

HIDDEN FROM VIEW

COMMUNITY CARERS AND HIV IN RURAL SOUTH AFRICA

This exhibition celebrates the often hidden work of community-based carers in poor rural communities in South Africa. They provide vital and often unpaid support to people living with HIV, helping them to overcome the barriers they face to making their right to health a reality.

Over the past two decades the HIV epidemic has had devastating effects on the health and well-being of communities in South Africa. More recently, access to life-saving antiretroviral treatment and care through state and non-governmental programmes has expanded remarkably. Both the improved ability of people living with HIV to maintain their health and stronger government leadership have helped reduce social discrimination.

But challenges remain. People living in rural areas still struggle to gain access to the food and services they need to maintain their health because of poverty and because they live in remote areas. In addition, women's ability to protect their health continues to be affected by discriminatory practices, economic marginalization and violence. The state must ensure that there is no discrimination in access to health services as part of making the right to health a reality.

The voices of the carers in this exhibition come from a particular area of KwaZulu-Natal, the province most affected by the HIV epidemic, where approximately one quarter of 15-49 year olds are infected. The concerns they express have a resonance across the country. Their role needs greater recognition and support as South Africa continues to develop its response to the epidemic.

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“Being a carer comes from loving or having a passion for working with the community. There are many challenges facing the community, and it can be difficult to get help from outside. It is useful for there to be someone who understands the community and can give care.”

“When I wake up in the morning I prepare my children to go to school. Then I go out. I am able to visit three homes if they are close together but the days are short.”

“If I find that someone doesn’t have food, I’ll take from my own groceries. If a person is immobile, I’ll cook for them and make sure they have taken their treatment. If someone comes to me and says they don’t have money for transport to the clinic, I try and help them with the money.”

Thandi Mdletshe, carer

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Good nutrition is important for people living with HIV and improves the benefits for them of taking antiretrovirals. Food insecurity in rural areas, however, is undermining their ability to maintain their health, partly because of the widely held but incorrect belief that antiretrovirals should not be taken on an empty stomach. Worryingly, carers report that some community members tell them that they had abandoned their treatment because they did not have any food.

“When people come to our home, especially because my husband is the induna [local traditional leader], they come looking for help, and if someone comes and is hungry and I know they are on antiretrovirals, then the first thing I will do as a home-based carer is to cook for them and give them food, then they can start talking about other problems.”

Ma Gwala, carer



Kitchen in a rural home, KwaZulu-Natal province, May 2011.



“There is no food in the house, in the cupboard or the pots. A sick person lives inside the house and finds taking treatment problematic on an empty stomach.” A group of carers wrote this caption, describing this kitchen in rural KwaZulu-Natal, in June 2011.

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“When [this person I care for] is very ill, I take her to my home and I look after her and give her food on time. As soon as she is feeling a bit better I give her food and take her back to her home so she can look after herself. This week on Friday, she started antiretrovirals again. She is not in a good state, not good at all. She has serious problems with her stomach. I haven’t contacted her as I have no airtime [cellular phone credit] to find out how she is.”

Glorya Dladla, carer, June 2011, referring to a patient who abandoned her treatment for 18 months as she was unable to afford food to take with her treatment.

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Many people supported by the carers rely on social welfare grants or a family member's pension in order to meet the costs of food and other basic needs.

“One concern I have is that people end up relying on the pension grant of an old lady in the house to live. That pension will buy food for everyone in the household. With that food, a person taking antiretrovirals can continue taking treatment, but if things don't go well and that grant stops, well, then there is no food, and that person stops taking the treatment.”

Nelisiwe Masondo, carer

Rural homesteads, KwaZulu-Natal province, June 2011.

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“My mother only recently got the pension grant, but before that she didn’t get it and what would happen is that we couldn’t afford food. And my child [who is HIV positive] would tell me he wasn’t taking the medication without food, if there was no food he wasn’t taking it. Then he got sick and went to hospital... but that doesn’t happen now [because of the pension money]”

Community member, pictured

Member of a rural community, supported by a carer, KwaZulu-Natal province, May 2011.
The carer also helped her mother to obtain a state pension.

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Kitchen in a rural home,
KwaZulu-Natal province,
June 2011.

“If I get to a place and find that someone is very sick, I go back home and look at my own foodstuffs and see how I can help them. I don’t give them food I don’t want; I give them food I like.”

Margaret Khumalo, carer

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Although HIV services have been increasingly decentralized in the last few years, people living in remote rural areas still have less access to health care than those living in urban centres.

“There are lots of problems in our communities. There is no clinic in our community, there is no transport or roads and when we call for ambulances, they don’t come, or they come very late.”

“My greatest desire is for a clinic to be built close by.... Currently, if someone is taking antiretrovirals, they need to travel far to the clinic to get their treatment. If that person doesn’t have money, then you as a home-based carer in the community need to find means to help them afford the costs of transport. If you have money then you give it to them. Often the person taking antiretrovirals doesn’t even have a social welfare grant, and you are the only one left to help them.”

Gloria Dladla, carer

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Long journeys and the cost of transport create barriers to access to HIV clinical services in poor rural areas.

“As carers, we really try and avoid the situation where someone is not able to continue on their treatment because they can’t afford transport.”

“A patient gets antiretrovirals on a particular day and needs to go back to the clinic on a particular day to get the next month’s supply. But because of not having money for transport, they are not able to return to the clinic on time.”

“In that situation, I try and find money for the person because I know what the consequences are. I know that the person will relapse, and may even die without treatment. I also know that if a person takes antiretrovirals, then stops, then starts again, then they are not as efficient as they should be.”

Thandi Mdletshe, carer

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“One person that I support can’t get to the clinic because she can’t afford to get there. This person is in a situation where death is imminent.”

Zikhokhile Ntombela, carer

“When someone who asks me for money for transport, I might not be able to give them the 16 rands [approximately US\$2] for a shared taxi but I might be able to give them 11 rands for the bus. When someone needs money from me and I don’t have the money, that’s very difficult for me.”

Sihle Xulu, carer

Three carers walk to a rural homestead, KwaZulu-Natal province, June 2011.

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Some patients are unable to reach clinics or referral hospitals because of poorly maintained roads, the impact of bad weather or because they live a long way from a main road.

“The bus stop is close by, but if it rains, there is no way you are going to be able to get a bus. Taxis don’t come into the community because of the poor state of the road.”

“The road becomes very slippery. So what will happen is that in the rain the bus won’t take the whole route, it will only go through a portion of the route where it is safe to drive.”

“You can’t travel anywhere if it is raining. Even if you call an ambulance, if it is raining it won’t be able to come.”

Community member, pictured

A member of a rural community living in an area where there is no transport in adverse weather conditions, KwaZulu-Natal province, June 2011.

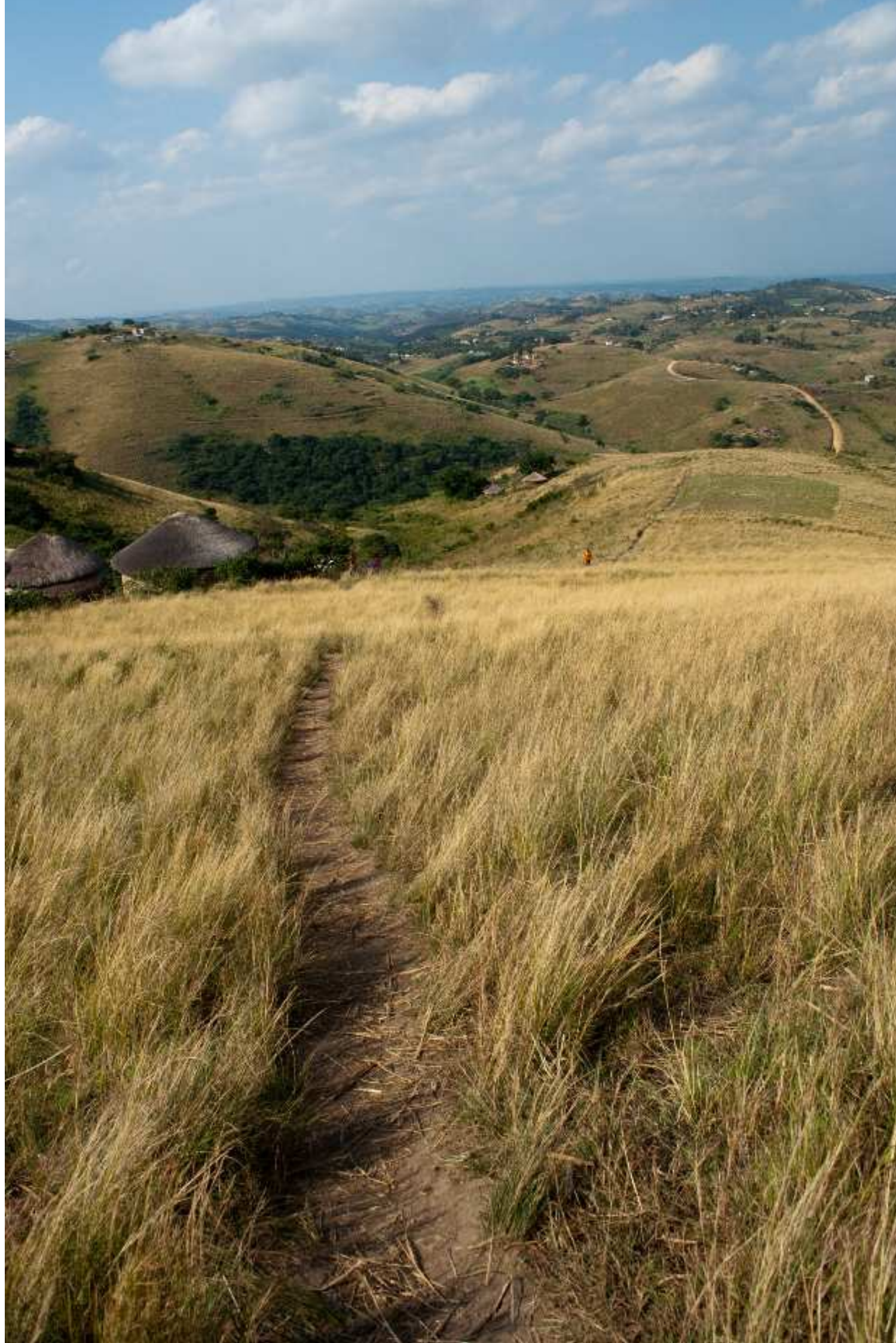
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“We use a wheelbarrow [to take someone who is unwell to the main road]. But it is difficult. And it is very steep, a person may get harmed in the process.”

A patient who lives a long walk from the nearest tarred road

“There is a 50 minute walk from the community to where the buses are. The only bus leaves at 8am from the main road so you have to leave quite early to catch it.”

Hlengisiwe Mpanza, carer





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Carers sometimes become involved in supporting women who are experiencing domestic violence. Women exposed to abuse from their partners and denied their sexual and reproductive rights are at an increased risk of HIV infection.

“Domestic violence is a widespread problem for the people that I care for. Although some women try to hide it, I might find out about it through rumours, from someone saying so and so was physically abused by their partner.”

“One of the women I work with is HIV positive and is scared to tell her partner that she is HIV positive and scared to ask him to use a condom. She is frightened that it will look like it is her fault, that she will be seen as the infector.”

“I said to her, well, you don’t know what your partner’s status is, so maybe the best way to deal with this is that you both go for the test, and deal with the results together. But she is too scared to do that.”

Sihle Xulu, carer



Thembi Xulu, carer,
May 2011.

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More women than men are infected and affected by HIV. In KwaZulu-Natal province, almost 40 per cent of women attending antenatal clinics are HIV positive.

“A woman came to me who needed help because she had been physically abused by her husband. She said he wanted to have sex with her and she had declined because she is unwell.”

“I explained to the husband that according to law, you are actually abusing your wife.”

“I was concerned to ask her to get an HIV test, so I suggested she go to the clinic to get a blood test. But the husband won’t let her go to the clinic. He won’t really let her do anything that will protect her health.”

“I feel this is a heavy burden. I can see she is unwell, and also unwell in her spirit. I want to help her but I don’t have the means to, I don’t know how.”

Thembi Xulu, carer

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“We have an arrangement in the network which loosely means that if a woman wants to escape from her community, she can go to one of the other carer’s homes in a completely different community.”

“This is because if a woman wants to run away from her house and stay in her own community, it is not a hundred per cent safe because the abuser can still come to the house. If another carer elsewhere in the network offers their house, there will be somewhere for her to go safely.”

Sihle Xulu, carer

Entrance to a rural home, KwaZulu-Natal province, June 2011.

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Closed door to a rural home, KwaZulu-Natal province, June 2011.

“Sometimes it is very difficult to support a woman experiencing domestic abuse who wants to escape that situation. If we advise the woman to leave the house, the husband, because he knows us, and knows our work in the community, accuses the wife of doing our bidding. Also he will become suspicious that we tell people what is going on. This is not the case, we don’t go spreading news about what is happening in people’s households.”

Nonhlanhla Khumalo, carer

“If there is a situation with child abuse or domestic violence in the community, the carers can end up becoming victims in that community.”

“There is no police support in the rural communities. The police stations are very far away and there is no public transport to get there.”

Patti Joshua, coordinator of Senzokuhle Community Based Organization Network

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Women carry the burden of largely unpaid care work within rural households and communities affected by HIV and AIDS, further entrenching gender roles. The scarcity of jobs in rural areas and long-established patterns of men's migration to urban centres for work sustain this imbalance.

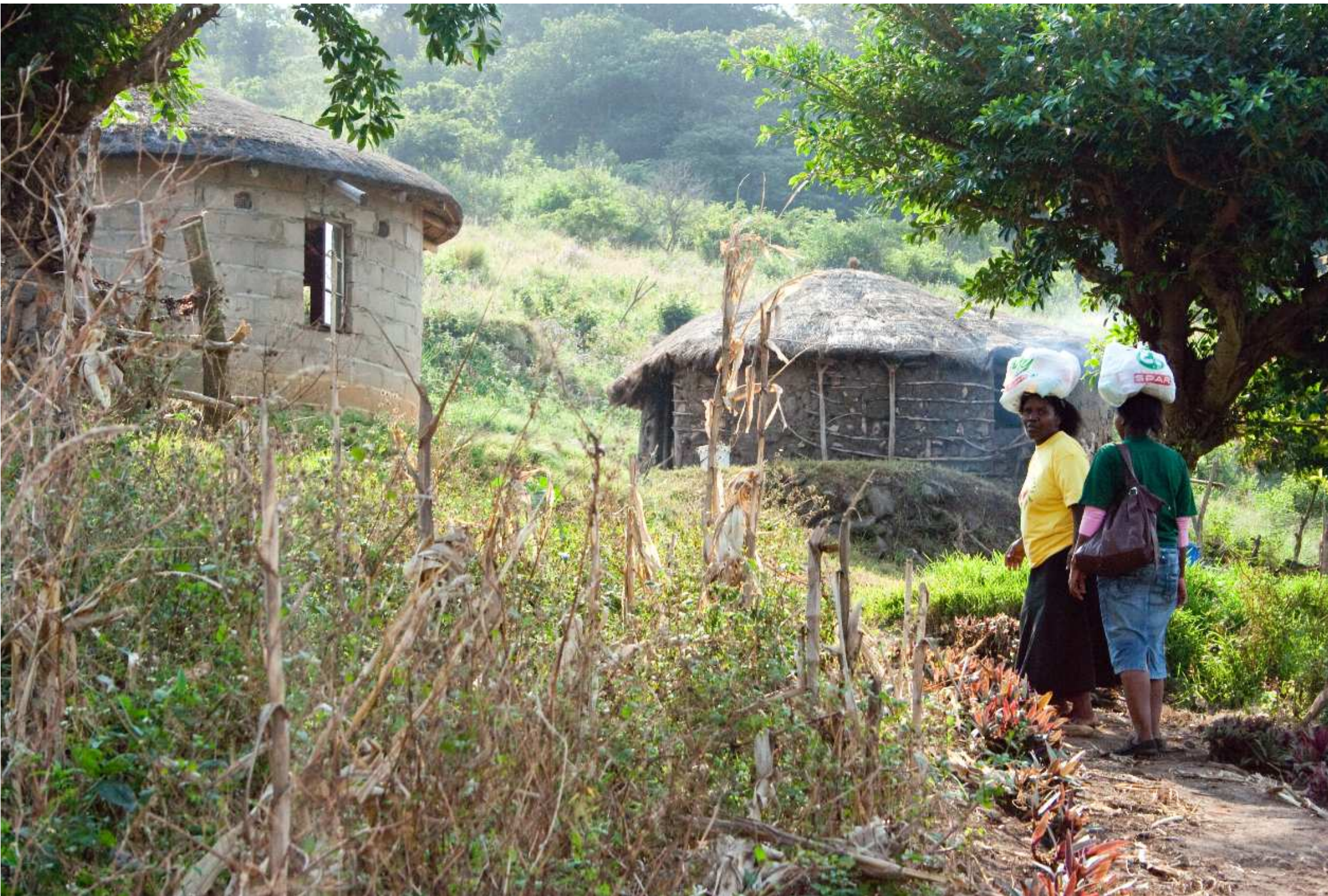
“As far as I know it has always been women that do care work. I personally wish that there were men carers so that the men can talk to each other. Sometimes you as a woman feel uncomfortable or scared talking to men about these issues, and it happens the other way round also, that they are uncomfortable talking to you.”

Hlengisiwe Mpanza, carer

Woman walking up a road carrying a load, rural KwaZulu-Natal province, June 2011.



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Carers sometimes have to struggle with the persistence of HIV-related stigma in order to support people who are scared to learn or disclose their HIV status.

“What sometimes happens is that I recognize that the person that I am supporting is living with HIV because they may hide their status. They will say they have TB.”

“We can say if you get tested and find out your status you’ll be able to get antiretrovirals and be able to work and be independent and function. But the one thing we don’t do, we don’t say to a person we can see that you are HIV positive. We just encourage people to take the test.”

Nonhlanhla Khumalo, carer

Two carers walk towards a homestead, KwaZulu-Natal province, June 2011.

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“People are grateful for the work that we do. They feel they can’t go to a hospital or clinic and get tested for HIV because if they are told they are positive they won’t be able to handle it. What we do is we sit with them and talk and encourage them to go to the health facility. You can see that when they start treatment they are burdened, but after some time, they get better, they get fat.”

Nelisiwe Masondo, carer

A woman living with HIV holding antiretrovirals, June 2011.

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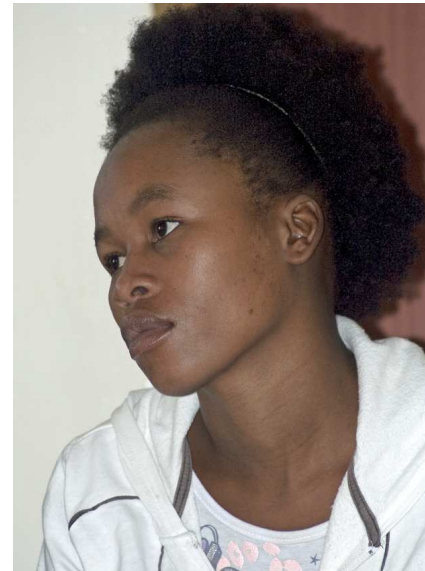


Top row left to right: Ma Gwala and Zikhokhile Ntombela; Hlengiwe Mpanza.

Second row: Fikisiwe Ndlovu; Margaret Khumalo; Margaret Khumalo, Thembi Xulu, Patti Joshua, Fikile Magubane, Hlengiwe Mpanza.

Third row: Sihle Xulu crouching, Sebebzile Biyele playing with her hair, and Fikile Magubane in the background; Nonhlanhla Khumalo; Fikile Magubane.

Bottom row: Nelisiwe Masondo.



Amnesty International wishes to thank all the carers who shared their stories and opinions with us, including those featured earlier and those pictured here.

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The Senzokuhle network of community-based carers, some of whom are featured here, seeks to raise awareness of the barriers faced by women living with HIV in their communities in making their right to health a reality.

Senzokuhle and Amnesty International have collaborated in this initiative which also aims to increase recognition of the importance of community-based care work in supporting people living with HIV and AIDS. To contribute to wider civil society campaigning, we are urging the government of South Africa to ensure that such care work is valued and resourced. We believe that this will strengthen the state's efforts to meet its obligation to ensure non-discriminatory access to health services.

Amnesty International has campaigned locally and internationally since 2008 for action to overcome barriers to the right to health in South Africa. It has called on national and provincial authorities to address these barriers with the support of donors and civil society. Its research and advocacy have focused on women living with HIV and the impact on their right to health of factors including gender-based discrimination, poverty and poor road and transport infrastructure in rural areas. This work is part of our global Demand Dignity campaign, which seeks to enable people living in poverty to claim their human rights.

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