Community attitudes towards individuals living with HIV in rural KwaZulu-Natal, South Africa

C. NDINDA¹, C. CHIMBWETE², N. MCGRATH³, R. POOL³, & MDP GROUP⁴

¹Formerly of Africa Centre for Health and Population Studies, Mtubatuba, South Africa, ²Consultant in HIV Prevention, Johannesburg, South Africa, ³London School of Tropical Medicine and Hygiene, London, UK, ⁴Microbicide Development Programme, Medical Research Council, UK

Abstract
Antenatal sero-prevalence rates of 30% and more have been reported in KwaZulu-Natal since 1998 and over 50% of all adult deaths in 2000 were due to AIDS. Understanding the changing social and cultural attitudes to AIDS is important in providing contextual information to aid the design of interventions. This paper examines community attitudes towards individuals living with HIV. Eleven focus groups were conducted with men and women. Participants were asked to discuss how people living with HIV were treated within the family and community. The discussions were recorded and transcribed in isiZulu and then translated into English. These were coded using Nud*ist 6 software to identify key themes and sub-themes using content analysis. Gender and area differences were investigated. Generally participants expressed positive attitudes to the treatment of AIDS patients and felt that people living with HIV were being cared for within families. However, they reported more negative attitudes to those living with HIV by the general community and suggested these attitudes and acts of discrimination influenced disclosure. Discrimination included physical isolation and symbolism such as referring to them using a ‘three finger’ gesture. Participants also reported mixed responses to known HIV-positive individuals, ranging from sympathy to a lack of care, on the grounds that the person is certain to die. There are gender differences in terms of the attitudes towards people living with HIV. Compassion and hopelessness seem to be more common among women than men.

Introduction
This paper presents the findings of research gathered on issues around HIV awareness, and how people living with HIV are treated, prior to a Microbicide Feasibility Study (MFS). The target population were women, aged 15 and older attending family planning or immunisation clinics within a Demographic Surveillance Area (DSA) and the surrounding area in rural KwaZulu-Natal. Focus group discussions (FGDs) were conducted at the beginning of the MFS to explore issues around HIV awareness, sexual behaviour and how people with HIV are treated. The aim of this paper is to explore the attitudes towards HIV-infected individuals in a predominantly rural Zulu population and the implications of these attitudes on AIDS interventions. This paper begins by providing a background to the study and the methodology used in gathering data on the attitudes of the community towards those infected with HIV. The findings of the study are presented and these are followed by a section in which the authors discuss the findings and the conclusions drawn from the paper.

Background
The MFS was conducted within the Africa Centre Demographic Surveillance Area (ACDSA) and the peri-urban area. The DSA is approximately 435 km² in size. The population was expected to be typical of rural populations in KwaZulu-Natal and, to a lesser extent, of rural African population elsewhere in South Africa. As of January 2001, the total number of households in the DSA numbered 11,314 and these had 88,358 members, 28% of them residing outside of the DSA (Chimbwete et al., 2003). There is no indication that this distribution has changed.

The health infrastructure in the Hlabisa district is typical of many other rural health districts in KwaZulu-Natal and, to a lesser extent, of districts elsewhere in South Africa. The central fixed health facility in the district is a community or non-specialist hospital run by generalist medical practitioners and nurses. It provides a wide range of curative and emergency services, including surgical and obstetrical care, as well as the usual range of primary healthcare services offered at fixed clinics. Scattered throughout the district are 12 fixed nurse-run clinics, providing routine health services and...
treatment of a wide range of minor complaints. All conditions considered to exceed the capacity or skill of the resident nurses are referred to the hospital. The clinics are supervised from the hospital and ideally should be visited bi-weekly by a medical doctor from the hospital.

By 2005 the number of voluntary counselling and testing (VCT) counsellors in the government clinics had gone up to a meagre six. However, in the last three years the Hlabisa health district has availed itself of Africa Centre-supported VCT services in the government clinics. The Paediatric AIDS Foundation has placed ten VCT counsellors in the clinics. In addition the vertical transmission study has 19 counsellors who offer VCT and baby feeding counselling to mothers in the district. Out of 34 counselling centres initially established in the DSA, 17 are fully operational. The centres provide voluntary counselling and testing to individuals tested in the HIV serosurveillance study and any other people who are interested in testing for HIV. No doubt this area is better endowed with VCT services than other rural areas of South Africa. The MFS provided a further six counsellors to the district. Understanding the changing social and cultural attitudes to HIV/AIDS provides important contextual information to aid the design of AIDS interventions.

Attitudes towards people infected with HIV vary across contexts and these have also been changing with more awareness around the epidemic (Gielen, 2002; Lau & Tsui, 2004). While some studies focus on the attitudes of the infected in the general population, highlighting the gendered dimension, others focus on the attitudes of the infected individuals (Gielen et al., 2002; Lau & Tsui, 2004). Studies draw out issues such as stigma, discrimination, women being disinnherited on the death of their husbands, the break-up of marriages and the loss of employment due to HIV status as well as the general attitude of the population towards those affected by HIV (Human Rights Watch 2003a; 2004a; UNFPA, 2004). Due to existing discrimination against women in various societies, attitudes towards those who get infected are often less accommodating compared to the attitudes towards men in the same situation. Infected women are often blamed for infecting their husbands and unborn children and are described in stigmatising terms such as ‘vectors’, ‘diseased’ and ‘prostitutes’—terms that are rarely used when describing infected men (UN/WHO, 2000).

In Africa various human rights violations have been reported, such as sexual abuse and coercion, discrimination in access to health information, discrimination in property inheritance, rape and labour exploitation (Human Rights Watch, 2003b). In Kenya women who become widowed find themselves disinnherited by their in-laws particularly if they do not have sons and, in some instances, if they refuse to be inherited or to participate in ritual cleansing after the death of their husband. Such women have to return to their natal homes and where this is not possible many end up in urban slums where they had engage in multiple livelihood strategies in order to survive and support their children (Human Rights Watch, 2003a). Such examples illustrate attitudes towards individuals affected by AIDS but often the same people are also infected. In discussing attitudes towards people living with HIV it is inevitable to also touch on the affected. Human Rights watch laments that: ‘the policy paralysis that now surrounds gender-based human rights abuses linked to AIDS in Africa is scandalous and deadly’ (Human Rights Watch, 2003b). Previous studies have generally discussed attitudes in terms of individual perceptions and community perceptions in a gender-neutral way; this study discusses community attitudes by highlighting the gender differences. Although this article set out to discuss attitudes towards the infected, those affected by the disease are also impacted.

Various forms of stigma and discrimination, including internalised and secondary stigma, are discussed by Ogden and Nyblade (2005), who note that internalized stigma ‘occurs when one living with HIV/AIDS imposes stigmatizing beliefs and actions on themselves’. Being members of the same cultural group as their stigmatisers, they too ascribe to the same values and norms hence have the same ideas about HIV and what it means living with it. Yet they are the ones that have to bear the brunt of ‘cruel thoughtless and hurtful actions of others’ (Ogden & Nyblade, 2005; p. 32). Parker and Birdsell (2005) note that stigma is part of that identity that has to do with prejudice—the setting apart of individuals or groups through the attachment of heightened negative perceptions and values (Parker & Birdsell, 2005; p. 5). These analysts note that while the phenomenon may occur at the individual level it is also influenced by social processes related to existing assumptions and stereotypes of people as belonging to particular social categories. Parker and Birdsell underscore the idea that ‘stigma involves the social expression of negative attitudes and beliefs that contribute to processes of rejection, isolation, marginalization and harm to others’ (Parker & Birdsell, 2005; p. 5).

Ogden and Nyblade (2005) distinguish between internalized and secondary stigma. Expressions of internalized stigma include feelings of worthlessness, suicide, hopelessness, inferiority and the belief that one has no future. Secondary stigma, which occurs by association, often affects those related to the infected, such as the immediate family members, children, friends and caregivers. Ogden and Nyblade
(2005) note that family members of the infected may experience the same expressions of blame as those infected with HIV, for instance through gossip, being socially ostracised, loss of income, employment or housing. Stigma and discrimination go against the notion of human rights and equality. The study by Ogden and Nyblade (2005) found that stigma and discrimination are fanned by sensationalist public messages in which immorality is linked with promiscuity, moral transgression and bad behaviour and punishment from God, whereas normative social values are related to what is considered appropriate or good behaviour. Gender in AIDS is a cross-cutting issue where women are generally expected to be faithful, chaste and morally upright. In a study conducted in Soweto women who had experienced partner abuse were more likely to be HIV-positive than those who had not. Yet when women get infected they receive a greater attribution of blame than men (Parker & Birdsall, 2005).

Methods

Focus group discussions were conducted among men and women in the study area. Women were recruited from immunization and family planning clinics. We asked for permission to approach women at the clinic from the health authorities and we invited women for FGDs whilst they were in the waiting room. Men were recruited using the snow-ball technique from the community; it is assumed that these represented the likely partners for the target population of women to be recruited for the trial. The weakness in using this technique is that the sample might be biased, as people tend to recruit their own friends or relatives. However our fears of such biases were allayed when some of those invited did not show up and the findings show a diversity of views. In addition, we conducted at least two FGDs for each component of the study population.

The male participants were approached at shopping centres on a Saturday because that is where they usually socialise. We recruited men in the morning and invited them to participate in a group discussing HIV prevention at a specific venue and time, usually within two hours. In most of the areas the male participants agreed to participate in the discussion, except in one instance when a second group had to be reconvened because the participants had failed to turn up at the agreed venue. We know that in a number of African cultures it is considered impolite to say ‘no’; some people who had accepted our invitation simply did not turn up, which is a refusal.

At the beginning of each discussion, participants were requested to complete an anonymous attribute information sheet that asked about their ages, type of sexual partnership, partner residence and employment status. Some participants said they did not mind the research assistants filling out their information sheet since the participants considered it their job to do so. Since most of the participants were drawn from an area under demographic surveillance, they had previous experience with research related to AIDS. The discussions were conducted in Zulu by four Zulu-speaking research assistants. It should be noted that HIV status was not a criterion for selection of participants for the focus group discussions.

The objective of the focus groups was to gather from the general community views relating HIV awareness and sexual behaviour; important information for the MFS. The questions asked regarding attitudes related to how the community treats people living with HIV within the context of the family and the general community. The discussions took between an hour-and-a half to two hours each.

All interviews were recorded, transcribed and translated verbatim below each sub-section of the Zulu transcript. To ensure the reliability and validity of the data, the transcribed Zulu texts were given to an independent researcher to translate in order to verify. This approach has two advantages: first, it helps to identify and preserve the original words of the participants and, second, it assists in ensuring the reliability of the translations. Further data cleaning compared the meaning of the Zulu text with the English translation, explained the terms and contextualized usage. All the text files were imported into QSR Nud*ist 6. Transcripts were read by the two of the authors and coded independently. This ensured rigor in the analysis by the research team. The coding and interpretation of the data was then compared for consistency. There was general agreement on the major themes. All the authors discussed the coding further and reconciled any differences.

Findings

There were between seven and sixteen participants in each FGD, with a total of 107 participants (Table I). Although our focus was on the attitudes towards HIV-infected people at the family and community level, our analysis of the discussions shows that the participants’ perceptions extended to government

<table>
<thead>
<tr>
<th>Gender</th>
<th>Area</th>
<th>Mean age (years)</th>
<th>% currently employed (N students)</th>
<th>% living with partner</th>
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<td>Rural (39)</td>
<td>26.8</td>
<td>17 (5)</td>
<td>21</td>
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<td>P-urban (28)</td>
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<td>52 (4)</td>
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<td>Rural (16)</td>
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<td>P-urban (24)</td>
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Interventions. This paper presents five broad categories: (1) the socially desirable attitude, (2) compassion, (3) ambiguity, (4) discrimination and stigma and (5) hopelessness.

Socially desirable attitudes. In six out of the eleven FGDs conducted, participants provided responses which pointed to socially desirable attitudes towards people living with HIV. The participants in the women’s groups spoke in terms of what should be but not what was actually happening. The desirable attitudes in the family included treating the infected well and supporting them, meeting their emotional, material and spiritual needs and accepting them. There was also emphasis that infected people should not be ridiculed, harassed or constantly reminded of their illness:

‘We must take care of them with everything, with the food they like... some do not do this but others do it.’ (Woman)

‘We are supposed to give them love because if we are not, they will not feel that they are accepted well... They should not be ill-treated. It means that the person will not see himself as different from other people.’ (Woman)

‘We are supposed to treat them well and to take care of them and be careful not to let them to suffer spiritually.’ (Woman)

Women were sympathetic towards the infected individuals. Although they may not have had personal encounters with infected individuals, their responses point to a level of understanding of how people living with HIV should be treated but not how they are actually treated.

We have selected one quote from men, which raises the question whether the family would have cared for the sick relative had they known that she was HIV-positive:

‘My aunt was suffering from AIDS virus. We were not told at home that she was suffering from AIDS when she was sick. We were told late when she was dead... The whole family was doing everything for her they were taking care of her as just a person.’ (Man)

In two focus groups both men and women indicated that they would not change towards their friends if they knew they were living with HIV. On the level of discourse, our analysis suggests that community members know how people living with HIV should be treated; however there are challenges in translating the discourse into positive action.

Compassion. The idea of accepting people living with HIV emerged in eight out of the eleven focus group discussions conducted. Four were composed of men and four of women. The work that the women in the four groups said they were doing among people living with HIV showed their level of compassion. Similar responses were not forthcoming from the men’s groups except in one case.Analysing the discussions showed that HIV-positive people are cared for in the family. The attitudes reflected are those of real care, providing for their needs and showing them compassion:

‘That is what I am saying that we care for them...’ (Woman)

‘We make sure everything they need they get it, we take care of them.’ (Woman)

‘We take care of them and give them love.’ (Woman)

‘I looked after a sick person for a long time last year. Really I was caring for my child; she did not want bad food... I was nursing her while she was sleeping.’ (Woman)

‘We treat them the way we have been treating them.’ (Woman)

Women were most vocal about caring for the infected but there is also evidence that this role is also shared among family members. Women might be more involved due to the gender division of labour that allocates them this role. People living with HIV are supposedly given emotional support and their basic needs provided for, although it is not clear if these needs are satisfactorily met.

Ambiguity. Ambiguity is a theme we could identify in eight out of the eleven groups. The ambiguity was expressed in terms of mixed responses with regard to how people living with HIV were treated. Four of the groups comprised men and the rest women. There appears to be a co-existence of binary oppositions. Care was mentioned alongside neglect; concern alongside disinterest and compassion alongside discrimination and stigma as shown in the extracts below:

‘People are not the same. Others sympathize with them; others mistreat them.’ (Woman)

‘The problem is with the community. (When) you are just passing then you hear people talking about you, that you are HIV-positive but the family really doesn’t have a problem. Just because you are the part of the family they accept you.’ (Man)
The extracts suggest that, while some people are likely to treat those who are infected well, there are also others who mistreat and even dislike them. The men argued that, although the community might not be supportive, families are often compassionate because the infected are their members.

**Disclosure.** A sub-theme was identified regarding disclosing one’s HIV status. The analysis illustrates that compassion towards the infected seems to be conditional or dependent on disclosure. This was noted in three groups (two men’s groups and one of women):

‘I think that will make you to be free in your mind because you can not assume that such group now is talking about my HIV status because you have already told the community that you are living with HIV though others can talk whatever they like but it is good to tell them.’ (Man)

‘I think you should encourage those who are HIV-positive to tell the community about their status to avoid people talking on your back, “That so and so is HIV-positive.”’ (Man)

Disclosure of HIV status and the uncertainty among participants whether individuals living with HIV should or should not disclose emerged. Publicly declaring one’s HIV-positive status was cited as a positive thing that helps to reduce the speculation around who is or is not infected. The question of whether this leads to acceptance and reduction of stigma arises. A further question would be, for whose benefit is it to disclose? Such mixed attitudes suggest that it is difficult to point to a particular attitude as being held by a specific social category and further reinforces the notion of ambiguity.

**Discrimination/stigma.** Discrimination against the infected was identified as a key theme and was mentioned in seven out of the eleven groups but more often in the men’s groups. Four out of the seven groups comprised men. The men argued that the infected were isolated but women indicated the people living with HIV isolated themselves. Participants noted that there are those who would not like to associate with infected individuals; community members shun and refuse to greet people living with HIV, they are isolated and treated differentially (Men). The excerpts of focus group discussions below illustrate the extent of isolation that infected individuals experience:

‘Number 4 (focus group member) is telling the truth because if you are HIV-positive in other areas you live on your own, using your own dish and spoon.’ (Woman)

‘They run away and don’t like sitting where the person sat (laughing shyly). The cup and which he drank from, they don’t like using it anymore.’ (Woman)

The theme of discrimination has a number of nuances associated with ignorance, fatigue, fear of infection, denial and symbolism.

**Ignorance.** The extracts point to a level of ignorance regarding how to treat people with AIDS symptoms. It is notable that the community did not distinguish between HIV and AIDS although this distinction was made by the group facilitators. Notions exist that if one touches an infected individual they too will become infected. Community members would like to assist infected individuals but the lack of knowledge on what to do holds them back. In one women’s group it was argued that discrimination arises out of the lack of knowledge or understanding:

‘We treat them well especially when there is understanding about it but if you do not understand there is discrimination.’ (Woman)

‘In a certain homestead... I used to see these people who are suffering from AIDS. It is difficult to treat them, you see. You become unable to treat them... you say perhaps if I touch him or her perhaps I will also get it... He also sees or feels as if perhaps you are isolating him. But you discriminate against him or her because you are not taught very well.’ (Man)

‘... as nobody is sure of his status maybe he is suffering from TB.’ (Man)

This shows that when there is an understanding about AIDS, it enables people to treat the HIV-infected without discrimination.

**Denial.** Instead of openly stating that there is AIDS, individuals, families and the community in general speak of TB:

‘Sometimes you find a person drops the treatment before finishing the course then we say he is HIV-positive and sometimes we don’t believe that a certain person is under TB treatment but we assume he is HIV-positive.’ (Man)

‘According to this community and even to my family I have never heard of a person who said to
the public that he is HIV-positive, no one really in this community... Sometimes you just meet a person and feel sorry for him... maybe he told you about TB and he is on TB treatment. But according to the community and to my family nobody I meet is suffering from AIDS.' (Man)

Euphemisms are used to describe AIDS both at the family level and at the community level. Instead of saying that one has AIDS, one is said to have TB, which appears to be more socially acceptable than AIDS. While the notion that AIDS is associated with morality is not explicitly stated and instead the men excitedly speak about sex. The AIDS prevention campaigns that promote abstinence, being faithful and condomising (ABC), suggest that the disease is associated with promiscuity.

Fear of infection. Relationships may break-up due to fear of infection and the sick end up isolated. Some men emphasized that if they realized that their partner had HIV they would end the relationship. This may be genuine self-protection but is also viewed as a form of discrimination:

'It is difficult if I a male who has no virus and a woman has the virus, there will be a need to agree with each other that obviously love is eventually ending. If I continue with her I will eventually get it, you see.' (Man)

Community members are scared of infection but are not sure who is infected. They want to help, but at the same time they stigmatize.

Symbolism. The complexity around the attitudes towards infected individuals in the community was underscored by the euphemisms, symbols and metaphors used to describe the phenomenon in four out of the eleven groups. The groups comprised men:

'When you are walking in town, you see them pointing at him saying (raising and shaking three fingers) they say three (raising and waving three fingers)... Yes. That thing is troubling... you see them pointing at him saying, “Mmm... My God” (with his three fingers raised). I do not know what can be done so that the community can be educated that tomorrow it will happen to you. Some may fear even to come to town because they know it is finished for them.’ (Man)

'Like at our homes they told us that as you go at night you would come with HIV (they laugh) instead of being advised in a good manner not to be intimidated by HIV-positive...’ (Man)

Afraid of mentioning AIDS, some people flush three fingers when referring to the disease and when verbalized people speak about ‘magama mathathu’ (the three words), instead of saying HIV or AIDS. Any other term with three letters is used as a euphemism for HIV, for example ‘OMO’ (washing detergent). HIV was also connoted to mean ‘Hlengiwe Ignatious Vilakazi’ (HIV), which would be the name of a woman.

The gestures indicate that stigma in the community is such that people do not discuss but rather use gestures and symbols with reference to AIDS. Where discussion occurs, it is surrounded with proverbs further clouding the meaning of what is actually under discussion unless the meaning is explicited. Such proverbs were used as a justification for stigmatizing people living with HIV, as it was argued that they were infected because they refused to heed advice and therefore they were totally to blame for their condition. Such attitudes have been used to neglect and isolate the infected. Such notions also suggest that the view of the community is that AIDS can be prevented by individual action:

‘That means there are common words that are used in the community like ‘isalakutshelwa sibona ngomopho’ (literally means those who refuse to heed to advice will bleed). (Man)

‘They say, “No. They will say I am going to kill the nation”. Others say, “I am not dying alone. Let me hunt for others”. That is why we see this pandemic travelling this fast. Each infected person is saying, “I want to clear off”... he says “I am not sleeping” (be on a mission to spread it everywhere)... ”Ngifuna ukuqotha imbokodo nesisekelo” (I want to finish everybody).’ (Man)

These extracts also highlight the danger that discrimination and stigma pose to communities. Some of the infected who might know their status fail to disclose and, instead, set out to infect others arguing that they have already been labelled as destroyers of the community. Thus discrimination and stigmatisation are not only a threat to the infected but to the uninfected also.

Hopelessness and fatigue. There is no doubt AIDS causes strain in a household. The care-givers can genuinely become exhausted and lose hope that their efforts are worthwhile. The quotations illustrate the frustration and helplessness associated with the reality of AIDS-related long-term illnesses:

‘I am saying that it is a problem because if it has infected you it is obvious it is not curable and also
you are cared for by nobody. Even neighbours
eventually do not care for you... When it starts
the neighbours care for you, but gradually they
become disinterested.’ (Woman)

‘... I can imagine how many days, weeks and
months I will be taking a person and putting him
out in the sun and he also says he doesn’t like the
sun, and I also take and put him in the shade and
he also says he doesn’t like the shade. After that he
says he does not like uphuthu (stiff porridge) and
imifino (vegetables) as if he can always eat bread.
No it is that, that makes love from people to
decrease.’ (Man)

‘Hope is lost because there is no help available so
that you get a chance to raise your children, which
you fear to leave behind.’ (Woman)

Hopelessness as a theme emerged in five out of the
eleven discussions, four of which comprised women.
People living with HIV were perceived as not
deserving care because ‘they will eventually die’
(Woman). Others disagreed with this view and
asked, ‘How can we not care?’ The sense of hope-
lessness emerged in women’s responses without any
attempts by the facilitators to probe:

‘... the parents and relatives lose hope so much, as
the community we say “she is better un cared for
because all is waste when you’ll end up without
her anyway” ... “You are trying for nothing”’.
(Woman)

‘We treat her but realizing that we are wasting
time.’ (Woman)

‘... You are aware of your HIV status but still
cannot accept yourself when you suddenly have
minor sickness you know you are going to die.’
(Woman)

These extracts point to the sense of hopelessness in
giving care to the infected by both the infected and
affected family members.

View of government interventions. Participants also
referred to interventions such as the prevention
of mother-to-child transmission and anti-retroviral
treatment (ART). At the time, the government
ART programme had not been rolled out in the
area and they were clearly longing for it. They felt
that, while the state intervenes to save children, little
is done to support the care-givers of the orphans:

‘... The government has done something to pro-
tect the unborn children but nothing is being done
for those who take care of these children when
their parents have gone.’ (Woman)

‘... but we are requesting a lot (stressing) the
muti4 (medicine-here refers to anti-retrovirals)
must really be found ...’ (Woman)

It is notable that, in the above extracts, the partici-
pants agreed with these views. The idea that the state
should provide support to those who care for AIDS
orphans is reflective of the expectation by society
that the state should provide for the poor. South
Africa has a grant system in which vulnerable groups
such as poor children, pensioners and the disabled
receive monthly grants.

In summary, the sense of despair, loss and hope-
lessness of providing humane care to individuals
living with HIV raises questions on how commu-
nities ought to respond and how they should be
assisted. The loss of members has made this rural
community feel that they are in a dilemma, caring for
their sick members while knowing that regardless of
how well they do it, all their efforts amount to
nothing.

Discussion

This paper set out to explore attitudes to individuals
infected with HIV in a rural community of South
Africa. The findings point to attitudes operating at
the individual, family, community and state levels.
Since individuals with HIV are not easily identifiable
in the community, there was a sense of fear and
suspicion regarding who is or is not infected where
participants wished that those infected would dis-
close their status. Some of the participants in our
study perceived that individuals who fail to disclose
their HIV-positive status are vindictive and respon-
sible for spreading the virus in the community.

The women’s focus group discussions noted that,
at family level, the attitude to the infected is
generally portrayed as compassionate. Although as
the disease progresses to AIDS, the family attitude is
still caring and compassionate, frustration sets in due
to having to deal with a dependent adult. Commu-
nity attitude towards the infected is more complex
and varies between compassion to those who dis-
close, to stigmatisation of those who fail to disclose
and show signs of infection with HIV. When HIV
progresses to AIDS, it was reported that afflicted
individuals become isolated in their own homes with
little community support. A limitation with our data
collection method is that it is based on how people
react to those living with HIV. Participants could
also be drawing this on the government campaign
against stigma, which speaks against isolating AIDS...
patients and encouraging care and support by the community.

Although state intervention in addressing AIDS through the prevention of mother-to-child transmission and the provision of nevirapine in public hospitals is appreciated, such interventions are interpreted as being partial, for while these address issues relating to children affected by AIDS, the study participants felt that these interventions failed to address the plight of the care-givers, who are often women. The call for the provision of ART came from women who are the main care-givers for their sick children. This study was conducted before the implementation of ART in government healthcare facilities in 2004. The programme is likely to lengthen the lives of individuals already infected with HIV but the question of support to the care-givers of AIDS patients and orphans remains a challenge in rural South Africa.

Specific attitudes identified were the socially desirable attitudes, compassion, ambiguity and discrimination and stigma. The focus groups suggest that community members know how to treat people who might be infected—with compassion—however, their actual treatment of the infected is different. The desired positive attitudes could be reinforced by community-based organisations such as faith-based institutions and AIDS support groups who can assist through providing emotional support. One such group providing support to people living with HIV in the study area is Mkalukulu Nathi (God is with us) a home-based care programme sponsored by the Catholic Church.

Gender roles relegate women to the tedious task of caring for the infected, questions arise regarding the role of men in the process. It is notable that, although some men spoke about care for the sick, other discussion groups were silent about the role of men in this regard. Men in this community carry the sick in and out of their houses and provide their basic needs such as food. Women were most vocal regarding their role in caring for the infected. Care for the sick has shifted the burden from the hospitals to the home. The privatization of care implies that the cost is no longer borne by the state but by citizens, the majority of whom are women who have neither the support nor the resources to provide adequate care. Internationally, 90% of care due to AIDS illness is provided by women (UNFPA, 2004). Consistent with the existing literature, our study brings out the voices of women who have been involved in caring for their adult children. Unlike previous studies, in which care-giving is assumed to be wholly the women's responsibility, men in our study voiced their involvement in caring for sick relatives alongside other family members.

The South African government has introduced a grant for those infected with HIV but little or no support has been extended to the care-givers, an issue that comprises the exploitation of women's labour. Added to the physical and emotional drain are the economic and social costs of caring for people living with HIV that have to be borne by the family. As women continue to care for the infected adults and affected orphans in rural KwaZulu-Natal, they feel that their work goes unrecognised and unappreciated, hence the argument that the government have taken action to protect the children but little has been done for those that care for the orphans. State attitude to care-givers of the HIV-infected and affected may be interpreted as being indifferent. The role of women in caring for the infected adults, children and affected orphans perhaps explains their compassionate attitude. However, this study suggests they are also the most hopeless. Whilst HIV infection may be the problem of an individual, the impact in rural areas is also borne by those that live with and care for the sick, as well as community members. This study argues that those involved in caring for the infected need to be helped not to lose hope because, when they do, their caring work becomes meaningless and may lead to greater stigma and discrimination against the infected.

The community too is faced with a dilemma. There are those with AIDS symptoms, but it is difficult to know who is infected and who is not. There is willingness to help those with symptoms, but there is also fear of infection, hence the suggestion that the infected should confess. Disclosure might protect the uninfected but the consequences for the infected can be positive or negative. The positive consequences might be in the form of support from the community because they would know how to relate to those who are open about their status. However there are also serious consequences of disclosure particularly for women. The example of Gugu Dlamini, a woman from Durban South Africa, who was stoned in 1998 for publicly declaring her HIV-positive status, is perhaps an extreme illustration of the consequences of disclosure (http://new.hst.org.za/news/index.php/20010904). Yet Gugu Dlamini is a metaphor for the African woman who is stigmatized and discriminated against in subtle and direct ways because of her actual or assumed HIV-positive status.

In the past, people with certain disabilities or terminal illnesses like cancer experienced stigma and discrimination but the AIDS pandemic has brought about stigma on an unprecedented scale. The question, then, is what is it that makes AIDS such a stigmatised disease? Parker et al. (2002) note that to understand stigma and discrimination there is
need to explore how it interacts with pre-existing prejudices based on sexuality, gender, race and poverty. The issues associated with the disease and its progression through body wasting and opportunistic infections put the mortality of individuals into the picture long before the disease claims their lives. It would be expected that, having moved to the general population, the stigma around AIDS would have declined and people would be motivated to change their attitude. Stigmatising people with the virus, as noted in a focus group in the Zulu phrase, ‘Ngifuna ukuqotha imbokodo nesisekelo’ which means ‘I want to finish everybody’, seems to help fuel the epidemic.

In our discussions participants said, ‘some people say this, some people say that’, thereby highlighting the contradictory and ambiguous attitudes towards individuals infected with HIV in this high prevalence area. We argue that with more open discussion regarding AIDS, how to prevent it and how the infected can protect themselves from re-infection, the stigma and discrimination around the disease would be reduced.

Most studies generally outline expressions of stigma and discrimination that are common among contexts. There is a glaring absence of the symbolism that the AIDS epidemic has generated and which also contributes to stigma and discrimination of the infected. Symbolism, as discussed by Giddens (1996), is also a use of language that allows us to become self-conscious, being aware of our own individuality and the symbol in this regard is important. A symbol stands for something else. In discussing symbolic interactionism, Giddens (1996) posits that we live in a symbolic world and we constantly look for clues about how to interpret what others intend. The notion of symbolic interactionism helps us to make sense of what others say. Symbolism uses a subtle and complex process that shapes the interaction between individuals.

In this community, as in the rest of South Africa, the use of symbols is common. Symbols are used to denote political party affiliation; public transporters use symbols to denote their destination and youngsters use symbols to communicate with one another. Similarly the metaphors used express complex ideas about AIDS in the local context. The gestures used, such as the three fingers to denote HIV infection, express symbolically a condition that is stigmatised in this community. The use of symbols in the case of HIV may be construed as the community’s way of making sense of AIDS in their community. However this raises the question of whether using symbols to identify or discuss those infected is less offensive than actually speaking openly about it. In the context of AIDS, symbolism plays a major role in the way we interpret attitudes towards those infected and affected by the epidemic. Much as the notion of HIV/AIDS symbols might be a global phenomenon, the symbols used, and their significance, is contextually localized.

Success in dealing with the AIDS epidemic can be achieved if different stakeholders are usefully engaged in providing their input. This entails getting the views of different social categories in the community regarding prevention, treatment and care and using these to design interventions. The different levels in which attitudes were identified suggest AIDS interventions need to address individual, family and community levels.

**Conclusion**

This paper highlights that families are compassionate and supportive to their members but community attitude is differential and stigmatizing. Interventions addressing attitudes towards those living with, and affected by, HIV need to take into account the gender dimensions for the interventions to be successful. The lack of discussion around the disease and the use of gestures, symbols and proverbs with reference to those infected suggest that fighting stigma and discrimination also has to be conducted at the level of discourse. Making AIDS part of the daily discourse of the community will help people to deal with the issues around it, as well as to accommodate their infected members. Addressing the AIDS issue in South Africa requires that the infected find a safe space in which to disclose instead of deny it; it also implies that the society clearly names the disease and openly speaks about it. Male involvement in caring for the infected and affected exists and needs to be highlighted.

The transfer of the burden of care to the home, and therefore to women, moves the costs from the state to the citizens, particularly women. State support is therefore necessary in the form of a grant, basic medical equipment and counselling for caregivers if the burden of care on households is to be eased. The introduction of ART in the public health sector in South Africa raises the question of how it will impact on disclosure of HIV status within the general population. The range of attitudes and how these are reflected at different levels provide contextual information to help in the design of AIDS interventions in the community, particularly with the shift towards a state-driven ART programme. The success of AIDS intervention programmes in the community requires the understanding of attitudes and the levels at which these are held at the individual, family and state levels. Change in
discriminatory attitudes requires greater awareness about AIDS.

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Notes
1 The term used in describing an individual in Zulu is gender neutral but when translated into English the issue of specifying gender arises. Henceforth, gender specific terms he/she in the quotations are used to put across the point. Where reference to gender is made this is highlighted in the quotations.
2 The three fingers’ sign is used to symbolize HIV. Sometimes the Euphemism magama mathathu (three words) is used in referring to HIV. Thus instead of saying directly that an individual is suffering from HIV, either the three finger sign or the euphemism ‘three words’ is used.
3 Connotes that those who are HIV-positive are paying for their actions.
4 This is a direct translation from the Zulu term for medicine. However although the term gives the connotation of a herb, in actual fact, it denotes antiretrovirals.

References