

## A review of the emotional, psychiatric and behavioural responses to bereavement in people with intellectual disabilities

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### Abstract

**Background** Our knowledge and understanding of grief and its consequences have grown rapidly in recent years. There is a growing understanding that bereavement and loss represent a very significant event in the lives of people with intellectual disabilities (IDs). To date, there is no systematic review of the literature on the emotional, psychiatric and behavioural responses to bereavement in people with IDs.

**Method** This comprehensive literature review firstly examines the current opinion regarding the phenomenology of pathological grief in the general population. Research examining the ability of people with IDs to understand the concept of death is explored. In addition, a systematic review of the literature looking at the emotional, behavioural and psychiatric responses to bereavement is carried out.

**Results** Bereavement and loss have distinct effects on the mental health, behaviour and emotional lives of people with IDs. Following a bereavement, symptoms of depression and anxiety increase, and general

behaviour is altered. Traumatic grief symptoms have not yet been specifically studied and quantified.

**Conclusions** Particular difficulties are associated with researching the effects of bereavement on people with IDs. Further work needs to be done to more accurately describe the nature, time-scale, severity and frequency of the symptoms of traumatic grief in people with IDs, in order to improve assessment and treatment of affected individuals.

**Keywords** bereavement, death, grief, intellectual disability

### Pathological grief reaction

The study of pathological grief suffers from a lack of clarity concerning definitions of normality and abnormality with numerous terms being adopted to describe pathological or traumatic bereavement responses: absent (Deutsch 1937), distorted (Brown & Stoudemire 1983), abnormal (Pasnau *et al.* 1987), morbid (Sireling *et al.* 1988), truncated (Widdison & Salisbury 1990), atypical (Jacobs & Douglas 1979) and traumatic (Prigerson *et al.* 1999).

Until recently, the literature appeared to be divided and unclear concerning the validity of the various

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syndromes of pathological grief (Middleton *et al.* 1993), in addition to the delineation of the overlap between pathological forms of grief and specific psychiatric disorders (Jacobs 1993). According to Fourth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association 1994), the only recognized complication of bereavement is depression.

Recent studies have shown that symptoms of pathological grief are different from symptoms of depression and anxiety (Bierhals *et al.* 1996), and have distinct clinical correlations from those associated with depression, including distinctive electroencephalogram sleep architecture (McDermott *et al.* 1997). Distinctive relationships to the deceased have been described in bereaved people that explain pathological grief (Van Doorn *et al.* 1999). The evidence is growing that pathological grief is a syndrome distinct from other disorders, which needs specifically defined diagnostic criteria. A group of leading experts in reactions to loss and trauma have formulated consensus diagnostic criteria (Prigerson *et al.* 1999) for 'traumatic grief'. This term was chosen to acknowledge the fact that many symptoms of pathological grief, such as subjective emotional numbness, and avoidance of reminders of the deceased, resemble those of post-traumatic stress disorder. In addition, traumatic grief contains symptoms of separation distress which includes intrusive preoccupation with the deceased person (e.g. yearning, longing, searching). The authors agreed that the presence of certain marked symptoms of grief, persisting for more than 2 months, should be a critical factor in distinguishing between normal and pathological or traumatic grief. This is quite different with other studies that usually define pathological grief on the basis of the amount of time that has elapsed since the loss rather than on the specific symptoms.

### **Grief in intellectual disability**

While research into pathological forms of grief is at a relatively early stage of development in the general population as described above, little work has been done to examine the effects of bereavement and loss on people with intellectual disabilities (IDs). Much of the recent literature firstly involves the debate concerning the ability of people with IDs to grieve, and

their concept of death, and secondly the effect that bereavement has on their behaviour and mental health.

### **The ability of people with intellectual disabilities to grieve**

Observational studies suggest that attachment theory (Bowlby 1980) may have an important place in the understanding of emotional problems in people with IDs, and the difficulties many have in establishing relationships (Frankish 1989, 1992; Clegg & Lansdall Welfare 1995; Esterhuyzen & Hollins 1997; Hawes & Hollins 1997). Currently people with IDs are living longer than previously and are experiencing more and varied relationships both within their families and within the community at large. In many cases, they are looked after at home by relatives well into adulthood. When these bonds are broken by the death of the family carer, it may prove catastrophic for the individual. The death of a parent, particularly a sole surviving parent, can lead to additional associated losses for someone who has an ID. They may have to leave their home at short notice and go to emergency accommodation, from where it is not unusual for people to move four or five times in the year following a major bereavement (Oswin 1991). These sometimes unexplained and often unexpected disruptions, which involve the loss of the life that has been led until now and all of the familiar details of it, can also lead to a loss of individuality, while the negotiation of new, often communal, environments can have the effect of making someone's disability appear worse. New carers may overlook the recent loss and assume that behaviours that are a reaction to it are signs of mental ill health rather than expressions of grief. Inappropriate 'treatment' of quite normal responses to loss can make a difficult situation worse (Bicknell 1983). As Meyers (1980) states, in reference to responses to death 'as in most other aspects of their lives, individuals with mental retardation are more like everyone else than they are different'. Thus, the adaptation of attachment theory as a theory of grief and loss in people with IDs seems justified.

It has been erroneously argued that people with IDs, irrespective of their age, are incapable of comprehending the finality, irreversibility and inevitability of death (Speece & Brent 1984). It has also been

assumed that they are unable to form the emotional bonds and intimate interpersonal relationships that ultimately could culminate in feelings of personal loss and mourning (Deutsch 1985; McDanial 1989).

It seems likely that the degree of ID will affect an individual's ability to formulate abstract concepts, such as death (McLoughlin 1986). Research suggests that the understanding of these concepts is more related to cognitive level as determined by Piagetian tasks than to chronological age (Bihm & Elliott 1982). It has also been shown that life experience acquired through aging enhances the ability of adults with IDs to understand the meaning of mortality, as assessed on an understanding of the universality, irreversibility and inevitability of death (Lipe-Goodson & Goebel 1983). Elderly individuals with IDs appear to have acquired a more accurate conceptualization of death than have their younger counterparts with comparable cognitive abilities (Seltzer 1989). McEvoy (1989) found that in his sample of adults with IDs, there was a relative lack of understanding of aging and death as a natural part of the life cycle, which may reflect the fact that some people with IDs continue to be treated as children and are not encouraged to act, speak or dress in age-appropriate ways. However, understanding the concept of death is not a prerequisite for experiencing the emotions associated with grieving. The absence of the person who has died is the tangible manifestation of his/her death, and people with learning disabilities recognize the absence of someone they love. They will grieve for this loss with or without comprehension of the abstract nature of death. Concepts of death have also been studied in the content of dreams of people with IDs (Turner & Graffam 1987); much of the dream content was similar to that reported by people without IDs who have suffered a traumatic bereavement.

### **The effects of bereavement on people with intellectual disabilities**

In the absence of a clear understanding of what constitutes a normal grief reaction in people with IDs, and whether or how it differs from grief in other adults, our understanding of the effects of bereavement on these individuals is largely based upon the observation of behavioural change, or the development of psychiatric illness. Understanding and

assessing the emotional states of people with IDs, in general, is in its infancy (Clark *et al.* 1991). As a result, the challenge to try to distinguish a 'normal' grief reaction from an 'abnormal' one is even greater in the people with IDs than in the general population.

People with IDs are particularly vulnerable to psychiatric illness. Actual estimates of psychiatric illness within this group have varied widely because of methodological problems concerning diagnosis and classification. Overall prevalence rates range from 20% to 70% (Corbett 1979; Eaton & Menolascino 1982; Lund 1985; Bregman & Harris 1996). A new diagnostic classification (DC-LD 2001) has been published, for use with adults with IDs, which is expected to help diagnosis and research. The relationship between life events, such as parental bereavement, and the development of psychiatric illness continues to be of great interest and various research findings are well documented (Brown & Harris 1989). This is an under-researched area in people with IDs (Nadarajah *et al.* 1995). However, it does seem reasonable to assume that this group is at least as vulnerable as the rest of the population to the effects of life events, especially as institutional living becomes less frequent and the exposure to a wide range of experiences becomes part of living in the community (Ghaziuddin 1988).

### **Materials and methods**

We attempted to carry out a systematic review of the literature to examine the clinical effects of bereavement on people with IDs and, in particular, to look for research into traumatic grief. We specifically looked for peer-reviewed psychiatry, psychology, nursing and social work papers that described psychiatric, emotional or behavioural reactions to bereavement, published from 1966 to date. We searched for potential articles for review from Pre-Medline, Medline, Embase, Psychlit, Psychinfo, CINAHL, and the Cochrane Library. In addition, a manual search was made through published books, relevant journals, dissertation theses and conference proceedings.

### **Results**

Altogether 77 articles were identified on the subject of bereavement and people with IDs, of which 27

presented the results of original research with the stated aim of investigating psychiatric, emotional or behavioural reactions to bereavement. The majority of these articles were descriptive single case studies; seven studies employed qualitative or quantitative methodology, and only one study involved the use of a control group. The most significant of these studies are discussed in the text.

### Psychiatric illness

Day (1985) examined over 300 long stay hospital residents and over 200 new admissions to a psychiatric unit for people with IDs, to carry out a hospital- and community-based study of psychiatric morbidity. He found a high incidence of 'reactive depression' and 'anxiety state' (using I.C.D. 9 diagnostic criteria) among the admission group (over 33%), in which almost 50% of these breakdowns were clearly precipitated by the death or serious illness of a family carer. He suggested that the onset of these psychiatric disorders might be viewed as 'bereavement reactions'. On a similar theme, McLoughlin & Bhate (1987) described the case of an individual with moderate ID, who developed a severe depressive episode, with psychotic features, following the death of her father. He described the relationship between father and daughter as being ambivalent before the death and wondered whether this contributed to the individual's difficulties. Similar cases have been reported by Reid (1972), Hollins & Kloeppe (1989), and Hollins & Sireling (1999). A case of mania and a case of a schizophrenic episode, both precipitated by a bereavement, have also been described (Singh *et al.* 1988; Yapa & Clarke 1989). Stoddart *et al.* (2002) evaluated the effect of bereavement on a group of 21 individuals with IDs, and also evaluated the effect of group work on measures of anxiety, depression and knowledge of death. Scores for depression, using the Children's Depression Inventory-Short Form (Kovacs 1992) were significantly elevated following the bereavement, as were scores for anxiety, using the Hopkins Symptom Checklist (Hesbacher *et al.* 1980).

Hollins & Esterhuyzen (1997) carried out a systematic study of the reaction of people with IDs to bereavement. They recruited adult subjects ( $n = 50$ ) from day centres, who had lost a parent in the preceding 2 years, and compared them with a non-bereaved matched control group. They used the

informant-based version of the Psychopathology Instrument for Mentally Retarded Adults (PIMRA; Matson 1988) to assess for psychopathology possibly related to the grieving process. Twenty-one participants showed 'case present' on at least one of the subscales of affective, anxiety or adjustment disorder, a score much higher than the control group, indicating the likely effect of bereavement on psychopathology scores. The authors point out that although increased symptoms of psychopathology were found, this does not automatically indicate pathological grief, because many of these symptoms form part of what we understand to be 'normal grief'. A follow-up study was carried out with the bereaved group, approximately 5 years after the parent bereavement (Bonell-Pascual *et al.* 1999). The PIMRA was again used to assess for psychopathology. Of the 21 'cases' described above, 18 no longer scored, the data suggesting an overall reduction in affective disorder and anxiety disorder symptoms since the initial study. However, other subjects scored as cases at follow-up, who had not done so at the initial assessment suggesting the possibility of a delayed grief reaction for these individuals.

### Behaviour and emotion

Emerson (1977) explored the incidence of bereavement and the onset of marked behaviour and mood change in adults with IDs. She found that 50% of the individuals had experienced the loss of a close contact before the onset of the symptoms. She also reported that carers for the individuals had minimized the significance of the death, or misunderstood the reactions to it. Strachan (1981) interviewed care staff closest to adults with learning disabilities in an institutional setting. Despite reports from care staff of having observed a wide variety of responses to bereavement, a typical comment was 'no response to the death'. Strachan wondered whether this was because of carers' expectation of little response to bereavement by these adults, and that distress was undetected. In the course of current bereavement research by two of the authors at St. George's Hospital Medical School, interviews with both carers and bereaved people themselves have been carried out. These interviews have again exposed the once common perception amongst carers, that people with IDs have no response or merely a limited response to a death. However, this was broadly contradicted by the

bereaved people themselves, who clearly expressed their sadness, distress and anxiety at their loss. Harper & Wadsworth (1993) carried out 43 structured direct interviews with adults with moderate to severe IDs, using the Iowa Loss Instrument (Harper & Wadsworth 1993) designed by the authors. They found 25 of the individuals questioned reported that at least one death was very disruptive to their lives, complaining of symptoms of anger, anxiety, confusion and discomfort thinking about the death. Eighteen of the individuals for whom the loss had occurred at least a year previous to the interview reported continuing problems in their lives including feelings of loneliness, anxiety, sadness and behaviour problems.

In the study by Hollins & Esterhuyzen (1997), behaviour was assessed for the bereaved group using the Aberrant Behaviour Checklist (ABC; Aman *et al.* 1985), and compared with the control group. Results showed a significant increase in irritability, lethargy, inappropriate speech and hyperactivity in the bereaved group compared with the control group. At follow-up, the ABC was again administered on most of the bereaved group. In general behaviour was found to have deteriorated between the initial assessment and the follow-up approximately 5 years after the reference bereavement, suggesting continued difficulties, possibly related to the bereavement.

Kitching (1987) described delayed grief in a single case study and suggested that grief is often delayed for people with IDs, who may not initially understand the loss, but come to do so later, and then enter an atypical grieving process. Allison (1993) used short case vignettes to describe patterns of bereavement in people with autism and found failure to grieve, delayed grief, apparent failure to understand the irreversibility of death and uncertain or inappropriate responses to bereavement. People with autism often have a very limited number of close relationships and the loss of one of these may be catastrophic.

### Discussion and future research

There are significant difficulties associated with researching the effects of a significant life event, such as a bereavement, on the mental health of people with IDs. Firstly people with IDs are not a homogenous group: there are wide differences in experience, envi-

ronment, personality and ability. Secondly the well-developed and validated grief scales that are used in the general population are frequently not appropriate for use in this population because of the complexity of the language and concepts used in them; examples include the Texas Revised Inventory of Grief (TRIG) (Faschingbauer 1981), the Grief Experience Inventory (Sanders *et al.* 1985) and the Inventory of Complicated Grief (Prigerson *et al.* 1995). Thirdly, interviewers may have to rely on the information provided by carers rather than by the individuals themselves, as many have difficulties communicating the relevant information; this may greatly affect the reliability of any research conclusions. However, people with IDs can often be reliable informants about their own emotional reactions to loss. In the course of current research at St. George's Hospital Medical School, London, interviews have been carried out with over 60 bereaved people with IDs who all have different abilities and communication skills. They were all able to offer insight into their feelings following their loss. They did this not just by talking but also by a variety of means, some using aids such as drawing, pictures, books or photographs, others through body language and changes in expression. Some people cried or rocked or clasped and unclasped their hands. What these research participants were 'saying' could be captured through qualitative methodologies, interviews and observation. In view of this experience, the lack of validated grief scales 'appropriate' to this population should not be regarded as an obstacle to further research.

Our study could not find a systematic large-scale study, using agreed and defined diagnostic and assessment criteria, carried out to examine the nature, time-scale, severity and frequency of the symptoms of grief in people with IDs. Despite the difficulties associated with researching this area of study, there is growing evidence that bereavement and loss has a distinct effect on the mental health of people with IDs. Many studies have shown that symptoms of depression and anxiety increase, and that behaviour changes following a bereavement. However, we are still unclear whether these symptoms and changes in behaviour represent so-called 'normal' grief symptoms, or the more serious 'traumatic grief' symptoms. This lack of clarity could lead to less than satisfactory outcomes, with possible misdiagnosis and inappropriate treatment of psychiatric

symptoms and behavioural changes. The authors suggest that symptoms need to be examined more carefully, with a view to accurately describing the specific symptoms of traumatic grief in this population. This should improve the ability of families and carers to empathically and effectively support bereaved individuals. Appropriate bereavement services need to be developed that have a clearer understanding of assessment and treatment of possible high-risk groups of people with IDs who develop traumatic grief symptoms.

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