Counselling Survivors of AIDS

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In the West many (though not all) of those dying from AIDS are homosexuals and relatively young. The authors are experienced in counselling the families and partners of those bereaved by AIDS, and the publication of this article is timely in view of the continuing rise in the number of AIDS deaths.

Editor

Many theorists and clinicians have provided exemplary discussions of the grief process and effective means of treatment. Perhaps the most well known is Elisabeth Kübler-Ross, who originally described five stages of grief—denial, bargaining, anger, depression, and acceptance. Others have challenged the concreteness of these as stages; they have suggested that the five concepts be viewed as psychological attributes of a bereavement process or an adjustment to a life-threatening disease or to death. Thus, as we interpret the phenomenon of grief in the AIDS epidemic, we will discuss how these five forces have affected the surviving family and lovers.

Family Grief in AIDS

Many families must face a double adjustment in coping with a son who is gay and who also has AIDS. This can create immense conflict and trauma for parents. The level of denial in such families was probably fairly high already if the sexual identity of the son is undisclosed before the diagnosis. Thus, the task of the family therapist includes helping parents to confront the psychological pain caused by the loss of this defence.

In many cases, once these conflicts are resolved, parents can approach their son with more love and support and can stay close throughout the illness, a response which substantially changes the fabric of the relationship, as well as relationships throughout the family.

Any painful event is better dealt with openly. Protracted grief can have a secretive and depressing but special and private aspect, one which usually dissipates when someone else is brought into the grief process.

The Chosen Gay Family

Many men, after leaving the family home, develop a new "chosen family" of significant friends. These friends usually rally to the bedside of the person with AIDS providing social, financial and life management support. In a smooth process after death, this network and the nuclear family can help each other with their grieving. One mother, after having come from the Midwest to her son's community for his memorial service, looked out from the podium at the many faces of his friends and said, "It certainly proves the feeling I've had for years that my son was loved and lovable to be here among his friends and to feel the love and support you have shown me this week."

In some cases, families do not cross these boundaries, creating ritual and personal grief processes that exclude friends of the gay man. Whereas this may honour the philosophical or spiritual needs of the family, it can also be alienating.

If the family does not recognise the viability of their gay son's lifestyle or the rights of his chosen partner to grief and to decisions regarding the estate, conflict can result. The situation is often extremely volatile, given the stress of all involved as well as the emotional and financial stakes. It may be necessary at this time for a therapist to mediate conflicts and, if alleviating confrontation, smooth the transition process and cushion feelings of anger and guilt in the family.

Like war, AIDS takes young people from their families. One mother confided, "It's not supposed to happen this way; he was supposed to bury me!" Becoming closer to a dying son may awaken a parent's own reaction to the approach of death. If helped by the compassionate clinician to integrate the experience, there is a profound wisdom to be learned by families who do suffer this loss.

Counselling Bereaved Lovers

When two people who love each other are separated by the death of one, the survivor normally confronts confusing thoughts and feelings that ebb and flow without apparent predictability. Certainly there is grief, one of life's more profound emotional experiences, but also celebration and solace that the dying is over. Characteristically, loneliness, memories, and heartache abound. It is a time of transition, when survivors reassess their beliefs and relationships to the rest of the world. During this time survivors often feel tearful, angry at the least provocation, misunderstood by those who have not also suffered loss, and even guilty for no good reason.

Many survivors of lovers who died from AIDS are young people who have never before experienced mortal loss, making their pain all the more confusing. It is not uncommon to hear the bereaved say, "I am going crazy." The clinician can offer simple validation of the bizarre nature of his client's experience with the reassurance that, yes, it is an enormous tragedy to lose a loved one to AIDS.

During clinical work with six surviving male lovers of men who died from AIDS, common characteristics were found that may be helpful to a clinician approaching treatment of bereavement in gay men.

First, these men were experiencing bereavement in a community which is itself becoming expert in the stages of bereavement, including denial. Each man seen for counselling complained that his friends were getting tired of hearing him talk about his lover. All of them described pressure from their associates to conduct their grief in various appropriate fashions.

At the beginning of therapy with these men, it was necessary to encourage them to use however much time they needed to talk about, think about, have erotic fantasies about, or cry about the loss of their loves, exclusive of any schedule. This permission alone seemed to help the process, because it counteracted whatever need the gay man's friends may

have had to bury the process of bereavement soon after the funeral.

After the death, the lovers became much more aware of their own possible susceptibility to AIDS, a fear of contagion that they suspended in order to remain close to their dying friends. Moreover, they were acutely aware of what AIDS looks like and were quite fearful of getting it from or giving it to anyone else. Consequently, sexual repression and anxiety attacks about contagion occurred in the men treated.

The survivor often felt stigmatised by his association with the victim. On becoming aware that he was seropositive with the AIDS antibody, one man expressed guilt that he had possibly transmitted AIDS to his lover. Simple extensions of understanding and compassion appeared to help soften feelings of alienation and to help lessen the person's horror of his own contagiousness. Since the disease required exhausting schedules before their lovers' death, these men have been too busy to worry about dating and safe sex. They may need good advice at this time with reassurances that they are capable of being close to men physically without exposure to or transmission of the AIDS virus.

In this instance, denial may lend some saving grace. Among the men in this small sample, those who denied casuality between their lovers' illness and their own susceptibility to AIDS adapted more quickly. They were more likely to become engaged in new relationships and less likely to have fears about contamination, even while being cautious about transmission.

In this population, research results that link bereavement and depression to suppression of immune function are particularly relevant. For the therapist, the question arises of how much depression and dysphoria should be encouraged as clients work through feelings about their lovers' death. This is a dynamic question that usually must be related to each individual's coping style and personality factors. Fortunately, it is most often answered by the clients themselves as they move naturally between the constituent phases of denial and acceptance.

Those who were primarily responsible for the day to day care of their lovers had a much more difficult time emotionally afterwards, particularly if they had conflicts with their lovers' families about the care. These men were caught in a stance of protective vigilance at the moment of their lovers' death, a tension-filled position which made relaxation very difficult.

A rigid idealisation of the dead lover can occur, making new boyfriends unwelcome. At the same time that our bereaved patients longed for the closeness and support they gave to their dying partners, they also compared anyone who approaches to the idealised image of their partners. This tendency only served to heighten their loneliness. In the last stages of his life, the person with AIDS and his lover return to a stage where romance is extremely high and ego boundaries are loose. Problems arise when the lover dies during this stage and leaves behind a fiercely devoted widower.

As most relationships progress, a working balance of autonomy and dependence is negotiated and maintained. Because of the inordinate dependency of those suffering from terminal AIDS, the youthfulness of the men it attacks, and the untimely interruption to intimacy that a lover's death brings, those who are left behind have sacrificed their autonomy but later need to regain it. Unlike a relationship which ends because of incompatibility, here it is difficult to mobilise anger at the departed partner as a means of resecuring one's sense of well-being and rightness. In the special instance of bereavement, a therapist can help the partner finish the dialogue of the relationship and prepare to move on.

Finally, those who got involved with volunteer activity in an AIDS organisation recovered more quickly after their lovers had died. Some reported that they found within these groups other men who had similar stories to tell. Since the loss of friends and lovers to AIDS has increasingly become a community-wide occurrence, a great deal of wisdom and support is available alongside the great amount of pain the community experiences.

This article is based on a paper presented at the AIDS and Mental Health: Policy Administration, Treatment conference held at the University of California, San Francisco, 13th-14th September, 1985.

BOOK REVIEWS

BASIC COUNSELLING SKILLS
Lyn Franchino, 1987. Cruse, 126 Sheen Road, Richmond, Surrey TW9 1UR. £25 + £1.50 p&p.

The content of Lyn Franchino's 'Basic Counselling Skills—a Training Manual for Bereavement Counsellors' is very similar to the content of the first module of the skills training offered to Marriage Guidance counsellors. This is hardly surprising since both draw heavily upon the work of Robert Carkhuff and Gerard Egan, those pioneers of counselling skills training.

I thought that the manual was excellent. It describes clearly the skills to be taught, it offers a brief, explicit rationale for their use by counsellors and it grounds the acquisition of each new skill very firmly in practice and repeated practice.

I liked the clear instructions to trainers at each new development and also the way in which trainers are urged to summarise what has been aimed for in each session, and to check back with the trainees that they understand and are able to use the skills taught.

This repeated checking out with the consumer is further enhanced by the use of handouts which act as a resumé of the material presented and the exercises used in each session.

Throughout the manual the focus of the practice sessions is kept firmly on the issue of bereavement and the role play scenarios and exercises are cleverly targeted on those aspects of loss and change with which the bereaved person has to wrestle.

The specific skills are clearly and straightforwardly described and examples of their use are offered frequently. I found myself uncomfortable with one of the sample responses used to illustrate immediacy, where it seemed to me that an important client nuance had not been responded to, but that is a minor criticism of an excellent manual.

As a final comment, counselling skills are tremendously useful in training volunteer counsellors but if the trainees are to develop beyond being merely skilful these skills need to be offered in relation to a model of the counselling process.

The Three Stage Model of Robert Carkhuff or the Four Stage Model of Gerard Egan would, if offered at the outset of this manual, anchor the very good skills content and drive home the fact that skills are to be viewed as re-cyclable and re-usable at each stage of the counselling process.

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GOOD GRIEF
Talking and Learning about Loss and Death. A Schools' Pack. Barbara Ward and Jamie Houghton, in association with Cruse—Bereavement Care. London: Good Grief Associates, 1987. £15 + £1.50 p&p. Available from Cruse, 126 Sheen Road, Richmond, Surrey TW9 1UR.

Having worked with the local branch of Cruse for the past 13 years, it is all too easy to forget the naïvety and anxiety with which I initially approached the topic of bereavement. My own understanding has been broadened and deepened through the privilege of contact with bereaved people in a variety of settings, including face-to-face counselling and leading a parents' circle for the past seven years. Consequently, it is with a tremor of concern that

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