Household coping with HIV and AIDS in rural South Africa: linking the experience of multiple episodes of illness and death to households' historical and social context

Victoria Hosegood[1,2], Joanna Busza[1], Sindile Moitse[3], Sayinile Zungu[4], Tania Boler[1], Ian Timæus[1,2] &Eleanor Preston-Whyte[4]

[1] Centre for Population Studies,
London School of Hygiene and Tropical Medicine,
49-51 Bedford Square,
London, WC1B 3DP, UK

[2] Africa Centre for Health and Population Studies
PO Box 198, Mtubatuba, 3935,
KwaZulu Natal, South Africa

[3]UNAIDS ICT/ESA
[4] HIVAN

Corresponding author: Victoria Hosegood[1]

Abstract

This paper examines the consequences of multiple experiences of illness and death for households in rural South Africa. The analyses of qualitative data place observed episodes of illness and death due to HIV/AIDS against the background of previous encounters with HIV/AIDS within households and among people connected to the household. It also considers the additional compound effects on the burden of illhealth and death from causes other than AIDS. A key lesson suggested by this paper is that studies examining the impact of HIV/AIDS on households and their members should also collect data on concurrent and recent episodes of illhealth and deaths both within and outside the household. If this is impossible care is needed in the interpretation of analyses describing the impact of mortality on household demographic and socio-economic outcomes.

Introduction

Families and households in rural South Africa currently face significant adverse demographic, social and economic changes resulting from the region's severe HIV epidemic. In a context of high HIV prevalence and incidence, many people experience HIV/AIDS illness and deaths in their own households, extended families and wider communities. Widespread HIV transmission between heterosexual partners and vertical transmission from mothers to children, mean that affected households are likely to undergo multiple episodes of illness and death, often in quick succession.

Empirical studies conducted in South Africa and Kenya have shown that households in which multiple adult deaths have occurred within the previous two years or are at statistically higher risk of dissolution, migration, and reduced economic status compared with households that experienced one or no adult deaths (Hosegood et al 2004a, Yamano & Jayne 2004). Nevertheless, studies that consider the impact of multiple shocks on households coping with HIV remain rare. Most model the impact of a single adult AIDS death on subsequent household outcomes and identify deaths only, lacking information on episodes of morbidity. With the exception of research into the impacts of parental mortality on children, we are not aware of quantitative studies that investigate the wider impact of illness and deaths of people who are not immediate members of the household, for example of close relatives such as grandparents and uncles/aunts.

This dearth of data is the consequence of the methodological limitations of population-based surveys and surveillance systems (Booysen & Arntz 2003, Bray 2002). Cross-sectional surveys rely on respondents' recall of past illness and death, which hinders the complete identification of deaths and illness episodes over all but the shortest time period. Longitudinal surveillance or panel surveys can provide fuller information about deaths within households, often with information about causes of death, however, they are constrained in their ability to identify and link events that occur outside the household. In addition, the structured, time-limited interviews typically used in population-based data collection may fail to capture the complex interactions between past events and current circumstances in a household, or to reveal the way in which multiple events shape a household's social and economic environment and its ability to respond to subsequent deaths.

To explore the interaction between multiple impacts, coping mechanisms, and experiences of HIV, we conducted an ethnographic study of twenty households in rural South Africa. In this paper we describe

the experience of repeated bouts of illness and death in the study households, which were observed for periods between one and two years. External events, such as those experienced in other, related households, and the role of community and government services, were included in data collection and analysis in order to widen the focus of inquiry.

Many authors have commented on the "stretched" and fluid nature of households in southern Africa (Hosegood & Timaeus 2001, Ross 1996, Russell 2003, Spiegel et al 1996, Spiegel 1986). The legacy of the Apartheid-era prohibitions on free movement by Africans, the entrenched migrant labour system and urbanization continue to exert their influence on households today. In the rural area where this study was conducted, 25% of those considered "household members" are not actually co-resident with the household (Hosegood & Timaeus 2001). Thus, the household becomes 'stretched' in space as members reside in different places. In addition, social groups are fluid and household membership is highly dynamic. Such processes results in situations where several households, often geographically separated, are strongly connected through common members and the transfer of people and resources between them. This study used the household as a point of entry, visiting and revisiting its residents while also seeking to meet and gather information about non-resident members and to find out about other external relationships with social or economic importance. As Ross (2003) wrote:

> *"People seldom attempt to form 'households' per se; their efforts are directed at creating and consolidating relationships, at making home, stabilizing domestic relations, ensuring the continuities of homesteads, securing genealogical relations over time, and so on. People attempt to forge relationships; they try, through a variety of means and in accord with diverse conventions, to create enduring associations. These are sets of relations that are both material and affective: that is, they entail practiced emotional and material investments over time."(Ross 2003)*

Most such significant relationships are with relatives, but neighbours, community groups, and government or voluntary agencies can also mitigate or exacerbate experienced consequences of illness and death. Their response at many levels, including helping with physical care, financial assistance and emotional support, is crucial for households coping with a highly stigmatized disease such as HIV/AIDS (Booysen 2002, Montgomery et al 2005, Zungu et al 2003). Yet inter-personal and inter-household relationships are not necessarily supportive. They may become marred by conflict, disappointment, and suspicion and weakened by distance, differing priorities and changing circumstances.

The Study Area

This study was conducted in northern KwaZulu Natal, South Africa. The area includes land under the Zulu tribal authority, formerly known as a homeland under the Apartheid-era Group Areas Act, and two urban areas under municipal authority, one formerly for Black residents, one formerly for Whites. Infrastructure development and population density across the area are heterogeneous, ranging from fully-serviced town houses to isolated rural homesteads without water, electricity or sanitation. Part of the area is included in a demographic surveillance system that routinely records information about births, deaths, migrations as well as health and economic data (Hosegood et al 2004b). The population in the surveillance area is highly mobile. Twenty-nine percent of all household members are non-resident but return periodically and maintain social relationships with households (Hosegood et al 2004a). Although it is a rural area, few households are engaged in subsistence agriculture, and most are dependent on waged income and state grants. Rates of both unemployment (22% of people aged 15-65 in 2001) are high (Case & Ardington, 2004).

KwaZulu Natal is the province with South Africa's highest HIV prevalence rate among antenatal clinic attendees. A 1998 antenatal survey in the immediate study area found that 41% of pregnant women were HIV infected [95% confidence interval (CI), 34.7–47.9] (Wilkinson, Connolly & Rotchford, 1999). By 2000, AIDS was the leading cause of death, accounting for 73% of female and 61% of male deaths at ages 15-44 years (Hosegood, Vanneste & Timæus, 2004). In 2000, 4% of all households experienced the death of an adult (15 years and older) from AIDS; 5% of children under 15 years were maternal orphans and 12% were paternal orphans (Hosegood & Ford, 2003).

Methods

This paper presents analysis of fieldnotes collected between 2002 and 2004 as part of a study examining the experiences of households coping with HIV/AIDS. The study collected ethnographic data through close observation during outreach visits by research staff to twenty households caring for at least one adult with disease symptoms indicative of TB or AIDS. Households were identified by volunteers in a local home-based care programme; by nurses from the demographic surveillance system who interview household members following a death to establish its cause; or by opportunistic contacts by research assistants in the course of their fieldwork.

Three research assistants paid frequent visits to study households and took part in household activities including funerals and visits to hospitals and welfare services. In addition, they accompanied home-based care volunteers in the area on their household visits and attended programme meetings and training sessions. The research assistants were all women and spoke fluent Zulu and English. Two had post-graduate level education, and all were trained in ethnographic methods. After visits, field notes were written up in English and managed and coded using the N6 software (QSR).

The analysis presented in this paper is based on detailed field notes from visits to twelve of the twenty households that were observed for more than one year, with specific attention to all mention of illness and death among household members both during the study period and in the recent past. Reports of illness and death of non-household members that were either connected to the household or in the wider neighbourhood and community were also included. These were grouped into themes and sub-themes as they emerged in order to explore both content (narrated events, described signs and symptoms, etc.) and discourse (perceived causes, language intimating stigma or support, etc.). We explicitly included our own perceptions, opinions, and behaviour in the analysis. Pseudonyms are used throughout this paper.

As no clinical tests were conducted during fieldwork, individuals' HIV status and diagnosis of AIDS reflect either respondents' self-reports of having received a positive test result (or report by proxy, after a death) or are conjectural and based on circumstantial evidence such as the signs and symptoms exhibited immediately prior to death.

Prior to starting fieldwork the study was the subject of several meetings with the Africa Centre for Health and Population Studies Community Advisory Board and ethical approval was granted by the Faculty

of Medicine Ethics Committee of the University of KwaZulu Natal. The research team provided support to study households in a variety of ways including arranging transport in emergency situations, and introducing households to home-based care volunteers and an Africa Centre social worker.

Findings

In HIV-affected households, the lives of household members were clearly dominated by their efforts to cope with direct and indirect effects of illness and death, regardless of whether specific episodes were caused by HIV or simply compounded them. The fieldnotes indicate that the episodes of HIV and AIDS illness and death we observed directly were often only a small part of the households' cumulative experiences of HIV and AIDS. Most households had already experienced HIV illnesses or death prior to the start of the study. In addition, households were affected by AIDS illness and death among people connected to the household although not resident in it. Such 'external' events often had important psychosocial, physical and economic repercussions for household members. In the following sections, we consider the consequences of multiple episodes of ill health and death.

Multiple episodes of HIV and AIDS illness and deaths within households

All twelve households were enrolled in the study because they were caring for a sick adult or child with signs and symptoms indicative of AIDS. Consequently, it is not unexpected that one or more members died of AIDS during follow-up in seven of the households. However, by eliciting information for previous years, the extent of multiple experiences of AIDS deaths was revealed: six households had experienced at least one AIDS death of a member in the year prior to enrolment. For example, in the Nzima household two adult daughters had died of AIDS in the previous two years. A third daughter died during the study. In the Ngubane household, by comparison, no member died during the period of fieldwork itself, but both a daughter and the child of another daughter had died of AIDS in the previous year. The mother of the deceased child and one of her sisters were severely ill.

These earlier experiences of HIV and AIDS had shaped the households' socio-economic circumstances and influenced the way in which members were able to respond to additional episodes of AIDS illness. In all households where an AIDS death had occurred before the study, at least one deceased person had been a parent and consequently the household was caring for one or more orphaned children. Nuclear households in which one partner had died faced particular difficulties during fieldwork. If the surviving partner was sick, assistance from people outside the household such as relatives, neighbours and volunteers, became essential. These households also demonstrated vulnerability to dissolution after the surviving partner's death. Prior deaths of adult relatives had led to a high ratio of children to adults in many

households, and fieldworkers noted the particular difficulties presented by this family structure. The Dube household, for example, consisted of two adult sisters (Thandile and Hlengiwe) and their children. Thandile was very ill with TB and AIDS and had three children, Hlengiwe had four children living with her and was the sole income earner. Neither woman currently had a partner. They had started living together when Thandile became ill when working outside the district. Thandile's partner, the father of the children, had died at that time. Hlengiwe moved to care for her sister but eventually Thandile lost her job. The sisters and their seven children were then unable to stay in rented accommodation and moved into the district. Hlengiwe started work as a street vendor but struggled to manage as Thandile's care needs increased.

Perhaps the most obvious impact of chronic AIDS illness is loss of economic resources and the threat that this represents to material survival. As has been well-documented (Barnett and Whiteside, 2002), households face increased spending on health care and funerals while often losing the income from the patient and/or the carer at the same time. For the poorest, those with several infected household members, or those with limited human and capital support, repeated episodes of illness and deaths led to deepening financial difficulties and result in increases in loan taking and debts.

> A few weeks before Pretty [the Mbata children's mother] died, the Mbata family was battling with an additional problem. The family had run out of sufficient funds to pay for the children's school fees. Nomsa [children's grandmother] pointed out that much of the limited reserves Mpho [the children's father and husband of Pretty] had, had been spent to pay off money lenders who had borrowed him money so he could take his wife to traditional healers. Most of the Mbata children are of school going age. In fact his last six [children] are still in school. [Fieldnote Mbata-3]

We observed lack of money preventing the households accessing health care and schooling, curtailing traditional funeral rituals, and hindering eligible individuals from accessing government support grants because they could not afford the transport and other incidental costs associated with the application process. Examples of this are extremely common in most case studies, however, in this paper we do not present illustrative examples of the impact of HIV illness and deaths on poverty *per se* given that this has been described elsewhere (Booysen 2002, Patel 1995, Williamson 2000, Yamano & Jayne 2004).

Psychosocial impacts also loomed large in observed and narrated household experience. Repeated bereavements were distressing for all household members, and particularly traumatic for those caring for

their own children, siblings or nephews/nieces. As many children in rural are cared for by adults other than their parents through a system of "fostering," they became vulnerable if their caregivers became sick with HIV/AIDS themselves, or experienced increased demands for caring for others and thus provided fewer emotional or economic resources. Each additional episode compounded these demands on household resources, and also left members extremely anxious about the seeming relentlessness of their problems. Respondents reported on financial and practical worries, but some also focused on their sadness and grief, exhibiting feelings of helplessless and despondency.

> Mthokozisi even mentioned that 'my mother [Zodwa's sister] was sick like Zodwa and I assume that Zodwa will die because Zodwa's sickness is the same as for my mother.' … They were all worried [because] they have the same idea as Mthokozisi of assuming that Zodwa would die and they say 'What we have done wrong in this household, months back Phumzile died and now Zodwa is sick?' [Fieldnote Msweli-4]

Experiences of HIV and AIDS compounded by other illness and death

While the HIV epidemic has resulted in a dramatic rise in adult mortality in rural South Africa (Hosegood et al, 2004), nearly half of all adult deaths remain due to causes other than AIDS. In several study households the burden of HIV and AIDS was compounded by illness and death due to other causes including tuberculosis (TB), stroke, high blood pressure, arthritis, mental and physical disability, haemophilia, violence and accidents. By explicitly including the experience of non-AIDS deaths in data collection, a more realistic assessment of the burden of morbidity and mortality in these households is achieved. The Msweli household was one affected by episode after episode of illness, death and disability. At the start of follow-up, the household included Rose, an elderly single woman, her adult daughter called Zodwa, and her grandchildren. The household had experienced several deaths due to AIDS as well as several other challenging situations. Zodwa had been injured two years before in a car accident and was receiving a disability grant. Two 13-year old twin grandchildren had been abandoned with Rose by their parents. One had severe mental and physical disabilities requiring constant care, the other had moderate learning disability and behavioural difficulities. During the study, Rose has a stroke and is hospitalized. Just afterwards, Phumzile, a married daughter of Rose's who had been living in Johannesburg moved into the household. Phumzile had been ill for some time

with haemophilia and her husband had refused to care for her anymore. She died within a month of returning home due to complications.

In some cases, non-AIDS disability, illness or death had a greater impact on the household than HIV/AIDS. This was often because these involved long-term disability, the illhealth of a socially or financially pivotally important member of the household, or were unexpected deaths. For example, we first met the Khumalo household when Maria Khumalo, her adult daughters and her grand-children were coping with the illness and death of Maria's husband, Bongani, from AIDS. Bongani had only recently returned to live with the household after years of being separated from his wife during which time he lived with another woman with whom he had two young children. Following the death of this partner from AIDS, he himself became ill and he returned to his wife for support. Although caring for Bongani had been difficult Maria and her daughters, they had continued to work and had started looking after his other two children. However, the household was placed in a considerably more vulnerable position when Maria and one of her daughters were later killed in separate violent assaults. The sudden deaths of these two women placed sole financial responsibility on Maria's 30-year old daughter who was living and working elsewhere, while the day-to-day care of the younger children was undertaken by a 27-year old cousin who had moved into the household to help.

Illness and deaths of older people[1] were common in many households. Five of the households were headed by people over 50 years, three by older women. During fieldwork, older members of households experienced tuberculosis (TB), stroke, high blood pressure, arthritis and long-term disability due to accidents at work.

> The first thing I noticed about Samuel's mother was that she was in a lot of pain. In fact she seemed like she was about to break down into tears. When we inquired about her health, she indicated that her whole body was in pain and that her bones were excruciatingly painful. Each time she moved, she winced. She never tried to put her grandchildren on her lap. [Fieldnote Zuma-1]

The illness and death of older people can have an enormous impact on the social and economic wellbeing of the household. The central role that many older people play in their households results from i)

[1] Older people in this study are defined as those age-eligible to receive a state pension: women 60 years and older, men 65 years and older.

the high mortality of younger adults, ii) the common practice of adult children leaving their children in the care of their own parents, and iii) the ability of older people to secure income from their government old age pensions if not from wages. At the start of the study several households were financially dependent on the income of an older person.

> Since Mpho's death [Dudu's adult son] coincided with the re-opening of schools in late Janauary, Dudu's concern was that she was not available for her grandchildren back home in order to help them prepare for school. Worst still was that she was chief mourner after her daughter-in-law's [Mpho's wife] death and was in seclusion at her son's residence for almost a month. [Fieldnote Mbata-3]

Many older women took primary responsibility for providing material assistance for their grandchildren and other dependent children. However, as we have described in a separate paper, older men also play important roles in the care and support of other members of their household (Montgomery et al, 2005). For example, in the Mbambo household, Siphiwe, a 10-year old boy was living alone with his grandfather following the death of his own mother and his grandfather's partner from AIDS. Siphiwe's father was not in contact with his son.

Carers becoming ill

At the time this study was conducted the public health services were not providing antiretroviral treatment to HIV positive people. Several primary caregivers of either sick adults or dependent children became sick themselves. Two carers were diagnosed as HIV positive during the study and both said that the possibility of obtaining a disability grant had motivated them to be tested. However, others who had disclosed the HIV status of their deceased siblings or parents, did not themselves want to be tested or to disclose their results to the fieldworkers. For example, Filikile Mbata was caring for her eight siblings after the death of their parents, and was repeatedly encouraged by her partner's mother to be tested because both Fikile and her partner were repeatedly ill and their child had recently died. Neither reported going for an HIV test. Similarly, Nqobile Ngubane was caring for her sister's child, was in poor health and recently had lost her boyfriend. However, neither she nor her mother openly admitted that HIV infection was the probable cause. Several very ill respondents that had been repeatedly admitted to clinics and hospitals nonetheless

continued to refer in vague terms about the 'tests' that had been carried out and said that they were not aware of the results. The avoidance of such ill respondents to openly discuss the possibility of HIV infection, hindered attempts by volunteers and fieldworkers to enquire about plans for children dependent on these ill household numbers.

The health of other carers was reported to have been compromised by the stress of bereavement, providing care, and financial worries.

> Hlengiwe related how difficult it was caring for her sister, and having to assume responsibility for her sister's three children who also stay with her in addition to three of her own. She recalled a time when her sister had a running stomach that kept her up at night, requiring that she be accompanied to the toilet in the middle of the night. […] Hlengiwe further indicated that because they have an outside toilet, she had had to sit outside half the night, waiting to help Thandile into the house. […] Hlengiwe indeed looked tired and stressed out. I admired her for being able to put up a brave face. [Fieldnote Dube-1]

Multiple AIDS deaths of people linked to the households

HIV and AIDS in people external to a household, yet connected to its members, were found to contribute to the multiple experiences of illness and death and have potentially important consequences across households. While discussing the situation of household members with HIV/AIDS, respondents frequently referred to HIV infection and AIDS illness and death of people connected to them such as current or former partners and children.

> We also talked about Thembi's past relationships. Lindiwe [Thembi's sister] told us that the father of Thembi's daughter died some two years ago and that a recent boyfriend of hers with whom she was living also died in April of this year. Lindiwe shared that she suspects that both these men died from AIDS related illnesses. [Fieldnote Nzima-1]

> Particularly disturbing was to learn at this time that Nqobile's last child died some few years ago and that the father of her children also passed away two years ago after suffering from persistent headaches. [Fieldnote Ngubane-1]

In several households, informants considered illness and death of a previous partner or child from TB, pneumonia or with symptoms of weight loss, as 'evidence' that another household member could be HIV positive, even in the absence of a positive HIV test. For three respondents, a death of a previous partner (or partner of an ex-partner) led them to suspect that they themselves were HIV positive.

> Gladys shared that the source of the rumor were people who had known about Vusi's [Gladys' son-in-law] love affair with a woman who had died from an illness that suspiciously looked AIDS related. She told me that when her daughter fell sick and lost a lot of weight, a friend who was concerned about her health came to her and advised her [Vusi's wife] to go for an HIV test because Vusi's girlfriend who was working with him died of AIDS. [Fieldnote Nsele-1]

> It took on a somber note when Maria Khumalo said 'we were four (referring to herself and the other three woman in her late husband's life)…and this man is killing us one by one…first the mother of the three girls I live with, now the mother of this boy…and now there's two of us left…and maybe I am the next in line.' [Fieldnote Khumalo-1]

Illnesses or deaths that occur outside a given household unit can often result in either adults rejoining it to seek care from their elderly parents, or the arrival of orphaned children. Thus they can have a major impact on that household's well-being. Households in the study were seldom involved directly in providing care or support for other non-household members such as ex-partners. Nevertheless, if these non-members had been providing financial and material support to former partners and children, these could cease when they became ill or died with serious consequences for the household affected.

The separation of parents prior to their death presented a particular set of difficulties for those caring for orphaned children. Customary marriage rites emphasize the involvement of both brides' and grooms' families in acknowledging the union and the children born within the marriage. For children whose parents were married and later died, there was greater involvement of maternal and paternal families in decisions about the arrangements for orphaned children, such as in the Nsele household where open discussions were held at a parent's funeral about who would care for the children. However, where parents had not been married or had been separated or divorced, there was often no relationship between maternal and paternal

households. Consequently, decisions about the subsequent arrangements for a child were taken exclusively by those people with whom the child was living.

In some cases a parent had no active involvement in their child's life prior to his/her death, and sometimes was not known to the child's current carers. This made the process of applying for government foster care grants very difficult.

> The social worker asked Hlengiwe about the father of Fikile's children [Hlengiwe and Fikile were sisters]. Hlengiwe said that she had told the social worker that she don't know where the father was since Fikilie had been living at Mandini when she had these children and now Fikile was dead. The social worker did not even take the name of the children's father but simply said Hlengiwe should leave and the social worker would call her if she found the father. Hlengiwe concluded by saying that the social worker was not interested in helping her and as a result she went back home hopelessly. [Fieldnote Dube-4]

In most cases, the deceased's relatives did not honour previous maintenance payments. Only one household took legal action to obtain payments from a child's parent. Indeed most carers appeared to assume that the other household would not offer support even if asked.

Government grants available for caring for orphaned and disabled children were a substantial cause of mistrust and suspicion between carers and other members of their family or that of the other parent. In several households, suspicions were voiced about other people's attempts to get grants by taking care of orphaned children. Several carers felt that relatives were only seeking to look after a child in order to access the grants.

> However, the news was not well received by the Msweli's [maternal grandmother and aunt] who felt that Dudu Zuma [Jacob's paternal grandmother] was stalling and refusing to cooperate with the documents because the foster grant, if issued, would not go to her but to them as foster parents of Jacob's. [Fieldnote Msweli-1]

> The grandfather has asked for the birth certificates for his grandchildren because he wants to apply for the foster care grant for them. He is not happy that Fikile [older grandchild, carer for her younger siblings] would apply for the grants because he says she will get married and go with all the money.

But Fikile knows very well that he won't give them the money after it [the grant] has been approved and he would use it only for himself. Therefore, Fikile was not prepared to give their grandfather the birth certificates. She further said he has for the first time asked Sanele and Smagaliso to pay a visit to him in Mfekayi. She wondered if this might be because if the children stay with him at Mfekayi he could apply for the grant. [Fieldnote Mbata-4]

Discussion

This study shows that many of the households affected by HIV and AIDS experienced multiple episodes of illness and death during the period of observation and prior to enrolment. These multiple experiences of HIV/AIDS illness and death also included those of people in other households.

Using longitudinal, population-based data, we reported elsewhere that multiple adult deaths, independent of cause, are significantly predictive of household dissolution and migration (Hosegood et al 2004a). Households' ability to respond to the increased demands placed on them by a single death may be exhausted if a second or third death follows in quick succession. In addition, while AIDS is an important cause of much of this ill-health and mortality in young adults and children, the difficulties faced by households in coping with HIV/AIDS were compounded by the burden of disease due to other causes. Thus our analyses of surveillance data suggest that the experience of multiple adult deaths and violent or accidental deaths are better predictors of household dissolution than AIDS deaths *per se*.

Many of the social and economic consequences of HIV/AIDS illness and death reported in this paper are similar to those reported by other studies, including increased expenditure due to illness and death leading to food insecurity and problems with keeping children in school (Booysen 2002, Guiness & Alban 2000, Patel 1995, Yamano & Jayne 2004). South Africa differs from other African countries in having several state support grants that can provide financial support to poorer households including old-age pensions, disability grants and child support grants (Booysen 2003, Case et al 2005, Hunter & Rushby 2002). Several households caring for the dependents of a young adult that accessed state grants were observed to reverse much of the extreme financial insecurity they faced during the period when they were coping with adults' illness.

Collecting information about mortality and illness in households over a long period of time revealed the extent to which the social and economic circumstances were already shaped by the time they were enrolled in the direct observation study. For example, a father began living alone with his two children after his wife died the year before and, in another household, the presence of several orphaned children was due to the previous deaths of two unmarried adult sisters. Such a longitudinal perspective permits a more nuanced interpretation of prospective information about responses to subsequent illness and death.

The methods used in this study facilitated the collection of data about illness and deaths of people outside the households that had direct or indirect repercussions on those within the household. Such

information is difficult to obtain through population-based survey methods where respondents are asked to provide structured information about themselves or other members of their household. This usually restricts the observations of illness and mortality to only those people listed as household members. However, as we show, the patterns of marriage and fertility to create a situation in which the current or previous partners of many HIV infected adults, and/or the children of these unions, were not members of the same household. Illness and death that occur 'off-stage' had important consequences for study participants.

This rural environment is marked by social dislocation of partners and children, and this has considerable impact on the way the HIV epidemic affects household composition in this context. In this regard, the findings of this study differ from those in other countries. Nyamukapa and Gregson (2005) describe the role played by extended families in rural Zimbabwe in determining the arrangements made for orphans. They report a process through which maternal and paternal relatives meet together after the death to make decisions about inheritance, who will take responsibility for the children, and who will provide financial assistance to the child and surviving partner. This kind of joint counsel between maternal and paternal families was only observed in this study where parents had been married. In the majority of cases, only relatives of the parent with whom the child had closest contact were involved in decisions about the children's future. In contrast to the cooperative structure described in Zimbabwe, we observed that many inter-familial relationships were contested and characterized by suspicions about the motives around inheritance and access to government support. While we were not able to conclusively determine whether conflict or non-cooperation between maternal and paternal families resulted in less optimal arrangements for orphaned children, this highlights a potentially important role for the wider community and government social services in ensuring that the rights and wellbeing of children in such situations are safeguarded.

We believe that our findings provide additional insights about the extent and nature of adult illness and mortality in rural South Africa in the era of HIV/AIDS. We argue that consideration is needed when interpreting cross-sectional survey data that provide little or no information about the historical antecedents of past mortality exposure in households. Even evidence of impact based on longitudinal data may be subject to bias. Given the transmission dynamics of HIV and the increased risk of mortality of orphans (Zaba et al, 2005), households that have experienced the death of an adult or child are at higher risk of experiencing a related death either of a member(s) or of a related person in another household. If a relatively short window of follow-up is used, it would not be possible to establish whether the poorer outcomes observed have

resulted from a single adult death or from the cumulative effects of multiple shock experienced prior to the study, both inside and outside the immediate household.

However, we are conscious that collecting retrospective data over a long recall period and about people in different households is presents its own limitations. Making links between people in different households requires considerable additional effort by fieldworkers and introduces complexities in data management and analysis. However, the impact of 'external' mortality can be examined in specific areas, for example, on financial remittances of non-resident parents or other relatives for children. At a minimum, it should be possible to collect information about parental mortality even in cases where one or both parents are not co-members of the child's household.

Acknowledgements

The authors thank Thandile Shandu, Nokuthula Buthelezi and Janet Okara for their support to this study and participating households. We also are very grateful to the households, volunteers and government staff who shared their experiences and time with us. This work was supported by The Wellcome Trust, UK through grants to the Africa Centre for Health and Population Studies (#50534) and Timæus/Hosegood (#61145).

References

Booysen F. 2002. The socio-economic impact of HIV/AIDS on households in South Africa: pilot study in Welkom and Qwaqwa, Free State Province.

Booysen F. 2003. *The role of social grants in mitigating the socio-economic impact of HIV/AIDS: evidence from the Free State Province. Rep. CSSR Working paper No. 56*, University of Cape Town, Cape Town.

Booysen FlR, Arntz T. 2003. The methodology of HIV/AIDS impact studies: a review of current practices. *Social Science and Medicine* 56: 2391-405

Bray R. 2002. *Missing links? An examination of contributions made by social surveys to our understanding of child well-being in South Africa. Rep. CSSR Working paper No.23*, University of Cape Town, Cape Town.

Case A, Hosegood V, Lund F. 2005. The Reach of The South African Child Support Grant:Evidence from KwaZulu-Natal. *Development Southern Africa* [In press]

Guiness L, Alban A. 2000. *"Economic impact of AIDS in Africa: a review of the literature," paper presented at the African Development Forum, Addis Ababa, 3-7 December.*

Hosegood V, McGrath N, Herbst K, Timæus IM. 2004a. The impact of adult mortality on household dissolution and migration in rural South Africa. *AIDS* 18: 1585-90.

Hosegood V, Timaeus IM. 2001. *Household Composition and Dynamics in KwaZulu Natal, South Africa: Mirroring Social Reality in Longitudinal Data Collection*. Presented at Paper presented at the African Census Analysis Project Virtual Conference on African Households: an Exploration of Census Data, 21-24 November 2001. http://www.lshtm.ac.uk/dfid/2002_105.htm.

Hosegood V, Vanneste A-M, Timaeus I. 2004b. Levels and causes of adult mortality in rural South Africa. *AIDS* 18: 1-19.

Hunter N, Rushby J. 2002. *Annotated bibliography of recent research on the living conditions of the main target groups of social security grants. Research report no. 53.*, School of Development Studies, Durban.

Moitse S, Hosegood V. 2003. Accessing grants: the never ending story. *Children First* 49 (June/July): 3-5.

Montgomery C, Hosegood V, Busza J. 2005. Men's involvement in the South African family: Engendering change in the AIDS era. *Social Science and Medicine* [In press]

Patel L. 1995. *The social and economic impact of HIV/AIDS on individuals and families. Rep. No. 40*, Centre for Health Policy, Department of Community Health, University of the Witswatersrand, Johannesburg, South Africa.

Ross F. 2003. Dependents and dependence: a case study of housing and heuristics in an informal settlement in the Western Cape. *Social Dynamics* 29: 132-52.

Ross FC. 1996. Diffusing domesticity: domestic fluidity in Die Bos. *Social Dynamics* 22: 55-71.

Russell M. 2003. Understanding black households: the problem. *Social Dynamics* 29: 5-47.

Spiegel A, Watson V, Wilkinson P. 1996. Domestic diversity and fluidity among some African households in Greater Cape Town. *Social Dynamics* 22: 7-30.

Spiegel AD. 1986. The fluidity of household composition in Matatiele, Transkei: a methodological problem. *African Studies* 45: 17-35.

Williamson J. 2000. Finding a way forward. Principles and strategies to reduce the impacts of AIDS on children and families. In *The orphan generation: the global legacy of the AIDS epidemic*, ed. C Levine, G Foster. Cambridge: Cambridge University Press.

Yamano T, Jayne TS. 2004. Measuring the impact of working-age adult mortality on small-scale farm households in Kenya. *World Development* 32: 91-119.

Zungu S, Moitse S, Hosegood V. 2003. Social grants in rural areas: beating a path through a maze of bureaucracy. *Children First* 47 (Feb/March): 5-8.