



[Catherine Campbell](#), Y. Nair, S. Maimane and Z. Sibiya

Home based carers: a vital resource for effective ARV roll-out in rural communities?

Original citation:

Campbell, Catherine and Nair, Y. and Maimane, S. and Sibiya, Z. (2005) Home based carers: a vital resource for effective ARV roll-out in rural communities? *AIDS bulletin*, 14 (1). pp. 22-27.

Copyright © 2007 Medical Research Council.

This version available at: <http://eprints.lse.ac.uk/2799>

Available online: October 2007

LSE has developed LSE Research Online so that users may access research output of the School. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Users may download and/or print one copy of any article(s) in LSE Research Online to facilitate their private study or for non-commercial research. You may not engage in further distribution of the material or use it for any profit-making activities or any commercial gain. You may freely distribute the URL (<http://eprints.lse.ac.uk>) of the LSE Research Online website.

This document is the author's pre-publication manuscript version of the journal article, and does not incorporate any revisions agreed during the peer review process. You are advised to consult the publisher's version if you wish to cite from it.

<http://eprints.lse.ac.uk>

Contact LSE Research Online at: Library.Researchonline@lse.ac.uk

Home based carers: a vital resource for effective ARV roll-out in rural communities?

*Catherine Campbell, Yugi Nair, Sbongile Maimane and Zweni Sibiyi
Centre for HIV/AIDS Networking (HIVAN), University of KwaZulu-Natal,
Durban.*

Prepublication version of paper that appeared in *AIDS BULLETIN*.

Please use the following citation:

Campbell, C, Nair, Y, Maimane, S and Sibiyi, Z (2005a) Home based carers: a vital resource for effective ARV roll-out in rural communities? AIDS Bulletin, 14(1), March 05, 22-27.

The proposed roll-out of ARV treatment provides the first glimmerings of hope for people living with HIV/AIDS – a disease which up to now has been effectively a death sentence. Besides providing hope for individual sufferers, the availability of ARV treatment is widely regarded as a key pillar of effective HIV/AIDS management at all levels. However, the roll-out process is associated with risks and fears, as well as hopes and opportunities. This is particularly the case in the face of the poverty and under-resourced health facilities that characterise many of the more remote communities in which HIV/AIDS flourishes. One of the most frequently mentioned fears relates to the risk of the development of long-term drug resistance due to poor adherence to the treatment programme, as has been the case with tuberculosis (TB) in some settings (Stevens et al., 2004).

The WHO has singled out the challenges of

- careful forward planning
- strengthening health systems; and
- building on the practices of primary health care

As crucial to the success of an ARV programme in South Africa (Walt, 2004).

In South Africa, many challenges face those seeking to implement effective primary health care in remote rural areas, leading some to argue that the infra-structural preconditions for effective roll-out are lacking. Others point out that effective ARV treatment has been implemented in a range of equally challenging settings, and that if the political will is there, much can be done, even within current constraints (Farmer et al., 2001; Obwogo, 2002). It is this view that informs the current paper.

Strong community participation has long been considered a cornerstone of effective primary health care (Baum, 1998; WHO, 1978, 2003). Despite this, discussions of the human resources necessary for effective roll-out tend to focus on medically trained personnel, such as doctors and nurses. Less

attention is given to the role that grassroots community representatives will need to play in ensuring the success of successful treatment, especially in 'hard to reach' settings. It is this latter group that are the focus of this paper.

In focusing on this neglected group we draw on a case study of HIV/AIDS management in the remote rural community of Entabeni¹ In KwaZulu-Natal province to highlight the key role which the full-scale involvement of local community health workers and home-based care volunteers will need to play in ensuring effective roll-out. Cadres of local health workers already exist in many areas in South Africa, where they often offer key services in the areas of AIDS- care, cholera prevention & the support of TB patients (DOTS) (Maimane et al., 2004). We argue that this cadre of grassroots workers constitute a vital but currently under-appreciated resource, and that urgent planning is needed to formalize a role for them, and to think through issues such as training, support and some form of small remuneration to cover their basic expenses – in order to maximize the role they could play in bridging the gap which exists in many communities between the formal health services and the people.

Method

We draw on a detailed case study of community responses to AIDS in Entabeni, a traditional authority in KwaZulu-Natal province where 16% of adults and 36% of pregnant women are HIV positive. The research was conducted in partnership with the area's traditional chief and local home based carers. Our study included 60 in-depth interviews and focus groups with a wide range of local residents (including people living with HIV and AIDS, carers, community health volunteers, local leaders) as well as representatives of various local private and public sector groups (hospitals, clinics, departments of health & welfare, local chamber of commerce).

¹ The name of our study community has been changed to protect the anonymity of our research informants.

In this paper we begin by highlighting the general context of ill-health and the paucity of health services, in the interests of highlighting the role that volunteer health workers have carved out for themselves in response to this situation. This frames our final section which focuses more specifically on the potential role of home-based carers in filling many of the gaps in current primary health care services, and in facilitating effective ARV treatment in remote areas.

Coping with 'sickness' in Entabeni: context and support structures

Ill-health is rife in Entabeni, with high rates of cholera, TB and 'sickness', a euphemism for AIDS. With over 40% unemployment, and a natural environment challenged alternately by disabling floods and droughts, with poor hilly terrain that makes subsistence farming difficult, poverty and hunger are rife. This has multiple implications for the care of the sick and their access to health facilities. Many sick people do not have access to regular or nutritious meals. Home based carers commented that many patients were not complying with various forms of medication because they were reluctant to 'take pills on an empty stomach'.

Formal infrastructure is poor. There are few roads (none tarred) or telephones, which means that many families and households are physically isolated. People don't have access to flush toilets or clean running water. They fetch water from the river which is also used by animals and for washing clothes. The lack of clean water often leads to outbreaks of cholera. Households also do not have electricity, thus limiting their access to television and radio and hence any form of health education that they could receive via these channels of communication.

Many complained that they were unable to keep their appointments at hospitals or clinics (follow up visits, medication) or to access welfare services (grants, assistance with food parcels) because of unaffordable transport costs. To access public transport patients would have to walk long distances, sometimes being carried by carers on their backs or being pushed in

wheelbarrows if they were too ill to walk along the hilly and dusty terrain to access buses. The poor road system, combined with the lack of regular transport, means that even those who could afford the journey to the health or welfare facility were often unable to make it to their destination.

Stigma and denial of the existence of HIV/AIDs was identified as a major stumbling block by many people we interviewed (Campbell et al., 2005a, b). Very few people talk openly about their HIV status. Carers themselves (be they family members or volunteer health workers) are often unaware of what the patient is suffering from. Aside from the carer being at risk of infection, informants feared that patient refusal to disclose their status to family members and carers was a potential obstacle to the 'take up' of antiretroviral treatment, and could limit adherence to drugs and/or the ability of carers to monitor drug regimens.

Public sector support

Formal welfare structures play a minimal role in HIV/AIDS management in the area. Despite the formal mandate for welfare workers to adopt social development approaches to HIV/AIDS, social work input tends to be limited to facilitating general applications for state grants, including those for people living with HIV/AIDS (PLWHAs and orphans). 'Pension officers' do visit the local tribal court regularly, ostensibly to facilitate grant applications. However, where grant enquiries require the access to computer records, people are required to visit their offices more than 50km away from the area, a journey unaffordable by many.

Hospitals and clinics are situated in neighbouring towns. While a mobile clinic visits the area once a month, services are basic, with no specialist services for VCT or PLWAs. In rainy months, the mobile clinic does not visit. The clinic is staffed by nursing staff, with no doctors, equipped to deal only with very basic illnesses and the very limited dispensing of medication. For the monitoring of and dispensing of more 'serious' medication - for tuberculosis for example –

people must attend the nearest permanent clinic (20km away) or hospitals (30km away).

Community members, especially the old and frail complained bitterly about what they regarded as the 'injustice' of inaccessible and poorly co-ordinated medical services. An extract from our interview with Mrs N, a 68-year-old woman, echoes some of this frustration.

I asked the nurses at T Hospital to transfer me to M Hospital because T is too far from here. At M they said I should get my tablets from the mobile clinic that visits this area once a month. My problem is that when it rains, this mobile clinic does not come here because the roads are very bad. Because of this, they told me to go to N (a local clinic approximately 20km away) to collect my medication. To go to N, I have to hire a car, as I can't walk. To go to the main road I have to use a chair to support me when I walk. When I lived in the township when I was younger, everything was near. I would get transport right in front of the clinic. Here the medical services move me from one place to another. I also have to renew my medication at the hospital. Where am I going to get all this money? When I go to hospital, I have to ask my niece to accompany me. I also have to pay her fare. Where do I get that kind of money?

Aside from the fact that health facilities are not easily accessible to people within Entabeni, staff at the formal health facilities outside of the community spoke of facing their own multiple challenges: under-resourced, with high staff turnovers, staff shortages, and a dearth of adequately trained and skilled health personnel.

Severe staff shortages being faced by rural hospitals will have implications for the implementation of a full-scale anti-retroviral programme. Dr X (head of a local hospital) indicated that the current doctor patient ratio at the hospital where she was employed was totally inadequate to meet the present patient needs, and that the introduction of any further responsibilities would pose strong challenges.

For the 440 beds that we have, we have around 20 full time doctors of whom 11 or so are junior doctors, 5 interns and 5 community service doctors and they are busy all the time. We are currently recruiting staff but with doctors being in such short supply in the country as a whole, there is no guarantee that we will be successful in our recruitment.

She went on further to say that the introduction of anti-retrovirals would require intensive medical input in terms of assessing patients response to medication, adjusting dosages and so on. With the high level of infection in the communities they served, they would require the services of a full time doctor and a highly trained professional nurse who was skilled in the assessment of general ailments and more specifically had HIV/AIDs training. She was concerned that they did not have that capacity available at the hospital at the moment.

Traditional healers

For many who cannot access medical care, traditional healers are the only source of health treatment in this community. As a health volunteer told us: *People here generally prefer to go to the clinic when they are sick but because it is not readily available, they quickly think of a traditional healer who is nearby. Going to a traditional healer will not cost them money to hire a car. They simply walk.*

Many of the traditional healers explain AIDS as the result of bewitching, based on jealousy rather than seeing it as an infectious disease that could be prevented. This provided a more 'respectable' diagnosis than AIDS with its shameful sexual connotations.

Traditional healers prescribe herbal medication or spiritual cures. Some (though not all) claim to have a cure for AIDS. To date, local healers have no AIDS education. Some local people, including the traditional chief, hold great faith in them. He expressed the view that efforts to address the epidemic

would only succeed with their co-operation. VCT counsellors from a nearby hospital flagged up the importance of including traditional healers in ARV treatment plans, fearing that if they interpreted ARVs as a threat to their professional territory, they might use their influence to negatively affect patient compliance.

Care of the sick

Family members

Within the context of limited health facilities, care of the sick usually falls on family members, most often women. Carers are often overburdened with other responsibilities aside from the need to care for the patient. Many carers we interviewed were not aware of the illness of the patient and hence not taking basic precautions (use of gloves, following proper hygiene procedures) when rendering care. They also felt ill-equipped to monitor whatever medication regime the patient might be on.

Volunteer home based carers

Volunteer home based carers often the only source of help for sick individuals and their families given the dearth of health facilities, and the almost overwhelming burden that nursing a dying person often imposes on untrained and otherwise unsupported informal carers. By default, they have become the major source of help for people dying of AIDS. They often provide basic AIDS-care education and general home-based care and support for sick people. They are often drawn into playing the roles of counsellor, mediator and general caretaker under very trying circumstances. Most of them receive no payment at all, indeed often having to spend their own money to assist their patients. Despite tremendous dedication, their role is often not acknowledged by local leadership. The majority of them do not receive any payment for their services. Whilst a minority of them have had basic training in DOTS support and cholera prevention by primary health care workers in neighbouring hospitals and two very small local missionary centres, none have any AIDS-

care training. They do not have any kind of basic medical kits or gloves and many spoke of their fears of the dangers of nursing people with AIDS.

In the hilly remote area, they often have to walk one or more hours to give help to households affected by sickness. The stigmatisation of HIV/AIDS in the community further hinders their work since many family members prevent them from seeing their patients. Home based carers cited hunger and the lack of proper nutrition as one of the main hindrances to the recovery of illnesses in the community. As one said: *When we visit a patient, we may find they don't have even a pack of maize meal in the house. What use is talking about health if a person does not have food?*

In interviews and focus groups, many volunteer carers feared that given the difficult circumstances in which they worked, they were prevented from offering 'good quality' services to PLWAs.

We are aware that our service is not sufficient. At times we find people that are in pain. We cannot offer those people a single painkiller because we have nothing to give them. The government must provide us with medical kits with common tablets that don't need any prescription. It is not enough to clean the house and cook food for a sick person and then leave him/her in pain. We go to the river to wash their clothes and also give them a bath, but the pain is still there. The government must do something about this. Our service is not complete.

The role of home based carers in ARV roll out? Building partnerships between health services and the community.

Within the context described above, much has to be done within this community to support the roll-out of ARVs. Interviews with local Entabeni residents highlighted issues such as facilitating the access of the sick to essential health facilities, boosting mobile clinics, and providing affordable transport to hospitals. Interviews with doctors and nurses in nearby hospitals and clinics highlighted issues such as the improved recruitment and training of

hospital personnel among other things. The interests of the authors of this paper lie in the challenges of developing 'HIV competent communities' within which PLWAs and their carers are given the support they need for optimal access and adherence to treatment.

We have already highlighted how AIDS patients and carers rely very heavily on the support of home based carers. Our study suggests that in a context such as ours, where health services are minimal and health facilities are difficult to access, home based carers could play a crucial role in the monitoring and adherence of ARVs in the area. This view was strongly endorsed by Dr X, the superintendent of a nearby hospital cited above:

I think they're a very important category of health worker in this whole effort and if we can get them that would be good. I know certainly when I was working at X with TB patients, community volunteers were a vital part of the TB management in terms of providing treatment support and supervising treatment- it would be very helpful if we could have a similar sort of working relationship with local volunteers in relation to anti-retrovirals. I think there is a definite role for this group.

In this paper we have highlighted the many challenges facing home based carers. However, in many ways they constitute an already-mobilised and currently under-utilised resource for bridging the gap between medical services and hard-to-reach communities such as Entabeni. They have excellent community access. They are enthusiastic, highly dedicated and committed to their work. They are willing to work very hard, under incredibly difficult circumstances, for relatively small gains. They already provide crucial support to overburdened informal carers and PLWHAs. In Entabeni, they meet regularly, supported by a local leader who is a trained community health worker – one of the few who is paid a small stipend by a regional NGO. Their leader is well-known and well-respected in the community and they have some support from a local CBO. Their potential role in the roll-out of ARVs is strongly appreciated by nearby hospitals that are battling with resource

shortages. Some have limited training in areas such as hygiene, cholera and DOTS, and all are desperately keen for training related to HIV/AIDS.

If home based carers are to be involved in the roll out of ARVs in this area, more especially in the monitoring of treatment in order to ensure adherence, they will need the following kinds of support:

- Training on how best to support AIDS care and treatment
- A financial incentive to cover their expenses and reward their efforts
- Access to appropriate resources (medical kits) in order to assist with the care of PLWAs.
- Regular supervision of their work & ongoing in-service training
- Counseling & emotional support to deal with the trauma of dealing with sickness & death on a daily basis
- Training in how to assist marginalized people in accessing grants
- Training in networking skills to mobilise support from local individuals and groups for their work.

Conclusion

Above we have presented a thumbnail overview of our case study of community responses to HIV/AIDS in a rural area in KZN. This case study has highlighted the positive role that community volunteers are currently playing in facilitating AIDS-care in a remote area with limited access to formal health services. It has also highlighted the view of a local hospital superintendent that effective ARV roll-out will have to be supported by some form of community outreach.

These findings are interesting in the light of the emphasis the international public health literature places on the need for community participation in delivering effective primary health care in under-served communities in general (Walt, 2004), and in ARV roll-out in particular (Loewensen and McCoy, 2004).

However, whilst our case study highlights this group as a potential and viable asset that could be mobilised by a treatment programme in a hard-to-reach community, much work remains to be done in thinking through the mechanics of how such community members might be formally incorporated into treatment plans, as well as thorny issues such as training and payment. As quoted in the introduction to this paper, careful forward planning has been cited as crucial to the success of an ARV programme in South Africa. In his review of the role played by community health workers in various contexts in South Africa, Friedman (2003: 179) warns that whilst community health workers currently offer the country one of its most viable means of assisting PLWHAs, the potential for mobilising this group depends strongly on the development of “clarity of conception and the development of systems to link the different elements of community based health care”.

References

- Baum, F (1998) *The new public health: an Australian perspective*. Melbourne: Oxford University Press.
- Campbell, C, Foulis, CA, Maimane, S and Sibiya, Z (2005a, forthcoming) “I have an evil child in my house”: stigma and the struggle against youth HIV/AIDS in South Africa. *American Journal of Public Health*.
- Campbell, C, Nair, Y, Maimane, S and Sibiya, Z (2005b, forthcoming) *Understanding and challenging HIV/AIDS stigma*. Durban: Centre for HIV/AIDS Networking (HIVAN).
- Farmer, P, Leandre, F, Mukherjee, J et al. (2001) Community-based approaches to HIV treatment in resource poor settings. *The Lancet*, 358: 404-9. (4 August)
- Fleck, F (2004) WHO report says AIDS offers healthcare opportunity. *British Medical Journal*, 328:10. (3 January).
- Friedman, I (2002) Community-based health workers. Chapter 9. *2002 South African Health Review*. Durban: Health Systems Trust.
- Loewensen, R and McCoy, D (2004) Access to antiretroviral treatment in Africa. *British Medical Journal*, 328: 241-2. (31 January)

- Maimane, S, Campbell, C, Nair, Y and Sibiya, Z (2004) The role of volunteer community health workers in a rural setting. Monduzzi Editore (Eds) *Proceedings of the XV International AIDS Conference*. Bangkok, 2004.
- Obwogo, N (2002) Use of anti-retrovirals in a slum-based home care setting: The slum doctor programme model. Presented at the XIV International AIDS Conference 2002, Barcelona, July 7-12. Abstract number: WePeF6630.
- Stevens, W, Kaye, S and Corrah, T (2004) Antiretroviral treatment in Africa. *British Medical Journal*, 328: 280-2. (31 January)
- Walt, G (2004) WHO's 'World Health Report 2003 Shaping The Future' depends on strengthening health systems. *British Medical Journal*, 328:6. (3 January).
- World Health Organisation (1978) *Alma Ata: primary health care*. Geneva, New York: WHO and UNICEF.
- World Health Organisation (2003) *World Health Report 2003. Shaping the future*. Geneva: WHO.