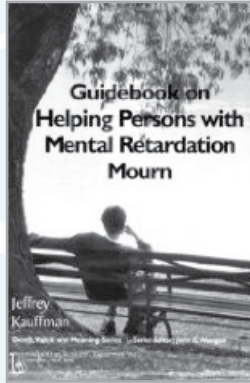
Cook, A. S., & Oltjenbruns, K. A. (1998). Cited in M. Stroebe & H. Schut (Eds.), (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies*, 23(3), 197–224.

Davis, B. (1987). Disability and grief. *Social Casework: The Journal of Contemporary Social Work*, 352–357.

Department of Human Services Victoria. (2001). *Acquired Brain Injury Strategic Plan*. Melbourne: Author.

- Doka, K. J. (1989). *Disenfranchised grief: Recognizing hidden sorrow*. Lexington: Lexington Books.
- Herman, J. (1992). *Trauma and Recovery: From domestic abuse to political terror*. London: Pandora.
- Ingram, K., & Perlesz, A. (2007). The getting and giving of wisdoms: generating hope. In C. Flaskas, I. McCarthy, & J. Sheehan (Eds.), *Hope and despair in narrative and family therapy*. Routledge: London.
- Kendall, E., & Buys, N. (1998). An integrated model of psychosocial adjustment following acquired disability. *Journal of Rehabilitation*, 64(3) 16–20.
- Larson, E. (1998). Reframing the meaning of disability to families: The embrace of paradox. *Society, Science, Medicine*, 47(7), 865–875.
- Lezak, M. (1989). Psychological implications of traumatic brain damage for the patients' family. *Rehabilitation Psychology*, 31(4), 243–250.
- Murray, J. (2001). Loss as a universal concept: A review of the literature to identify common aspects of loss in diverse situations. *Journal of Loss and Trauma*, 6(3), 219–241.
- Neimeyer, R. A. (2000). Searching for the meaning of meaning: Grief therapy and the process of reconstruction. *Death Studies*, 24, 541–588.
- Perlesz, A. (1999). Complex responses to trauma: Challenges in bearing witness. *Australian and New Zealand Journal of Family Therapy*, 20(1), 11–19.
- Perlesz, A., Furlong, M., & McLachlan, D. (1992). Family work and acquired brain damage. *Australian and New Zealand Journal of Family Therapy*, 13(3), 145–153.
- Rolland, J. S. (1990). Anticipatory loss: A family systems developmental framework. *Family Process*, 29, 229–244.
- Rolland, J. S. (1998). Beliefs and collaboration in illness: Evolution over time. *Families, Systems and Health*, 16(1/2), 7–25.
- Rycroft, P., & Perlesz, A. (2001). Speaking the unspeakable: Reclaiming grief and loss in family life. *Australian and New Zealand Journal of Family Therapy*, 22(2), 57–65.
- Sheinberg, M., & Fraenkel, P. (2001). *The relational trauma of incest: A family-based approach to treatment*. New York: The Guilford Press.
- Simpson, G., Simone, M., & McFadyen, M. (2002). The challenges of a hidden disability: Social work practice in the field of traumatic brain injury. *Australian Social Work*, 55(1), (March), 24–37.
- Stroebe, M., & Schut, H. (1999). The dual model of coping with bereavement: Rationale and description. *Death Studies*, 23(3), (April/May), 197–223.
- Swain, J., & French, S. (2000). Towards an affirmation model of disability. *Disability and Society*, 15(4), 569–582.
- TLC Institute. (n.d.). National Institute of Trauma and Loss in Children. Retrieved April 19, 2008, from <http://www.tlcinstitute.org>
- Williams, J. M., & Kay, T. (1991). *Head injury: A family matter*. Baltimore: Brookes Publishing.
- Young, J., Bailey, G., & Rycroft, P. (2004). Family grief and mental health: A systemic, contextual and compassionate analysis. *Australian and New Zealand Journal of Family Therapy*, 25(4), 188–97.

Book Reviews



Guidebook on Helping Persons with Mental Retardation Mourn

Jeffrey Kauffman (2005)

127 pp. ISBN: 978-0895033857

Amityville, NY: Baywood Publishing Company Inc.

US \$38.95

The title of Jeffrey Kauffman's book essentially describes its contents.

Kauffman, an American grief therapist, provides a number of case studies involving people with mild to moderate intellectual disabilities who have experienced a loss through death. He brings the reader an awareness of the special concerns involved in providing a supportive environment for the grieving process. He dispels myths about limitations the intellectually disabled may be presumed to have in understanding the concept of death and provides suggestions for helping to prepare someone for the death of a friend, helper or family member.

Unfortunately, the book starts slowly due to an awkward writing style. However, after the first chapter it becomes more readable and contains valuable assistance for anyone wanting to support a person with intellectual disabilities in the pre- and post-death processes. It highlights the need to be aware of the presenting behaviours of the disabled person, as their grief language is often largely expressed in their behaviour.

While one may be tempted to jump to judgment because the book is not evidence-based, and Kauffman does make assumptions about observed behaviours, I feel these assumptions are plausible because his interventions appear to help the person journey through the grieving process. The reduction or cessation of the presenting grief experiences speak for themselves.

Based on my own experience working in this field, I found the numerous suggestions valuable, especially those which help ensure that the disabled person is actively participating in the death activities and rituals. It is commendable that considerable emphasis is also given to the too frequent disenfranchisement that intellectually disabled people experience when death occurs.

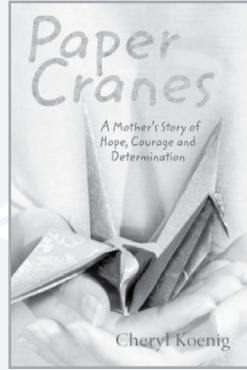
The book ends with a lovely story of a group session where a lot more conceptualisation among the disabled takes place than one might be tempted to believe could occur. This highlights the fact that the disabled grieve like everyone else and deserve the same level of support and understanding.

Mrs M. Rothman

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Paper Cranes

Cheryl Koenig (2008)

243 pp. ISBN: 978-1-877437-10-6

Auckland, NZ: Exisle Publishing Ltd.

AUD \$34.95 (includes GST)

Paper Cranes is the story of the grief of Cheryl Koenig and her family after her son Jonathan was badly injured in a car accident

close to home. Koenig starts with the accident and tells a haunting account of the first few minutes, hours and days after the incident, when Jonathan was scooped up from the road by paramedics and rushed from hospital to hospital, and from emergency ward to ICU to surgery ward in a desperate attempt to save his young life.

The book is based on the real-time diaries that Cheryl wrote at the time of her acute pain and captures the raw grief, powerlessness and fear any parent faces when their child's life is in such grave danger. Cheryl recalls an overt awareness, and questions her own ability to publicly grieve as she is standing on the road in front of her injured son pleading for one of the crowd of neighbours to start to perform CPR, with the sound of the ambulance siren in her ears and the question "Why can't I cry?" on her mind. She speaks of the invaluable support of family and close friends and the state of a mind in shock, taking in both everything and nothing of those fretful first days.

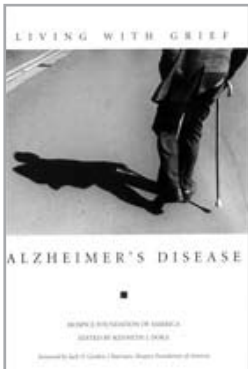
Koenig has the unique ability to capture the detail of her journey in a way that sets the reader alongside her in all of her fear, anxiety, sleeplessness and joy. We are transformed and taken inside her private space, her relationship with her husband Robert and their other son, Chris – then aged 10. She walks us with her through the hospitals and the confusion of the medical system, the busy staff, the inaccessible language and the corridors of the mine-fields that are shock and fear. She exposes us to the commitment, hard work and dedication of her family and of Jon, as they reach for the stars and hope without any evidence that hope exists, and as they succeed time and time again despite the odds.

Paper Cranes strips away the romanticism and forces the reality of the physical journey of rehabilitation after Acquired Brain Injury, whilst providing a strong and compelling explanation of a mother's voyage and a family's pain reacting to the grief life of living with an ABI.

Sally Robert

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Melbourne, Australia*



Living with Grief: Alzheimer's Disease

Doka Ken (Ed.) (2004)
290 pp. ISBN: 1893349055
Washington DC: Hospice Foundation of America
AUD \$45.95 (includes GST)
This four-part book aims to provide information and insights into families living with Alzheimer's disease and other dementias. It begins with a comprehensive

overview of the neurological basis of dementia, a dementia typology, and the cultural, ethnic and social implications for treatment and management. The very particular situation and consequences of a growing population of older people with a dual diagnosis of intellectual disability and dementia is discussed.

This is followed by discussion related to on-going losses and grief experienced by both individuals diagnosed with Alzheimer's disease and their family carers. When professionals develop a clear understanding of the unique nature of experiences and wishes of people in early stage dementia, they may more appropriately help them and their families handle decision-making in early, middle and end-stage dementia. There is an emphasis on exploring the 'heart' of what is happening to the whole family living with Alzheimer's disease.

The concepts of anticipatory grief and mourning are explored in some detail. Counsellors have a pivotal role in helping carers assess and review the inevitable changes in their situations, and in validating feelings of grief and a diverse range of emotions associated with their relationship to the person for whom they care. Some useful but as yet somewhat unverified assessment inventories are tabled. They provide tools for more precise and relevant intervention during the period of the illness. A spiritual needs-assessment model for carers based on three principles – finding strength through faith, caring for self and reaching out to others for support – is described.

Finally, hospice is promoted as a philosophy rather than a facility. Ethical challenges including balancing the needs of the person with dementia and family concerns are described. Support for families requires sensitivity according to the patient's wishes made in the early stages of cognitive impairment and their current health status.

This is an easy to read, practical, well researched and well referenced book for counsellors, all health practitioners and students interested or engaged in helping families in the areas of loss and grief and adapting to change. The book concludes with a comprehensive list of resources, all American, but the inclusion of website details makes them accessible.

Judy Whyte

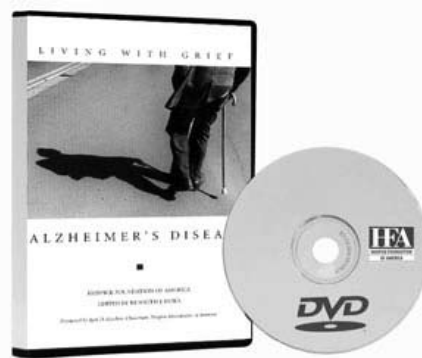
Counsellor, Alzheimer's Australia ACT

Canberra, Australia

(Reprinted from *Grief Matters* 9(1), Autumn 2006)

Living with Grief: Alzheimer's Disease (DVD) (2004)

Washington, DC: Hospice Foundation of America
Edited DVD US \$15.00
Unedited DVD US \$55.00



In this companion DVD to the text of the same name, an eight member expert panel discusses what is known medically about the diagnosis, progression, and treatment of Alzheimer's disease. The panel also focuses on particular grief issues that patients and families face during the course of this illness and examines the challenges facing policy advocates.

The panel is comprised of Kenneth J. Doka, PhD, MDiv; Parag Dalsania, MD; Jack D. Gordon; Lisa Gwyther, MSW, LCSW; William Haley, PhD; Lin E. Noyes, RN, PHD; Therese Rando, PhD and Leslie Fried, JD.

There are two versions of the DVD available, a condensed edition and an unedited, full-length edition.

Both editions can be ordered online from the Hospice Foundation of America at:
<http://store.hospicefoundation.org>

Abstracts

Dowling, S., Hubert, J., White, S., & Hollins, S. (2006).

Bereaved adults with intellectual disabilities: a combined randomized controlled trial and qualitative study of two community-based interventions

Journal of Intellectual Disability Research, 50(4), 277-287.

The authors of this UK study aim to find an effective and practical way to improve mental health and behaviour amongst bereaved people with intellectual disabilities. They manage two contrasting methods of intervention, measuring their effectiveness. The first method is traditional one-on-one counselling, using volunteer bereavement counsellors. The second method is an integrated intervention that is delivered by carers with a focus on bereavement specific support. Each of the counsellors, carers and support staff received specialist training before the commencement of the study; the bereavement counsellors were taught about IDs, while carers and support staff were taught bereavement counselling.

The integrated method was based on a theoretical model devised by Stroebe and Schut, which identifies the two key factors of grieving to be "Loss" and "Restoration". The integrated intervention was then divided into two parts: the loss-oriented grief work was done at home, while the restorative-oriented work was done in the day environment. The authors note their initial hypotheses that the integrated intervention would prove successful, believing the familial emotional support of the participants' usual carers would be more effective than individual counselling.

The participants' responses to the interventions were measured quantitatively to identify any changes in emotion or behaviour using the Aberrant Behaviour Checklist – Community (ABC-C), and the Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD). Qualitative measures were also applied, with participants interviewed in the presence of their carers. All of these measures were applied both before and after the interventions.

Contrary to their initial hypotheses, the counselling intervention was far more effective and practical than the integrated method, of which only two participants actually completed. The success of the counselling intervention extended beyond the participants' grief, but also to their general behaviour, communication and sociability. Also, the counsellors who had had no experience with clients with IDs, found themselves easily adaptable, challenged and rewarded by the experience. These developments are significant, the author's note, as they show this model can be applied easily to the existing bereavement support framework for the general population.

Marwit, S. J., & Kaye, P. N. (2006).

Measuring grief in caregivers of persons with acquired brain injury

Brain Injury, 20(13-14), 1419-1429.

While there has been little research of caregiver grief in general, there is a void in that research related to acquired brain injuries. Of the 338,700 Australians with ABIs, almost 50% are severely disabled and require day-to-day care. Most of these caregivers are family, and unlike other conditions requiring care, ABIs are sudden and without warning, and therefore, their grief is likely to be extreme and untreated.

The authors highlight the Marwit-Meuser Caregiver Grief Inventory (MM-CGI), which was used successfully with dementia caregivers to assess their levels of grief and coping. They determined the three factors of burden to be "Personal Sacrifice", "Heartfelt Sadness and Longing", and "Worry and Felt Isolation". The authors note that MM-CGI has also been successfully applied to caregivers of cancer patients, and in this study, they attempt to apply a modified version of the MM-CGI to test caregivers of people with ABIs, expecting similar results.

The authors tested volunteers using five different measures: 1) MM-CGI ABI revised, 2) Caregiver Well-Being Scale – Basic Needs sub-scale (CWBS-BN), 3) Caregiver Strain Index (CSI), 4) Perceived Social Support Questionnaire – Family sub-scale (PSSQ-F), and 5) Beck Depression Inventory (BDI).

Like with the original MM-CGI, caregivers with high scores (1 SD > mean) were deemed by the authors to require intervention or assistance. Likewise, caregivers with low scores (1 SD < mean) were deemed to be in either a state of denial or downplaying their distress, or alternatively showing no signs of suppressed grief, representing a positive adaptation to their burden.

The results, when compared to both the dementia and cancer caregivers' results, were "remarkably similar" in range, and deemed successful by the authors. While they acknowledge the limitations of their study (small pool of volunteers, mostly female) the authors note the comparable similarity of their pool to that of the previous studies, and argue that this reinforces the reliability and applicability of the MM-CGI.

Their revised MM-CGI for ABI is included in the article, along with suggestions for its application.

Meeusen-van de Kerkof, R., van Bommel, H., van de Wouw, W., & Maaskant, M., (2006).

Perceptions of Death and Management of Grief in People with Intellectual Disability

Journal of Policy and Practice in Intellectual Disabilities, 3(2), 95-104.

The authors note that people with intellectual disabilities, like the wider population, need to have their reactions to loss and the emotional consequences that flow from a death validated and recognised, and that this does not always occur, especially when fact of the death is withheld from the person concerned. In particular, the authors suggest, it is important for those with ID to be able to be involved in what happens after a friend or companion dies in ways appropriate to the context and the individuals' level of understanding.

The article observes that people with IDs do grieve and experience reactions to loss, both in similar ways to the population in general, and in other ways. Honing in on the effect of functional levels of intellect and how this influences understanding of matters pertaining to death and dying, the authors conclude that one important factor in how death and bereavement are perceived and responded to is the intellectual and social age of the bereaved person. Effective counselling thus requires insight into the person's social and intellectual age. The authors examine each of the global classifications for the four "age" groups, (as defined in DSM-IV-TR), addressing the different needs of each level in their experience and perceptions of death, grief and bereavement, while also offering practical solutions for counsellors.

Since an individual can inhabit different intellectual and socio-emotional "ages" and this discrepancy can contribute to significant psychological and behavioural problems, counsellors need to be aware of the complexity and contradiction of such an evaluation in order to best carry out their practice.

Using a theoretical framework informed by Piaget (including theories of cognitive development), Timmers-Huigens (concerned with "strategies of ordering experience") and Fowler (particularly the notion of "stages of faith"), the authors note the importance of the global classification in ascertaining socio-emotional development but with no absolute limits.

Programs and Services

The Australian Centre for Grief and Bereavement is located at McCulloch House, Monash Medical Centre, 246 Clayton Road, Clayton, Victoria. The Centre provides a range of programs and services to both individuals and organisations. These include:

Consultation and Advice

Centre staff are available for consultation on grief and bereavement issues. These may include advice on program development, staff training, client issues and evaluation. A flexible fee structure has been developed for consultation, which takes the type of organisation into account.

Clinical Supervision

Clinical supervision for those who work in bereavement support is essential. Centre staff are available to take on a limited number of supervisees on a regular basis. Both individual and small group supervision is available for a moderate cost.

Bereavement Counselling and Support Service

The Australian Centre for Grief and Bereavement has a confidential bereavement counselling service which is available to people who have been bereaved through any cause. This service is provided by experienced counsellors participating in advanced training in bereavement counselling. These counsellors are closely supervised by experienced accredited grief and bereavement practitioners.

Counselling appointments can be made by telephone and should be made directly by the bereaved person.

Contact the Bereavement Counselling and Support Service on (03) 9265 2111. The service is located at McCulloch House, Monash Medical Centre, Clayton, Victoria.

Research

The Australian Centre for Grief and Bereavement acknowledges that research is essential in the development of best practice in grief and bereavement education, support and clinical interventions.

The Centre conducts its own research in addition to collaborative national and international research projects.

Referral

The Australian Centre for Grief and Bereavement has a referral database and can put agencies and individuals in touch with private bereavement educators and counsellors. This referral database is comprised of professional educators and counsellors who specialise in grief and bereavement. For referrals to private grief counsellors phone the Centre's Bereavement Counselling and Support Service on (03) 9265 2111.

Education and Training Programs

The Australian Centre for Grief and Bereavement offers quality education and training opportunities for health professionals, interns, students, volunteers and any other individual or agency wanting to incorporate counselling, therapy, support and education into their current work practice.

Membership

Membership of the Australian Centre for Grief and Bereavement offers a range of benefits including receipt of *Connections* members' newsletter (issued twice yearly), *Grief Matters: The Australian Journal of Grief and Bereavement* (issued three times per year), special discount member rate for ACGB seminars, workshops and ACGB products, access to ACGB library for research purposes, discount on most books at Open Leaves Bookshop, free member functions and voting rights at the Annual General Meeting. Membership rates and details are as follows:

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Facsimile	(03) 9265 2150
E-mail	info@grief.org.au
Website	www.grief.org.au

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For more detailed information on the submission of manuscripts contact:

The Editor

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or by E-mail at: griefmatters@grief.org.au

The Internet



Internet Access

The Australian Centre for Grief and Bereavement has developed a home page for access on the internet, and includes information about the Centre's activities, resources and a range of grief and bereavement information. Entries include information about education activities offered during the current semester, an order form for resource materials available for purchase, details about the Bereavement Counselling and Support Service and information from Bereavement Support Services in Victoria (a list of agencies and organisations which provide free or low cost bereavement counselling, support and services). Direct access is also available from the home page to other grief and loss sites.

The URL for the Centre is: www.grief.org.au

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