

THE PREVALENCE OF GRANDMOTHERS AS PRIMARY CAREGIVERS IN A POOR PEDIATRIC POPULATION

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ABSTRACT: In the wake of the HIV/AIDS and crack cocaine epidemics, poor urban communities face growing numbers of older adults, largely grandmothers, who have become surrogate parents to children orphaned by these epidemics. This study is the first in the United States to determine the prevalence of older surrogate parents among families registered at pediatric clinics. The three clinics selected were in low income neighborhoods of New York City with a high incidence of female HIV/AIDS and substance abuse. Using a 50% random sample of 1,375 records of registered families, data were obtained on the number and ages of relatives serving as surrogate parents. In 11% of these 1,375 families with children 12 years and under a parent was not the caregiver. In 8% the caregiver was a grandmother. Forty-seven percent of these women were 55 years or older, 25% were 60 years or older and 8% were 70 years or older. Most of these women were caring for more than one child. Ten percent of the total of 2,445 children, 12 years and under, lived in non-parent headed families. Eight percent lived with a grandmother, 1% with other parental generation relatives and 1% in foster care.

Given the stresses associated with caregiving in late life and the greater risk of poor health among low income African-American and Hispanic elderly, older surrogate parents from these communities are a potentially high health risk population whose own needs may go unrecognized and unattended. The young ages of the children suggest that many grandparents may continue to be caregivers as they reach their sixties, seventies and even eighties. Clinical and longitudinal data are needed to determine how prolonged surrogate parenting in late life affects the health of older caregivers and the children in their care. Coordination between health and social services for the elderly and for children are needed to promote effective programs for these families.

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INTRODUCTION

The far reaching health and social consequences of the human immunodeficiency virus (HIV/AIDS) and the "crack" cocaine epidemics are already evident. A recent study projects that as many as 125,000 children under the age of 18 nationwide will be orphaned by HIV/AIDS by the year 2000.¹ The "silent legacy"² of both the HIV/AIDS and drug epidemics is signaled by the emergence of yet another vulnerable group: older adults who become surrogate parents to grandchildren because of death, illness or impairment of parents from drug use^{3,4} or HIV illness.

This paper reports on the first study conducted in the United States to identify older surrogate parents through pediatric services. The study's purpose was to determine the prevalence of older surrogate parents among families registered at New York City pediatric clinics. This was done in three low income, largely African-American and Hispanic neighborhoods where there was a high incidence of HIV/AIDS and substance abuse mortality among women.⁵ Older residents in these areas face a greater risk of poor health by virtue of income and ethnicity.⁶

As "crack" cocaine use escalated among women and as greater numbers of women became infected with the HIV virus, interrelated effects of these epidemics were noted by staff of programs for the elderly and programs for children's health. Nursing staff at several pediatric clinics expressed concern regarding the growing number of very young children being raised exclusively by elderly relatives who seemed to be in poor health themselves. Some of these older caregivers minimized their own health needs in order to demonstrate their ability to serve as surrogate parents. Many simply lacked the resources for transportation or baby-sitting and for medical visits to maintain their own health. Staff at community-based programs serving older adults reported two concurrent phenomena: the loss of some senior center members who had taken on primary caregiving responsibility for grandchildren and, at the same time, elderly home care clients who, despite chronic illness and frailty, suddenly had surrogate parenting thrust upon them because they were the only relative able to provide a stable environment for the children.

The 1990 US census confirmed these new caregiving responsibilities as a national demographic trend: between 1980 and 1990, the number of children living exclusively with grandparents increased to nearly one million.⁷ By 1990, of New York City's 1,686,718 children 17 years and younger, 241,329 or 14% were living in families without their parents or on their own. According to the unadjusted 1990 Census,⁸ the

number of children living with the families of other relatives, including grandparents, was 209,099 or 12.4% of the city's children. Also 1.9% or 32,230 children were living with non-relatives such as non kinship foster care, and 2,977 (0.2%) were living on their own or with a spouse.

Foster care data for New York City from the late 1980's through the early 1990's demonstrate the staggering rate at which children were no longer cared for by their parents. New York City witnessed a 200% growth in foster care placements between 1986 and 1990, compared with a 25% increase for the rest of New York State.⁹ Between June 1988 and June 1991, the number of New York City children in foster care increased nearly five and a half times, reaching a total of 49,825. Kinship foster care accounted for 45% or 22,250 of these children.¹⁰

Although no systematic research has determined the conditions under which grandparents assume exclusive child rearing responsibility, death or absence due to HIV/AIDS or to substance use appear to be central reasons for the custody shift. Nationally, between January 1987 and August 1991, AIDS death rates for women ages 25 to 44 years increased steadily and by 1989 AIDS was the sixth leading cause of death for females ages 15 to 44 years.¹¹ By 1987, it had become the leading cause of death among African-American women ages 15 to 44 years in New York State.¹² In New York City in 1990 it was the leading cause of death for all women ages 25 to 34 years and the second leading cause of death for females age 35-44 years.¹³ As female HIV/AIDS mortality rates increased in New York City during the mid to late 1980's, African-American women had the greatest number of deaths from this epidemic and the second greatest number of female HIV/AIDS deaths were among Hispanic women.¹³

Recent estimates¹ project as many as 22,000 children and adolescents to have been orphaned by HIV/AIDS in the United States by 1991, with the greatest number, 7,500 orphans in New York City. The latter number was projected to more than double by 1995. As Michaels and Levine observe, HIV/AIDS has "come to rival or surpass other important causes of death in taking the lives of mothers of young children".¹

"Crack" cocaine use rivals HIV/AIDS as a cause of "skipped generation" parenting.³ Not only is crack cocaine an inexpensive drug, readily available in poor neighborhoods across the United States, but it produces a rapid and intense "high", making it extremely addictive. Moreover, women are using "crack" more than other drugs such as heroin.¹⁴ According to birth certificate data obtained by the New York City Department of Health, the rate of maternal drug use per 1,000 live births (as indicated on the birth certificate) increased from 7.4 in 1980 to 29.7 in 1988.¹⁵ While

use of three major substances, (cocaine, heroin and methadone), increased during these eight years, the greatest increase occurred in cocaine, which showed a use rate more than 20 times higher than in 1980.¹⁵

Incidence and mortality rates for HIV/AIDS and substance abuse among women in Central and East Harlem have been among the highest in the city.⁵ In 1990, the AIDS rate among adolescent and adult females in these areas was more than double the city wide average rate.¹⁶ Central and East Harlem rank in the top ten neighborhoods citywide for total female and male cumulative AIDS cases among Blacks and Hispanics.⁵ The cumulative AIDS case rate among female IV drug users in these communities equaled nearly two and a half times the Citywide rate.¹⁷ AIDS mortality rates for males and females in Community Districts 10 and 11 (Central and East Harlem, respectively) continue to be among the highest in the city.¹⁷ The overall 1990 substance abuse mortality rates in Central and East Harlem were three and four times, respectively, the city average.⁵ Prenatal drug use in Central and East Harlem in 1990 was nearly twice that for all of Manhattan and nearly four times that for all of New York City.¹⁷

Increasing incarceration of women has also resulted in grandparents raising grandchildren.¹⁸ Close to three quarters of female prisoners are mothers and two thirds of them have children under the age of eighteen.¹⁹ A grandparent is the single most frequent caregiver during the mother's incarceration.^{18,20}

Although some middle class suburban elderly have become surrogate parents under similar circumstances, poor urban communities are more likely to have both a disproportionate number of orphaned children¹ and a greater share of poor older adults. According to recent Census data for community districts 10, 11, and 12 in Central and East Harlem in New York City, which was the location of the study, 37.2%, 34.2% and 22.3% respectively of persons sixty-five years and over were living below the poverty level, compared with 19.3% for the borough of Manhattan and 16.5% for New York City as a whole.²¹ Consistent with earlier findings on recent health measures, older African-American and Hispanic residents of poor New York City neighborhoods were more likely to report multiple chronic health conditions and greater functional disability than elderly whites.²² "Fair" or "poor" health was reported by about 40% of all "nonwhite", i.e. Black, Hispanic and Asian elderly in New York City, compared with 26% of white elderly. Poor health was reported by low income elderly not only in greater proportions but at younger ages.⁶ According to these data from the 1984 National Health Interview Survey, "poor" or "fair" health was reported by roughly equal proportions of city residents between the ages of 55 and 59 years and 60 to 64 years of age.⁶ Given the likelihood of poor

health at younger ages among low income elderly^{22,23} and greater prevalence of chronic health conditions among older African-Americans and Hispanics,^{24,25,26} older adults in poor communities who become surrogate parents are a high health risk population.^{27,28} Vulnerability to the physical and emotional health effects of late life caregiving^{29,30} may signal the potential formation of "hidden patients", a term used by gerontologists to describe older adults whose own health needs go unattended while they care for elderly frail family members.³¹

METHODS

The study, jointly designed and directed by staff from the Bureau of Child Health, New York City Department of Health and from the Bureau of Research, Planning and Policy Analysis, New York City Department for the Aging, was conducted from June through August 1990 at three child health clinics, two in Central Harlem and one in East Harlem, New York City. Data were collected by students of the New York City Department of Health Research Training Program. These data were handled manually without computer assistance.

Information from records of families registered at each clinic was analyzed to determine the prevalence among all registered clinic families of older surrogate parents. Ages of family members had been documented on the family folders. Although the focus of this study was on the grandparents, the number and ages of children in their care were also gathered for the study.

Each clinic was located in or near public housing and resident families from those buildings were the primary clinic registrants. At the time of the study, approximately 17% of the entire child population of the health areas of Central and East Harlem attended NYC child health clinics.³² Families registered at the two Central Harlem Clinics were primarily African-American and at the East Harlem site primarily Hispanic. Approximately 60% of area residents near the two Central Harlem sites were African-American and 18% Hispanic while at the East Harlem site 63% of area residents were of Hispanic origin and 26% of area residents were African-American.³³

A family was registered when a parent or guardian brought a child to the clinic for the first time. Details of all household members were taken at that time and updated as family circumstances were identified by the nurses at later visits. A special effort was made to update all family histories during the period of the study in 1990. A child was not counted

as in the custody of the grandparent unless the grandparent said that the parents were unreachable and asked if she could sign the consent for immunization. Confirmation of the caregiver was often in the physician's notes which stated who gave the child's history. Where the student had any doubts as to the identity of the primary caregiver, the record was brought to the attention of the Medical Director (one of the authors), who would review the family history with the nursing staff to identify the consent signatures and other details in the record.

A 50% random sample from each site was selected by marking every second family record in the alphabetical files. This yielded 1,375 active family records from three clinics, 309 records from the St. Nicholas Clinic, 220 from the Pologrounds Clinic and 846 from the East Harlem Clinic. Only active records were used. These were records where visits had been made within the last year. For each record, the following information was recorded on a separate log: age and relationship of primary caregiver to children; number and ages of children in the household; number and relationship of other persons in the household. Data on caregivers were reported for registered family rather than for registered children thereby avoiding errors of duplication. As the three clinics studied do not serve children over the age of 12 years, data on the adolescents in the households were not included.

All adults of the grandparent or great grandparent generation were classified as grandmothers for the purposes of this study. All other relatives serving as caregivers were of the parental generation. As the study was designed to identify older adults serving as surrogate parents, exact ages were entered in the study when these elderly women were willing to disclose information on their age and when it had been recorded in the family history by the nursing staff. Caregivers were classified according to two age groups, those age 54 years and below and those 55 years and older. Eligibility for many publicly funded services for the elderly is determined by federal law as age 60 years. However, the best predictor of health is not always chronological age especially among poor African-American and Hispanic elderly for the reasons previously discussed. Therefore, those aged 55 to 59 years were also identified as older caregivers.

According to the clinic records, these older relatives had reported themselves to be the sole guardian of one or more children. When the parent was known to the clinic staff as being present in the home but not fully capable of caring for the child, a grandmother sharing the household was not counted as the primary caregiver. Accuracy concerning guardianship in the absence of the parents was confirmed by the signatures of the caregivers in the clinic records giving consent for immunizations. Grand-

TABLE 1

Primary Caregivers of Children 12 years and Under Attending
Three Child Health Clinics

<i>Type of Family</i>	<i>St. Nicholas</i>	<i>Pologrounds</i>	<i>East Harlem</i>	<i>Total</i>
Parent Caregiver	270 (87.3)	179 (81.4)	771 (91.1)	1220 (88.7)
Non-parent	39 (12.6)	41 (18.6)	75 (8.8)	155 (11.3)
Total Caregivers	309 (99.9)	220 (99.9)	846 (99.9)	1375 (100.0)

parents bringing children to clinics wanted them immunized and expected that written parental consent was required. For this reason, they would try to get the mother's signature even if the mother was using drugs and only sporadically in the home. Thus, grandmothers were not likely to under report the mother's presence in the house.

RESULTS

As Table 1 shows, a parent was the primary caregiver in 89% of families and a non-parent in 11%. Table 2 shows that a grandmother was the primary caregiver in 8% of all families. Other non-parents such as aunts, cousins and unrelated foster parents together represented just over 3% of the total universe of caregivers. The range of grandmothers as surrogate parents at different clinics was from 11% at the Pologrounds Clinic in Central Harlem to 7% at the East Harlem Clinic. Grandmothers were 84% of all kin caregivers other than parents as shown in Table 3. Although

TABLE 2

Non-Parent Caregivers at Three Clinics in New York City

<i>Family</i>	<i>St. Nicholas</i>	<i>Pologrounds</i>	<i>East Harlem</i>	<i>Total</i>
Grandmother	26 (8.4)	24 (10.9)	62 (7.3)	112 (8.1)
Other Relatives	11 (3.6)	3 (1.4)	8 (0.9)	22 (1.6)
Unrelated Foster	2 (0.6)	14 (6.4)	5 (0.6)	21 (1.5)
All Families (parents included)	309 (99.9)	220 (99.9)	846 (99.9)	1375 (100.0)

TABLE 3

Grandparent Headed Families as Percentage of Total Non-parent Kin Headed Families

	<i>St. Nicholas</i>	<i>Pologrounds</i>	<i>East Harlem</i>	<i>Total</i>
Total Non-parent kin headed families	37 (100.0)	27 (100.0)	70 (100.0)	134
Grandparent headed families as percentage of kin headed families	26 (70.3)	24 (88.9)	62 (88.6)	112 (83.6)

grandfathers and other older male relatives may also be surrogate parents⁴ in this present study no men other than fathers were acting as primary caregivers. In many but not all cases, the reason that a relative had assumed the parental role was noted in the family record. These reasons included death, HIV/AIDS, drug use, incarceration or disappearance in the city described as "out of the house".

Surrogate Parenting by Older Relatives

The age of grandparent caregivers was recorded in 76% of family folders from all three clinics with a range of 54% at St. Nicholas and Pologrounds and 94% at East Harlem. At the East Harlem clinic there were more nurses and therefore more time for encouraging the grandmothers to disclose their exact ages. These grandmothers ranged in age from 35 to 77 years. The mean age of grandmothers at St. Nicholas was 52 years, at Pologrounds was 57 years and at East Harlem was 55 years with a mean age of 55 years for all three clinics as shown in Table 4. As 94% of grandmothers ages were documented at East Harlem, the implications are that the distribution of grandmothers' ages is similar in the unrecorded and recorded cases. As shown in Table 5, women 55 years and older were more than 25% of non-parent caregivers and represented 3% of all primary caregivers. The study found that 47% of the grandmothers were at least 55 years of age. Grandmothers 60 years of age and older were 25% while those 70 years of age were 8% of primary caregiving grandmothers.

Relatives (aunts, cousins) other than grandmothers who had assumed parenting responsibility were, on average, younger than grandmothers. The mean age of these relatives was 39 years. Unrelated foster

TABLE 4

Numbers of Grandmothers with Documented Ages at the Three Clinics

	<i>St. Nicholas</i>	<i>Pologrounds</i>	<i>East Harlem</i>	<i>Total</i>
Grandmothers age documented	14	13	58	85
Grandmothers age not documented	12	11	4	27
Grandmothers mean age where documented	52	57	55	55

TABLE 5

Distribution of Recorded Age of 55+ years Grandparent Caregiver in the Three Clinics

	<i>St. Nicholas</i>	<i>Pologrounds</i>	<i>East Harlem</i>	<i>Total</i>
Numbers of Grandmothers disclosing Age 55-59 yrs	5	2	12	19
Numbers of Grandmothers disclosing Age 60-69 yrs	1	2	11	14
Numbers of Grandmothers disclosing Age 70+ yrs	0	2	5	7
Total with known Age 55-70+ yrs	6	6	28	40
Total number all caregivers	309	220	846	1375
Total number non-parent caregivers	39	41	75	155
55-70+ yrs as percentage of all caregivers	2.0%	2.7%	3.3%	2.9%
55-70+ yrs as percentage of non-parent caregivers	15.4%	14.6%	37.3%	25.8%

care parents were slightly older and had a mean of 47 years but this was younger than the grandmothers.

As illustrated by Table 6, more than half of the grandparents were raising two or more children. This contrasts with less than one third of other non-parent caregivers, (aunts, cousins, unrelated foster parents). Thirty-eight percent of grandparents had responsibility for two children. Ten percent had responsibility for three and another 6% for four or more children. The distribution of the number of children is similar but larger than that for the parents. It should be noted that in some cases the grandmothers were taking care of the children of more than one addicted, incarcerated or deceased daughter. The number of children per family is

TABLE 6

Families with Different Numbers of Children by Category of Caregiver

<i>Families</i>	<i>St. Nicholas</i>	<i>Pologrounds</i>	<i>East Harlem</i>	<i>Total</i>
<i>Parents</i>				
with 1 child	132 (48.9)	95 (53.1)	366 (47.5)	593 (48.6)
with 2 children	80 (29.6)	56 (31.2)	254 (32.9)	390 (32.0)
with 3 children	39 (14.5)	20 (11.2)	102 (13.2)	161 (13.2)
with 4 children	12 (4.4)	7 (3.9)	35 (4.5)	54 (4.4)
with 5 children	3 (1.1)	1 (0.6)	12 (1.6)	16 (1.3)
with 6 children	3 (1.1)	— —	2 (0.3)	5 (0.4)
with 7 children	1 (0.4)	— —	— —	1 (0.08)
Total Families	270 (100.0)	179 (100.0)	771 (100.0)	1220 (100.0)
<i>Grandmother</i>				
with 1 child	9 (34.6)	10 (41.7)	33 (58.2)	52 (46.4)
with 2 children	11 (42.4)	10 (41.7)	21 (33.8)	42 (37.5)
with 3 children	3 (11.5)	4 (6.5)	4 (6.5)	11 (9.8)
with 4 children	3 (11.5)	— —	4 (6.5)	7 (6.3)
with 5 or more	— —	— —	— —	—
Total families	26 (100.0)	24 (100.0)	62 (100.0)	112 (100.0)
<i>Other Relatives</i> (<i>aunts or cousins</i>)				
with 1 child	7 (63.6)	3 (100.0)	6 (75.0)	16 (66.7)
with 2 children	3 (27.3)	— —	2 (25.0)	5 (20.8)
with 3 children	1 (9.1)	— —	— —	1 (12.5)
with 4 or more	— —	— —	— —	— —
Total families	11 (100.0)	3 (100.0)	8 (100.0)	22 (100.0)

TABLE 6 (continued)

<i>Families</i>	<i>St. Nicholas</i>	<i>Pologrounds</i>	<i>East Harlem</i>	<i>Total</i>
<i>Non-kin Foster</i>				
with 1 child	—	10 (71.4)	4 (80.0)	14 (66.7)
with 2 children	1 (50.0)	4 (28.6)	—	5 (23.8)
with 3 children	1 (50.0)	—	1 (20.0)	2 (19.5)
with 4 or more	—	—	—	—
Total families	2 (100.0)	14 (100.0)	5 (100.0)	21 (100.0)
Total of all				
Families	309	220	846	1375
Total children in these families	570	363	1512	2445

probably even larger than estimated because teenagers were not attending these clinics and therefore not included in these data.

The number of children being raised by type of caregiver is given in Table 7. The total number 12 years and under in the sampled families was 2,445 children. The total number being raised by someone other than a parent was 256 children or 10% of all children in these families. The number of children cared for exclusively by a grandparent was 197. This demonstrates that where there was no parent, a grandmother was the most likely person to be the primary caregiver. Of these 197 children, 92 (47%) were in the care of a grandmother 55 years or older. The percentage documented was 4% of all children 12 years and under, as shown in Table 7. Of

TABLE 7

Number of Children 12 years and Under at the Three Clinics by
Type of Caregiver

<i>Caregiver</i>	<i>St. Nicholas</i>	<i>Pologrounds</i>	<i>East Harlem</i>	<i>Total # Children</i>
Parents	497	300	1392	2189 (89.9)
Grandparents*	52	42	103	197 (7.8)
Other Kin	16	3	10	29 (1.2)
Unrelated Foster	5	18	7	30 (1.2)
Total	570	363	1512	2445 (100.0)

*The 197 children with grandparent caregivers included 92 children, or 3.6% of the total 2445 children, who had grandparent caregivers known to be 55+ years.

TABLE 8

Mean Number of Children 12 years and Under in Family by
Type of Caregiver

<i>Caregiver</i>	<i>St. Nicholas</i>	<i>Pologrounds</i>	<i>East Harlem</i>	<i>Total</i>
Parent	1.8	1.7	1.8	1.8
Grandparent	2.0	1.8	1.6	1.8
Non-Grand Kin	1.5	1.0	1.3	1.3
Unrelated Foster	2.5	1.3	1.4	1.4
All Families	1.8	1.7	1.8	1.8

the 256 children living in non-parent families 92 or 36% were being raised by a grandmother 55 years or older.

Table 8 shows that the mean number of children 12 years and under per type of caregiver showed little variation. Table 9 shows that increasing age of the grandparent caregiver did not give any respite concerning the number of children in her care. Little variation was found in the ages of children being raised by grandmothers, compared with other caregivers. As summarized in Table 10, the average age of the children among all families was close to four and a half years.

An important finding from this study is that a grandmother was most frequently the primary caregiver where children were not being

TABLE 9

Mean Number of Children 12 years and Under by Age of
Non-Parent Caregiver

<i>Caregiver (Type)</i>	<i>St. Nicholas</i>	<i>Pologrounds</i>	<i>East Harlem</i>	<i>Mean in 3 Clinics</i>
Grandparents				
<55 yrs	2.1	1.6	1.8	1.8
≥55 yrs	2.2	1.7	1.6	1.7
Other Kin				
<55 yrs	1.8	1.0	1.4	1.5
≥55 yrs	—	—	—	—
Non-Kin Foster				
<55 yrs	—	1.2	1.4	1.3
≥55 yrs	2.0	1.0	—	1.5

TABLE 10

Mean Age of Children 12 years and Under Cared for by
Type of Primary Caregiver

<i>Caregiver (Type)</i>	<i>St. Nicholas</i>	<i>Pologrounds</i>	<i>East Harlem</i>	<i>Mean for 3 Clinics</i>
Parents	5.6	4.4	4.3	4.6
Grandmothers	4.6	4.8	4.7	4.5
Other Relatives	6.0	3.7	3.1	4.8
Non-Kin Foster	5.6	3.0	2.6	3.3
All Caregivers	4.5	4.4	4.3	4.4

raised by a parent. In addition, for more than a third of these children not being raised by a parent, a woman at least 55 years of age was the surrogate parent.

DISCUSSION

These findings have important implications for the older adults and children living in poor urban communities and for community health and social service agencies serving these populations, today and in the coming decade. What extrapolation of prevalence of parenting by grandparents over 55 years can be made to New York City as a whole? Given the size of the New York City population and the prevalence of HIV/AIDS and substance abuse among poor urban women, even a small number of documented cases among a sample of records from three clinics suggests the existence of thousands of other older women who are surrogate parents raising their grandchildren. Because not all grandmothers disclosed their ages there are actually more than the recorded number who are surrogate parents to their grandchildren.

The prevalence of surrogate parenting by grandparents in this paper is based on nursing histories and therefore may be higher than that found from kinship foster care records or legal custody records because nursing histories contain family histories of children who have not yet entered the kinship foster care system and who have not yet been through lengthy proceedings for legal custody. Another observation from this study suggests that the prevalence of surrogate parenting by grandmothers is actually higher than that found in this study. Some grandmothers may

not have reported themselves as primary caregivers because they feared their grandchildren would be placed in foster care if the mother's drug habit were known. These grandmothers were reluctant to discuss a daughter's drug use and her recent absence from the home. Any lack of reporting may bias the data and underestimate the extent of primary care responsibilities by grandparents.

Citywide prevalence of children being raised by older grandparents can be estimated from the unadjusted 1990 Census. The unadjusted Census showed 1,233,727 children 12 years and younger in New York City.⁸ Since 8% of 2,445 children are being raised by grandparents (Table 7) and since 47% of the grandmothers whose ages are known were 55 or older, then it can be estimated that 68,037 or 4% (47% of 8%) of children 12 and under are being raised by grandparents over the age of 55 years. This may be a low estimate because, although the study found 10% of the children in the clinics were living in non-parent families, according to 1990 Census data 15% of New York City's children were in non-parent families. It also may suggest that the figures in this study are conservative and that a more stable population may be attending the NYC pediatric clinics than that shown by the Census. However, it should also be noted that because not all neighborhoods in the city are experiencing HIV/AIDS to the same extent caution should be used in extrapolating the results of this study to other areas of the city or city wide.

Therefore the prevalence of surrogate parenting by older adults on a city wide scale may be projected cautiously from the results of this study. This is achieved by dividing the total number of children ages 0 to 12 years, estimated at 68,037, by the average number of children per older caregiver household, 1.7 found by this study. Accordingly, there would be approximately 40,022 older adults in the city who would be surrogate parents for these 68,037 children. Using a broader definition of surrogate parenting which includes regular although not exclusive responsibility, a recent study of the quality of life among older adults in New York City conducted by the New York Center for Policy on Aging of the New York Community Trust, *Growing Older in New York City in the 1990's*, found 10% of all elderly, 19% of African-American elderly and 15% of Latino elderly serve as a surrogate parent on a regular basis, "daily or several times a week".³⁴ Based upon projections by the latter study, ". . . upwards of 100,000 older New York City citizens (are) caring regularly for grandchildren or great-grandchildren." This number is very high because it includes part-time and shared responsibility. This study stressed ". . . the impact of poverty and the greater exposure to crime, drugs and AIDS in the minority communities of New York City (which) are forcing more and more African-American and Latino grandparents to substitute for parents. . . ."³⁴

Two recent documents compiled separately by the Citizen's Committee for Children³⁵ and the Health Systems Agency of New York City³⁶ rank communities in New York City for severity of social and health related needs. Both documents show the same eleven communities in the highest risk category. Included in these eleven communities are Central and East Harlem where the study was done. According to these documents, there is a convergence of poverty, HIV/AIDS, drug abuse and TB in certain areas. According to the Citizen's Committee for Children, more than one half of the children in these eleven high risk communities receive public assistance. Any neighborhood with a convergence of poverty, HIV/AIDS and drug abuse is likely to produce children who have lost their parents. The total number of children 0 to 18 years in the eleven high risk communities was 330, 932, which is 19.6% of a total city population of children of 1,686,718. The total number of children³⁵ in the two study communities (0-18 years) was 56,730. It is difficult to estimate how many of these 56,730 children are being raised currently or will be raised in future years by their grandparents.

The convergence of epidemiological and demographic factors in poor urban communities would indicate high degrees of prevalence of surrogate parenting by older adults in other cities where there are similar rates of HIV infection and drug dependency among women of childbearing age. In Burton's qualitative study of psychological, physical and economic costs of surrogate parenting by older adults, she reports among elementary school age African-American children a rate of 30% being "raised" by grandparents in the northeastern US community and a rate of 60% in the northwestern US community.⁴ These findings are based on school enrollment and school census records which seem to employ a broad definition of grandparents "raising" grandchildren. As Burton notes, "school officials attribute the high incidence of grandparental child care responsibilities to the economic hardships experienced by some young single mothers . . .".⁴ These mothers may not have been entirely absent but working and present at night and weekends as in so many struggling families. Caution is needed in comparing prevalence estimates from other studies which may be based on individual reports by school administrators and social service providers, rather than on systematic data. Because the school records cited included grandmothers who were sole guardians and those with shared child care responsibilities, these give a higher prevalence than that found by this study of Central and East Harlem which excluded resident grandmothers who were present in the household and helping to raise the children. Consistent with the New York Community Trust study of older adults in New York City cited earlier, Burton's study's confirms that surrogate parenting is a common occurrence in low income, urban communities.

The relatively young ages of the children suggest that many grandparents may continue to be caregivers as they reach their sixties, seventies and even eighties. Close to one third of grandmothers identified by this study would be, if living, at least 70 years of age or older when the children reach the age of graduation from high school. Current caregiving demands and the likelihood of extended responsibilities for as long as 10 to 15 years or more have important implications for the health of older caregivers.

This study did not try to obtain data on the physical health or mental health of the older surrogate parents. However their race/ethnicity and socio-economic status place them at high risk for one, if not more, chronic health conditions such as diabetes, hypertension, obesity, cardiovascular disease, and arthritis.³⁷ Moreover, the physical, emotional and financial stressors associated with caregiving may exacerbate these conditions, especially when the individual is responsible for more than one child and is sixty years of age or older.³ Diminished physical and emotional health following the initial process of becoming surrogate parents was reported by about a third of grandmothers studied by Minkler and Roe in Oakland, California.³ Compounding the psychological stress experienced by inner city grandmothers is the profound anxiety about both random violence in their communities and their ability to sustain their own energies when the children are in their teens. Some caregivers face the additional stress associated with raising children who have special health and psychological needs.^{3,38}

Clinical and longitudinal data are needed to determine how late life childrearing impacts on physical and psychological health and on the functional capacity of older surrogate parents. An important research question is how surrogate parenting affects health behavior, including self-care and access to health care resources. How prevalent are negative health behaviors such as increased alcohol or tobacco consumption as ways of coping with the stresses of caregiving?^{3,4} To what extent do caregivers neglect their own health because they lack the resources of time and money for baby-sitters needed to keep their own medical appointments? Those below the age sixty-five and therefore not yet on Medicare may lack adequate health insurance. Internal barriers to health care may include inflated self-reported health³ and minimization or denial of poor health as strategies for coping with stress. In addition, it would be valuable to examine whether self-neglect through the minimization of physical and psychological symptoms reflects the attribution of such conditions to "normal aging" and the belief that such symptoms do not warrant medical attention because they are age-associated conditions rather than indicators of disease states.³⁹

Research on the health status of both older and younger generations in these new households would be valuable to determine how best to support and enhance caregiving in order to ensure the optimum physical and mental health of the children. Given the circumstances under which older relatives assume parental responsibility for grandchildren, some of these children require special care because of a range of physical, emotional and behavioral problems associated with prenatal exposure to cocaine or other drugs, HIV infection, or parental neglect and abuse.³⁴ Systematic research is also needed to determine how surrogate parenting by older relatives impacts on the health of the children in their care. In particular, studies which identify areas for caregiver education and support regarding children's health status are urgently required.

Policy and programmatic implications can be briefly outlined. Attention to the health of the older caregiver is vital not only to strengthen the capacity of the older adult to continue as the surrogate parent but also to preserve optimal functional health and independence. In turn, their ability to provide an enduring and stable family is vital to the physical and emotional well-being of the children in their care. Efforts to assist these families must strengthen the capacity of community agencies to care for the physical and psychological problems of both the old and the young. Immunization against influenza and pneumonia should be easily accessible to prevent the grandparents from succumbing to influenza brought into their homes by the children from school based epidemics. The shortage of basic social services, adequate housing, nutrition and safe recreation programs must be addressed. Multi-level strategies are needed which include adequate respite, child care/baby-sitting and transportation to provide immediate support to grandparent caregivers. Because of the increase in poverty among large numbers of urban elderly of African and Hispanic descent,⁴⁰ as reflected in the 1990 New York City census data, many older African-American and Hispanic adults who become surrogate parents are likely to have limited financial resources. In 1990, in New York City, 27% of older African-American and 33% of Hispanic elderly had incomes below the poverty level.⁴¹ These resources will be insufficient to cushion the stresses of child-rearing in late life and to ensure adequate income. Therefore, adequate financial benefits, including kinship foster care payments equivalent to non-kinship payments, are justified in view of the complications of foster care.

Targeted outreach and education are vitally important to facilitate access to health care and to support self-management of chronic illness and stress. Strategies to improve self-care would promote the physical and psychological health of older surrogate parents and would delay functional

limits associated with chronic illness. Because the attention of caregivers may be focused on the children's health rather than on their own health,^{3,4} special educational efforts are required to promote full use of health services. Linkages to programs and services for older adults will be necessary in order to secure appropriate and comprehensive caregiver support.

The projected number of children who will be orphaned due to HIV/AIDS and substance abuse indicates that future pediatric health programs in poor urban communities will serve growing numbers of families in which an older person, most likely a woman, will be the surrogate parent. These older caregivers are likely to be identified through their relationship to programs and agencies serving children, such as those in this study, as well as day care centers, schools and social service programs for children. Community-wide efforts are essential to develop, strengthen and publicize programs for older adult caregivers and to provide access to all necessary health and supportive services.

Parenting by older relatives represents a valuable national resource that can help prevent children from entering the foster care system with all its tragedy and cost. Effective planning and coordination at the state and local levels should be promoted between health and social services for children and the elderly to provide comprehensive care for both generations. Ultimately, however, the well-being of these caregivers and their families can be protected only through aggressive federal health and social policies.

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