At the age of sixty-three, Ella McIntyre buried her thirty-seven-year-old daughter and three-and-a-half-year-old granddaughter within three months, both dead of AIDS. Despite glaucoma, arthritis, osteoporosis, and chest and back pain, she has not been to a physician in more than four years, except for a fractured ankle. When she quit her job three years ago so that she could care for her daughter and granddaughter full time, she lost all health benefits. A widow living on Social Security, she cannot afford private health insurance, is too young for Medicare, and has an income that exceeds Medicaid eligibility limits. “I can’t afford to be hospitalized and I can’t go for a checkup,” she says. Uncertain of how to move forward with her life, she stays away from home as much as she can, running errands, window shopping, and looking for craft projects so that she can keep busy. Her house has too many memories, and the depression she thought would lift after the Christmas holidays has continued into the early spring. “Sometimes I think I am crazy,” she says, lighting another cigarette. She does not know how to find a job at her age and doubts that anyone would hire her.

Like Ella McIntyre, Rose Crimeri has felt the crushing impact of AIDS on her family. Also widowed, she is the sole caregiver for her eight-year-old granddaughter, Julia. After Mrs. Crimeri’s thirty-three-year-old daughter died of AIDS in Florida the year before, Julia moved to live with her sixty-seven-year-old grandmother in a northeastern suburb. Conflict abounds between Mrs. Crimeri and Julia’s father’s family. He, too, died of AIDS, and although none of his sisters want primary responsibility for Julia, they expect Mrs. Crimeri to bring her to visit each week, regardless of homework or after-
school activities. Mrs. Crimeri would like to adopt her granddaughter, but one aunt told her, “You can’t adopt. You’re too old.”

Julia’s grief and fears related to her mother’s death are among her grandmother’s major concerns. Julia watched the ambulance take her dying mother away. The child then threatened to jump off her loft bed. “I was able to get her to go to a children’s art therapy program given by a hospice program here. I talk with my minister when I’m upset or to a close friend. But my sister is a cold person and not sympathetic.”

Extremely agitated during the interview, Mrs. Crimeri does not know whether Julia is infected. “I am afraid to have her tested. I don’t want to upset her. What would be said to her about the test? Does the school tell the child? Would I have to inform the school [if she tested positive]? I don’t even know what I should tell her about her mother’s death. I don’t know if I want to know [if she is infected].” Although Mrs. Crimeri is financially secure, the unanticipated responsibility of parental surrogacy contributes to her anxiety. “I have no health insurance for her and I don’t know how long I can do this. I am healthy now, but . . .” Her voice trails off as she shrugs hopelessly. “I have to live until she’s eighteen.”

Unwilling to be interviewed in her apartment, Thelma Davis talks about her experience as we sip coffee at a local diner. Employed as a case-worker at a group home for adolescent girls, Ms. Davis is divorced and lives with her infected four-year-old granddaughter Alana, whom she has been raising since birth because of her daughter’s drug addiction. A twenty-six-year-old daughter also lives in the household and helps with some of Alana’s care. Alana’s mother is dying of AIDS and has been living in a residence for infected women. “I am always running—between the hospital [where her thirty-two-year-old daughter is dying of AIDS], home, and work. I never have time for myself. I’m tired and depressed from having lost my father last year.”

Ms. Davis enjoys talking about her granddaughter, although she feels overwhelmed by the responsibility of caring for her. “She is so bright. I can’t keep up with her questions. And I enjoy her company. But I feel like a prisoner. I try hard not to be resentful. I had my kids young and thought I would be free. It feels like she’s been with me forever. I have no time to myself. I can’t just go home and say “I’ve put my eight hours in, now I can rest.” It’s story time, bath time, dinner time. My other daughter and son help out, but it’s on their good will. They won’t cancel their plans. And Alana’s health is always on my mind, even though she is in excellent health now.”
Ms. Davis’s emotional stress profile\(^2\) shows high levels of depression and anxiety. Sleep problems, an ulcer, back pain, and tension are among her physical stress symptoms. “Alana’s four-year-old active mind and my fifty-seven-year-old tired body just don’t go together. I am thankful [given her HIV status] that she has so much energy. She’s doing what a normal four-year-old should do, but I’m doing what a fifty-seven-year-old should not have to do. I know she should be in a regular daycare center. But my sister keeps her, and that gives me peace of mind, especially if I am running late at work.” Managing the disclosure of her granddaughter’s HIV status is stressful. “If I start to look for a regular day care—and I know I have to when she starts school—it means that I have to tell them she’s infected. I don’t want to.”

As these personal narratives illustrate, older adults become surrogate parents to HIV-affected and orphaned children under complex and painful circumstances. Research on African American grandmothers raising children of the crack cocaine epidemic found three patterns by which they assumed parental surrogacy: sudden, negotiated, or inevitable assumption. Whether they assumed responsibility without warning, in tandem with the mother’s parental care, or after a protracted period of maternal behavioral decline, grandmothers felt a profound sense of loss (Roe, Minkler, and Barnwell 1994). Similar patterns and a sense of loss describe the assumption of parental surrogacy for HIV-affected children. Some, like Rose Crimeri, not having known the parent’s HIV status, become the caregiver suddenly when the child’s parent dies. Others offer intermittent household help, HIV care, or childcare over a protracted course of HIV disease. Some, like Thelma Davis, begin caregiving because of parental drug addiction, becoming the primary parent as HIV disease progresses or as addiction disables the mother’s parental capacity. Still others, like Ella McIntyre, quickly assume parental surrogacy because of rapid and progressive physical decline of the infected parent. In each pattern, minor children may be infected, and at different disease stages.

**Chapter Overview**

HIV disease imposes unique and complex circumstances of surrogate parenting determined by the trajectory of HIV disease, medical treatment and family care, AIDS stigma, isolation, death, and loss. This chapter outlines key issues that will be discussed in later chapters. Because most HIV-affected surrogate parents are grandparents and, for some period of time, care for a
family member with HIV disease, usually an adult child of grandchild, I will summarize here the relevant literature pertaining to “grandparents as parents” and HIV caregivers. The extent and patterns of HIV-affected surrogate parenting over the coming decades will be shaped by many factors. I will also review trends in female HIV infection and mortality and access and adherence to new antiretroviral therapies by infected women, especially mothers.

In chapter 2, “Caregiving Profiles,” Carol Mevi-Triano and Elizabeth Paskas present the personal narratives of three women who are raising HIV-affected or orphaned children. In her own voice, each describes how she came to be raising her grandchildren, her fears and frustrations, and sources of support and comfort. Prominent in each caregiver’s profile is a strong spirituality. In chapter 3, “Stigma, Isolation, and Support,” Cynthia Cannon Poindexter describes the nature of the toxic social and interpersonal environment created by AIDS stigma and discusses how health and human service practitioners can address caregiver isolation and reluctance to seek support. The complexity of HIV-related death and grief is the focus of chapter 4, “Death, Loss, and Bereavement,” by Joan Levine-Perkell and Bert Hayslip Jr. They examine bereavement in older adults and children, the impact of multiple family deaths, disenfranchised grief, and cultural determinants of grief and bereavement. In chapter 5, “Caregiver Physical Health and Emotional Well-Being,” Ruth Harrison and I use the concept of the “hidden patient” as a framework to describe caregivers’ chronic and stress-related health problems. Health-promotion needs of older surrogate parents are examined in relation to self-care, help-seeking, and access to medical care.

In chapter 6, “Stress and Social Support in Older Caregivers of Children with HIV/AIDS: An Intervention Model,” Phyllis Shanley Hansell, Cynthia Hughes, Wendy Budin, Phyllis Russo, Gloria Caliandro, Bruce Hartman, and Olga Hernandez describe the role of social support in buffering caregiver stress. The chapter presents findings from an innovative model to improve coping strategies through enhanced social support. The HIV-infected child and adolescent are the focus of chapter 7, “Caring for the Infected Child,” by Jenny Grosz. She examines how pediatric HIV disease and medical treatment affect children’s psychosocial needs and behavior, using cases from a caregiver support group at a pediatric mental health program for infected children. In chapter 8, “Their Second Chance: Grandparents Caring for Their Grandchildren,” Lockhart McKelvy and Barbara Draimin use case experiences from a social service program to describe areas of family conflict as well as caregiver resilience. The chapter offers strategies of family intervention. Chapter 9,
“Custody and Permanency Planning,” by Jan Hudis and Jerome Brown, examines custodial and legal issues related to infected parents’ need to plan for the future care of their children. They present legal options including guardianship, adoption, and foster care with case examples, illustrating the complex permanency planning process. Drawing from a model supportive service program for older HIV-affected parental surrogates, Carol DeGraw describes caregiver case management needs in chapter 10, “Case Management Challenges and Strategies.” She discusses supportive service arrangements, barriers to client outreach and recruitment, and client and system advocacy strategies.


As a global epidemic, HIV disease affects families across national boundaries. With growing rates of HIV infection among women of childbearing age worldwide and rising tides of immigration fueled by war, persecution, and globalization, older caregivers may be recent immigrants who have left their country of origin to care for an adult child and/or her surviving offspring in another country. Terence Doran, Howard Lune, and Rachel Davis use case histories from Mexican families in the South Texas border region to discuss late-life surrogate parenting in the context of migration and immigration in chapter 12, “Immigrant and Migrant Families.” Policies and programs related to child welfare, health insurance, aging, HIV/AIDS care, and welfare reform are examined in chapter 13, “Policy Implications for HIV-Affected Older Relative Caregivers,” by Nathan Linsk, Cynthia Cannon Poindexter, and Sally Mason. The authors discuss how program eligibility, benefits, payment mechanisms, and policy assumptions affect older surrogate parents and their families. Broadening the book’s focus beyond the United States, in chapter 14, “The Global Implications,” Namposya Nampanya-Serpell draws attention to the pandemic’s catastrophic impact on families in sub-Saharan Africa, South and Southeast Asia, and the Caribbean. Nampanya-Serpell presents initiatives at the community level with recommendations for national and international strategies to support the elder generation of caregivers. In the concluding chapter, I propose a framework of elder, family, and community empowerment to guide program and policy initiatives that are designed to support older HIV-affected surrogate parents. Strategies to enhance caregiver well-being, I argue, must promote not only greater personal efficacy but also social
justice, reducing disparities in wealth and income that are concentrating HIV disease and late-life surrogate parenting among impoverished and marginalized communities.

Grandparents as Parents

In part, the strains faced by HIV-affected surrogate parents are no different from those of caregivers who serve because of parental neglect, abuse, drug use, incarceration, abandonment, or non-HIV deaths. By the 1990 census, the dramatic increase in grandchildren living with grandparents or other relatives reflected an unprecedented number of grandparents who were “parents of last resort.” Capturing this national trend in changing household composition and parenting roles, 1997 census data showed 3.7 million grandparents in the United States who were raising minor children below the age of eighteen (Lugalia 1998). Earlier reports found that in one-third of these households the children’s parents are absent (Saluter 1992). More than one in ten grandparents raise grandchildren for at least six months, with manyshouldering the responsibility for at least three years (Fuller-Thomson, Minkler, and Driver 1997). Despite many satisfactions, custodial grandparents face overwhelming physical, economic, and emotional demands reflected in greater psychological distress (Kelley 1993), depression (Fuller-Thomson, Minkler, and Driver 1997), neglected physical health (Rogers 1996; Joslin and Brouard 1995; Burton 1993; Minkler, Roe, and Price 1992) and poorer self-reported health (Marx and Solomon 2000). For many, custodial grandparenting continues a pattern of heavy life burdens, family distress, and economic strain (Burnette 1997; Strawbridge et al. 1997).

Parental surrogacy imposes a financial burden on the vast majority of older caregivers. Fixed incomes are insufficient to meet the needs of an expanded household and growing children. Employed grandparents who reduce work to part-time or withdraw entirely from the labor force lose income, health insurance, and other benefits (Odulana, Camblin, and White 1996; Simon-Rusinowitz et al. 1996). Exclusion of grandchildren or other minors from health insurance policies imposes yet another financial strain. African American and Latino surrogate parents are more likely to assume this additional familial responsibility with low incomes (Fuller-Thomson, Minkler, and Driver 1997). The economic vulnerability of custodial grandparents was documented by an AARP study finding that 56 percent of grandparent-head-
ed households had incomes below $20,000 in 1992 (Chalfie 1994) and that nearly 25 percent of custodial grandparents were living below the poverty line (Fuller-Thomson, Minkler, and Driver 1997). In the absence of comprehensive policies to assist older surrogate parents, those needing financial support face inadequate and means-tested programs such as the Personal Responsibility and Work Opportunities Act of 1996 (PRA) (Mullen 2000).

Financial strain, inadequate housing, and anxiety over children’s developmental, medical, and psychological needs create enormous stress. While resenting the loss of personal time, privacy, and money, grandparents may also feel guilty and inadequate because of their adult child’s failure to fulfill the parental role (Musil, Schrader, and Mutikani 2000). Normal childrearing problems are magnified for those raising children with behavioral needs associated with maternal drug use, parental neglect, and child abuse. Grandparents with drug-abusing adult children contend with theft, physical threats, erratic behavior, and household disruption (Minkler and Roe 1993).

Poorer self-reported health among custodial grandparents cannot be attributed to surrogate parenting alone. Yet consistent findings from small nonrandom and large random samples mark older surrogate parents as a high health-risk population, with poorer self-rated health, greater risk of functional disabilities interfering with mobility, and somatic stress symptoms such as back or stomach pain (Minkler and Roe 1993). Poorer health is especially noted among residents of poor communities and those of color (Dowdell 1995; Joslin and Brouard 1995; Burton 1992; Minkler, Roe, and Price 1992), and those raising children alone (Marx and Solomon 2000). Lack of time, physical exhaustion, anxiety, and depression cause grandparents to neglect their own health (Joslin and Harrison 1998; Jendrek 1996; Joslin and Brouard 1995; Burton 1992; Minkler, Roe, and Price 1992), resulting in missed medical appointments and exacerbation of chronic conditions (Grant 1997; Miller 1991).

**HIV-Affected Surrogate Parenting:**  
**Convergence of Stigma, Stress, and Loss**

HIV disease compounds the stress experienced by older surrogate parents, imposing a *convergence* of HIV-determined issues related to diagnosis, disclosure, stigma, disease progression, symptom and treatment management, dying, and bereavement. The portraits that open this chapter capture some of the problems
older surrogate parents face: neglected physical health, social isolation, depression, AIDS stigma, family conflict, financial strain, and the children’s grief and their own. Those raising infected children have organized their entire lives around the disease and its associated anxieties and responsibilities.

“I sometimes worry about which one of us will die first. Either is more than I can bear to think about,” said Anita Marrone, who is raising her thirteen-year-old infected granddaughter. New antiviral therapies require constant vigilance and fail to abate anxiety. “It’s like being under a cloud. You never know when they could fail... She’s healthy now, but you have to watch every little thing. She’s been complaining of headaches and being tired for weeks. She had bronchitis this winter. You look at everything and wonder...”

**Stigma and Social Isolation**

Exacerbating caregivers’ social isolation because of HIV care, childrearing, and housekeeping, the toxic social environment created by AIDS phobia and stigma erodes emotional and practical social support, leading to social withdrawal by both infected and uninfected (Crawford 1996). AIDS stigma extends beyond the infected person to caregivers and other uninfected family members (Poindexter and Linsk 1998, 1999; McGinn 1996; Fair, Spencer, and Winer 1995; Lesar, Gerber, and Semmel 1995–1996; Christ and Wiener 1994; Roth, Siegel, and Black 1994; Herek and Capitanio 1993; Powell-Cope and Brown 1992). In the face of real or anticipated rejection, caregivers become both socially isolated from family, friends, neighbors and religious institutions (Poindexter and Linsk 1999; Roth, Siegel, and Black 1994; Powell-Cope and Brown 1992), and are reluctant to seek assistance from formal agencies (Lesar, Gerber, and Semmel 1995–1996; Powell-Cope and Brown 1992; Cates et al. 1990).

Ella McIntyre’s world shrank when she become the sole caregiver to her daughter and granddaughter, both with AIDS. “I don’t go out much any more. I’m only relating to doctors, nurses, and family, so I don’t see other people. I don’t have the money to go out and I don’t have many people that I trust.” Support groups for HIV-affected families may be inaccessible to those raising infants and young children, or also caring for an ill or dying adult. At the same time, older adults may be reluctant to attend a support group, having been raised in a generation that maintains the privacy of family issues and speaks less in terms of personal feelings. Cultural values may also prohibit sharing “family business’ outside of the family. Knowing that HIV
is a disease largely of the young, older adults may be reluctant to join support groups where they feel they might be out of place.

Even in families where children are not infected, HIV stigma, internalized shame, and social isolation haunt young and older generations. “My grandsons were teased. "Your mother has AIDS." They didn’t want to play outside. They were getting into fights. I told them to just let it go.” Mae Hawkins’s eyes fill with tears as she talks about her three adolescent grandsons.

Given the fear and reality of social rejection, surrogate parents must often maintain the secrecy of HIV diagnosis even within a close circle of family and friends. In a pristine metropolitan area suburb, I complete an interview with a seventy-two-year-old grandmother who, in a difficult informal arrangement with her former son-in-law, is a co-parent to her six-year-old uninfected grandson. She and I sit in her living room; her sister visiting from California and a neighbor sit across the room, curious about a study on grandparents raising children. Oddly, Evelyn Connor is comfortable continuing the interview in the same room with them, although she lowers her voice to a whisper when discussing her daughter’s death from AIDS. “They don’t know,” she said, gesturing toward her sister and neighbor. Only my niece in New York knows why Ann died.”

Adult children’s reluctance to disclose their own HIV status can impose the burden of disclosing both the parent’s and child’s infection on the surrogate parent (Tasker 1992). Anita Marrone recalls, “My daughter Angela didn’t want anyone to know [she had AIDS] so I couldn’t say anything to anyone. She wouldn’t even let me call any agencies to get help or let me tell Jessie [her granddaughter]. So after her mother died, I had to tell [her granddaughter] that she died from AIDS. And I was the one who told her that she was HIV positive.” Compounding the shame of a stigmatized disease, caregivers may feel responsible for what has befallen their family, wondering, as a forty-nine-year-old grandmother did who had buried her daughter and an infant grandson, “What did I do wrong? My other kids turned out fine . . .”

**HIV/AIDS Caregiving and Stress**

HIV disease intensifies the normal strains of family care of the chronically ill (Pearlin, Aneshensel, and LeBlanc 1997; Walker et al. 1996; Wardlaw 1994), becoming the caregiver’s all-consuming focus. Coordinating medication regimens and medical appointments, managing treatment side effects and disease symptoms, contending with the ill person’s emotional needs, and providing hands-
on personal care and housekeeping assistance impose overwhelming physical and emotional demands on the caregiver. Many older surrogate parents are serial caregivers for several infected relatives, often as they assume responsibility for young children, who may also be infected. Letitia Williams, raising a three-year-old infected granddaughter, had also cared for a daughter and infant grandson, both of whom died of AIDS. Typically, the infected adult is a daughter, daughter-in-law, or son, with many elders facing the infection, illness, and deaths of multiple members of the same generation. Caregiving patterns for infected women in the United States are not well known, although a recent study of HIV-infected parents and their children in that country found that grandmothers were the predominant caregivers (Schuster et al. 2000). Studying infected adults in Thailand, researchers have found that almost two-thirds of those who died of AIDS had been cared for by a parent (Knodel et al. 2000).

Chronic fatigue and physical exhaustion (Turner and Pearlin 1989), somatic physical and psychological symptoms (Trice 1988; LeBlanc, London, and Aneshensel 1997), emotional exhaustion (Turner, Catania, and Gagnon 1994) and depression (LeBlanc, Aneshensel, and Wight 1995) are common among HIV caregivers. A catastrophic illness with an unpredictable course, HIV disease has been termed a “physiological and emotional time bomb” (Roth, Siegel, and Black 1994). Minor health problems of childhood—colds, ear infections, flu, headaches—assume different proportions in families where the child is infected, which explains Anita Marrone’s constant vigilance. Parental surrogates must learn to cope with infected babies and children who may have difficulty swallowing and eating (Marder and Linsk 1995). Caregivers can feel overwhelmed in trying to disinfect the environment to protect the infected family member(s) and in handling blood and bodily wastes to reduce transmission risk to themselves and others (Goicoechea-Balbona 1998; Levine-Perkell 1996). How new combination therapies are transforming family care of HIV-infected children and adult has not been studied. Recent research suggests that as HIV becomes more of a chronic condition, the intensity and length of caregiving may shift (Theis et al. 1997), with family members assuming responsibility for long term care (Cates et al. 1990). Older parental surrogates are likely to be providing HIV-related care to infected adults and children over a prolonged and unpredictable period that includes acute infections, severe symptoms, and treatment side effects. Caregivers are called on to administer medications and treatments and to observe the infected person’s response to treatment (Baker 1999; Baker, Sudit, and Litwak 1998; Freeman, Rodriguez, and French 1996).
Employed caregivers of infected family members worry about taking time off from work when a child is ill or for medical and other appointments. “My boss doesn’t understand my responsibilities for these [seven] grandchildren. She thinks I am just the grandmother. I’m afraid I will lose my job.” Caring for her daughter with AIDS meant that Mae Hawkins had to reduce her job to part time. Like Ella McIntyre, she lost medical benefits when she assumed dual roles of HIV care and surrogate parenting. With the loss of income, Ms. Hawkins worries about how she will pay for medical and dental care for her grandsons, who are ineligible for Medicaid because they are uninfected. Stress and shame are compounded for those seeking financial assistance for infected family members or their surviving uninfected children when they encounter a hostile and demeaning public assistance system (Cates et al. 1990).

Death and Dying

Historically, death has been the most common reason for grandparents assuming parental responsibility for children. Today, HIV/AIDS has “come to rival or surpass other important causes of death taking the lives of mothers of young children” (Michaels and Levine 1992). Older caregivers to HIV-affected and orphaned children often suffer the emotional trauma of an adult child’s death, usually a daughter. Parental loss of a child of any age produces unparalleled and prolonged grief (Levine-Perkell 1996; de Vries and Lana 1994; Gorer 1965). As they assume parental responsibility for a grandchild or other young relative, these older adults confront the loss of the caregiver for their own later years.

Caregiver bereavement over the loss of a daughter or daughter-in-law may be suspended in order to focus on children’s grief, fear or rage at death’s intrusion into their lives. Moreover, as the opening vignette of Ella McIntyre describes, it is not uncommon for HIV-affected families, particularly those of infected women, to face the deaths of multiple family members within a short time (Honey 1988). Grieving for one family member is interrupted by another death. Where HIV has infected multiple members of young families, grandparents and other third- and fourth-generation caregivers face an endless shadow of death. Fearing personal rejection and ostracism, many AIDS caregivers and other affected family members hide the cause of death. “Disenfranchised” grief, spawned by the stigma of AIDS, disrupts the grieving process by isolating the bereaved from potential social supports (Doka 1989). When the tragic circumstances under which surrogate parenting was
assumed cannot be shared, death’s impact as a major cause of stress in one’s life is amplified.

**The Epidemic’s Course:**
**New HIV Therapies and Demographic Trends**

Treatment advances have transformed HIV disease from a fatal illness to a chronic illness that can be stabilized for many years. Highly active retroviral therapy (HAART) can reduce and maintain the HIV viral load, the amount of HIV virus in the blood, to undetectable levels. Infected persons gain extended symptom-free periods and overall improved quality of life. But HAART requires rigid adherence to complex combinations of antiviral agents and prophylactic medications to prevent further damage to the immune system, viral replication, and development of opportunistic infections. Complex therapies may fail, produce drug resistance, and have powerful side effects. Adherence is complicated because multiple drugs must be maintained at the proper temperature, taken at exactly the right time and in relationship to food consumption and digestion. Medication regimens may include as many as four different antiretroviral medications on a daily basis—as many as twenty to twenty-five pills a day—with conflicting dosage schedules (e.g., with or without food) and interrupted sleep. Infected persons must engage in active problem-solving in order to organize personal and family schedules around dosing and medical care, cope with severity and frequency of side effects (dizziness, nausea, vomiting, diarrhea, peripheral neuropathy, and disfigurement [“protease paunch”]), maintain medication refrigeration, get prescriptions refilled, and manage general stress (Erlen and Mellors 1999; Proctor, Tesfa, and Tompkins 1999). In order to minimize disabling side effects and reduce the risk of drug resistance, frequent medical visits are needed for viral-load monitoring and medication readjustment (Linsk and Keigher 1997). Medication regimens can disorder daily life, with a resulting adherence rate ranging from 20 percent to 80 percent (Holsemer et al. 1999).

Media images of the end of AIDS are appealing, particularly at a time of political belt-tightening for social programs that appear to cater to the morally weak and socially marginal, as the HIV-infected are often portrayed. The management of the epidemic appears reducible to the right combination of medications, vigorous medical management, and self-care. Yet as public health and HIV/AIDS communities know well, success stories associated
with the new combination therapies do not tell the whole story (Altman 1997, 1998). Drug resistance and cross resistance to combination therapies result in failure rates as high as 30 percent to 50 percent. In a study of almost three thousand infected U.S. residents, nearly a third who were receiving antiretroviral therapy were noncompliant. Because the sample included only those receiving care over a two-year period, those less adherent to medical regimens and with greater limitations in accessing care may have even greater deficiencies in medical monitoring and antiretroviral therapy (Shapiro et al. 1999). By 1998, the 42 percent decline in AIDS mortality from 1996 to 1997 had dropped to 20 percent for 1997 to 1998. Although the smaller decrease still reflects successful early and aggressive combination therapies, viral drug resistance and adherence barriers are making a mortality rate plateau likely (Fleming et al. 2000).

Early testing, access to expensive therapies, and dedicated, single-minded attention to drug adherence is greatly limited by poverty and family responsibility. Once an epidemic primarily of white, gay men, infected individuals or those at risk are increasingly poor, female, and people of color. In the United States, the majority of new AIDS cases are African American or Latino/a, populations that tend to lack regular medical care and encounter multiple access barriers to testing and treatment (Levi and Kates 2000). Recent data show that infected African Americans and Latinos are tested at a later stage of disease (Fleming et al. 2000) and are less likely to receive HIV care (Shapiro et al. 1999). Between 800,000 and 900,000 individuals in the United States were living with HIV as the new century began (Centers for Disease Control and Prevention 2000), with nearly 300,000 of those women, men and children diagnosed with AIDS (Centers for Disease Control and Prevention 1999).

**HIV Disease and Women**

Female HIV infections represent 30 percent of approximately 40,000 new infections each year (CDC 2000). New infections among women occur at a more rapid rate than among males (Stein et al. 2000; Wortley and Fleming 1997), making women one of the fastest-growing infected groups in the United States. Twenty-three percent of new AIDS cases are female (Levi and Kates 2000), reflecting a steady increase. African Americans and Latinas show consistently higher AIDS rates than do white women (Wortley and Fleming 1997). AIDS continues to be a leading cause of death for women of repro-
ductive age in the United States and elsewhere around the globe. Although female AIDS deaths have declined in recent years, the decline has been less pronounced than for men. Again, the burden of disparity is borne by African Americans and Latina/os.

The course of HIV disease among infected women cannot be separated from socioeconomic and familial circumstances, inasmuch as the majority of infected women are low-income mothers or women of child-bearing age (Sowell, Moneyham, and Aranda-Naranjo 1999). Compared with 18 percent of infected men in the United States, 60 percent of infected women have children, more than three-quarters of whom live with their children (Stein et al. 2000). Because others’ needs take priority over theirs—caregiving responsibilities for children, and often for an infected male partner as well—infected women delay seeking medical care for themselves (Stein et al. 2000; Sowell, Moneyham, and Aranda-Naranjo 1999; Linsk and Keigher 1997). Infected women often neglect their own health because they focus attention on their children, fulfilling their own psychosocial needs in the face of their and their infected children’s mortality. S. N. Broun (1999) describes psychotherapy clients who lacked the energy or strength to eat yet prepared dinner for their husbands. Women may refuse medications to avoid family questions and schedule medical appointments around family obligations and the need to maintain secrecy in the family (Hackl et al. 1997).

In families burdened by HIV and poverty, an older adult, usually the infected woman’s mother or mother-in-law, is vital to sustaining familial and household organization and in providing social support to infected mothers. Among a national sample of infected adults, 30 percent of parents of minor children had AIDS and another 60 percent had symptomatic HIV disease. As further indicators of conditions that would interfere with parental capacity, 21 percent of these parents had been hospitalized during the prior six months, 18 percent had home health-care needs, 45 percent exhibited psychiatric symptoms, and 15 percent had drug or alcohol dependence (Stein et al. 2000). In a study of infected mothers of young children, more than 80 percent said their own mothers were aware of their HIV status, compared with only 20 percent of their fathers. More than two-thirds named their mothers as part of their support network, compared with only 17 percent of their fathers (Williams et al. 1997). Where children of infected females lived with another relative, grandmothers tend to be the predominant caregivers (Schuster et al. 2000). The grandmother or great-grandmother may be the only uninfected person capable of raising children and caring for infected adults.
Because the use of Zidovudine (AZT) has decreased perinatal transmission, there are fewer children infected with the virus. However, improved pediatric treatment means that prenatally and perinatally infected children are surviving into adolescence in families where parents may have died or are also living with HIV disease. In the latter case, mothers may also be substance abusers, living on the streets, or incarcerated—situations where grandmothers are likely to assume parental responsibility. Infected parents may be well enough to parent their children but with intermittent symptomatic periods of a life organized around treatment regimens and side effects. In families where the mother is living with HIV-infected, older adults may be co-parents, fulfilling permanent, temporary, or intermittent parental surrogacy. Practically, helping an infected mother means that the caregiver either shares a household with the younger generations or goes to their home almost on a daily basis. Mornings are especially difficult for someone living with HIV disease. Pain from peripheral neuropathy, chronic fatigue, interrupted sleep, wasting syndrome, strokelike symptoms, and chronic diarrhea make it difficult for a mother with young children to manage HIV symptoms, medication regimen, and side effects and also get children dressed, fed, and off to school. In addition to help with child care and housekeeping, the children’s mother may need encouragement to eat, follow treatment regimens, and get to medical appointments. Loneliness, social isolation, and depression—common among infected women (Hackl et al. 1997; Kaplan, Marks, and Mertens 1997)—can further debilitate an infected mother, increasing her dependency upon an older relative for assistance and support.

Elder Caregivers to Affected and Orphaned Children: A Persistent Need

In the early 1990s the AIDS epidemic was projected to orphan between 82,000 and 150,000 children in the United States by the year 2000 (Michaels and Levine 1992). New estimates that reflect the impact of new therapeutic strategies and continued increase in female infection have not been made, nor are there systematic data as to the number of older adults raising AIDS-orphaned children. However, using the estimated 150,000 orphaned minors, the number of older adults raising HIV orphaned children could reach more than 50,000 by 2010. Grandmothers are the surrogate parents in nearly two-thirds of docu-
mented custodial responsibility for HIV-affected children (Cohen and Nehring 1994; Draimin 1995; Schable et al. 1995) and are raising, on average, two children (Joslin, Mevi-Triano, and Berman 1997). Thousands of other grandparents will care for children whose parent is living with HIV disease yet disabled by the symptomatic periods, acute infections, and treatment side effects. The greatest share will be from poor, African American and Latino/a families, given the disproportionate female infection rate among from these populations. Not all caregivers will be elderly. Childbearing patterns in poor communities yield grandparents in their thirties. Yet where documented around the globe and in the United States, raising HIV-affected and infected children is a late-life generation task, primarily of grandmothers. In countries hardest hit by the pandemic, such as Zimbabwe, recent data show that 45 percent of caregivers of orphaned children were grandmothers, with one-third being sixty years or older (Foster et al. 1996). Data from two New Jersey projects documented caregiver ages from forty-seven to seventy-five and forty-six to seventy-nine, respectively, with mean ages of fifty-nine and fifty-seven (Joslin et al. 1997; Joslin and DeGraw 1998).

Invisible Caregivers

Paradoxically, rather than being more visible because their lives are so multiply burdened, older parental surrogates to HIV-affected and orphaned children and adolescents have been nearly invisible in research and program initiatives. Media vignettes are heart-wrenching and sentimental, but few identify caregiver needs and how community resources are responding to this group of older parental surrogates (Lee 1994). Most AIDS-care research has either focused on caregivers to gay men or has not identified the special issues related to older adults raising affected and infected children (LeBlanc, London, and Aneshensel 1997; Theis et al. 1997; LeBlanc, Aneshensel, and Wight 1995). Though valuable, the scant gerontological research on older adults as HIV caregivers (Poindexter and Linsk 1998, 1999; Hansell et al. 1998; Longman 1995; Brabant 1994; Dolan and Nokes 1992) has not focused on surrogate parents per se but rather on the strain associated with caring for a terminally ill adult child, AIDS stigma, and social isolation. One exception is a phenomenological study of grandmothers raising infected grandchildren (Caliandro and Hughes 1998) that identified common themes in caregivers’
experiences, such as normalization of the infected child, spirituality as a coping mechanism, and diminishing resources. The consuming focus of HIV care, childrearing, social isolation, bereavement, reluctance to self-identify as a family affected by AIDS, and poverty’s grip on family priorities may render older surrogate parents less accessible as a research population (Poindexter 1998; Joslin 1996).

The invisibility of HIV affected older parental surrogates in current gerontological and HIV/AIDS research is paralleled by benign neglect of community agencies, notably those serving HIV-infected persons and those serving older adults. Although nurses, social workers, case managers, and physicians in AIDS care may be aware of the stress experienced by caregivers, the catastrophic nature of HIV disease tends to focus professional time on medical management of infected persons and their psychosocial needs. Moreover, funding guidelines mandate professional attention to only the infected person. The caregiver is brought into focus only as she or he assists the infected person. The Ryan White Comprehensive Resources Emergency (CARE) Act, which is the basis of publicly funded HIV programs, restricts publicly funded services to infected persons or to family members in their caregiving capacity. Services must be terminated once the infected person dies. Comprehensive, family-centered systems of care established under CARE’s Title IV include noninfected family members, but only from the vantage point of the infected person’s needs. Access to case management, transportation, mental health, and psychosocial and family support services is determined by the care plan for the infected family member. Federal technical support documents from the Health Resources and Services Administration (HRSA) outline the Title IV goals as providing funds to “coordinate medical, psychological/social and social support services for women, children, youth and families’ (Health Resources and Services Administration 1997). Yet the needs of caregivers are not specified, and publicly funded initiatives under CARE have not targeted the older caregivers in HIV-affected families.

Seeking to address the unmet needs of HIV-affected older surrogate parents, a countywide AIDS coalition in Passaic County, New Jersey, began its program initiative with a needs assessment conducted with staff of HIV/AIDS agencies. Case managers, social workers, nurses, and program administrators provided insight into the barriers older adults face in accessing supportive services. In particular, staff pointed to systemic issues that contribute to older caregivers’ being overlooked, such as the lack of formal procedures
for screening and assessing caregiver needs. As one social worker noted, “Because they aren’t the focus of the agency, no one stops to assess what they need as they take on responsibility for the children.” Another case manager observed, “We need an evaluation process that would identify at risk grandparents and let them know what services are available. Of course, that also means that we would have to have services in place to refer them to.” The director of an adult HIV medical day program observed, “Most agencies can’t help the grandparents because they don’t have any place to send them for help. There is no central point of information or access for caregivers. Agency staff do not know what is available.” Without programs designed to assist older surrogate parents and accessible to HIV-affected caregivers, staff are not able to offer referrals for supportive services and information. Ironically, as an illustration of these barriers, during one interview a social worker received a telephone call from a grandmother in her mid-fifties who was raising three uninfected grandchildren, ages two, six, and eight. Their mother, an agency client, had died earlier in the year. After reducing her employment to part-time in order to care for the children, the grandmother could not pay a $2,000 utility bill. Because no one in the household was infected, the family was ineligible for both emergency financial assistance and case management under Ryan White funding. HIV diagnosis of a household member confers service benefits that are terminated when the infected person dies. Not only are financial and housing benefits lost, but caregivers and uninfected children are also cast into a “no service zone” where they disappear from the HIV service delivery system, no longer eligible for case management assistance.

Benign ageism and lack of gerontological education also contribute to caregivers’ programmatic neglect. Several staff noted that knowledge of community resources and public benefits for older adults were beyond the training and experience of many professionals in HIV/AIDS care. Even outside the HIV service system, when seeking services from age-integrated programs, older adults are often ignored, losing out in competition with younger age groups for professional attention and assistance (Monk 1990).

Although eligibility for supportive services funded under the Older Americans Act is not dependent on disease diagnosis, chronological age restricts in-home and community services to those sixty and older. Yet, even where older surrogates would qualify for age-restricted in-home and community supportive services, such as case management, housekeeping, respite, and transporta-
tion, the AIDS stigma and ignorance prevents many aging network programs from conducting outreach or program development to assist such caregivers. Although collaboration between HIV/AIDS and aging programs has occurred in New York City, San Francisco, northern New Jersey, and southern Florida (Joslin and Nazon 1996), AIDS-phobia in the larger society infects the aging network as well (Lloyd 1989). Implementing a case-management program for older surrogate parents, a local AIDS coalition’s outreach efforts to a county office on aging were met with, “There's no AIDS here” or “It doesn’t affect seniors” (Joslin and DeGraw 1997).

Vision and Purpose

We live in a time of intense concentration on the part of the media on the bizarre and the tragic. Daytime talk shows glitter with refugees from family turmoil. Ironically, as public and political support for social programs for the economically disadvantaged has diminished, public appetite for stories of personal tragedy has seemingly become insatiable. To focus on older surrogates to HIV-affected and orphaned children runs the risk of sensationalizing yet another group of individuals cast adrift in hopeless circumstances. However, without informed and systematic attention by community programs, practitioners, and policy makers, older HIV-affected parental surrogates will continue to absorb the burden of care with tremendous costs to themselves and their families. The professional practice, political advocacy, and academic research that inform this book express the hope that this written forum will stimulate public advocacy, program development, staff training, and service coordination. Through its relevance to those who work with older surrogate parents, or on behalf of HIV-affected and orphaned children and their families, this book seeks to support those individuals in health and human services, education, public policy, and academia whose commitment is to serve those on the margins of society, living in the shadows without a voice. Produced in a climate of “welfare reform” and in the absence of political debate about national health insurance, the book’s authors affirm collaboration across professional disciplines and service systems. The isolation that compromises caregivers’ well-being is paralleled by our professional isolation within and across disciplines and programs, an isolation that weakens our capacity to be truly effective advocates and innovators.
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Notes

1. The names of caregivers have been changed to protect their privacy.
2. The cases described here are drawn from an exploratory study conducted in 1996 in northern New Jersey whose purpose was to gather descriptive information about older surrogate parents of HIV-affected and orphaned children. Study objectives, methodology, and findings will be reported in greater detail in chapter 5, “Physical Health and Emotional Well-Being.”
3. Not all older surrogate parents to HIV-affected and orphaned children are grandparents. Great-grandmothers and great-aunts also assume this role. Yet because case records from HIV service programs indicate that most older parental surrogates are grandmothers, the relevant literature on these “parents of last resort” provides a framework for understanding the issues faced by third- and fourth-generation family members raising children.

References

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