

# Women and children living with HIV infection

## Some psychological concerns

*Diane Melvin and Lorraine Sherr*

HIV infection is a relatively new disease affecting families (Pizzo & Wilfert, 1994). As with other chronic and life-threatening illnesses, families are faced with many changes and losses as well as much uncertainty about the future (Eiser, 1990). Unlike most other conditions, however, there can be extra stigma-related stresses, such as fear and secrecy, which can compound existing burdens of illness and coping (Richmond & Ross, 1995). As further knowledge of the full impact on HIV on families evolves, there is a need to consider the effects of multiple loss and changes on the mental health and adjustment of the children as well as their parents (Melvin & Sherr, 1995; Reidy, 1995).

Depression, grief, suicidal thoughts and attempts are commonly reported in studies of adults with HIV infection (Catalan, 1990; Perry *et al.*, 1990; Dean, 1995; Sherr, 1995). However, these studies have generally concentrated on populations of gay men or drug-using adults (Pugh, 1995). Less has been documented about the impact on the mental health of women and children, but it seems likely that there may be equally serious consequences (Pizzo & Wilfert, 1994). Psychological effects on other family members and contacts may be profound and long-term and compounded by the stigmatism, blame and secrecy which still surrounds HIV (Draimin, 1993; Richmond & Ross, 1995).

### Findings from a London clinic

A case note review was carried out retrospectively of the first 72 families seen by a psychologist

attached to a paediatric HIV service in London during 1992–94. The cohort included only those children exposed to the risk of HIV through vertical transmission. All families had been seen on several occasions over time (ranging from three months to two years). Data collected included family structure, parental illness, number of family deaths, evidence of suicidal ideas and referral for depression or changes in functioning. There had been no systematic collection of measures of depression or other psychological states in this population. A few cases were recorded in detail to elaborate crisis times and care issues. Background information on the parents in the 72 families is shown in Table 1.

The incidence of previous intravenous (IV) drug use was about 10–12% in this population, with only three of the women known to be using drugs at the time of engagement with this paediatric service. Data were not so readily available on the fathers, but rates were estimated to be no higher than for the women. Drug use, past or present, was not an issue for any of the African parents. Sexual intercourse was the likely source of HIV infection for most of these parents, even if there had been known drug use.

Over 75% of the parents originated from countries other than the UK, many from African countries. For many of these there were additional issues to do with people living out of culture and isolated from personal support networks. Some families had experienced traumatic life events in their past. In particular, for eight (11%) families, one or both parents had witnessed

Table 1. HIV status and demographic data for parents in sample

	<i>n</i>	HIV status			Single parent	Country of origin		
		Tested positive	Tested negative	Untested/unavailable		UK	African	Other
Mothers	63	63	–	–	29	10	46	7
Fathers	39	15	16	8	5	13	18	8
Total	102	78	16	8	34 (33%)	23 (22%)	64 (63%)	15 (15%)

killings, torture or rape resulting from war or conflicts in their country of origin. Many families also faced considerable ongoing practical, financial and social problems (Melvin & Sherr, 1995). Severe relationship conflicts were frequently reported and in nine cases led to complete separation.

One hundred and thirty-five children resided in these 72 families; 39.3% were HIV-positive, 34.8% were HIV-negative and 25.9% were indeterminate at the time of this study (the majority of this latter group were found to be HIV-negative at later follow-up). The HIV status of a baby born to a positive woman can be unclear for many months if antibody testing is used, since maternal antibodies remain in the baby's system for up to 18 months. Testing for the presence of the virus rather than antibodies is now becoming more widely available and reduces the period of uncertainty to about six months.

There were noted concerns about parenting and childcare issues in a few of these families resulting in the involvement of the children and families social work departments of the social services. Only one of the children, an affected child, was on the child protection register because of concerns about neglect and emotional abuse. This was a child of a single, unsupported, IV drug-using mother.

Deaths and mental health events occurring in these families were collated and are shown in Table 2. This shows that over half the families (57%) have experienced a parental or child death within the core family. An emerging factor of concern is the small but growing group of families (nearly one in ten) who have experienced more than one death. Although there were no suicides recorded in this small cohort, there were four self-harming episodes (all women), and another three parents expressed suicidal ideation of a magnitude to trigger referral to a mental

health agency. For one in five families there was a parent whose depressive episodes triggered referral for psychological support. Seven of the 11 women who experienced serious depressive episodes were single parents. A few of the parents had some signs suggestive of the presence of some central nervous system (CNS) disease, but none of those alive had an AIDS dementia diagnosis. In the parents who had died, over a third were noted to have had severe neurological problems in the terminal stages of their lives.

One of the infected children had been referred to a psychiatric service because of depression, and one of the 47 affected children was known to have been referred to outside agencies because of an adjustment problem associated with the presence of family illness. None of the school-aged children, whether they were infected or not, had been referred for extra help because of concerns at school. However, many of these children, whatever their HIV status, had been seen by the clinical psychologist attached to the paediatric HIV service. This was sometimes because of parental concerns over behaviour or routines, or to help with coping at times of stress and change (e.g. illness or death of sibling or parent). It may be that this involvement has helped prevent later distress, but longer term follow-up is required to ascertain the full impact of living with HIV.

### Protective factors and triggering events

Using case examples, this paper now focuses on possible protective factors for women in these families and speculates on events which may act as triggers or precipitants, increasing the likelihood of notable changes in the mother's mental health, behaviour and coping abilities.

#### *Parenting and the needs of the child*

A protective and caring role is central to most parent-child relationships. When events bring about a major readjustment to this parenting role, extra considerations are necessary.

#### **Case 1**

*Jenny's baby daughter died of an AIDS-related illness just before her first birthday following several months of chronic ill health. Jenny had been diagnosed as HIV-positive during pregnancy but had not shared her daughter's or her own diagnosis with any of her family. She had been abandoned by the child's father soon after the birth. A couple of days after her daughter's funeral she was found by the home support nurse having taken some sleeping pills. Later in hospital after regaining consciousness she said she hadn't really meant to take her life but "just wanted some time out*

Table 2. Death and suicide experiences (n=72)

Event	Number of families
Death of parent(s) experienced in the core family	21 (29.2%)
Death of a child experienced in the core family	20 (27.8%)
Families experiencing multiple death (parent & child)	6 (8.3%)
Completed suicide	0 (0%)
Suicidal acts (including deliberate self-harm)	4 <sup>1</sup> (5.6%)
Suicidal ideation requiring referral	3 <sup>1</sup> (4.2%)
Depressive episodes requiring referral	14 <sup>2</sup> (19.4%)

1. All women.

2. Eleven women, two men, one child.

to try and make some point to her life now her child did not need her".

#### Possibilities

- there was nothing left in Jenny's life when her parenting role was ended
- the thought of her own future illness and death was too painful to contemplate
- there was no one who Jenny felt cared for her and would look after her as she became unwell
- Jenny had such little control over what might happen that this was the one choice (to end it all) that she could make.

The death of a child obviously breaks the protective role. However, there are other times where the parenting role is perceived to alter and may precipitate changes in the mother's emotional state, as this second case illustrates.

#### Case 2

Mary was a single, isolated, HIV-positive mother. She had a history of drug use but had not been using drugs since her partner's death just before her son was born. Her baby son was nearly 18 months old before it was confirmed that he was not HIV-positive himself. Since his birth she had rather neglected her own health needs. The day after being told the news about her son's HIV-negative status, Mary was found in a collapsed state and admitted to hospital in a coma from which she never recovered. She died a few days later; a cocktail of drugs and alcohol was identified as the cause of her collapse.

#### Possibilities

- Mary no longer needed to be strong in case her son fell ill
- she was facing a change in her future parenting role
- there was emotional turmoil surrounding relief from uncertainty
- Mary made an error of calculation in what had been a celebration of the 'good' news
- her underlying immune system was severely suppressed, making her reaction to the drugs and alcohol extreme.

It is likely that a combination of factors were involved in this tragic outcome. Several other cases have also illustrated that there can be changes, sometimes detrimental, in the physical and emotional health of the mother following the time when the child's HIV status was confirmed as negative. Some reported that they no longer needed to 'keep going' or 'stay strong' as their child would not be facing illness and possible death in the future. For others this was the first time they had allowed themselves to concentrate on their own self and personal health, their parental responsibilities having put these issues on hold or delegated as a lesser priority.

Approaches to care which focus on the family and give equal consideration to the adult's and the child's needs and the interrelationship between them may help to reduce the emotional

impact of such changes (Moore & Appleby, 1993).

#### Purpose and worth

Bearing and rearing children may give a woman a cause or purpose and increase self-esteem and a sense of responsibility. The following case illustrates how a mother's behaviour changed when this role was lost.

#### Case 3

Julie and her partner were both HIV-positive, as was their young son Peter. Their older daughter was not infected. Both parents originated from an African country but had lived in the UK for several years and had been diagnosed in the UK. Julie had none of her wider family in this country and had only told her sister about the HIV diagnosis. Peter died from an HIV-related illness when he was five years old. Both parents were devastated and some of the father's anger at his son's death seemed directed towards his wife. Julie became extremely depressed and felt numb both physically and emotionally in the months after his death. Julie sought help in an excess of medications, using a variety of herbal remedies which were subsequently found to have a toxic effect and contributed to changes in her functioning. On several occasions she deliberately burnt herself and once cut herself with a razor, explaining to her daughter who witnessed these events that "I just want to see if I can feel anything. At least if I can feel pain I will know I am real."

#### Possibilities

- pain at the loss of the child made Julie think she would never feel anything again; perhaps by harming herself and feeling physical pain the emotional pain would thaw
- Julie felt that as she had not been able to save her son, she was an unworthy person and incapable parent and did not deserve to survive herself
- as a boy child in their culture, Peter had represented the embodiment of their parent's future which was lost at the time of his death
- the use of alternative medications may have been a deliberate overdosing attempt or the effects of this medication resulted in disordered thoughts and emotional turmoil
- there already existed some deterioration in Julie's mental and neurological functioning resulting from the influence of HIV on the brain and CNS; the stress of Peter's final illness and death triggered further changes and deterioration.

Again, it is likely that a combination of the above factors led to the self-harming behaviour. The above case also raises questions about the impact of a parent's self-harming behaviour on any child who witnesses the event. Explanations removing feelings of blame, shame and helplessness need to be given. The quality of parenting offered to children by a distressed mother must be questioned.

### Presence of substitute dependants

The introduction of new caring or dependent relationships can influence the future adjustment to a significant loss.

#### Case 4

*Beatrice became extremely depressed after the death of her baby from an AIDS-related illness. She was offered psychological help and expressed some suicidal ideation during her initial sessions. Her family arranged for her older daughter, aged seven, to be brought over from Africa to live with her. They had not seen each other for four years. Beatrice's suicidal thoughts receded quite soon after her daughter's arrival and her depression slowly lifted. She stopped her sessions with the psychologist. The relationship between mother and daughter was strained and some family work was carried out to help this reconstituted family to function more effectively.*

#### Possibilities

- Beatrice was able to re-establish her parenting role with the alternative child, who in part substituted for the one who died; in turn this helped with her grieving process
- in her country of origin, having children was considered to give a woman status and made her a 'real' woman in the eyes of her family and partner.

This example suggests that there were benefits for this woman in being re-united with her daughter, but little account is taken of the needs of the young girl. Not only was she separated from the family and community in which she grew up, but she was expected to behave as a dutiful compliant daughter. Not surprisingly it took a considerable time before this girl was able to integrate into her new life and to establish a relationship with her mother. The future adjustment and care of this little girl may be in jeopardy if more changes occur such as the illness and death of her mother, or if a new baby is born into the family. In this population, dilemmas and conflicts frequently arise between the needs of the parents and the well-being of the child.

### Discussion and conclusions

There emerges from the above review the clear need to monitor the evolving and often compounded burden of grief, loss and change that emerges as the course of HIV infection and illness unfolds within a family. While the sample reported on here is small and this review was retrospective, comparisons with other populations affected by HIV infection suggest that suicidal behaviour and ideation may occur or be identified less frequently in this heterosexual population. Episodes of depression were reported, especially in the women, but the number accessing psychological support was quite low.

Emotional pressures on parents as well as children in these families was found to be high, with considerable social stresses as well as chronic illness and multiple losses. Relationship problems were frequently noted and there were many single, isolated or unsupported mothers, often as a result of separation or abandonment or the death of a partner. A high percentage of parents originated from other countries and were having to cope without their personal and community support systems and without their families being aware of their HIV diagnosis.

It may be that there are certain factors which protect the women from some of the more overt expressions of distress. The parenting role is suggested as one of these, and the case examples illustrate that major changes in emotional and sometimes physical well-being can result when this role is disrupted or distorted. Cultural and ethnic factors cannot be ignored as major influences in the recognition and assessment of psychological problems and in the provision of appropriate support. There is little knowledge about the emotional or psychological impact on children who are infected or affected by HIV infection, and this is an area needing detailed, longitudinal research using models and ideas developed from studies of other chronic illness. The competing dilemmas between parental wishes and desires and children's needs and rights deserve particular attention. Furthermore, as treatments help extend physical health there is likely to be an increase in the numbers of HIV-positive individuals with neurological signs. This may have serious implications for caring and parenting roles and for issues of child protection.

It is suggested that services providing care for women and children living with HIV infection need to focus on the whole family and provide for emotional as well as physical health. An awareness of the crisis times that families face, and providing extra support and help which acknowledges the cultural and ethnic backgrounds of the population being served, are essential components of future care. It may be that available counselling and psychological therapies are not appropriate or wanted by the kinds of families described here. However, better liaison and consultation between mainstream mental health services and specialist HIV agencies must develop to ensure that the quality of the present and future lives of both adults and children living with HIV is enhanced.

### References

- CATALAN, J. (1990) Psychiatric manifestations of HIV disease. *Baillière's Clinical Gastroenterology*, **4**, 547-562.

- DEAN, L. (1995) Psychosocial stressors in a panel of New York City gay men during the AIDS epidemic 1985–1991. In *AIDS, Identity and Community* (eds G. M. Herek & B. Green), pp. 201–215. New York: Sage.
- DRAIMIN, B. (1993) Adolescents in families with AIDS: growing up with loss. In *A Death in the Family – Orphans of the HIV Epidemic* (ed. C. Levine), pp. 13–23. New York: United Hospital Fund.
- EISER, C. (1990) *Chronic Childhood Disease*. Cambridge: Cambridge University Press.
- MELVIN, D. & SHERR, L. (1995) HIV infection in London children – psychosocial complexity and emotional burden. *Child: Care, Health and Development*, **21**, 405–412.
- MOORE, C. & APPLEBY, S. (1993) Caring for families in the community. *Health Visitor*, **66**, 438–440.
- PERRY, S., JACOBSBERG, L. & FISHMAN, B. (1990) Suicidal ideation and HIV testing. *Journal of the American Medical Association*, **263**, 679–692.
- PIZZO, P. & WILFERT, C. (1994) *Pediatric AIDS. The Challenge of HIV Infection in Infants, Children and Adolescents* (2nd edn). Baltimore, MD: Williams and Wilkins.
- PUGH, K. (1995) Suicide in patients with HIV infection and AIDS. In *Grief and AIDS* (ed. L. Sherr), pp. 30–45. Chichester: John Wiley.
- REIDY, M. (1995) AIDS and the death of a child. In *Grief and AIDS* (ed. L. Sherr). Chichester: John Wiley.
- RICHMOND, B. J. & ROSS, M. W. (1995) Death of a partner – responses to AIDS related bereavement. In *Grief and AIDS* (ed. L. Sherr), pp. 146–161. Chichester: John Wiley.
- SHERR, L. (1995) Suicide and AIDS: lessons from a case note audit in London. *AIDS Care*, **7**, 109–116.
- \*Diane Melvin, *Principal Clinical Psychologist, Department of Clinical Health Psychology, St Mary's Hospital, London W2 1NY; and Lorraine Sherr, Senior Lecturer in Psychology, Royal Free Hospital School of Medicine, London*
- \*Correspondence