Bereavement interventions for people with learning disabilities

'My mother's name was Marjorie'







Sandra Dowling
Researcher

Jane Hubert
Senior Research Fellow

Sheila Hollins
Professor of Psychiatry of Learning Disability

Department of Mental Health, St George's Hospital Medical School, London

Existing research[1] shows that people with learning disabilities experience significantly more emotional difficulties following bereavement than the general population. In response to this, a research study was set up aimed at finding an intervention that could be shown to be beneficial to bereaved people with learning disabilities. This paper reports on the findings, which have important implications for existing bereavement support services.

In January 2000 the Department of Psychiatry of Disability at St George's Hospital Medical School in London, in partnership with L'Arche UK, embarked on a three-year research study which focused on bereavement in the lives of people with learning disabilities. L'Arche is a worldwide organisation providing home and work environments for people with learning disabilities and non-disabled people who live together in a community structure. The study piloted two therapeutic interventions for bereaved people with learning disabilities and assessed their comparative effectiveness and practicability in a variety of settings. The objective was to develop an intervention which could be shown to improve outcomes.

Learning disability includes the presence of a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence), together with a reduced ability to cope independently (impaired social functioning), where these started before adulthood and have a lasting effect on development[2].

BACKGROUND

As little as thirty years ago, people with learning disabilities were thought not to experience the emotions associated with grief following a loss through death. However, the work of practitioners and researchers such as Oswin[3,4], Hollins and Sireling[5] has established that people with learning disabilities experience grief in essentially the same way as anyone else. Moreover, their grief often goes unrecognised or ignored, in part because of the failure of carers to connect behavioural expressions of emotion to grief, but also because some people continue to regard people with learning disabilities as incapable of experiencing grief. Risks to health are increased when loss experiences are not acknowledged or are hidden[6,7,1].

Grief can be prolonged for many people with learning disabilities, with some experiencing severe symptoms of distress and anxiety[1]. Bonell-Pascual *et al* [8] highlighted the fact that many people in this group continue to be excluded from the events surrounding the death of a loved one. They may not be offered the opportunity to go the funeral, visit the grave or to have a memento to help them to grieve and remember the deceased person. They may not even be told that someone has died and therefore have no explanation of their unexpected and unexplained absence.

Harper and Wadsworth[9] proposed a link between an individual's life experiences and their coping ability and strategies. They suggested that inclusion brings opportunities to accumulate knowledge, and that this can offer a route to understanding at times of loss. Not telling people what has happened, excluding them or being inattentive to how they may feel, could hinder the resolution of grief and contribute to the development of complicated grief. Oswin[3] noted that the difficulties experienced by many people with learning disabilities following bereavement may be related to the actions of others around them, which can serve to confuse and compound initial loss with further related

EDITOR'S NOTE

Many people are deterred from carrying out scientific evaluations of bereavement counselling and other forms of support because of the ethical and other difficulties involved. Those that have been carried out have often obtained negative results because they include a large proportion of people who are well-supported by their families and not in need of outside help. The research group at St George's Hospital, London, have already demonstrated the special difficulties which commonly arise when people with learning difficulties suffer a major loss. Clearly these are one group in special need of help. In this paper the researchers go on to compare two very different types of help for these people. They convincingly demonstrate the effectiveness of bereavement support, by carefully selected, trained and supervised volunteers. This kind of help is widely available from Cruse Bereavement Care and similar organisations in the UK and in many hospices and other palliative care units elsewhere. ***CMP***

losses. For instance, she noted that many people with learning disabilities will move house five to six times in the first year following the death of a sole surviving parent. An unplanned and abrupt move from the family home, often on the very day of the parent's death, may be followed by a series of inappropriate and temporary placements before a final permanent home is found. The inevitable complications that such disruption will bring, following a major loss, are obvious.

Bereavement support for people with learning disabilities is available, though it is rare. A few specialist services exist and are described in the literature[10, 11, 12]. However, this study, through evaluating the usefulness, effectiveness and practicability of bereavement interventions for people with learning disabilities, aimed to identify an appropriate intervention that could demonstrably improve outcomes and be easily replicated.

THE STUDY

Bereaved people with any degree of learning disability were referred to this study from four L'Arche communities in the UK and from learning disability services in the London boroughs of Merton and Wandsworth. Parental bereavement was the most common experience of participants, although others were bereaved of siblings or other family members, friends or carers. Length of time since bereavement varied greatly but for the majority it was from two to six years. Each person referred was sent accessible information about the study, prepared in conjunction with a co-researcher with learning disabilities. Everyone who consented to take part was then randomly allocated to one of the two therapeutic interventions.

THE INTERVENTIONS

External bereavement support

This intervention was based on the widely available and commonly used model of bereavement support based on stages and tasks of bereavement (see, for example, Worden[13]) adapted for use with people with learning disabilities. Volunteers were recruited from Cruse Bereavement Care, the UK national bereavement charity, and Merton and Wandsworth Bereavement Services in south west London. These volunteers had already been carefully selected and trained as either bereavement supporters or counsellors, and supervision was available to them through their usual supervisory structure. The volunteers attended a two-day training event, which focused on bereavement in the lives of people with learning disabilities, the practicalities of the intervention and the skills required to work with this group. They were encouraged to use a range of modes of communication[11] and were made aware of the need to recognise grief when expressed through behaviour, especially in people who cannot easily communicate through language.

Integrated support

This intervention was woven into the usual daily lives of participants and was delivered by a team of two people whom they knew well. It was derived from Stroebe and Schut's dual process model of bereavement[14]. This model identifies both loss-orientated work (focusing on emotions) and restoration-orientated work (solving practical problems) as necessary aspects of grieving, and suggests that the bereaved person needs to oscillate between the two.

Parents and care staff were trained in the delivery of this intervention. One member of the duo delivering the intervention was required to focus on issues of loss, grieving and activities associated with remembering. The partner in delivery focused on restoration, taking a forward-looking approach and thinking about plans for the participant's future and reasserting their identity following their loss. The training considered issues of bereavement and grief in general and in relation to people with learning disabilities specifically. It also concentrated on the techniques for delivery of the intervention.

EVALUATION OF THE INTERVENTIONS

Both quantitative and qualitative methods of data collection and analysis were used in the evaluation of these interventions. Changes in the emotional well-being and outlook of participants, before and after the intervention, were observed and assessed focusing on behaviour, skills and outlook. Interviews with both carers and participants with learning disabilities were conducted. Carer interviews also looked at the practicability of the two interventions.

SUMMARY OF FINDINGS

External bereavement support

The findings unambiguously showed that the external bereavement support intervention was effective and practicable in improving outcomes for bereaved people with learning disabilities. One example is given here.

> Daphne looked at me in horror. I had told her that I was interested in talking to people about how they felt after someone they loved had died. She thought I was a disgrace. Daphne evaded all questions about her own bereavement and tutted when I introduced the topic of death generally. After a while we sat together in silence. I didn't know what else to say and was thinking about ending the interview. Then quietly, and as if just speaking to herself, Daphne said, 'My mother's name was Marjorie'.

This was how things went during my first research interview with Daphne, one of the participants in this study. Daphne avoided talking about death and dying at all costs, therefore no-one ever talked to her about the death of her mother two years earlier. However, the staff had recognised that something had changed in Daphne since her mother's death. She was described as being quite a nervous person and someone who would not stand up for herself. She was sometimes bullied a little by two of her housemates and would become subdued and go to her room when this happened. Daphne had not always been like this. She had been lively, outgoing and popular. Daphne received bereavement counselling through her participation in this study. When I went back to see her after her counselling, I found that she responded differently. Though still a little shocked at my interest in death and dying, Daphne was happy to talk about some of her memories of her mother and to show me some photographs of her. Staff said that they were surprised at the change in Daphne since her counselling. They described her as now being quite assertive, and able to reply to bullies in a witty and confident manner. She had been spending much more of her free time in the company of others and was no longer so isolated. They said that they were quite challenged by the 'new Daphne' as now she rarely just went along with what was happening but asked for support to do what she wanted. It had made their job a little more difficult!

The experience of the volunteers

Volunteers reported that they had found their involvement in the study had been enriching. It had confirmed their hopes that people with learning disabilities could successfully be included in generic counselling and support services. Adjustments to their usual practice, primarily a broadening of communicative techniques and a flexibility in duration of sessions (often shorter than the standard one hour), were acceptable and were thought to help the development of a therapeutic relationship. Many volunteers said that they would be willing to continue to offer counselling and support to bereaved people with

learning disabilities as part of their routine practice. One volunteer reported:

> Counselling someone with a learning disability is really just like counselling anyone else. They have the same feelings and the same worries and they need someone to help them through. I was apprehensive before I started to see my client. I didn't know what to expect.
>
> I began with 'Getting to know you' sessions. We spent a lot of time getting to know one another; we used drawings and photographs and took our time. I started to get a picture of my client's family life and how she saw herself in relation to the rest of her family. This turned out to be very important in what had happened around the time of her bereavement and how she felt about what happened. This time spent at the beginning was vital: it was the foundation of all our later work. It gave me some confidence to communicate using images instead of words and to realise that they can work. My client was far more skilled in communicating without words than I was. I learnt a lot from her about that.
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> My client held on to a lot of anger about things that had happened to her in the past. We were really able to work with that. We talked about it and she described in words and pictures how she felt and what it was that made her feel angry. We developed ways for her to deal with how she felt and I think this really helped. People who work with her told me that things had started to get much better and she did seem to me to be much calmer.
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> It was really worthwhile. I enjoyed working with this client. I saw that it made a difference and at the same time my own preconceptions about what it is to have a learning disability changed completely. I would definitely be happy to work with a client with learning disabilities again.

Integrated support

Significant difficulties were experienced in the delivery of the integrated intervention. In social service locations carers reported problems finding time to devote to one-to-one bereavement work. Staff regarded it as their role to support people with practical tasks rather than emotional problems. In L'Arche, no difficulties regarding time to work with bereaved people was reported, but the work was given low priority. In both settings many said that their partner in delivery of the intervention had not prioritised the work or had failed to maintain contact with them. In many instances both people involved in delivering the intervention blamed the other for the fact that the work was not carried out. In some cases, contrary to what was stated at the outset of the study, participants were said not to be grieving, and therefore not in need of any bereavement support. This was not borne out in follow-up interviews with the bereaved people themselves.

Carers also expressed concerns about trying to do this kind of work with participants. They were uncertain of their ability to support people in coping with the emotions that might be aroused. Many said they thought it better to maintain the status quo rather than to disrupt people's emotional states through working with grief. Commonly, people also said that they were reminded of personal losses, and that made it harder for them to do this kind of work.

Most of those in the integrated group were found to have similar behavioural difficulties or depressed outlook in follow-up interviews as at the outset of the study. In the light of the study findings, the research team has recommended to service managers that these participants are offered bereavement counselling or support from an external agency.

The difficulties with the integrated intervention were not related to the model used but to problems of delivery, both in terms of practical obstacles and the confidence of staff in working with people on emotional matters. The authors regard it as an unviable intervention because of these impracticalities of delivery.

IMPLICATIONS OF THE STUDY

- Outcomes following bereavement amongst people with learning disabilities could be significantly improved if bereavement counselling and support were routinely available to them.
- Bereavement services should consider including people with learning disabilities within their regular client group and develop support and training for their volunteers to facilitate this.
- The need for extra support for bereaved people with learning disabilities often goes unrecognised. It is important that carers become skilled in interpreting individual expressions of grief, and make appropriate and early referrals to bereavement counselling and support services.
- The value of the day-to-day emotional support that staff can give should be recognised and further developed by service managers but should not replace support by fully trained bereavement workers. BC

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EVENTS IN 2003

Road to recovery: helping families affected by road crashes. BrakeCare conference. Keynote speaker: Lord Falconer. 17 September. Birmingham, UK. Further details from Abi Heath ☎ 01484 559909; aheath@brake.org.uk

Psychosocial aspects of bereavement associated with old age. 2 September. **Understanding disenfranchised grief. Seminars. 31 October. Clayton, Australia. Contact the Centre for Grief Education ☎ +03 9545 6377; info@grief.org.au**

Loss, grief and bereavement. 3, 4 September; Edinburgh. 5, 6 November; Inverness. **Supporting bereaved families. 26 August; Edinburgh. 4 September; Glasgow. UK training events. Details from Marie Curie Cancer Care ☎ 0131 456 3711; educationscotland@mariecurie.org.uk**

Rites of life: exploring the power of ritual. 1 December. Oxford, UK. Workshop. Contact Sir Michael Sobell House ☎ 01865 225886; ssc@orh.nhs.uk