HIDDEN IMPACTS: "NEAR OLD" WOMEN'S EXPERIENCES OF ADULT MORBIDITY AND MORTALITY IN RURAL SOUTH AFRICA

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Abstract

This paper explores the experiences of "near old" women with regard to adult morbidity and mortality in their households in the HIV/AIDS era. It focuses specifically on the coping strategies they adopt as non-pensioners during crises such as an adult illness and death. In-depth semi-structured interviews were conducted with 30 women aged 50-59 in the MRC/Wits study site in rural northeast of South Africa. Findings show that "near old" women, like women over 60, have caregiving responsibilities but they do not have coping strategies such as a pension grant, *stokvel* and burial society. Despite the fact that they are engaged in economic activities such as trading and farming, they are still overwhelmed with financial responsibilities of giving care to sick adult kin and orphans/foster children. Many thought a pension grant would have made a lot of difference when there was an adult illness and death in their households. Therefore they long for the day they will become pensioners and able to cope better with crises such as adult morbidity and mortality in their households.

Introduction

It is now over two decades since HIV/AIDS was first discovered and millions of people across the globe are still suffering from its impact. HIV/AIDS impacts those that have it, their families, and their communities; this may be especially true in developing countries. Families, in developing regions of the world, are normally left with not only the burden of caring for the sick for a long period of time, but also the expenses incurred during the sickness and death of loved ones infected with HIV/AIDS. In most cases, prime-aged adults are the ones dying, and their older (or younger) kin are the ones left with multiple burdens. These kin must give care to sick individuals and to orphaned children, and cover expenses incurred from the sickness and funeral (HelpAge International (HAI) 2003).

In Africa, gender plays an important role in determining duties assigned to family members. For instance, women are normally expected to give care to the sick and children in the family. The implication of this, in the era of HIV/AIDS, is that older women will experience a large brunt of the epidemic as a result of increased caregiving responsibilities caused by caring for the sick, dying children and grandchildren, and by becoming surrogate parents to orphaned children (Ferreira 2004). Even though many studies on the effects of HIV/AIDS on people in Africa highlight the important role played by older people, especially older

women, there is still a need to increase our knowledge and understanding about the roles older women are playing and how HIV/AIDS is impacting the well-being of these older women and their households in sub-Saharan Africa.

Early work reveals that older women play a crucial role in South African rural households as a result of the national means-tested non-contributory pension program (Ogunmefun and Schatz 2006; Schatz 2007). These older women use their pensions to sustain their multi-generational households, as a substitute for unemployed children's income and to cushion economic shocks such as HIV/AIDS morbidity and mortality (Schatz and Ogunmefun 2007). However, women below the age of 60 were excluded because in South Africa, female citizens are eligible for pension grant as from age 60 (and male citizens from age 65). In the literature on older women and HIV/AIDS, there is a paucity of knowledge about women aged 50-59 or the "near old", who traditionally in African culture are considered as elderly. This group is sometimes overlooked since they have not yet reached the pension age of 60 (Hunter and May 2003). As a result of the need for more information on this group, and in order to get a better understanding of coping strategies in households without pensions, this study focuses on "near old" (aged 50-59) women and their experiences of HIV/AIDS.

Aims

This study builds on the Gogo (Grandmother) Project[1] by focusing on the experiences of "near old" women aged 50-59 with regard to adult mortality and morbidity in their households. It explores how HIV/AIDS is impacting their lives, as well as the coping strategies used in the absence of pensions in their households. I hypothesize that the experiences of HIV/AIDS for women aged 50-59, with regard to how they cope with the financial impact of HIV/AIDS morbidity and mortality necessarily will be different from those women aged 60-75, because of their inability to access pensions.

[1] The Gogo Project, conducted by Dr. Enid Schatz and Catherine Ogunmefun, commenced in 2004 at the MRC/Wits Unit study site (see Ogunmefun & Schatz 2006 and Schatz & Ogunmefun 2007 for findings from the initial stage of the project). This paper reports findings from the third phase of the project which took place between November 2005 and February 2006.

Literature Review

A long term illness is likely to impact a household financially, especially if it is a terminal disease like HIV/AIDS. The reason for this is that a long term illness increases the expenditure on medical care (medicines, transportation to services, as well as allopathic and traditional medical treatment) and food, therefore an adult HIV-related illness (and death) is likely to reduce the household savings drastically (Barnett and Whiteside 2002). The time and energy spent on caregiving also reduces those hours spent on economic activities and household chores. And, if the ill individual was an income-earner for the household, their income is lost during sickness and after death.

Studies have shown that HIV/AIDS has a great impact on the economic well-being of elderly people, particularly elderly women, and their households (Saengtienchai and Knodel 2001; Knodel, Watkins and VanLandingham 2002; World Health Organization (WHO) 2002; Lindsey et al. 2003). Not only do these elderly people lose a (potential) source of income when their HIV positive children become too sick to work, but they also have to spend the little they have on taking care of them, as well as paying for their funerals. In the study conducted in Zimbabwe, the WHO (2002) found that some of the elderly people's households lost the savings that they have accrued over a long period due to the long term illness of their adult children and the cost of taking care of their children's health care needs before their children eventually died. The elderly people's limited resources were also used to pay for funerals and care for orphans left behind. In Botswana, Lindsey et al. (2003) also found the cost of funerals to be a compounding problem for older caregivers, especially when three or four family members died within a short period of time. As a result of this, there is a curtailment of elaborate and costly funeral rituals (Lindsey et al. 2003).

HIV/AIDS had a huge impact on the economic well-being of AIDS parents in Thailand, despite there being a government intervention policy in place to help alleviate this impact on them. This intervention is a basic government health insurance, which covers the costs of available treatment and thereby reduces the economic impact of an illness on a family. Knodel, Watkins and VanLandingham (2002) show that 60% of the adult children, who died of AIDS, were covered by this health insurance and that this helped to reduce the economic

impact of AIDS on their parents. This type of intervention by the government that helps to reduce the economic impact of HIV/AIDS was not reported in other studies (WHO 2002, Lindsey et al. 2003). The implication of this is that, in countries where this kind of policy is not in place, the elderly are likely to feel an even greater economic impact due to HIV/AIDS. In some of these countries e.g. South Africa, where the policy is not in place, the cost of medical care may not be high, but other factors such as transport cost and use of traditional healers may increase the financial impact of HIV/AIDS on older people with sick children. There is therefore the need for more studies, like this one, that focuses on the financial difficulties faced by elderly women in rural South Africa when there is an adult illness and death, especially when due to HIV/AIDS, in their households.

An old age pension program, like those available in a few developing countries, is another type of government intervention that may reduce the vulnerability of older people to poverty (HAI 2003; Case 2001; May 2003). Such programs have had a significant impact on poverty in Brazil and South Africa. Even though the pension is meant for the elderly, it is usually shared between the recipient and members of his/her household (HAI 2003). HelpAge International (2003) found that in South African households where there are pensioners, there was greater financial stability and lower probability of experiencing a decline in living standards. May (2003) also found pension payment to be an important safety net for the elderly and their household members in South Africa. In the initial phase of Gogo Project, Schatz and Ogunmefun (2007) found that older women think of the pension as a grant to the household, not just to themselves as individuals. Most women, when asked 'who is the pension for?' answered, "For me and my grandchildren."

An implication of the pension as a household safety net is that in a country like South Africa, the pension may serve as a stable and reliable income for older people and their families to alleviate poverty, and to mediate crises. Older women, in particular those that have adult children that are dying or have died of HIV/AIDS, may use their pension in a way that reduces the economic impact of HIV/AIDS. However, for rural households with no pensioners, there may be other coping strategies that are being adopted, especially when there is a crisis such as adult morbidity and mortality. Despite the high prevalence rate of

HIV/AIDS in South Africa, not much empirical work has been done to explore the coping strategies of elderly "near old" women who are non-pensioners when faced with crises caused by the epidemic. Schatz and Ogunmefun (2007) explore the usage of pensions in households with and without HIV/AIDS deaths, but are not able to focus on households with no pensions. For this reason, this study focuses on the coping strategies of "near old" women during crises such as adult morbidity and mortality in rural South Africa in the era of HIV/AIDS.

Data and Methods

The data for this study was collected in the Medical Research Council/Wits Rural Public Health and Health Transitions Research Unit (MRC/Wits Unit) study site situated in rural northeast of South Africa, bordering on Mozambique. The study site is based in Mpumalanga Province (South Africa), which had an estimated 32.1 HIV prevalence among antenatal clinic attendees in 2006 (Department of Health 2007). The AHPU has been conducting an annual census in the fieldsite since 1992 and this has yielded the Agincourt Health and Demographic Surveillance System (AHDSS) data, which provides information on demography, health status and population dynamics of rural communities at the fieldsite. The AHDSS data also includes verbal autopsy data, which identifies the cause of each death in the study site.

Using the AHDSS census and verbal autopsy data (2001-2003), I did a purposeful sampling of subjects for this study by selecting a sample of 30 women (plus 15 alternates) aged 50-59 years and their households. The sample was stratified by household mortality experience. Thus I had 10 households with an adult HIV/AIDS death, 10 households with another type of adult death and 10 households with no adult death between 2001 and 2003. The purpose of the stratification is to compare the experiences of "near old" women with regard to type of adult morbidity and mortality in their households. Out of the 30 respondents (in the original sample), 3 women were away from home at the time of the fieldwork and were replaced by alternates.

The fieldwork took place between November 2005 and February 2006. Before the fieldwork commenced, ethical clearance was first obtained from the University of the Witwatersrand ethics committee. The three local interviews that conducted Gogo Project Phase I and II were rehired and 3 in-depth semi-structured interviews were conducted with each respondent. The interview guides included most of the questions from Phase I and II such as experiences of HIV/AIDS, caregiving of the sick and orphan/foster children, and some new questions such as expectation of getting a pension grant at age 60, the difference a pension grant would make during crises, effect of caregiving on physical/mental health and economic impact of caregiving. Before interviews were conducted, the interviewers obtained informed verbal consent from the respondents. The interviews were taped, fully transcribed, coded and analyzed with Nvivo.

Results

Older people are sometimes regarded as individuals over age 60 and those between 50 and 59 years are referred to as "near old" (Hunter and May 2003). However in many African societies people are more likely to be regarded as elderly when they start having grandchildren. As a result of the attainment of motherhood at an early age, many women are likely to become grandmothers as from age 50. Despite the elderly status of "near old" women, they are usually forgotten or neglected in programmes that target older people. For instance, the non-contributory old age pension scheme that is available in a few African countries often uses 60 years as a cut-off age for women (and 65 years for men). However as elderly people, they also face the same challenges or may be more than those over age 60 because they have no pensions to rely on during crises, such as adult morbidity and mortality in their households.

As findings from other studies and the initial phase of this project have revealed (WHO 2002; HelpAge 2003, Ogunmefun and Schatz 2006; Schatz and Ogunmefun 2007; Schatz 2007), women over age 60 are becoming caregivers for spouses, adult children and their grandchildren as more adults fall prey to communicable and non-communicable disease such as malaria, tuberculosis, stroke and HIV/AIDS. In this study, I also found that women "near old" women aged 50- 59 are also caregivers to spouses, adult children, other relatives and grandchildren.

Despite stratifying the sample by household mortality experience such that I had 10 households with no adult death between 2001 and 2003, nearly all the respondents had experienced adult mortality or morbidity in their households. Some of them experienced prior 2001 and some after 2003. One of the respondents lost her husband a few months before the interview took place. A few of the respondents' experience of adult illness and death, especially when due to HIV/AIDS, was/is as a result of a kin living in another household, and this is precisely what was found out at the initial stage of this project (Ogunmefun and Schatz 2006). Table 1 shows the kin the respondents gave care to by household mortality experience.

Table 1 : Caregiving for the sick

	Took/taking care of ill adult child	Took/taking care of ill husband	Took/taking care of other ill kin
HIV/AIDS Households	8	1	1
Other Death Households	2	5	2
No Death Households	3	3	4
Total (N=29)	13	9	7

Out of 30, 29 respondents said they had or are currently taking care of a loved one. Women from households with an adult HIV/AIDS are more likely to care for an adult child, while those from households with another type of adult death are more likely to care for a spouse. Out of ten respondents that had no death in their households (between 2001 and 2003), four reported that they took care of other kin such as an in-law, three took care of a spouse and three, an adult child. Elderly women are therefore bound to be involved in caregiving responsibilities because of gender roles, as some of the respondents reported, whether the patient is a close relative like a child/spouse or an in-law.

When elderly women take over caregiving responsibilities, they also take on some burdens such as financial expenses for taking their patients to hospitals/traditional healers and buying

medicines. And, funeral and morning expenses when these patients die as well as financial support for children left-behind (Ogunmefun and Schatz 2006). In order to cope with the financial burdens of caregiving, pensioners usually use their pensions to sustain their households during crises (Schatz and Ogunmefun 2007), but how do elderly non-pensioners cope with such crises in the absence of pensions in their households? In the sections below, I examine (through narratives) the financial difficulties of "near old" women and the coping strategies they adopt when faced with crises such as adult morbidity and mortality, in the absence of a pension grant. Quotes from the respondents will be followed by a pseudonym, age and household's mortality experience.

Engaging in economic activities

Unlike elderly women over the age of 60, who are more likely to retire from active work or economic activities when they start receiving a pension grant[2], I found that most of the respondents are involved in one economic activity or the other, in order to earn an income or provide food for their households. Nearly half of the respondents sell items such as (traditional) brooms, grass mats, tomatoes, ice blocks/cream, soup and bread, niknaks, scones, clothes and traditional beer. Four of the remaining respondents are kitchen helpers, three are workers (labourers) on a road/dam construction project, one is a volunteer at a local crèche and one used to be a primary school teacher. Four out of seven respondents that are currently not working had never worked before. All except two of the respondents said they engage in farming to produce food for household consumption. However, one respondent said she used to sell some of the maize she harvested. One of the two respondents that do not farm said it is because she has a small compound.

Surprisingly, I found that four of the respondents have started getting a pension. One of them said she has been on a disability grant for a long time but was recently changed to an old age pension. The reason why the other three women (who are below age 60) are getting a pension grant may be due to the miscalculation of their age. Many of the respondents are not literate and some complained (especially those who have not started receiving a pension

[2] In Gogo Project Phase 1 and 2, many of the respondents (over age 60) said they stopped working when they started receiving a pension grant.

grant) that their age has been "cut off" in their Identity Document (ID). This means that sometimes the age of elderly people may be miscalculated in their ID.

Even though being engaged in economic activities such as selling and working as a labourer may seem as a way to cope with the financial responsibilities of caregiving, this is not sufficient in the case of these women. I found that those that sell items such as scones, niknaks and ice blocks/cream barely make a profit. When Makosi, who supports 11 people in her household, was asked about the profit she makes from selling, she said, "I can't say exactly how much I get for profit because I sell nik-naks and ice block, what I do know is that I get R20 ($3) sometimes. Now that the schools are closed, I don't get enough money" (Makosi, 55 years, No death Household). Nearly all the respondents that sell said they make between R20 ($3) and R50 ($7) per day; this is likely gross and not net profit. Some sell at local schools, like Makosi, and therefore they barely get any profit from selling during school holidays.

Selling is profitable, however, for the respondents who are traditional beer sellers. Mpfuleni, a traditional beer seller, said, "It depends on that day; sometimes I make R80 ($11) or R100 ($14) in a day" (Mpfuleni, 58 years, Other Death Household). Mpfuleni supports 7 people, including her husband who is no longer working (but not yet a pensioner). She attested that since she started selling traditional beer, she has bought a stove, fridge, grocery cupboard, bed and built (a house with) two rooms, besides buying groceries for her household. When asked how life is since she is not getting a pension yet, she replied, "To me, life is good" (Mpfuleni, 58 years, Other Death Household).

Other respondents that work as a kitchen helper or construction worker do not think pre-pension life is good. These women earn between R400 ($57) and R700 ($100) per month and complained about how they struggle to support their households. Bulelwa is a widow that supports 5 people including 2 children (from her deceased brother) and 1 grandchild. She works, on a contract basis, as a road construction worker and earns R700 ($100) per month. She reported, when asked about how she supports her family, "…We are suffering…. It is difficult for me because even when I am sick I have to work in order to make money to support the family" (Bulelwa, 57 years, No Death Household).

Considering the kind of work that Bulelwa and some of the respondents do, and the fact that the income they earn may not be enough to support their households, pre-pension life may truly be difficult for elderly "near old" women.

"Credits? No!"

Regardless of whether the respondents earn enough money or not, they all reported that they use their money to support their households, the same way pensioners do. When asked about what they use their money to buy, they reported that they buy *mielie-meal*, soap, potatoes, cooking oil, sugar, electricity, etc. Also, like most pensioners, they do not have left over after buying these household needs.

From the initial phase of Gogo Project, I learnt that pensioners buy household needs on credit. This serves as a coping strategy during crises in their households. In order to find out whether "near old" women have the same coping strategy as pensioners, they were asked whether they buy on credit. Most of them reported they do not have such a coping strategy.

Fanie, a widow who used to sell grass mats, is one of those that do not buy on credit and she explained why, "No, I am afraid [to buy on credit] because I am not working" (Fanie, 52 years, HIV Death Household). Fanie supports nine people including children and grandchildren and relies only on child grants for four children (and grandchildren). She said the money from the child grants is not enough to support her household. She is therefore vulnerable to financial hardship because she is no longer selling and therefore cannot buy household needs on credit.

A few of the respondents who sell are able to buy on credit, for example, Mpfuleni (as mentioned earlier) bought some of the household items on credit. However, it is not all sellers that are able to buy on credit. Brenda, who supports 9 people (like Fanie) and sells cold drinks and ice blocks, is reluctant to buy on credit. She said, "No, I am not able to buy on credit since I am neither working nor getting a pension" (Brenda, 50 years, Other Death Household).

Even though a few of the respondents who sell make enough profit and therefore able to buy on credit, most of them barely make profit and therefore it is difficult for them to use buying

on credit as a coping strategy. Thus, non-pensioners are more likely to face financial hardship, even when they are involved in economic activities such as selling.

Besides buying on credit, pensioners also join a burial society, which helps when there is a death in their household, and also a *stokvel* (a rotating scheme), which gives them access to some cash sometimes. Joining a burial society or a *stokvel* is beyond most of these "near old" respondents. Only 6 (2 pensioners) respondents joined a burial society. When asked, those who did not join, like Euginia said, "I don't have money to pay for it" (Euginia, 57 years, HIV/AIDS Death Household). The same reply was given when they were asked about why they did not join a *stokvel*. The implication of this is that non-pensioners, unlike pensioners who use *stokvel* and burial society as coping strategies, may be more vulnerable to financial hardship, especially when there is an adult morbidity or mortality in their households.

Coping with adult illness and death

Despite the non-availability of coping strategies such as buying on credit and joining a burial society or stokvel, the majority of these "near old" respondents had experienced an adult illness and death in their households, like those over age 60 (Ogunmefun and Schatz 2006; Schatz and Ogunmefun 2007). Many said it was financially difficult for them during the illness, death, mourning and funeral of the loved one that they cared for. The few that did not have a financial difficulty was either because a family member helped them or the deceased joined a burial society (that assisted with the funeral).

One of these respondents, Khosi, was a widow that took care of her daughter who was sick with HIV/AIDS for 2 years before she eventually died. When asked about the difficulties she experienced, she replied,

> Haa! It was very difficult. I remember a day when I wanted to take her to the hospital and I didn't have any money so I had to walk to my relatives at Newington B [another village] to ask for money. They gave me, and then I took her to Matikwana hospital…. [And when she died] it was still the same. I didn't have money to transport the corpse from here to the mortuary so my cousin helped me by phoning his burial society to come and take her corpse to Elite funeral parlour…. [During the funeral], my relatives and one of my sons did help me by contributing money to buy

> food, coffin and other needs for the funeral (Khosi, 52 years, HIV/AIDS Death Household).

Even though Khosi confessed that it was difficult for her when her daughter was sick and later died, she was fortunate to get some assistance (at some point) from her relatives like some of the respondents. However a few respondents were in a more desperate condition when a loved one died. Bulelwa was one of them. She took care of her husband who was ill for 10 years with a kidney problem and later died. She related her experience:

> It was difficult financially because we failed to go to medi-clinic because there was not enough money. Even to go to the hospital was a problem. We had to use a bus which took a longer time, meanwhile there were many taxis. …My husband corpse was never at the mortuary, we used planks to make a coffin, which we bought from someone in the village. …. [At his funeral], people never ate, they just came to burry my husband and they went back home (Bulelwa, 57 years, No Death Household).

The narratives show that "near old" women who are non-pensioners may find it difficult to cope financially when a loved one is sick, especially when there is an absence of any regular income. Unlike pensioners who rely on pensions to take care of caregiving expenses, the burdens of caregiving weigh heavily on them. And, non-availability of coping strategies such as joining a burial society or stokvel makes the situation more difficult, especially when the loved one passes away. Some of the respondents felt bad that they were not able to give their loved one a befitting burial. They lamented about not being able to buy a "nice" coffin and food for mourners. Therefore, due to the absence of a pension grant, "near old" women are prone to feel the financial impact of adult morbidity and mortality, especially when due to HIV/AIDS.

"*A pension grant would have made a big difference"*

For many of the respondents, especially those that experienced financial difficulties when a loved one died, a pension grant would have made a lot of difference. When asked what difference a pension grant would make during crises such as adult illness and death in their households, many said it would have helped them to give their loved one a befitting burial by buying a coffin/casket (instead of using planks), flowers to put on their grave,

and food for those who came to mourn. Brenda was one of the respondents that thought a pension grant would have made a difference when her loved one passed away. "It would have made a big difference because I would have bought a casket for my daughter" (Brenda, 50 years, Other Death Household).

A few even believed a pension grant would have kept their loved one from dying at the time he/she did. Winnie was one of the respondents who said a pension grant could have made a difference with regard to her daughter's illness and death. "If I had been getting pension I would have bought expensive tablets for AIDS and given them to my daughter, and even now she would still be alive" (Winnie, 52 years, HIV/AIDS Household). Like Winnie, Euginia also believed a pension grant could make a difference when a loved one is seriously ill. She explained,

> It would have helped me to take my daughter to an expensive hospital where there is good care for patients. And, maybe my daughter would not have died. But because I didn't have enough money to take her to the hospital at Nelspruit [a nearby city], she died. [She died because] she didn't get strong tablets (Euginia, 57 years, HIV/AIDS Household).

The absence of a pension grant not only affects "near old" women but also the loved ones in their care by preventing them from getting proper medical treatment when ill and a befitting burial when they pass away. As a result of this, many of the "near old" respondents long for the day they will start receiving a pension grant because, they believe it will help them to cope better with their caregiving responsibilities.

Conclusion

The findings from this research show the experiences of "near old" women with regard to adult morbidity and mortality in their households in the era of HIV/AIDS. I found that "near old" women, like women over 60, have caregiving responsibilities but coping strategies such as a grant, *stokvel* and burial society are almost non-existent for them. Even though they are more likely to be involved in economic activities such as working or trading, and sometimes get assistance from family members, they are still overwhelmed with financial responsibilities of giving care to sick adult kin and orphans/foster children. Many thought a pension grant would have made a lot of

difference when they had an adult illness and death in their households. Therefore they long for the day they will become pensioners and able to cope better with crises in their households.

As illustrated in this paper, “near old” women are heavily impacted by financial responsibilities of caregiving, especially when due to HIV/AIDS, in the absence of a pension grant. Even though the women in this study will eventually get a pension grant when they reach age 60, other women will become “near old” and therefore “step into their shoes”. There is therefore the need for programmes to target elderly women in this age group, who though feel the impact of adult morbidity and mortality like those over 60, but are being neglected. Lowering the cut-off age for getting a pension grant may not be a good option, as it may cause a financial constraint for the government. However, there is need for special programmes that target caregivers aged 50-59. These programmes should not only lighten their burdens as elderly caregivers, but also help them with the transition to respective old age.

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