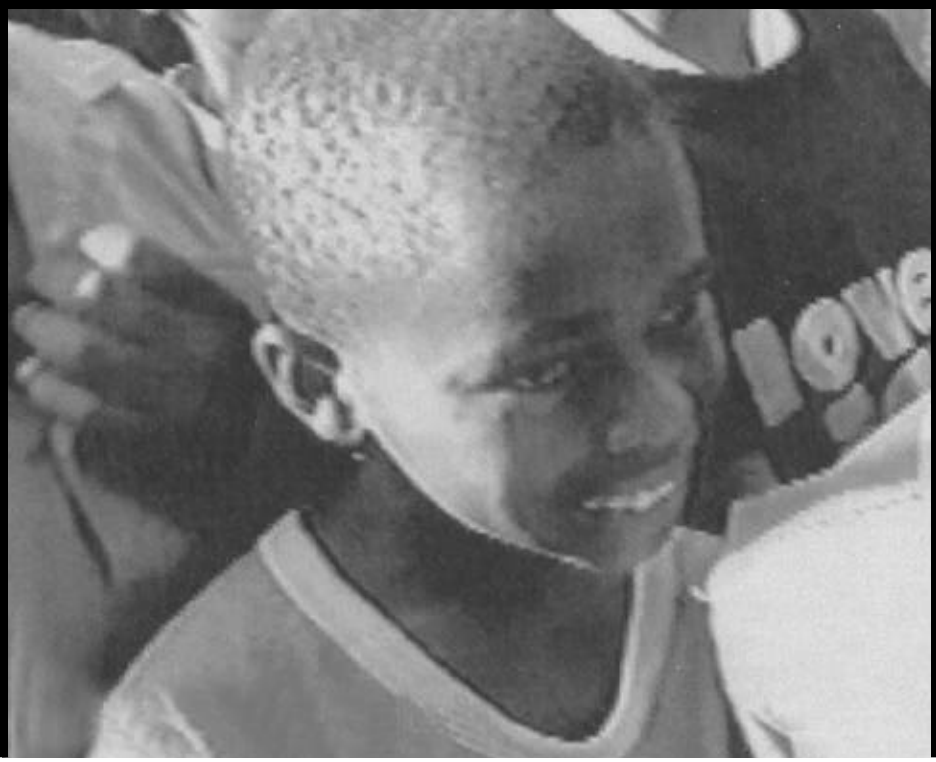
HITTING HOME

How Households Cope With The Impact Of The HIV/AIDS Epidemic

A Survey Of Households Affected by HIV/AIDS in South Africa



THE HENRY J. KAISER FAMILY FOUNDATION

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A Survey Of Households Affected by HIV/AIDS in South Africa

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HEALTH SYSTEMS TRUST

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The Henry J. Kaiser Family Foundation, based in Menlo Park, California, has since 1987, maintained a program in support of South African efforts to establish a more equitable national health system. An important part of this effort is providing information and analysis on health issues to policymakers, the media and the general public.

The Health Systems Trust, based in Durban, South Africa, is an independent non-government organisation established in 1992 to support the transformation of the South African health system. The trust actively supports the current and future development of a comprehensive health care system through strategies designed to promote equity and efficiency in health care delivery.

EXECUTIVE SUMMARY

This report summarizes the results of a survey of 771 AIDS-affected households in different parts of South Africa. The households were randomly selected from the client lists of non-governmental organizations providing support to AIDS-affected households in the regions where the survey was conducted. The survey and this report are an attempt to document the impact of HIV/AIDS on South African households. Although it is not representative of all AIDS-households in South Africa, the report provides a snapshot of the devastating impact of HIV/AIDS on already poor families. As bleak as the findings of this survey are, the households in this survey are likely better off than most since all households in the survey had contact with non-government organizations providing support to HIV-affected households.

No sector of the population is unaffected by the HIV epidemic, but it is the poorest South Africans who are most vulnerable to HIV/AIDS and for whom the consequences are inevitably most severe. The average age of the AIDS-sick person in the households surveyed was 35 years—in most cases these were breadwinners and the parents of young children. This report illustrates that in already poor households HIV/AIDS is the tipping point from poverty into destitution.

This report documents the impoverishing impact of HIV/AIDS on households and the inordinate burden of caring for AIDS-sick family members. It also documents access to and satisfaction with public services, as well as access to government financial support for AIDS-affected households.

Children are the worst affected

Forty four percent of the households in the survey had monthly income less than R1000. Two thirds of these households reported loss of income as a consequence of HIV/AIDS. Increased expenditure on medicines and medical care, and the high costs of funerals are also contributing to the financial burden. Among the most profound consequences of AIDS-related illness and death, and the resulting erosion of household income are:

- Almost a quarter (22%) of all children under 15 years in households included in the survey had lost a parent.

- More than two thirds (64%) of the AIDS-sick individuals in the survey were female on average 33 years of age.
- Increasing childhood malnutrition—almost half of the households in the survey reported having insufficient food at times and that the children in these households often went hungry.
- The break-up of families—more than 12% of households had sent their children away to live elsewhere, most often with a grandparent or another relative.
- Increasing childhood malnutrition—almost half of the households in the survey reported having insufficient food at times and that the children in those households often went hungry.

The burden of care

The households worst affected by HIV/AIDS are also those most underserved by basic public services such as sanitation and piped water. Only 43% of households in the survey had a tap in the dwelling and nearly a quarter of the rural households in the survey had no toilet at all. These harsh circumstances substantially add to the burden of caring for an AIDS-sick person, as well as the patient's suffering and loss of dignity:

- 68% of the caregivers in the households surveyed were women or girls—7% of them younger than 18 years and 23% older than 60 years.
- One in six of AIDS-sick individuals in the households surveyed could not control their bowels and about the same number could not control their bladders. About 20% could not wash without assistance.
- More than 40% of households reported that the primary caregiver had taken time off from formal or informal employment or schooling to take care of the AIDS-sick person adding to the loss of household income and the under-schooling of girls.
- Households reported that on average the AIDS-sick person was chronically ill for a year before dying.

Government grants are not getting through

The households surveyed for this report are the lucky ones in as much as they are all receiving some level of assistance from non-governmental organizations including help in accessing government grants. Even though all the households in the survey were eligible for at least one

form of government grant, fewer than 16% of households were receiving government grants of any kind.

- Only about 10% of households reported getting home-based assistance from government welfare services.
- Eighty percent of households used public clinics, but 50% reported that they also used private doctors.
- About 40% of respondents who used public health services said they were less than happy with these services. The reason most often given for this dissatisfaction was the uncaring attitude of health workers and inadequate treatment ranging from medication that did not work, to the lack of beds for the chronically ill and early discharge of ill patients.

Denial is Still Widespread

Only about 50% of the households in the survey said that the sick person they were caring for had HIV/AIDS. Most often respondents only mentioned opportunistic infections such as tuberculosis and pneumonia. But where respondents had revealed the AIDS-related cause of their illness, families tended to be supportive.

- About 80% of those who had been open about their HIV status said that the household had been very supportive. Hostility from family members was rare.
- But only 35% of those who had revealed their HIV-status reported a supportive response from the community. One in ten reported hostility and rejection.
- Of those in the survey who said they had been employed at the time of their HIV diagnosis, half said that their employer had been very or fairly responsive. Eight percent said their employers had responded unfairly or with hostility.

Conclusions

This report confirms what perhaps is already obvious: that poor people in South Africa are the most adversely affected by HIV/AIDS, that the public health service is struggling to satisfy the medical needs of AIDS-sick patients, support to AIDS-affected households is limited and available government grants are not getting through. But it also points to some of the more profound longer term ramifications of the HIV epidemic:

- deepening poverty among the already poor;
- disruption and premature termination of schooling for children, especially girls;

- increasing early childhood malnutrition;
- and increasing strain on extended family networks.

Although most respondents in the survey had little difficulty accessing clinic-level care and were generally pleased with the service they received, more sick patients are routinely referred to district hospitals. Respondents were substantially less happy with the service received at district hospitals mainly because AIDS-sick patients are only kept in hospital a short time and the lack of appropriate treatment. Terminally ill AIDS patients are generally sent home to die and access to home-based care programs is very limited. AIDS-affected households are spending up to a third of their income on private medical care. The lack of AIDS treatments in the public health system together with the lack of home-based care and support is further exacerbated by difficulties in accessing available government grants.

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INTRODUCTION

The HIV/AIDS epidemic in South Africa is most often described with statistics too overwhelming for most to comprehend. This study is an attempt to personalise the epidemic by documenting the impact of HIV/AIDS on families and households, and to illustrate the broader consequences of the epidemic in areas such as: early child development, education and gender equity; the impoverishing impact of HIV/AIDS in already poor households; and the burden of care on affected households, public services, and the social welfare system.

There are presently an estimated five million people (approximately 12% of the population) in South Africa living with HIV/AIDS. Although no sector of the population is unaffected by the HIV epidemic, it is the poorest South Africans who are most vulnerable to HIV/AIDS and for whom inevitably the consequences are most severe. Catastrophic illness of any kind invariably has a serious impact on families and households. But the impoverishing impact of HIV/AIDS is so much more acute, because it is the economically active sector of the population—the breadwinners—that is mostly sick and dying. For already poor households HIV/AIDS is the tipping point from poverty into destitution.

This study is not a nationally representative survey of all South Africans households affected by HIV/AIDS and likely is an under representation of the reality because all households in the survey have association with non-government organizations providing assistance to AIDS-affected households. Nonetheless, the survey does document the real-life circumstances of a cross-section of AIDS-affected households. The detailed response of the household unit to HIV/AIDS has not yet been fully documented. And although this study is not nationally representative, it is a record of how affected households are responding to the epidemic, the help they manage to access, and the financial implications for the household and the country.

APPROACH

This cross-sectional and descriptive research project was designed to provide a snapshot of households affected by HIV/AIDS and how they were responding to the socio-economic consequences of the disease. The inherent difficulty in this study is developing a sampling frame. Since there is no list of AIDS-affected households in South Africa, a sample was drawn from lists of households that are being supported by community organizations, other non-government organizations or clinical services. These households are not representative of all AIDS-affected households and could be expected to be in a better position than many by virtue of their access to some form of support. Given the constraints of this study, if anything, the situation described here might be considered a "best case".

771 households were included in the survey. The survey was conducted in either a rural or an urban part of Gauteng, Mpumulanga, and Free State and in two sites (one urban, one rural) in KwaZulu-Natal. This use of two sites in KwaZulu-Natal province reflected its status as the region with the highest HIV prevalence.

The research population was all households that contained an AIDS-sick individual, or where someone had recently died of HIV/AIDS. Households with an HIV infected, but not sick, member were not included in the sample.

To ensure that the sick-people in the households in the sample indeed had been diagnosed with HIV, the sample was drawn from lists of households associated with HIV/AIDS support organizations. To focus on the financial impacts, only households where the sick person was between the ages of 15 and 60 were included – this being regarded as the economically active age range.[1]

Although 771 households were included in the survey, 43 households were excluded from the final analysis for a variety of reasons. Adults over 60 were excluded on the theory that they were

[1] Organizations were asked to create two lists; one of households containing an AIDS-sick individual, and another of households where there had been an AIDS-related death. Since this study looked at household impact, only one sick person was counted for each household. Each organization was given a list of randomly generated numbers which it assigned to households, before approaching them about participating in the study. This randomization was to remove unconscious bias in the selection of interviewee households. The number of interviews from each organization was in proportion to the number of households in the study area that it was responsible for.

unlikely to have HIV/AIDS, while children under 16 were disqualified since they were unlikely to be formally economically active. A number of other interviews were discarded for various reasons such as chronic illness that was obviously not HIV-related, or where death was accidental or for non-AIDS causes, such as a bolt of lightning.[2]

Research was carried out by fieldworkers from different organizations working on HIV/AIDS in the area of the study sites. Interviewers were given a quantitative questionnaire and in some cases households were selected for follow-up qualitative interviews. Feedback and monitoring of fieldwork was conducted on an ongoing basis, although standard verification check-backs were not conducted for fear of breaching confidentiality. But the follow-up qualitative interviews provided a random check on the initial interviewing process.

Table 1: Distribution of the final sample

	Chronically Ill	*Deceased*	*Total*
Gauteng	150	112	262
Free State	78	58	136
Mpumalanga	64	67	131
Jozini, KZN	37	54	91
Durban, KZN	65	86	151
TOTAL	**394**	**377**	**771**

In each household the head-of-household was interviewed. In 31% of cases the head-of-household was also the AIDS-sick person or index case, or was also chronically ill. Due to the lack of a comparison group it was considered important to compare some of the findings of the research to non-AIDS households. Unfortunately the most current data available from Statistics South Africa—the body officially charged with collecting this type of data—was from 1995, limiting the usefulness of the comparisons. [3]

[2] Many sampling errors were only detected after fieldwork was completed, in which case it was not financially possible to interview a substitute household in the same area. Therefore a final "mop-up" to replace discarded interviews and boost the sample size was conducted in Gauteng. As a result the number of households from Gauteng was proportionately larger than envisioned in the original study design.

[3] As a cross-sectional study, this research is clearly limited and only provides a snapshot in time. It is therefore difficult to know whether the financial plight of households was directly due to the death or illness of an individual, or whether it was pre-existing. The lack of a control group is also problematic, and it is difficult to tell whether the households affected by HIV/AIDS were in any case poorer than their neighbours. Although where possible comparisons were made with aggregate national data, this was complicated by the fact that this study deliberately focused on poorer communities. The method of choosing households for interviews introduced a bias, in that it excluded households with no access to home-based care and community based organizations. It may also have tended to exclude wealthier households who would not have used such support organizations. Overall it is likely that the households interviewed in this research were a fair representation of households affected by AIDS in the relevant provinces, although they are more likely than most to have access to support mechanisms.

SNAPSHOTS OF HOUSEHOLDS

The people behind the "index case"

In South Africa women are not only more likely than men to be infected with HIV, but they also tend to become infected at an earlier age. Both these trends are borne out by this study. More than two thirds (64%) of the AIDS-sick individuals monitored were female.

Not only were there more AIDS-sick women than men, but the women on average were 33 years of age, compared to 37 years for the men. Overall the average AIDS-sick individual in this survey was 35 years old. The median age – the most commonly occurring – was 33 years. These are young adults in the prime of their economically active lives, and mostly with young children.

The survey focused on households where a person was sick with HIV/AIDS but still alive, and also on households where a member had recently died as a result of AIDS. The average age of the dead individuals was a year higher than that of the living.

Table 2: Age profile of the index case by mortality status

Age	*Index Case ill*	*Index Case Deceased*	*Total*
16-20	6	6	12
21-24	38	31	69
25-34	158	150	309
35-44	107	101	208
45-54	47	41	88
55-60	7	13	20
No Response	5	13	18
Total	**368**	**355**	**724**

Although AIDS related death can occur relatively quickly – several of the individuals in the study had been sick for less than two weeks before dying – usually it is a long drawn out process. The majority of the AIDS-sick people surveyed had been sick for more than three months, but the average was one year. Households in which a member had already died of AIDS reported on average that the person had been ill for six months before dying.

Table 3: Duration of illness by whether index case ill or deceased

Duration of illness at time of interview	*Ill*	*Deceased*	*Total*
<2 weeks	7	9	16
2 weeks-3months	50	114	164
>3months-<1year	160	151	311
1-2 years	63	42	105
>2 years	88	44	132
Total	**368**	**360**	**728**

What is a household?

Households surveyed had an average of six members, although this concealed a wide range from individuals living on their own to one family with 29 members. On average rural households were larger than urban households. Rural households averaged seven people, compared to five in the urban areas.

The vast majority of households, or 72%, were female headed. Usually these women household heads were between the ages of 25 and 60 years. The study also confirmed the growing importance of grandmothers in maintaining family groups. One in five households were headed by a woman over the age of 60, while only 5% were under the age of 25.

In seventeen percent of cases the head of the household was also the individual suffering from AIDS-related illnesses. Another 14% of household heads were described as chronically ill, a possible indicator of unrecognised HIV infection. The fact that so large a proportion of AIDS-sick people were also the head of household, and mostly mothers, has profound implications for the children in those families.

COPING MECHANISMS

The reality behind the "caring"

This survey and its qualitative component provided graphic insight into the wide-ranging levels of care households were giving people sick with AIDS. It also illustrates the loss of dignity of HIV/AIDS victims as they lose the ability to care for themselves in even the most private of functions, as well as the extreme burden of providing care with minimal resources.

Roughly one in six individuals could not control their bowels (16%) and fractionally more lacked bladder control. About 17% needed help to get on or off the toilet, and getting in and out of bed. Approximately one in five people could not wash without assistance (19%) while just over 17% had to be helped to dress. One person in ten had to be helped to eat.

Weight loss, pain and constant coughing were the main symptoms of AIDS. Nine out of ten households (89%) reported that the sick person was becoming wasted, while 87% said that pain was a problem. Almost three quarters of households said that the sick individual had a chronic cough (74%), and 56% reported breathing difficulties. Chronic diarrhoea and confusion was a symptom among more than half of the cases.

"Godfrey passed away four months ago. This is Godfrey's mom's house. He couldn't work, he lost weight and he was going blind and his girlfriend ran away when he became sick. So the family hired me to look after him. At sixteen years he was staying at the hostel and he was arrested. He was in jail for fifteen years for murder so he came out when he was thirty one. He was only out for a couple of years. At the end Godfrey couldn't do anything, he couldn't even control his bladder or his bowels and he needed nappies. I bought big ones, R55 for twelve at the chemist."

"How many did he use per day?"

"Five. He also had bedsores and he used to go to the hospital for a day when he was bleeding. His mother paid me R500 to look after Godfrey and now that he died they still pay me almost the same. He told me he did get AIDS from a lady in Jo'burg."

Qualitative Interviews

Under even the best of circumstances, lack of control over bodily function is humiliating for the patient and unpleasant for the carer. But when access to a toilet is difficult and there are not proper facilities for the safe disposal of faecal matter, conditions are so much more miserable, and there is high risk for contamination and infection of others as well.

One fifth of the sick individuals had to have assistance walking even on level ground, while almost half had to be helped on stairs or uneven surfaces. This becomes a particular problem when toilet and washing facilities are not in the house, or are even not in the immediate vicinity of the dwelling. Chronic diarrhoea becomes even more debilitating when the sick person may have to struggle outside the house to relieve him or herself. Only 20% or rural households in this survey had access to a flush toilet. And substantial proportions of both rural and urban households still depend on pit or bucket latrines.

Figure 1. Urban households and access to different forms of sanitation

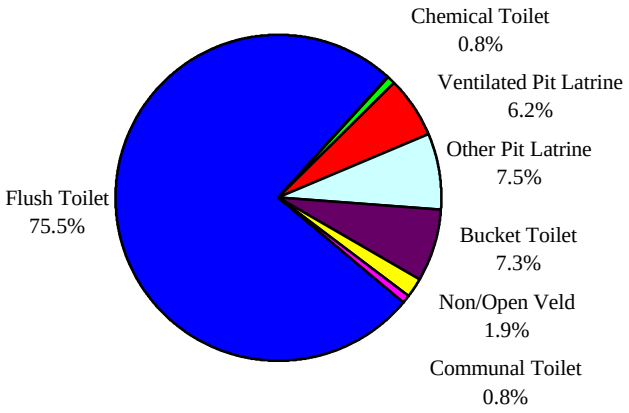
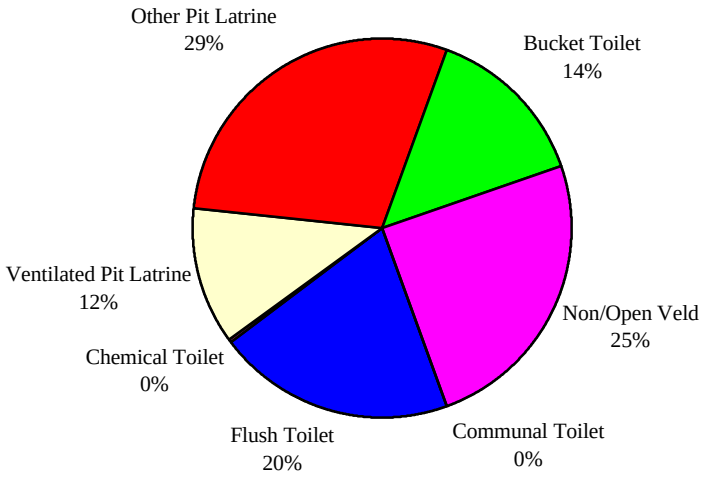
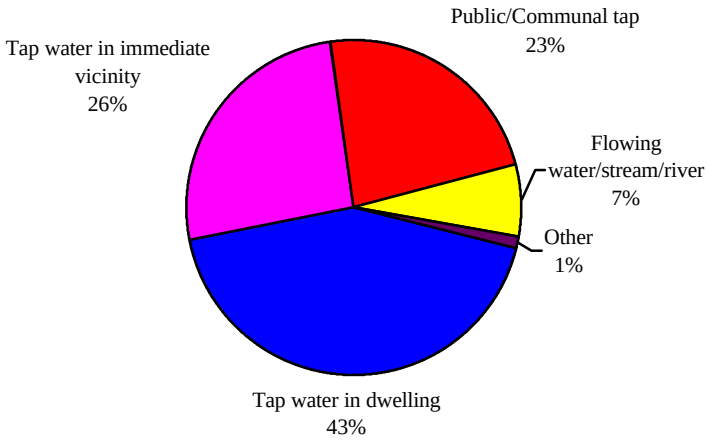


Figure 2. Rural households and access to different forms of sanitation



Along with safe sewage systems, the other fundamental requirement for good public health is easy access to clean water. While most of the households surveyed had access to potable water, less than half had a water tap in their homes.

Figure 3. Household access to water.



Who are the caregivers?

The main caregivers are women – in more than two thirds of households women or girls were the primary caregivers. Almost a quarter of caregivers (23%) were over the age of 60 and just under three quarters of these were women.

In more than one in three households the primary caregiver was also the only caregiver, and in another 8% of families the sick person had no one to care for them. Children under 18 were the caregivers in 7% of households, with girls again being most likely to fulfil this role. However, 68% of households had someone available to help the sick individual most of the time, 22% had someone some of the time.

Taking care of an AIDS sick person is not only an emotional strain for household members, but also a major strain on household resources. In 40% of households caregivers had to take time

off from work and other income-generating activities, or school. This had repercussions for household income: In almost 12% of cases time was taken from formal employment, and in a further 10% of cases it was from other income generating activities. One in five caregivers spent school/study time caring for the sick person. This too has serious implications for the educational development of these individuals. Almost 60% took time from other housework or gardening activities – the latter would affect the ability of poor households to grow food for consumption or sale.

Impact on Income

Almost two thirds of households experienced a fall in income

The devastating financial impact of AIDS sickness was amply demonstrated with two thirds of households reporting a fall in household income as a result of having to cope with HIV/AIDS. Twenty nine percent of households reported no change in household income, and the remainder did not know.

This drop in income was exacerbated by the fact that most of the households studied were already very poor. Although the range of household income was very wide, from R40 to R24,500 a month, 44% of households were surviving on less than R1000 a month.

Table 4: Household income

Monthly Income	*Number*	*Percent*	*National Data (Percent)*[4]
R500 or less	136	19%	26%
R501 – R1000	185	25%	24%
R1001 – R1500	111	15%	23%*
> R1500	131	18%	27%**
No response / Don't Know	165	23%	
Total	**728**	**100%**	**100%**

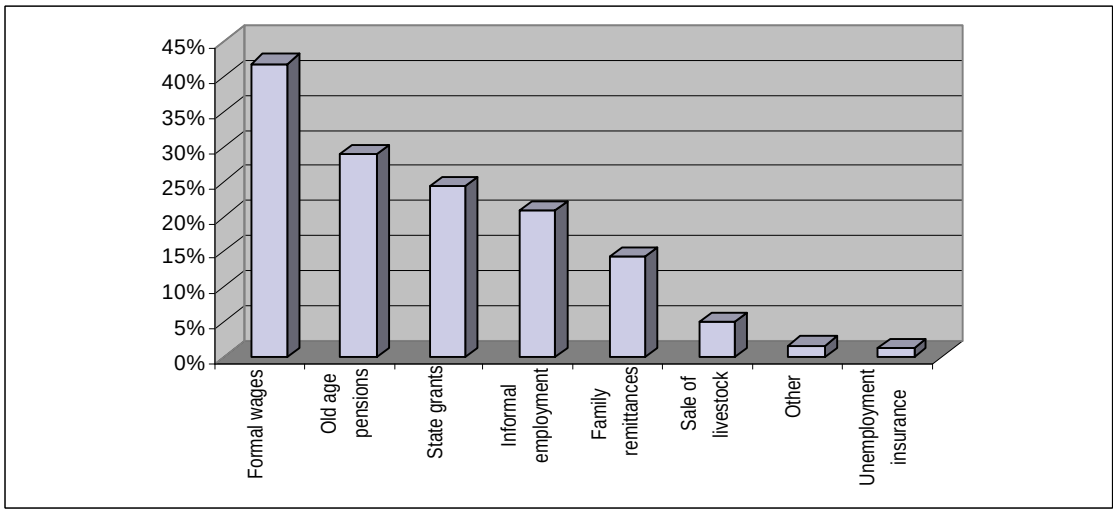
*R1000 – R2000 **>R2000 Data only available in these categories. National data for 1995, adjusted to 2001.

Over a quarter of households were benefiting from an old age pension, indicating that at least one member in those households was over the age of 60. Only four in ten households were

[4] Hirschowitz R. Earning and Spending in South Africa: Selected findings of the 1995 income and expenditure survey. Statistics South Africa. Pretoria 1997.

receiving income as a result of formal employment, while slightly more than 10% were benefiting from family members remitting money.

Figure 4: Percentage of households receiving income from different sources



The loss of income was a result of the caregivers being diverted from income generating activity and the inability of the AIDS-sick person to contribute financially. In 337 of the 728 households included in the analysis the individual with AIDS had been contributing to family income before becoming ill. The increase in expenditure on medicines and medical care, and the high cost of funerals are also contributing to the financial burden of HIV/AIDS.

Households were coping with asset poverty as well as loss of income. As households become more desperate, assets were sold to raise funds – for example, one household reported selling the shoes of a child whose school fees could not be met.

How the poverty stricken reduce spending

Already poor households coping with an AIDS-sick member were reducing spending on necessities even further. The most likely expenses to be cut were clothing (21%), electricity (16%) and other services (9%).

What little money this family had they spent on Godfrey looking after his needs. Now they do not have something to eat. They live in grace. The son of Godfrey is not working and they do not have money to further his studies. What worries me is that the son of Godfrey will end up doing bad thing because he even mention that he better go to jail than living this life of no point and in misery.

Qualitative Interviews

Almost half of families go hungry

Falling incomes forced about 6% of households to reduce the amount they spent on food. Overall, almost half of households reported having insufficient food at times. The problem was more acute in rural areas, where more than half the households (55%) reported food shortages compared to 42% in urban households. Children in these households were reported as going hungry as often as other members.

Thin frames of adults and children were moving in and out of the house. To my surprise the interview told me that the entire family was numbering 25.

She then led me to the kitchen and showed me empty buckets of food and said they had nothing to eat that day just like other days. Dust was all over the place. No soap, no broom, no nothing and three members are already diagnosed with TB.

As if it was not painful enough what I heard about that family on that first visit I was told another family baby who had been hospitalised had died at age four months.

Another expenses. Another funeral, another tears. For how long is this family going to endure pain, despair, unemployment? God is watching!

Qualitative Interviews

Changing expenditure priorities

A third of income spent on healthcare

The households surveyed were having to cope with a simultaneous drop in income, and increased demand for healthcare spending. On average households spent a third of their income (34%) on medical related expenses, representing amounts between R8 and R4,000 a month.

But there were significant differences between rural and urban dwellers. In rural areas households were spending more than half of total monthly income on healthcare, compared to

just over a quarter in urban areas (26%). The national average household expenditure on health care is 4% per year.

The cost of death

While death may relieve a family of healthcare related expenses, it brings its own costs. About 55% of households had paid for a funeral in the preceding year and were able to estimate the cost. On average they had spent four times the total household monthly income (one third of total annual income) on a funeral, a mean average of R5,153. The figure concealed a wide variation, with one family spending R40,000 on a funeral.

More than half of these households (53%) carried the full burden of funeral costs, and these families spent an average of 3.5 times their total monthly income on the funeral. A third had financial help in the form of a burial society or funeral plan, and 14% had the costs fully covered by a burial society, stokvel (community savings group) or commercial insurance policy. Where the individual had commercial burial insurance, the funeral cost on average five times more than the household income.

Rural households spent 350% of total household income on funerals, compared to 500% in urban areas.

CHILDREN

Almost a quarter of children orphaned

Almost a quarter (22%) of all children under the age of 15 in the sample were maternal orphans in that they had lost either their mother or both parents. The greater number of these orphans are girls.

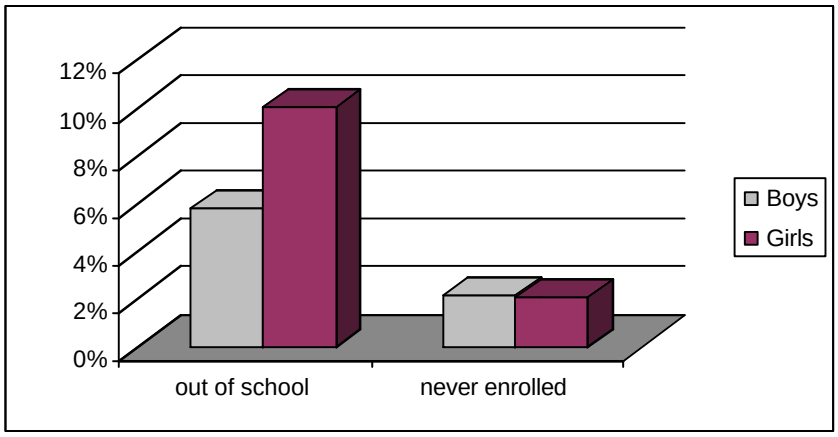


Figure 5: Percentage of boys and girls in the household who have dropped out of school or never enrolled

Not only does HIV/AIDS mean children lose their parents or guardians, but it sometimes means they lose their childhood as well. In about 8% of households children under the age of 18 were responsible for caring for a family member sick with AIDS.

Although many families hesitated to cut school fee payments even when they could no longer afford them (4% of households had done so as a result of having an AIDS-sick person to care for), poverty forces many children to drop out of school. Girls are more likely than boys to drop out of school or be forced to stay home because of financial limitations or to care for a sick person.

Mpho and Nosipho

The first problem with this family, " says Nosipho, "is that no one is working. There are three children who must go to school but there is no one to pay their fees and uniform. There is no food and no clothes, her mum is not working and there is no father."

"Where is he and the father of your child?" I ask Mpho.

"I have never seen my father and the father of this one is in Johannesburg."

"I can see that it is not possible for you to be in school now but how far did you go with your education?"

"I passed standard five but because of money I dropped out and then I got pregnant."

"How long have you been out of school?"

"For four years."

"Her brother is sixteen," says Nosipho "he is also not in school, he is looking after someone else's cattle for little money. The last born girl has been taken by another pensioner who is not a relative, they see her on holidays "

Qualitative Interviews

Gender impact

The survey found that almost 10% of girls were out of school, and just under 2% had never enrolled for formal education. The disproportionate numbers of girls falling out of the educational system occurred across all ages.

For boys the number out of school was about 5% - about half the proportion of girls - while fractionally more boys than girls had never enrolled at a school. The primary reason for leaving school was lack of money for school fees, uniforms or books. The second most common reason for girls leaving school prematurely was pregnancy.

The perceived importance of male children was also suggested by the fact that while almost all households knew the school status of non-resident boys, almost a quarter did not know the same information about non-resident girls.

Breakup of families

Even before children are orphaned the strains of coping with HIV/AIDS cause families to split up. The survey found that illness or death had resulted in 12% of households sending children

away to live elsewhere. The vast majority of households who had non-resident children were in urban areas. Of these children, half were sent to rural areas to live with other family.
Despite all the pressures, the safety net provided by the extended family was still holding, although often starting to fray. Even when children could no longer be accommodated by a household they were most often sent to be cared for by another family member. Just over a third of these displaced children were sent to live with another parent, and 35% were sent to a grandparent. Only two percent of children ended up in institutions, but in the same proportion of cases the households did not know the whereabouts of the non-resident children.

Social consequences

Denial and Hostility

An indication of the stigma associated with HIV/AIDS, was the fact that even in their final sickness, many people preferred not to disclose their HIV status to family members. Only half of the households surveyed said that the sick person they were caring for had HIV/AIDS. Households who were not aware of the underlying cause of the person's ill health most often mentioned opportunistic (HIV-related) infections such as tuberculosis or pneumonia.

Where people had revealed the AIDS-related cause of their illness, families tended to be supportive. About 80% of those who had been open about their HIV status, said that the household had been very supportive. Hostility from family members was rare.

The community at large tended not to be so understanding. Only 35% of households reported a very supportive response from the community, with one in ten recounting hostility and rejection. These figures conceal heart rending stories of discrimination, such as the one women surveyed who reported having to bribe other children with food to play with her son.

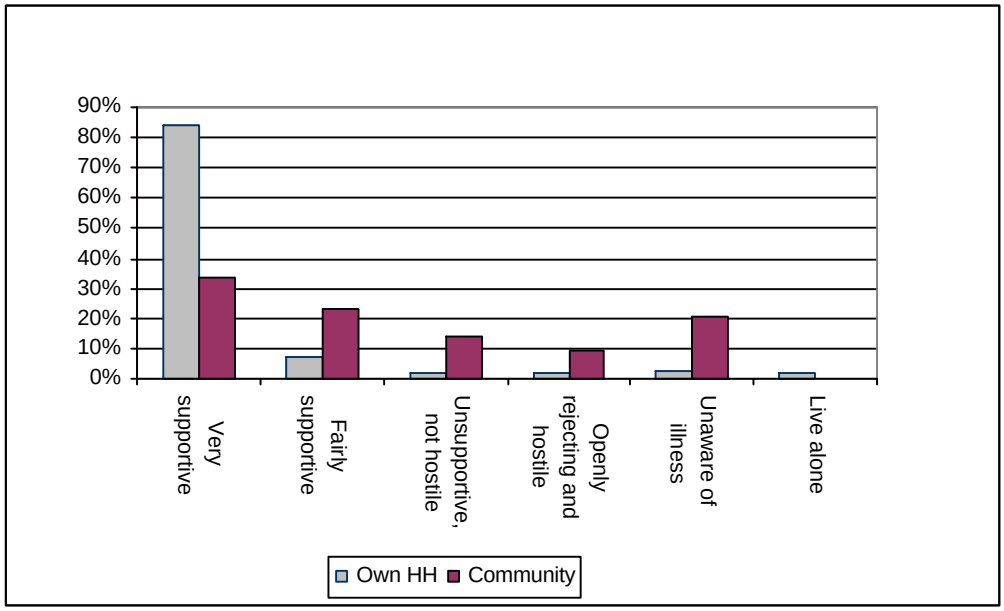
Once again a pre arranged interview falls through. We have two hours to kill so I ask Ayanda to choose another household. She thinks for a minute then directs me to number 51 Mandela Street. The windows are smeared with ash. We don't even try to go inside.

"It is a sign to the community that there is a funeral here," says Ayanda. "I interviewed this house only last week. I was going to write it for you to visit but I was too tired. I spoke to the woman. Her husband got work in a contract to extend the Coca Cola factory in Durban. He recruited his neighbours. That house on that side, and that one on the other side and also that one. They were all relatives and one was his uncle. They all went to KwaZulu-Natal for two to three years then they came back, all four of them, one by one, all sick. They said that they were sent home by their employees without money, nothing. First the uncle, the oldest one died. Then the neighbour. Now this one. Only one is alive. A whole street nearly."

Qualitative Interviews

Employers tended to be more supportive. About a third of the individuals counted as index cases had been working when they became ill. Of these half said their employer had been very or fairly supportive. Eight percent said their employers had responded unfairly or with hostility.

Figure 6: Household and community responses to HIV infection

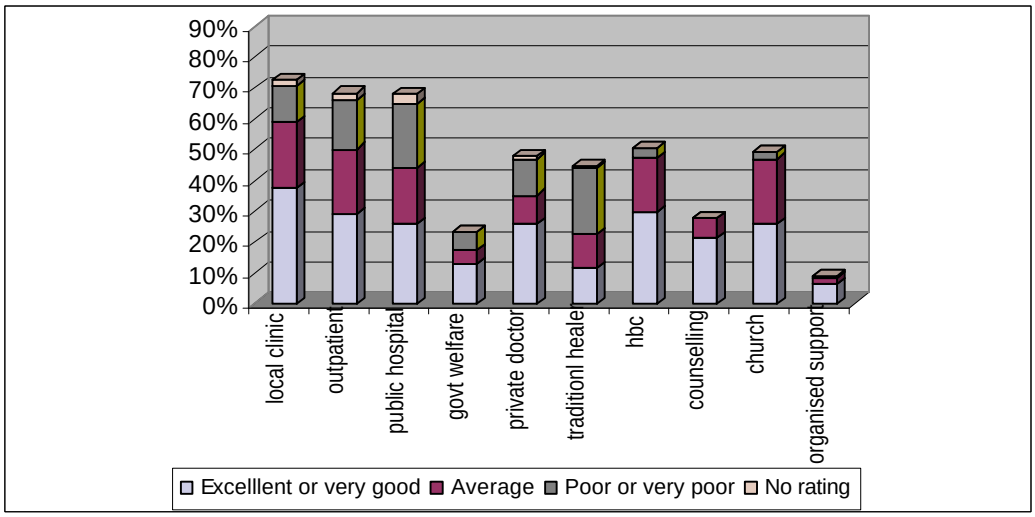


SOURCES OF HELP

Medical assistance

Almost 50% of people in the survey had consulted a private doctor. Roughly the same percentage made use of caregivers from non-government home based care organizations or churches. Traditional healers were also consulted in about 40% of cases, but most respondents were not happy with the service they received. Only about a quarter of the patients said the service they received from a traditional healer was excellent or very good.

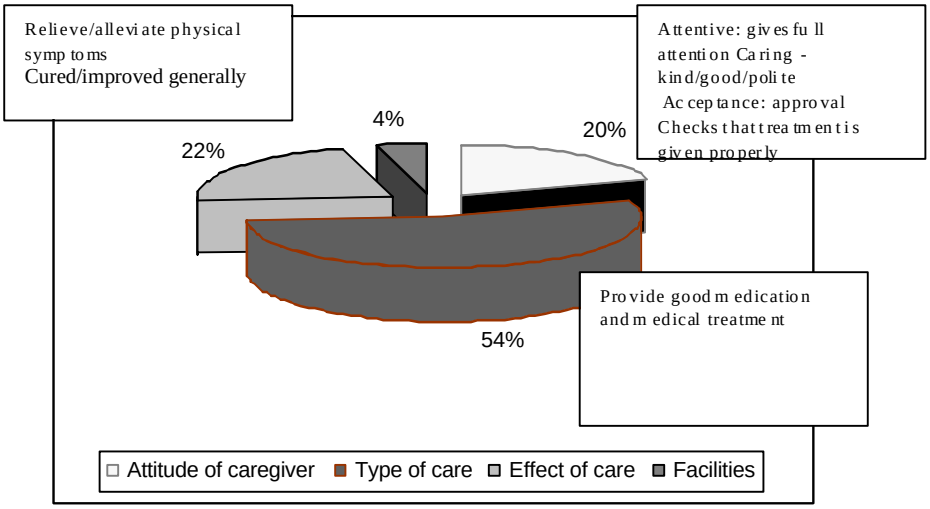
Figure 7: Service utilization and satisfaction among rural households



[BB1]

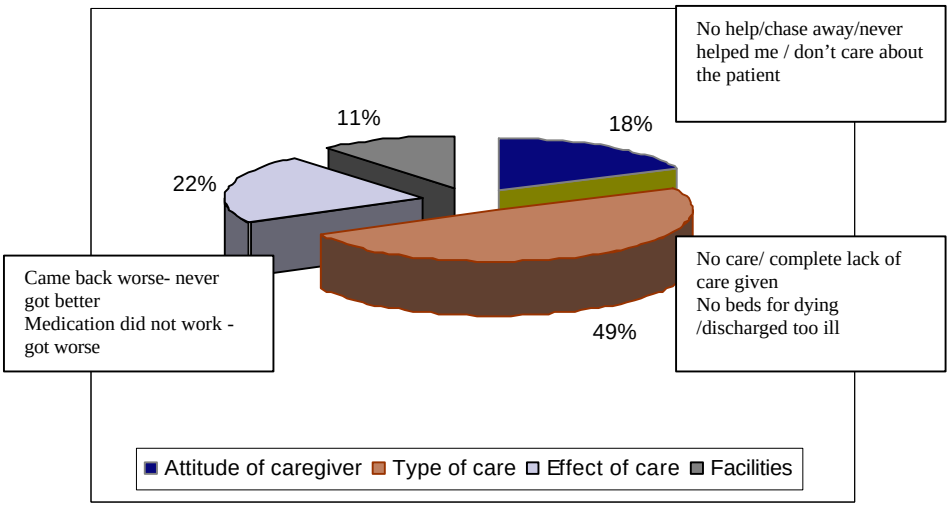
The most commonly used service were local clinics, used by almost 80% of households in the sample, followed by public hospitals and outpatient facilities at over 60%. Local clinics got a higher satisfaction rating than hospitals – 62% of households said they were very happy with the service they received at their local clinic, versus about 25% for public hospitals. Seventeen percent rated the services at their local clinic poor or very poor versus about 25% for public hospitals.

Figure 8: Reasons for rating local clinics good or very good



Satisfaction with health facilities was linked to health worker attitude, the type of care received, the effectiveness of the care, and the facilities available.

Figure 9: Reasons for rating public hospitals poor or very poor



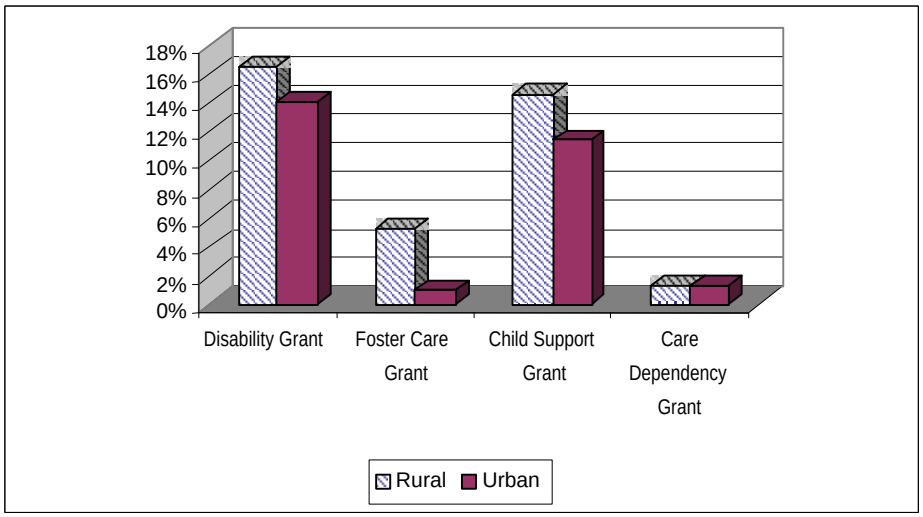
Other helping hands

Only about 10% of households were using government welfare services, the gap here was filled by non-governmental organizations. In particular about 30% of households were being helped by churches. But fewer that 50% of households were getting any direct assistance from home-based care organizations of any kind.

Government financial support[BB2]

The study looked at the number of households getting financial aid through the Disability Grant, Foster Care Grant, Child Support Grand and Care Dependency Grant. Of these only the child support grant is means tested. Old age pensions were reported as the second most common source of household income, after formal employment. Overall uptake of government grants was low, with about a fifth of households accessing them. Disability grants were the most commonly received, perhaps a reflection of easier access or greater awareness.

Figure 10: Percentage of households receiving government grants by urban / rural

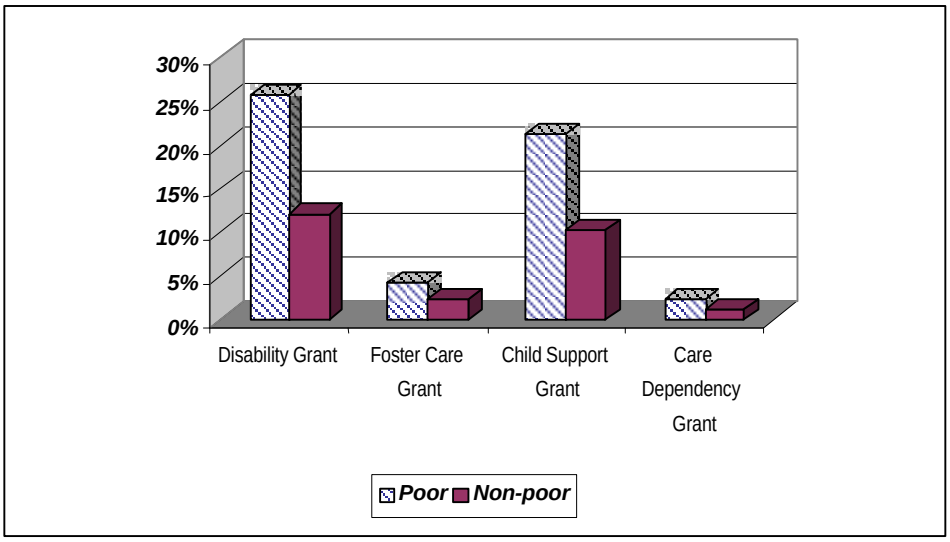


An interesting finding was that rural households appeared to be more aware of government grants, or at least to be more successful at accessing them, than urban households.

Proportionally more poorer households were receiving some form of state financial aid, even though of the four grants only one, for child support, is means tested. For this analysis, government grants were stripped out of the total household income, leaving a median average of R600 a month. The poor – classified as those families receiving less than the median income –

consistently report greater access to government grants than the less poor – those above R600 a month.

Figure 11: Percentage of households receiving government grants by income



Although poorer households are accessing government grants in a higher proportion than others, overall the level of access is low (fewer than 16%). In addition, households in this survey are likely to be at an advantage over others, because a higher proportion are receiving assistance from non-government organizations and churches in accessing services and support.

The 2001 *Committee of Inquiry into a Comprehensive System of Social Security* (the Taylor Committee), set poverty line at between R400-R500 per individual per month. Using this definition, the average household in this study had income below the poverty-level.

The importance of government grants in alleviating extreme poverty is aptly highlighted by the following qualitative interview.

"I love this HIV, now at least with the grants I am trying. I buy these rolls of orange chips and biscuits. I'm doing zama zama, meaning I'm trying. I don't only sell these things. I want them to accept us.

Before they would say I won't eat that food of Zandile and Bulelwa, my late sister and my son Nikki. I give out some so they can accept us and be friends with my son. He is at hospice day care school, playing with other kids who are also coughing and positive where they accept."

Nikki my son here is four years positive. Me six and him four. He is strong like his mum. Bulelwa however died after six months. The difference is that I disclosed. When she died she was blind and didn't know how to speak.

I get the disability grant and the child support grant. Before I was staying with my mother and father and sister they didn't work. Maybe I was taking three to four days without food. People discriminated me and no one come in the house. The only thing that was helping was my grandmother's pension. We were surviving on that money. Concerning the illness our lives are changed completely.

Yes I like this HIV/AIDS because we have grants to support us. The R110 child support grant and the R570 disability grant. I applied for another grant for R390 but they were asking too many questions. They wanted to know how I bought Bulelwa's coffin so I cancelled it.

Even now they have cut electricity and water. At the municipality as my parents are dead I asked them about the debt to be cancelled but they did not consider me. I have no parents no sister no brother. Just me and Nikki."

Qualitative Interviews

In contrast the failings of the state welfare net, were illustrated by the following interview, with a respondent who had not been able to access the help to which she was entitled.

Inside we meet Thandi. When the tin door swings shut I cannot see my notes at all.

"Are all of these children your own or your grandchildren?" I ask.

"Six are my own grandchildren," says Thandi, "three are my children, four are relatives, this one with the white face is my aunt's daughter she came to see those who are sick. Not only my son Hlanhla is in hospital," says Thandi, "also my other child. I have no money to visit them. Life here is very painful. Before Hlanhla went to hospital, he had spots on his body and holes on his other thigh. When he feels the pain he screams so loud and sometimes cry. I don't know what is killing my son. He never talks to me about his ways. Clinics must have helping medicine for those who are sick. Doctors must please tell us as parents about our children's health. We gave birth to these children and suddenly we have no right of knowing why they are so sick."

"How many people are living in this house? I ask.

"We are sixteen and soon we will be seventeen people," says Thandi, "we only get food from the mercy of our neighbours and food parcels.

"Do you receive an old aged pension?"

"No, I am a granny of nine grandchildren but the pension only comes when you are sixty. I am forty-nine."

"How do you feed everyone?"

"The electricity we take for nothing. The Home Based Care give us food parcel but it is not enough for this big family. When I cook I boil the water with no mielie meal till the children fall asleep.

Crying we walk back to the car. A very old woman is on one knee digging bones out of a rubbish heap.

Qualitative Interviews

CONCLUSIONS

This report confirms what perhaps is already obvious: that poor people in South Africa are the most adversely affected by HIV/AIDS, that public health services are not able to satisfy the medical needs of AIDS-sick patients, home-based services are virtually non-existent and government grants are not getting through. But it also points to some of the more profound longer term ramifications of the HIV epidemic:

- deepening poverty among the already poor;
- disruption and premature termination of schooling for children, especially girls;
- increasing early childhood malnutrition;
- and increasing strain on extended family networks.

Although most respondents in the survey had little difficulty accessing clinic-level care and were generally pleased with the service they received, sicker patients are routinely referred to district hospitals. Respondents were substantially less happy with the service received at district hospitals mainly because AIDS-sick patients are only kept in hospital a short time and the lack of appropriate treatment. Terminally ill AIDS patients are generally sent home to die and access to home-based care programs is very limited. AIDS-affected households are on average spending a third of their income on private medical care. The lack of AIDS treatments in the public health system together with the lack of home-based care and support is further exacerbated by difficulties in accessing available government grants.

APPENDICES

Methodology

This research focused on households where someone was either sick with AIDS, or had died as a result of the disease. The decision was made to exclude households with an HIV positive member who was not yet sick for two reasons. The first was practical in that the household may not yet have suffered any ill effects as a result of a member being infected on HIV. The second was ethical. There was serious concern to avoid inadvertently revealing the status of an HIV infected, but still healthy person. Full blown AIDS is difficult to conceal and therefore the community would likely already be aware of the person's diagnosis. Nonetheless, in all cases confidentiality was paramount.

To ensure that illnesses and deaths where indeed due to HIV/AIDS the study found its sample through organizations providing care for people infected by the virus. However, this method meant that a bias was introduced. Pitiful though the stories on the households are, these households are likely to be relatively better off. These are the households which have the ability to access some kind of help.

This study was descriptive and cross sectional, attempting to provide a snapshot of participating households and how they were coping with HIV/AIDS. It could also provide the basis for on-going research if resources are found for such study.

The nine provinces of South Africa are different in terms of HIV prevalence, cultural groupings, socio-economic conditions. The study focuses on four provinces where the HIV epidemic was considered advanced, or very advanced. KwaZulu-Natal's sad distinction of being the most affected province meant that the study was carried out in two sites – one urban and one rural. In the other three provinces only one site was visited.

- Gauteng

  The study site in the East Rand, took place in a culturally mixed urban community, with no predominant language. Although considered a higher socio-economic community, it is regarded as being at an advanced stage of the HIV epidemic. The 2000 provincial antenatal

survey figures showed prevalence of 29.4%. Fieldwork in late 2001 took place in Germiston, Kempton Park and Brakpan.

- Mpumulanga

The study site was in Piet Retief, a lower socio-economic community in a rural area. Again there was no one predominant language, and the HIV epidemic in the area was classified as advanced, with prevalence among pregnant women in 2000 running at 29.7%. The research was carried out in Amsterdam, Dirkiesdorp, Driefontein, Ethandukhukhanya and Rustplaas.

- Free State

This research site in Bloemfontein had the lowest prevalence rate of 27.9% in 2000. The predominantly Sotho and higher socio-economic communities studied were both informal urban and rural. Households visited were in Mangaung, Botshabelo, and Thaba Nchu.

- KwaZulu-Natal

Both sites in KZN were classified as in very advanced stages of the epidemic, with infection rates running at 36.2% in 2000. The urban site was among informal yet higher socio economic communities in Cato Manor, Lamontville and Wentworth in Durban. The comparison sites were rural and lower socio-economically. There were at Ingwavuma, Manguzi, Mhlekazi and Mseleni at Jozini. Both sites were Zulu speaking.

All of the households which participated in this study consented to do so. Initially identified by different stakeholder organizations, the details of households were not revealed to the researchers of this study until consent had been given.

The utmost care was taken on the issue of informed consent and confidentiality. In some cases individuals sick with AIDS had not disclosed the true nature of their illness to their families. There were occasions when the home-based care visitor was the only person who knew the HIV/AIDS diagnosis.

Often the person participating in the interview was the individual sick with AIDS. However where that person was too sick to participate – but had given consent – they were asked to name another responsible adult to be interviewed. Similarly, another adult was identified to be interviewed where the index case had died.

First do no harm

Some individuals, communities and organizations have expressed unhappiness at research projects which, as they see it, require their input and yet give them nothing in return. Aware of this, this study made an effort to ensure that benefits went both ways. The interviewers were selected on the basis of experience of working with HIV/AIDS, and high levels of empathy, sensitivity and good communication skills. The intention was that the research should, if possible, be therapeutic for the person being interviewed.

Fieldworkers reported that interviews were emotional encounters. Many respondents wept during the interviews, but most continued with the often lengthy discussions. Interviewees sometimes volunteered information to the field worker. In these instances the interviewers were trained to respond by offering help, after the interview, in order not to affect the research process.

With interviews sometimes taking over an hour, fatigue among the chronically ill participants was common. Rest breaks were sometimes needed, and there were occasions when interviews had to be finished the following day.

Apart from providing a chance for individuals to talk freely about their illness and its impacts on their family, interviewers often did their best to help households. For example, they brought newly orphaned families to the attention of the welfare authorities. Other attempts to integrate households into community helping structures included the provision of mielie meal, where it was deemed appropriate.

Problems

Location

Interviewers sometimes found it difficult to locate households they were going to interview. This was particularly true in rural areas, and in retrospect it would have been more efficient and cost saving to have hired guides for the field workers.

Substitution

Since this was a household study, each family could only be interviewed once, even if it contained more than one AIDS sick family member. In these circumstances the research field supervisor selected one person as the index case on a random basis.

Even though the time lag between households giving consent to an interview and the field worker arriving was usually less than a week, there were a number of cases where the person to be interviewed had died. Where the death had occurred recently the fieldworkers would avoid intruding on the family's grief, rather paying their respects and then leaving. In all these cases other households were substituted. Occasionally this also happened when the potential interviewee had moved away, or when consent was later withdrawn.

The sensitivities of such research were shown by an incident in KwaZulu-Natal where the relevant home based care (HBC) organization became unhappy at its clients being interviewed by "foreign" care workers. Households were told to withdraw their consent. In this case either households were substituted, or the workers from the aggrieved HBC organization were used to conduct the interviews.

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