

**An Assessment of How Government's Care Policy is  
Working in Practice: Findings from KwaZulu-Natal**

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## **ACRONYMS AND ABBREVIATIONS**

AIDS	Acquired Immune Deficiency Syndrome
CSG	Child Support Grant
DG	Disability Grant
DHS	District Health System
HIV	Human Immunodeficiency Virus
KIDS	KwaZulu-Natal Income Dynamics Study
NGO	non-governmental organisation
OAP	Old Age Pension
PHC	Primary Health Care
WHO	World Health Organisation

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## INTRODUCTION

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Home-based care is considered by some to be an appropriate policy response to the growing care needs that are being presented in both developed and developing countries. The burgeoning elderly population in the former, and the HIV/AIDS epidemic in the latter, with their related care needs, have meant that the issue of care provision has taken on increasing policy significance in recent years. In sub-Saharan Africa the leading cause of adult morbidity and mortality is HIV/AIDS (Barnett and Whiteside, 2002). South Africa has some of the highest HIV prevalence rates in the world: estimates range from 19.2 percent to 26.5 percent depending on the study and on the form of measurement used (Doherty and Colvin, 2004:197). These figures point to large numbers of people that will be in need of care when infected individuals become symptomatic.

The South African government has articulated a clear response to the care needs that the HIV/AIDS epidemic will present. Largely because of cost considerations government acknowledges that hospitals cannot constitute the central response in terms of treatment and care (Department of Health, 2001a; 2001b). The chief focus will be on providing treatment and care at the primary level, and home- and community-based care will be prioritised. This study aims to assess this policy approach in South Africa's KwaZulu-Natal province in which HIV prevalence rates range from 22.1 percent to 36.5 percent of the population (Doherty and Colvin, 2004:197). It seems pertinent to assess care provision in this province since, in addition to the high HIV prevalence rates, KwaZulu-Natal is among the poorer provinces in South Africa (May et al., 2000), with an official unemployment rate of 31.7 percent (Statistics South Africa, 2005:39).

Thus far, research on home- and community-based care in South Africa has focussed on identifying the community-based care programmes in place (Russell and Schneider, 2000) and the means by which these programmes can be extended (Goudge et al., 2003; Johnson et al., 2001), as well as the experience of morbidity and mortality within households (Johnson et al., 2002). In KwaZulu-Natal, research on home- and community-based care has focussed on the contexts in which this care is provided (Ngubo, 1996; Nkwe-Mabua, 2000) and the gendered impacts of its provision (Akintola, 2004a; 2004b), as well as on the practice of community-based caregivers (Uys, 2002).

However, an explicit assessment of how the home-based care policy is working in practice, through a reflection on the perspectives of different home-based care participants, from within and outside of the household, has not taken place. The findings from an ethnographic study undertaken in six research sites, and in some of the households within these in which care was being undertaken, in South Africa's KwaZulu-Natal province, will be used to this end. The ethnographic methodology employed in the study lends a certain value, which is useful in investigating this issue. Living in a research site means that trust is gained which enables information to be gathered that otherwise may not. Moreover, the fieldworker is able to observe, enquire and verify with different sources, and obtain first-hand experience of the actual support available to ill people within an area, and through frequent visits to and observations in households, to obtain information on the experience of care for family caregivers within the home.<sup>2</sup>

The objective of this paper is to ascertain what provision of care and assistance ill people in need of care are receiving, and to compare this with provisions made in government's home- and community-based care policy. The central question is: What service provision is being made in KwaZulu-Natal, South Africa, for the care of people who are ill? The paper seeks to provide answers to a number of additional questions: What does national government plan to do for people who are ill and in need of care? What does provincial government indicate that it will fund, and indeed fund, in terms of care for people who require it? What is being done in practice to assist ill people in need of care – from the perspectives of family caregivers and those involved in health care provision? What is the lived experience of family caregivers in providing care within households to people who are ill?

To begin, the government's intentions in terms of care provision, as spelt out in its home- and community-based care policy, will be detailed. After this the budget allocation and spending figures of the KwaZulu-Natal departments of health and social welfare will be examined, in order to understand what the provincial government says it will fund, and indeed funds, in terms of care for those in need. Next a review of the research methodology will be undertaken. The findings section begins with perspectives on health issues of focus group discussants from 58 research sites in KwaZulu-Natal. Information from interviews undertaken at the community and household level will then be presented. The perspectives of family caregivers and those involved in health care provision will be juxtaposed with regard to different forms of care provision, first assistance obtained outside of the home, and then assistance received

within the home. Care provision at hospitals and at clinics, other forms of provision such as the Disability Grant (DG) and private forms of care provision such as traditional healers and private doctors, and finally, assistance from community caregivers will all be outlined. A case study of unpaid care provided in a home environment will then be presented in order to gain insight into the lived experience of providing care. A reflection on the institutional support provided to family caregivers will also be undertaken. To end, a discussion will take place in which the disjuncture of policy prescription and actual experience will be pointed to, and policy implications will be drawn.

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## **THE SOUTH AFRICAN POLICY CONTEXT AND PROVINCIAL ALLOCATIONS**

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The South African Department of Health sees the largest single impact of HIV/AIDS on the public health sector as lying in the hospital sector, with demand for hospitalisation increasing steadily each year, and other workload being crowded out. Largely because of limited health care resources, it is noted that even if hospital or other institutional care may be the best response to an individual's condition, it may not be available to him or her due to the shortage of hospital beds, an inadequate number of health professionals, and the cost of institutional care (Department of Health, 2001a).

Home-based care is described as a cheap, cost-effective and flexible means of providing basic symptomatic and palliative care for people with HIV/AIDS (Department of Health, 2001a). In the National Guidelines on Home-Based Care/Community-Based Care (Department of Health, 2001b:1), home-based care is defined as 'the provision of health services by formal and informal caregivers in the home, in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death'. It is to be provided for a wider group of people with care needs: the elderly, the disabled, others with chronic conditions – not only for people with HIV/AIDS. No clear definition is given of community-based care, but home-based care is defined as an integral part thereof. Abrams (1977, as cited in Means and Smith, 1998:5) has called community care 'the provision of help, support and protection to others by lay members of societies acting in everyday domestic and occupational settings'.

The Department states that most of the conditions affecting adults with HIV infection can be effectively managed at home, and that this is most convenient and cost-effective for the individual and their family

(Department of Health, 2000b). Home-based care is described as requiring little or no medical input, with nurses as lead actors and most activity undertaken by nursing assistants or community workers with basic training (Department of Health, 2001a). The scope for Primary Health Care (PHC) management of HIV-infected individuals and their families is proposed in the form of psychosocial support to families, supervision of palliative care for patients with late-stage AIDS, and follow-up of patients discharged from hospital (Department of Health, 2000a; 2000b).

Stakeholders will come from the formal system (doctors, nurses, psychologists, rehabilitation therapists, social workers), the non-formal system (non-governmental organisations (NGOs), community- and faith-based organisations, traditional healers, traditional leaders), the private sector, the informal sector (caregivers, families, community health workers, volunteers), and finally, the client/consumer. The goals and objectives of home-based care include ensuring access to care and follow-up through a functional referral system, and empowering the client, the caregiver(s) and the community through appropriate targeted education and training. It is noted that provision of assistive devices, pharmaceutical supplies and dietary supplements are the responsibility of the referral facility (Department of Health, 2001b).

The care guidelines emphasize that home-based care is not intended to be 'second class care' or 'cheap care' for those who cannot afford hospital care. However, this form of care provision is seen as a means by which increased demand for care can be diverted away from hospitals and into a lower-cost environment. It is repeatedly mentioned that referral to hospital should only occur if treatment or care is unavailable at the primary level. Moreover, 'admission to hospital for in-patient management should only occur when the individual would clearly benefit and where there is a specific, defined indication, such as the management of a reversible or treatable condition or initiation of palliative care' (Department of Health, 2000b:8). Further, the Department makes reference to two trends that have been evidenced in African settings: HIV/AIDS crowding out other workload, and choosing not to provide care to the dying, in order to deal with patients with 'treatable' conditions (Department of Health, 2001a). The Department emphasizes that these phenomena 'imply a degradation of care quality and an application of crude rationing which is both preventable and unacceptable in the South African context' (Department of Health, 2001a:2), and that the provision of sub-standard care or the failure to provide basic care is also unacceptable.

In sum, the care guidelines make no reference to gender and there is little, if any, focus on family caregivers within and from the home. It is not clear what 'ensuring access to care' means. Could it be that government is placing on itself not the onus of providing care but rather the task of seeing that it is possible for care to be accessed? This however contrasts with the stated intent of providing health services to those in need of care within the home.

It is important to be aware of the institutional transformation context within which this policy unfolds. The idea of a District Health System (DHS) was introduced as the new vehicle for the delivery of health care services post-1994. Upon introduction, the DHS was regarded as the means to achieve the end of 'an equitable, efficient and effective health system based on the principles of the PHC approach' (McCoy and Engelbrecht, 1999:132). Efforts have been made to link DHS development to local government development, the idea being that it is possible to be more responsive to the needs of people at the local level. This should make it easier to run home- and community- based care programmes, but is this the case in practice?

National government is responsible for policy formulation, and the provinces are required to base their policy response on that of national government (Hunter et al., 2003). For KwaZulu-Natal there is as yet no separate policy response to the provision of care, and these care guidelines also form the central policy document at the provincial level.<sup>3</sup> It is also necessary to know what is being allocated towards care for ill people within the province, since this is what provincial government states that it will fund.

The bulk of health and welfare spending occurs at the provincial level and within the provincial departments of welfare and health, funding for the care of ill people falls under home-based care services, which includes care for the elderly, the disabled, children and the ill. Most of this funding is allocated to NGOs who sign service-level agreements and deliver the home-based care service. For the 2004/05 financial year, the KwaZulu-Natal Department of Social Welfare and Population Development allocated R15.7 million to home-based care.<sup>4</sup> This allocation represents 0.2 percent of the total amount to be appropriated within this department (own calculations using budget allocation figures in KwaZulu-Natal Treasury, 2005b). R12.4 million of this was spent. This is likely due to service-level agreements not being signed before the end of the financial year, meaning that these funds could not be transferred to the NGOs.<sup>5</sup>

This under-spending is of concern, particularly in light of the cancellation of the HIV and AIDS Conditional Grant for the Department of Social Development, which in itself is likely to result in the under-funding of home- and community-based care services (Ndlovu, 2005). For the KwaZulu-Natal Department of Health the allocation towards home-based care – for all groups in need of care – was R28.5 million. Only R8.9 million of this allocation was spent, again pointing to substantial under-spending of allocations towards home-based care in general.<sup>6</sup> Home-based care constitutes just 0.3 percent of the total amount to be appropriated towards health in KwaZulu-Natal (own calculations from budget allocation figures in KZN Treasury, 2005a). In addition to home-based care, the provincial Department of Health funds community health workers as part of the district health services.

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## **POLICY APPROACHES ADOPTED ELSEWHERE**

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Home- and community-care policies are not unique to the South African context, but rather this has been the chief response to care needs in many countries in recent decades, often referred to simply as community care. Advocated as being more appropriate care for those in need, and regarded as a cheaper form of institutional care, community care policies have been used as a means of cutting the high costs of caring for people in large institutions (Dalley, 1996; Means and Smith, 1998). In developed countries, home- and community-based care has largely focused on the elderly (Blank and Burau, 2004; Tester, 1996). In England, there is increasing evidence that more intensive home care services are being concentrated on a smaller number of high-risk service users, as part of efforts to cut costs (Glendinning, 1999; Hardy et al., 1999). In sub-Saharan Africa, due to the lack of well-developed health services there is little alternative to caregiving by family members (Chimwaza and Watkins, 2004). Research in this region has documented the difficulties that home-based care presents for family caregivers, the limited support by home-based care organisations, and how the caregiver essentially singly takes responsibility for the ill person (ibid; Jackson and Kerkhoven, 1995; Seeley and Kajura, 1993). Ogden et al (2004:3) refer to unlinked care as care that is provided in the home by unpaid and untrained family members who are usually female, and friends and neighbours of those living with HIV/AIDS, which is not linked to any formal care and support service. They note that up to 90 percent of illness care in developing countries is provided in the home by the unlinked system of home care.

Some (for instance, Dalley, 1996) have argued that community care policies represent an intensification of the exploitation of women since they involve a shift of responsibility from paid staff in institutions to unpaid care, largely by female relatives in the community. The assumption that underlies community care policies, that the family is the appropriate unit and location for care, has also received criticism. Dalley (1996:xiv) further argues that ‘much of the debate about caring and the provision of care is still premised on the principle of familist ideology; much of it fails to examine the case that there is to be made for a collectivist approach to caring and an extension of state responsibility rather than a retrenchment’. According to Means and Smith (1998), assumptions about the role of the family and the role of the state underlie much of the discussion about community care, but are rarely made explicit and widely accepted as given. Community care policies have also been criticised for the assumption that this form of care is appropriate to all categories of dependency (Dalley, 1996). Richard Titmuss – a noted social policy commentator – articulated concern that the reduced reliance on hospitals would not be balanced by a major expansion of community-based services (Means and Smith, 1998). Indeed, practitioners have long insisted that satisfactory community care that is properly implemented can only be achieved with major injections of resources (Dalley, 1996).

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## **RESEARCH METHODS**

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So how are the care guidelines unfolding in practice? In order to obtain insight into care provision from the perspective of those involved in providing it, as well as from family caregivers, and in order to gain an idea of the lived experience of providing care, qualitative research obtained between June 2004 and March 2005 will be analysed. Thirty-six households across six research sites in KwaZulu-Natal province in South Africa were extensively visited by three fieldworkers as part of the qualitative component of the 2004 KwaZulu-Natal Income Dynamics Study (KIDS).<sup>7</sup> Two urban and four rural KIDS clusters (within Ndaleni, KwaBrush, Umlazi L Section, KwaDunuse, Mpakama, Osisweni) were selected using a careful, purposive process. Information collected in preparation for KIDS 2004 was used to select the study sites. The clusters selected were stratified on the following variables: (1) rural/urban; (2) geographical spread within the province; (3) degree and types of activities (mainly presence but also absence) pertaining to the four research themes (described below); (4) whether they had been part of another qualitative study linked to KIDS in 2001 (the Socio-Economic Study of the Persistence of Poverty and Inequality); (5) whether they were a part of the Political Economy of Social Capital study (another qualitative study

linked to KIDS 2004); (6) whether the fieldworkers would be safe from a security standpoint. Telephone interview information obtained from local leaders in the KIDS clusters was used to provide information on (3) and (6).

Within each cluster six households were selected – a small number but one which allowed data of sufficient depth to be collected on the research themes. The following themes were adopted for study in these households: ‘care’, ‘orphans’, ‘livelihoods’, ‘the Child Support Grant’ (CSG), and ‘changing household structure’. The first household selection criterion was that households be part of KIDS 2004, as an aim was to compare qualitative and quantitative data. The second criterion was that households contain a pair of conditions to enable data collection on two of the above four themes, apart from the ‘changing household structure’ theme, which was covered in all households.

To begin, a mini-survey that contained information on all themes was conducted in all KIDS households in each cluster.<sup>8</sup> It was not always possible to select households with the ‘care’ theme through a mini-survey of KIDS households, since the criteria were not always met.<sup>9</sup> That is, it was relatively easy to find theme combinations that did not include the ‘care’ theme. In these cases household selection was purposive. One or more of the community caregivers in the study area, or other key informants if these were not present, were approached for assistance in identifying possible ‘care’ households.<sup>10</sup>

Permission to conduct the research was obtained from various local leaders, for the six clusters chosen for the study. After explaining the background and purpose of the study and assuring confidentiality, consent was obtained from the six case study households in each cluster. A ‘modified’ extended case study method was chosen.<sup>11</sup> Each fieldworker lived in two clusters for two one-month periods, and travelled between the two clusters at intervals.<sup>12</sup> Repeated visits were carried out to study households, and formal and informal interviews and discussions were conducted with different household members. Ethnographic techniques were used, including interviewing and household events mapping and events mapping of illness periods, and observing and participating in activities related to the topics of the research, both at the household and community level.<sup>13</sup> The purpose of these methods was to build trust and rapport with households, and to observe and learn in a way that is not possible with more rapid research methods (Adato et al., 2004; 2005). Note-taking and elaboration on fieldnotes after household visits occurred

in the field. This material was then typed up when the fieldworkers returned to Durban between field visits.<sup>14</sup>

As a result of purposive sampling, three of the households in each cluster contained an adult who was ill and being cared for by at least one household member. Across the six study sites, in 18 households 22 family caregivers were undertaking care for 19 people – in one household there were two ill people receiving care. In seven of the 19 cases the HIV-positive status of the ill person was volunteered.<sup>15</sup> Given the age range of the ill people (23 to 51 years), as well as the high HIV prevalence levels in KwaZulu-Natal, and since nine of the ill people were known to have died non-accidentally by the time fieldwork was completed, it is likely that a number of the ill people had HIV/AIDS.<sup>16</sup> Key informant interviews with community caregivers and heads of clinics were – as far as possible – also conducted in most of these study areas. Supplementary interviews with three medical managers at some of the hospitals that serve these areas were also completed by the researcher.

It should be emphasized that the information collected is not representative of the situation in KwaZulu-Natal. However, the study areas were scattered around the province, and there is no reason to think that care situations would be substantially different in other parts of the province. While it is not possible to get a confident sense of the extent to which an occurrence is widely experienced, the strength of this qualitative information is that it provides in-depth insight into lived experience. The study information was coded by the researcher. In line with Chimwaza and Watkins' (2004) approach, the findings presented focus on typical experiences, but extremes are also pointed to in order for the reader to obtain an idea of the diversity of experience. When selecting material, an attempt has also been made to allow the perspectives of different study participants to be heard.

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## **PERSPECTIVES ON THE PROVISION OF CARE/ASSISTANCE**

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The WHO (2000, as cited in Ogden et al., 2004:24) developed and promoted the idea of a continuum of care provision, with various care domains: home care, community care, PHC, secondary health care, tertiary health care. A range of forms of care can be accessed at different points along the continuum. From this perspective the provision of care extends from the home to the hospital, through various levels of care, and back to the home. In the following sections the perspectives of family caregivers for ill people and key informants involved in the provision of care will be presented. While the care guidelines emphasize that home-

and community-based care should be provided within the home, it is noted that government shall be responsible for ensuring access to care – which seems to place the focus outside of the home and on individuals obtaining care. Therefore, all possible types of provision – received by study participants within the home and accessed outside of the home – will be the focus of this analysis.

With regard to different types of provision, experiences of ill people and their family caregivers will provide information about the extent to which care provision is being made, and the perspectives of those involved in health care provision will give insight into some of the realities of and challenges faced in providing care. Household and key informant interview material and events mapping information, as well as interviews conducted separately by the researcher, have been analysed. Throughout voice is in the second person, and is not provided in the form of quotes, but rather as narratives, as relayed by fieldworkers from what was told to them by interviewees.

Table 1 indicates the individuals involved in health care provision within the study areas. Friedman (2005) notes that the National Health Act makes specific provision for all facilities, including clinics and community health centres, to have advisory committees or boards. Health committees – referred to in the table – are such structures.

**Table 1: Individuals involved in health care provision within research sites**

Individuals/groups involved in health care provision	Rural 1	Rural 2	Rural 3	Rural 4	Urban 1	Urban 2
At least one paid community caregiver	Yes	Yes	Yes	Yes	Yes	No
At least one volunteer community caregiver	No	Yes	Yes	No	Yes	Yes
Directly Observed Treatment Short-Course worker	No	No	Yes	No	No	No
Shopkeeper who dispenses public hospital medication	No	No	No	No	No	Yes
Health committee	No	Yes	Yes	Yes	Yes	No

This information was obtained by fieldworkers through observation, asking questions in study households and from key informants at the community level – community caregivers, heads of clinics and heads of health committees. All of those providing care assistance were female except for one of the community caregivers in one of the rural areas, and while health committees were mixed in terms of gender, all were headed by males.

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## **FINDINGS FROM COMMUNITY FOCUS GROUP DISCUSSIONS**

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Focus group discussions were held in all 58 of the African KIDS clusters, with a minimum of three and a maximum of five individuals living in these clusters.<sup>17</sup> In this section the results as they relate to health related issues will be included. The aim was for participants to be diverse in terms of gender and in terms of their roles and involvement in the study area. To begin, two key informants were approached in each KIDS cluster and were asked for a list of possible participants. The list was probed further with others living in the study area, and in this way the list was refined and reduced to the eventual focus group participants. An average of 3.75 individuals took part in each focus group discussion in these clusters. In this document reference will be made to a community since this is the term that was used in the focus group discussion to refer to those living in the cluster.

Focus group discussants were asked to state what they understood to be the key problems which the people in their community faced. As many as five problems could be stated. In 38 of the 58 clusters a health related issue was stated as one of the main problems for that community. This ranged from HIV/AIDS to – even more frequently mentioned – no clinics or infrequent visits from mobile clinics to the area. The link between poverty and ill health was also raised – for instance, the problem of sick people having to take medication on an empty stomach, and a lack of money to travel to health facilities. Other main problems which were mentioned and which have a bearing on care provision within the home were a problem with water supply (30 of 58 clusters) – usually a lack of adequate water – and a problem with sanitation (12 of 58 clusters) – inadequate toilets or a lack of toilets. In order to provide satisfactory care for an ill person within the home, clean water and an adequate amount of water is required. Many of the sick will need to be taken to the toilet if they are not using a bedpan, and therefore the state of or presence of toilets will have a bearing on the ease with which this form of care can be

provided. The large number of households with water supply problems is therefore of concern.

With regard to perceptions of service delivery, focus group participants were asked to say how the people of this community felt about particular public services at present and before the last elections in 1999.

**Table 2: Perceptions of service delivery: hospitals or clinics**

	Hospitals or clinics	
	1999	2004
Unhappy/very unhappy	40.9	66.7
Happy/very happy	50.0	24.4
	n=44	n=45

Table 2 indicates that with regard to hospitals or clinics, whereas in 1999 40 percent of participants describe being broadly unhappy with this service, by 2004 this percentage has climbed to two thirds. The picture is the opposite with regard to community home-based care, as seen in Table 3. While in 1999 over three quarters were unhappy or very unhappy, by 2004 this drops to over a quarter. No doubt the latter finding would be in large part attributable to the fact that home- and community-based care programmes are far more common now than they were in 1999. The care guidelines were only introduced in 2001. The perception is therefore likely to be that this service has improved but it could be because of the increased prevalence of such programmes in 2004 as compared to 1999. It is also likely that there is a lack of awareness that home- and community-based care is the government's policy approach to care, and that the perception remains that clinic and hospital provision are the primary sources of care provision.

**Table 3: Perceptions of service delivery: home- and community-based care**

	Community home-based care	
	1999	2004
Unhappy/very unhappy	82.2	29.2
Happy/very happy	11.1	39.6
	n=45	n=48

Focus group participants were also asked which public service had improved most since the last democratic elections in 1999. Out of a range of types of public service delivery, 5.3 percent said that hospitals or clinics had improved in first rank, and 8.8 percent identified home- and community-based care as having improved most in first rank. As noted above, this finding again could be at least partly explained by an increase in the number of such programmes over time.

Participants were also asked which public service needed to be prioritised now or in the future. About 20.7 percent of participants placed hospitals or clinics in first rank in terms of a public service that needs to be prioritised, while 3.4 percent placed home- and community-based care in first rank. Participants were also asked to identify the service which required urgent attention. In first rank, 19.3 percent placed hospitals or clinics, and 3.5 percent placed home- and community-based care. Therefore the perception of about a fifth of these focus group discussants is that hospitals or clinics require prioritising and urgent attention. It seems that this form of health care provision is not meeting the expectations of these community members, while the same does not seem to be true of home- and community-based care.

Further questions of relevance related to information on individuals who were able to help people in the community with regard to certain ‘problems’. The problems of relevance here are access to health care or medicine and access to home-based care for sick and dying people, and the findings are reflected in Table 4.

**Table 4: Assistance with access to health care, medicine and home-based care**

	Someone who provides members of the community with:	
	Access to healthcare or medicine (%)	Access to home-based care for sick and dying people (%)
Yes	82.8 (n=58)	75.9 (n=58)
Female	100 (n=46)	90.3 (n=42)
Approachable	100 (n=47)	100 (n=44)
NGO employees/volunteers	89.4 (n=47)	81.4 (n=43)
Government employees	4.3 (n=47)	9.3 (n=43)
Living in the community	95.7 (n=47)	88.6 (n=44)

The results indicate that, according to focus group participants, a very high percentage of community members are able to access health assistance – whether it be health care, medicine or home-based care for the ill and dying. Those who assist are nearly all female, all are described as approachable, and the vast bulk are either NGO employees or volunteers, although, as mentioned, it seems likely that most are volunteers since the vast majority live within the community.

Finally, focus group participants were asked if any of a range of employees from different sectors had assisted the community with a project or programme to uplift the conditions of vulnerable groups in the area of care for the terminally sick and dying. The results are reflected in Table 5 below.

**Table 5: Employee assistance with care programmes**

Employees assisted community with a care programme for the terminally sick and dying	%
Government (n=58)	43.1
Private sector (n=58)	6.9
NGO (n=58)	48.3
CBO/FBO (n=57)	19.3

There is not substantial assistance on the whole from various employees within the research sites, although NGO and government employees seem to provide more assistance than other employees. Overall then, focus group discussants speak strongly of problems with clinics and hospital service delivery, while there is not much dissatisfaction with home- and community-based care. It seems that there are individuals available to assist those who are ill in most of these communities. It will also be necessary to obtain viewpoints at the household level on care provision to see if household members who are having to care for ill people agree with the perspectives of the focus group participants.

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## **ASSISTANCE FROM PUBLIC HOSPITALS**

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In this section, the perspectives of family caregivers and of three medical managers at regional and district public hospitals that serve some of the study areas will be reflected, on the issue of hospital provision of care for ill people, but specifically those with HIV/AIDS. Public hospitals and clinics perform the same function in terms of providing those seeking

health care with a consultation and medication, but at a hospital an ill person will be seen by a doctor instead of a nursing sister, and may be admitted to a hospital bed.

### **Family caregivers' perspectives**

Some family caregivers mentioned that having to care for the ill person, but at the same time not knowing what was wrong with them was not easy. Others stated that what they found to be difficult was that the person was not getting better, and they did not know what to do to help them. Some expressed a need for an environment in which the ill person's needs would be met by those trained to do so, as highlighted by a 16 year old family caregiver in a rural area:

*When a person has reached an advanced stage of illness ... he needs the professional hands.*

However, in this particular case the ill person refused to visit a hospital, since she did not want to be tested for HIV. By contrast, nearly all ill people have visited public hospitals for a consultation and received medication, and about half have been admitted to a public hospital for a hospital stay.

Why are public hospitals visited? Illness events maps show that a number of ill people are referred from the local clinic, by a private doctor or by a district surgeon when applying for a DG. Several visit when they find that clinic treatment is not proving to be effective. Some do not access clinics but go directly to hospital for treatment. The description is usually of the ill person being in a weak physical state when they visit hospital.

In some cases there is relatively frequent admittance to hospital. In one such instance a mother in an urban area asks for her daughter to be discharged because she is '*not getting any better*'. In another such case 'pass-outs' are requested so that the ill person can spend Christmas at home, and to check on a DG application. Family caregivers relate how they visit frequently when ill people are in hospital, if transport money is available, and take food items to the ill person. In other instances despite frequent attempts to seek more than a consultation and medicine, the ill are not admitted or rarely admitted to hospital, in spite of, in some cases, being described as desperately ill.

Some ill people and their family caregivers describe sleeping on hospital benches overnight because of having to wait in long queues during the day, the ill person not being admitted but given a prescription, and then having to wait for the pharmacy to open the following morning in order to access their prescribed medication. In other cases where ill people are admitted, some are discharged after a short stay, despite little

improvement in their condition. Frequently family caregivers state that the ill were no better after they were discharged from hospital than when they were first admitted. The following case, in which events over the illness period are recounted by family caregivers in an urban area, highlights many of these instances well:

***August 2004***

*Thembi could not do anything for herself, she was bedridden. They took Thembi to the hospital. She was admitted for two weeks. She was discharged after two weeks but she was not better. When Gladys [a family caregiver] asked why she was discharged in that condition, the staff said that they do not have enough beds. Gladys said that she asked what was wrong with Thembi but she could not get an answer from the hospital staff. Zodwa [the other family caregiver] and Gladys then bought medicine from the traditional healer for Thembi that did not help.*

***September 2004***

*They took Thembi back to the hospital. She was complaining about kidney pains. She was given painkillers and the family was never told of the problems she might have. The hospital never admitted her. The hospital staff said there was no reason for keeping Thembi at the hospital, the family must take her home. The family decided to take her to a traditional healer. Thembi needed assistance with everything; she could not lift a finger by this time. Thembi was just like an infant.*

***October 2004***

*Thembi was not eating, she was getting worse. Thembi refused to go back to the hospital because they did not help her before. Thembi was taken to a relative's house where she died on the 6<sup>th</sup> of October.*

It can be seen that there are persistent attempts to get help from the hospital by family caregivers – most of which do not meet with success. Alternative methods of healing are then sought. While one ill person in the study spent over a month in hospital, and passed away while he was in hospital, in another case, and contrary to the government's stated intention to not turn the dying away from hospital, this was indeed the case. A fieldworker recounts what an urban family caregiver – the mother of the ill person - told him. This example also illustrates the difficulty of the home care situation for the family caregiver:

*During this month Malanga decided to move Zweni inside the main house. Malanga said Zweni was complaining about so many pains, always calling for help. That is why she had to share her bedroom*

*with him. She said she let him use the bed and she slept on the floor. Zweni was not eating, only drinking liquids. His body was now like that of a 10 year child. Malanga now could not take it anymore. She decided to take him to hospital. On a Saturday her neighbour called for an ambulance ... At the hospital Zweni was put onto a drip and was told that he must go back home with her. She said she was not angry about what they said. Anyone could see that he was dying. Malanga came back with him. In the early hours of Sunday Zweni died.*

### **Medical managers' perspectives**

Interviewees at public hospitals that serve some of the study areas were asked about the means used to determine whether people with HIV/AIDS should be admitted to hospital or not. At one relatively small district hospital a policy of never turning anyone away was noted, with non-admittance only occurring if there is no free bed in the hospital. At another district hospital the medical manager mentioned that criteria were being developed, but that the decision to admit someone with HIV/AIDS was made on the basis of resources, and on both the medical condition and the social condition of the patient – that is, whether care was available at home or not. Two of the medical managers indicated that their hospitals were linked to the home-based care system and that it was important to make sure that the person would not have to be readmitted after discharge because of a lack of proper care at home. This interviewee from a small district hospital further stated:

*It is very hard to turn patients away, but we are cognisant of the resources we have. We provide care on the basis of the resources that we have.*

Finally, the medical manager at a regional hospital indicated that at this hospital draft guidelines were used to guide the admission decision for chronically ill patients to medical wards, although the fact that these were guidelines was emphasized, as '*in medicine there are many grey areas*'. One interviewee observed that there were only a limited number of beds for terminally ill patients, and that the nature of the care required by these patients is basic nursing care, as opposed to acute nursing care. In the case of the former, less nursing time is usually required, but hospital beds are likely to be used for longer periods of time. However, a shortage of nursing staff was pointed to as a noteworthy constraint in the functioning of all three of the hospitals. At the regional hospital it was noted that at one point an entire ward had been closed and combined with another ward because there were not enough nurses to care for patients. One interviewee stated that the function of a hospital is to make people better,

and noted that some terminally ill patients are discharged when nothing more can be done to make them better. The medical manager at the small district hospital noted that other larger hospitals transfer patients to this hospital for nursing care as they are able to provide this service at a much cheaper rate at this hospital. The medical manager of the regional hospital indicated that a step-down care programme was in the process of being put into place for terminally ill patients who have spent a certain length of time in hospital, but are now ready to be discharged. The maximum length of stay in this ward was five days, and the interviewee expressed concern that the families of the ill would see this as a chronic care ward. A need was expressed by interviewees for infrastructure for home-based care and training for community caregivers – one interviewee argued for a place where nursing care could occur, in order to prevent re-admittance of discharged patients within short periods of time.

### **Summary**

The experiences of ill people and their family caregivers in accessing hospital care point to access to admission as being relatively arbitrary. No one experience seems to characterise hospital visits or hospital stays. Likewise, medical managers point to a range of approaches to admission that are applied. Some family caregivers describe the condition of ill people as not improving when they are in hospital. Medical managers believe that nursing care is what is needed for terminally ill patients, whose condition will ultimately not improve. However, a shortage of nurses is a key problem in providing this care, as are hospital resources. Family caregivers express a need for professional care, but medical managers express a need for support at the community-level in caring for terminally ill people.

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## **ASSISTANCE FROM CLINICS**

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Clinics lie at the core of PHC provision, and home- and community-based care is included as part of the PHC strategy. In this section, the perspectives of first family caregivers, and then two heads of rural clinics will be heard on assistance provided to ill people at clinics.

### **Family caregivers' perspectives**

About half of the ill people have accessed clinic assistance (mainly medicine), most on a regular basis and with no bad experiences. However, in one case a bad experience is described as the reason for no longer accessing this form of assistance. The family caregiver was no longer staying in this urban household and here an ill person described the experience to the fieldworker:

*Bheki said he went twice to the clinic but could not get any help from them. He said they asked for a sputum sample and gave him sample bottles on each occasion but when he came back for the result they said he must give them another sample because they lost the others. Because of that Bheki decided not to go there any more and he became very sick.*

This is not the only mention of lost sputum samples. In yet another case an ill person did not want to go to the clinic because she did not want to be tested for HIV/AIDS, while another ill person went but consistently refused to be tested. Educational talks are given by clinic staff, usually while patients and their caregivers are waiting in the queues at clinics, however, financial constraints mean that it is not always possible to put what is heard into practice, as in the case of this family caregiver from a rural area:

*This proper nutrition was common talk at the clinic. People would be given material to read at home with regard to the kind of food that they should eat. However, she found this difficult to worry about because for the poor families, the information was useless. Her own household sometimes goes to bed on an empty stomach.*

There are positive stories of the clinic working together with hospitals and community caregivers to provide health assistance to the ill people in the study. In a number of cases, after ill people are discharged from hospital a list of medication is sent to the nearest clinic in order for medication to be accessed closer to home. What follows is an example of clinic and community caregivers working together, in a rural setting:

*Sister Mkhize was the most supportive of all the nurses. When Bongiwe was not coming to collect tablets for a long time, she would convey a message to Mpume [the community health worker] to inform her about the fact that Bongiwe was ignoring treatment. In turn, Mpume would visit Bongiwe and find out the reason. If Bongiwe was not able to go to the clinic herself, Mpume would then go there for her.*

Further stories are of ill people in a very bad state of health being allowed to skip queues and being given preferential treatment at clinics.

### **Heads of clinics' perspectives**

A number of problems relating to the functioning of local clinics were relayed by interviewees and included a shortage of nurses, a shortage of medication and overcrowding and long queues. One clinic head related the following:

*She further pointed out that the people arrive as early as three in the morning and when they eventually are told that the medicines*

*are finished, they obviously get very angry as they have spent their last money on travelling... With regard to staff shortages, Sister Mkhize said that this was creating a lot of problems because they have to deal with the patients on a skeleton staff basis. This affects the staff physically as they have to deal with large numbers of patients. The situation creates tensions between the patients and the nursing staff.*

The second interviewee pointed to a need for care materials for family caregivers, which the clinic is not able to meet:

*There are also cases where the caregivers do not have soap, bandages and ointment and the people come and complain to them and the people think that the clinic is being unreasonable in not giving out the needed accessories.*

Another problem that was raised by the clinic heads was of individuals not wanting to take an HIV test. One of the interviewees recounted the following:

*The patients tend to hide their real status and only start coming to the clinic when it is already too late to save them. The other problem is that if they hide their status they will not be given the relevant medicines.*

It seems that in some cases, patients' fear of being stigmatised is meaning that HIV tests are not being taken and that in turn this is one of the reasons for clinic staff not being able to meet the needs of patients.

### **Summary**

With regard to assistance provided by clinics, poverty emerges as a noteworthy barrier. Family caregivers are not always able to take the advice of clinic staff (with regard to healthy eating, for example). It is evident that in some areas there are fundamental problems in the provision of essential items for care – medicine and care materials – which these households need. The care guidelines state that these should be obtained from the referral facility, but these clinics do not seem able to provide these items to those in need. Stigma too is a barrier to care provision: many ill people do not want to be tested for HIV, and in turn this makes it difficult for clinic staff to provide the appropriate treatment, and for ill people to receive proper assistance.

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## **OTHER ATTEMPTS AT ACCESSING CARE/ASSISTANCE**

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### **Family caregivers' perspectives on the Disability Grant**

At the time this study was conducted, according to the KwaZulu-Natal Department of Social Welfare and Population Development, the DG

could be obtained in KwaZulu-Natal by adults in late stage HIV/AIDS – either if they were in World Health Organisation (WHO) stage three or four<sup>18</sup> or if they had a CD4 count of less than 200 –subject to the decision of a District Surgeon. Being HIV-positive does not mean that one qualifies for the grant.<sup>19</sup> Medical doctors at public hospitals seem to play a role in DG access. In one regional hospital referral letters are written in order for patients to obtain the DG application forms from welfare offices; at the other two district hospitals medical doctors take on the role of district surgeons, playing an important role in assessment of the applicant. Two of the three medical managers interviewed indicated that it is only patients in WHO stage four who are considered eligible for the grant, while the understanding of the third medical manager was in line with that of the Department of Social Welfare. It is not possible to be conclusive about the eligibility of the study participants for the DG. Those who are HIV-positive may not fall within the criteria outlined above, and even if they did, the District Surgeon’s decision could still indicate that they are not eligible.

Three of the ill people in the study (all in rural areas) were receiving the DG – one only started receiving it shortly after fieldwork was completed and therefore there is no information on this grant receipt. Apart from these three, two ill people had applied for the grant but died before their application could be processed; three had applied and were awaiting the outcome of their application; one had applied twice but the application had been refused both times. It is interesting to note in the latter case that the ill person applied between illness periods – when she was healthier physically – and that this is likely to have had a bearing on her application. For 10 of the ill people no application for the DG was made (three of these ill people identified themselves as being HIV-positive) – some could not apply because they did not have identity documents, others could not apply because they refused to have an HIV test completed.

For the two ill people who received the grant during the course of the fieldwork period it was possible to gauge what the grant money was spent on. One of the recipients was female and 24 years old. She received the grant for nine months before she died. The grant money was spent on food for herself and for the household (she lived with her mother and her two year old daughter) and on medication. For some months over this nine-month period her mother was building a mud brick dwelling with a corrugated iron roof, as the house in which they were staying was falling apart, and some of the grant money went to this purpose. The other DG recipient was a 34 year old male who received the grant for a number of

months before he passed away. The money was spent on food for the household, and a small amount was kept behind for his own entertainment. In all it can be seen that very few of this small sample are receiving state social assistance in the form of the DG, but when it is received it goes towards meeting the needs of the ill person and the household in which they live.

### **Family caregivers' perspectives on private provision**

The care guidelines also include reference to the private sector being involved in home- and community-based care provision. Most ill people access both public and private health care facilities. There is a sense that ill people and their caregivers are – as far as finance allows – trying to access all options available to them. Moving from pillar to post in order to access treatment, whether it be to private doctors, traditional healers, clinics, public hospitals or buying the latest 'cure', features prominently in the stories of illness periods. There are constant attempts to get the ill person better – although these are constrained by finance.

In the care guidelines traditional healers are described as being a part of the non-formal system. However, since traditional healers are usually paid for their services these stakeholders will be included in this section. One family caregiver points to visits to traditional healers as part of the overall process of trying to find a means of getting the ill person healed:

*Patricia says that she does not believe in traditional healers but they have no choice. They have to try all different types of medication.*

Nearly all of the ill people had visited traditional healers for a consultation and/or medication. Traditional medication is usually used in conjunction with western medicine obtained from public or private health facilities. Some ill people visit traditional healers frequently, for others visits are relatively infrequent. For some a difference in their health is noted, while for others this is not the case and this medication is then abandoned. In one rural area a group of HIV-positive people club together to cover transport costs for a member of the group to travel once a month to an urban centre to obtain a traditional immune booster. In many cases, in the process of trying to find out what is wrong with the ill person, and in trying to get them better, noteworthy costs are incurred as the following story details. The only income to the household at the time was the CSG – an amount of R160 per month. The family caregiver, Thabile, recounted the following to the fieldworker:

*In August 2003, Thabile went to the traditional healer, Mrs Khoza, about Gloria's sickness. The traditional healer told Thabile to do a*

*small ceremony where she did not need to invite people. It's a small family thing. She paid R300 for the consultation and the treatment. They used the CSG money and they were assisted by Thabile's mother. The traditional healer said that Gloria's sickness was caused by their ancestors. She had to do a spiritual ceremony. The healer told them to buy a black chicken for R25, one red candle, and one yellow candle for R2 each. The traditional healer told them to buy monthly traditional medication for R30 from August to November. Gloria has been taking the medication but she never finished a bottle. Thabile bought the traditional medication ... because the traditional healer insisted that Gloria can't stop taking the treatment. Thabile says that they gave up on traditional medication. Gloria lost the interest in medication because there was no change at all ...In December 2003, Thabile went to see another traditional healer to help Gloria. She paid R70 for the consultation and the treatment. They used Ayanda's CSG to pay for the traditional healer. Thabile was very concerned about Gloria. Gloria got sick and went to the clinic to do an HIV test. Thabile says that she was tired of Gloria's illness. She forced Gloria to do the test. The results came back positive. She lost interest in traditional healers. She was so angry thinking about the money she spent on traditional healers.*

Only one ill person in the study was on medical aid, and therefore was able to access private hospital care. Over half of all ill people visited private doctors. Some visit private doctors who also act as District Surgeons in order to obtain medical reports to apply for the DG. In some cases the prescription given by the doctor is too expensive for the ill to obtain, and they therefore return home, having received a diagnosis but no medication from private doctors. Many who receive medication describe an improvement in their condition.

Supermarkets, spazas and/or pharmacies are also visited in order to obtain over the counter medicines and immune boosters. The more expensive treatments cannot always be frequently obtained due to their high cost, although in a number of cases where these treatments have been taken an improvement in the health of the ill person is noted.

It is also essential to remember that finance is required to access public and private health institutions, and that transport costs in most cases add a noteworthy burden on the ill and their caregivers. In one household in a rural area there was not enough money for the ill person to visit the local clinic where she could have obtained medication for free, but there was enough money to obtain painkillers at the local shop. This gives an idea

of the kinds of constraints that transport costs impose on the ability to access health care assistance.

Another ill person in the same area visited the local clinic and was given a referral letter to go to a public hospital. However, he did not have the transport money necessary to get to the hospital and was only able to visit the hospital the following month, after lending the transport money from a neighbour. In this case unaffordable transport costs meant that this ill person was unable to receive the necessary treatment when he required it. For some, taxi or bus rides are the only option financially; others hire cars to take the ill to health facilities as it is not always possible for the ill person to get from their home to the taxi or bus stop. A hired car can come as close to the homestead as possible to pick up the ill person. One ill person was referred from one public hospital to another public hospital over two hours drive away with a referral letter and an appointment date, but no transport provision. The family caregiver had to hire a taxi for R600 to take him to the hospital on the appointed date. The income to this household consists of an Old Age Pension (OAP) and a DG, therefore this represents a substantial portion of the household's monthly income. In all, ill people and their caregivers are accessing private forms of care provision in addition to public health care provision, but high costs – particularly transport costs – represent an enormous constraint to access.

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## **ASSISTANCE FROM COMMUNITY CAREGIVERS**

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Community caregivers are community-based health worker cadres who are selected, trained and work in the communities in which they live.<sup>20</sup> Their role is to act as agents for health promotion, care and health development (Friedman, 2002; 2005). According to the Department of Health (2004), the role of community health workers is, amongst others, to provide specified primary health care services to community members, as well as a basic counselling service, disseminate health information, carry out health promotion activities, and transfer health and wellness skills to community members. Friedman (2005) notes that KwaZulu-Natal is the only province in which there has been provincial government support for community health workers since the new government came to power in 1994. In the study areas the community caregivers identified were paid and unpaid community health workers – with generalist functions – and home-based caregivers – with specialised functions in providing home-based care. Only community caregivers that were paid were interviewed, since it can be assumed that they have some type of obligation to do their work, as opposed to volunteers who are not under the same obligation. In this section, first the perspectives of family

caregivers and then of four community health workers and two home-based caregivers will be heard on the issue of their care provision.

As table 1 showed, community caregivers were present in five of the six research sites. With regard to training received, among community caregivers this varied in terms of amount and extent. Most have covered the basics of home-based care and the basics of health care. Some have received basic counselling training. A number of those presently paid as community caregivers volunteered for a number of years – one for seven years – before being paid. Each is responsible for more than 100 households. This is in line with the number of households that community health workers are meant to be responsible for: 80 to 100 households in rural areas, and 100 to 150 households in urban areas (Department of Health, 2004). Nearly all community caregivers state that they work full work days, five days a week – and sometimes on weekends if a need arises. About half are paid by the Department of Health, while the other half are funded by NGOs, which are in most cases funded by the Departments of Welfare or Health. All community caregivers complained that they were receiving insufficient pay for their work. Five freely stated their earnings: two community health workers in rural areas earn R1800 a month, one community health worker in an urban area earns R1400 a month. A home-based caregiver in an urban area earns R500 per month, while another in a rural area earns R300 for working three hours a day, five days a week. As a point of comparison, over this time period the minimum wage for domestic workers in rural areas ranged between R700 and approximately R755 (Department of Labour, 2004a), while the minimum wage for agricultural work – the chief form of employment in rural areas – was about R715 per month for rural areas (Department of Labour, 2004b). Therefore, here community health workers are paid approximately double these wages.

### **Family caregivers' perspectives**

Over half of the study households had not received any visit from a community caregiver. In one rural study site, when households were being selected to be part of the study, the two community caregivers for the area had indicated to the fieldworker that an ill person was receiving care in a certain household. However, the family caregiver in this household said that a community caregiver had never visited the household:

*She thought, and then came up with the conclusion that the reason the community health workers were not visiting them, is because they are poor ... they were aware about Michael's sickness ... but*

*none of them was prepared to visit. They would just pass by the house on the road.*

However, some ill people and their family caregivers do not want to be visited by community caregivers. In one household, not wanting a community caregiver to visit appears to be directly related to the stigma of HIV/AIDS. In this rural household the ill person was identified as being HIV-positive:

*Babongile says that they are not visited by the community health worker. She says that it was their decision not to inform the community health workers about Sanaz's sickness because they might spread gossip in the community and talk about Sanaz's illness. They don't want that to happen.*

In another case in an urban area no visit had been received during the illness of the family caregiver's son who subsequently died, and a community caregiver then visited at a very late stage in the illness of the second son. This was given as the reason for not wanting the community caregiver to visit the household:

*In January Zweni was very weak and bedridden. He was very sick and did not want to go for help. The community health worker visited them and Malanga chased her away saying that Zweni was no longer sick and he was not home. The reason she said this was because the lady never came when they needed her the most.*

Of those ill people that are visited by a community caregiver, in a number of cases visits seem to be extremely infrequent. Two ill people in different study areas are visited once a month – however, this relative frequency is the exception. In two households in different areas the ill people were visited once only over their illness periods. In one study area the community caregiver came twice in seven months to one household, and twice in 12 months to another. In yet another rural area the community caregiver previously assigned to that area had visited the area twice in the past two years. This leads to the question of what good such a service can bring if the ill and their family caregivers are so infrequently visited?

In a number of the households that are visited, it is mentioned that community caregivers do nothing but talk to the ill person. However, in one instance a family caregiver in a rural area describes the verbal encouragement and advice received from a community caregiver to be what is necessary:

*The community health worker, Nokwanda, has been visiting the household several times. Helen [the family caregiver] says that it was Nokwanda who motivated Siphon [the ill person] to visit the*

*doctor at the hospital. Sipho did not want to go to hospital when he was sick. He had lost so much weight at that time ... Even though the community health worker could not provide much [material] support, she was able to help or encourage the sick person to take his monthly medication in the correct way, says Helen.*

In some of these households it is also mentioned that the community caregivers already knew the ill person socially or relationally, and there are hints that it is therefore not appropriate for anything more than friendship and verbal support to be offered. In one case a male community caregiver is a friend of the female ill person, and therefore does not feel able to visit as a community caregiver but rather as a friend. In another household in a rural area the ill person and community caregiver are related:

*The home based care giver, Simo, has been visiting the Luthuli household every month. Harriet [the ill person's sister] says that Simo is their neighbour and their relative. So, even though Simo has never assisted or cared for Mbeje [the ill person], they didn't take that seriously.*

The fieldworker noted that it seemed like the household wanted help with caring for the ill person, but that it was felt to be inappropriate to receive assistance with care from the community caregiver because they were related.

### **Community caregivers' perspectives**

A number of themes emerged from interviews with community caregivers. A common theme was the difficulty of being confronted by the poverty in the households that these workers visited. The following is an account of what the community caregiver in a rural area had to say:

*The main difficulty that she deals with is that she works for a poor community. She finds it difficult to help the people. They need more than what she can offer them ... It is difficult to help the very sick people who are also poor. She finds that these people don't have food to eat while they are dying in their beds.*

Another community caregiver in a rural area sometimes uses her money to buy bread for households that have no food. A further theme was of a lack of care materials. A community caregiver in an urban area had the following to say:

*She said the main difficulty she has is when she has to go to households that need her assistance, and she has no working materials. She gave the example of not having gloves and having to bath someone who has sores ... She said if she does that she will be putting her life in danger ... She is forced not to bath that person or*

*she has to use a plastic bag. She said using a plastic bag creates some problems because she has to answer many questions from the family of the ill person. She also thought that the ill person would not be happy to see that.*

This community caregiver states that she has sometimes used her own money to buy gloves for her work. Others complain about a lack of soap and antiseptics, and one community caregiver fears that she will not be regarded as a professional because she does not provide these materials to the households she visits. A further theme that emerged was a need for medical care by households, and of counselling not being sufficient, as evidenced here from a community caregiver in a rural area:

*She also visited a household that had a seriously ill person, and they needed medical assistance. She advised them to go to the clinic, but they had no money for transport. She started to counsel them and this created serious problems because they could not reconcile her counselling with the fact that they badly needed medical assistance. This created a serious problem and she realized that counselling was not a solution ... unless it is done together with medical assistance.*

From this case it appears that households value medical input over psycho-social support – which is what community caregivers are able to offer. One community caregiver, from a rural area, talks about the fact that she is not accepted by the ill person because she is not a nurse, but is trying to do the job of a nurse. A final theme was of community caregivers not being welcomed in or accepted by households with ill people. There are various reasons given for this, but the most frequent one seems to be a fear of being stigmatised. A community caregiver in a rural area, referring to herself and other community caregivers in the area, recounted the following:

*She says there are situations where they are not accepted by family members when they want to help the sick people. She says it is good that they are doing this job but you find that some families don't want them in their households. They learn that the families don't have time for them. The families don't allow them to spend enough time with the ill person. They can feel and see that they are not accepted.*

Clearly the stigma described, most likely associated with HIV/AIDS, makes the provision of care by community caregivers an even more complex task than it already is.

## **Summary**

From the interview material reviewed it is clear that there are a number of barriers to care provision by health workers. Poverty is a key barrier: it means that it is difficult for community caregivers to visit households in which there is an ill person, and that the needs of households in which care is taking place are magnified. Stigma too emerges as a barrier to care provision: it means that community caregivers are not wanted in some households, and in turn that it is difficult for them to visit households. It appears that basic care materials – such as gloves and soap – are not being made available to community caregivers, making it difficult for them to properly undertake their work, and for the ill and their family caregivers to regard them as professionals. Moreover, there is a need for medication in households that these workers visit, and this seems to be desired over any psycho-social support. A lack of these care materials and medication seems to be a barrier to care provision. Finally, being part of the community in which they are called to provide care means that health workers are more aware of the needs of the community than an outsider would be, but this familiarity also makes it difficult for them to provide care, and for ill people and their family caregivers to receive assistance.

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## **THE LIVED EXPERIENCE OF PROVIDING CARE**

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This section consists of a case study of a fairly typical care situation, which gives insight into the lived experience of providing care for the family caregiver. Other study households will be reflected on in relation to this household, mainly where the case study differs markedly from the typical situation in study households.

The 22 family caregivers ranged in age from 16 to 74, with all but one of the caregivers' female. The 19 cared-for ranged from age 23 to 51 – eight were female, 11 were male. In some cases the caring task was shared. In most cases the family caregiver was not working for an income. However, a number of those family caregivers who were working gave up their work, or substantially reduced their work activities, in order to care for the ill person. Two of the family caregivers are traditional healers and both gave up on their work for some of the time during the care period. Another family caregiver has to get other women to cultivate her land as she is unable to do so because of her care obligations. Two family caregivers sell goods informally – in the case of both this work is curtailed or stopped over the time that the ill require a lot of care. Another family caregiver is able to continue with her recently acquired half-day work in a school kitchen, but states that she is fortunate that she did not have this work when her daughter required substantial amounts of care.

Apart from this, seven family caregivers were unemployed, one was studying and seven were receiving an OAP – one of whom still works informally.

In the case study household, the ill person, Ntokozo, is 28 years old, and tells the fieldworker that he is HIV-positive. The family caregiver, Virginia, is his 67 year old mother. She is a pensioner, and the household is located in a rural area. There are five other household members: three are under 18 and are attending school. This case was selected because it is a fairly typical care situation in many ways. For one, there is only one family caregiver, and she is the mother of the ill person. In all but one instance the family caregiver(s) were female – the exception was a nephew who, along with the ill person's mother, cared for his uncle. In 10 of the 19 households the mother of the ill person was the only family caregiver. In all but one case the family caregiver was related to the ill person – in this instance an ill person's brother's girlfriend. These findings on who provides care in the home are in line with the literature on caregiving in sub-Saharan Africa (Chimwaza and Watkins, 2004).

In the case-study situation the family caregiver was dedicated to providing the best care that she could to her ill son, and this was the case in nearly all care situations. In three cases fieldworkers did not believe that the care provided was 'dedicated'. Rather, care here was described as being 'uncommitted' and 'not easily given'. The case-study care situation is fairly typical in that there are financial constraints which limit access to private provision of treatment and care. Only in one of the study households was the ill person covered by medical aid and therefore able to visit private doctors and be admitted to private hospitals for care.

### **24-hour activity diary of a family caregiver:**

#### **Yesterday:**

##### **08h00**

*She went to the traditional chief to complain about the burning down of the wattle trees. She left Phindile to look after Ntokozo. [Phindile is 21, Ntokozo's niece, unemployed].*

##### **09h00**

*She went to check if Ntokozo was okay. She administered medicine after giving him food.*

##### **10h00**

*She turned Ntokozo over. She provided him with the bedpan to pass urine.*

**11h00**

*She cleaned the yard. Ntokozo called and wanted water. [She gave it to him]. She went outside to wash his clothes.*

**12h00**

*Ntokozo called for traditional medicine. Ntokozo asked to be taken outside into the sunshine. She went to get the neighbours to help.*

**13h00**

*She served Ntokozo with lunch. He asked for painkillers [and she gave them to him].*

**14h00**

*She prepared food for the other children. Phindile attended to Ntokozo in case he needed something. She saw to a complaint from a neighbour. The goat had eaten crops.*

**15h00**

*Ntokozo wanted to be brought in. She got the neighbours to help.*

**16h00**

*She turned Ntokozo over. She massaged him. Ntokozo called for the bedpan to pass urine. [She gave it to him].*

**17h00**

*Ntokozo called for the bedpan to pass stool. She took off the linen ... it was dirty. She put on fresh linen.*

**18h00**

*She dished out supper. She fed Ntokozo.*

**19h00**

*She organized prayer. Other household members went to bed. She sat by Ntokozo.*

**20h00**

*Ntokozo asked to be turned [and she turned him]. She gave him medicine.*

**21h00**

*Ntokozo called out for water [and she gave him some]. He asked for the bedpan to pass urine [and she provided one].*

**22h00**

*She slept. Ntokozo also slept.*

**23h00**

*She slept. Ntokozo also slept.*

**Today:**

**24h00**

*Ntokozo called to be rubbed under the foot [and she rubbed it]. She went back to bed.*

**01h00**

*Ntokozo called for pain killers [and she gave them to him]. Ntokozo asked for traditional medicine to get rid of cramps [and she gave it to him].*

**02h00**

*Ntokozo slept. She also slept.*

**03h00**

*Ntokozo called for sleeping tablets...his chest was congested. [She gave them to him]. She went back to bed.*

**04h00**

*She woke up to prepare food and warm water for the children for school.*

**05h00**

*She woke up the children. She gave them bread and tea.*

**06h00**

*She gave the children errands ... to sweep the floors, to get water from the borehole.*

**07h00**

*She saw the children off to school. She went to the clinic to fetch tablets for Ntokozo. Phindile remained behind with him.*

From this 'diary' the sheer burden of care is evident. In addition to the many other household tasks, the ill person requires constant attention, on a 24-hour basis, allowing the family caregiver only a few hours of sleep during this period. The family caregiver essentially undertakes nursing work and domestic work: she administers medication, feeds and turns the ill person, changes his bed linen, helps with toileting – in addition to other household chores. No running water is available to the household, which gives some idea of how difficult it must be to provide the care that he requires. Rather, water has to be collected from a water pump in the area and then stored in large drums in the house. Virginia's case is relatively unusual with regard to the amount of assistance received by neighbours. In many of the study households, friends of the ill person and/or the family caregiver and neighbours visited, but did not provide care assistance. There are a few cases where extended family and neighbours helped with actual care provision. However, if care provided by extended family, friends and neighbours is what is meant by community-based care, then the term 'home-based care' seems more applicable than 'community-based care' to the care that is being provided

to ill people in the study. By and large, within households the central care is provided by family caregivers from within the household, with additional assistance received from children or other household members relatively infrequently. Phindile's assistance is also noteworthy, as it enables Virginia to undertake a number of non-care activities. In many of the households the family caregiver was more restricted because such help was not available.

A further point is that it should not be assumed that carers are themselves healthy. One family caregiver indicated that she was HIV-positive and could not always care properly for her ill son. Another family caregiver had been sick and died while fieldwork was underway, a few months before her ill son died. A further family caregiver was pregnant. In a number of cases family caregivers were elderly and themselves not physically strong. Some family caregivers also had to look after more than one person at a time: one 16-year old was caring for her mother and her aunt; another was caring for her ill son and a disabled granddaughter; yet another was looking after her ill daughter and granddaughter, both of whom were HIV-positive.

More than nursing work and domestic work, something known as the carer's burden is attached to providing care. This refers to social, emotional and physical problems associated with providing care (Pakenham et al., 1995). As Dalley (1996) indicates, not only does the family caregiver care for the ill person (a task), but she also clearly cares about him (has feelings for him). The comment below illustrates something of the emotional lived experience of the family caregiver in the care situation, and how she approached the caring role:

*When he came out of hospital seven months ago, she did not know how to address herself to the illness. She asked herself one question: if medical doctors, with their experience, can release or discharge him, who was she to handle him or his illness? She had no answer to this question and no-one could provide one. She told herself that this was a challenge to her as a parent and she needed to deal with it ... Her son looked emaciated and could not walk properly. He was coughing quite constantly and had no appetite for food. She started to pick advice from neighbours and friends ... Each time she went to sleep, she hoped that the following day her son would be walking. But that was not to be. Each day passed with her son glued to his bed. She cried openly and her son said 'don't cry, I will be alright'. From then onwards she survived on hope and her son's confidence.*

Virginia also relates how caring for her son crowds out other activities she previously undertook, including her social activities:

*The whole situation changed considerably when she had to start caring for Ntokozo. She can no longer attend community meetings nor do some cultivation. Ntokozo has taken over her activity time ... She cannot go to the river or do the washing for the household. She can only wash Ntokozo's clothing as it is made up of a few clothes. Even then, she cannot do the washing all at once as Ntokozo calls her quite frequently ... She cannot go out now and gossip with other local women. Even going to the shop is no longer on her monthly agenda. Instead, she has to rely on other local women. She gives them a list of items to be bought at the supermarket. This seriously disturbs her budgeting as she is not there to do the shopping. She pointed out that she recently had the misfortune of having her wattle trees burn down and she did not have time to help track down the culprit.*

It is evident that Virginia's social life has been impacted upon as a result of having to provide care for her son. From the 24-hour care diary it is clear that Virginia is not receiving much sleep at night because of the needs of her son at night. Physically, this is a striking burden for this 67 year old woman to be carrying. At the end of the fieldwork period, Virginia had been caring for her bedridden son for a total of seven months. When she started caring for Ntokozo, she had no training in how to provide care:

*Without any basic training, she felt constrained in taking care of her ill son. She did not have gloves and used her bare hands. A neighbour who is a nursing sister gave her a few gloves and she had to use these all the time. The gloves have developed cracks and that means no protection ... She had the problem of not understanding how to massage properly until the sister who gave her the gloves showed her how to do it. The community health worker was not visiting at the time.*

Both the community caregiver and the clinic gave Virginia guidance on how to use gloves and on healthy foods for her son to eat. Moreover, the clinic gave her guidance on how to administer medication, while the community caregiver showed her how to massage. This has been the sum total of institutional support she has received in caring for her son.

In about half of the study households no training or guidance whatsoever had been received by the family caregiver. In just over half of the households no guidance had been received from a clinic or a community caregiver or both, as in Virginia's case. Three family caregivers had

received formal training on various aspects relating to caring, and this helped them in their caring role, but this had been received prior to their being in, and not related to, the care situation. A number of family caregivers had cared for a household member who had already died, and some described this as their 'training', as in this case in an urban area:

*Malanga did not receive any training to be a caregiver. She said it all started when her younger son fell sick ... Her son Mandla was still at school when he died. He also did not say what was wrong with him but the signs were there that it was related to HIV/AIDS. During those days no community health worker came to visit her house. She learnt from that time to care for a sick person. She said it was very hard for her.*

In sum then, what is evident from the case study presented is the sheer burden of care work – nursing work and domestic work – that is single-handedly being undertaken by the unpaid family caregiver on a 24-hour basis, with little training or external assistance. With regard to the other study households, the institutional isolation in some cases, and in others the lack of systematic institutional support, is also striking. The lack of external assistance seems to contradict many of the findings of the community focus group discussions outlined towards the beginning of the paper. Finally, the fact that many family caregivers have to give up on work activities over illness periods in order to provide care is clearly of concern.

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## **CONCLUSIONS AND IMPLICATIONS FOR POLICY**

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The South African home- and community-based care guidelines and other policy documents emphasize that hospitals cannot provide the central response to the HIV/AIDS epidemic, and that instead nurses, nursing assistants and community caregivers will play an important role in responding to the growing need for care within the home. This care should be provided within the home by formal and informal caregivers. According to Mosse (2004), ethnography can offer the policy process an element of critical reflection, as well as a means to understand in individual cases how policy is linked to actions.

The detailed findings from this ethnographic study suggest that implementation of the home- and community-based care policy in KwaZulu-Natal falls far short of its policy intent. There are indications that the system is failing ill people and their family caregivers. Little, if any, medical care is received within the home. The only assistance from formal caregivers is outside of the home, with ill people and in many

cases their caregivers visiting public and private doctors, nurses and traditional healers, often at great financial cost. Hospitals and clinics face notable constraints in their functioning. Although in some cases hospitals fill a gap in provision, this response seems to be *ad hoc* and not substantial. A considerable number of households in which care is taking place have received no visit from the part of the informal system that is present in most communities and has been trained in aspects of care provision, namely community caregivers. Under-spending with regard to home-based care is therefore of concern, especially as evidenced in the KwaZulu-Natal Department of Health. When visits are received, these seem to occur extremely infrequently. A definite problem seems to be that there are not enough of these community caregivers to visit households in need. To what extent could an increased number of community caregivers through the Expanded Public Works Programme be a solution? The results from the ethnographic study indicate that it is unlikely that simply increasing their number will be the answer to the limited assistance received by family caregivers.

It is important to consider the nature of this form of care provision. Where the ill person has HIV/AIDS, this is home- and community-based care for the definitely dying – it is neither preventative, nor curative. Rather it is community-based hospice work that needs to be provided. To what extent then is there a need for a particular cadre of people with specialised training to visit the terminally ill? Friedman (2005) recommends that skilled health professionals such as palliative care nurses could provide technical support and supervision to improve the quality of home-based care programmes. Such nurses could fill the gap in medical assistance that is lacking within households in which care is taking place. However, with current human resource shortages in the public health system, this is likely to be a challenging proposal to fulfill.

The issue of care provision to ill people is complex. Each perspective reflected in this paper highlights very real difficulties and constraints. Overall, the reality of care provision at the household and community level is markedly complicated by stigma and poverty which act as key barriers to care provision, and are more challenging to seek solutions to than a lack of care materials or medication, which increased funding and improved administration could begin to address.

It is evident that the burden of care provision is falling at the household level, and almost entirely upon individual female family caregivers, with little external support to the ill and their caregivers in these households. Findings indicate that unpaid care work by female relatives is forming the

backbone of actual care provision for ill people in KwaZulu-Natal. Clearly the care guidelines are discriminatory against women. The sheer burden of care for family caregivers is evident from the case study presented. These family caregivers are undertaking nursing work and domestic work with little, if any, training, guidance or support in this environment from other stakeholders, as outlined in the care guidelines. This social policy is adding to women's unpaid care work, but at the same time it is not in line with South Africa's economic policies.

Casale (2004) indicates that there has been a continued and dramatic feminisation of the labour market that has occurred in South Africa over the second half of the 1990s. The increase in employment among women has been largely due to the increase in self-employment in the informal economy, which is associated with lower earnings and insecure working conditions (ibid). While government has encouraged women to participate in the labour market, this economic approach is not in line with government's policy of welfare retrenchment. No guidance is given on how women are meant to provide both unpaid care and work at the same time. Chen et al (2005) argue that there is little evidence of men taking on substantially more caregiving responsibilities and that as a result women are paying the price of free-market economic policies.

Fundamentally the government's policy raises the issue of how cost-effectiveness is defined. HIV/AIDS undoubtedly presents many challenges for the functioning of the public health sector. However, the home- and community-care policy is resulting in cost-effectiveness for government, but not for those in home environments undertaking care work. The latter are, for the most part, poor and from previously disadvantaged areas. A decade after Apartheid has ended, many of those who previously struggled with limited service provision, are now carrying a striking care burden with limited assistance. Criticisms of community care policies outlined earlier also hold true in the South African context. The balance of responsibility appears to lie unevenly between the state and individual family caregivers. While the stated intent is that home-based care does not become 'second-class care' or 'cheap care', are adequate resources being sown into this form of care provision in order for it not to become just this?

For Barnett and Whiteside (2002) the challenge in dealing with the HIV/AIDS epidemic is to manage the burden on the formal public health care system without shifting an unsustainable burden onto individuals, families and communities. While home-based care may reduce the impact on public systems, these authors argue that unless families are provided

with adequate support they may be overwhelmed, and home-based care could become home-based neglect. It seems from these findings that the latter is already occurring in the South African context.

What then is to be done? Ultimately, in order for the needs of ill people and their caregivers to be properly met, creative policy and practical responses to the complex challenges of care provision in the South African context should be regarded as a priority, not an option. Without a substantial flow of resources towards home- and community-based resources and care programmes, and a revision of how home-based care is being undertaken in practice – a revision that would bring it closer to the South African home-based care policy – it is likely that this problematic will remain. A first step could consist of expanding the current Expanded Public Works Programme on home-based care provision, and on other home-based care programmes, by focussing on and prioritising the role of community caregivers in providing training to family caregivers. A second step could be to prioritise a new role for community caregivers in transferring care materials to family caregivers, with the necessary accountability structures put in place. Ogden et al (2004) point to the importance of facilitating and enabling this caring work by women outside of the health sector, and of not taking it for granted. Dalley (1996:18) reminds us that ‘to question the nature of community care is to seek solutions which are equitable, comfortable and acceptable for chronically dependent people as well as for women as (potential) carers’. Such solutions urgently need to become the aim in the South African context of care provision.

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## ENDNOTES

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1. Research fellow, School of Development Studies, University of KwaZulu-Natal, Durban. Thanks are due to Francie Lund, Julian May, Caroline Skinner and Myriam Velia for very useful comments on earlier versions of this paper. The research in this paper is based on findings from the KIDS 2004 qualitative study. The important contribution of the team involved in the qualitative study is gratefully acknowledged – thanks are due to Makhosi Dlalisa, Themba Mbhele, Themba Mpanza, Cathy van de Ruit, Myriam Velia, Michelle Adato and Julian May. I would like to acknowledge the Department for International Development – Southern Africa (DFID-SA) for their funding for the qualitative study, and the South African national Department for Social Development (DSD) for their support, as well as the Mellon

Foundation Poverty Node for funding towards the qualitative study. The KIDS 2004 study was funded by DFID-SA and supported by DSD, the Mellon Foundation, and grants from the International Food Policy Research Institute (IFPRI) and the London School of Hygiene and Tropical Medicine (LSHTM). The project is a collaborative venture between UKZN, the University of Wisconsin-Madison, LSHTM and IFPRI. The opinions expressed herein are those of the author and do not necessarily reflect the views of DSD, DFID-SA or the Mellon Foundation Poverty Node.

2. Hereafter any reference to ‘family caregiver’ will be to an unpaid household member who provides care to an ill person within the home on a regular basis. In the qualitative study on which this paper is principally based, all but one of the caregivers within the home were related to the ill person, and therefore this term is largely appropriate.
3. Personal communication, Manager: Home Based Care, KwaZulu-Natal Provincial HIV/AIDS Action Unit, 15 August 2005.
4. It was not possible to obtain a breakdown of home-based care allocations or spending for the different groups it was provided to from either the KwaZulu-Natal Department of Health or Welfare. Therefore, these figures are not specific to home-based care for ill people or for people with HIV/AIDS.
5. Personal communication, Welfare Analyst, KwaZulu-Natal Treasury, 23 August 2005.
6. Personal communication, General Manager: Public Health Services, KwaZulu-Natal Department of Health, 14 November 2005.
7. KIDS is a panel survey of 1,100 households within 67 clusters in KwaZulu-Natal, South Africa, surveyed in 1993, 1998 and 2004. ‘Clusters’ or research sites refer to census units, equivalent to a small locality. It is important to note that clusters are not communities *per se*, and that there is differentiation within clusters. Hereafter, reference to these clusters may be to a rural or urban area or to a research site.
8. In the mini-survey the following questions were asked in order to identify care for ill people: During the last 30 days has anyone

been frequently or continuously ill? Has anyone in this household been bedridden over the last month? Is anyone in this household being treated for TB at present? Has anyone in this household been admitted to hospital for pneumonia in the last month? If yes was the response to any of these questions, the age and sex of the person and information on any caregivers was obtained. Only households in which the ill person was over 10 and under 60, and in which informal care was taking place were eligible for selection, since the aim was to increase the likelihood of people with HIV/AIDS being selected.

9. In some cases the fieldworker was told why care was required. Households in which care was being received for those with chronic, non-HIV related conditions – such as diabetes, arthritis, high blood pressure – were not included, as the aim was to increase the likelihood of people with HIV/AIDS being selected.
10. These individuals were told that the study team was interested in studying care within households in the area, and were asked to identify households in which there was someone who had been frequently or continuously ill over the last month, who was aged over 10 and under 60, who was not ill because of an injury, and who was receiving care by at least one other household member. The mini-survey was then administered in identified households, followed by theme selection.
11. The term ‘modified’ was used because the period in the field and the period with each case study household was shorter than is most often the case using an ‘extended case method’ (Burawoy, 1998). Moreover, fairly structured interview guides were used, primarily because of the low level of experience of the fieldworkers with the ethnographic method. Structured guides were developed for each of the research themes, and fieldworkers were trained in their use.
12. The fieldworkers were first language Zulu speakers. The fieldworkers undertook training in ethnographic methodology.
13. Events mapping involved identifying key events in the illness periods, with a specific focus on access to institutional support.
14. The interview material has been edited for clarity of reading. In addition, all names have been changed for the sake of

confidentiality, and all material relating to identity has been placed in secure storage.

15. Ethical clearance for the KIDS was obtained from the Research Ethics Committee of the University of KwaZulu-Natal, Durban. Fieldworkers were given instructions to ask no questions about HIV status because of ethical reasons and because of the stigma associated with HIV/AIDS. Grocery packs, including staple foods such as maize meal and morvite porridge, were given to each study household as an acknowledgement of their time spent participating in the study. Fieldworkers were given the option of attending counseling sessions.
16. None of the ill people admitted to be on Anti-Retroviral Therapy.

17. While the KIDS was undertaken in 67 clusters in total, only 58 of these were African clusters. Since the qualitative study on which this paper is largely based was only undertaken in African clusters, only results for these research sites have been analysed here.
18. See Evian (2003:118) for the WHO staging system for HIV infection and disease. This clinical staging system emphasizes the use of clinical parameters to guide clinical decision-making for the management of HIV patients. Stages 3 and 4 are the final stages, and stage 4 includes AIDS defining conditions.
19. Personal communication, Chief Director: Social Security, KwaZulu-Natal Department of Welfare, 7 September 2004.
20. General reference to community caregivers will be to various cadres of community-based health workers; specific reference to one cadre of community caregivers such as to a community health worker means that the information applies only to this type of community caregiver.

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