EDITORIAL

The whole world was shocked by the massacre of 16 children in Scotland this March. It seemed barely credible that only a month later another similar slaughter could occur on the other side of the world, in Tasmania. The effects on the community of previous disasters prompted the UK government to commission a report from the Disasters Working Party convened by Cruse Bereavement Care (the Allen Report, HMSO, 1991). This recommended that each district prepare a team, co-ordinated by social services, of trained counsellors and mental health professionals to offer appropriate intervention following a disaster.

A survey of the response to this report showed that only a fraction of districts had read or implemented the recommendations, and even fewer had any plan for responding to psychosocial needs in such an event. *File on Four* researchers (BBC Radio, April 9) found that the result is often chaotic and can bring counselling into disrepute.

Yet we have evidence (see p17) that the high incidence of post-traumatic symptoms in children affected by disasters can be alleviated by brief trauma/grief-focused psychotherapy. In this issue we publish an article on a training programme in child trauma counselling (p17). We hope to report on other innovative programmes which are soundly based on research and should help to allay the concerns expressed recently about the value of counselling.

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HIV infection: systemic family therapy with the bereaved



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HIV disease became a major health problem over a decade ago and there remains no cure. The quality and expectancy of life for those affected is improving but, nonetheless, mortality related to HIV disease continues to challenge medical, nursing and social care practice. Working in the field of HIV has brought into sharp focus the concept of loss and the benefits of using systemic family therapy, an approach which considers the family as a whole, to deal with the range of issues arising for individuals and their close contacts.

EFFECTS OF HIV INFECTION ON BEREAVEMENT

The death of the patient with HIV infection can be the beginning of a new problem. Specific issues related to HIV infection increase this possibility[1].

Death of young people

Many HIV-related deaths are young people, unaccustomed to illness. Death may be more difficult to accept because expected milestones have not been reached, and the natural life cycle of parents dying before children is reversed[2].

Health care workers' reactions to HIV illness and death may be more personal than is the case with some other illnesses. Having a similar age group and background to the majority of their patients makes it more difficult for them to remain neutral and maintain professional boundaries[3].

Same-sex and bisexual couples

The close bonds or 'marriage' between same-sex couples have contributed to a wider definition of family, which

EDITOR'S NOTE

AIDS has been described as the modern plague. It is difficult to remember that it 'became a major health problem' less than 15 years ago. Riva Miller, with her colleague Robert Bor, set up the first counselling service for patients infected with HIV at the Royal Free Hospital where the Ian Charleson Unit offers a comprehensive medical service. Riva had trained as a family therapist and found that the Milan school of family therapy, developed by a team of Italian psychiatrists (Selvini-Palazzoli, Boscolo, Cecchin and Prata) best enabled her to help the families of the patients who were dying or had died of AIDS. Here she illustrates some of the principles on which she bases her work and her useful bibliography will enable those interested to take their understanding further.

Training courses in systemic family therapy are available in several parts of the UK and of the world. In Zimbabwe, from where I have just returned, there is a flourishing family therapy institute and much of their work is with HIV-infected families since the disease is rife in Africa. The WHO has estimated that over half of the population of Zimbabwe is HIV-positive. In many families the children are doubly orphaned and there may be no-one left alive in their family to care for them.

includes that of 'choice' and that of 'origin'[4]. Conflict between these two is not uncommon and this, and other unresolved issues, may come to the fore after the patient's death[5]. Resentments, anger, blame or guilt may also surface at this time, especially if the family of 'origin' unexpectedly finds a will settled in favour of a partner or friend.

Bereaved wives or partners of bisexual men are an isolated, complex group. Confidentiality, infidelity and sexual practice all complicate reactions to death. Children of these relationships may be unaware of the cause of death. Nevertheless, long protracted periods of illness, with declining physical and mental health, inevitably cause stress in these families.

Cultural pressures

Secrecy and social stigma associated with HIV complicate reactions to death and the mourning phase afterwards. Previously undisclosed life-styles may be revealed, such as drug use, homosexuality or bisexuality. Sometimes dilemmas about who should be informed about the diagnosis have not been settled before the patient's death.

The bereaved may be reluctant to disclose the cause of death, inhibiting them from gaining support from their natural network of friends and family. This in turn may mean a heavier reliance on nurses and other health carers. Conversely, in big cities with close homosexual communities, support may be derived from others in similar situations. Secrets about HIV bring some families closer together because of the shared information; for others, it can pull them apart. In families with haemophilia and HIV it is not uncommon for some family members to be informed about the diagnosis whilst others are shielded from open discussion for a variety of reasons[6].

The grieving process of heterosexual men and women may also be complicated by cultural pressures, past infidelities or drug use revealed by HIV.

Infection and other family members

The fear of carers that they have become infected with HIV can interfere with bereavement and coping with the future unless this uncertainty is eliminated by HIV testing.

Reactions to death may be compounded if bereaved sexual partners or children are themselves infected with HIV. Some may gain courage to face their own death through the experience, whilst others may have increased fears about illness and death. Future care of a child with HIV may be more difficult to arrange.

HIV-infected and uninfected children may be orphaned[7]. Although the long period from infection to death could allow for early preparation for assimilation into new families, this does not always happen[8]. Parents may have difficulties in facing their own illness and death, or fear that disclosure of HIV could lead to discrimination and isolation of themselves and the child. Guilt and remorse may also colour judgement.

A common phenomenon is the multiple loss of family members and friends with HIV disease, with little time to recuperate from one loss before another has to be faced[9].

Effects of the long illness

Those infected with HIV can have many symptom-free years before acute and terminal illness[10]. This allows time for family and close contacts who know about the diagnosis to anticipate and, in some measure, prepare for loss[11]. Conversely, life may be kept 'on hold' for family and friends for a long period of time during the symptomatic and terminal stages of HIV. The death of the patient can bring not only grief but relief. Disbelief is a less common grief reaction than is the case with some other illnesses.

Grieving may begin when close contacts become aware of the diagnosis. Losses and adjustments in relationships may occur early on, for example, changes in sexual activity and to roles in partnerships.

A SYSTEMIC APPROACH TO HIV COUNSELLING

Beliefs about loyalty to family members, parent-child relationships, and the influence of sex, marriage and death on relationships and day-to-day life are all accentuated by HIV[12]. So a family systems approach which links information, behaviour, relationships and beliefs, fits well with HIV infection[13]. The bereaved can be helped to articulate such beliefs, their origins and how they might affect responses to loss and the recovery period thereafter[14].

The systemic approach, based on the techniques of the Milan Associates[15], has been adapted to the clinical setting. Guiding principles, aims, defined bereavement counselling tasks, and a 'map' for the session have been developed and underpin practice[16].

The main tenets of this model are that behaviour occurs in a context, that there is a reciprocity in relationships and that relationships are punctuated by beliefs and behaviour. Guiding principles include making no assumptions about the bereaved's concerns, wishes, beliefs or knowledge, and recognising that everything said has an impact.

The counsellor should set small, achievable goals, and share responsibility with the bereaved to avoid creating dependence. Hypothesising, circular questioning and neutrality[2] are used to address beliefs and relationships both within and outside the family; to take into account the disruptions to the expected life stages of patients and their close contacts at different stages of HIV infection; and to create a balance between maintaining hope and being realistic in the face of life-threatening illness[12].

The main aims and tasks in systemic bereavement counselling focus on:

- Enabling the discussion of concerns, or of issues that might need settlement, to help the process of disengagement with the deceased and encourage looking to the future;
- Helping reduce anxiety and reactions to the loss to manageable proportions by identifying and ranking concerns;
- Enabling the bereaved to gain a different perspective on the loss by linking them with individuals and ideas that they might not have previously considered;
- Deciding about the frequency of, and time between, bereavement sessions (seeing the bereaved too frequently may give a message that they cannot manage alone);
- Considering whether the bereaved return for counselling to those connected with the deceased, or whether referral outside the hospital setting is more appropriate (general medical practitioners often have responsibility for other members of the family).

The structure of the counselling session

Having a 'map' or structure for the counselling session helps to ensure that important issues are effectively addressed in the available time.

A hypothesis or calculated guess is made before the start of the session based on information about the deceased and the bereaved – their positions in the 'family', the age, understanding and knowledge about HIV of the bereaved, and the social, religious and cultural contexts. Goals for the session are set with the bereaved. Main concerns of the bereaved and other family members are elicited early in the session and ranked in order of importance or severity for individual family members, enabling the most pressing issues to be addressed.

Questions are asked to test the hypothesis, elicit and impart information, explore beliefs, avoid assumptions and to maintain neutrality. Hypothetical, future-orientated questions ('if' and 'when' questions) are used to address fears, concerns, family members' perceptions of each other, and beliefs about HIV.

'If your son had any concerns about you on his death, what do you think that these might have been?'

Problems are reframed to help people consider their predicament from a different angle while being realistic about the nature of the loss and its effect on relationships.

'You say that you do not think that you could ever get over the death of your son from HIV. Is there anything that you think John might have said about his life that might be of consolation to you now?'

The bereaved are helped to make connections with how they have managed previous losses. At the end, a summary is made of the strengths and difficulties by drawing together what has happened in the session.

A case example

Mr H had severe haemophilia and contracted HIV infection through the treatment. Before becoming terminally ill, Mr H was seen for counselling twice yearly. After he married, his wife, and then his daughter, joined the sessions. At the time of his terminal illness and death, Mr H's extended family also came for counselling, and his wife and daughter, both free from infection, were seen more frequently. A systemic approach was used to engage the family members, help in early preparation for death and to respond to the needs of the child after her father's death.

Mr H's way of dealing with his illness was to disregard it as far as possible: he would confront problems as they occurred and it was very difficult to encourage him to discuss them. When he decided to marry, it was considered necessary to raise issues which would prepare the family for loss. A series of circular questions, which explore people's perceptions of one another, helped to open up the subject of HIV transmission:

'In marrying your wife, if you had any concerns what might they be?

Would her concerns be the same or different?'

'A major concern was that their daughter, if she knew about the HIV and told friends at school, might suffer from being isolated'

After marriage and the birth of his daughter, Mr H resorted to drinking heavily in the evenings, affecting communication with his wife. A working hypothesis was that he was withdrawing into silence and sleep to prepare her for a future alone, and protect himself and his daughter from the closeness of a relationship which he might not be able to continue. However, he did involve S in his interests so that he would not be forgotten, and always agreed to couple and family sessions. Circular questions were used to engage the family and identify problems. A major concern which emerged was that their daughter, if she knew about the HIV and told friends at school, might suffer from being isolated.

Using future-oriented questions helped address many difficult, sensitive issues with Mr and Mrs H, and S.

'If you were to get ill, what might concern you most for yourself, your wife, your daughter and your mother?'

'If your husband were to get very ill and perhaps die, what would be the things that would concern you most?'

'If we are not able to get Daddy better, what would be the things that would be most hard for you?'

During the terminal phase of illness, it was hypothesised that Mr and Mrs H wanted the therapist to help them to talk to each other, and deal with their daughter to protect them from the responsibility and the fear that they might not cope. Mr H became more amenable to discussing his family's problems and drew in the therapist to 'take care' of his wife. Conflicts arose in the extended family, distracting them from the pain of Mr H's impending death. S was protecting herself and her mother and preparing for the future by wanting to be closer to a cousin and out of the hospital.

At this time, and after her father's death, S was seen alone on four occasions, but always some part of the session was with mother present. Mrs H acknowledged that S was very close to her father, and that she and her daughter rarely talked. She herself was very distressed, relying on her daughter for companionship and for help at home. The aim was to identify, using circular questions, what the child understood and what her main concerns and fears might be.

Counsellor: Mrs H, you and S have been up at the hospital all day. What do you think S is thinking about it all?
Mrs. H: She is worried about her father and it is very hard for her to see him like this. She is going to her cousin's tonight.
Counsellor: S, is Mummy right? You are worried about Daddy.
S: (Just stares.)
Counsellor: S, right now what is worrying you most?
S: I don't know.
Counsellor: What do you think is worrying S most?
Mrs H: Her father.
Counsellor: Is Mum right, S? Are you more worried about Mummy or Daddy?
S: Mummy.
Counsellor: Did you know this, Mrs H? What do you think she is worried about?

After Mr H's death, Mrs H was seen monthly for three months and then four monthly. She was insecure about her role as a parent and treated S as an adult, rarely seeing that her dependence on her daughter was placing an added emotional burden on the child.

It was hypothesised that S had always been a 'sister' to her mother. The balance had now changed and she became a 'parental' child, privy to her mother's disturbed thoughts, for example about approaches made to her by other men. A recurring theme of sexual guilt and conflict emerged. S still wanted to protect her mother and both showed signs of grief, but S kept close to her father by following his hobbies and not wanting her mother to find another husband. Mrs H's loyalty to her husband, and her shyness continued to keep her from allowing herself to think of her needs as a woman.

The family were able to hear each other's concerns during family sessions and to talk in a way that they never did at home. S became more settled as her fear of her mother's unhappiness was brought into the open. After Mr H's death Mrs H slowly started moving into independent activities and talking with her daughter, and has found work outside the home. She continues to be faithful to her husband's memory and discussions have taken place about what would have to happen to allow her to think about her own future and possible relationships with other men. Mrs H reports that S has grown more independent, but that she and S have an arrangement that they eat together at night. The loss is still acutely felt by these two, rather separate, individuals and Mrs H continues to come to counselling for reassurance. The latest information is that Mrs H sold the house that Mr H had refused to leave in his lifetime and moved with S to a new home.

CONCLUSIONS

HIV bereavement counselling may start as a discrete phase after death, but more frequently begins from the earliest contact with those close to a person with HIV before the patient dies. Using a family perspective helps this process. Comprehensive care can be offered through the stages of HIV from diagnosis to death by identifying, assessing and addressing the complex repercussions not only for the patients, and their close contacts but those who give the treatment and care[17]. By engaging the wider healthcare team, responsibility is shared[18], training in bereavement counselling skills is integrated into day-to-day practice, and stress on staff is reduced.

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Training in work with traumatised children: a placement at the Traumatic Stress Clinic, London, UK

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The clinic was founded in 1993 under the direction of Dr Dora Black who, in collaboration with colleagues, had accumulated experience of the long-term effects of horrifying events on children when they are not helped to grieve and to process the trauma.

THE WORK OF THE CLINIC

The functions of the clinic extend beyond offering direct help to children and families, through consultation, assessment and treatment, to various research projects, teaching, lecturing, and attending conferences here and abroad. The team now consists of Dr Dora Black, Consultant Child Psychiatrist and Director; Dr Jean Harris Hendriks, Consultant Child Psychiatrist; a family therapist; two clinical psychologists; a child psychotherapist; a research psychologist; and a team secretary. The clinic operates one-and-a-half days a week and all are part-time. Funding is complex and various, but the UK Department of Health has sponsored some staff, as well as the trauma training of Cruse counsellors.

Referrals to the clinic are widespread, from all over the UK. Social workers often accompany clients, to observe and to take part in the interview, as do lawyers acting on behalf of parents, relatives, or children where divided loyalties could emerge in the history-taking. In circumstances so highly charged, such decisions can sometimes feel persecutory to one side or the other.

Appropriate placements for children are often at the heart of the assessment, requiring a review of parenting skills, the preparation of meticulously detailed court reports,

EDITOR'S NOTE

A cohort of Cruse counsellors selected to receive training in trauma child counselling report on their experiences. They are participating in a seeding or cascade programme – training those who in their turn will be the trainers of larger groups, and so on. Such techniques are the best way to disseminate knowledge and skills widely, swiftly and economically, suggests Professor Parry Jones of Glasgow University' who advised the Macedonian Government on helping refugees from former Yugoslavia.

Evidence that children affected by disasters can be helped by such interventions includes findings recently presented by Goenjian et *al* from the Trauma Psychiatry Program at the University of California at Los Angeles, headed by Professor Pynoos. After the 1988 earthquake in Armenia they worked in schools with pre-adolescent survivors, using a matched, untreated control group for comparison. They found that the severity of post-traumatic symptoms increased significantly over the three years following the earthquake in the untreated young people, and decreased significantly in the treated group.

Other school-based programmes have been set up for children affected by civil conflict or war. For example, in Bosnia Professor Yule of the University of London, in partnership with UNICEF, and in Mozambique Dr Richman and colleagues working for Save the Children, devised programmes which target teachers as the main resource for troubled children. The aim is to teach them the appropriate skills for identifying children needing help and to train them in how best to give that help.