34

AIDS and Its Traumatic Effects on Families

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Hardly over, perhaps barely begun, the epic of acquired immunodeficiency syndrome (AIDS) involves multigenerational losses and redefinitions of individual, family, and community roles and responsibilities. An AIDS diagnosis dramatically alters the emotional climate of the family system. It creates a profound sense of dislocation in the timing and order of major life events. Years of parenting are compressed into a few, and roles are reversed. A 12-year-old girl changes her mother's diapers. A 65-year-old grandmother takes over the care of the seven children of her three dead daughters. A 17-year-old promises her dying mother that she will take care of her younger brothers and sisters, and not let them be separated.

The personal odyssey of a Brooklyn, New York, grandmother named Ada Setal resembles the stories being played out again and again in the United States and around the world today. Eddie, Ada's son, and Armida, the woman with whom he lived, were both infected with the human immunodeficiency virus (HIV). Their three children were also HIV-infected. When Eddie told his mother this devastating news and asked her to take the children because Armida was too ill to care for them, Ada wavered.

> I came home and thought about how I'd be treated by the church and the community. I thought, "If I take these children, I am going to be isolated, abandoned, left alone. I'm not going to be able to walk out of my house with my head up because there is going to be so much shame around me." I was only 51, but I saw myself as a woman with no future. (Setal, 1993)

Somehow fortified by her religious faith, she nonetheless took the children and struggled through a succession of deaths, becoming a community activist for children and families with AIDS in the process.

AIDS affected three generations in Ada Setal's family—her son and his girlfriend, their children, and herself. Yet her story is unusual only in that all three of her grandchildren were HIV-infected. Typically, most of the children born to an HIV-infected mother are not themselves

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infected. In the United States, the transmission rate of HIV from infected mother to fetus has been about 20–25%.

The generation most at risk for contracting HIV is young adults. As they grow ill and die, they leave the older and the younger generations to cope alone. Coping takes many forms. Once-independent young adults go home to die in their parent's care. Grandparents and extended families take in orphaned children. The oldest child becomes the parental figure and primary caregiver. Children enter foster care or are placed for adoption. Siblings are separated to make it more likely that relatives will be able to house them. Older children live on their own, often in precarious situations without adult supervision. Whatever the individual solutions, they reflect a world out of balance, a profound upheaval in the natural order that takes as a given that grandparents ought not to have to assume parenting responsibilities for two consecutive generations, and that parents should not have to bury their children.

This chapter describes the American experience, since that is the one the authors know intimately. Moreover, it focuses on families in which parents of children or adolescents have AIDS, and not on multigenerational traumas in families with gay men (see Lipmann, James, & Frierson, 1993; Macklin, 1989; Walker, 1991). Some excellent studies of the impact on families in other countries have been published (Brown & Sittitrai, 1995; Imrie & Coombes, 1995; Hunter, 1994). Most of these studies so far focus mainly on the service needs of affected communities, families, and children, and on the economic and structural dislocation of family life. There is little analysis yet on the impact of multigenerational legacies of AIDS-related trauma in other societies.

THE DEMOGRAPHICS OF AIDS

The World Health Organization (WHO) estimates that since the beginning of the pandemic, 18 million adults and 1.5 million children have been infected with HIV, and that over 4.5 million have developed AIDS. By the end of the century, WHO estimates that between 30 and 40 million people will have been infected with HIV. Although sub-Saharan Africa has been the hardest hit area, HIV is spreading rapidly in Asia. The toll in countries such as India and Thailand is particularly severe. The gender ratio has been equal in Africa, but in Asia, trends indicate more new infections among women than men. Everywhere in the world, the generation hardest hit has been young adults (World Health Organization, 1995).

AIDS is not a single epidemic, but a series of epidemics that began in different places around the world at different times and with different trajectories. Even within a single country, the path of HIV has varied. In the United States, for example, the epidemic in the West Coast city of San Francisco, California, has affected primarily gay men, while on the East Coast in Newark, New Jersey, male and female drug users and their sexual partners have predominated. A city as complex as New York has several epidemics, each with a distinctive profile.

How did this medical and social disaster happen so rapidly? The epidemic began slowly, almost imperceptibly. In the United States, the signal event was the report of the Centers for Disease Control and Prevention (CDC) in June 1981, that in Los Angeles, extremely rare cases of *Pneumocystis carinii* pneumonia (PCP) had been diagnosed in five previously healthy homosexual men (CDC, 1981a). This was not, of course, the actual beginning. One month later, the CDC reported that since January 1979, 26 homosexual men in New York City and California had been diagnosed with Kaposi's sarcoma, a rare cancer. Many had also been diagnosed with PCP and other viral diseases; eight had died (CDC, 1981b). In August 1981, the

CDC reported that five heterosexuals, including one woman, had been diagnosed with similar symptoms of severe immune deficiency now called AIDS (CDC, 1986).

In the nearly 15 years since AIDS was first identified, it has become endemic in the United States, particularly in poor communities of color. AIDS is now the leading cause of death for all Americans aged 25–44 and the leading cause of death among women aged 15–44 in New York and New Jersey (CDC, 1995a). In 1994, HIV infection became the fourth leading cause of years of potential life lost before age 65 (CDC, 1996). Among people in the United States infected with HIV between 1987 and 1991, one of four was under the age of 22 (Rosenberg, Biggar, & Goedert, 1994).

As of October 31, 1995, more than 500,000 AIDS cases had been reported to the CDC. More than half of these individuals have died (CDC, 1995b). The number of HIV-infected people who have not yet reached a diagnosis of AIDS in the United States is generally estimated at 750,000 to 1.5 million. In 1992, the CDC noted: "The recognition of a disease and its emergence as a leading cause of death within the same decade is without precedent" (CDC, 1992).

HIV infection is spreading most rapidly among women and adolescents. In 1994, women made up 18% of the total number of adult AIDS cases, nearly threefold more than the proportion of cases among women reported in 1985 (CDC, 1995a). These women—75% of them African American or Latina—are typically mothers and the primary caregivers for their children. An increasing percentage of young people are becoming infected through sexual activity. Between 1992 and 1993, the largest increases in AIDS case reporting occurred among persons aged 13–19 years and 20–24 years, heterosexual transmission accounted for 22% of the transmission in the younger group and 18% in the older group (CDC, 1994). Children born with HIV infection are now living into their teen years; many have become sexually active, and some have become pregnant. The National Institutes of Health study that showed a reduced rate of maternal–child HIV transmission in pregnant women taking zidovudine (AZT), for example, enrolled a 15-year-old girl as its youngest participant (Gelber & Kiselev, 1994).

Throughout the world, mothers are the primary caregivers of their children. Although fathers' deaths are certainly traumatic and may bring on family crises, it is mothers' deaths that most directly affect children's caregiving. In the United States, by the year 2000, an estimated 82,000–125,000 children and adolescents in the United States will have lost their mothers to AIDS (Michaels & Levine, 1992). The vast majority of these youngsters are not HIV-infected but are at serious risk for a range of emotional and behavioral problems. Their substitute caregivers are also under enormous emotional and financial stress. Michaels and Levine also estimate that the number of young adults (18 years and older) in the United States whose mother will die of HIV/AIDS–related causes will reach 35,100 by 1995 and 64,000 through the year 2000. The number of children worldwide who will have been orphaned by HIV/AIDS by the end of the decade has been estimated to be between 5 and 15.6 million (Chin, 1994; Mann & Tarantola, 1996; U.S. Agency for International Development, n.d.). The size of the range can be attributed to variations in the parameters and assumptions used in the models, as well as the different definitions used for orphan (children without mothers, or children who have lost either or both parents).

LITERATURE REVIEW

Before 1992, there were only a few references in the burgeoning AIDS literature to children surviving the death of a parent and their new caregivers. Most of the literature about AIDS and children focused on pediatric AIDS (Anderson, 1986, 1990; Pizzo & Wilfert, 1991).

Among the earliest references to affected, rather than infected, children are Walker's (1987) discussion of AIDS and family therapy, and Demb's (1989) clinical vignette about adolescent survivors of parents with AIDS. Macklin's (1989) was among the first collections to examine AIDS from a family perspective.

Several publications began to raise awareness of the problems of affected children and their new caregivers in 1992. Grosz and Hopkins (1992) described family circumstances affecting caregivers and siblings. Draimin, Hudis, and Segura (1992) outlined the mental health problems of well adolescents in families with AIDS. Michaels and Levine (1992) offered the first estimates of the numbers of children who would be left motherless in the United States because of AIDS.

These initial works were followed by Levine (1993), a collection of essays, including personal stories, that presented some innovative programs in New York City and analyzed some of the legal issues facing new caregivers. Levine and Stein (1994) focused on policy changes and services needed to assist orphaned children and their new caregivers. Dane and Levine (1994) explored the psychological and social aspects of bereavement in AIDS and described some programs for grieving children. Bauman and Wiener (1994) edited a series of papers on priorities in psychosocial research on pediatric HIV infection that includes several essays on uninfected children. Geballe, Gruendel, and Andiman (1995) is a collection of essays from medical, legal, psychosocial, and other perspectives. It also contains children's drawings. Boyd-Franklin, Steiner, and Boland (1995) deal with psychosocial and therapeutic issues, mostly focused on children with pediatric HIV infection.

Beyond these books, the number of articles on specific topics is growing. These include disclosure of a parent's or child's HIV status (Lipson, 1994), creating a legacy of memories through videotapes and other techniques (Taylor-Brown & Wiener, 1993), legal options (Herb, 1993; Pinott, 1993), bereavement (Boyd-Franklin, Drelich, & Schwolsky-Fitch, 1995; McKelvy, 1995), and psychotherapeutic techniques (McKelvy, 1995).

Recent publications in trauma theory as it relates to children have added to the understanding of the impact of an AIDS diagnosis. In particular, *Children in Danger* (Garbarino, Dubruow, Kostleny, & Pardo, 1992) describes children living in communities of poverty and violence, and examines the value of mental health treatment to help children resolve traumatic experiences. In writing about the psychological effects of specific traumas, Kerr (1991) identifies the long-term impact of unresolved feelings.

A book that examined parenting by women who lost their own mothers at young ages hints at the multigenerational impact of losing a parent to AIDS. Edelman (1995) describes mothers who are afraid they lack adequate parenting skills and, even more tragically, that they will not live past the age of their own mother's death. The author's sample consisted primarily of white, middle-class women who generally did not face the multitude of other stressors that saturate the lives of young people who have lost parents to AIDS. These factors almost surely complicate the losses she described.

Other literature has helped explain how emotions are transmitted in families. Most of this research has its roots in Freud's understanding of the unconscious and mental health as a result of early family relationships (Kerr, 1991). Bowen (1978) and many others have written about the now commonly held belief that families are emotional systems.

The literature to date reflects consensus that (1) services to meet the needs of all the involved generations should be improved and expanded; (2) research data, particularly long-term studies of children and new caregivers, is scarce; (3) the period before the parent's death should be emphasized in terms of making custody plans; and (4) relatively little attention is being paid to the problems faced by new caregivers.

WHO ARE THE FAMILIES WITH AIDS?

The children who struggle with AIDS in their families are typically living with their mothers in single-parent homes. Poverty, loss of community services, overcrowding in sub-standard housing, frequent displacement due to fire or criminal activity, and substance abuse are all characteristics of what Fullilove and Fullilove (1993) describe as the "seeding of the epidemic." The deterioration in communities erodes families' capacity to provide the emotional and financial support necessary for healthy functioning. Many children are raised in a perpetual shadow of scarcity. One Family Center client from New York City said, "I hate the end of every month, when we have no food." With poverty comes a reliance on subsidies and public housing, often in high-crime areas where random violence is common. Every family member faces the risk of stray bullets, robberies, and assault on a daily basis.

A more subtle erosion of a family's sense of self-esteem is caused by society's continued racial discrimination, especially within African American and Latino communities. Certain cultures, such as the Haitian immigrant population, are especially scapegoated because of their association with a high rate of HIV infection.

In New York City, 60% of the women with AIDS were exposed to HIV by sharing needles while using injection drugs (New York City Department of Health, 1995). Many of the absent fathers are also drug users, often with a history of incarceration. Because drug-using parents are preoccupied with their substance of choice, they have little time or patience for the de-mands of parenting. As a result, their children are at greater risk for exposure to child abuse and neglect (Zuckerman, 1994). Children who have been born to drug-using mothers are also at risk for low birth weight, being born addicted, developmental delays, and HIV, making them especially poorly equipped to confront the multiple stressors within the family. In addition, family members with a history of drug use or violence have generally learned how to avoid painful truths. The resulting habits of secrecy and isolation, coupled with poor communication skills, are greatly magnified by HIV.

Drug use, especially crack cocaine, has accelerated the phenomenon of "skip-genera-tion parenting." Grandmothers have taken over when their own children have abdicated par-enting responsibilities, or when they have chosen to remove their grandchildren from a dangerous environment. This phenomenon has particularly affected African American com-munities. As of 1990, 12% of black children in the United States were living with grandpar-ents, compared to 5.7% of Hispanic children and 3.6% of white children (U.S. Bureau of the Census, 1991). The percentage of black children living with grandparents in some urban areas is significantly higher, with estimates ranging from 20% in a Head Start population in Oakland, California, to 30–70% in parts of Detroit, Michigan, and New York City (Minkler & Roe, 1993).

AIDS has created further pressures for alternative caregiving arrangements for children. Although data are scarce, it appears that when a mother dies of AIDS, children most often go to live—at least at first—with a grandmother or aunt. Sometimes the grandmother or aunt has already been taking care of the children. In a pilot study examining the outcome in 43 cases that were closed shortly after the mother's death, the New York City Division of AIDS Services found that 58% of the children went to live with grandmothers or aunts (Levine, Draimin, Stein, & Gamble, 1994).

Efforts to make permanent plans for children in families with AIDS are relatively recent. In Chicago, Illinois, 21 of 72 HIV-infected mothers who were interviewed indicated that they would like their mothers to take the children. Nine women designated their sisters, 20 were

unable to identify anyone, and the remainder designated other relatives (LSC and Associates, 1993). It is unknown how many of these plans will actually work out, however, especially since only 14 mothers had made legal arrangements for their chosen caregiver. Nor do we fully understand the factors that influence placement choices. For example, one study looking at infants born to HIV-infected women in six regions of the United States concluded that maternal drug use may be the most important factor in determining whether a child lives with a biological parent. In all locations and for all racial and ethnic groups, newborns whose mothers used intravenous drugs were more likely to be placed with someone other than their mother (Caldwell *et al.,* 1992).

WHY AIDS IS UNIQUE

While any life-threatening illness has profound consequences to every generation that is affected, many aspects of AIDS distinguish it from other serious illnesses and make it even more difficult for the affected children, parents, and grandparents. In particular, the populations affected, the social stigma, the lack of a surviving parent, the transmissibility to children, and the number of losses experienced by affected families provide special challenges to every generation.

The populations that are most likely to have AIDS are homosexual men, drug users, and women and children of color. Discrimination against these populations in housing, health care, and insurance has been extensively documented. Moreover, there comes a time when the physical impact of HIV makes anonymity almost impossible. When the disease becomes physically apparent, so does a history of behaviors. Disclosing illness to family members may occur at the same time that drug-using behavior or sexual orientation is disclosed, adding layers of complexity to the trauma that is involved.

When other serious illnesses strike, there is usually a surviving parent who can take full responsibility for the care of the children. With AIDS, this is seldom the case. The other parent may be deceased, incarcerated, or simply absent; other surviving family members must step forward. At the same time that these relatives suffer the loss of a sibling or child, they must try to help surviving children deal with their own despair and loss.

The secrecy, stigma, and isolation that characterize AIDS are far greater than the stigma associated with other illnesses. Seldom is the same degree of moral responsibility attached to the lung cancer patient who smoked or the overweight executive who had a heart attack. In these instances, we extend caring and curing to all, recognizing that disease can, and often does, happen to anyone. By contrast, AIDS is more likely to be treated as a social and cultural curse, and a moral or religious punishment than as a medical condition.

Even within families, there can be an attempt to blame and ostracize an individual for "bringing this horrible disease into our home." Because of its association with unsafe drug use and sexual behavior, myths and misunderstandings abound. Truth is often hidden or denied. The moral judgments of family members may render any discussion of the illness and its origins completely taboo. Children of parents with AIDS may have fears of contagion that they are too embarrassed to share with anyone. The stigma is intensified by societal reaction. In a recent newscast, for example, a New York City television station publicized the plight of AIDS orphans while describing their parents as "junkies," reflecting the endemic failure to view drug addiction as a medical problem (WWOR, Channel 9 News, New York City, August 17, 1995). The self-esteem, pride, and self-image of the family are therefore affected by both the intrafamily and external oppression of those who are infected.

Another unique aspect of AIDS is that a mother can transmit the causative virus to her baby during pregnancy or delivery. Mothers who have infected their children speak openly about their fear of not living long enough to care for their children; others face the sadness of having to bury them. Their medical choices are complicated by recent research suggesting that identifying HIV-infected pregnant women and treating them with AZT may help reduce the rate of perinatal transmission (Connor et al., 1994). This raises complex and difficult questions about confidentiality, testing, and treatment. The need for intense counseling and education of pregnant mothers is clear. It is especially troubling that legislative efforts to mandate unconsented HIV testing for newborns or pregnant women portray mothers as more concerned about their privacy than about their babies' health. In this dichotomy, mothers are labeled "guilty" because of their HIV status, and their babies are characterized as "innocent."

A final, unique element of HIV is that many of the affected families have already suffered multiple losses. Rarely is a family dealing only with AIDS. In a study by Draimin et al. (1992), the average family with AIDS had experienced four major losses, defined as HIV diagnosis, death, incarceration, or divorce, within the last 2 years. These losses have devastated families and the communities in which they live.

HOW AIDS AFFECTS CHILDREN

Families with AIDS typically face a combination of challenges and traumatic stress whose "psychic scars" are passed on from one generation to the next. For the affected children, trauma comes early and with a vengeance.

In general, parents are largely responsible for the consistency, duration, and intensity of the feelings in the home. Their children absorb information on acceptable ways to express anger, love, and sorrow. Parental attitudes of self-esteem, hopelessness, and powerlessness, as well as the feelings of anxiety and fear associated with an AIDS diagnosis are also passed to the next generation (Halpern, 1990). Even if parents choose not to speak about their HIV status, children will sense danger in the home. Some of these emotional communications are passed between parent and infant nonverbally; later, language becomes another way to transmit emotions between generations.

In order to bond with an adult, infants require warmth, food, and language, either from their mothers or other consistent caregivers (Bowlby, 1973). The security provided by an attachment figure is vital to the child's ability to defend him- or herself against the anxiety caused by separation, discomfort, and unfamiliar surroundings. Unfortunately, mothers who spend the vast majority of their emotional resources simply struggling to survive may not able to provide what an infant needs to feel secure.

An AIDS diagnosis adds its own stressors and anxieties to an already overtaxed emotional family system. The effects of these multiple stressors "potentiate" each other (Rutter, 1979). In other words, the emotional impact of the combination of loss, poverty, drug-using parents, and AIDS in the family is far worse than these stressors experienced separately.

When children discover that a parent has been diagnosed with AIDS, they typically spend enormous amounts of energy defending themselves against the fears and fantasies that are associated with it. Children are afraid of contagion and how they will be viewed by their peers. Denial or desensitization is a common adaptive defense, learned from repeated exposure to guns, acts of violence, and the experience of other deaths in the family. Often children have known other people with HIV and many eventually become numb. When one teenager in a

support group was asked if she was worried because her mother was in the hospital, she replied with a shrug, "I'm used to it."

Delinquent behavior is another common response to the disintegration of community structures. Some adolescent boys become particularly aggressive. One young man in psychotherapeutic treatment said, "I feel alive when I fight and I want to hurt people like I have been hurt." The challenges presented by an aggressive teenager are exacerbated by the mother's poor health. At a time when curfews and the obligation to attend school need to be reinforced, parents with AIDS may be too weak to assert their authority. Teenagers begin to identify with their aggressive environment and adapt to a world of violence by "gang banging," playing dangerous, thrill-seeking games, and relinquishing their ideas of a future. As one teen described in therapy, "I'm just grateful each New Year's Day to be alive." Young men and women who feel they lack a future may avoid long-term attachments, drop out of school, or refuse to plan ahead in any way. Their lives become governed by impulse, which often leads to sexual or drug-using behavior that puts them at high risk for contracting HIV. They are likely to pass on a "live fast, die hard" legacy to their own children.

Not every young person has the same reaction to living with a parent with AIDS. Some may respond by intensifying their attachment or becoming emotionally enmeshed to the point of sharing medical symptoms with ill parents. For example, some young girls who witness their mother's slow weight loss will lose their appetites. A teenage boy who lived alone with his mother was twice hospitalized at the same time that his mother was being treated for opportunistic infections. After many tests, the young man's "heart problems" proved inconclusive; however, his neurotic attachment to his mother was evident.

In a reversal of roles, young people may also manage their anxiety by caring for a parent. In one case, a teenage girl repressed her own fears and focused solely on the needs of her ailing mother, refusing all forms of outside help, including home and hospice care. Caretaking was a lifelong survival tool for this teenager, a common adaptation in drug-using families. Unfortunately, her caretaking did not flow from a fully realized sense of self, but instead from a "false self," which Winnicott (1990) describes as a seemingly responsible and responsive cover for an impoverished inner self. Sadly, the false self will not support the emotional demands of adulthood. As parents, "parentified" teens are at high risk for depression, experience intense feelings of longing and emptiness, and risk passing on to their offspring a tradition of excessive sacrifice.

In many cases, the fear, denial, and stigma associated with HIV may shroud the family in silence, preventing children from expressing their anxieties. One of the most traumatic experiences for both parents and children can be the feeling of total helplessness in the face of obvious physical or mental deterioration. Processing this type of trauma and anticipatory grief depends on communication, but many families overwhelmed with stress are not accustomed to analyzing and articulating emotions. Others view the expressions of feelings as futile or as a sign of weakness. Whatever the reason, the trauma of an impending parental death is intensified if the ideas and feelings that surround it remain family secrets.

Without therapeutic intervention, children may live with the unresolved effects of trauma for the duration of their lives. Kerr (1991, p. 293) notes, "Trauma does not ordinarily get better by itself. It burrows down further and further under the child's coping and defensive strategies." Bereaved young people who attempt to master their feelings either by acting out or by "parenting" their own parents ultimately pass along the experience of trauma to their children. Without a supportive extended family, social network, or a mental health professional, bereaved children who become parents will taint the emotional climate of their new families with a legacy of unresolved feelings about their own parent's death from AIDS.

HOW AIDS AFFECTS FAMILY CAREGIVERS

The role reversals that accompany the devastating course of illness are traumatic, but they are also adaptive. Faced with enormous barriers, many, perhaps most, families find some way to survive, at least in the short term. Until we have long-term research, however, we cannot say what may be the costs of coping on the family caregivers and on the children they try to raise.

The African American and Latino families that make up the vast majority of families affected by AIDS in the United States have much experience in finding their own solutions to caring for kin. "Informal adoption"—raising a child as one's own without any legal sanction—has long served as a traditional adaptation to a parent's economic or personal inability to nurture and support a child. Among the strengths of black families identified by Hill (1977) are "strong kinship bonds" and "adaptability of family roles." Similarly, Latino families practice informal adoption called *hijos de crianza;* typically children have *compadres* and *comadres* (godparents) who accept at birth responsibility for their care should the parents be unable to do so (Garcia-Preto, 1982).

However, AIDS—compounded with other contemporary social ills—is placing extraordinary pressures on these informal systems. Families must cope not only with the disease and death of one member, but of several. The stigmatized nature of the disease often isolates them from the few community resources that might be available. If drugs are involved, the older generation may also suffer the guilt of a perceived failure to raise their children properly and the pain of witnessing their own offspring mistreating the beloved next generation. At the same time, they may be overly involved with their adult children, enabling their dysfunctional behavior by giving them money and housing because they are unfamiliar with the various models of drug treatment—such as "tough love," narcotics anonymous, treatment communities, and so on—that may be more helpful (Walker, 1995).

In addition, family members today are often more isolated geographically from each other. The informal adoption of a Puerto Rican child whose parents are dead may mean that he or she is sent from the mainland to Puerto Rico, where he or she faces not only the aftereffects of loss but also of uprooting and adjusting to the differences between the mainland and the island culture.

Women have traditionally taken on the role of family caregiving. Many of the grandmothers and aunts who take over the care of children whose mothers died of AIDS have additional responsibilities caring for children, spouses, partners, elderly parents, and other relatives. Two general outcomes are predictable.

First, some of these women, no matter how willing and devoted, will be unable to continue to bear the escalating burdens of child rearing. Grandparents caring for their grandchildren sacrifice leisure time, health, and financial security. They may become angry, resentful, or emotionally exhausted as they confront the job of raising children who have lost developmental milestones, have poor eating habits, and are difficult to soothe (Minkler & Roe, 1993). Children with HIV have complex needs and require frequent medical appointments, psychotherapy, and special school programs. The final trauma for these grandparents is that they often survive the death of both their children and their grandchildren. In one study of black grandparents, health problems such as diabetes, hypertension, back problems, and low energy were often ignored because the health needs of the children took priority. Some of the grandparents viewed illness and death as their only escape from their burdens (Poe, 1992).

Second, there will be no new generation of grandmothers to take their place. The lost generation of daughters will become a lost generation of grandmothers. For children, this vacuum represents a serious break in family continuity, which is already fragile in many cases. For the

child welfare system, the shortage of grandmothers will mean increased pressure on alternatives to family placements, such as foster or congregate care, possibly within a relatively short time, say 5–10 years.

Writing about African American families, Boyd Franklin, Aleman, Jean-Gilles, and Lewis (1995, p. 56) assert:

> The family myth that grandmothers and extended family caretakers are "towers of strength" is absolutely true, but it does not allow the caretakers to protest when their burdens become too great. As a result, help from extended family members, as well as from medical and social service systems, is usually not forthcoming. Too often, no one discovers the degree of burden until a caretaker has become completely overwhelmed and can no longer care for an HIV-infected child.

For parents with AIDS, the loss of their children either from AIDS or to their parents or other relatives is also traumatic. They suffer terrible guilt and the loss of autonomy that comes from the obligation to negotiate with relatives, or with child welfare agencies, for the right to visit their own children. These parents are no longer in charge of the lives of their children and are vulnerable to feeling rejected by their own children and disapproved of by their families. These feelings emerge especially at the beginning of each visit. Visitation is important, but it is difficult for everyone involved. Grandparents want to maintain ties between the parent and child, but after a visit, grandchildren may require days to settle down (Minkler & Roe, 1993).

"Skip-generation parenting" works in another direction as well. The younger generation may also be pressed to take on caregiving responsibilities out of the normal sequence of family life. While there are no data on the extent of the practice, and it is probably not typical, there are many anecdotal reports about teenagers and young adults (from ages 17 to 20) taking over the care of younger brothers and sisters while the parent is ill and after the parent's death. Sometimes these young people become the parent's primary caregiver during the illness, and it is the parent's wish that the oldest child or oldest girl take over the care of the family (Pinott, 1993). This "parentification" of teenagers will have long-term consequences for their own futures as well as for those of their younger siblings (Zayas & Romano, 1994). On the positive side, these adolescents may learn responsibility, effective coping mechanisms, and nurturing skills. However, they may also feel overwhelmed and resentful of having to assume such a caregiving role, especially when their peers are in school, at work, or simply having fun.

A possible service model for orphaned adolescents is shared foster family care. Traditionally, this option places both parent and child in a foster home; young mothers take full responsibility for their children but are offered support and guidance from the foster parents (Barth, 1994). Adolescents who become "parents" to their siblings could benefit from similar support.,

However, there are legal implications to arrangements in which an adolescent is the primary caregiver. For example, a medical provider may be reluctant to allow a teenager to consent to elective surgery for a younger sibling. If the arrangement comes to the attention of a lawyer, it may be possible for an older person to be named as coguardian. Assessing the stability and security of these new family configurations and finding ways to maintain viable households, while still allowing the young person in charge access to educational and career opportunities, is a formidable challenge.

The generational impact does not end with those already born. The continued spread of infection means teenagers or young adults will face the same excruciating dilemmas about custody of their babies faced by older cohorts of women, in some cases, their own relatives. The procedures, still new and exploratory, that now guide women toward permanency planning

will have to be refined to address adolescent development and to deal with the reality of diminished family resources.

BREAKING THE LINK

How does one deal with loss after loss? How do the grandparent, parent, and child integrate these losses into their view of themselves and their world? How do they maintain hope and avoid despair? What happens to a family that has faced two or three generations of AIDS?

The cumulative effect of the generational losses, added to the losses from drugs and violence, devastates the social, cultural, and economic life of a community. Productive, or potentially productive, young adults cannot contribute to their families' and communities' income and welfare. More intangibly, the continuous psychic assault of deaths upon deaths in the repressive atmosphere of stigma and secrecy inhibits community mourning, healing, and growth.

Yet a reservoir of spiritual strength and resiliency still exists among individuals, families, and communities. Many grandparents have strong connections to the church, and their faith may bring some meaning to the random and seemingly endless tragedies that permeate their lives (Levine & Gamble, 1995). In some families, HIV has, ironically, been a source of positive change. Although no parent could wish HIV to be the catalyst for putting lives in order, many admit that it has forced them to become more responsible in their personal relationships, to remain drug free, and to devote quality time with their children. The Herculean efforts of these parents may help their children break out of the cycle of drug use, poverty, and AIDS.

In the face of enormously challenging conditions, some children in families with AIDS emerge relatively unscarred. Research has identified some of the characteristics that foster resilience. Rutter (1972) found that they had generally bonded with at least one parent or an extended family member. Typically, the most resilient children are girls who are intelligent and are able to respond to a challenging environment. These children have also been able to take advantage of available resources, such as schools, extended families, and religious institutions. Age is also an important factor: Children younger than 11 are three times more vulnerable to the long-term effects of trauma than older children (Davidson & Smith, 1990).

Garbarino et al. (1992) also note that self-esteem, confidence, and a good-natured disposition contribute to resilience, whereas Bowen (1978) sees the resilient child as the one who "differentiates" emotionally from the family system. Bowen has observed that resilient children are generally not the focus of the attacks or emotional brutality that occur within families with limited emotional resources. Combined with the brilliant adaptive responses of children in general, an arsenal to fight the traumatic effects of AIDS exists for some young people. The challenge is to find ways to enlarge it.

All members of a family affected by AIDS are likely to benefit from psychotherapeutic treatment. With proper support, families can learn communication skills that allow them to speak more openly and to grapple with the difficult topics of sex, drug use, disease, and death. Referrals to appropriate community resources may also provide families access to advocacy, entitlements, and legal and housing support.

A number of model programs have emerged to address the psychosocial needs of children and families infected, or affected, by AIDS. In New York City, Beth Israel Medical Center and the Special Needs Clinic at Columbia–Presbyterian Medical Center offer a full range of psychiatric services to all members of an affected family. At The Family Center, a freestanding service and research facility, a clinical social worker, an attorney, a nurse, a housing expert, and other family specialists work in the home to link families to health care systems and to

create a custody plan for the children. Other innovative programs include the Children's Evaluation and Rehabilitation Center at the Rose Kennedy Center and the Community Consultation Center at Henry Street Settlement, which provide a full complement of counseling to families with AIDS, with a special focus on children.

Using a range of techniques—including multifamily groups that involve several generations, children's therapy groups, art therapy, reaction, and home-based care—each of these programs offer a helping hand that may be critical to survival. By tapping into the hidden strengths of most families and helping them to deal with the reality of illness and make viable plans for the future, their efforts may at least partially offset the multigenerational effects of the trauma of AIDS.

Model programs have also been developed in other parts of the world (WHO/UNICEF, 1994). The focus of many programs has been on strengthening the capacity of families and communities to provide for children and to support the caregivers who take over after the parent's death. Some of the services provided include medical care, housing, food, skills training, and education (payment of school fees is a particular problem in parts of Africa). Although the extended family as an institution has great resilience, it is being severely tested by extreme poverty, poor health of family members, and increased burdens of care. A review of the impact of AIDS on the urban Ugandan family, for example, found that AIDS disrupts family life in both material and intangible ways. Limits on a family's mobility—the freedom to take advantage of economic opportunities—because of caregiving burdens is one long-lasting effect (McGrath, Ankrah, Schumann, Nkrumba, & Lubeza, 1993). In Thailand, children, particularly daughters, are the traditional means of supporting parents in old age. AIDS is changing the roles.

> In accepting responsibility for their grandchildren from their deceased sons or daughters, grandparents will be facing increased family support costs at the same time they lose their traditional means of economic support. Given the advanced age of many elderly couples, the likely outcome is . . . that the pressures on young orphaned children to work will be immense. (Brown & Sittitrai, 1995, p. 145)

Despite the real differences in culture, resources, and experience with disease between the United States and other areas affected by the global epidemic, at the most basic human level, there are also strong similarities. Parents grieve the deaths of children; grandmothers take on the care of their grandchildren; children's lives are irrevocably altered by a parent's death. There is much to share, and much to learn from each other, even as we pursue different strategies to heal the wounds.

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