Mama Jaja:

The stresses and strengths

of HIV-affected Ugandan grandmothers

Cynthia Cannon Poindexter

submitted to*: Journal of Health and Social Policy, special Africa issue*

Mama Jaja:

The stresses and strengths of HIV-affected Ugandan grandmothers

ABSTRACT

This paper reports an exploratory qualitative project in the Entebbe - Kampala area Uganda with 11 grandmothers who are raising orphans because of a parent's death from HIV. In sub-Sahara Africa the highest HIV infection and mortality rates are in women, especially in child bearing years, leading to a tremendous number of orphaned HIV-infected and affected children. Uganda has the world's highest rate of HIV orphans. In Uganda, extended family members, especially grandmothers, provide general orphan care, AIDS care, and care for HIV orphans. If orphans have places to stay, they are most often with grandparents and other elderly relatives in rudimentary village dwellings. Many of these elders are in poor health, recovering from nursing their adult children as they died of AIDS, and suffering from an extreme lack of financial resources. The burden of HIV-affected orphan care is enormously heavy. Services are not being provided adequately to custodial grandparents who are enormously challenged spiritually, socially, emotionally, financially, physically, and mentally. The following themes emerged from the interviews: experiencing extreme economic deprivation; feeling physically challenged with care giving; being concerned for the children under their care; and struggling to cope through action, resilience, and relationships. Recommendations for research, practice, and policy are offered.

Mama Jaja:

The stresses and strengths of HIV-affected Ugandan grandmothers

I don't know when we will see the end of this AIDS....You think, you think, you cry, you cry, and sometimes things don't work out. ...AIDS in Uganda is not over. Because the number is still up...Many who are infected have died....Children are suffering here - those children who are having AIDS, and those also who don't have AIDS. Even if they don't have AIDS, but if the parents die, they are stuck ....And older people like me, even older than me, they are the ones who are looking after the children....They are weak. They are down. I don't know how many years I'm still in this world....You came to Uganda to see how we are. You have seen how we are? You will go back and tell them what you have witnessed?

- Nalumansi, 62 year old English-speaking care giver of AIDS orphans in Kampala, Uganda

This article reports a qualitative study of 11 older women in Uganda who are raising from 4 to 10 AIDS orphans [HIV-infected or HIV-affected children whose mother and/or father died of HIV]. As one of the participants eloquently stated above, with so many people in the middle generation dying from AIDS, the older generation - mostly women - have taken on child-rearing responsibilities for minor grandchildren, some of whom have HIV. Families, communities, and the nation suffer in this context of impoverishment and grief. As recipients of these stories, with this report we are attempting to tell what we have witnessed.

In Uganda, mothers are often called "Mama," and grandmothers are called "Granny" in English or "Jaja" in Luganda. An older woman can be called "Granny" even when she is not literally the grandmother; it's more a term of respect and endearment of older women who are closely tied to children. One of the respondents said that she was called "Mama Jaja" ["Mother-Grandmother"] by the grandchildren she was raising, to acknowledge her dual role. We have used this designation in our title to honor these mother-grandmothers, who are older women who have been forced by tragic circumstances to move beyond the traditional role of "Granny" and once again into the role of mother and primary care giver for minor children, thus striving to fulfill both roles.

METHODOLOGY

The authors - both social work professors, longtime HIV advocates, and researchers in the field of HIV care giving - conducted and tape recorded 11 semi-structured interviews in the Entebbe-Kampala area of Uganda between July 19, 2003 and July 29, 2003[1]. K., a black male Uganda native, conducted 6 of them in Luganda (the primary native language) and P., a white female U.S. native, conducted 5 of them [4 through Luganda interpreters and 1 in English]. Interviews were semi-structured, with the researchers using a checklist of topics [specifics of the care giving situations, management of stigma, experience of loss, needs and challenges of care giving, strategies for coping, and services received and needed]. Each participant was interviewed once, in her own yard or home [except for the one in English, conducted in the interviewee's office]. All interviews were audiotaped with signed consent from the grandmothers. Each interviewee was paid in Uganda shillings [the equivalent of between $20 and $25]. Nine of the respondents were referred to us by AWOFS [AIDS Widows, Orphans, and Family Services[2]]; those 9 also received a bag of used clothing for herself and/or the children.

For 7 of the interviews, staff of AWOFS was present as observers and/or translators. The English interview was transcribed by P.; all others were transcribed by K. [translating the 4 P. conducted in Luganda]. Themes and conclusions were developed and cross-checked in several ways. Both investigators kept a research journal to record impressions, observations, thoughts, and feelings, and shared these reflections with each other. Transcribed interviews were repeatedly read and coded, first by a research assistant who is an African-American gerontological social worker, then by P.,

[1]We began this study during a week that President Bush spent a few hours in the Entebbe-Kampala airport (July 11, 2003) to call attention to AIDS in Africa, also touting the "ABC" model of prevention there (although the focus was almost exclusively on the "A" for abstinence.) Also during our time there, Idi Amin was dying, and there was much talk about his family's attempts to return him to Uganda.

[2]AWOFS' mission is to provide social and economic support to HIV- affected households so that children can remain healthy and cared for after the death of their parents. They serve approximately 600 families per year (Nkuusa, 2004).

who then grouped quotes according to patterns and themes. K. reviewed the themes and interpretations and commented on cultural and linguistic nuances. A draft of this article was reviewed by two of the AWOFS staff members, and their feedback was incorporated.

BACKGROUND: HIV IN UGANDA

AIDS [called "silimu," meaning a disease that makes one slim] was identified in Uganda in1982, very early in the pandemic (Kaleeba, Kadowe, Kalinaki, & Williams, 2000; Mukiza-Gapere & Ntozi, 1995a). Emerging from the brutal regime of Idi Amin, in 1985 the Ugandan government was among the first to confront the epidemic openly with a widespread media and education campaign called "ABC or D," meaning "abstain, be faithful, condom use, or disclose and decide" (Wax, 2004). Uganda has been a model for intervention and prevention (Kaleeba, Kadowe, Kalinaki, & Williams, 2000; Konde-Lule, 1995; Mukiza-Gapere & Ntozi, 1995b; Williams & Tamale, 1991), nearly eradicating HIV stigma[3] and reducing the HIV prevalence rate from 30% of the population to 5% over the past decade (Wax, 2004). The Ugandan government has been working since 1996, when combination therapies became available, for access to anti-HIV drugs for its citizens (Garbus & Marseille, 2003).

Despite this admirable history of dealing with HIV and stigma head on, Uganda - one of the world's poorest countries (Kaleeba, Kadowe, Kalinaki, & Williams, 2000) - struggles to care for over a million HIV-positive children, adolescents, and adults (Garbus & Marseille, 2003; Konde-Lule, 1995; Mukiza-Gapere & Ntozi, 1995b). More than 800,000 people have died of AIDS in Uganda

[3] We asked each interviewee about the experience of HIV stigma. Although several grannies reported feeling the effects of HIV discrimination at one time, and several eloquently described people's fears about getting tested for HIV or disclosing their HIV status, they all felt that stigma was no longer as much of a threat, mostly because, tragically, HIV is so commonplace. Several participants explained that the frequency of AIDS-related illnesses and deaths served to normalize HIV and thus lessen stigma. "Of recent so many people have died of AIDS so they no longer mistreat us" (Meeme). "It can happen to any one. People know that tomorrow it might be them" (Namusoke). "Somebody else died here from the same illness....Now they are all used to it" (Saawoamaaso). "AIDS is rampant; any one can die" (Mbekeka). "You never know who's got the AIDS. God knows how you will be. You never know when you may have this" (Nalumansi). "In Uganda when one is sick most people believe it is AIDS" (Nalubega). "People do not judge because it the common situation" (Namuddu). We heard from AWOFS staff that younger widows tend to feel HIV stigma more than do children or older women (Lubega, personal communication, 5/30/04).

since its onset and 1.4 million Ugandans - slightly more females than males - have reported that they are living with HIV (Lubega, 2004). HIV still accounts for 12% of deaths annually, and among those aged 15 to 49 - the child bearing years - AIDS is the leading cause of death (Garbus & Marseille, 2003). Adult life expectancy in Uganda has decreased by 17% as a result of AIDS (Garbus & Marseille, 2003). Each year more than 25,000 Ugandan infants are born with HIV (Kaiser, 12/19/03). The loss of young adults from the work force, as well as the high financial costs of caring for persons with AIDS, has had a deleterious impact on Uganda's economy (Bollinger, Stover, & Kibirige, 1999). HIV, while an individual tragedy, intensely and negatively effects families, communities, and the country (Ankrah, 1991; Mukiza-Gapere & Ntozi, 1995a; Ntozi & Mukiza-Gapere, 1995; Ntozi, Lubaale, & Nakanaabi,1997).

Uganda has had a high number of orphans in the past due to war and disease, and HIV has only worsened this situation. The percentage of orphans due to AIDS rose from 17% to 51% over 11 years. As a result Uganda has more than two million HIV orphans, the largest number in the world (Garbus & Marseille, 2003). HIV greatly exacerbates the situation for orphans. Not only has HIV increased the number of orphans in Uganda, there is an intensified problem because many of the orphans themselves are infected and dying. Unlike the situation with the orphans of soldiers in wartime, HIV frequently causes children to lose both parents and some siblings as well. Even when children have one parent, that parent may be too sick with HIV to provide guidance and care. Furthermore, because of the cost of medical and palliative care, HIV care can leave the surviving family members impoverished. Even though relatives may want to provide orphan care, they are often already caring for too many orphans and are burdened physically and fiscally (Ntozi & Mukiza-Gapere, 1995).

African orphans are more likely to be deprived of education because there is no one to pay their school fees (Kamali, el al, 1996; Muller, Sen, & Nsubuga, 1999) and are susceptible to being forced early into labor, especially hazardous labor (UNICEF, 2001). Being an unprotected orphan in Uganda can be highly dangerous, especially in the north, where the Lord's Resistance Army rebels

routinely kidnap and brutalize young children and often force them into service as soldiers (BBC, 2/22/04). Sometimes HIV-affected orphans do get abandoned by families and are left to fend for themselves (Lubega, 2004). Ugandan orphans are more likely to be heads of households (raising other children), or separated from their siblings and divided among relatives; they are vulnerable to economic and sexual exploitation; and they are overburdened with grief (Kamya, 2003 & 2004).

Family care is a respected tradition in Uganda, where extended families act without question as care givers for the frail, sick, old, or young. Extended family members traditionally provide general orphan care (Hampton, 1990), HIV care (Ntozi, 1997a), and care for HIV orphans (Nampanya-Serpell, 2002). In Uganda there is no talk of "permanency planning" in advance: it is understood that extended families are supposed to take care of orphans if they can. The past two decades have brought a huge increase in the need for care; family members, particularly older female relatives, are providing care to persons with HIV and orphans, despite social, economic, emotional stress, and inadequate social and medical services (Muwonge, et al, 1996; Ntozi, 1997a and 1997b; Ssamula & Brehony, 1993). Nampanya-Serpell (2002) calls AIDS "the grandmother's disease" in sub-Saharan Africa because of the enormous burden put on older women to care for sick adults and children and surviving children. The scarcity of family care givers for an increasing number of orphans is likely to worsen.

Typically there are intense financial and psycho-social effects on care giving families, such as financial hardship due to expenditures for food and care and the care giver's having to leave a job, and psycho-social effects like depression, anticipatory grief, isolation, and stigma (Ntozi, 1997a). HIV has disrupted the usual family development trajectory, where the middle generation cares for young children and elders; with the absence of the middle generation, elders no longer have family care givers when they are frail; in addition, they are likely to take on child rearing duties (Barnett & Whiteside, 2002). The grannies cannot have an uncomplicated or carefree relationship with their grandchildren, because death of a loved one is what has brought them together. HIV orphans tend to have unrecognized and untreated emotional problems due to their parents' agonizing illnesses and

deaths (Sengendo & Nambi, 1997) and to be impoverished financially, socially, and educationally (Ntozi & Mukiza-Gapere, 1995). Maintaining discipline for grieving, impoverished, and bewildered orphans can be a problem for an older guardian (Ntozi & Mukiza-Gapere, 1995; Ssamula & Brehony, 1993). Aging grandparents and other elderly caretakers have their own struggles with health and finances as well as being stressed by orphan care (Hunter,1990; Kaleeba, Kadowe, Kalinaki,& Williams, 2000). The older relative care givers get no break during the day, because the children are not in school due to inability to pay school fees. Living quarters are extremely cramped; there is often no water or electricity (Bartholet, 2000). Even for willing care givers, the burden of HIV-affected orphan care has proven too burdensome (Hampton, 1990; Hunter,1990; Mukiza-Gapere & Ntozi, 1995a; Ntozi & Mukiza-Gapere, 1995).

There has been a tremendous community response to the pandemic in Uganda, with more than 1000 community-based and faith-based AIDS Service Organizations (Kaleeba, Kadowe, Kalinaki,& Williams, 2000) that advocate, provide services, and incorporate persons with HIV into service provision (Hampton, 1990; Williams & Tamale, 1991; Wawala, et al, 1998). Despite much good effort, it is unclear whether there are enough services for extended family members, particularly custodial grandparents (Ntozi, 1997a & 1997b) who are enormously challenged spiritually, socially, emotionally, financially, physically, and mentally. This exploratory study is a beginning step in learning of their lived experiences. It also offers an opportunity to examine the social, psychological, and societal implications of HIV orphan care in Uganda.

PARTICIPANTS AND THEMES

Seven of the grandmothers were in their 60's; the youngest was 52, and three did not disclose age. Five were the paternal grandmothers and 2 the paternal aunts. This is to be expected because in Uganda - where polygamy is still practiced in some cases - it is traditional for the paternal family to "inherit" orphans (Lubega, 2004). Two were raising orphans from both sons and daughters who had died, one was the maternal grandmother, and the relationship of one was unknown. They were all raising multiple orphans: the lowest number was 4 and the highest was 10. Nine of the ten grannies

interviewed at home lived in mud houses with worn furnishings, living in abject poverty and barely surviving. The table details their individual situations [Table about here].

It is necessary to set the context for the participants' interviews. For those of us in industrialized countries, to contemplate AIDS in Africa we must try to enter a different reality, an alternate world. HIV disease in Uganda occurs within the context of abject poverty; overwhelming suffering, loss, and grief; and the total absence of antiretrovirals. HIV still means unmediated and unmedicated illness and certain death. The comments and themes offered by the older women in this study must be considered within the frame of that unusually harsh environment. The participants do not list HIV treatment as a need, for example, because that was not even considered a possibility. Furthermore, the level of loss is mind boggling. Not only have all of the grannies in this study lost adult children to AIDS, several of them have also lost siblings and cousins to the disease, and several have suffered the deaths of HIV-positive grandchildren under their care. These AIDS deaths are in addition to the deaths brought about by other diseases, Idi Amin's regime, war, and famine. When asked about the circumstances of becoming care givers for minor children - an open-ended question designed to solicit a story - each respondent answered by stating specifically who had died [sons, daughters, brothers, sisters, cousins] and explaining this is how the orphans were "inherited."

The major themes arising from this study are as follows, discussed below in detail: experiencing extreme economic deprivation; feeling physically challenged with care giving; being concerned for the children under their care; and coping through action, spirituality, and the relationships with the grandchildren.

ECONOMIC DESTITUTION

Overwhelmingly, their major concern was lack of financial resources. When we asked what was most difficult about being a care giver for minor children, ten of the eleven grandmothers said they did not have enough money to provide the children with food, medication, clothing, beds, shelter, and school fees. They did not have the resources necessary to sustain life. These families were connected to services and expressed gratitude for them, but they all said they did not have

enough if they were going to support children and give them a shot at survival. Their meager resources had been spent in taking care of their dying adult children. Now that they are raising the orphans, they have no resources, no jobs, no micro-businesses, and are in a deeper level of poverty. Not having school fees was the immediate concern for 6 respondents, because they felt that not getting educated would ruin the children's chances at a future.

Running one's own small business (micro finance) is a norm in Uganda. Six of the grandmothers, whose age and health would have qualified them in the U.S. as retired or disabled, longed for enough money to start a small business. Micro-financing was their answer to getting out of their financial holes. They dreamed of making bricks; raising chickens, goats, or a cow; or tending to small crops, but they didn't have the starter funds to do so. Examples are: "I need to buy chickens for my farm; can you help me?" (Meeme[4]). "If I had money to establish a business, I could survive....I want to establish my market stand....I want to get some money to start out a business" (Saawoamaaso). "I wish I could get enough money to help me establish a business....The business I have in mind is growing Matooke. I also want a restaurant. And if I get this my grand children can work there too" (Mbekeka). "If I get money, I can get charcoal, it's what we are using to cook. You can buy that and sell it. You can buy firewood and sell it. You can do so many things to get money, if you have money....And you don't have to do just one thing, you can do the other. You can dig {for vegetables for others}, you can have a garden of casava. Tomatoes, everything" (Nalumansi).

LOGISTICAL CARE GIVING DIFFICULTIES

Eight grandmothers discussed the difficulties inherent in raising a second family in later life when one is under much duress. They spoke of feeling emotional stress, being isolated and without logistical help, and living with their own physical challenges:

> "Because of the promise I made to my son I keep going on, but it is very hard....It's emotional stress" (Namusoke).
>
> "I work a lot and have no help" (Saawoamaaso).

[4] All names are Luganda pseudonyms

"Why is it always AIDS? By this point I should be myself, doing what I like, at my age. But you can't do it because of the children. Wanting, asking things. This one is asking this. And you have to help them" (Nalumansi).

"My body is getting weak since I am getting old, with high blood pressure and ulcers. It's not easy. Generally it's not very easy to take care of these children and that worries me a lot" (Mbekeka).

"I now have ulcers and this {care giving} has made me weak....I have no strength to go looking for food and I'm getting sick" (Kagere).

"It has been hard to raise such young children. I am old and I have no one to help me" (Nalubega).

"Sometimes it is hard to be alone raising all the children" (Namuddu).

The following exchange with Ndagire illustrates that those raising orphans are too busy to access support from each other:

"In this area there are a lot of people who have got children with HIV." [I[5]: Do you get support from each other?] "No, everybody is on their own." [I: So you don't talk to them?] "Sometimes when we meet in hospital we ask about each other's children." [I: No time at home?] "At home we have a lot of responsibility." [I: So there is no time to have your heart or emotions taken care of.] "Yes."

CONCERN FOR THE CHILDREN

The grannies described multiple intense worries and burdens regarding the children under their care. Seven expressed concern about what would happen to the children if the grannies got sick or died; the children would then be "double orphans," having lost their guardians twice. Five worried

[5]When interviewer utterances are included, they are in brackets, preceded by "I" for "interviewer" [I].

about the children's health, especially those who are HIV-positive. Three mentioned being anxious about the children's emotional and mental well-being in the face of mourning deceased parents and being worried about their own health and futures.

The following excerpts illustrate the grannies' concern for the children's future if they (the grannies) should die: "My main worry is I don't know what the children will do if I die and leave them without a house" (Naamu). "All I pray is that God might keep me alive for some years, because if I pass away and they are left, life will be very hard. But as long as I am alive, even if they disobey, I can tolerate that and be with them....I install it in the eldest {who is HIV-positive} that she has to take care of her siblings if I pass away" (Namusoke). "It's hard; I worry a lot about it, like if I get in an accident one day what will the kids do" (Saawoamaaso). "I have a sister who knows our problems, and hopefully the rest of the family may help too if I die. But my worry is that the other children might also die and they also have children" (Mbekeka). "For me, I don't know how many years I'm still in this world..... Now if I die, they would have to get somebody to help. The children are from different mothers and fathers. That's why I'm struggling. Anyway, who would have my family? ...You can't help but worry, because of the situation" (Nalumansi). "Since my last-born {youngest adult child} is sick I'm worried - He should have taken care of them. So I might give them to other people. The children's Aunties and Uncles are also sick" (Kagere). "I now an old woman and I get worried about how these children will be taken care of when I die" (Namuddu).

In addition, the respondents were worried about the health of the grandchildren who have HIV:

"When they get sick; taking care of them is very hard" (Meeme). "The twins {with HIV} are the worst and get an attack at least every 3 to 5 months. And the other one has a problem in the skull and can only hear with one side because she gets infections, headaches and had meningitis and was admitted for about 2 weeks in hospital....When they are sick, I am very sad....I don't remind them that they are sick, but comfort them., not tell them that they will die soon" (Ndagire). "I used to provide well for my sick children before they died, I wanted them to eat well before their death. So I

spent a lot....You also need money to pay for treatment because they {the grandchildren} can die" (Mbekeka). "I do not know what to do when they {the orphans} fall sick" (Namugga).

Finally, the grannies were also concerned about the grandchildren's emotional and mental health. Saawoamaaso said that a grandchild pined for her father: "Some times it is not easy; like one of them went to church and they told them that one day people will resurrect and she said 'I wish my dad will come back and buy us some books'" Namusoke told this story about how her grandchildren responded to their parents' death:

> After the burial every morning the children went to the grave and prayed, hoping that God will bring him {their father} back. {Crying} Sorry for crying before you. They got used to the idea that he was dead, but shortly afterwards their mother died too and they went through the whole process again. And they hurt again....But the most difficult thing is that they might feel well but every small thing can capture their minds and remind them of the deaths. I don't know what causes those incidences, and don't know what to do about...There are some things we can't erase from their hearts. It takes them by surprise."

COPING STRATEGIES

These grannies are not thriving, but they are surviving. When asked how they got through their days, they spoke of coping through taking action, inner resources or spirituality, and getting meaning from their relationships with their grandchildren.

Five participants described coping through taking action, such as striving to house and teach the children, trying to take care of oneself physically, and working hard to make financial ends meet. Two spoke of getting meaning out of being able to take care of children: "I can work and prepare a good place for the children. I have tried to teach these children at least to a stage where they can write and read" (Naamu). "We treat all the children well and they are blessed because we are here to help them. Some other children don't have any help. Other orphans are struggling on their own. So I'm consoled in that {in being able to care for them}" (Namusoke). Two talked about rudimentary

self care, as shown in these exchanges:

[I: When everything becomes so difficult, what do you do?] "I go and sleep, rest and then think about the situation later. Sometimes I just give up" (Meeme).

[I: When every thing becomes so difficult what do you do?] "I do some knitting" (Namugga).

Three said that working hard helped them to cope:

[I: How do you go on, how do you cope?] "I have been working and just surviving trying to make ends meet" (Meeme).

[I: But you are also hardworking; does this help?] "It does, for I work a lot all day" (Saawoamaaso).

[I: What helps you especially as you raise your children?] "I have been working hard" (Namugga).

When asked about how they coped with all their challenges, 7 out of 11 spoke of spiritual strength and/or inner resiliency: "Even praying helps" (Meeme). "Even God helps. And I ignore some things" (Namusoke). "I do my best. What can I do? I pray a lot" (Nalubega). "I am a strong woman and I have a lot to live for....I pray a lot" (Namuddu). Naamu said: "I just have to be strong; it's very hard but there is nothing to do about it....It has been rough....But life has to go on.... I thank God for his help. I guess thinking about God and the way the priest encourages us has been a source of help in some way." Saawoamaaso said: "I have to be strong; we have come far....But even when I worry it's only God who determines what will happen....I am strong, hoping that I will get some help. God answers prayers....I have been strong, though sometimes I think a lot....I prayed a lot and I would go to church. I used to cry a lot, but now I close my door and pray."

The interviewers had the opportunity to observe most of the grannies with their grandchildren, and there was a noticeable physical bond between them. Two of the participants spontaneously described the love between Granny and grandchildren or the joy at being able to meet the grandchildren's needs. It was clear that the loving, joyful side of care giving was sustaining to them. Mbekeka said: "When they brought them {the children} I felt happy, because if you have

grand children when your son dies you have a reminder, you forget your child and start caring for them....When I see my grandchildren are alive and I have food for them I'm happy. I see them playing and listening to the radio and that makes my day." As she said this to the interviewer, Mbekeka was doing a little sitting-down dance to illustrate her joy. Namusoke beautifully expressed the love between herself and the children:

> They {the grandchildren} love me so much and call me "Mama Jaja" [mother-granny]. I went for treatment in America and left them with their grand father and they kept looking up at the planes and shouting to them to bring back their granny mother. One time I was sick and couldn't go to school to visit them on their visiting day in the boarding school and they asked the grand father for their mother-granny. One of them usually says "Granny, I love you so much." I asked her why and she said "you are all we have, our father and mother."

IMPLICATIONS

These 11 mama-jaja's described a life full of stress, fear, poverty, and dread. They are grieving for beloved ones who have died of AIDS, financially impoverished, physically challenged by raising children in older adulthood, and worried about their grandchildren's health and future. The researchers were deeply moved and inspired as we sat with them and heard stories of heartbreaking loss, pain, and struggle.

Yet in the face of severe hardship, these mother-grandmothers coped through concrete activities to nurture and raise the grandchildren, viewing their challenges through a lens of spirituality, and loving and rejoicing in their grandchildren. They demonstrated hope, wisdom, and generosity. Although we wish to honor this strength, we are reluctant to call this "resilience" out of a fear that focusing on their coping will serve to excuse the world's neglect or apathy. As Fullilove (2004) proposes, humans do not just bounce back into their previous shape (resilience) after the type of severe trauma that these respondents are living through; rather, they exhibit fortitude, endurance, and refusal to succumb to despair. This is how we view these respondents. Just because they make do

and are not destroyed does not mean that they are unscathed or that they do not urgently need the world's intervention. Society should work to eliminate the need for the level of super-human strength that is required of these grandmothers.

Below we offer research, practice, and policy implications. We offer them as starting points, believing that all practice and policy interventions, as well as research projects, must be developed and conducted in full partnership with Ugandans, especially care giving grannies, so that responses are culturally responsible, effective, and respectful.

Research is greatly needed to determine what responses are appropriate to meet the needs of the grandmothers and their grandchildren. An ongoing conversation should be facilitated between community leaders, extended family members, and social service providers regarding ways to keep Ugandan families afloat. Many of the grannies are frail and weary, and will not be able to care for the children without supportive services. Research ought to examine the relevance of traditional methods of community and family support as well as formal services. Research should help to explore the possibility of fostering by non-relatives, which is not the Ugandan way, but which might be necessary in the future so that orphans are not without homes and families. Research will also be needed to help generate non-traditional ways of caring for elders, because the sons and daughters who would have cared for these grannies are no longer alive to do so.

Research interviewers should be native Ugandans. We recognize as a limitation the fact that one of the interviewers was a white non-Luganda speaker from the U.S. As Shibusawa and Lukens (2004) point out, cross-cultural and cross-language qualitative research presents linguistic and interpretive challenges which often go unacknowledged. While this researcher's presence in the interviews and in Uganda greatly enhanced her ability to draw conclusions, the fact that she could not interact directly with the respondents limited the data collection and analysis. The co-investigator from Uganda and the translators and case managers strove to provide cultural, historical, and economic contexts for this researcher as we traveled between appointments, and the co-investigators talked at length about each encounter, yet we clearly lost some opportunity for reaching deeper

meaning because one of the interviewers did not speak the language of the respondents. In retrospect the researchers wished that they had hired and trained local research assistants [our translators could have served as interviewers instead] and we recommend that other researchers do so.

Direct practice agencies, whether faith-based, governmental, or community-based, need the resources to support these families. Ugandan children who are orphaned by AIDS face an especially hard life. Many HIV-affected families in Uganda are called "child-headed" because there are no adults in the home; this is a post-HIV concept and new to Uganda (Nkuusa, 2004). The care giving elders are vital to the survival of Ugandan children, but they are growing more frail, impoverished, and stressed as they care for an increasing number of AIDS orphans and with an incredible lack of resources and hope. They can only continue to provide orphan care in their homes if they have the financial and social support to do so.

The grandparents who are raising multiple orphans in Africa are among the poorest on earth. The income-producing middle generation is dying. The meager financial resources of the grandmothers, as well as their place in the job market, make it almost impossible to provide adequate care for the children. The grannies and orphans need the basics: food, running water, electricity, adequate shelter, school fees, transportation, and clothing. In addition to outright financial assistance, the grannies would like "seed" money to begin micro-businesses. They need adequate health care for everyone in the family, including medications to fight HIV and opportunistic infections. These families need legal services to help them make wills so that the orphans do not lose housing when the grannies die. The care giving grandmothers need practical support to negotiate the physical challenges of parenting in later life, such as: respite care, child care, parenting support, support groups, and skills development and recreational opportunities for the grandchildren. The grandmothers spoke of tremendous emotional distress as a result of their care giving and the death of family members. Many of them could benefit from bereavement counseling for themselves and the children.

Since many of the care giving grannies live in rural areas, accessible satellite centers should be

funded and transportation should be made available to them so that they can get to support groups and apply for economic relief. It would be useful if community organizers could assist the grandparents who are caring for orphans to find ways to make their voices heard in service and governmental affairs, as well as to become more visible globally.

Social service and medical care providers may benefit from training about the assets and needs of granny-headed households so that they can provide adequate assessment, crisis intervention, counseling, and case management. The staff who facilitated our research interviews spoke about their own burden of loss. The secondary trauma in which they live constantly should be addressed through supportive administrative and clinical supervision and organizational structures that allow for self-care and peer support.

There may be program development opportunities that build upon various faith traditions and/or upon the family-centered nature of Ugandan culture. It is possible that churches, temples, mosques, and animist leaders can become more involved in supporting the care giving grannies and their orphans. Perhaps organizations can be developed to house aging ailing grandmothers with their grandchildren, not breaking up the families when someone needs intense care, since foster care and nursing homes are not congruent with Ugandan practices. Finally, now that antiretrovirals are finally becoming available in Uganda, education on adherence to medication protocols and support for older care givers in monitoring and encouraging adherence might be useful.

AWOFS and other social service agencies are struggling to meet basic needs, provide supportive counseling, and give loans and grants for small businesses, but these resources are stretched and need help. AWOFS report an increasing client load with overwhelming need juxtaposed to limited funding and staff (Nkuusa, 2004). Increased funding and support for the AIDS-service organizations of Uganda are vital.

There are implications for policy as well. The Ugandan prevention model, which has been so successful, must be fully funded, fully implemented as designed, and made a continuing priority. The private and public sectors of the industrialized world must continue to allocate resources to develop

health infrastructures, strengthen governmental responses, increase access to treatment and medical care, fight pharmaceutical copyright regulations, and establish child and elder care systems. Efforts must continue to reduce stigma and provide money, training, and personnel so that health care and antiretroviral medications are widely accessible. Patents and profits must not be the reason that Ugandans die without treatment or a chance at care or comfort. Advocates must continue to agitate so that African adults and children do not perish.

The following excerpt from a speech by Stephen Lewis (2003), the UN's special envoy for HIV/AIDS in Africa, aptly describes the challenge ahead:

> It is now commonplace that grandmothers are the care givers for orphans...but that is no solution. The grandmothers are impoverished, their days are numbered, and the decimation of families is so complete that there's often no one left in the generation coming up behind.....Millions of children live traumatized, unstable lives, robbed not just of their parents, but of their childhoods and futures. How can this be happening...when we can find over $200 billion to fight a war on terrorism, but we can't find the money to prevent children from living in terror?

At this time there is a mixed picture in Uganda. Uganda has begun receiving money from the Global AIDS Fund for HIV treatments and medical care, making Uganda one of the first few to provide free antiretrovirals (Kaiser, 12/19/03). However, the country continues to struggle with war, refugee displacement, extreme poverty, gender inequality, sex trafficking of women and children, and increased strain on insufficient health care and maintenance programs (Garbus & Marseille, 2003). President Museveni, while progressive and effective in many ways, has recently declared that there are no homosexuals in Uganda, a warning sign that all is not well regarding HIV prevention messages (CDC, 2002). In addition, there is some fear that resources from the Global AIDS Fund will be misused by corrupt governmental officials (Lubega, 2004). Ugandans need the attention and support of the rest of the world.

One cannot help at times but feel hopeless and helpless in the face of the overwhelming,

staggering African HIV epidemic. We have presented these stories - admittedly a drop in an ocean - in fervent hope that this study will be of use to advocates and planners and that it will move individuals and organizations to continue to fight for treatment and services in the developing world. Truly hearing narratives and seeing the story-tellers can make a difference if and when we take to heart the need for immediate justice and access. We hope that we have been good witnesses.

REFERENCES

Ankrah, E.M. (1991). AIDS and the social side of health. Social Science and Medicine, 32, 967 - 980.

Barnett, T. & Whiteside, A. (2002). AIDS in the twenty-first century: Disease and globalization. Palgrave Macmillan.

Bartholet, J. (2000). The plague years. Newsweek, January 17.

Bollinger, L., Stover, J., & Kibirige, V. (September, 1999). The Economic Impact of AIDS in Uganda. Research Triangle Institute and the Centre for Development and Population Activities.

BBC [British Broadcasting] News (2/22/04). Uganda rebels' raid kills 170. Http:// newsvote.bbc.co.uk.

CDC News Updates (3/4/2002). Ugandan president honored for AIDS fight says nation has no homosexuals. Atlanta, GA: Http://www.thebody.com/cdc/news_updates.

Nkuusa, F. (2004). Empowering ourselves and our clients: Strategies for helping to shape the future of HIV/AIDS Care in Uganda. 16th Annual National Conference on Social Work and HIV/AIDS, Washington, DC, May 27 - 30, 2004).

Fullilove, M. (2004). The yin and yang of poverty. Presentation for International Women's Day, Fordham University Graduate School of Social Service, New York, NY, March 8.

Garbus, L. & Marseille, E. (November, 2003). Country AIDS Policy Analysis Project: HIV/AIDS in Uganda. San Francisco, CA: AIDS Policy Research Center, University of California.

Hampton, J. (1990). Living positively with AIDS: The AIDS Support Organization [TASO],

Uganda. Strategies for Hope #2. Oxford, U.K.: G & A Williams.

Hunter, S.S. (1990). Orphans as a window on the AIDS epidemic in sub-Saharan Africa: Initial results and implications of a study in Uganda. Social Science Medicine, 31(6), 681 - 690.

Kaiser Daily HIV/AIDS Report (12/19/2003). Uganda Receives $37 Million in U.S. AIDS Funding. http://www.kaisernetwork.org/daily_reports.

Kaleeba, N., Kadowe, J.N., Kalinaki, D. & Williams, G. (2000). Open Secret: People facing up to HIV and AIDS in Uganda. Strategies for Hope #15. Oxford, U.K.: G & A Williams.

Kamali, A. Seeley, J.A., Nunn, A.J., Kengeya-Kayondo, J.F., Ruberantwari, A. & Mulder, D.W. (1996). The orphan problem: Experience of a sub-Saharan Africa rural population in the AIDS epidemic. AIDS Care, 8(5), 509 - 515.

Kamya, H. (2003). HIV/AIDS mental health issues and street children: The case of Uganda. Presentation at 15th Annual National Conference on Social Work and HIV, Albuquerque, New Mexico.

Kamya, H. (2004). War and HIV/AIDS: The psychological impact on children. 16th Annual National Conference on Social Work and HIV/AIDS, Washington, DC, May 27 - 30, 2004.

Konde-Lule, J.K. (1995). The declining HIV seroprevalence in Uganda: what evidence? In Orubuloye, I.O., Caldwell, J.C., Caldwell, P., & Jain, S. (Eds). Health transition review: The third world AIDS epidemic, supplement to Volume 5, pp. 27 -33.

Lewis, S. (September 21, 2003). Speech at the Official Opening of the 13th ICASA conference, Nairobi, Kenya. Reported on af-aids@lists.healthdev.net.

Lubega, B. (May 30, 2004). Personal Communication.

Lugeba, B. (2004). Empowering the youth in efforts to curb the spread of HIV/AIDS in Uganda. 16th Annual National Conference on Social Work and HIV/AIDS, Washington, DC, May 27 - 30, 2004).

Mukiza-Gapere, J. & Ntozi, J.P.M. (1995a). Impact of AIDS on the family and mortality in

Uganda. In Orubuloye, I.O., Caldwell, J.C., Caldwell, P., & Jain, S. (Eds). Health transition review: The third world AIDS epidemic, supplement to Volume 5, pp.191 - 200.

Mukiza-Gapere, J. & Ntozi, J.P.M. (1995b). Impact of AIDS on marriage patterns, customs and practices in Uganda. In Orubuloye, I.O., Caldwell, J.C., Caldwell, P., & Jain, S. (Eds). Health transition review: The third world AIDS epidemic, supplement to Volume 5, pp. 201 - 208.

Muller, O., Sen, G., & Nsubuga, A. (1999). HIV/AIDS, orphans, and access to school education in a community of Kampala, Uganda. AIDS, 13(1), 146 - 147.

Muwonge, A., Ssentongo, R.M., Sharpe, U., Nantezza, C., & Auma, E. (1996). Women as caretakers for HIV/AIDS infected and affected people under Kitovu mobile AIDS program. International Conference on AIDS, 11(2): 490, abstract # Pub.D. 1339.

Nampanya-Serpell, N. (2002). Global Implications. In Joslin, Daphne (Ed). Invisible Caregivers: Older Adults Raising Children in the Wake of HIV/AIDS, pp. 278 - 296.

Ntozi, J.P.M. (1997a). AIDS morbidity and the role of the family in patient care in Uganda. In Ntozi, J.P.M., Anarfi, J.K., Caldwell, J.C., Jain, S. (Eds), Vulnerability to HIV infection and effects of AIDS in Africa and Asia/India, Supplement to Volume 7, pp. 1 -22.

Ntozi, J.P.M. (1997b). Effect of AIDS on children: the problem of orphans in Uganda. In Ntozi, J.P.M., Anarfi, J.K., Caldwell, J.C., Jain, S. (Eds), Vulnerability to HIV infection and effects of AIDS in Africa and Asia/India, Supplement to Volume 7, pp. 23 - 40.

Ntozi, J. P.M., Lubaale, Y.M.A., & Nakanaabi, I.M. (1997). AIDS mortality in Uganda: Circumstances, factors and impact of death. In Ntozi, J.P.M., Anarfi, J.K., Caldwell, J.C., Jain, S. (Eds), Vulnerability to HIV infection and effects of AIDS in Africa and Asia/India, Supplement to Volume 7, pp. 207 - 224.

Ntozi, J.P.M. & Mukiza-Gapere, J. (1995). Care for AIDS orphans in Uganda: findings from focus group discussions. In Orubuloye, I.O., Caldwell, J.C., Caldwell, P., & Jain, S. (Eds). Health transition review: The third world AIDS epidemic, supplement to Volume 5, pp. 245 - 252.

Pickering, H. & Nunn, A.J. (1997). A three-year follow-up survey of demographic changes in a Ugandan town on the trans-African highway with high HIV-1 seroprevalence. In Ntozi, J.P.M., Anarfi, J.K., Caldwell, J.C., Jain, S. (Eds), Vulnerability to HIV infection and effects of AIDS in Africa and Asia/India, Supplement to Volume 7, pp. 41 - 47.

Sengendo, J. & Nambi, J. (1997). The psychological effect of orphanhood: A study of orphans in Rakai district. In Ntozi, J.P.M., Anarfi, J.K., Caldwell, J.C., Jain, S. (Eds), Vulnerability to HIV infection and effects of AIDS in Africa and Asia/India, Supplement to Volume 7, pp. 105 - 124.

Shibusawa, T. & Lukens, E. (2004). Analyzing Qualitative Data in a Cross-Language Context. In Padgett, D.K. (Ed). The qualitative research experience, pp. 175 - 188. Belmont, CA: Thomson, Brooks/Cole.

Ssamula, J. & Brehony, E. (1993). In discipline with orphans: A community approach to the problem. International Conference on AIDS, 9(2): 931, abstract # PO-D31-4281).

UNICEF (United Nations Children's Fund) Eastern and Southern Africa Regional Office. (2001). Child Workers in the Shadow of AIDS: Listening to the Children. Nairobi, Kenya: UNICEF.

Wawala, P., Kaggwa, S., Banage, D.M., Kakande, V.C., & Mugisa, S.M. (1998). Developing family-centered care for HIV/AIDS orphans: a collaboration across disciplines. International Conference on AIDS, 12: 480, abstract # 24203.

Wax, E. (2004). No longer taboo to talk about HIV/AIDS in Uganda, Washington Post reports. http://www.kaisernetwork.org/daily_reports, February 19.

Williams, G. & Tamale, N. (1991). The caring community: Coping with AIDS in urban Uganda. Strategies for Hope #6. Oxford, U.K.: G & A Williams.

PSEUDONYM	AGE	INTER-VIEWER	# OF MINORS	NOTES ON CIRCUMSTANCES
Naamu #1	unknown	K.	4 total[6] orphans	grandchildren are siblings; both parents died of AIDS; paternal grandmother
Meeme #2	62	K.	6 total orphans; some have HIV	grandchildren are siblings; both parents died of AIDS; paternal grandmother
Namusoke #3	63	P.	5 total orphans; 1 has HIV	grandchildren are siblings; both parents died of AIDS; paternal grandmother; also raising 2 children from a son with mental illness
Ndagire #4	52	P.	8 total orphans; 3 have HIV	minor children are siblings; both parents died of AIDS; paternal aunt
Saawoamaaso #5	62	K.	4 total orphans; all 4 have HIV	grandchildren are siblings; both parents died of AIDS; maternal grandmother
Mbekeka #6	66	P.	10 orphans [2 have died of AIDS]; 3 out of 8 surviving have HIV	grandchildren are cousins, from several parents [her sons and daughters]
Nalumansi #7	62	P.	5 total orphans [1 has died of AIDS]	she is the paternal aunt for 3 and the grandmother for one; she is raising two other orphans [not because of HIV]
Kagere #8	66	P.	4 total orphans and 2 paternal orphans	grandchildren are cousins; 4 of her 5 adult children died of AIDS; these minor children are theirs
Nalubega #9	unknown	K.	5 total orphans	grandchildren are cousins; paternal grandmother; all 6 sons died of AIDS and these are their children; 5 wives died and one left
Namugga #10	unknown	K.	8 total orphans; disclosed some have HIV	children are siblings; both parents died of AIDS; paternal grandmother

[6]In Uganda, orphans are usually categorized as a "paternal orphan," "maternal orphan," or "total orphan," meaning that both parents are dead. When the grandparent or other secondary caregiver dies, they are called "double orphans" (Lubega, 2004)

Namuddu #11	66	K.	7 total orphans	children are siblings; both parents died of AIDS; unknown whether grandmother is maternal or paternal

Mama Jaja:
The stresses and strengths of HIV-affected Ugandan grandmothers

IDENTIFYING AUTHOR NOTES

This report is dedicated to the 11 grandmothers who invited us into their lives and revealed their pain and strength in the hope that their experiences would make a difference to others. Drs. Kamya and Poindexter say thank you ["webale"] to the following colleagues for recruitment, translation, or feedback on the transcriptions or article: Juliet Nsiimye, Josephine Kizito, Francis Nkuusa, and Beatrice Lubega [staff at AIDS Widows, Orphans, and Family Services (AWOFS)], Dr. Edward Kayondo, and Sister Annette Nazziwa. Dorothea Roberts of Fordham University and Kevin Mahoney of Boston College helped us think through the findings. Readers are encouraged to contribute to AWOFS [awofs@infocom.co.ug.] by transferring money to Stanbic Bank Uganda, account # 0140058539401.

This study was funded in part through the Fordham University Graduate School of Social Service Faculty Research Fund and the Boston College Graduate School of Social Work. This paper was presented in various stages of development in November 2003 at the Gerontological Society of America in San Diego, California; in April 2004 at a Fordham University GSSS faculty meeting in Tarrytown, NY; and in May 2004 at the Annual National Conference on Social Work and HIV/AIDS in Washington, DC.

Mama Jaja:

The stresses and strengths of HIV-affected Ugandan grandmothers

Hugo Kamya

Boston College Graduate School of Social Work

McGuinn Hall

Chestnut Hill, MA 02467

617-552-2539 phone

617-552-3199 fax

Kamya@bc.edu

Cynthia Cannon Poindexter

Fordham University Graduate School of Social Services

North Hall, Neperan Road

Tarrytown, NY 10591

718-817-5616 phone

914-524-0586 fax

Poindexter@fordham.edu