

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

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### Abstract

**Background** Bereaved adults with intellectual disabilities are known to experience prolonged and atypical grief which is often unrecognized. The aim of this project was to find an effective way to improve mental health and behavioural outcomes.

**Methods** Subjects were randomized to two different therapeutic interventions: traditional counselling by volunteer bereavement counsellors, and an integrated intervention delivered by carers which offered bereavement specific support. Qualitative and quantitative methods were used to determine their effectiveness and efficacy.

**Results** The counselling intervention resulted in measurable gains both clinically and in terms of quality of life; the second intervention proved impracticable in most settings and no improvement in mental health or behaviour resulted.

**Conclusions** Despite small numbers, the quantitative findings were highly significant, were supported by the qualitative data, and were of practical relevance

to primary care practitioners and specialist mental health and intellectual disability staff.

**Keywords** bereavement, carers, counselling, grief, intellectual disability, social exclusion

### Introduction

There is growing evidence that many people with intellectual disabilities (IDs) experience atypical and prolonged grief following the death of a family member or close friend (Harper & Wadsworth 1993; Hollins & Esterhuyzen 1997; Bonell-Pascual *et al.* 1999). Furthermore, these bereavement experiences are often unrecognized, denied or ignored by other people, including family members and care staff. The aim of this research was to develop and establish an intervention that would improve psychological and behavioural outcomes for people with IDs following bereavement.

Counselling in primary care is becoming well established with a growing evidence base (Relf 1995; Bower *et al.* 2003; Department of Health 2001a), but the evidence for its use with people with IDs is very limited (Read 1996). Support for the psychological needs of people with IDs tends to be located in specialist learning disability teams, or in day and residential services, rather than in mainstream coun-

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selling and psychological therapy services, and is poorly developed (Royal College of Psychiatrists 2004). This is the first comparison of alternative bereavement interventions for people with IDs.

## Materials and methods

It was hypothesized that people with IDs would gain no measurable benefit in their mental health, behaviour and quality of life from bereavement counselling and support offered by local volunteer counsellors, but would benefit significantly from enhanced bereavement-specific support, provided by their usual informal or formal carers. Many paid carers emphasize the importance of their role in supporting the emotional needs of the people in their care.

### The interventions

The study piloted and evaluated two different models of bereavement support: (1) a traditional counselling intervention (Worden 1991), delivered by volunteer bereavement counsellors; (2) an 'integrated intervention', offering bereavement-specific support, delivered by two people who already knew the participant well, i.e. their usual formal (paid) or informal (e.g. family) carers based in the usual home and day settings of the participant's life.

#### *The counselling intervention*

This intervention was delivered to participants in a fixed setting of their choice, usually at home or in their day centre. They received an average of 15 sessions, initially offered on a weekly basis and latterly fortnightly. Sessions were generally one hour in length, though occasionally shorter sessions were held, depending on the needs of individual clients.

The bereavement counsellors received a 2-day training about ID, because the majority of those volunteering had had no previous experience with this client group. The training focused on adaptations that might be needed in the counselling and support to be offered, particularly in communication. Counsellors were encouraged to use a variety of communication strategies, tailored to the needs of individuals, including drawing, looking at photographs and pictures, including books from the Books Beyond Words

series (e.g. Hollins & Sireling 2004a,b; Hollins *et al.* 2003), and making life story books and memory boxes.

Counsellors' usual supervision arrangements within their bereavement counselling service supported the project and advice on working with people with IDs was available from the research team.

#### *The integrated intervention*

This intervention was based on the theoretical model of bereavement work devised by Stroebe & Schut (1999), which identifies loss and restoration as fundamental components of the experience of grieving, with typical grief oscillating between the two. Loss-oriented grief work was to be carried out in the person's home, and restoration-oriented work in the day environment.

Staff and family carers who had agreed to participate in the integrated intervention also received a 2-day training, this time focusing on bereavement issues, and the therapeutic intervention they were to deliver. Two carers were identified for each participant, one to support the person at home, and the other in their day environment. The family member or paid carer supporting the individual at home was asked to introduce some loss-oriented activities to remember the deceased person, such as looking at photographs, or visiting the grave. Day-centre staff were asked to engage in restorative and forward looking activities, and to discourage any continuing expressions of grief while at the centre. The two partners in this integrated intervention were given communication books to record their progress and maintain contact with each other. Supervision was available on request from named bereavement counsellors in each area, and advice from the research team was also available.

### The sample

A sample of adults with IDs who had experienced a significant bereavement (e.g. a parent or sibling had died) was drawn from a range of residential and day care facilities in South-west London and from L'Arche residential communities in various parts of the UK. The only exclusion criterion was a diagnosis of dementia or psychosis. For inclusion in the study there was no requirement to demonstrate any partic-

ular level of distress or disturbance. This was because previous research found that 72% of carers failed to associate behavioural symptomology with grief (Holins & Esterhuyzen 1997), tending instead to attribute it to the ID itself. In addition, this earlier study and its follow-up 5 years later (Bonell-Pascual *et al.* 1999), showed that atypical and prolonged grief was so commonplace that the researchers anticipated that bereaved individuals would demonstrate high scores on the standardized measures.

The decision not to use a control group was based on the outcomes of Bonell-Pascual *et al.*'s study of 50 parentally bereaved adults, using the same instruments, which followed up people without any therapeutic intervention for 7 years, and found no improvement in mental health or behaviour in the group as a whole (Bonell-Pascual *et al.* 1999).

#### Randomization

Cluster randomization was used to allocate residential units to one or other of the two interventions (this was because more than one person was referred from some residential units, and it would not be possible to offer different interventions to people in the same household). Subjects identified through day centres in south-west London were individually randomized, both using sealed allocations. The allocation sequence was generated by the research team, with an independent observer present to verify that allocation was indeed concealed. Because of the nature of the interventions, it was not possible for participants or those administering the interventions to be blind to the group to which they had been randomized.

#### Consent

A consent package, which explained the research in an easy-to-read and understand form, was developed and trialled with the help of a co-researcher with IDs who had been involved in the project since the earliest design stages. The package was given to carers to work through with potential participants.

#### Quantitative measures

Two informant-based outcome measures, the Aberrant Behavior Checklist – Community (ABC-C) and the Health of the Nation Outcome Scales for People

with Learning Disabilities (HoNOS-LD), both validated for use in the ID population, were administered by the researcher (SD) before and after the interventions. The informants were staff and family carers (who also carried out the integrated intervention). The ABC-C (Aman *et al.* 1995) comprises five scales: (1) Irritability, Agitation, Crying. (2) Lethargy, Social withdrawal. (3) Stereotypic behaviour, (4) Hyperactivity, Non-compliance, and (5) Inappropriate speech. The ABC-C has been shown to be a useful measure of change after an intervention at all levels of disability (Aman *et al.* 1995). The HoNOS-LD (Wing *et al.* 1998; Ashok *et al.* 2002), developed by the Royal College of Psychiatrists, identifies changes in behaviour over time, or before and after an intervention. These two measures were chosen to test the hypothesis that changes in participants' mental health and behaviour would be demonstrable.

#### Qualitative data

Semi-structured interviews were conducted separately with participants, and with their parents/carers, before and after the intervention. Information collected included details of the participant's bereavement history, the degree of their involvement in the rituals of mourning at the time of the death(s) and their responses to the loss. Participant observation was undertaken at intervals throughout the study, with the researcher spending periods of time (with overnight stays of several days) in each of the research locations. Observations were recorded in detailed field notes.

#### Analysis

The relationships between subjects' HoNOS-LD scores and ABC-C scores were stratified according to treatment group. Within each treatment group pre- and post-intervention comparisons were made using the Wilcoxon Signed Rank Test in the case of the ABC-C and Paired *T*-tests for the HoNOS-LD. An independent samples *t*-test was used to compare the magnitude of change between the pre- and post-intervention scores for both standardized measures, between the counselling group and the integrated intervention group, in an 'intention to treat' analysis. All quantitative analysis was carried out using SPSS v10 for Windows.

Qualitative data derived from questionnaires was coded nominatively and entered into a database thus facilitating comparisons between and within cases. Interviews were transcribed and coded with the analysis based on grounded theory carried out in conjunction with field notes.

## Results

Many service providers were reluctant to identify or refer bereaved people to the study, with anxiety being expressed about raising such sensitive subjects with people with IDs. Fifty-six people were eventually recruited who consented to participate in the study. Figure 1 and Table 1 show the demography of this sample.

Thirty-two participants were randomized to the counselling intervention, of whom seven did not meet inclusion criteria. Of the remaining 25, 15 were randomized by cluster (2 sites) and 10 individually. Twenty-four were randomized to the integrated intervention. Two of these did not meet the inclusion criteria. Data was available for the 11 who attempted the intervention, and the analysis was conducted on an 'intention to treat' basis.

The relatively small numbers in the study did not allow factors such as time since bereavement, the nature of the loss, the degree of ID, age and gender, to be examined. However, Table 1 shows the two groups were well matched on all these criteria.

The most common bereavement experienced was the loss of a parent. Time since the death ranged from 1 to 30 years, with just over 60% of deaths occurring in the last 6 years. The decision to include less recent bereavements is justified by the evidence that many people with IDs experience prolonged grief following a death (e.g. Bonell-Pascual *et al.* 1999).

## Quantitative material

Contrary to the initial hypothesis group comparisons of the ABC-C found significantly improved outcomes for the counselling group following the intervention, and no improvement or a deterioration in scores for the integrated intervention group (Table 2). Those responsible for the integrated intervention were unable to complete the intervention for a mixture of practical and emotional reasons.

Findings for the HoNOS-LD (Table 3) for the counselling intervention showed a significant improvement in post-intervention scores, but the integrated intervention group showed no significant change.

Table 4 shows that the counselling intervention resulted in a significantly greater change than the integrated intervention, as measured by both the ABC-C and the HoNOS-LD, in all measures except inappropriate speech.

## Qualitative data

The detailed qualitative material was chosen and written up for this report before checking the individual HoNOS and ABC scores for each of the individuals quoted. Subsequently, when the scores were checked, the qualitative material was found to fully endorse the findings derived from the quantitative data for each individual, providing fuller understanding of the successes and difficulties evident in the two interventions.

### *The counselling intervention*

*Responses among participants.* Changes among participants varied in degree, being mainly positive and found to be directly related to problems that had been identified by carers and participants themselves

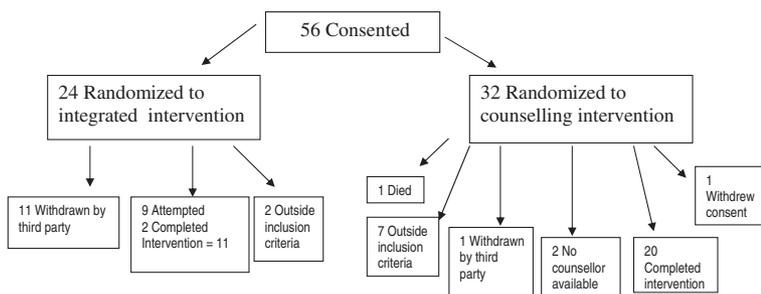


Figure 1 Demography of the sample

Table 1 Demography of the sample

	Gender		Age (year)					Degree of learning disability			Where living		Time since bereavement (year)						
	Male	Female	<30	30-40	41-50	51-60	>60	Mild	Moderate	Severe	L'Arche	residential	Home/	≤1	2-6	7-10	11-15	>15	
	N	N																	
<i>Counselling intervention (n = 32)</i>																			
Did not meet inclusion criteria*	7	5	2	2	1	1	3				7								
Withdrawn by self	1	1			1							1				1			
Withdrawn by third party	1	1		1								1							
Died	1	1		1							1				1				
No counsellor available	2	1	1	1		1			1		2				1				1
Attempted intervention but did not complete	0																		
Completed intervention	20	10	10	2	5	8	4	1	5	10	13	7		2	11	2	1	4	
Outcome data (HONOS/ABC) available	23	11	12	3	6	9	4	1	6	11	15	8		2	12	3	1	5	
<i>Integrated intervention (n = 24)</i>																			
Did not meet inclusion criteria*	2	2				2					1	1							
Withdrawn by self	0																		
Withdrawn by third party*	11	8	3	2	6				1		6	5				1			
No counsellor available	0																		
Attempted intervention but did not complete	9	1	8	1	6	2		1	7		3	6			5	2	1	1	
Completed intervention	2	1	1		2				1		1	1					1		
Outcome data (HONOS/ABC) available	11	3	8	2	7	2		2	7		4	7		1	6	1	2	1	

ABC, Aberrant Behavior Checklist; HoNOS-LD, Health of the Nation Outcome Scales for People with Learning Disabilities.

\*Missing demographic data for some of these clients.

Table 2 Summary of pre- and post-intervention scores and *P*-values for the Aberrant Behavior Checklist (ABC) for the counselling intervention and integrated intervention

	Counselling intervention				Integrated intervention			
	Pre-intervention Median (min, max)	Post-intervention Median (min, max)	Wilcoxon Signed Rank Test, z	<i>P</i>	Pre-intervention Median (min, max)	Post-intervention Median (min, max)	Wilcoxon Signed Rank Test, z	<i>P</i>
ABC irritability	14 (1, 36)	6 (1, 37)	-3.8	<0.001	18.5 (7, 29)	17 (5, 40)	-1.2	0.235
ABC lethargy	9 (1, 29)	5 (0, 19)	-3.3	0.001	9.5 (1, 24)	12 (4, 24)	-1.3	0.182
ABC stereotypy	3 (0, 10)	1 (0, 6)	-2.8	0.005	2 (0, 7)	1.5 (0, 15)	-0.4	0.684
ABC hyperactivity	12 (1, 34)	6 (1, 29)	-3.4	0.001	12.5 (3, 24)	11.5 (5, 24)	-0.4	0.721
ABC inappropriate speech	3 (0, 11)	2 (0, 32)	-2.1	0.039	4 (0, 11)	3.5 (0, 11)	-0.7	0.509

in pre-intervention interviews. Such problems included angry behaviour, isolating and withdrawn behaviour and reluctance to talk about the person who had died.

For example Jack had found it almost impossible to talk about his memories of loss and the events surrounding the day on which his mother was buried, although this had taken place over 30 years ago. His family had not discussed the funeral with him and he had been held back in his grandmother's house while his father and brothers left to attend it. His mother had not been mentioned again. This made Jack angry: 'Angry, that's how I felt, if you want to know, angry, angry, angry'. Before the counselling intervention, Jack could not bear the subject of his mother's death being brought up, he simply repeated 'I don't want to talk about it' and put his hands over his ears as if to block out the words.

Things changed remarkably for him after the intervention, and he is now able to talk freely about his mother, about what happened and how it had made him feel. He is much less distressed, and has a greater degree of self-assurance, which has led to improvements in his personal relationships and daily interactions with others. The reports by his counsellors and his paid carers were supported by the changes in his ABC-C scores, which reduced from 76 before the intervention to 52 after it, and his HoNOS-LD scores, which reduced from 28 before the intervention to 13 after counselling. These changes are in a positive direction.

Carers usually perceived behavioural reactions to loss as features of an individual's ID, although they did associate withdrawn behaviour with bereavement. However, following counselling carers noted that anxiety or irritability provoked by being in groups of people had lessened, and some people had developed better strategies for communicating their feelings. The consequences of these changes for individuals were very positive. For some their increased sociability led to the growth of new friendships and others had been able to develop new interests. One woman, for example, who had often expressed her feelings through anger, changed after she received counselling, as one carer describes:

I had thought of her as an 'angry person', we were wary of her, she used to be fiery at times. She is really different now, I am surprised to be saying

**Table 3** Summary of Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) scores for the two interventions

	Pre-intervention score (SD)	Post-intervention score (SD)	Mean difference	95% confidence interval
Counselling intervention	23.1 (6.02)	15.7 (7.44)	7.43	4.23–10.63
Integrated intervention	23.2 (7.11)	22.8 (7.66)	0.4	–3.84–0.467

**Table 4** Comparison of the change in pre- and post-intervention scores, on both standardized assessments (ABC and HoNOS-LD), between the two intervention groups

	Counselling intervention Mean change (SD)	Integrated intervention Mean change (SD)	Difference in change	95% confidence interval	P
ABC irritability	6.1 (4.41)	–0.9 (5.78)	7.1	3.4–10.7	>0.001
A ABC lethargy	5.7 (6.37)	–1.8 (4.52)	7.4	3.1–11.7	0.001
AABC stereotypy	1.5 (2.04)	–0.8 (3.41)	2.3	0.4–4.2	0.020
ABC hyperactivity	6.2 (6.53)	–0.3 (4.49)	6.5	2.1–10.8	0.005
ABC inappropriate speech	–0.1 (5.46)	0.4 (2.11)	–0.5	–3.8–2.9	0.781
HoNOS-LD	7.4 (7.03)	0.4 (6.69)	7.0	1.9–12.1	0.009

ABC, Aberrant Behavior Checklist; HoNOS-LD, Health of the Nation Outcome Scales for People with Learning Disabilities.

this. She is just so much calmer, more easy-going . . . you can have a laugh with her now.

The participant herself says that talking to her counsellor helped her a lot. They made a book together, recording her memories and the things that are most important to her, and she now keeps the book with her all the time and appears to be comforted by it. The counsellor also helped her to re-establish relationships with other members of her family. These positive changes are reflected in this participant's ABC scores (pre = 23; post = 6) and HoNOS-LD scores (pre = 18; post = 7).

Nathan had also been full of anger. He tended to break things when he was angry, often those things that were most important and precious to him. He said he broke them so that he could get them fixed, as though trying to exert some control over what happened around him. Following the intervention a carer reported:

In the past eight or nine months I am only aware of one occasion on which Nathan has broken something, and on that occasion the provocation

was clear, and it is usually something we are able to avoid. He is really a lot calmer and seems to be coping much better. I am sure the counselling has played a big part.

Now that Nathan's life was less often disrupted by anger he could work at things that he said were important to him, such as finding a job or continuing with his college courses. He was less intent on the minutiae of life that had previously caused him stress and provoked angry outbursts. He seemed more focused on the future as well as able to enjoy what was happening in the present. Again these findings are reflected in his ABC scores (pre = 79; post = 42) and HoNOS-LD scores (pre = 34; post = 20).

Another participant had often shown verbally and physically abusive behaviour towards others in his day centre. Staff had found this difficult to cope with, and people tended to try to avoid him. He developed strategies with his counsellor to cope with his feelings when he felt sad or angry, and although he hardly had to make use of them, he was helped by the fact that he knew he had ways to cope with his feelings.

He said that his counsellor had helped him to feel better. People no longer kept away from him and he had started to make friends (ABC scores: pre = 31; post = 7 and HoNOS-LD: pre = 21; post = 7).

These examples typify the remarkable changes experienced by some of the people who had received the counselling intervention. Others experienced less dramatic changes, but nevertheless ones which improved their quality of life and emotional well-being. They had a more optimistic outlook, able to plan new activities or college courses, or had become more settled in their home environments, particularly when moving had been associated with the experience of loss. Others were joining in more willingly with things that were going on around them. Participants talked about their memories without the anxiety that such discussions had previously evoked. It is clear that the relationship with counsellors was of great significance to participants. Not only were they unused to having someone to talk to about their feelings, but it was also a new experience to have someone who was there solely for them.

The issue of confidentiality was vital to participants, both in their relationships with counsellors and in their agreeing to take part in the study. Having control over who had access to information that they divulged, both in counselling sessions and in interviews, was of the utmost importance, and many people checked during interviews to make sure that what they were saying was indeed confidential. This was of particular importance to those participants who revealed that they had had an ambivalent or difficult relationship with the person who had died.

In three instances no clear changes were noted, either qualitatively or quantitatively, after counselling. In one, the participant experienced the death of two close family members during the counselling programme, and the overwhelming feelings of grief made it very difficult for him to engage with his counsellor or to gain any comfort from the counselling process (ABC scores: pre = 34; post = 32, and HoNOS-LD: pre = 21; post = 27). In another case, the participant was taking anticonvulsant medication which appeared to be making her too sleepy to concentrate during the counselling sessions (ABC scores: pre = 31; post = 23, and HoNOS-LD: pre = 15; post = 24). Thirdly, one participant, after six visits from the counsellor, said that although she liked the counsellor, she preferred to stay in her class at the

day centre than talk to her. After many attempts to engage her in counselling, the counsellor eventually accepted her reluctance to become involved as a statement of withdrawal. In her follow-up interview this participant said that she was fine and did not need to talk about her feelings (ABC scores: pre = 77; post = 79, and HoNOS-LD: pre = 30; post = 32).

*Carers' reactions.* Many of the carers were surprised and pleased by the outcomes of the counselling. They had not anticipated such positive reactions among participants, and many recognized that easing the intensity of the pain of loss had led to improvements in mood and behaviour. With regard to one participant, a carer said:

It is much easier to work with him, he will talk to us and join in; he never wanted to before and would always just sit on his own. When he got upset he used to say he would get his dad on us (his father had died some years ago), he hasn't said that for ages. You even get a smile out of him now.

The confidentiality of the counselling relationship received a mixed response from carers. Some fully accepted the confidential nature of counselling whereas others would have liked to have known more about what was said in the sessions, in case the participant was upset or distressed afterwards. In fact, there were no reported instances of such upset happening. Participants were said to look forward to sessions and appeared keen to see the counsellor when they arrived.

Many carers later said that they would now regard this intervention as a useful one for bereaved people with IDs. They considered it to be effective, practical and easy to incorporate into people's usual working day or home life.

*Counsellors' responses.* All counsellors who took part in the study did so on a voluntary basis. They understood the need for support to be available to people with IDs within their services, and were very enthusiastic and committed to the work. However, few of them had met anyone with IDs before, and some did have concerns about how they would cope in this unfamiliar counselling role. Through the training it was possible to reassure them, and to offer strategies in relation to communication and developing a therapeutic relationship with their client. Three themes

recurred in the counsellors' reactions to the experience of counselling someone with IDs. First, many were surprised by just how well the counselling had gone. They had been challenged by the different aspects of the work, particularly in relation to communication, but had found the creative process of devising and trying different ways of communicating with their client to be both personally enriching and professionally rewarding. Second, counsellors were gratified to realize that the work that they did with participants really was making a difference to how they felt and coped with their feelings of loss, and many said they could see the changes in people as the weeks went by. Third, many counsellors said that their experience of working in a counselling situation with someone with IDs had been one of personal change and development. This was often attributed to the relationship that they developed with their client. Many said this was unusually deep and trusting, and they gave the impression that this relationship had touched their lives just as it had that of the participants.

#### *The integrated intervention*

The integrated intervention raised very different issues, and difficulties were apparent from the outset of the study. Eleven participants were withdrawn from the study by a third party when they were randomized to this intervention rather than the counselling intervention. Eleven carers (four parents and seven staff) made their own decision that they did not want to participate in the study, usually giving the well-being of the person with IDs as the reason, despite having been apparently confident earlier about the validity of their consent. It appears that the carers were in fact withdrawing themselves from the study, perhaps because the role requested of them was too demanding, although all, at the recruitment stage of the study, had declared their role to include emotional support.

There were some practical difficulties in carrying out this intervention, including lack of time, insufficient contact between the intervention partners, and new and inexperienced staff. In many cases the intervention appeared to be given a low priority. Carers were often reluctant to reawaken memories of loss among the people they cared for, fearing the potential emotional (and possibly behavioural) repercussions.

Some parents and carers found that their own experiences of loss through death made it difficult for them to offer support to the bereaved people in this study.

Although supervision and support was offered to all carers and counsellors, only two carers in the integrated intervention took this up. The researcher contacted all carers and counsellors on between 4 and 10 occasions during the study to remind them of her availability, and to enquire about progress.

*Participants' reactions.* The integrated intervention was only delivered as designed for two individuals of the 11 who commenced it, and only these two subjects completed the intervention. Those delivering the intervention to the remaining nine subjects in this group made up to four attempts to do so, but subsequently abandoned the work.

For those participants for whom the intervention was aborted, the problems relating to their loss that were evident at the outset of the study were still present at the time of the post-intervention interviews.

Florence, who thought her father had been 'lost', because she misunderstood the euphemistic way in which his death had been described to her, continued to express the same confusion and concern for her 'lost' father:

Me dad is sad, he's worried, he thinks we don't want him, I'll tell him to come home when he sees me next time. He doesn't know me mum's gone, I'll tell him that too. I waited all day on Sunday and he didn't see me.

Florence is still convinced that her father will be coming home again. She rejects any suggestion that he is dead and thus cannot grieve for him. However, because Florence seemed to have come to terms with her mother's death, which had been properly explained to her, her carers decided that she was fine, and that she was no longer grieving for her father either. The decision was taken to stop the intervention. The standardized measures confirmed the qualitative reports that her level of disturbance remained high (ABC scores: pre = 62; post = 64 and HoNOS-LD: pre = 37; post = 37).

Some participants were clearly disappointed by the failure of the intervention, having been promised that they would have some dedicated time with a carer to

talk about their memories and feelings about the person who had died. In some instances the broken promise led to tension in relationships between participants and carers. Frank, for example, found it difficult to control his temper. He had been very keen to get involved in the study and had been looking forward to having someone to talk to about how he felt. There were a couple of early attempts to begin the work but these were soon aborted, primarily because of staff shortages. Frank reacted badly to this, and blamed a member of staff at the day centre:

John said he's gonna talk to me about my mam but he hasn't time. He's busy and he can't talk to me on my own. It makes me too cross, I'm not speaking to John now.

Frank's anger had not dissipated, and was now directed at the person with whom he had previously had a good relationship. This carer had found it hard to make time to work with Frank on a one-to-one basis, and he accepts the fact that Frank is disappointed, but belittles it by suggesting that Frank is just in 'one of his grumps', and would soon 'come round'. His scores (ABC: pre = 78; post = 107, and HoNOS-LD: pre = 18; post = 25) confirm Frank's own perception of his continuing needs.

*Better outcomes following the integrated intervention.*

In only one case was the integrated intervention delivered effectively and successfully, with individual changes similar to those found in the counselling group (ABC scores: pre = 56; post = 20, and HoNOS-LD: pre = 27; post = 11). The success in this particular case may have been influenced by the fact that the two people delivering the intervention were also, coincidentally, bereavement counsellors. A second participant received consistent and structured support from his father, although not from the intervention partner at the day centre. This proved to be of benefit to both father and son, but was not an integrated intervention, and his scores (ABC: pre = 39; post = 37, and HoNOS-LD: pre = 24; post = 16) showed slight improvement.

*Implications of the problems with the integrated intervention.*

No positive change was found among the nine participants who received only a partial and often haphazard attempt at the integrated intervention. On the contrary, in some instances, there

appeared to be an intensification of the problems associated with bereavement.

The problems encountered in the delivery of this intervention suggest that it is not a practical possibility for the support of bereaved people within learning disability services. This is not to say that carers in learning disability services cannot offer any support to bereaved people with learning disabilities, but that this form of structured support appears to be impracticable, and that half-hearted attempts to provide support may make things worse rather than better. In addition to practical obstacles, it is also likely that bereavement support is best delivered by people who have come to terms with their own losses, and have the emotional maturity, confidence and time to commit to providing adequate support to a vulnerable adult.

## Discussion

It is unfortunate that very few registered psychotherapy or counselling training programmes include people with IDs as training 'cases'. The Institute of Psychotherapy and Disability was established in 2001 to promote training and research for this client group, and a Council Report has recently been published by the Royal College of Psychiatrists about the provision of psychological therapies for people with IDs (Royal College of Psychiatrists 2004).

Cruse Bereavement Care, the most significant national bereavement organization in the UK, gave its full support to this project, and a number of their centres now extend their routine support and counselling to people with IDs.

The findings from this study are relevant to primary care based mental health interventions, including counselling, and may be relevant for the training and role of graduate mental health workers (Department of Health 2003). The study also supports the policy direction in the UK towards inclusion of people with IDs within mainstream service provision, with specialist IDs services providing any necessary training and support (Department of Health 2001b).

## Clinical implications

1 Bereavement counselling by trained counsellors can achieve significant improvements in mental

health and behaviour for adults with IDs, regardless of degree of ID or length of time since bereavement.

**2** With relatively little additional training volunteer bereavement counsellors can adapt their skills for use with people with IDs.

**3** The role of psychiatrists, psychologists, psychotherapists or nurses who specialize in ID should include facilitation of bereavement counselling work through referral to bereavement counselling and support services, and the provision of information and training about working with people with IDs, in particular about communication, and the availability of specialist resources.

In conclusion, limitations of the study could be considered to include the wide inclusion criteria, given the sample size. Future studies based on a larger sample could look more closely at possible different presentations and different psychological processes by using narrower criteria. These might include such factors as the time since bereavement, the nature of the loss, the degree of ID, age and gender.

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