The Uninfected Children of HIV-Seropositive Parents

INTRODUCTION

The uninfected children of HIV-seropositive parents are often neglected. Limited health care resources tend to be focused on the infected person, his or her partner, and any infected children. Uninfected children’s emotional needs may go unattended. Michaels and Levine (1992) estimated that, by 1995, 45,600 children in the United States would have been orphaned to AIDS and that by the year 2000, approximately 80,000 young people will have lost both parents to AIDS.

Parental illness and death are particularly difficult for children. Loss of a parent, combined with the stigma associated with HIV and AIDS, leads to special problems that therapists may not frequently encounter.

CASE STUDY

ADOLESCENTS

When Henrich was diagnosed with HIV, he had to disclose his bisexuality and his infection to Margaret, his wife, Allison and Leah, his two daughters (ages 19 and 15, respectively), and Phil and Len, his two sons (ages 12 and 8, respectively). He refused to discuss his illness or his bisexuality with the family, however, and he was often hostile and angry with his children, particularly rejecting his sons. Henrich deteriorated rapidly and died within a few months, so the family had no
opportunity for anticipatory grieving.

Margaret did not know her husband was bisexual and reacted to the HIV diagnosis with suicidal ideation, loss of functional capacity, and loss of emotional control. She was depressed, angry, hurt, and conflicted about telling her children how she felt. She had several psychiatric hospitalizations and relied on her children, particularly Allison and Leah, for emotional support. A church pastor, she was unwilling to tell her coworkers that her husband had died of AIDS.

All the children were affected by the situation and were forced to take on parental roles with their mother. Allison went on a trip, missed her father’s funeral, and cancelled her plans to go to university. Torn between her home duties and her desire to move out, she established a relationship with a much older man, probably as a father substitute, and then became attached to a younger man she planned to marry.

Leah became enmeshed with her mother. Because Margaret would not disclose Henrich’s diagnosis to her coworkers, Leah was unable to discuss it with her friends in her church community. She became depressed and eventually developed symptoms of major depression, requiring antidepressants. A long-standing problem with bulimia nervosa became much worse, and Leah eventually had to attend an inpatient hospital program for it.

Phil was silent and emotionally inexpressive inside the family. He had few words for his emotions. He began to act out: not doing his school work and not coming home after school. He began to smoke cigarettes and marijuana and relied on his friends and girlfriend for support.

Len was afraid that his father’s “leaving” would prompt others to leave as well. He too was enmeshed with his mother and, as a result, was largely neglected. He was quietly anxious and fearful that, if he expressed his emotions, he would prompt further decompensation in his mother.

In therapy, the children had trouble discussing how they felt about their father because they didn’t want to upset their mother. They conspired to avoid talking about her incapacitation and so resisted attending the family sessions.

After some initial grief work, they stopped therapy for three months. They returned to treatment to talk about their anger at their mother’s inability to assume the role of a strong head of the family.

What clinical problems did the family experience?

- The mother’s dependency needs were brought to the fore by the father’s death.
- The family faced the threat of disintegration.
- The inner image family members had of themselves was irrevocably altered by the revelation of the father’s double life and the stigma of HIV.
- The children experienced a loss of hopes and expectations, such as their expectation of attaining postsecondary education.
- The family’s opportunity to grieve and deal with bereavement issues was constricted.
- Because of the lack of communication both among family members and between the family and other people, they experienced denial and isolation which, in turn, intensified their feelings of anger, guilt, and depression.
- The children had their normal adolescent development interrupted. At a time when the older children were ready to leave the family and establish their autonomy, they felt compelled to remain inside.

What factors influence a child’s adjustment to a parent’s death?

Siegel and Gorey (1994) identify three factors that influence a child’s adjustment to a parent’s death: 1) the quality of care and support from the primary caregiver after death; 2) open family communication; and 3) environmental stability.

In this case, quality of care and support from the primary caregiver suffered because of Margaret’s inability to deal with Henrich’s bisexuality and HIV infection. There was almost no communication within the family about the father’s illness and
death or their feelings about their father and the way their mother reacted. As a result of their father’s death and their mother’s incapacitation, the children did not have the environmental stability necessary to help them adjust.

How would a psychiatrist treat this family?

In this situation, the therapist would:

- assess the family’s premorbid function, looking particularly at the mother’s dependency needs and the younger daughter’s earlier problems with bulimia nervosa
- begin grief work to help the family go through the process of grieving the loss of their father and the loss of the previously idealized family structure and previous entitlements
- help the family integrate the new information and develop new roles and a new view of the family structure
- pay particular attention to the quality of care and emotional support that the children were receiving from their mother
- deal with the mother’s issues by liaising with her personal psychiatrist and supporting her to take on as much leadership in the family as possible within her limitations
- encourage open communication among family members
- help the family reestablish normal family routines to create a greater sense of cohesion, such as marking all the important family anniversaries during the first year after the father’s death and having a regular dinner together
- encourage family members to take on new roles to fill those vacated by the loss of the father
- take steps to help the children resume their age-appropriate roles and tasks, including seeking autonomy outside the family
- allow the family members to express anger at their father for leading a double life

With respect to treatment, Roth and others (1994) have developed an intervention program to assess the family’s needs and match them to available community resources. Because sharing strong emotions and fantasies can help adolescents to cope, Roth and others also recommend groups to foster peer culture and diminish social isolation. The groups also serve a didactic function when the children need information about HIV.

How do adolescents differ from younger patients in their response to the chronic illness of a parent?

Adolescents present special problems. They are at a stage when their normal development entails the loss of the idealization of their internalized parent and a normal grieving process to establish their autonomy. Demb (1989) describes the increased risk for self-destructive acting out in this population. Adolescents may mimic their parents’ behaviour and take to drug abuse or promiscuity. If an acting-out adolescent is placed with extended family members, he or she may be seen by the caregivers as similar to the ill parent. The extended family may not be able to tolerate
the adolescent’s behaviour and emotional disturbance.

Halperin (1993) has described denial in the behaviour of fostered adolescents. He points out that denial protects them from the stress of coping with their parent’s illness and helps them organize their shame of the illness, the parent’s death, and their need to be placed into foster care. When denial breaks down, adolescents often develop chronic suicidal ideation as a way to identify with the parent and to deal with their rage at what has occurred.

How is losing a parent to HIV different from losing a parent to other causes?

Siegel and Gorey (1994) identify certain complicating factors for adolescents grieving the loss of a parent to HIV. The first is the stigma associated with HIV infection, which may mean that the cause of the parent’s death is kept secret. Children may not be given the true diagnosis, or they may be told not to reveal it to others. Secrecy means that families may not receive the support normally given when a parent dies from a more socially acceptable illness, such as cancer. If the diagnosis is made public, adolescents may experience the direct effects of stigma in the form of housing problems, social ostracism, ridicule, and rejection. The stigma intensifies their guilt, depression, and anger, the last of which may be focused on the deceased for the shame he or she has brought on the family. Many teenage boys are fearful of homosexuality so, for them, the stigma can be more intense. In the case described here, Phil and Len lost not only their father, but also their “straight” father. As the children’s own needs are neglected, they may develop ambivalent feelings about the deceased parent.

EPILOGUE

Margaret currently lives with Phil and Len, who are still in secondary school. Her periods of emotional instability are far fewer, and she continues to work in the church.

Allison is married and working, but she deals with chronic emotional instability. Leah lives in a common-law, heterosexual relationship and is working. Neither daughter pursued postsecondary education. The loss of their father ultimately caused them to lose that opportunity, and their expectations for the future were profoundly changed.

CASE STUDY

YOUNG CHILDREN

Khadija, a 32-year-old woman originally from sub-Saharan Africa, developed Pneumocystis carinii pneumonia when her only son was about six months old. She had acquired HIV infection heterosexually during a previous relationship. Her husband, Bashere, also tested HIV-seropositive, but after 12 tense months, doctors were able to confirm that their son, Warsame, was HIV-seronegative.

When Warsame was about four years old, his parents complained to their doctor of being unable to control his aggressive behaviour, particularly toward his father, and they were referred to a psychiatrist. After some probing by the psychiatrist, it was revealed that Warsame had developed secondary enuresis and had symptoms of separation anxiety disorder, including following his mother around the house and being unable to sleep alone. He talked about being frightened of monsters in his room.

Khadija and Bashere did not consider the separation issues significant. Because Warsame was not infected, they considered him a wonder child and indulged him. They saw his attachment to his mother as a way for Khadija to express extra caring for him. They were concerned, however, about his aggressive behaviour toward his father.

Although Khadija had been hospitalized repeatedly over the previous few years, the family did not discuss her condition. Warsame knew something was wrong with his mother, but no one would talk to him about it.

A family history revealed that Bashere had been physically abused as a child. He was terrified of repeating the abuse, so he did not try to assert control over Warsame. Although he was medically well, Bashere presented as fragile and underassertive. He depended on Khadija for instrumental tasks.
and emotional support. Bashere felt overwhelmed at the thought of having to take sole responsibility for parenting and, at the same time, maintain his job and visit Khadija in the hospital.

On one occasion, when Khadija was in hospital, Bashere and Warsame came to the session together. When the psychiatrist broached the subject of Bashere’s dependence on Khadija, Bashere could not deal with the issue. He called soon after to say that the family no longer needed any help.

What are the clinical issues in this case?

Roth and others (1994) point out that chronic medical illness in a parent has been associated with such behavioural problems in children as enuresis, poor school performance, school refusal, and separation difficulties. Children may also experience somatic problems similar to the ill parent, such as headaches and abdominal pains. Children of parents with medical illness have been described as having increased anxiety, low self-esteem, and feelings of rejection, isolation, and neglect. Bereavement adds issues, and the children may be prone to depression and school difficulties, as well as sensitive to the threat of loss. They are also at increased risk for adult depression, especially if their general supports are limited.

In this case, the clinical issues include:

- the child’s frustration at knowing that something is wrong with his mother, but being unsure about what it is. His acting out can be seen as a manifestation of his anxiety about possibly losing her.
- poor communication between the parents, probably because the topic of mother’s death is too anxiety provoking. This communication problem, combined with guilt about abandoning their son, makes it difficult for the parents to impose discipline and limit Warsame’s behaviour.
- the stress of illness, which has exacerbated unhealthy dynamics in the family. From a family systems’ perspective, Warsame’s uncontrollable behaviour and anxiety disorder have diverted the family from the real issues of Khadija’s illness and Bashere’s fear of being more assertive in parenting.

How can the family deal with the potential loss of both parents?

Given that the father is also infected and may die of AIDS, the family must be encouraged to recognize the impact that a parent’s death will have on the child and do some practical planning.

Siegel and Gorey (1994) point out that children do not, as adults do, detach memories and hopes from the dead person. Instead, they keep the parent alive in their minds as a way to continue to possess their parent. They may have reunion fantasies. Children
also need more denial to cope because they cannot tolerate the intense emotions. As a result, they often alternate between grief and denial.

Many parents die before they have planned adequately for their children. If both parents have died or if there is only one caregiver, the need for fostering may increase the children’s problems—particularly if it involves separating siblings or if the foster parents are uninformed about HIV or unable to talk about it. By contrast, some children—such as those whose parents’ lives were chaotic—may receive better care and enjoy a more stable environment when they are removed from the family.

In this case, the issue of environmental stability is critical. Warsame will likely have to cope first with the loss of his mother, then the loss of his father. Bashere will have to be encouraged to take a stronger parenting role.

What is the appropriate therapeutic approach with this family?

Faced with Khadija’s likely death from AIDS, it is important for the family to develop new norms. The parents must be encouraged to communicate more openly about the problems they face and to explore the process of disclosing the fact that mother is sick and will probably die. Bashere must be encouraged to take more responsibility for parenting and, in particular, find ways to deal with Warsame’s aggressive behaviour.

If possible, individual play sessions with Warsame may help the child learn to express some of his conflict in words and diminish his need to act out his anxious feelings.

During this period, Bashere may need ongoing support with practical matters, such as child care for Warsame and planning for the future, when he may be too ill to parent.

EPILOGUE

As Khadija became more ill, Bashere and Warsame moved in with Bashere’s sister, who is helping with instrumental tasks. Warsame continues to have problems with violence and aggression at school.

RESOURCES


MULTIPLE-CHOICE QUESTIONS

1. Which of the following is a common adolescent reaction to diagnosis of HIV in a parent?
   a) Denial with overreliance on peer group for emotional support
   b) Drug and alcohol abuse
   c) Sexual promiscuity
   d) Overcompliance and parentification with denial of emotional difficulties
   e) All of the above

2. Which of the following problems can children develop as a result of the stigma of HIV?
   a) Shame, social ridicule, and rejection
   b) Guilt and self-blame
   c) Housing problems
   d) Anxiety about contracting HIV
   e) All of the above

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