

The "Hidden Patient"¹: Older Relatives Raising Children Orphaned by AIDS

**DAPHNE JOSLIN, PhD, MPH
RUTH HARRISON, RN, PhD**

In the United States today, thousands of grandmothers and other third- and fourth-generation relatives are raising children and adolescents whose primary parent, usually the mother, has died from acquired immune deficiency syndrome (AIDS) or is too ill to serve as the primary parent. More than 100,000 children below the age of 18 are expected to lose their mothers to AIDS by the year 2000, most in poor communities. Isolated by the demands of caregiving, child care, and the stigma of AIDS on even uninfected family members, this group of older surrogate parents is at risk not only for chronic conditions and stress-related somatic complaints, but for neglected health. Using the gerontological concept of the "hidden patient," this article presents four cases drawn from an exploratory study of the physical and emotional health risks and health behaviors of older adults raising children orphaned by AIDS. External and internal barriers to self-care are described, including lack of child and respite care and health insurance, caregiver depression, and denial of health problems.

The silent legacy of human immunodeficiency virus (HIV) is a generation of motherless children and adolescents² and a generation of grandparents and other older relatives who have become their surrogate parents. As many as 125,000 US children and adolescents are expected to lose their mothers to AIDS by the year 2000, most in poor, urban communities.³ The projected number of HIV-

orphaned children and adolescents in New York State will reach 24,000 to 33,000⁴ and in New Jersey 14,300 to 20,500 by 2001.⁵ Where custodial arrangements have been documented,⁶ grandmothers are typical primary or sole caregivers to children whose primary parent is living with or has died of AIDS. Less prevalent third- and fourth-generation caregivers include great-grandmothers and great-aunts.

"Skipped generation parenting" has become a national trend over the past decade, with at least three million children living in households headed by grandparents, according to US Census figures.⁷ Recent social and epidemiological trends associated with late-life surrogate parenting, such as the HIV/AIDS and crack cocaine epidemics and increased incarceration of women, disproportionately affect poor communities.⁸ National data on custodial grandparents indicate a greater likelihood of late-life surrogate parenthood among African Americans, low-income individuals, and single women.⁹

This article describes the health status of older adults who are raising AIDS-orphaned children and adolescents and identifies barriers to self-care. The article uses four case studies to present data on health, somatic complaints, chronic conditions, health-related limitations, and health behaviors among these caregivers. Implications for patient education and counseling and for public advocacy are discussed.

Gerontologists use the concept of the "hidden patient"¹ to describe the neglected physical and mental health needs of family members caring for chronically ill older relatives. The experience of older adults who are raising AIDS-orphaned children and adolescents suggests new relevance of the concept. Recent studies of grandparents serving as parents identify these older caregivers as a high-risk population, particularly if they are in poor communities or marginal

economic circumstances.^{8,10,11} Grandmothers raising children because of mothers' crack cocaine addiction reported deteriorated physical and emotional health since assuming custodial responsibility.¹² Nearly half assessed their physical health as "poor" or "fair," a sharp contrast to the majority of older adults in the United States who report their health to be good, very good, or excellent.¹³ The time demands of child rearing can preclude attention to the caregivers' own health,^{8,10,11} resulting in missed medical appointments and exacerbation of chronic conditions.¹⁴ Older surrogate parents' poor physical health may be associated with the stresses of surrogate parenthood, life burdens prior to custodial grandparenthood,¹⁵ and inadequate income.¹⁰

Compounding economic and familial strains associated with late-life surrogate parenthood are stresses imposed by HIV diagnosis and disease progression, including the stigmatizing of infected and uninfected family members;¹⁶⁻¹⁸ social withdrawal and isolation;¹⁹⁻²² the eventual death of children, siblings, parents, and other family members; and disenfranchised grief, that is, grief associated with a death whose circumstances must be hidden.²³ Thus child rearing often occurs in the context of grieving the loss of (multiple) family members,²⁴ including grandchildren, sons, and daughters.

Even with new treatments that lengthen the time between diagnosis and incapacitating illness, HIV continues to be a catastrophic disease with an unpredictable course, numerous remissions, complex treatment regimens, and debilitating side effects. Described as a "physiological and emotional time bomb,"²¹ the disease process itself exacerbates the strains of familial caregiving,²⁵⁻²⁷ giving rise to somatic physical and psychological symptoms^{28,29} and emotional exhaustion.³⁰ In addition to coordinating medical appointments and medication regimens, managing symptoms and treatment side effects, caregivers must also

Dr. Joslin is associate professor in the Department of Community Health, and Dr. Harrison is associate professor in the Department of Nursing, both at the William Paterson University of New Jersey.

cope with the infected child's fears and anger. Those raising adolescents contend with the child's grief and rage at the prospect of a shortened life and a disease that marks them as different from others.

Despite physical and emotional health risks, older adults raising children orphaned by or infected with HIV are likely to be "hidden patients."¹ As a family disease,^{18, 19} HIV can become the consuming focus of a family's attention and time, overshadowing all other needs. Internalized shame and stigma, social isolation, lack of child care and transportation, and inadequate finances also reduce the likelihood that the older relative her/himself will seek attention for less than acute care needs. Although the caregiver may be in contact with on-site and in-home health care providers, funding restrictions limit medical and nursing care to the HIV-infected person. Family caregivers raising uninfected children become more invisible once the HIV-infected person dies and there is no longer a household member who is receiving HIV-related services.

Methods

While recent studies of grandparents as parents have included those raising AIDS-orphaned children,^{31, 32} no systematic research has addressed these caregivers' needs. To redress this neglect, we conducted an exploratory study to gather descriptive information about self-reported physical and emotional health, physical and psychological stress symptoms, self-care behaviors, and access to health care. The study was conducted in 1996 in northern New Jersey, using a nonrandom sample of 20 older caregivers recruited through HIV/AIDS programs in Bergen and Passaic Counties. Potential subjects were referred by home care agencies, hospice programs, HIV pediatric and adult outpatient programs, social services agencies and other professional contacts. Eligibility criteria included having major daily responsibilities for at least one child 18 years or younger whose primary parent had either died of AIDS or was too ill to function as the primary or sole caregiver. In addition, the caregiver had to be a third- or fourth-generation relative of the child and at least 45 years of age. Representa-

tive sampling was used to insure a balance of African-American, Latino, and Euro-American caregivers. Fifteen English and five Spanish face-to-face interviews were conducted.

The research tool consisted of a modified questionnaire used in a study of custodial Latino grandparents in New York City.³² Global measures of self-reported physical and emotional health that had been used effectively in studies of older adults,³³ African Americans,^{34, 35} and African-American surrogate parents in the crack cocaine epidemic¹⁰ were incorporated into the research instrument. Data on self-reported health, chronic conditions, somatic complaints, medical care, health insurance, and demographic information were gathered. This included information on the HIV status of the child, exclusive or supplementary parental responsibilities, the number and ages of children, difficulties encountered as a surrogate parent, and the circumstances under which responsibility for children was assumed. Semi-structured questions provided qualitative data on how much attention caregivers devoted to their own health, the impact of caregivers' health on daily activities, and self-care. Given the sample size and its lack of random selection, the study findings cannot be generalized. Rather, the four cases are used to identify common themes in caregiving circumstances, self-reported health, and self-care.

Results

To provide a context for describing perceived health and health needs of the four cases, findings from this pilot study (Joslin and Harrison, unpublished data, 1997) are summarized in the table.

Six caregivers had experienced the death of an adult child from AIDS within the year prior to the interview. Forty-six percent of those raising an infected child were sole caregivers. Although all of the children's parents had diagnoses of AIDS, the initial reason for surrogate parenthood also included parental drug use (20%), child abuse or neglect (10%), and parental incarceration (5%).

Subjects' global physical health assessments were about evenly divided, with 45% of the sample reporting their physical health as "excellent" (n=5) or "good"

Characteristics of Study Sample (n=20)

	No.	%
Age (Mean 59. 6 s.d. 7. 21)		
47 - 49	2	10
50 - 54	2	10
55 - 59	7	35
60 - 64	5	25
65 - 69	1	5
70 - 75	3	15
Race/Ethnicity		
African American	9	45
Hispanic	5	25
Euro-American	6	30
Asian	-	0
Native American	-	0
Household income		
Under \$7,499	1	5
\$7,500 - 13,499	3	15
13,500 - 19,499	7	35
\$19,500 -24,499	3	15
\$25,000 +	6	30
Primary caregiver	17	85
Not primary	3	15
Sole caregiver	8	40
Not sole caregiver	12	60
Number of children being raised (Mean: 2.25, s.d.: 1. 94)		
1	12	60
2	2	10
3	2	10
5	2	10
6	1	5
7	1	5
Child's HIV status		
Positive	13	65
Negative	7	35
Relationship to child		
Grandmother	18	90
Grandfather	1	5
Aunt	1	5

(n=4) and 55% as "fair" (n=9) or "poor" (n=2). These proportions parallel those of the Oakland study¹⁰ of grandmothers of the crack cocaine epidemic and may reflect income. National data⁷ on adults 65 and older show that 41% of those with incomes below \$10,000 and 30% of those with incomes between \$10,000 and \$20,000 view their health as "fair" or "poor." An important contrast, however, between the Oakland study¹⁰ and ours is that 55% of the AIDS-affected caregivers reported a decline in health over the past year, compared to 28% of the grandmothers of crack cocaine-affected children. Surrogate parents to the AIDS-affected children had an aver-

age of three chronic health conditions, ranging from zero to seven. Although statistically significant associations among a small sample must be interpreted with great caution, consistent patterns of poorer health were found among those who were sole caregivers, raising more than one child, raising an HIV-infected child, and age 59 or younger.

Case Studies

The cases selected for presentation are typical of caregivers whose self-rated health was poor or fair. All four reported multiple chronic health conditions, arthritis being the most common. In addition, all mentioned stress-related somatic complaints and chronic conditions aggravated by stress.

Case # 1. Ms. H is a thin, tired-looking, 57-year-old African-American woman employed as a nutritionist for a Head Start program. Divorced, with some college education, she lives with her seven grandchildren, ages 5 to 13, in a relatively spacious, low-rise public housing project in the center of one of New Jersey's poorest cities. The family has a household income of less than \$17,000 a year.

None of the children are HIV infected. Ms. H is proud of her grandchildren, the oldest girl is "an A and B student and very active in church." She is raising the five granddaughters and two grandsons alone and has been the surrogate parent for 11 years. Her two daughters, the children's mothers, are both drug users, one of whom is infected with HIV. Ms. H's concerns as a custodial grandparent speak directly to the stress she faces. "I'm afraid to let them out to play. I worry about the neighborhood with the drugs and police activity. Police race through the walk way, endangering the children who play there. I won't let the children, especially the girls, go out alone."

Raising her grandchildren has meant reducing her hours of work. "I'm supposed to work from 8 to 4 and I have to take time off from work to get [the youngest] to school. I'm afraid to keep taking time off because the job may be laying people off. I almost got fired because of the children. If they're sick or not in school, what am I to do? When they're out of school I have to take them to work with me. My boss is not sympa-

thetic. But I'm not going to leave them to run around by themselves."

Financial needs, discipline concerns, and coping with children's emotional reactions to their mothers' addiction and illness are compounding pressures. "I have no time for myself. I am pooped. By the time I get home, do dinner, help with homework, get them from [sports] practice. There's no time left for me. I had planned to travel but I can't now. I miss doing things I used to do, like going to plays, visiting other churches. I was really into a lot of things. Like tomorrow, there's a trip to a church in Pennsylvania. I was supposed to go but I told them no. I want to get my ironing out of the way. I have to be where I am needed. My grandkids come first."

Ms. H described her health as "fair," although worse than before she began raising her grandchildren. "I had no problems then." Her health has deteriorated over the past year. She has lost weight, gets less exercise, experiences greater fatigue, and has greater difficulty sleeping. A tobacco user, Ms. H is smoking less than one year ago. As she described these health problems she noted, "I have two asthmatic [grand]children. The doctor says [sleep problems] happen as you get older." Ms. H wears a neck brace for pain, which she attributes to stress and to an accident several years ago.

Self-reported chronic health problems include vision problems, diabetes, arthritis, high blood pressure, and an undiagnosed lung problem. "There is a milky substance on my lungs. The doctor says it could be cancerous. I gotta go for tests." Ms. H has medical insurance for herself through her job, but it does not extend to any of the grandchildren, including the two who have asthma.

Several months following the interview, the HIV-infected daughter died on the street, of hypothermia.

Case #2. Mrs. F is a 62-year-old Euro-American widow living in her own home in a working class suburb with her 37-year-old daughter and 2 1/2-year-old granddaughter, both of whom have AIDS. She completed some high school and was employed as an office worker until she was laid off when her daughter was pregnant. Once they both became ill, she could not go back to work as she

maintains their home — providing meals, housekeeping, transportation, and other basic tasks. "I've used up lots of money to care for them. Social Security doesn't make it. My charge card is maxed out." Even though the family receives financial assistance through Social Security Disability for both the daughter and granddaughter, Mrs. F is having difficulty paying their bills. She is especially worried about paying the mortgage once her daughter and granddaughter die and disability payments are terminated.

Mrs. F's daughter, weakened by AIDS, still cares for her daughter, but relies on her mother's daily help with the child's medication regimen and other needs. The granddaughter is physically disabled, unable to walk or speak, and stands only with assistance. Medical appointments and hospitalizations for both the daughter and granddaughter organize Mrs. F's life. "I learned that Janna, my granddaughter, was HIV positive on her first birthday. She was born with a lot of problems. I didn't think she'd live. Finally, she was diagnosed at Babies Hospital. That is how my daughter learned that she [also] was infected."

Family conflict over the HIV diagnosis also burdens Mrs. F. One daughter-in-law has been very unsupportive. "She thinks I didn't tell them right away, that I lied. And I don't know what she told her kids because they don't come around as often."

The sense of social isolation is profound, as it was in the case of Ms. H. "I went to a group for other mothers of women with AIDS, but they were ready to fight. I was ready to sob, so I never went back." I don't go out much anymore. 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 I trust." Her confidant is a sister who lives across the country in Texas. Her enjoyment of social events with other HIV-affected families with children is evident as she shows photos from a Christmas party for HIV-infected children.

Mrs. F showed little emotion of any kind during the interview, but when asked how her own health compared to the time before she assumed care for her daughter and granddaughter, she became

tearful. "I get very emotional talking about them." Her outlet is gardening. "When I get upset, or it gets too much, I go outside and dig." One area of the garden is named for her granddaughter.

She assessed her health as "fair" and as having deteriorated over the past year. Chronic problems include glaucoma, hearing deficits, arthritis, and osteoporosis. She also complained of dental pain, indigestion, sleep difficulties, chest and back pain. Nervousness and tension may occur at times and may last for a few hours or persist for several days. Mrs. F lost medical insurance when she stopped working to care for her daughter and granddaughter. Despite her chronic conditions and symptoms, she has no regular source of medical care. "I can't afford to be hospitalized and I can't go for a checkup." At age 62, she is too young for Medicare, but her income exceeds Medicaid eligibility. Her last physical exam was more than four years ago.

Her daughter died 11 months and her granddaughter 13 months after the interview.

Case #3. Ms. T is a 60-year-old, divorced, Puerto Rican grandmother who is raising two grandchildren by herself. A high school graduate who also completed beauty school, she is employed as a factory worker. The family's household income is between \$16,500 and \$19,499 a year.

She was extremely agitated during the interview. Her grandson, age 15, the younger of the two, has AIDS and "is always sick." His parents died from AIDS; his father, Ms. T's only son, six months prior to the interview. A major focus of the interview was Ms. T's emotional distress. She rated her emotional health as "very poor" because of "all the problems I've been through." Depressed and experiencing tremendous anxiety and "nervousness" she cried through most of the interview. When asked what she does when feeling down or blue, she responded: "Cry, cry, cry. There is no other escape." Her sense of isolation is acute. "I cry at work" but "have no one to talk to. I speak only Spanish and everyone in the neighborhood is 'old' American." She talks on the telephone frequently to her daughter in Puerto Rico, "but she has her own three chil-

dren." Ms. T feels greatly burdened in caring for her grandson because her "grandchild is very sick and I am helpless." The volatility and stress of the situation were evident during the interview: The grandson screams at her, "I hate you. You're not my mother. I want to die, I don't want to live this life anymore."

Ms. T stated, "I am seeing a mental health counselor now and on medications for my nerves. There is a lot of tension, and I suffer from great lack of sleep. I am extremely tired but I have to work to take care of my two grandchildren." Ms. T reported "fair" health, about the same since she began raising her grandchildren and slowly improving over the past year. She reported hearing loss, arthritis, a hernia, and "stress-related" high blood pressure. Fatigue, arthritis pain, dizziness, shortness of breath, chest and back pain, and poor appetite were somatic complaints.

Although Ms. T has a regular source of medical care and medical insurance, she often lacks the money for a taxi. Chronic arthritic pain makes public transportation inaccessible. She had seen a physician once in the past six months for her arthritis.

Case #4. Ms. W. is a soft spoken, 58-year-old, divorced African-American woman who is employed part time as a food production demonstrator. Her annual household income is approximately \$24,000 a year, including her daughter's Social Security Disability payments, which will be terminated on her daughter's death.

Ms. W is raising her daughter's three adolescent sons, ages 16, 15, and 10, none of whom are infected. The family lives in a housing project in a poor section of the city. "I worry about the unsafe neighborhood. I'm screaming if they're not upstairs by 9 o'clock." Financial needs are a major problem. "The kids want things and I can't afford it. I would like to go out to eat or to shows as a family but we can't afford it." The children receive welfare payments that do not cover both household expenses and health care. "Andrew's money has to be used for the rent and other things we need. Something should be done about medical care when you don't have insurance." One grandson has asthma and

needs glasses, and all three need to see a dentist.

Ms. W was tearful during the interview. She acknowledged feeling very depressed and would like counseling to deal with her own emotions and those of her three grandsons. "Sometimes they see me crying and ask what the matter is. They're good boys. They appreciate what I do for them, my cooking. I consider myself a good mother and grandmother."

The children's emotional pain weighs upon her. "They ask a lot of questions I can't answer. I don't know what to say. Will their mother die soon? I tell them she could. I'm crying because I can't answer." Tearfully, she described the stigma of AIDS on her grandsons. "Before her sickness was verified, the kids around here teased them. 'Your mother has AIDS.' They'd throw it up in their faces. They [grandsons] wanted to move. I'd just tell them to let it go."

Ms. W's self-reported health is "fair" and worse than one year ago. "I'm dealing with my daughter's poorer health. I look at her and that bothers me, because she once was up and around. This past year has been very hard on me. She was in the hospital, very sick and it was very hard." Somatic complaints—headaches, dizziness, shortness of breath, back pain, and nervousness—may last for as long as two hours; headaches can become so extreme that "I can't lift my head." Chronic health problems include arthritis, angina, which is "under control," and high blood pressure.

Ms. W's daughter died ten months after the interview.

Subjects were asked whether their daily activities were affected by somatic symptoms or other health problems, about self-care for health problems they experienced, and whether there were changes in six health behaviors (exercise, sleep, appetite, psychotropic medication use, smoking, and alcohol use). They also were asked whether they had enough time to take care of their own health, whether they had medical insurance and a regular physician, and whether they had seen a physician within the past year.

Case #1. Somatic complaints included shortness of breath, neck and back pain, sleep difficulties, and tension. For problem's attributed to stress, Ms. H does

“nothing, I just go to my room for some peace. The children know I need to be alone for a few minutes. I also seek medical advice. My doctor advised me to get my daughters out of the house or it would affect my health.” Ms. H has been seen by her physician three times over the past six months.

As the sole caregiver for seven grandchildren, Ms. H is only “sometimes” able to devote enough time to her own health. “If I have fewer kids home because they’re gone on a trip with church then I do have more time.” But her sense of responsibility for meeting their needs takes precedence over time for herself, including time to relax and socialize. “On weekends I do my laundry. I do my ironing on Friday night. I’d rather get my ironing out of the way. I do less now, I used to iron all their jeans and shirts and dresses.”

Despite multiple chronic conditions and pain, when asked whether any health problems interfered with or limited what she needs to do or would like to do for her grandchildren, Ms. H said emphatically, “No. I won’t let it.” Earlier in the interview she stated “I struggle with the (neck) pain to do what I need to do. I may have to go back to therapy.” Somatic complaints interfere with what she needs to do “only when I exert myself.”

Case #2. Self-care for somatic symptoms is “going to bed,” while general self-care is described flatly as “nothing.” Mrs. F’s last medical visit was four years ago, and she has no regular primary care physician. She reported adequate time for her own health needs, which means getting a nap every day. “I sleep terribly, about four to five hours a night.”

Over the past year, she has gained weight, is smoking more, and experiencing greater fatigue. “When I’m tired, I smoke more.” When asked whether any health problems or physical symptoms limited what she’d like to or must do for her granddaughter, Mrs. F replied, “Is anyone else going to read this? I’m afraid if something happens that Janna’s father, who has wanted nothing to do with her, will fight me for custody. But I’m really old. I tire quicker.”

Case #3. Somatic symptoms and chronic conditions “only temporarily” affect Ms. T’s daily activities. However,

she noted earlier that “sometimes (she) feels extremely limited” by arthritis pain in what she would like or needs to do for her grandchildren.

When asked whether she is able to devote enough time to her own health, she replied, “No, I’m careless. I go to a doctor only when I can’t go on. I have to think about other people before I think about myself. I don’t have enough time to take care of my own health.”

Because of her agitation, Ms. T did not respond to the question, “If you are having a problem with your health, what are you most likely to do?” She merely listed her health problems again—arthritis, hernia, and tension. Self-care for somatic symptoms (shortness of breath, chest pain, tension, dizziness, and poor appetite) is to “lay down.” When asked about exercise she says, “I have to work to take care of the children. I have no financial help.”

Case #4. Ms. W reported that stress-related somatic symptoms, especially headache pain, affected her activities. “Sometimes I can’t lift my head.” Yet earlier in the interview, she reported that health problems did not interfere with or limit what she can do for her grandchildren.

Over the past year, Ms. W has gained weight and is getting less exercise. She admitted that she is “too heavy” and that being overweight probably contributes to her back and leg pain and shortness of breath. “My friend and I used to walk before I went to work. But now I want to make sure the kids are off to school. I want to be sure they eat, and that everything is just so. They appreciate what I do for them—I make pancakes for breakfast and cinnamon buns. But I was just talking about that with my friend, and I want to start walking again.” When asked whether she has enough time to devote to her health, she replied “Yes. I get headaches and my grandsons will say, ‘Sit down.’ I try to get rest.”

Ms. W is ineligible for Medicare because she is only 58. She receives no medical insurance from her job because she works only part time. She asserted, however, that she seeks medical care when needed from a local hospital. “When I need medical attention I get it.”

Discussion

With renewed interest in health promotion for older adults, greater attention has been given to the concept of self-care, which can be defined broadly as “intentional behavior that a layperson takes on his or her own behalf, on behalf of the family, friends, or community to promote health or to treat illness.”³⁶ Management of chronic illness³⁷ and health promotion activities such as diet, exercise, seeking medical care, and compliance with prescribed treatment plans are all components of self-care.³⁸ These case studies illustrate the complexity of self-care by older adults whose socioeconomic circumstances, family responsibilities, psychosocial and behavioral responses to the stress of their lives compromise their efforts in health promotion and disease management.

The cases also illustrate areas for patient education and counseling to support and promote self-care. Despite “fair” self-reported health and reports of fatigue and chronic pain, all four women described themselves as having no global health-related limitations, especially when it comes to caring for their grandchildren. In general, caregivers were reluctant to report any negative impact of health problems on caregiving capacity. Yet in discussing specific symptoms, several described having to lie down. Ms. T reported feeling “extremely limited” by arthritic pain.

The need for self-care is evident in these four women, but compromised by external and internal barriers that detract from their ability or motivation to attend to their own health needs. External barriers identified by this study included no health insurance; no respite from AIDS-related caregiving, child care, or housekeeping; and lack of transportation. Older surrogate parents who are without health insurance are caught in a bind: too young for Medicare, too rich for Medicaid, and too poor for private insurance.

For those who are caring for HIV-infected adult children, grandchildren, or other relatives, the catastrophic nature of AIDS determines daily priorities. Medical appointments, hospital visits, medication regimens, pain and infection management, and negotiation with enti-

tlement systems can overwhelm the caregiver, leaving no time or energy for all but the most pressing problems. It is not surprising, therefore, that caregivers themselves spend little time attending to their own health needs.

The demands of child rearing and running a household, especially as the sole caregiver, or where raising two or more children, or an infected child, leave no time for self-care except in acute episodes. Housekeeping, child care, helping with homework, escorting children for safety, and securing necessary benefits, crowd waking hours.

Prior negative experience with the health care system and perceptions of lack of holistic, respectful care by medical personnel is an external barrier that can create internal barriers. One grandmother raising her infected four-year-old granddaughter was "turned off" to doctors recently by the lack of sensitivity of staff at the HIV treatment center where her granddaughter is a patient, by hospital staff during her daughter's final days before she died of AIDS, and by the lack of compassionate care by a physician she feels "doesn't really care about me." Despite an ulcer and other somatic complaints, she has not visited a physician in more than a year.

Evidence from our pilot study (Joslin and Harrison, unpublished data, 1997) and national data⁹ show that older surrogate parents in the HIV epidemic are likely to be heading economically marginal households. Poverty, an external barrier to self-care, may give rise to internal barriers. Economic survival is a constant, daily issue, with only acute medical needs receiving attention. Preventive or primary care is a luxury beyond the capabilities of these families. For some poor or marginal income surrogate parents, ignoring health problems "until I can't go on" as one caregiver stated has been a lifelong practice.

Individual attitudes, beliefs, values, and problem-solving strategies can all be internal barriers to self-care. Ms. H and Ms. W illustrate similar strategies for managing the emotional stress of loss and caregiving and of providing a stable home for children whose parents were lost to the streets and drug use: they invest themselves in household chores.

Both women have multiple, stress-related health problems, yet when faced with the possibility of taking time for socialization, relaxation, and exercise, Ms. H irons clothes for seven children, and Ms. W makes her grandsons fresh cinnamon buns and pancakes for breakfast.

Other internal barriers include denial or diminishment of health needs, doubt about the efficacy of self-care, a culturally diminished sense of one's own needs as a priority, and caregiver depression. Denial of health needs is associated with several factors. Mrs. F illustrates fear of disclosing a health problem or limitation of energy and stamina. Will admitting to health problems alert family members or child welfare authorities that the older person is physically unfit as a caregiver? This anxiety can be kept at bay if one denies that health problems require medical attention. Custodial grandmothers raising children affected by the crack cocaine epidemic also denied any limitations in their ability to carry out normal activities of daily living, running a household, and caring for their grandchildren.¹⁰ Although older surrogate parents deny health problems, they are anxious about their ability to continue in this role, given their age and overall health.

A sense of relative health also contributes to denial. Older relatives who become surrogate parents, especially in the wake of HIV, are the "survivors" who outlive their own children. The caregiver's own medical problems may pale in comparison to those of a person living with AIDS. As Minkler and Roe observed, grandmothers in the crack cocaine epidemic are the hardy ones of their generation and self-select for this responsibility.¹⁰ Surrogate parenthood may be an affirmation of health. Burnette distinguished between denial of health problems and reframing them in the context of the demands of one's daily life.¹⁰ Caregivers may also reframe their health problems in the context of peers, as Ms. H did. "Many people my own age are not as active."

Assumptions that equate medical symptoms with normal aging³⁹ also mask caregiver health needs and contribute to older caregivers becoming hidden patients. If physical complaints are viewed as signs of aging rather than as disease symptoms,

they are likely to be neglected by both the older adult and health care providers. Mrs. F attributed her fatigue and lack of energy to being older, and Ms. H reported that her physician interpreted her sleep problems as normal for her age.

Cultural and generational values may also diminish the importance of the caregiver's own health needs. Giving attention to one's own problems may appear selfish. Indeed expressing "needs" apart from those of one's family may run counter to world views common among people of African, Asian, and Latino ancestry that emphasize the interdependence of family members.⁴⁰ For many third- and fourth-generation caregivers, the family is the basic unit of reference, not the individual, as expressed by Ms. T, "I must put other's needs ahead of my own."

Finally, caregiver depression is also an internal barrier to self-care. Emotional distress may undermine motivation to engage in health-enhancing behaviors, as the following excerpt from Mrs. F's interview illustrates. Describing herself as being a "little depressed," Mrs. F said "I don't look toward the future." A sense of hopelessness marked her observations about changes in her health over the past year. "I've gained weight—I put on ten pounds from eating ice cream. It's like I don't care."

Policy and Practice Implications.

Despite the promise of new treatments that extend life for those infected with HIV, the number of older surrogate parents raising HIV-affected and infected children will not diminish over the coming decade. Female mortality rates, especially for women of color, have decreased much less dramatically than those of white men, and female infection rates continue to increase (*New York Times*, September 1997: A26). Zidovudine has decreased perinatal transmission,⁴¹ thus even more children will survive HIV-infected mothers to be raised by third- and fourth-generation caregivers.

Nearly a decade ago the concept of "secondary survivor"⁴² was used in African countries to refer to the older generation of family caregivers experiencing the devastating impact of HIV on the lives of young parents. While older adults who become surrogate parents may be

healthier than others who decline this responsibility,¹⁰ these “parents of last resort” are still a high health risk population.¹² Neglected health among today’s older surrogate parents will affect their health and well-being as they continue to age, placing them at greater risk for chronic illness and functional deficits, and may compromise their capacity to provide stable homes for dependent children and adolescents. In addition to the human costs of this neglect are the potential costs to taxpayers for children’s foster care and more costly medical care for the aging caregiver.

Physicians and other medical personnel who encounter these older adults often wonder why they appear to neglect their own health, especially when the welfare of the children depends so heavily on it. Although grandparents and other older caregivers may deny their own health problems, they also express concern about staying healthy and alive to see these children fully grown. This concern can be the basis for self-care motivation in patient counseling and education. By recognizing internal barriers to self-care, physicians and other health professionals can emphasize that attending to one’s own health contributes to their efforts on behalf of their families. Because these caregivers may have infrequent contact with their own physicians, pediatricians and HIV physicians are well positioned to encourage self-care and to make necessary referrals. Making caregiver well-being a priority of daily life will require professional intervention through referrals and, where necessary, “medical orders” for caregiver use of community resources such as transportation, housekeeping assistance, and respite/babysitting. To the extent that caregiver depression compromises self-care, physicians can initiate screening, assessment, referral, and support.

Advocacy for publicly and privately funded support programs including respite, mental health and counseling, child care, after-school and summer programs, and transportation is also needed. Community-based agencies may need to aggressively target outreach to older caregivers in order to reach “hidden patients.” Where supportive services are lacking, collaboration between the HIV

and aging networks⁴³ can stimulate program development.

External barriers also expose fundamental seams in public policy that affect families and poor communities and extend beyond the HIV epidemic. Lack of universal health insurance, a paucity of drug treatment programs for women, especially mothers, and inadequate income supports for children all contribute to older surrogate parents becoming hidden patients. And the web of publicly funded services for the HIV infected and their families is terminated once the infected person dies. As HIV becomes defined more by chronicity than death, publicly funded in-home support services such as housekeeping are being restricted to those with acute medical needs. Ultimately, as with other chronic diseases and in the absence of adequate long-term care, the hidden costs of HIV caregiving are borne by the caregivers and their families.^{29, 44} Indifference to the well-being of older surrogate parents and the HIV-orphaned and affected children they raise reflects a failure to understand the generational implications of this epidemic both now and in the future. As Fineberg⁴⁵ prophetically noted nearly a decade ago, “The AIDS epidemic exposes hidden vulnerabilities in the human condition that are both biological and social. AIDS throws new light on traditional questions of value, compels a fresh look at the performance of the institutions we depend on, and brings society to a crossroads for collective action that may, with the passage of years, mark a key measure of our time.”

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