Death and people with learning disabilities:

Interventions to support clients and carers (part 2)

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SUPPORT IN BEREAVEMENT

People with learning disabilities may be denied any time or privacy to grieve[1,2]. Families and carers may be uncertain how to help even when their grief is recognised. Many current interventions follow the work of Worden[3] who describes tasks of 'grief work' based on Bowlby's attachment theory or Mawson, Marks, Ramm & Stern[4] who used guided mourning and view pathological grief as phobic avoidance. There are several studies which suggest ways of supporting bereaved clients with learning disabilities.

Individual support

Some clients may be helped by making up a personal album about their relationship with the dead person which could incorporate photos, drawings or illustrations chosen from magazines. A piece of familiar clothing may have comforting associations of touch and smell[5].

Kitching[6] describes the use of guided mourning.

> A client had moved to a large institution when her mother became terminally ill. She was told of the death but did not attend the funeral. The nurse who told her reported that 'she had taken it well', that is without crying, and doubted if she understood. In the following weeks, she became apathetic. Ten months later, she was weepy and anxious and would ask staff if they were going to leave her. She also had some uncharacteristic episodes of aggression. The psychologist encouraged her to express both her positive and negative feelings about her mother. She was able to express her anger and review painful memories. This work was complemented by sessions with the art and drama department. Relatives accompanied her on a visit to the hospital where her mother had died and to the cemetery.

Kitching concludes that this intervention appeared to help the client.

The varied reaction of two people following the death of their friend, Philip, was described by Thurm[7].

> One cried openly, expressed feeling of confusion and had difficulty with tasks she had previously done well. She took part in the funeral and attended the cemetery. She used opportunities with staff to express her feelings and tried to understand more fully the implications of death. 'She wanted to know if Philip could still see her or if he were still feeling pain.' Philip's room-mate also mourned his friend. He dreamed of him and had a strong sense of his presence. He became socially withdrawn and depressed. Both were offered the opportunity to view the body but declined. His girlfriend subsequently regretted this but his room-mate did not.

There is evidence that while few people regret viewing the body, many of those who do not view eventually regret the missed opportunity[8,9]. This decision should be made individually and people may need sensitive assistance to make an informed decision[10].

There is no report of a therapist using the client's understanding of Kane's components of the death concept in a clinical setting. Assessing a client's understanding of these could provide useful information when planning a treatment intervention[11].

Mansdorf & Ben-David[12] used a behavioural and cognitive intervention with an adolescent who had aggressive outbursts following the death of his brother. He was encouraged to verbalise overtly and rehearse appropriate behaviours and cognitions. His positive behaviour was praised by the family who received support for their own grief. The number of aggressive outbursts fell from an average of 30 per week to zero. The involvement of other family members and the support given to them may be important. Earlier work by Black[13] indicated that the mental health of a child following the death of a parent is dependent upon the surviving parent's mental health and the family's acceptance of expressions of grief such as tears.

Cognitive therapy alone was used successfully with a client with mild learning disability who worried about the future death of his elderly parents[14]. He feared that he would be unable to cope with daily life without them. A simplified adaptation of cognitive therapy enabled the client to manage his negative thoughts and become more confident about this.

Group support

Death may become a topic in a group which meets to discuss other issues. The aim of Turner and Graffam's study[15] was to gather data on the dreams of people with learning disabilities and it had no direct therapeutic intent. The group members shared ways they had found of coping with their frightening dreams of death, for example, recounting the names of all living friends. They expressed gratitude to Turner and Graffam for 'curing' them of their unpleasant dreams even though their only intervention had been to listen. A group would provide an opportunity to discuss concerns such as those expressed by Thurm's client[7].

It had been suggested[15] that some people with learning disabilities use magical thinking and are reluctant to talk about the dead for fear of bringing them back. Not all clients fear this. None of the 79 people reported by Bihm and Elliott[16] was reported as being upset by the topic. The authors' comment on this may have reflected the structured nature of the interview which assessed comprehension of death only and did not explore emotional concerns. It is probable that people with learning disabilities find talking about death no less, but no more, difficult than other people. A two-day workshop was held for seven clients who had experienced a major change or loss within the previous year[17]. They do not say how many had experienced a close personal bereavement. The group members 'were already very keen to talk in depth about death and what this meant to them'.

RESOURCES

There are many books written for bereaved people but few for bereaved people with learning disabilities. Hollins & Sireling[18] have produced two short parallel books *When Dad Died* and *When Mum Died*. (The difference in the stories is that one parent is cremated and one is buried.) The books have clear illustrations and large simple text. Each relates the story of a young man, Steve, who is bereaved by the death of a parent following illness. The surviving parent tells the son and daughter who subsequently view the body and attend a funeral service. They are depicted choosing mementos and sharing their memories. The story describes the common emotions of shock, disbelief, anger, sadness, confusion and also loss of appetite. The books could be used to introduce the subject or help someone who had been bereaved understand their own experience.

The resource pack, *When Dad Died*[19] suggests tasks and topics for group discussion. Illustrations from the short books of the same name are available as workcards within the pack. These may be used to prompt people to explore their own experience; for example, there is an illustration of the son looking upset and disbelieving on hearing the news. Another depicts a group of people at a memorial service. This could provide an opportunity to explain why the person may encounter many unfamiliar people at that time such as distant relatives or workmates.

There is a series of three short books about death and people with learning disabilities, *Understanding Death and Dying*[11]. The first illustrated book in the series is for clients. Reactions to loss, death and bereavement are described and illustrated simply. The second book in the series advises families and friend who are supporting a relative or friend with a learning disability who is facing death or bereavement. The third book, for professionals and other carers, discusses the same material in more depth.

A video *The Last Taboo* by Hollins and Sireling[19] depicts various situations; Antony grieves for the loss of a close friend, Melanie recalls her distress at the death of her father and a group of mourners with learning disabilities attend simple memorial ceremony. Some clients would be able to watch and comment on the content. It can be particularly useful for staff who have no experience of people with leaning disabilities.

STRATEGIES TO SUPPORT STAFF

People caring for clients with learning disabilities may form close relationships with them and grieve over their death. Traditionally, their grief was judged as 'unprofessional' and concealed. The impact of a death in an institution was minimised by the discreet and prompt removal of the body and personal possessions. Patterns of care are changing. Clients and carers often live together in small units sharing meals and daily routines. Frequently, carers are young and have not experienced bereavement. This setting makes more personal demands but there are more opportunities to meet them. Carers expect to discuss the death with each other and residents. Both groups may expect to participate in the funeral. Residents, carers and relatives are more likely to plan the funeral and a memorial together.

There are many training courses organised by the health and social services, as well as voluntary agencies such as Cruse Bereavement Care, to help prepare staff working with dying and bereaved people. Unfortunately, there are fewer courses which bring together staff working with terminal illness or bereavement and those working with learning disabilities[20]. Joint training would help carers to benefit from each other's expertise. Some workshops have been part of general staff training about death and bereavement. Others may be held to prepare staff for the anticipated imminent death of an individual. These encourage staff to consider what support they will need to give other clients as well as consider their own needs for support. Training plans need to be flexible. One meeting which was planned to prepare staff for a death within a few months had to be revised when a different client died unexpectedly three hours before the meeting was held. While it may be known that a person's condition will shorten their life, the death may be unexpected when it happens.

The nature of 122 sudden deaths in a large institution over a 28-year period was examined by Simpson, McFarland & Calvert[21]. The causes of death and type of resident affected changed over time. There was an increase in deaths from asphyxia from food bolting or choking during an epileptic fit. There were eight traumatic deaths (defined by Simpson *et al* as death without warning within two hours of collapse). Seven of these were in the latter half of the time period studied. Three were due to road accidents which involved residents with mild mental handicap who were walking unaccompanied to the local town. The authors warn that new policies produce new hazards.

Parkes & Weiss[22] suggest that a sudden death may create more problems for bereaved carers than an anticipated death. It has already been observed that death may cause sadness for professional carers[23] and those caring for someone who dies suddenly may require additional support. Critical Incident Stress Debriefing (CISD)[24] is one model of supporting staff who may have been affected by a traumatic death. This was developed for use with the emergency services but can be adapted to staff working in other situations. It encourages staff to ventilate their feelings and establish a sense of cognitive control over the past events.

An adaptation of CISD was used to support carers in a small group home following the unexpected death of a young resident[25]. The structured group meeting and a follow-up meeting enabled staff to share their shock and anxiety. They were saddened at his untimely death at a time of new opportunities. They lost confidence in themselves as competent and caring people and some expressed the view '...I can't do this job if it happens again'.

There were some specific difficulties. The carer in charge that night felt guilty that she had not detected some noticeable change in his behaviour.

One person experienced intrusive imagery of the dead face and another slept with the light and radio on at night for several weeks. The CISD intervention helped staff to resolve their distress and plan with the residents how they wished to remember the dead man. A flowering bush for their small garden was chosen as a memorial which was poignant in view of their sadness that he was beginning to reveal concealed qualities.

RECOMMENDATIONS

Much pioneering earlier research has weak methodology and has not considered many important variables. Many studies have been limited to examining IQ, age and time spent in an institution. Bereavement outcome in the general population depends on many factors such as gender, social support, the nature of the relationship and the manner of the death[26]. These variables are likely to be important for people with learning disabilities too, although there has been no research to explore this.

The impact of a death on both clients and carers should be acknowledged by service managers and appropriate support given. The nature of the support will depend on the cultural and religious backgrounds of the individuals. There is potential for conflict when a client, relatives, keyworker and supervisor bring different traditions and ideas about the 'right' way to show feelings and express respect for the dead. Few training courses explore these issues but they need to be addressed if sensitive care is to be given[27].

There are complex legal and ethical decisions about treatment at the end of life. Some individuals prepare advanced directives to ensure their wishes about future treatment will be respected in the event of their becoming mentally incapacitated. There is continuing debate about the status of such documents in law. The dilemma is increased when the person has a learning disability. The debate about people with leaning disabilities and informed consent to treatment has focused on contraception and sterilisation. This needs to be extended to decide, for example, in what circumstances a person with a learning disability can refuse life-saving treatment. They may have had few opportunities to make choices about their lives and may find they have few choices in their death.

The difficulties people with learning disabilities may have in communicating pain and other symptoms can have tragic consequences[28]. Non-verbal ways of working with people with multiple handicaps need to be developed further. This would enable carers to understand more readily their physical and emotional needs in illness and death.

In conclusion, there is growing recognition that most, perhaps all, people with learning disabilities have some understanding of loss and many have some understanding of death. They grieve. Effective ways of supporting them in their own death and in grieving for the death of others are being developed. They have yet to be evaluated.

References

1. Oswin M. Am I Allowed To Cry? London: Souvenir Press, 1991.
2. Oswin M. Don't ask us to dance. *Clinical Psychology Forum* 1992; **44,** June, 16-21.
3. Worden W. Grief Counselling and Grief Therapy. London, UK: Tavistock, 1983.
4. Mawson D, Marks IM, Ramm L, Stern RS. Guided mourning for morbid grief; a controlled study. *British Journal of Psychiatry* 1981; **138:** 185-193.
5. Cathcart F. Bereavement and mental handicap. *Bereavement Care* 1991; **10:** 9-11.
6. Kitching N. Helping people with mental handicaps cope with bereavement. *Mental Handicap* 1987; **15:** 60-63.
7. Thurm A. I've lost a good friend. *Nursing Times* 1989; **85:** 66-68.
8. Finlay I, Dallimore D. Your child is dead. *British Medical Journal* 1991; **302:** 1524-1525.
9. Singh B, Raphael B. Postdisaster morbidity of the bereaved: a possible role for preventive psychiatry. *Journal of Nervous and Mental Disease* 1981; **169:** 203-212.
10. Cathcart F. Seeing the body after death. *British Medical Journal* 1988; **297:** 997-998.
11. Cathcart F. Understanding Death and Dying. A series of three booklets for the client, relative and professional carer. Wolverhampton, UK: British Institute of Learning Disabilities 1994. Available from Cruse - Bereavement Care, 126 Sheen Road, Richmond, Surrey TW9 1UR.
12. Mansdorf IJ & Ben-David N. Operant and cognitive intervention to restore effective functioning following a death in a family. *Behaviour Therapy and Experimental Psychiatry* 1986; **17:** 193-196.
13. Black D. Children may benefit from help in mourning. *Modern Medicine;* February, 13.
14. Lindsay W, Howells L, Pitcaithly D. Cognitive therapy for depression with individuals with intellectual disabilities. *British Journal of Medical Psychology* 1993; **66:** 135-141.
15. Turner J, Graffam J. Deceased loved ones in the dreams of mentally retarded adults. *American Journal of Retardation* 1987; **92:** 282-289.
16. Bihm E, Elliott I. Conception of death in mentally retarded persons. *Journal of Psychology* 1982; **3:** 205-210.
17. French J, Kuczaj E. Working through loss and change with people with learning difficulties. *Mental Handicap,* **20**: 108-111.
18. Hollins S, Sireling L. When Dad Died. When Mum Died. Swavesey, Cambridge CB4 5RA: Silent Books, 1989.
19. Hollins S, Sireling L. When Dad Died. A resource workbook published by NFER. Also a video 'The Last Taboo' which is available from St George's Hospital Medical School, London SW17 ORE.
20. Crick L. Facing grief. *Nursing Times* 1988; **84:** July 13, 61-63.
21. Simpson J, McFarland E, Calvert GJ. Sudden deaths of patients in a mental handicap hospital. *Irish Journal of Psychological Medicine* 1990; **7:** 129-131.
22. Parkes CM, Weiss R. Recovery from Bereavement. New York: Basic Books, 1983.
23. Strachan JG. Reactions to bereavement: a study of a group of mentally handicapped hospital residents. *Apex* 1981; **9**: 20-21.
24. Mitchell J. When disaster strikes. *Journal of the Emergency Medical Services* 1983; **8:** 36-39.
25. Cathcart F. Bereavement and people with learning disabilities; interventions to support clients and staff. Paper for Third European Conference of the European Society for Traumatic Stress Studies; Bergen, Norway, 1993.
26. Stroebe W, Stroebe M. Bereavement and Health. Cambridge, UK: Cambridge University Press, 1987.
27. Neuberger J. Caring for Dying People of Difference Faiths. London: Lisa Sainsbury Foundation, Austin Cornish, 1987.
28. Woodward J. Death in care highlights GP difficulties. *Mims Magazine Weekly* 1993; May 4, 32-34.

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Author's comment

*Dr Cathcart wishes to make two comments on the Editor's Note which accompanied Part 1 of this article (*Bereavement Care *1996; 15(2): 7):* 'It is flattering to be described as pioneering this work but it would be wrong for me to accept this. I believe the credit should be given to Maureen Oswin to whom I refer in the article. The second comment concerns the parallel with children. Studies of the concept of death in children are useful in suggesting areas which a counsellor may consider when working with a bereaved person who has a learning disability, for example, causality or irrevocability. I did not wish to imply the person with a learning disability is a child in an adult's body. The parentheses around the phrase "children in adults' bodies" suggest it is a quote from the article but the phrase is not mine.'

LETTER TO THE EDITOR

Dear Editor

Last year in Bradford a woman, whose baby had died in the hospital maternity unit many years previously, discovered from the cemetery administration that it was possible to locate the plot where her baby had been buried. She was so relieved that she made this known through the local press. As a result many other parents, who had assumed that they would never know what had happened to the bodies of their babies, were also able to discover where they had been buried.

A local vicar arranged a commemoration service for these parents and relatives with the help of the bereavement care group of the local authority. As the recently retired hospital chaplain, I was invited to preach and suggested that, if they had not already done so, naming their baby, privately in their hearts, would bring comfort.

The Sister of the neonatal unit of the maternity department also spoke, apologising to all the parents who had not been encouraged to share their grief when their babies had died and explaining that the hospital staff had been not uncaring, but ignorant, of their needs. She described the current, more enlightened practice after a death and many ways in which babies can be remembered, and invited the parents present to allow the hospital to help now if they felt it would be appropriate.

Light refreshments were laid on afterwards so that the 200 or so present might talk to each other, and this was a further help to so many whose grief had been hidden for years.

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