The impact of adult illness and death on households in rural South Africa

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This study examines the responses of households and their members to multiple deaths of young adults using indepth qualitative histories of families coping with adult and illness in a rural area of South Africa that is experiencing a rapid and severe HIV epidemic.

Introduction

As the most fundamental social institution, the family is an essential focus of study for social scientists. Numerous social, demographic, economic, political and cultural processes determine the continuity and transformations in family structure. In South Africa, historical and contemporary events have led to substantive changes in these determinants, most notably the existence of the Apartheid political system and its recent dismantlement, the system of labour migration, and the rapid and severe HIV epidemic of the last decade. There have also been significant declines in fertility, marriage, and employment opportunities, which have been matched by increases in non-marital fertility, urbanization, and young adult mortality. Consequently, there is considerable diversity in the types of family structures and household living arrangements that exist today(Hosegood & Solarsh, 2001). The instability of marital and non-marital unions because of separation/divorce(Hosegood & Preston-Whyte,2002; Niehaus,1994), high levels of early adult mortality(Dorrington et al, 2001; Hosegood et al,2004b), residential mobility(Hosegood et al, 2004a; Murray, 1981; Van der Walle,1996), and the social fluidity of households(Speigel et al, 1996), particularly in relation to the care of children(Jones,1993; Madhavan, 2004); mean that many people undergo numerous changes in their living arrangements during their lifetime.

Families and households are the primary agents of health, social and economic status. An individual, regardless of their age, is profoundly influenced by other past and present members of their household. This may be through some members owning, and being willing to share, financial and material assets, or less tangibly through the knowledge, attitudes and behaviour of other members of their family. Over time, and under different circumstances, households may consciously change their composition and their members play different roles. Our research suggests that a households’ flexibility is a critical component in successfully responding to extreme crises such as the illness and death of an adult due to HIV/AIDS(Hosegood et al,2004a). Without such adaption, either through altered structures or roles, or through external assistance, families and households may become non-functioning social and productive units and ultimately dissolve(Hosegood et al, 2004a). This may have profound short- and long-term consequences for the surviving individuals(Ford & Hosegood, 2003).

Our preliminary findings suggest that households affected by HIV/AIDS experience a significant reduction in their economic status and undergo changes in their household structure(Hosegood et al, 2004a; Hosegood & Timaeus, 2004). The increased expenditure by households affected by illness and death, compounded in many cases by the loss of income, negatively impacts on households' financial security, particularly in those with a high dependency ratio. When the ill or disabled adult remains at home they require considerable care from other household members, most often women(Danziger, 1994; Kempkes, 1999; Siedel, 1996; Taylor et al, 1996). These carers may need to curtail other income-generating activities, thus further reducing the household income. Increased expenditure on health care and the substantial costs of the burial often exacerbate loss of income. Studies have shown...
that reductions in financial resources following adult illness and death, resulted in an inability to pay for school fees, a lower nutritional status, less health service utilisation, a reduction in agricultural production, the depletion of savings, and debts (Ainsworth et al., 1995; Chevallier & Floury, 1996; Yamano & Jayne, 2004).

Changes in household structure due to HIV/AIDS can include an increased in- and out-migration of household members, an increase in the rate of fostering, higher rates of remarriage for surviving spouses (Ntozi, 1997; Urassa et al., 1997). Changes in household structure have been shown to be part of households’ coping strategies. For example, fostering spreads the impact of HIV/AIDS over several households (Bledsoe, 1995; Page, 1989). Several authors note that many foster households are also poor. An increase in the number of child-headed households in Zimbabwe (Foster et al., 1997) has not been found by studies in Tanzania, Uganda and South Africa (Urassa, 1997; Hosegood and Timaeus, 2001, Nalugoda, 1997). Not in South Africa is there evidence of an increase in the number of skipped-generation households (Hosegood and Timaeus, 2004; Merli & Palloni, 2004; Noumbissi & Zuberi, 2001) Another determinant of socio-economic status and household structure is inheritance. In sub-Saharan Africa traditional and civil inheritance laws are patriarchal and kinship based. Several studies have reported that the failure of surviving widows and non-marital partners to inherit increases the risk of poverty, household dissolution, migration, and reduced support due to family disputes (Lloyd, 1995; Ntozi et al., 1997; Patel, 1995).

Although there is an emerging literature examining the impact of HIV/AIDS in sub-Saharan Africa, previous studies focusing on the consequences for households have been subject to a number of conceptual and methodological limitations. This study addresses the gaps in existing knowledge and seeks to provide an enhanced conceptual framework for assessing the impact of HIV/AIDS on households.

The study has two main areas of investigation:

1. Longitudinal dimensions of the HIV/AIDS impact on households

There are two time-related determinants of HIV/AIDS impact on households that are not adequately addressed by other studies: a) the stage of the disease, and b) other events that occur prior to, during or after the HIV/AIDS illness and death. For example, early HIV/AIDS related illness might not cause major financial or social adjustments, but as the illness episodes become more severe, more frequent and prolonged, socio-economic status and household structure may change. Household responses at the early stages may influence the impact of HIV/AIDS later on. Multiple HIV/AIDS infections will occur in many households in addition to non-HIV/AIDS illness and death. The cumulative effect of several previous deaths in a relatively short period of time may exhaust the economic and social resources within the household and its support networks.

The quantitative studies in Uganda and Tanzania have used cross-sectional or repeated cross-sectional survey data that does not permit the longitudinal analysis of multiple HIV/AIDS morbidity and mortality on households. In addition, qualitative studies have generally sampled households who have already experienced a death and were therefore limited in their ability to measure the impact at different stages of the disease.

Research hypotheses to be tested:
- Household responses during the early stages of illness will influence subsequent coping strategies during the later stages of disease and after death.
- Multiple experiences of HIV/AIDS illness and mortality in a household will compound adverse impacts on individuals and household's socio-economic status, health and, social and residential mobility.

2. Vulnerable members of extended households

Most studies that examine the impact of adult HIV/AIDS on the household restricted their observations to biological children, spouses and parents. This essentially nuclear rather than extended concept of households limits our understanding of the impact of HIV/AIDS on households(Spiegel et al, 1997). In South Africa household members can include adult siblings, nieces, nephews and other relations of the head or spouse(Spiegel, 1997). In addition, other household members contribute and share in the household's resources. These non-core household members include foster children, friends, domestic and farm workers(Hosegood and Solarsh, 2001). Foster children are already a prevalent feature of rural households in many African countries and their numbers are expected to rise(Bledsoe, 1995; Van der Waal, 1996). Domestic and farm workers (both adults and children) are often not in a conventional employer-employee relationship. Some have been resident with the household for many years and may have no or limited financial or social support outside the household.

These non-core household members are therefore potentially more vulnerable to the adverse impact of HIV/AIDS than core members. Non-family or distant family members are less likely to be supported by the household if they themselves have HIV/AIDS related illness. They have no kinship right to inheritance and relatives of the core household who live elsewhere may feel no social obligation to assist them. In addition, non-core members are likely to have joined the household because of previous adverse circumstances.

Research hypothesis to be tested:
- Household members who are unrelated or distantly related to the head of household are more likely than other household members to experience loss of employment, migration, educational disruption, and reduction in nutritional and health status following illness or death of a core member of the household.

Linkages with empirical data and previously published findings

This qualitative study is a part of a larger research project to examine the impact of HIV/AIDS on rural households in South Africa. Previous published research from this project have analysed quantitative longitudinal data from the Africa Centre Demographic Information System, a demographic surveillance system that has been visiting 11,000 households since 2000. Two of the co-authors of this paper, Hosegood and Timeæus, have published several papers that use the ACDIS data to examine the adult mortality and its consequences on household migration and dissolution, children’s mobility and older people (Ford & Case, 2003; Hosegood et al, 2004a; Hosegood and Timeæus, 2004). Other work by Case et al (2004) has used ACDIS data to examine the update and reach of government child support grants targeted towards the poorest children(Case et al, 2004).

The population-based data provides valuable contextual information for interpreting the qualitative findings. We are able to compare the characteristics of the relatively small sample of households observed in the qualitative study with those of the total population of households with respect to composition, headship, economic status and mortality experience. The qualitative data in turn will allow us to pursue our interpretations of the empirical findings further, for example, those related to the factors that child migration following parental death.
Study area

The study area is located in northern KwaZulu Natal. The study area is located about 250km north of the provincial capital of Durban. The area includes both land under tribal authority that was designated as a Zulu ‘homeland’ under South Africa’s former apartheid policy and a township under municipal authority. Infrastructure is poor. In 2001 only 13% of households had access to piped or public tapped water. Fifty percent of households have no electricity supply. Although this is a rural area, there is little subsistence agriculture and most households rely on waged income and pensions. Unemployment is high: in 2001 25% of people aged 15-65 reported that they were unemployed and actively seeking work(Case & Ardington,2004).

KwaZulu Natal is the province of South Africa with the highest HIV prevalence rate among antenatal clinic attenders. An antenatal survey conducted in the study area in 1998 found that 41% (95% CI 34.7-47.9) of pregnant women were HIV-infected. Mortality in the study area rose sharply in the late-1990s. By 2000 the probability of dying between ages 15 and 60 was 58% for women and 75% for men. AIDS, with or without tuberculosis, was the leading cause of death in adulthood (48%)(Hosegood et al,2004b).

Study methodology

The primary source of data used in this paper are participant observations of twenty households in rural KwaZulu Natal, South Africa who experienced the illness and death of one or more adult members over the period 2002 to 2004.

The households were selected through a variety of contacts. Ten were identified by the research assistants accompanying volunteer home-based care givers on their visits. In a preliminary phase of the research we focused on the activities of the volunteers, over time we altered the focus to a sample of their patients and the households to which they belonged. Another five households were referred to us by Africa Centre nurses who interview family carers of people who have died in order to collect cause-specific mortality data. In the process of interviewing the family these nurses became aware of other adults who were currently ill and requested the family if we might make a follow-up visit. Other households were identified by the research assistants as they spent time in the neighbourhood, typically these were households of neighbours or relatives of households already in the study.

We used a participant observation approach in which the research assistants made numerous visits to each of the households over the two year period. Over the period of the study the research assistants became increasingly involved in the events and activities of the household and therefore were able to collect information in a wide range of different situations for example, while accompanying a mother to the welfare office to apply for a child grant, attending a funeral; bringing a caregiver who could advise the household about caring for a sick member, visiting a respondent in hospital, offering support to someone going for an HIV test, or while making an unscheduled visit to check-in with the household.

The three research assistants varied considerably in research experience but all spoke fluent Zulu. Two had grown up locally. One was a post-graduate level trained ethnographer with previous research experience. Two had extensive experience as fieldworkers with other projects in the Africa Centre. One gained post-graduate qualifications during the project, the other was completing a graduate degree. Two research assistants wrote up their fieldnotes in English while the third wrote first in Zulu and then translated the notes into English. All documents were managed using the QSR N6 software.
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