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Everyday mobilisations among grandmothers in South Africa: survival, support and social change in the era of HIV/AIDS

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ABSTRACT
In many sub-Saharan African communities, caring for vulnerable children in the era of HIV/AIDS appears to be creating deep financial, physical and psychological strains for care-givers, the great majority of whom are ageing women or 'grandmothers'. Yet, limited primary research has been carried out with older women in specific communities, and therefore grandmothers' collective responses, sources of support, complex lived experiences, and diverse family situations are not well understood. This paper presents the findings of research undertaken in four communities in KwaZulu-Natal, South Africa, between 2006 and 2010. The purpose was to understand the daily stresses, collective responses and mobilisations of older women in these communities. The research involved repeated focus groups, interviews and participant observation involving approximately 100 older women. In the analysis, attention is given to the diversities among participants, the ways in which HIV/AIDS intermingles with other stresses in their lives to drive their mobilisations, and their collective responses, even amidst highly constrained conditions. Through these lenses, the paper illuminates how older women in these communities are organising in response to the combined, devastating and diverse effects of HIV/AIDS, poverty, violence and illness. It also suggests that, counter to some stereotyping of 'African grandmothers' as frail or passive, these women are forming associations in order to generate incomes, resist stigma, connect with broader support networks and provide care to hundreds in their communities.

KEY WORDS – older women, mobilisation, grandmothers, HIV/AIDS, South Africa, violence, stereotypes.

Introduction

Approximately 33.3 million people worldwide live with HIV, with more than two-thirds of these in sub-Saharan Africa (UNAIDS 2010). Prevalence in South Africa's province of KwaZulu-Natal is among the highest in the world;

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some 40 per cent of women attending antenatal clinics test positive (Department of Health 2010). In this area, as in much of the region, young adults are falling ill and dying, leaving older women to care for the sick, vulnerable and orphaned in their families (Bicego, Rutstein and Johnson 2003; Freeman and Nkomo 2006*a*; Hosegood and Timæus 2005; Monasch and Boerma 2004). HelpAge International (2006) estimates that 40–60 per cent of orphans in several sub-Saharan countries live in households headed by grandmothers.

While policy makers and development agencies have long focused on 'orphans and vulnerable children', the conditions faced by those caring for these children have been slower to gain recognition (*e.g.* Lewis 2005; Marais 2005). Since 2006, the Canadian Stephen Lewis Foundation (SLF) has been facilitating an ever-growing solidarity network of Canadians seeking to mobilise resources, raise awareness and effect international policy change around issues faced by grandmothers on the African continent (*see* www.grandmotherscampaign.org). A number of international declarations have also committed governments to addressing the needs of older people in high-prevalence communities. These include the United Nations Declaration of Commitment on HIV/AIDS (United Nations 2001), the Madrid International Plan of Action on Ageing (United Nations 2002) and the Valletta Declaration (2005).

However, limited primary research has been undertaken on the diverse lives and associations of older women affected by AIDS in African communities (Fuller-Thomson, Hayslip and Patrick 2005). Existing research has focused primarily on establishing who is caring for the region's vulnerable children, indicating that, across southern Africa, the majority of children affected by AIDS are being cared for by extended families, most commonly by their grandmothers (Bicego, Rutstein and Johnson 2003; Freeman and Nkomo 2006*a*; Hosegood and Timæus 2005; Monasch and Boerma 2004; Munthree and Maharaj 2010; Mutangadura, Mukurazita and Jackson 1999; Schatz 2007; Schatz and Ogunmefun 2007; Seeley *et al.* 2009). In other research on 'care-givers' of AIDS-affected children (many, but not all, of whom are grandmothers, and some, but not all, of whom live in southern Africa), scholars have examined the care capacities of extended families, noting that the two dominant theories (*i.e.* that families are reaching the point of social rupturing and that families are continuing to demonstrate resilience and adaptability) are both too simplistic (Abebe and Aase 2007; Chirwa 2002). Researchers have also looked at factors influencing care-givers' decisions to provide care, identifying children's ages and the availability of financial assistance as common considerations (Freeman and Nkomo 2006*b*). Furthermore, several studies have examined the challenges associated with care-giving, highlighting financial stresses (Freeman and

Nkomo 2006*b*; Jones 2006; Miller *et al.* 2006), children's health issues (Linsk and Mason 2004) and issues relating to children's behaviours (Oburu and Palmerus 2005), as well as the health of care-givers themselves, including their physical and psychosocial wellbeing (Joslin and Harrison 1998), their stress levels (Oburu and Palmerus 2005) and adverse health outcomes potentially related to care-giving (Hansell *et al.* 2002). Together, this research demonstrates that, in the context of HIV/AIDS, caring for vulnerable children is creating deep and complex financial, physical and psychological strains on care-givers, the great majority of whom are ageing women.

Yet much remains unknown. This paper seeks to extend the research literature on HIV/AIDS and older women in sub-Saharan Africa by addressing three areas of limitation. First, most work in this area has focused on the impacts of the epidemic on older women, placing much less emphasis on understanding how older women might be collectively mobilising or responding (Kuo and Operario 2009);[1] this paper introduces new research evidence on older women's networks, sources of social support and forms of association. Second, the diversities among grandparent care-givers, even within culturally similar settings, have not yet received sufficient analysis (Fuller-Thomson, Hayslip and Patrick 2005); this paper therefore pays particular attention to diversity within participants' family structures, care-giving responsibilities, and social and economic conditions. Third, researchers have not fully grappled with ways in which the HIV/AIDS epidemic intermingles with multiple other stressors in older women's lives (Casale 2011; Nyambedha, Wandibba and Aagaard-Hansen 2003), and thus this study specifically explores the complex and interacting stresses faced by older care-givers.

Because of these limitations, certain assumptions about 'African grandmothers' and their struggles with HIV/AIDS have arisen (*see also* Chazan 2008). For instance, the dominant focus on these women's challenges tends to perpetuate certain stereotypes of 'African grandmothers' as old, frail, passive, victims, isolated and dependent (Casale 2011). Moreover, the minimal research on these women's multiple, interacting and context-specific stresses upholds popular discourses of AIDS as an exceptional stress in southern Africa. Indeed, in academic, advocacy and policy circles, it is often assumed that AIDS is the most profound pressure older women are facing and that it is radically altering their roles in their families (Marais 2005).

This paper adds to existing research evidence by detailing the lives and associations of older women from four high HIV-prevalence communities in the province of KwaZulu-Natal, South Africa. It is based on research through repeated focus groups, interviews and participant observation with

approximately 100 older women, carried out between 2006 and 2010. In the analysis, attention is given to the diversities among participants, the ways in which HIV/AIDS intermingles with other stresses in their lives to drive their mobilisations and their collective responses.

This research was undertaken in partnership with the Hillcrest AIDS Centre Trust (HACT), a well-establish and highly networked non-governmental organisation (NGO), which provides home-based and hospice care to AIDS-affected families, as well as assists these families with food parcels, community gardens, school fees and income-generation projects (*see* www.hillaids.org.za). The HACT receives funding from multiple sources, including international donors (*e.g.* German Agri Action, Oxfam Australia and the SLF), private sector and, in earlier years, the South African Departments of Health and of Social Welfare (Julie Hornby, HACT, personal communication, 31 July 2008). The HACT is located in an area called the Valley of 1000 Hills (Kwadedagendladle in isiZulu), which spans approximately 250 square kilometres of hills, plateaus and ravines. The south-easterly-most part of this area is located 40 kilometres west of Durban in KwaZulu-Natal, South Africa. In this area, some 100,000 people, mostly isiZulu-speaking, live in loosely clustered rural and peri-urban settlements (Valley Trust 2009). The Valley of 1000 Hills is situated on the border of the former Bantustan of KwaZulu and province of Natal, and thus is characterised by profound class, race and gender inequalities (Campbell *et al.* 2008). At its edges, closest to Durban, lay several affluent rural–suburban communities (such as Hillcrest and Kloof), which were part of the former Natal; these growing pockets are inhabited primarily by 'white' and some 'Indian' South Africans. By contrast, residents of the nearby settlements, which were part of KwaZulu, are almost exclusively 'black' and isiZulu-speaking. These areas remain extremely under-resourced, with high unemployment levels, poor housing conditions, inadequate sanitation, limited social services and a disproportionate HIV/AIDS epidemic. The majority of the HACT's clients come from the Valley's poorer settlements, including the four settlements where HACT-supported grandmothers' groups – which are central to the research presented in this paper – have mobilised over the past decade: Inchanga, Molweni, Lower Molweni and KwaNyuswa.

The HACT has long provided support to care-givers, many of whom happen to be grandmothers. However, the needs of 'grandmothers' *per se* only explicitly made it on to the Centre's agenda in 2007. This was a direct result of the HACT's connection to the SLF and its transnational 'Grandmothers to Grandmothers Campaign'. In short, following exposure to this budding international advocacy network in 2006, two nurses employed by the HACT founded the Valley's first 'gogos' support group' ('gogo' meaning 'grandmother' in isiZulu), in the peri-urban settlement of

Inchanga. This was followed by the rapid and energetic mobilisation of grandmothers across the Valley, so that by 2010 there were 26 groups connected to the HACT nurses. Our research tracked and documented this mobilisation of gogos' groups between 2006 and 2010. It also included an in-depth examination of the lives of the gogos involved in the four initial groups, seeking to understand the stresses they face and their motivations for organising.

Methodology

This study centred around the following questions: How, why, and to what effect were older women mobilising and linking to the Hillcrest Centre network between 2006 and 2010? What were the key stresses these women faced? How were they collectively responding to these stresses? Based on a feminist and participatory methodological framework (*e.g.* following the works of Fine 1994; Frank 2005; Moss 2002; Pratt 2000; Ruddick 2004), the project ran from 2006 to 2010 and was comprised of three main parts.

The first part involved tracking the mobilisation of the Valley grandmothers, their connections to other groups, and their key activities, challenges and successes. This was done through participant observation and key informant interviews with group leaders, community health workers, nurses and the HACT staff. The majority of these interviews were carried out in English by the primary researcher, although some were conducted in isiZulu by the primary researcher and one highly trained research assistant. Detailed logs were kept of all observations and interviews were transcribed verbatim.

The second part entailed administering a preliminary questionnaire with four of the gogos' groups to gauge participants' health concerns and healthcare access, family arrangements, income sources and housing conditions. These questionnaires were initiated and prepared by the HACT nurses, with input from the primary researcher, administered by the HACT nurses and analysed (using a series of Excel spread sheets) by the primary researcher.

The third part comprised repeated focus groups and in-depth interviews with gogos from the four initial support groups. The interviews involved 'household mapping', in which family trees were drawn in order to examine the family structures and responsibilities, and 'photo journaling', in which participants were asked to photograph key stresses in their lives. These photographs were then used as a basis for the interviews. During this part of the research, the primary researcher and one research assistant attended the weekly meetings of the four gogos' groups under study over a period of five months. These meetings were carried out in isiZulu with English translation. All discussions were audio-taped, transcribed, translated and proofread for

accuracy, while analysis involved repeated close-readings of the transcripts and coding each according to specific issues and broader themes.

The first two years of the project, 2006 and 2007, were dedicated to preliminary research and relationship building. During this time, the primary researcher worked predominantly with the HACT nurses to establish research questions and areas of mutual interest and concern. Most of the intensive research then took place over the course of the following year, in 2008, during which time the researchers were in daily contact with the gogos. In 2009 and 2010, preliminary analyses were undertaken and these were shared with the gogos and other key actors in a series of feedback activities. In 2010 follow-up research was carried out, including group visits and interviews with gogos, in order to track changes that had taken place since 2006, as well as to further verify the emerging analyses and conclusions. All stages of the research underwent review and received ethics clearance through the primary researcher's home institution, Carleton University.

The knowledge produced in this study was conditioned by complex relationships across differences in language, nationality, skin colour, generation, class and education: all of the gogos were older, isiZulu-speaking South Africans, with limited formal education and scarce material resources, from the rural areas outside Durban; the primary researcher was university-trained, well-funded, 'white', English-speaking and not from South Africa; and the three research assistants were younger, isiZulu-speaking South Africans from urban townships near Durban. Nevertheless, the gogos were extremely open and candid throughout the research, possibly due to the fact that they were introduced to the researchers by the HACT nurses. Indeed, the nurses were themselves older Zulu women from the Valley settlements and were trusted among the gogos' families; talented group facilitators, they each possessed a half-century of experience in community outreach work. In addition, the primary researcher worked in South Africa over several years, spoke some isiZulu, and prioritised building trust and credibility with participants. Yet, as in all intensive research, the negotiation of these research relationships was not without its challenges and complexities; thus, the analysis was undertaken with careful attention to how power operated throughout the study and the findings that follow should be considered within this context.

Findings

Mobilisation: Gogos organising in the Valley of 1000 Hills

In 2006 the HACT did not offer any support programmes explicitly designed for 'grandmothers', although older women from the area had long come

into contact with the Centre via its home-based care programme. In August 2006, two of the HACT nurses participated in a grandmothers' gathering, hosted by the SLF, which brought together 300 Canadian and Africa grandmothers for three days in Toronto, Canada. The purpose was to build a transnational network of older women and to mobilise Canadian grandmothers around the cause of African grandmothers affected by AIDS. This experience became the catalyst for a major shift that took place at the HACT: the nurses returned home determined to begin working directly with 'support groups for gogos caring for orphans'. They started the first gogos' group in the peri-urban settlement of Inchanga in September 2007. Later that year, they began working with another support group in Molweni and in early 2008 they spread their efforts to a third group in Lower Molweni and a fourth group in KwaNyuswa. The nurses helped the gogos build income-generation projects, connect with other NGOs, and access training and materials; they also provided support, spiritual counsel, information and food. Word spread quickly in the Valley, so that each month additional groups of 'gogos'[2] joined the HACT network.

Much of the early mobilisation took place in a spontaneous and piecemeal fashion, riding on the energy and leadership infused by the HACT nurses. As of 2008, there was not yet any formal funding and the gogos' groups were not central to the HACT mandate or operations. However, by mid-2009 the gogos' groups were profiled as the HACT's 'Grandmother Project' on the Centre's website and in its 2008–09 Annual Report. The Grandmother Project received significant local media attention in late 2009 and early 2010 and, as a result, private donations began trickling in. In late 2009 one of the nurses was invited to present her 'success story' at the first African Grandmothers' Gathering, which was then being organised (and set for May 2010) by a SLF-supported group in Swaziland. Moreover, new funding was extended to the HACT's Grandmother Project by the SLF in February 2010. This was immediately put toward purchasing sewing machines, organising training sessions for the grandmothers and hiring a part-time Grandmother Project staff member to work support the nurses.[3]

By late 2010 there were an estimated 1,000 women (and a few men) involved in the support groups and, with each caring for on average ten people, benefits were being felt by up to 10,000 people across the Valley. Some were entirely new associations, but most were older groups that had been reconfigured, renamed and renewed as a result of their connection to the HACT; all were gaining new support from the nurses and from their linkages with the ever-expanding network. This mobilisation clearly depicts these gogos as actors involved in AIDS response and as key agents in building networks of support and care.

Diversity: meet the Valley gogos and their families

A closer look at the women involved in this mobilisation reveals both areas of commonality and areas of diversity among them. Most of the gogos in this research were grandmother care-givers, many of whom were caring for 'orphaned children', as per the HACT nurses' initial conceptualisation of the groups. There were, however, some non-grandmothers among the study's participants: of the 100 participants, two were young women, two were older men, and the remaining 96 were grandmothers. Most participants were between the ages of 45 and 65, but ages varied significantly with the oldest in her eighties and the youngest in her twenties. In 2008, the average age was estimated at 60 years (*i.e.* born in 1948, the year the apartheid government came to power). In line with historical trends in which older women have long raised children in impoverished rural areas while adults worked away from home in migrant labour positions (Madhavan 2004; Upton 2003), most of the gogos were raised by their own grandmothers in the impoverished Bantustan of KwaZulu, with limited (if any) access to formal education. Most had their first children in their late teens or early twenties (*i.e.* in the late 1960s), and became grandmothers for the first time in their early forties (trends which have also been documented elsewhere, *e.g.* Chazan 2008). Many were not only grandmothers, but also great-grandmothers, which is an important conceptual distinction because each additional generation in their families appeared to increase their care-giving responsibilities significantly. Most of the gogos were also widows who had lost their husbands in the political violence that took place in this area in the 1980s and 1990s, during the decline of the apartheid government (Jeffery 1997). Going back several decades, many told stories of trying to raise children under the immense insecurity of daily murders, home invasions, armed conflicts and house burnings. Many described themselves as active Christians and as religious women.

As primary care-givers for their extended families, most of these women described their fluid family networks as ranging from one to more than 20 people, with an average family size of approximately ten. These included children, grandchildren, brothers, sisters, nieces, nephews, neighbours and great-grandchildren. Caring for on average seven children each, gogos cited a number of reasons why children were ending up in their care: the parents had passed away, fallen sick, were working elsewhere or had simply 'left them'. As one grandmother from Lower Molweni noted:

> I have a family of 15, including my two grandchildren who are orphans … These children are not really orphans because they still have their mother, but she gave them away because she is sick. She has this disease and their father died. (Gogo, Lower Molweni, August 2008)

Despite the original emphasis of the support groups on 'grandmothers caring for orphans', the women in this research emphasised that their care-giving stresses were not necessarily a result of the *orphans* in their care but rather the overall number of *children* in their care, their relationships with these children, and their lack of financial and emotional support. In some cases, the grandmothers noted that orphaned children were easier to care for because (a) there was the possibility of accessing foster care grants for them; (b) death often meant the end of long protracted illness in the family, which alleviated some of the associated financial stress and the trauma of watching a loved one suffering; and (c) it was easier to explain that a parent had died than that a parent had left or abandoned the family, which many gogos felt to be the case. Such complexities around orphanhood and children's vulnerabilities in the context of HIV/AIDS have been noted elsewhere (*e.g.* Meintjies and Giese 2006; Skinner *et al.* 2006). Moreover, many of the 'children' in the gogos' care were teenagers and unemployed young adults, adding a different dimension to the nature of their care-giving: teenagers were reportedly more 'unruly', 'rebellious' and 'promiscuous'. As one grandmother from Molweni lamented:

> I have a problem with my granddaughter: she does not want to stay at home. She goes and stays with different boyfriends every night. She really hurts me because I would call her and beg her to come home until I cry but she does not like to stay at home. We all know what will happen next: she will have children, she will get sick, and it will become my problem. (Gogo, Molweni, July 2008)

Most of the gogos were supporting their families primarily with government grants:[4] old-age pensions, child support grants, foster care grants and disability grants. More than half were receiving government old-age pensions, available to women over the age of 60, although it is noteworthy that just under half were not receiving pensions because they were not yet 60. Approximately 80 per cent were receiving other government grants (most often child support and/or foster care grants for children in their care), while less than 20 per cent reported income arising from the formal or informal employment of any family member. The gogos did not perceive these grants as 'belonging' to one family member, but rather as contributing to their household incomes, to be used for basic expenses like food, medicines and school fees, and to be distributed as needed. Despite often being difficult to access (because of missing identity documents, problems filling out forms or lack of access to government offices), the source of resource struggles within families, and inadequate to support families comfortably, such grants were crucial to the survival of the grandmothers' extended networks (as has been reflected elsewhere in South Africa; *see* Legido-Quigley 2003).

TABLE 1. *Gogos' families and income sources (from preliminary questionnaire)*

Aggregated personal data from questionnaires	Total
Percentage of gogos caring for three or more orphans	46.3
Average number of orphans in care per gogo (range)	2.7 (1–8)
Average number of non-orphaned children in care per gogo (range)	3.7 (0–12)
Average total number of children in care per gogo (range)	6.5 (1–17)
Percentage of gogos receiving pensions	66.3
Percentage reporting pensions as only income	55
Percentage receiving child support and/or foster care grants	80
Percentage reporting income from employment, including informal	18.8
Average number supported by income (range)	10.2 (2–20)

Note: N=80.

Table 1 summarises some of the information on the gogos' families and income sources, according to the nurses' preliminary questionnaire. These figures are not disaggregated by community, by age of the gogos (*i.e.* older or younger than 60) or by whether or not they were receiving old-age pensions, because there was very minimal variation in these figures along any of these axes of difference. Moreover, these numbers are not intended to provide statistics that can be generalised to all gogos in the Valley, but simply to give some background information on the members of the participating gogos' groups. Where averages are given so too are the ranges of responses, in order to depict some of the diversity that emerged. For instance, while it is important that the average number of children being cared for by each gogo was approximately seven, it is just as significant that some gogos were caring for only one child, while others were caring for as many as 17. Indeed, it is crucial not to overlook the diversity that emerged among the gogos' and their family networks.

Three of the gogos' 'household maps' illustrate this diversity well.[5] Figure 1 was drawn with Bongiwe[6] from Inchanga. More than the other two maps featured in this paper, Bongiwe's map depicts certain themes that permeated the research. Bongiwe is represented by the circle at the top; she was born in 1951 and at the time of the interview in 2008 she was 57. She, like many of the other gogos, considered herself to be the head of her household. She lost her husband in the political violence in the 1980s. Her family network, and thus her care-giving responsibilities, spanned four generations, with members living in multiple locations. The 'children' in Bongiwe's care were diverse in terms of age; one grandchild was 26 while she was also caring for a two-year-old. Very few family members were employed and her family depended on government grants. Furthermore, many of the 'middle generation' in Bongiwe's family had passed away as a result not only

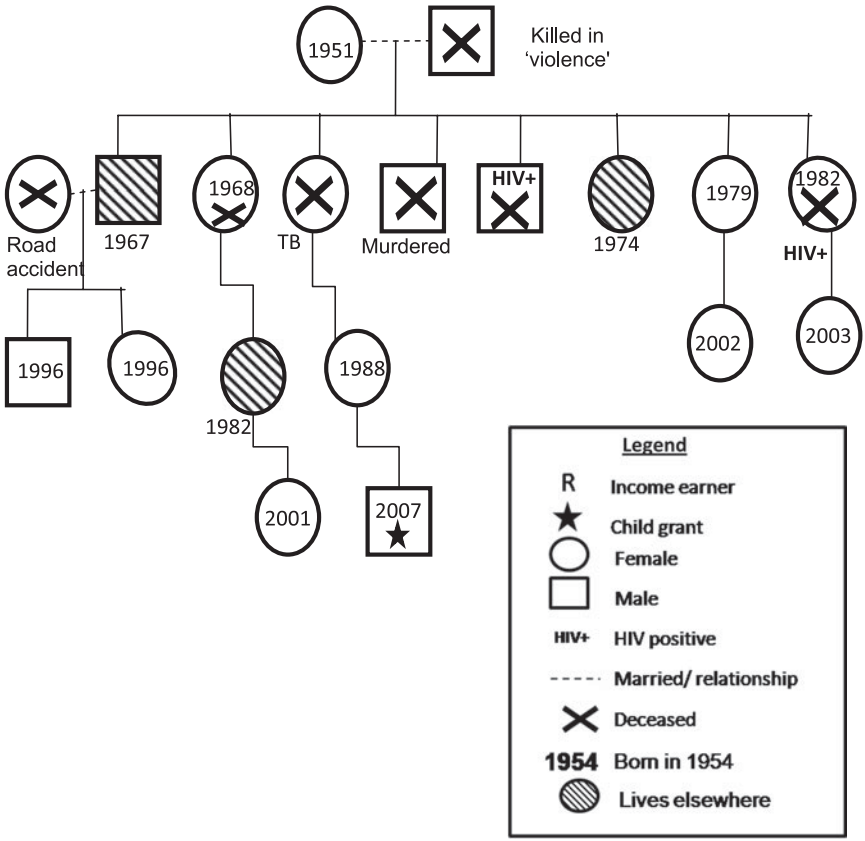

Figure 1. Household map of Bongiwe (Inchanga, 2008).

of illness, but also of violent crime. Bongiwe's family highlights many overarching trends among the gogos in this study; that is, her situation represents more of a 'norm' than an 'outlier'.

The contrast between Figures 2 and 3 draws some of the differences between the gogos into focus. Figure 2, the household map of Vuyelwa from Molweni, shows a woman responsible for six children, 17 grandchildren, two great-grandchildren and four nieces. In 2008 she was not yet eligible for a pension and thus relied on selling used clothing (received from the HACT). The family also received one disability grant and two child support grants. Vuyelwa's family had been in constant flux and had been mourning continuously over a number of years. She had recently lost two children, three grandchildren and one great-grandchild; with these deaths, she also lost access to two foster care grants. She was dealing with extreme stress, grief and exhaustion.

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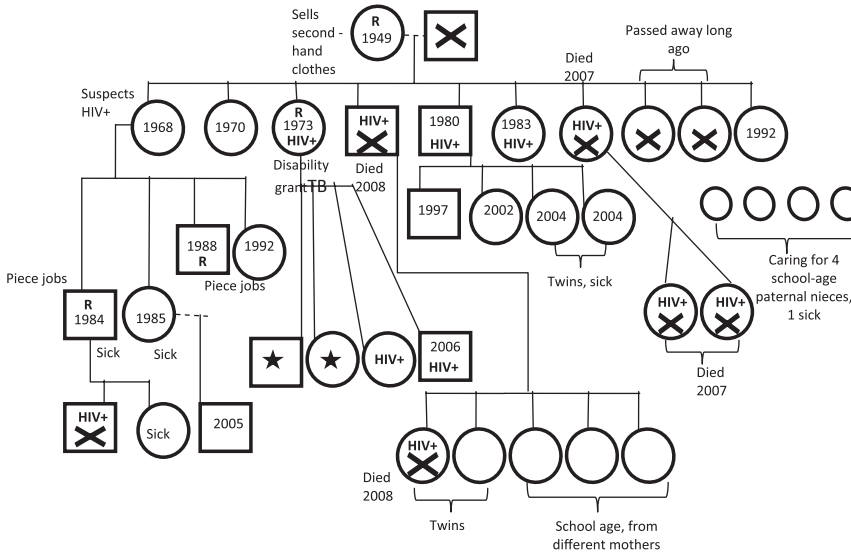

Figure 2. Household map of Vuyelwa (Molweni, 2008).
Note: For the legend, *see* Figure 1.

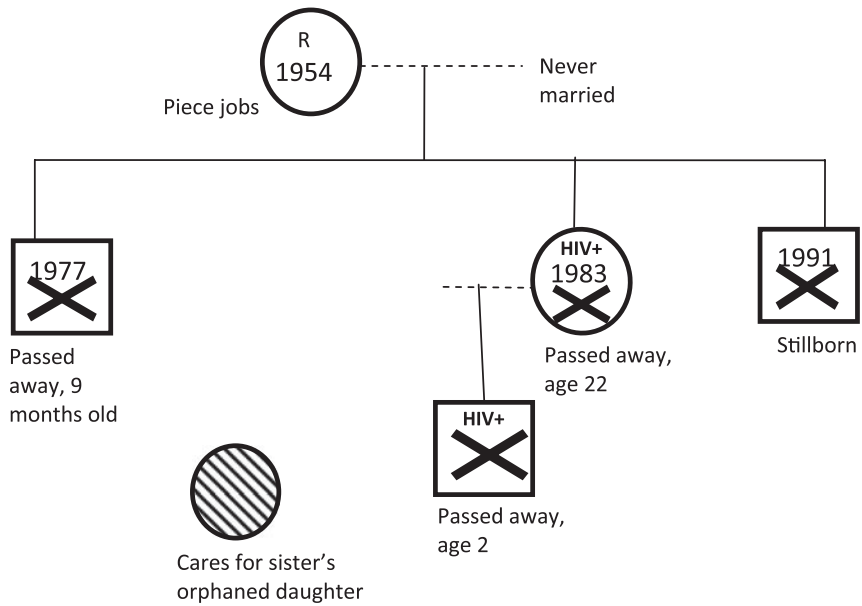

Figure 3. Household map of Mandisa (Lower Molweni, 2008).
Note: For the legend, *see* Figure 1.

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By contrast, the story of Mandisa (*see* Figure 3) from Lower Molweni paints a very different picture. Mandisa lived alone, was never married but had three children. Two of her children passed away in infancy, the third one in 2005, and the grandchild from this child passed away shortly thereafter. In 2008 she was alone and felt extremely insecure, in part because she had recently been threatened with accusations of witchcraft. Although the huge care-giving burdens on many gogos, like Vuyelwa, tend to be more widely recognised (*see e.g.* Marais 2005), the loneliness and fear that some gogos, like Mandisa, face are far less well understood.

Many (though not all) of the gogos were care-givers to large, extended families, which were often (though not always) made up of four generations, dependent on government grants, living in multiple locations, geographically mobile and losing middle-generation members. The gogos' household maps illustrate these dynamics, while also serving as a reminder of the diversity in what was observed.

Multiple stresses: motivations for joining gogos' groups

With this diversity ever-present, certain themes emerged in our research, most notably the complex reasons why these women were joining the gogos' groups and the multiple, converging stresses at play in their lives. Their support groups were evidently a response to multiple daily stresses – including, but extending beyond, HIV/AIDS – and about seeking physical, financial, emotional and intergenerational survival. Speaking to certain assumptions outlined earlier around HIV/AIDS as an exceptional, isolated and transformative stress on 'African grandmothers', this section delves into what was driving the women in this research to gather together, what issues their groups were responding to and what specific stresses they were facing in their lives.

Financial stresses. When asked why they joined their group, the first response in all of the groups was unanimously 'financial stress', specifically food insecurity, inadequate housing and the strains of school fees. Financial stress, and the hope that the groups would assist them to generate incomes and access resources, was always cited among their primary motivations for organising. As one grandmother in Molweni explained:

> I live in a one-room house that has a metal roof and the roof is now old. When it is raining, we get rained on. The building is also falling apart. The other thing is that there are lots of us and the house is small for all of us. I have people sleeping on the floor. In the morning, I worry whether the children will eat before school, and whether we will have money to pay their fees . . . At least now there is some chance, I mean if we sew things and sell them in the pension points, that we will ease some of these worries. (Gogo, Molweni, August 2008)

The underlying causes of these financial stresses most often included loss of income earners in their families, high unemployment levels and difficulties accessing (or maintaining) government grants. In discussing these financial strains, intense power–resource struggles were revealed within many of the gogos' families. As one grandmother from Lower Molweni described:

> I was taking care of this child before both his parents passed away. While I was sick, one of my children stole this baby's birth certificate without my consent and went and applied for the grant for the baby, claiming that the baby was hers. She did not say anything to me; I only found out that the baby was already receiving a grant when I went and tried to apply for the grant myself. (Gogo, Lower Molweni, August 2008)

Among the tensions discussed were adult children stealing the gogos' pensions or the child grants intended for children in their care, parents 'abandoning' their children with the gogos and collecting child grants for themselves, and teenage grandchildren bullying the gogos into giving them grants (and pensions) to buy cell phones, expensive clothes, alcohol and drugs. The influx of resources in the way of grants, though vital to counter-balancing poverty in the grandmothers' families, therefore seemed to reveal, exacerbate and/or create deep intergenerational tensions in many cases.

Violence, abuse and insecurity. As trust developed in each community, discussions shifted to emphasise not only financial stresses, but also the tremendous violence and insecurity the gogos were enduring and the view that, by gathering and sharing their experiences, they became witnesses to each other's violation, pain and grief:

> This is a safe place for us, unlike our homes and communities. Here we pray and speak and mourn openly. It is important that we can tell others about the abuse and violence we have in our lives, so others will know the truth. This is what women do; this is what we have always had to do to protect ourselves. (Gogo, KwaNyuswa, August 2008)

The grandmothers in all four communities reported extremely high levels of violence and insecurity, both within their homes and in their broader communities. This supports similar findings elsewhere in South Africa of how violence and abuse shape the everyday lives of many older care-givers (Bohman *et al.* 2007). In a particularly difficult focus group in KwaNyuswa for instance, one of the gogos described her loss of eight children, three of whom were murdered. Her grief was palpable and yet by telling her story and weeping, and by having the others comfort her with touch and prayer, she was able to carry on.

As part of these accounts of violence came stories of domestic abuse of all forms (physical, emotional and financial), with the most common

being toward the grandmothers and the young children in their care. This gender-based violence (in every reported case of physical abuse in the research, the abuser was male and the abused was female) typically shared a range of features as follows: a teenage or young adult child stole money from the grandmother/household, abused alcohol and/or drugs, and then became physically and emotionally abusive toward the women or girls in the home. Many grandmothers did not trust their family members not to steal their possessions, and some said they had no privacy or security in their homes. Even when they were trying to pray, they were interrupted in disrespectful, often abusive, ways. As this grandmother from KwaNyuswa explained:

> I have a cardiac problem because I have to deal with my children who are drunkards. They steal my possessions so that they can sell them to satisfy their drinking habits. They steal my pension and drink it away, and then there is nothing left for the family. And one son, he takes my money to buy drugs, and then at night he comes to the house and harasses me. He knocks on the door and would kick it down if I did not open it. I worry for myself and the other girls because he is so abusive when he is like that. (Gogo, KwaNyuswa, July 2008)

Many of the gogos revealed that their support groups functioned as a 'safe place' to pray, weep, grieve and speak about what was happening at home, noting the importance of having other women witness the violence in their lives. Moreover, it was evident that violence had deep roots in their families and communities. They spoke frequently about alcoholism and spousal abuse when their husbands were alive, as well as about the impacts on their families and communities of numerous murders, home invasions, armed conflicts and house burnings. It was also evident that gathering with other women to bear witness to each other's lives had long been one of their responses to this profound stress. Even before considering the devastating effects of AIDS in these communities, some of the gogos' complex reasons for mobilising become apparent, in that their groups were responding to the long-standing and endemic stresses of poverty and violence.

Enter HIV/AIDS. The gogos in this research did not describe their groups as responding specifically or solely to the impacts of HIV/AIDS on their families. Yet it was clear that most of their families were deeply affected by the epidemic and that part of what motivated the gogos to join these groups was their need for support in dealing with the (at times indirect) impacts. They expressed, for instance, their need for spaces in which to grieve the deaths of their children without fear of discrimination. When asked directly, most of the gogos discussed the profound toll the epidemic was having on them, as family members with HIV would become sick slowly and intermittently, suffering on and off over long periods of time.

The combination of how AIDS progresses and the silence that surrounds it was devastating to many.

The tragedies associated with AIDS came on top of, and served to exacerbate, existing insecurities, tensions and financial burdens. The gogos in this research described the distinct financial impacts of HIV/AIDS on their families, which have been reported elsewhere (*see* Marais 2005 for an excellent synthesis of South African research). They explained that the epidemic was depleting their family resources, leading to increased medical, food, transport, childcare and funeral expenses, and resulting in a loss of income earners. This woman's story is illustrative of a widespread finding:

> My daughter had this thing and it was terrible. First she would not talk about it and she would not get tested, and she would not tell me what it was. She got sick and we were taking her to the doctors and traditional healers, spending so much on transport here and there, and on different cures. Nothing worked. Then she finally disclosed to me what was happening . . . We went to the clinic and they started the treatment with her, and they also had to treat her for TB [tuberculosis] and diarrhoea. She was very sick but she did get a little better. I cared for her, selling off everything to pay for transport back and forth to the hospital to get her treatment, and to pay for her food. I had hopes that she would live. Even her sister, who was 14, told me that she was working to pay for her transport and treatment, but I am scared to think what she was doing . . . then it got worse again . . . She turned into a skeleton. We were cleaning up diarrhoea all the time, right up until she died. I borrowed money to bury her. This was one year ago but we still haven't recovered. (Gogo, Molweni, September 2008)

As conversations evolved, many gogos described the complex emotional consequences of HIV/AIDS for them, including their feelings of fear, anxiety, helplessness and betrayal. Much of this stemmed from difficult intergenerational communication. While the grandmothers encouraged their children to test for HIV, many of their children did not disclose their status to them. These gogos felt betrayed by this, feeling that their children did not care enough about them to protect them. As one woman from Inchanga explained:

> We thank God because we did not contract this disease when we were caring for our children. They did not tell us that they were sick with this disease, so we did not protect ourselves by using gloves when bathing them and caring for them. This happened to me. Even though I gave my daughter everything, I cared for her up until her death, she never trusted me enough. She did not care about me enough to tell me to use gloves. (Gogo, Inchanga, July 2008)

In telling these stories, many gogos expressed high levels of fear and felt that no one was safe once HIV entered the family. They never uttered the words 'HIV' or 'AIDS', but instead referred either to 'this thing' or to 'this disease'. Some of the gogos described the virus as a kind of supernatural force or mystical being, something 'unnatural' and out of their control, which would enter a family and slowly destroy one member after another, while creating

conditions of extreme stress for all who witnessed it. As conversations about HIV/AIDS became more open, the grandmothers steadily began to disclose some of their worst traumas, including the immeasurable pain of caring for loved ones who were suffering.

At the height of these discussions, the gogos were asked whether and how their groups might be responding to the epidemic. The following response, from a gogo in KwaNyuswa, demonstrates the complexity of their answers:

> As women, we have long come together to pray and to support each other, and to witness the stresses we each face. Now we are witnessing this disease too, even if many still do not want to admit it. So it is not that our group is meeting because of this disease. We are dealing with illness and death in our families, but this is from TB, murders, meningitis, car accidents, and some are probably from this thing too. Our group gives us a place to grieve and get support . . . Another thing is, it is harder to handle deaths now, especially if the person was young, because everyone talks and says it was this thing. It can be very stressful and you feel all alone, no one wants to come near you because you have been touched by this. But in the group we don't ask questions, and we feel open to talk the truth, and we don't turn people away who are caring for their kids who have this. (Gogo, KwaNyuswa, August 2008)

Like many of the gogos, she did not distinguish between death associated with AIDS and death from other causes, but rather conflated the epidemic's impacts with the existing strains of care-giving and the grief of losing family members. She did not disentangle the trauma associated with the epidemic from other traumas in her life, although she did note the increased stigma for care-givers as a result of the epidemic. She articulated the widely held view among gogos that AIDS was one part of their multifaceted and long-standing struggle. She also alluded to the history of women gathering to witness each other's lives, and thus to the possibility that this form of mobilisation pre-dated the epidemic.

What emerged, then, was a picture of older women bearing witness to suffering and death far beyond what they considered to be 'natural'. Their frequent experiences with death were caused not only by HIV/AIDS, but their far-too-common experience was that of burying the generations beneath them. Their groups, while not responding to AIDS exclusively, were sources of support and spaces in which they could attempt to resist the fear, discrimination, isolation and stigma associated with HIV.

Family change, chronic illness, fears for the future. On top of and related to these profound stresses, the gogos worried about their age and, with such losses among the middle generations in their families, about who would look after the children in their families when they passed away. Most were suffering from chronic illnesses (such as hypertension, arthritis and diabetes), making it difficult for them to care for others, and making them acutely aware of their own physical limitations. Their fears also

extended to concerns over who would look after them when they could no longer provide care for others.

Many felt that their adult children and grandchildren, those who were still living and healthy, did not have the kind of commitment and responsibility toward extended family that their generation of women had. These gogos alluded to broader changes taking place in the mobility of young girls, declining marriage rates, and a shifting sense of family responsibility among young adults:[7]

> I don't think my children or grandchildren will be here when I need them, which is very sad. The girls are now in the city running around, just like the boys. Some of them are here, some of them are helping us, but a lot are healthy enough but don't want to be stuck here where there are no jobs. It's different now. We always expected that we would look after the children, and then the children would look after us. But now families don't stay together this way anymore. And the girls are not getting married too. That's the other thing is that we don't know the fathers of the children and the men don't feel they should send money even. (Gogo, Lower Molweni, September 2008)

In the context of this perceived family breakdown, alongside the middle-generation loss and the grandmothers' declining health, several of the gogos said that their groups functioned as a kind of security net. As one woman from Molweni poignantly explained:

> As old women, our group can look out for each other . . . because we are old and sick, and we might not be around forever. Our children are dead or they have gone away, and we don't see the mothers taking the same responsibility as we take. They are in the city or running around. They don't support us. We are on our own to raise the children with nothing. What will happen next? At least like this, we can watch out for each other's children and make sure someone raises them. In our group, we support each other and take care of each other when our own kids don't. (Gogo, Molweni, July 2008)

Their groups were functioning, in part, to build and re-build communities that could act as extended care-giving networks.

In considering these findings – the multiplicity of stresses in the gogos' lives and the ways in which these underpinned their mobilisations – it is noteworthy that similar trends emerged in all four of the groups. There was clearly diversity among the gogos and their families, yet the stresses they reported and their motivations for joining their groups did not differ significantly or systematically according to place, age, whether they were receiving old-age pensions or between what was revealed in focus groups *versus* interviews. This analysis is thus not intended to homogenise the Valley gogos, but instead to reveal the strength of these findings and the ways in which the reported stresses and traumas were likely embedded in larger societal processes (*e.g.* deeply ensconced violence, poverty, gender inequality, and so on).

Discussion and concluding remarks

Based on detailed research carried out with grandmother care-givers from four South African communities, this paper has portrayed some of the complexities involved in understanding older women's lives and associations within the context of a rapidly changing society and a massive HIV/AIDS epidemic. It has told a story of older women mobilising (or re-mobilising) into support groups as a result of the leadership infused by two nurses employed by a local NGO and connected to a budding transnational advocacy network. It has also revealed the diversity among these women and their families, and their complex and multifaceted motivations for joining these groups. In so doing, it has sought to extend existing research on older women and HIV/AIDS in African contexts (and on ageing women more generally), thereby providing important insights for both scholars and practitioners.

First, by focusing on the Valley gogos' support groups and evolving forms of mobilisation, this paper has sought to address a gap in understanding care-givers' networks and forms of association (Kuo and Operario 2009). It has highlighted the contributions older women are making, not only within their families, but also within their broader communities. Indeed, the gogos in this research are care-givers within their often-large family networks, yet they are also community organisers. Their groups are, at least in part, spaces in which they can speak openly about AIDS and resist the stigma and discrimination many face. These gogos are also organising in order to generate livelihoods and offer each other support, and they are reinvigorating existing associations and generating new organisations in order to connect to the HACT and the SLF. Most importantly, their organisations, whether new or existing, are significantly improving the lives of hundreds of vulnerable women and children with a focus on survival, support and social change. These findings provide insights into the collective responses of women living in extremely harsh conditions in South Africa in the era of HIV/AIDS, while also speaking to recent efforts within feminist gerontology more broadly (*e.g.* Garner and Mercer 2001; Hardill 2009; Sawchuk 2009). They document not only older women's vulnerabilities, but also their contributions within particular societal contexts. In terms of implications for practitioners, the findings reported in this paper suggest that one potentially effective way to assist these care-givers is to infuse social and economic support into their own associations, allowing them to bolster, but remain in control of, the important work they are already doing.

Second, by analysing some of the ways in which family responsibilities, stresses and motivations were, or were not, differentiated among study participants, this paper depicts some important diversities among the gogos,

as well as some practical implications for policy and practice. While it is noteworthy that there was no systematic differentiation found in the gogos' reasons for mobilising according to place, age or income sources, there was considerable diversity among the gogos in terms of their family situations and the 'children' in their care. For example, some gogos were isolated and alone, while others were caring for over a dozen family members. Some gogos were over 75 years of age, facing declining health, caring for grandchildren and great-grandchildren, but able to access old-age pensions; others were in their forties and unable to access pensions, and thus were relying on other forms of state support and informal work. Some gogos were responsible only for young children and infants, while the majority were caring for extended multi-generational and multi-locational networks that included children, teens and young adults. Understanding these diversities has important material implications. For example, understanding that not all 'orphans and vulnerable children' are young generates space for supporting grandmothers caring for teens and young adults. Broadening the lens on children's vulnerabilities (as is being done elsewhere, *e.g.* Meintjies and Giese 2006; Skinner *et al.* 2006) also brings to light the specific vulnerabilities of those who are grieving parental death, compared with those who are watching their parents suffer with illness and others who have been abandoned, abused or cast out. Moreover, given the reliance of so many families on old-age pensions and other social grants, and the inconsistency with which these were being accessed, our findings support efforts to put in place a means-tested basic income grant and support to assist families with access. Further analysis of trends and diversities among older care-givers in other high-prevalence communities is also clearly warranted.

Third, by examining AIDS as one of the many interacting processes underlying the gogos' vulnerabilities (following, for example, the work of O'Brien, Quinlan and Ziervogel 2009), this paper has revealed how these gogos are deeply affected by the converging, perhaps multiplying, effects of poverty, violence and illness. The gogos' stresses extend well beyond the devastating consequences of AIDS to include inadequate food, shelter and income, family tensions, domestic abuse and violence, as well as chronic illnesses. HIV/AIDS is clearly serving to exacerbate and deepen these long-standing strains. Most of these women find themselves sacrificing their own health to care for their families, amidst unfathomable pressures. As much as they worry about their ever-increasing care-giving duties, they are also bearing witness to premature death in such magnitude that they wonder: will I end up all alone? What will happen when I die? Who will raise the children? This research has captured some of these women's collective responses to these combined stresses. Between 2006 and 2010, they mobilised under

the umbrella of 'gogos' groups' while the catalyst for the discursive framing was the HACT nurses, who, following their international encounters with the SLF, sought to infuse new support for 'grandmothers caring for AIDS orphans' in the Valley of 1000 Hills. Closer examination of these groups and their members, however, has revealed that what was often taking place was a re-mobilisation of existing networks, including women's responses to historical violence and well-established 'prayer circles'. From the gogos' perspectives, these groups (whether new or re-mobilised) were about accessing support in dealing with the multiple stresses in their lives, resisting stigma, generating safety nets and creating safe spaces for grieving – again, amidst long-standing trauma and more recent change, these groups were not simply about AIDS response, but about survival, support and social change.

Building on existing scholarship on HIV/AIDS and older women in African communities (*e.g.* Schatz and Ogunmefun 2007, among others), this paper has aimed to extend certain understandings about 'African grandmothers' and their struggles with HIV/AIDS. It has moved beyond images of older women as frail, passive or marginalised. Despite the massive pressures on the Valley gogos, they were clearly involved in complex forms of mobilisation that provided them with support and tied them into regional and transnational advocacy networks. It has also demonstrated the diversity in ages and situations among the gogos and those in their care (Casale 2011; Chazan 2008). Finally, this paper has moved beyond assumptions of HIV/AIDS as an exceptional stress in the lives of care-givers in southern Africa. Instead, it has depicted HIV/AIDS as compounding the existing pressures of violence, poverty and other illnesses, while suggesting that new resources and networks emerging as a result of HIV/AIDS (*e.g.* the support and leadership infused into the Valley by HACT nurses following their connections to the SLF network) were generating new forms of association and support in the face of complex and long-standing trauma.

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NOTES

1 This reflects trends in gerontology and ageing research elsewhere (*e.g.* Garner and Mercer 2001; Hardill 2009; Harper and Laws 1995; Pain 2001; Sawchuk 2009); this work tends to emphasise the *challenges* associated with ageing (*e.g.* health decline, discrimination, decreased mobility, and so on), while it often obscures the *contributions* that older women are making to their societies. In addition, it is worth clarifying what is meant by 'older' in this paper. While in most literature 'older' refers to either over the age of 60 or over the age of 65, this research did not designate such an age cut-off. Rather, the 'older women' in this study self-identified as 'older', 'elders', 'grandmothers' or 'gogos', and the majority were caring for people from at least two generations below them in their families. In not designating fixed age criteria, this research recognises that such categories are context-specific and that women can be considered elders and can become grandmothers long before age 60 (Chazan 2008).

2 Note that these groups called themselves 'gogos' in order to join the HACT network; they were made up predominantly, although not exclusively, of grandmothers. When referring to participants collectively, they will be called 'gogos'. This is for clarity sake, not to diminish the participation of non-grandmother participants.

3 Previous funding from the SLF was directed to the HACT's care activities only (*i.e.* home-based care and building their respite unit). According to the HACT director, in 2010 funding from the SLF increased: this included both additional funding allocated to the care project and an added R140,000 (or Can $20,000) for the gogos.

4 Details on accessing government grants are available at http://www.capegateway.gov.za/eng/topics/10104. There may be some discrepancy between official and actual eligibility requirements; this was certainly reported by the grandmothers in this study.

5 These are basic schematics akin to family trees. Gogos defined their households according to responsibility and entitlements, irrespective of kinship relationships or location of dwelling. For most, these were fluid networks of people, often residing in multiple locations, for whom they felt responsible for providing care. Their 'maps' were drawn by asking the gogos to detail who they included in these networks (Hosegood and Solarsh 2004).

6 Note that all names in this paper are pseudonyms.

7 For an interesting and critical analysis of the changing nature of love relationships (including marital trends, gender identities and life in urban shack settlements) in the context of KwaZulu-Natal's HIV/AIDS epidemic and transitioning political economy, *see* Hunter (2010).

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