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Bereavement and grief in adults with

learning disabilities

SHEILA HOLLINS and ALEXANDER ESTERHUYZEN

Background This paper reports the results of the first systematic study of the reaction of people with learning disabilities to bereavement.

Method A sample of 50 parentbereaved people with learning disabilities was compared with a matched control group of 50 non-bereaved people. A semi-structured bereavement questionnaire was used along with the following instruments: the Aberrant Behaviour Checklist (ABC), the Psychopathology Instrument for Mentally Retarded Adults (PIMRA) and the Life Events Checklist.

Results Highly significant differences are demonstrated between bereaved and non-bereaved samples on both the total scores and most of the subscores of the ABC and PIMRA. Staff and carers did not usually attribute behaviour problems to the bereavement and its concomitant life events, nor was there a recognition of psychopathology due to bereavement.

Conclusions The impact in terms of psychiatric and behavioural morbidity of loss of a parent, with its concomitant life events, in adults with learning disabilities has been underestimated.

Little research has been published on the effect of bereavement in people with learning disabilities, but it is thought to precipitate major effects which are largely unrecognised as part of grieving in this client group. Since it is not clear to what extent the evidence for this is anecdotal, it was decided to investigate whether bereavement, together with its concomitant life events, has an observable effect on people with learning disabilities. In addition, the involvement of the study population in the events surrounding the death of their parent will be described.

BEREAVEMENT IN PEOPLE WITH LEARNING DISABILITIES

As a result of medical and social advances, people with learning disabilities live longer, experience more fulfilment in relationships and are consequently more affected by death and separation. Furthermore, the number of elderly carers is rising, and according to Farmer *et al* (1993), in the North Thames (West) Region, around 400 of the estimated 3722 principal carers of adults with learning disabilities are expected to die before the turn of the century.

There are conflicting opinions concerning the ability to grieve in relation to the level of cognitive development. Oswin (1991) suggested that the response of people with learning disabilities to a bereavement was essentially the same as in anyone else, and confirmed this with detailed oral histories of bereaved people. Brelstaff (1984) found that those people with learning disabilities who did not grieve were not necessarily those of lowest cognitive ability. Bereaved people may be referred to a mental health professional for advice regarding disturbed behaviour, without recognition by the referrer of the nature of the link between grief and behaviour. Clinical experience suggests that such behaviours do not remit spontaneously (Kloeppel & Hollins, 1989). McLoughlin (1986) argued that a higher incidence of psychiatric illness following bereavement should be expected because of impaired adaptive behaviour. However, there are no quantitative data available to confirm or disprove any relationships between bereavement and psychopathology.

When death of a close family member occurs, it is common for a person with learning disabilities to be denied the opportunity to take part in the funeral. News of the death may be withheld for weeks or months or even forever (Bicknell, 1983; Oswin, 1991). If this happens, the cultural rituals surrounding a death, including the funeral service itself, which may have a direct role in aiding the mourning process, are denied.

Many people with learning disabilities have difficulties with communication, and if they are unable to express themselves verbally, they may be treated as though they experience no feelings. Sometimes the one person who has been able to understand what may be a very individual means of communication is the one who has died, thus complicating the loss further (Hollins & Sireling, 1991). Death education and counselling materials which are accessible to people with learning disabilities have been published, some including guidelines for specific interventions (Hollins & Sireling, 1991).

THE IMPORTANCE OF BEHAVIOUR

Generally people with a learning disability do not refer themselves, but are referred by care-givers because of problem behaviours. Behavioural disturbances are frequent in this population group, present varied management problems, and prevent the individual with learning disability from reaching his or her full potential. Disturbances may increase or decrease as a function of internal or external environmental changes, and there is no simple and consistent relationship between psychiatric disturbance and specific behaviour (Fraser et al, 1985). Treatment interventions are often directed at suppressing the rate and severity of the problem behaviour without addressing underlying possible causative factors. This may achieve less than optimal results, and deny the opportunity to understand both the function that a particular behaviour has for an individual client and its origin, thereby failing to select a treatment intervention which addresses these needs (Sovner & Lowry, 1991).

Psychopathology and grief

Questions about the overlap of grief and defined disorders persist (Stroebe et al, 1993). There is no clear identification of areas of psychopathology that are griefspecific. This is complicated by the fact that grief in the general population is not a static entity, but progresses through somewhat overlapping stages of resolution. Given symptoms may be present throughout grief, although more prominent in some stages than in others. The temporal context of symptoms is therefore important. A time limit of two years after bereavement has been set, on the basis that usually symptoms of psychopathology and grief have reached resolution in the general population within one to two years of the bereavement (Parkes, 1972). Anxiety, anger, depression, guilt, a sense of being overwhelmed, mental disorganisation, loneliness and apathy are all recognised as part of normal grieving. Most grief inventories are too sophisticated for use in people with learning disabilities, and it was therefore necessary to identify other instruments already in use in this client group which might elicit symptoms of grieving indirectly.

METHOD

Specialist local authority day centres for people with learning disabilities provided convenient sources of adults with learning disabilities who had lost a parent in the preceding two years, and non-bereaved controls. Unlike carers at the client's family home, key workers in day centres are not grieving themselves as a result of the loss being investigated. It was anticipated that their interpretation and recording of the clients' feelings and behaviour would be less likely to be influenced by their own reaction to the death than the interpretation given by the surviving parent or care-giving relative. Carers of bereaved clients at their place of residence were also approached, and a total of 33 carers in this setting agreed to participate in the study. The results from this subsample would enable comparison of findings on the same clients in two different settings and ratings by two independent sets of raters.

Fifteen day centres in the southwest sector of Greater London, within easy geographical access of the study's base, were approached. Seven of these agreed to participate and provided referrals. Five reported that they had no current referrals, and on that basis declined participation. Informed consent was obtained from the subjects and/or their carers.

Subjects

Staff of participating day centres were asked to identify all adults (over 17 years of age) currently attending their centre who were bereaved of a parent in the previous two years (Group 1). These subjects were coded numerically (1-50) in order of referral. Clients still living with their families as well as those currently in residential care were included in the study. Clients who were recognised by key workers to be autistic or to have autistic traits were excluded from the study; one bereaved client and two controls were excluded for this reason.

A second group of 50 adults, matched with Group 1 for age, sex and degree of learning disability, but without a loss of parent or primary carer in the previous two years, were also identified (Group 2). For reasons of confidentiality, it was not possible to access day centre registers to select matched controls randomly. Therefore, staff were requested to select control subjects using the following procedure. The two largest day centres were each provided with a list of the code number, age, sex and level of disability of half of the bereaved subjects. Managers were asked to identify, from an alphabetically ordered list of non-bereaved clients registered at their centre, a control to match each bereaved subject in order of the code number of that subject. They were instructed to select the first matching nonbereaved client starting at the beginning of an alphabetically ordered list. The matched control client thus identified was then removed from the list and the bereaved subject next in numerical order was matched with a control in the same way, but starting at the end of the alphabetical list of non-bereaved clients. This helped spread the selection of clients throughout the alphabetical list and provided a practical way of identifying matched control clients in a systematic, but unbiased way.

Assessment interview

After meeting the client and obtaining their consent, the researcher (AE) interviewed the key worker at the day centre to determine the observed behaviour of the client over the previous four weeks. The interview took the form of a questionnaire and structured interview to gather information from the key worker relating to the following areas: (A) identifying, demographic and physical data; (B) behaviour; (C) psychopathology; (D) life events; and (E) bereavement data. Published rating scales and checklists were used for B, C and D. The structured interview was completed by key workers of clients in Group 1 and Group 2. It was also completed by carers at home who agreed to participate in the study (either remaining relatives or residential staff).

(A) Identifying, demographic and physical data

The following information was collected: level of disability (according to ICD-9), using the functional description rather than specific IQ measures for the categories mild (IQ 50-70), moderate (IQ 35-49) and severe (IQ 20-34); age; sex; primary carers and current residential setting; and medical status (presence of epilepsy, currently diagnosed psychiatric illness, disabilities in addition to intellectual impairment, medication).

(B) Behaviour

The instrument used to assess behaviour over the previous four weeks was the Aberrant Behaviour Checklist (ABC; Aman *et al*, 1985). It is an informant-based scale originally developed to assess the effects of treatment and also for identifying individuals in need of intervention. The actual rating portion of the ABC has 58 behavioural items which describe maladaptive or inappropriate behaviour. These items resolve into five subscales as follows:

- (1) irritability, agitation, crying
- (2) social withdrawal and lethargy
- (3) stereotyped behaviour
- (4) hyperactivity, non-compliance
- (5) inappropriate speech.

(C) Psychopathology

The instrument used to assess psychopathology over the four weeks prior to interviews was the Psychopathology Instrument for Mentally Retarded Adults (PIMRA; Matson, 1988). The PIMRA comprises 56 items, with seven items contributing to each of eight subscales: schizophrenia; affective disorder; psychosexual disorder; adjustment disorder; anxiety disorder; somatoform disorder; personality disorder; and inappropriate adjustment.

Factor analysis of the PIMRA reveals three factors: "affective", "somatoform" and "psychosis" (Matson *et al*, 1984). The validity and correspondence between checklist scores and specific psychiatric diagnoses in this client group at this time remains questionable. However, the PIMRA affective disorder scale of the informant-based version has been shown to correspond with ratings of depression on the Beck, Zung and Hamilton scales (Helsel & Matson, 1988). It should be emphasised that this instrument was used, not to make specific psychiatric diagnoses, but in an attempt broadly to identify evidence, if any, of psychopathology, which may be related to the grieving process. There are no published standards for PIMRA scores for the 'healthy' or 'psychiatrically ill' among people with learning disabilities in this country.

The informant-based version (rather than self-report) was used because of the wide variation in level of learning disability anticipated among clients in the sample, and poor test-retest reliability of the self-report version. 'Cases' were those clients who scored positive for four or more of the seven items in each subscale.

(D) Life events

The instrument used was the Life Events Checklist developed by Stack *et al* (1987) for their study on the relationship between stressful life events and hospitalisation in adults with learning disabilities.

(E) Bereavement details

Full details of the client's bereavement and participation in grieving rituals were noted, and these are summarised in the text.

Statistical methodology

Comparison between the information collected on the bereaved group and their controls was carried out using matched odds ratios and McNemar's chi-squared corrected test for binary data. Comparisons between the information collected at the day centres and from home carers were made using Fisher's exact two-tailed test.

RESULTS

The subjects and controls were compared on a number of parameters as shown in Table 1, none of which showed the groups to be significantly different.

Behaviour

Mean scores of bereaved and control groups for the five subsections of the ABC are presented in Table 2. A comparison of
 Table I
 Demographic data for 50 bereaved adults

 and 50 control subjects matched for age, sex and level
 of learning disability

	Bereaved	Controls
Mean age (s.d.)	37.8 (8.9)	37.1 (9.1)
Number of males	28	Matched
Number of females	22	Matched
Level of learning disability		
Mild	8	Matched
Moderate	22	Matched
Severe	20	Matched
Verbal skill		
Makes sentences	32	33
Three words or less	18	17
Medical status		
On medication	17	12
Psychiatric illness	4 ¹	5

I. Three were diagnosed before bereavement and one after.

bereaved and control subjects scored by key workers at day centres revealed that the mean scores for the following four subsections of the ABC are significantly different, with the bereaved group showing an increase in irritability (P=0.0018), lethargy (P=0.0002), inappropriate speech (P=0.0179), and hyperactivity (P=0.0013). In response to the last question in the questionnaire ("Do you consider that the client's health or behaviour has been affected in any way by the bereavement?"), 72% of raters responded negatively.

Data analysed to compare the bereaved clients' scores at home with the scores of the control group revealed significant differences in all five ABC categories: (irritability, P=0.0002; lethargy, P=0.0058; hyperactivity, P=0.0004; stereotypy, P=0.0666; inappropriate speech, P=0.0000). A comparison of mean scores of subsections of the ABC for bereaved clients scored by key workers at the day centres and the same clients scored by different carers in residential settings (n=33)

are also presented in Table 2. Only inappropriate speech was found to be significantly different (P=0.0297), with clients at home scoring more inappropriate speech. There is a trend towards scores at home being the same or higher than scores at the day centre for the other sections.

Psychopathology

Those subscales of the PIMRA in which clients scored as 'cases' are shown in Table 3. The same scorings are shown for the bereaved group in Table 4, but split between informant results at the day centre and at home.

Life events

The bereaved group experienced significantly more life events both in the month prior to interview, and after the bereavement. In the time-span between the bereavement and the interview, 18 bereaved clients had between two and six life events in addition to the bereavement. Only three control subjects had a similar number of life events during a matched period of time. Of the bereaved group, 39% moved home as a result of the deceased parent's final illness.

The experience of bereavement

Of the 50 bereaved clients, 22 lost a biological mother and 24 a biological father; one client lost a stepmother and three clients a stepfather. In 30% (n=15) the index death was that of the last remaining carer. Of the deceased parents, 44% (n=22) were described as primary carers, while 18% (n=9) shared equal responsibility for the client's care; 64% (n=32) of clients were living with the deceased carer until the time of their last illness. Of the 72% (n=36) of clients not actually resident with the deceased parent at the time of the death, only 17% (n=6) of this subsample had regular weekly or fortnightly visits to their ill relative. Given that 64% (n=32) of the

Table 2 Mean ABC scores for the control and bereaved groups

Subscale	Control n=50	Bereaved (home) n=33	Bereaved (day centre) n=50
Irritability	1.56	4.09	3.27
Lethargy	2.40	4.61	4.74
Hyperactivity	2.00	4.45	4.15
Stereotypy	0.58	1.18	0.98
Inappropriate speech	0.52	1.67	1.04

parents did not die suddenly, this represents a very small proportion who had the opportunity to visit. In only 30% (n=15) of cases was a named person at the day centre designated to speak to the client about the bereavement. In 16% (n=8) the possibility of the parent's death was discussed with the client before the death occurred; 64% did not have this possibility discussed with them, and in 20% it was not known whether the possibility of their parent's death was discussed before the event.

Fifty-four per cent (n=27) of clients attended the funeral of their parent, but for 20% (n=10) it was not known whether they had attended, and 26% (n=13) were definitely known not to have attended. Of those who did not attend, in 46% (n=6) it was because relatives felt it would be too disturbing for the client, 15% (n=2) because staff were concerned that attendance would be too disturbing for the client, and in the case of 15% (n=2) the client themselves refused to attend. In 23% (n=3) it was not known why they did not attend. Only 16% (n=8) of bereaved clients had had the opportunity of visiting the grave or the place where ashes of their parent were scattered; 68% (n=34) were known to have mementos of the deceased.

Carers at the time of interview were aware that 60% (n=30) of bereaved clients still mentioned their deceased parent spontaneously, and those who attended the funeral were approximately 3.5 times more likely to do so ($\chi^2=4.06$, d.f.=1, P=0.04, odds ratio 0.87 < 3.6 < 16.21). Most carers (72%, n=36) felt that the bereaved client's behaviour had not been affected by the bereavement in any way at the time of interview. Sixteen per cent (n=8) of the bereaved clients had received at least one formal session of bereavement counselling.

DISCUSSION

The effect of diagnostic overshadowing and the interview setting

Clearly, carers were aware of which clients were bereaved, so the interviews were not double-blind. It is a matter of some concern that the majority of carers at the day centres did not subjectively perceive the bereaved client's behaviour to be affected by the bereavement, in spite of the fact that, objectively, there were significant differences between bereaved and control groups. This suggests that the bereavement and its
 Table 3
 Numbers of control and bereaved clients

 who scored as 'cases' for disorders using the Psychopathology Instrument for Mentally Retarded Adults (at the day centre)

Disorder	Control (n=50)	Bereaved (n=50)	Р
Depression	4 (8%)	13 (26%)	0.015
Adjustment disorder	2 (2%)	7 (14%)	0.07
Anxiety	5 (10%)	22 (44%)	0.000 I

associated life events were not related to the level of the client's behavioural disturbance in the minds of carers. The aberrant behaviours in the majority of cases were assumed to be due to the innate personality of the client or to the learning disability itself. This concurs with Reiss et al (1982), who showed that professionals were more likely to attribute behavioural symptoms to presumed learning disability than to other pathology, if clients were known to suffer from a learning disability. It should be noted that this sample only includes subjects currently attending day centres, and therefore excludes subjects who may not attend on the grounds of behavioural disturbance and current psychiatric or other illness.

The differences noted for scores at home and the day centre, for the same bereaved clients, may simply be a reflection of the fact that in residential settings the staff:client ratio is higher than in day centres, and behaviour of clients is therefore more likely to be noted by staff/carers. It is of importance that the scores of bereaved clients for aberrant behaviour at home consistently reinforce the scores of bereaved clients at the day centre as being higher than the scores for control clients, in spite of being scored by raters independent of those at the day centres.

Normal or pathological grief

Because of their dependency and the consequent nature of attachments, the impact of the loss of a parent on a person with learning disabilities is difficult to isolate from the many important and major life events often associated with the bereavement, the most important of which is likely to be the simultaneous loss of his/her home. Nevertheless, the functional significance of the increased scores for aberrant behaviours in the bereaved group clearly indicates the Table 4Numbers of bereaved group who scored as'cases' for disorders using the PsychopathologyInstrument for Mentally Retarded Adults at the daycentre (n=50) or at home (n=33)

Disorder	Bereaved (day)	Bereaved (home)	Ρ
Depression	13	14	NS
Adjustment disorder	7	12	0.018
Anxiety	22	10	NS
Personality disorder	0	I	NS

significant and disturbing impact of loss of an important attachment figure.

It should be noted that the symptoms of psychopathology noted by use of the PIMRA (i.e. depression, anxiety and adjustment disorder) do not necessarily imply pathological grief, since to some degree these symptoms are well recognised to be part of normal grief. For this reason the authors hesitate to label these effects as mental illness, being unsure how many of the symptoms measured may be those of normal grief as it affects this population.

Opportunities to grieve

The non-involvement of the majority of bereaved people with learning disabilities in the rituals surrounding death and dying is very striking. Exposure to cues relating to the bereavement (rather than avoidance of these) have been shown to be crucial in the recovery from grief. From the results of this study, there seems to be a tendency towards minimising exposure to cues which act as reminders of losses experienced by people with learning disabilities. Although 68% had mementos of the deceased, only 16% had had any bereavement counselling. Spontaneous mention of the deceased parent was made more often by those who had been involved at the time of death.

Involvement in events before and after the death

Most people in the study were not helped to say goodbye to their dying parent, but were kept away from the sick bed to avoid upsetting them, but perhaps also because their presence increased the pain for the parents and other carers. There were also the logistical difficulties of arranging regular visits and the failure to recognise the significance that such contact might have. Seeing other people coping with grief can help people with learning disabilities appreciate how normal the uncomfortable feelings associated with loss are. It is widely recognised among specialists that nonverbal methods of communication, and repeated attempts to explain new experiences, are needed to ensure understanding and avoid behavioural disturbance (Hollins & Sireling, 1991). Instead, carers seem to exclude people with learning disabilities from these experiences, perhaps with the unrealistic hope that the person with learning disabilities will not be aware of the loss or because they (the carer) were themselves denying the profound impact of the loss and its associated life events.

CONCLUSIONS

Further research is needed in order to differentiate the effects of bereavement itself (as opposed to other additional associated life events) on the behaviour and psychopathology of adults with learning disabilities. However, this study clearly demonstrates that aberrant behaviours are more frequent among a group of adults with learning disabilities who have been bereaved of a parent, than a comparable group who have not been bereaved of a parent. There were also significantly more 'cases' of psychopathological morbidity in the bereaved group. The results also indicate that staff do not usually attribute behavioural problems to the bereavement and its consequent life events. Nor is there a recognition of the increased rates of psychopathology due to bereavement. This may explain the lack of emphasis on helping bereaved clients to participate in and deal with this important loss. In the light of this evidence, the present service responses seem to be quite inadequate. Work is urgently needed to develop intervention strategies which might be effective in reducing psychological morbidity in this group.

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CLINICAL IMPLICATIONS

 Diagnostic overshadowing may lead to a failure to recognise behavioural expressions of grief.

- Always elicit a bereavement history as part of behavioural and psychiatric assessment of people with learning disabilities.
- Seek to support people with learning disabilities in participating in the events surrounding a parent's death.

LIMITATIONS

- This was not a double-blind study.
- The study relied upon informant ratings.
- The effects of bereavement could not be clearly differentiated from the effects of associated life events.

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