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Hearing community voices: grassroots perceptions of an intervention to support health volunteers in South Africa.

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Campbell conceptualised and designed the research outlined in this paper, supervised the data analysis and contributed to the writing and revision of the manuscript. Gibbs analysed the data and drafted successive versions of the manuscript in discussion with all four authors. Maimane conducted and translated the interviews and focus-groups. Nair is coordinator of the Entabeni project on which this research is based.

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Abstract

With the scarcity of African health professionals, volunteers are earmarked for an increased role in HIV/AIDS management, with a growing number of projects relying on grassroots community members to provide home nursing care to those with AIDS – as part of the wider task shifting agenda. Yet little is known about how best to facilitate such involvement. This paper reports on community perceptions of a three -year project which sought to train and support volunteer health workers in a rural community in South Africa. Given the growing emphasis on involving community voices in project research, we conducted 17 discussions with 34 community members, including those involved and uninvolved in project activities – at the end of this three year period. These discussions aimed to elicit local peoples' perceptions of the project, its strengths and its weaknesses. Community members perceived the project to have made various forms of positive progress in empowering volunteers to run a more effective home nursing service. However, discussions suggested that it was unlikely that these efforts would be sustainable in the long-term, due to lack of support for volunteers both within and outside of the community. We conclude that those seeking to increase the role and capacity of community volunteers in AIDS care need to make substantial efforts to ensure that appropriate support structures are in place. Chief amongst these are: sustainable stipends for volunteers; commitment from community leaders and volunteer team leaders to democratic ideals of project management; and substantial support from external agencies in the health, welfare and NGO sectors.

Keywords: Evaluation, home-based care, volunteers, task shifting, participation, stipends, leadership

INTRODUCTION

There is growing concern about the disappointing outcomes of many HIV/AIDS management projects in sub-Saharan Africa (Gregson, Adamson, Papaya *et al.*, 2007). One reason offered for disappointments is that many projects are imposed by outside professionals and experts onto passive communities, failing to resonate with the worldviews and perceived needs and interests of their 'targets' (Campbell, 2003). Within this context there is a growing emphasis on the need to include the views of target communities in programme planning, implementation and research.

Parallel to these interests is the growing emphasis on the role of community health volunteers in running prevention programmes, providing home-based care, and increasing access and adherence to anti-retroviral therapy, especially in sub-Saharan Africa where there is a dramatic scarcity of health workers (Ogden, Esim & Grown, 2006; Schneider, Hlophe & van Rensburg, 2008; UNAIDS, 2004). This situation is exacerbated by a 'brain drain' of health professionals to the 'developed' world, which has substantially undermined healthcare provision (Pang, Lansang & Haines, 2004; Van Damme, Kober & Laga, 2006). One recent estimate suggested that in 2000 about 65 000 African-born physicians and 70 000 African-born professional nurses were working in 'developed' countries (Clemens & Pettersson, 2008). Health volunteers can start to fill this gap through contributing to the increased care and support of people living with HIV/AIDS (PLWHA), and the concept of 'task shifting' of responsibilities from trained doctors and nurses to community health workers and trained grassroots community members is strongly endorsed by organisations such as the WHO, UNAIDS and PEPFAR¹ (WHO, 2008). Ideally participation in healthcare projects also provides volunteers with more general skills in project planning, management and leadership, and builds their confidence and capacity to tackle the impact of factors such as poverty and gender inequalities both in their own lives, and also in their communities (Rifkin, 1996; UNAIDS, 2004; WHO, 2008).

Against this background, we report on community perceptions of a three-year programme seeking to facilitate grassroots responses to HIV/AIDS – primarily through health volunteers – in a rural community in KwaZulu-Natal, South Africa. The Entabeni Project evolved out of a two-year research process into community responses to

¹ These acronyms refer to the World Health Organisation (WHO), UNAIDS and the US President's Emergency Plan for AIDS Relief (Pepfar).

HIV/AIDS in Entabeni² (Campbell, Nair, Maimane & Sibiyi., 2008a), followed by a consultation process where researchers and the community jointly formulated the project plan (Campbell, Nair, Maimane & Sibiyi, 2008b). The resulting three-year Project worked to strengthen grassroots responses to HIV/AIDS in three ways. Firstly it provided training to a pre-existing cadre of local volunteers (mostly women and youth) who had already been offering home nursing support to households affected by AIDS for several years prior to the research. Initiated by local community members, this group provided the only support available to many AIDS-affected households. However volunteers said they urgently needed further training and support to improve their service. The second goal of the Project was to strengthen local support for volunteers by strengthening their links with local leaders, youth and women's groups and so forth, who had traditionally kept a distance from volunteers in a context of AIDS denial and stigma. The Project's third goal was to build bridges between volunteers and support agencies outside of the community, including regional branches of the public health and welfare sectors as well as AIDS-related NGOs (referred to as the Project's 'External Partners'). Due to the geographical isolation of the community, as well as the lack of networking skills by volunteers, such links were minimal at the start of the Project.

The authors of this paper are part of the 'Community Responses to HIV/AIDS Project', located in the Centre for HIV/AIDS Networking at the University of KwaZulu-Natal, and from now on referred to as the 'HIVAN project team'. The third and fourth authors facilitated the Entabeni Project in partnership with local health volunteers. All four authors have been involved in a detailed research project documenting the history/progress of the programme. This process research study – which forms the wider context of the research in this paper – has sought to generate data from two sources: community insiders and community outsiders.

Our community 'outsiders' data reflect the views and experiences of (i) the Project's 'external partners'– elicited through extensive interviews over a three-year period; (ii) detailed fieldworker diaries kept by the fourth author, as the fieldwork manager; and (iii) regular interviews with the third author in her role as Project Facilitator. Analyses of these data have yielded detailed understandings of the Entabeni Project's limitations and successes from the outsiders' perspective (Campbell, Nair & Maimane, 2007a; Campbell, *et al.*, 2008a; Nair & Campbell, 2008). Our 'community insiders' data consist of interviews and focus groups with local Entabeni residents, including those who have

² Entabeni is a pseudonym to disguise the identity of the community

implemented the project and those who have been targeted by it. This material is the focus of the current paper – which reports on community insiders' perceptions of the Project's strengths and weaknesses at the end of the three year Project implementation period.

Volunteer health workers in community healthcare are not new. Since the 1978 Alma Ata declaration on primary health care, community participation in the provision of health, through volunteers, has been a central issue (Rifkin, 1996). Health volunteers are seen as increasing access to primary healthcare and also being agents of change in communities. Yet in a review of three health volunteer programmes in Botswana, Colombia and Sri Lanka, Walt (1990) convincingly argued that whilst volunteers were used to provide cheap labour to reduce government costs for the provision of basic health services, the experience of volunteering did not lead to positive changes in the health or well-being of the volunteers or their communities, neither did it lead to any long-term gains in communities' ability to respond more effectively to health problems.

Current research into health volunteers in the HIV/AIDS pandemic has tended to focus narrowly on the impact of the work on the well-being of volunteers. Research highlights that the majority of work is done by women and that such work has high negative emotional, financial and physical impacts for them (Akintola, 2006; Campbell & Foulis, 2004; Rugalema, 2000). Less attention has been given to the potential empowerment of health volunteers.

Rifkin (1996) argues that the experience of volunteering should ideally lead to the development of skills and confidence which volunteers can apply to the wider challenges of improving the health and well-being of themselves, their families and their communities. As such, she argues that health programmes which seek to 'empower' volunteers – through training them to play a key role in programme decision-making, management and leadership – rather than simply expecting them to carry out instructions imposed on them from above – can serve as a springboard for positive social change in poor communities.

The focus on 'insider' perceptions of the community Project in this paper has two underlying rationales. Campbell (2003) argued that one reason for the poor outcomes of HIV/AIDS management programmes is that many interventions treat the intended 'targets' of programmes as *objects* of the development process rather than *subjects*. Target communities may be bombarded with HIV-awareness information from outside

experts, often giving people unrealistic guidelines, which they are unable to carry out in the contexts of their daily lives and struggles. Advising married women to use condoms, when they are economically dependent on condom-averse husbands, is unlikely to have much impact. Neither is telling young men to delay sexual debut, when sexual activity is a key marker to entry to popular male peer groups. Neither is telling people that it is wrong to stigmatise, given the complex roots of stigma in a range of social and economic as well as unconscious psychological factors that lie way beyond the reach of 'HIV-awareness programmes' (Campbell *et al.*, 2007).

Various studies have highlighted the problems of projects that pay inadequate attention to the complex social dynamics into which they are inserted. Gruber and Caffrey (2005) discuss an AIDS project in Nigeria which failed to consider the local context. The project – which sought to build youth and women's leadership skills – was perceived as a threat by powerful male community elders who undermined its efforts. Campbell (2003) explored the failure of a project to increase condom use amongst sex workers in South Africa. She ascribed the failure of the project to the narrow biomedical/education approach to condom promotion advocated by the senior project management committee – in opposition to the views of the project workers who were actually running the project from day to day – which ignored the realities and worldviews of the sex workers with whom the project was trying to work.

On the basis of such experiences, it is argued that those designing and evaluating programmes should work closely with community members to ensure efforts are not undermined by a mismatch between community understandings and programme efforts.

The second reason for our commitment to 'insider' approaches relates to our commitment to participatory research methodologies. These are driven by a critique of 'traditional' approaches to research conducted by external researchers sitting outside of a community and focusing on issues that they – the researchers – consider worthy of study. Participatory research – which seeks out the views of project participants and target communities – is said to generate 'equally important' research "grounded in the perspective and interests of those immediately concerned, and not filtered through an outside researcher's preconceptions and interests" (Reason & Bradbury, 2001, p.4). Such approaches open up the possibility of generating novel and useful insights into the problem at hand (Chambers, 1994; Flick, 2002).

PROJECT FRAMEWORK, SETTING AND IMPLEMENTATION

Project framework

The research in this paper is underpinned by our conceptualisation of an 'AIDS competent community' – a social environment that provides an enabling and supportive context for HIV/AIDS prevention, care and treatment (Campbell, Nair, Maimane & Sibiyi, 2005; Campbell *et al.*, 2007). This concept delineates the psycho-social features most likely to support the likelihood of health-enhancing behaviour change, optimal support for people living with HIV/AIDS and their carers, and the reduction of stigma. An AIDS competent community has five features:

1. Knowledge: Members of an AIDS competent community have relevant knowledge and skills about HIV/AIDS treatment, care and support.
2. Social spaces, dialogue and critical thinking: For people to translate new knowledge about HIV/AIDS into action, they require 'social spaces' in which they can critically reflect on the obstacles to effective community responses to HIV/AIDS, and negotiate feasible strategies for tackling these.
3. Confidence: Members of an AIDS competent community have confidence in their ability to make a difference.
4. Ownership and responsibility: People see themselves as having a contribution to make to addressing HIV/AIDS (rather than seeing it solely as someone else's responsibility).
5. Bridging relationships: Members of AIDS competent communities are able to access support and resources from appropriate external organisations – be these NGOs, government and/or the private sector.

Setting

The Project site is the rural community of Entabeni. This is a community of around 21 000 people, covering 350 square kilometres. It is estimated that one in four of the general population and 34.6% percent of pregnant women are HIV-positive (Barron, Day & Monticelli, 2007), and AIDS deaths, especially of young people, are a common feature of daily life. Despite this, levels of AIDS denial and stigma are high. Access to government health facilities is limited; the nearest hospital is 30km away, while a mobile clinic comes to the community once a month.

There are high levels of poverty in Entabeni, and many men, and an increasing number of women, migrate to urban centres to work – a factor exacerbating the local HIV/AIDS pandemic (Hunter, 2006; Lurie, Williams, Zuma, *et al.*, 2003). While South Africa has successfully increased access to welfare grants for children and the elderly (Samson, MacQuene & van Niekerk, 2005), people in this community struggle to access these grants, citing long distances to welfare offices, the need for documentation they do not have, and long queues as barriers.

Governance of Entabeni is formally shared between the elected government of the local municipality³ and the traditional chief (*Inkosi*), who delegates control of day-to-day matters to his traditional councillors (*Indunas*). In reality the municipality plays a minimal role in this particular community and residents are effectively under the control of the *Inkosi* and the *Indunas*.

Project implementation

The Project worked to facilitate the emergence of AIDS competence in Entabeni in three ways. Firstly, it sought to improve the skills and knowledge of a group of health volunteers offering home-based care to AIDS-affected individuals and households. Volunteers were trained in HIV/AIDS management and primary healthcare by a local NGO and Department of Health representatives. Both volunteers and an external evaluator were extremely satisfied with the quality and appropriateness of this training (Campbell, Gibbs, Maimane & Nair, 2008; Mqadi, 2007). Secondly, the Project sought to strengthen local support for the health volunteers. This involved training a range of local groups in HIV/AIDS awareness, peer education and counselling. These included local traditional leaders, youth and the *Inkosi's* wives. In addition, a number of public events, including a youth HIV/AIDS rally and graduation ceremonies for health volunteers on completion of training were held, to build the status of and support for the home-based carers (Campbell *et al.*, 2007a). Thirdly, the Project sought to improve external agencies' support for the health volunteers. External agencies involved included the local Departments of Health and Welfare, the local municipality and a number of small NGOs (Nair & Campbell, 2008). External partners and health volunteers met every three months for partnership meetings and evolved into a co-ordinating body – the Entabeni

³ The provincial Department of Local Government and Traditional Affairs is the closest sphere of government to communities. They have district municipalities that are responsible for development planning in communities. These are further sub-divided into local municipalities, one of which services Entabeni.

Health Partnership – which became officially recognised as an NGO in the final year of the Project.

RESEARCH METHODS

Qualitative research within the social constructionist paradigm

We used qualitative methods of data collection and analysis, the most suitable approach to the study of subjective meanings and everyday experiences and practices (Flick, 2002). Our methodology is shaped by our commitment to a social constructionist approach (Gergen, 1999; Kvale, 1996; Silverman, 1993). This approach is increasingly common in the critical social sciences, but stands in contrast to the positivist approach which dominates the biomedical sciences and mainstream behavioural psychology. The latter seek to explain human behaviour in terms of universal and generalisable laws which apply across a given population. For this reason positivist researchers use research 'quality indicators' such as sampling, reliability and validity.

By contrast, social constructionist researchers believe that human experience is shaped by situation-specific social knowledge which is constructed and reconstructed by particular social actors from one situation to the next. The aim of social constructionist research is to map out the range of meanings that particular social actors give to particular situations in particular settings, without assuming that their findings are necessarily generalisable across situations or across different members of a particular group or community. The generalisability of social constructionist research findings to new situations is seen as best judged on a case-by-case basis by a skilled social scientist (Flyvberg, 2001).

Rather than aiming for criteria such as validity and reliability, the social constructionist researcher is required to provide a range of information about the research procedure to enable readers to evaluate its value and usefulness. We followed Gaskell and Bauer's (2000) criteria for the 'public accountability' of the qualitative researcher. These include a detailed description of the researchers' relationship to the social situation under investigation, the milieu of the social actors under investigation, the selection and characteristics of the respondents, the research topic guide, the coding frame, and the procedures and assumptions guiding data collection and analysis. Research findings are reported using what Geertz (1983) refers to as 'thick description' viz: the verbatim

reporting of sources, which gives the reader space to accept the interpretation offered, or to come to a different view.

Rather than seeking to find a representative sample of the population under study, in the interests of discovering generalisable accounts of social experience that would hold true across the population and irrespective of situation, the social constructionist researcher aims to maximise the variety of perspectives in the population under scrutiny – and does so through selecting as wide a range of research participants as possible, and interviewing them until ‘saturation’ is reached (i.e. until the search for diversity is exhausted and the same views start being repeated in interviews). Whilst most methodologists are reluctant to commit to a minimum number of informants for such research, Sandelowiski (1995) suggests that a minimum of 12 interviews are necessary for saturation.

Research informants and sampling

The data for this paper were collected by the third author, involving a total of 17 discussions (12 in-depth interviews and 5 focus groups) with a total of 34 community members (27 female and 7 male). The predominance of women is consistent with a general unwillingness by Entabeni men to engage in AIDS-related issues (Campbell *et al.*, 2008). To achieve a diverse range of views of the Project, discussants were purposively selected across two groups.

The first group included 23 participants who had either participated in Project activities or received Project training. These included health volunteers (the Project’s central participants), out-of-school youth (trained by a counselling NGO, and involved in running the Project’s outreach centre) and traditional leaders (who had received AIDS training). These are referred to as being ‘involved’ in the Project.

The second group were 11 people who had no direct involvement in the Project: a teacher, male and female youth and adults. They were included to explore the nature (if any) of diffusion of learning or experience from Project participants into the wider community – a precondition for the development of community-wide AIDS competence. We refer to these people as ‘uninvolved’. Table 1 provides a detailed breakdown of participant numbers and gender. All the uninvolved participants were aware of the presence and work of the home-based carers, if not of the Entabeni Project of which

they were part. When they were not aware of the Project, the questionnaire was adapted to refer to the carers and their work.

[INSERT TABLE 1 HERE]

We used a convenience sampling method. The 'involved' group consisted of people who happened to be available to be interviewed during the research fieldworker's two-week visit to Entabeni to conduct this research. They were mobilised by the volunteer leader. The 'uninvolved' group were recruited by the fieldworker from the community's tribal court – a centralised area where people would gather for the collection of pensions and grants, to attend the local market, and to access buses and taxi's. She approached people randomly and interviewed anyone who said that they had time. She approached a total of 16 people, five of whom declined to be interviewed due to time constraints.

Topic guide

Our topic guide included six open-ended questions to generate discussion of peoples' understandings of AIDS in the community and of local responses; their views of the Project, what went well and what could have been done better; and of the long term sustainability of the Project (see Appendix A). Interviews averaged 1 hour (range: 40 minutes to 2 hours). Focus-groups were on average 1.5 hours long (range: 45 minutes to 2 hours). They were conducted in Zulu by the third author, who tape recorded and later translated and transcribed them.

Method of data analysis

Data were analysed by thematic content analysis (Attride-Stirling, 2001). Initially responses were categorised in terms of themes raised by informants. These themes were then grouped according to their relevance to our five criteria for AIDS competence, which constituted the core themes in our coding frame. Data were analysed in three stages, which are outlined in Appendix B.

RESULTS

Table 2 summarises the findings of our analysis, presenting our final 16 themes, grouped according to the five dimensions of AIDS competence.

[Insert Table 2 here]

Knowledge

In nine discussions people said the training had increased knowledge. A female traditional councillor told us how she had learnt about HIV/AIDS and the process of stigmatisation through attending a Project workshop:

Makhosi (F): I gained lots of information from the training. In my household three people have died of AIDS and at that time I didn't have any information. When the Project was training us, I realised that they died of AIDS. I learnt not to stigmatise HIV-positive people because it is very easy to do that. Like when you care for a sick person, you do things in such a way to stop yourself getting infected, but the sick person knows that you are treating them differently.
(TRADITIONAL COUNCILLOR)⁴

After health volunteers had received workshop facilitation training, they ran training courses for other community members. People recognised the important role health volunteers played in spreading information about HIV/AIDS throughout the community:

Themba (M): The home-based carers have educated people about AIDS. As they visit people, they talk a lot about it, and they conduct workshops in the community. Something like this hasn't happened before. This has made a great change in this community. (UNINVOLVED YOUNG MAN)

Although around half the discussants said HIV/AIDS knowledge *had* increased in the community, an almost equal number (eight discussions) suggested such knowledge was either not as widely diffused as suggested in more positive interviews, or that competing rationalities undermined people's abilities to act on new knowledge.

Beliefs in witchcraft provided one 'competing' framework through which HIV/AIDS was understood. One home-based carer told of how she tried repeatedly and unsuccessfully to get a family to believe in HIV/AIDS:

Hlengiwe (F): I visited one family where the father of the house was saying his daughter was bewitched. I begged him to send his daughter to the clinic. I kept

⁴ All quotes are classified in this way: *Name of person (sex, M = male, F = female): The quote. (POSITION IN COMMUNITY)*. Pseudonyms have been used to protect the identity of respondents.

saying I agreed that she was bewitched, just to get him to allow me to take the daughter to the clinic. I said they would give her something to make her better.
(HEALTH VOLUNTEER)

Four discussions referred to the role of male resistance to change in preventing women from translating knowledge about HIV/AIDS into action (particularly the importance of condom use with unfaithful husbands). Many women were pessimistic about the potential for changing male behaviour:

Celiwe (F): This woman said to me, “My child I have a big problem now because while I have been educated about ‘this thing’ [HIV/AIDS], my husband has not, and he refuses to use condoms. He says he paid *lobola* for me and he cannot use a condom for something he has paid for. He refuses completely.” One day I visited her house and her husband was there. The woman was very happy to see me. I wasn’t sure how to approach this topic of condoms with her husband but I tried to educate him. But he still insisted he would not use a condom with his wife. (HEALTH VOLUNTEER)

Problems of competing knowledge were referred to in a pessimistic manner as an unchallengeable part of everyday life, falling beyond the reach of an AIDS project.

Social spaces, dialogue and critical thinking

Interviewees also differed as to whether the Project had succeeded in producing social spaces for open dialogue and critical thinking about HIV/AIDS, its causes and how to avoid it. In five discussions churches were identified as significant new social spaces in which such dialogue had emerged as a result of the Project. The role of church leaders in facilitating this was particularly important:

Ms Kheswa (F): When I go to church on Sundays I hear my pastor talking about HIV and the training that has been going on in the community, encouraging church members to also attend such workshops when the home based carers ask them to. (TEACHER)

Several discussants said that when they had had the courage to introduce the topic of HIV/AIDS in church groups, congregants were surprisingly willing to engage:

Philile (F): In our church, women have regular weekly prayer meetings. One day before we started praying, I introduced the topic of HIV and asked our leader if I could talk. She then said, 'It is fine you can talk about *your* HIV'. It has now become *my* HIV because I am always talking about it. When I introduced this topic I thought I would be the one doing the talking but I found the women discussing this among themselves. (HEALTH VOLUNTEER)

In four in-depth discussions people said the community was becoming more open to speaking about HIV/AIDS. Parents were increasingly discussing it with their children, and there was greater recognition that it was a crucial issue. Participants suggested this was partly because of awareness raising by the health volunteers:

Makhosi (F): I notice people talking to each other about what they hear from the home-based carers. Families now are able to educate each other. It is no longer taboo to talk about sexual issues – everybody is now aware that HIV/AIDS has to be talked about. Otherwise people will continue to die. (TRADITIONAL COUNCILLOR)

Some emphasised that the increased openness derived from the impetus the Project had given to leaders such as church ministers and the *Inkosi*:

Gladys (F): Everybody is talking about HIV/AIDS in the community lately. Even the *Inkosi* talks about it a lot. Whenever there are community meetings, he talks about it. Before you came here people were shy to talk about it. Since since you have been here people in high positions have started talking, telling people they also have infected family members. This has made it easier for people to come forward. Stigma is no longer a problem. (OUT OF SCHOOL YOUTH)

Contrary to this, six discussants said stigma was still a major barrier to dialogue, with people still reluctant to admit that they, or a relative, were living with HIV/AIDS:

Sanele (F): There are still many people who are sick but don't want to tell other people. A young woman nearby is very sick. She has been in hospital and she almost died. I suspect she is HIV positive. (UNINVOLVED FEMALE)

Stigma was often perpetuated through gossip, and fear of gossip deterred many from disclosing their status. One discussant, a woman living with HIV/AIDS, said while she

was willing to disclose her HIV-status to the home-based carers, she did not want the wider community to know.

Two people disagreed that churches were becoming more open. One woman said that while her church minister had tried to encourage people to talk about HIV/AIDS, church members were unwilling:

Interviewer: Who else in this community educates people about HIV/AIDS?

Sanele (F): I only know of the home based carers. I have heard the minister in church saying people should talk about HIV/AIDS in church but nobody has come forward. (UNINVOLVED FEMALE)

Church leaders who were involved in the Project were far more likely to facilitate spaces in which congregants could overcome stigma and denial and talk openly about AIDS.

Discussions suggested the Project had not succeeded in developing critical thinking about the roots of HIV/AIDS in factors such as gender and poverty, and the need for widespread community solidarity and collective action to tackle the problem. People often referred very narrowly to 'further training' as the solution to Entabeni's AIDS problem, rather than acknowledging its roots in factors such as poverty and gender, and not just in ignorance. A simplistic belief in the power of information and training to solve this complex social problem was implicit in many discussions. For example, one health volunteer said the reason why men were still resistant to using condoms was that they had not attended Project workshops:

Delisile (F): The men refuse when their wives at home ask to use condoms when they suspect the men have other partners where they work in big cities. They say, 'After so many years or marriage, now you are telling me to start using this plastic?' *The problem is that women attend the workshops we conduct in the community and yet the men do not.* (HEALTH VOLUNTEER)

Similarly a female *Induna* emphasised that as long as training continued, HIV/AIDS infections in the community would be reduced:

Ms Mbambo (F): I want thank HIVAN people for educating us. We are now able to pass accurate knowledge about HIV transmission to others. We teach them how to protect themselves. *I think as long as we keep educating people there will*

be fewer infections. We encourage people to disclose their status and talk about ARVs. I am really grateful for the training I got from HIVAN. (TRADITIONAL COUNCILLOR)

Training and workshops *are* obviously vital for providing information about AIDS and social spaces to discuss it. However they are a necessary but not sufficient precondition for change. Discussions suggested that the Project had not succeeded in its key goal to raise community members' consciousness of the need for wider social action to tackle the epidemic - in addition to vigorous HIV-awareness and AIDS training.

Confidence

A significant Project achievement was building the confidence of volunteers, as well as community members' confidence in them. With their previously low levels of AIDS education, all the volunteers said the training had dramatically boosted their confidence in their skills and in the value of their work with AIDS-affected households:

Mamuntu (F): This is what I would like to thank HIVAN for. The training opportunities you have given us are unbelievable. We are not sure what will happen once you are gone. Even our families are grateful for the knowledge you have provided us with. When I talk to people I am confident of what I am talking about. I really treasure this. Now when we get training from others, we know it's just revision because we have got real training from HIVAN. I am sure I could even get a job through this training. When I am asked questions in the community I answer with ease because I know what I am talking about. (HEALTH VOLUNTEER)

Many health volunteers also pointed to the small temporary stipend paid to carers by the HIVAN Project team as a key source of the pride they felt in their work. A key Project priority had been to get the home-based carers a sustainable government stipend, but to date this has not occurred, despite many promises by local and national government:

Zinhle (F): You [HIVAN] even went to the extent of finding us a stipend. That was really great. Getting something at the end of the month made a big difference. We could even buy soap. (HEALTH VOLUNTEER)

The HIVAN Project team also provided a basic uniform for the home-based carers, which increased their confidence and self-esteem:

Nokuzola (F): We used to walk on foot until our shoes and dresses got old but today HIVAN has been able to make us better people by providing us with uniform. (HEALTH VOLUNTEER)

The increased confidence of health volunteers went hand in hand with increased community confidence in what the home-based care volunteers had to offer, as seven discussants mentioned. Ms Zondo, a traditional councillor, emphasised that prior to the formal Project training of the volunteers, community members had viewed them negatively, but since being trained, they were highly respected:

Ms Zondo (F): The volunteers have a vital role to play in this community – especially now they have been trained and know what they are doing. Before the Project came, people used to undermine their efforts, saying they were not trained for their work. They were the laughing stock of the community. (TRADITIONAL COUNCILLOR)

Community members also explained it was because the Entabeni Project had formalised the health volunteer work and codified their knowledge as important that they were now so highly respected.

Ownership and responsibility

In discussions with health volunteers and community members it became apparent that the Project had not succeeded in building a sense of local ownership of the HIV/AIDS problem, or local responsibility for tackling it.

This was despite the Project's three-year efforts to encourage the volunteers to play a key role in Project decision-making and leadership. The volunteers had played a role in organising community-based activities, in training new volunteers in AIDS-related skills, and in evaluating the complex training they received. Furthermore the Project provided opportunities for them to interact with representatives of external agencies such as the regional health and welfare departments, and AIDS-related NGOs. All this was done in an attempt to build an inclusive, democratic Project that would enhance volunteers' sense of ownership of the Project to ensure its sustainability when the HIVAN team withdrew.

In all four discussions with the health volunteers, it was clear they lacked such a sense of ownership. They were not confident that the work would continue once the HIVAN Project team left Entabeni:

Phumeza (F): Ey, I really don't know what to say, because if one tyre of this wagon can burst, then the whole wagon will not move. HIVAN is one tyre of this wagon ... without HIVAN, I really don't know what we will do. HIVAN must continue to be in touch with us. (HEALTH VOLUNTEER)

A key Project disappointment was that although the volunteers were almost all women, two of the only three male volunteers carried almost all leadership responsibility throughout its life. Great efforts had been made to encourage the development of female leadership, and two women had in fact taken on substantial leadership roles at various stages. Both of these women had 'dropped out' in the Project's third year. One was recruited to a paid job in one of the external NGOs involved in the Project, which took up most of her time. The other one – a young unmarried woman – fell pregnant, and was ostracised by other volunteers for her 'failure to set a good example' to other young women in the community (a somewhat ironic situation, given the Project's aim to foster non-judgemental attitudes to sexuality and its complex consequences).

The volunteer discussions highlighted female volunteers' bitterness at what they described as leaders' failure to include them in Project decision-making. One group of volunteers said they were unable to ask male group leaders about basic issues such as their uniforms:

Interviewer: What are the chances that this work will be sustained once HIVAN has left? For instance what will you do when your uniforms get old. I can see your T-shirt has faded. You will need to ask Mr Mzobe (group leader) to give you another one. I left a box with T-shirts with him.

Nokuzola (F): I suggest that you ask Mr Mzobe. We are afraid of him.

Interviewer: Why are you so afraid of him?

Thembeni: He shouts a lot. (HEALTH VOLUNTEERS)

Similarly, many female volunteers referred to the poor communication between themselves and their male leaders. Few trusted their ability to sustain the Project effectively once the HIVAN team withdrew from the community after their three-year involvement:

Zinhle (F): For instance, I don't think our leaders would be able to get a stipend for us. They won't know how to go about doing that. I understand as you are leaving we are no longer going to be getting this stipend?

Interviewer: Yes, I think it has stopped already.

Zinhle (F): You see! I don't even know if our leaders have made any plans about stipends in the future. (HEALTH VOLUNTEER)

In relation to ownership/responsibility for HIV/AIDS, 'uninvolved' community members said there was nothing they could do to contribute to HIV/AIDS management, saying it was the responsibility of the volunteers and community leaders. Discussants said that the combination of poverty, the lack of effective leadership and the scale of HIV/AIDS in the community completely paralysed any sense of grassroots capacity for meaningful contribution. Discussants often spoke of the overwhelming nature of AIDS-related illness and death in the community, and how this limited people's sense of ownership to tackle it:

Sanele (F): I really don't know what can be done. There are so many HIV graves in this community. A young woman was buried last week over the hills. She was HIV positive. Her husband died first. My sister gave up on caring for her because the young woman insisted she was not suffering from any illness – even though she was dying. (UNINVOLVED FEMALE)

Five discussions called attention to the role poverty played in undermining collective action around HIV/AIDS. One female teacher argued that poverty undermined people's confidence to respond:

Ms Kheswa (F): I think it is because this community has nothing and people are aware that they lack many resources. So they don't think anyone can just stand up and claim to know something about anything. (TEACHER)

Another central Project disappointment was its failure to recruit male participation in Project activities. One of the three male health volunteers said this was because men were more concerned about searching for employment:

Interviewer: Why are there are so few male home-based carers?

Sthembiso (M): Males are not really interested in being home-based carers. Males want jobs that would give them money to support their families. (HEALTH VOLUNTEER)

Discussants also emphasised that local traditional councillors (*Indunas*) continued to be unwilling to engage with HIV/AIDS. The Project had made concerted attempts to involve the *Indunas*, running workshops for them, inviting them to Project celebrations and occasionally attending the *Induna's* weekly meetings. However one frustrated female *Induna* said any proactive discussion of HIV/AIDS and potential community responses was not on the agenda of the weekly meetings, unless a specific AIDS-related emergency arose:

Interviewer: Is HIV/AIDS on the agenda of your weekly meetings?

Makhosi (F): We don't talk about HIV/AIDS unless there is a particular emergency that makes us discuss that. (TRADITIONAL COUNCILLOR)

Getting HIV/AIDS established as an agenda topic was difficult:

Makhosi (F): They don't give themselves time to discuss important issues like HIV/AIDS. Everything is done in a rush.

Interviewer: Who draws up the agenda for the *Induna's* weekly meetings?

Makhosi (F): it is the secretary. We are not given a chance to add items to the agenda. In most cases we deal with criminal cases like assault, stock theft and such cases. (TRADITIONAL COUNCILLOR)

This lack of leadership was part of a more general unwillingness to respond proactively to HIV/AIDS. Those community responses that did exist were overwhelmingly reactive, responding to particular crises on a one-off basis (e.g. the fate of particular orphans), rather than discussing ways in which such crises might be avoided. This was despite the Project's on-going efforts to create opportunities for local people to play a role in a united community response – through, for example, taking up the issue of AIDS in their local community organisations (like church or womens groups and youth clubs), contributing to prevention and care efforts, putting pressure on leaders to devote more attention to tackling HIV/AIDS and so on.

That degree of ownership of the problem that did exist was ascribed to the way HIVAN had interacted with Project participants over the course of the Project's life, though this

was only mentioned in three discussions. From the start of the Project the HIVAN Project team had been committed to a facilitation style that favoured on-going improvisation in the light of community needs and talents, rather than the imposition of an externally imposed blueprint for action (Eyben, 2006). This style governed the Project's decision to provide small financial stipends to health volunteers – going against the Project's founding philosophy that its role would be to facilitate links between the community and outside support agencies, rather than providing any support itself. Despite having access to potential funding to cover stipends for a limited period of time, the Project initially sought to help the community access long-term and sustainable government funding for stipends to cover their expenses and to reward their participation. Yet over time, as discussed above, the Department of Health repeatedly rescinded on promises of support to the volunteers, and no stipend was forthcoming. The health volunteers lobbied and argued with the HIVAN Project team to provide stipends for them, and in the end stipends were provided for 18 months during which further (unsuccessful) attempts were made to secure long-term Department of Health funding.

In three discussions, health volunteers specifically lauded HIVAN's flexibility – and their willingness to change their initial policy in response to evolving circumstances rather than a predetermined and rigid Project plan. They said HIVAN's responsiveness to their expressions of need was an indication that they also had some control over the shape of the Project.

Dumi (M): HIVAN went as far as breaking its own rules. When they first came here they told us clearly that it was against their policy to give money to volunteers, but over time they did the opposite because they saw the need and the motivation from the home based carers. They started giving us compensation [stipends] from their funds. (HEALTH VOLUNTEER LEADER)

Bridging relationships

As discussed above, bridging relationships are essential for the development of AIDS competence in marginalised communities, which lack the power and resources to implement health projects without help from external support agencies. Against this background, the third pillar of the Entabeni Project, which absorbed a significant share of Project energies, was the 'Entabeni Health Partnership'. This body co-ordinated links between external partners (including representatives of regional public sector and NGO health and welfare agencies) and the local community. This Partnership was officially

defined as the body that ran the Project with input from – and on behalf of – the health volunteers.

In six discussions, despite the importance of the Entabeni Health Partnership to the wider Project, discussants said they knew little or nothing about the Partnership. This was a significant lack of awareness, given that the guiding principle of all Project activities had been to maximise grassroots awareness of the Partnership, not only amongst the health volunteers and community leadership, but also amongst ‘uninvolved’ community members. While four of these discussions involved those *not* directly involved in the Project, two focus-group discussions with ‘involved’ people also indicated that they knew little about the Project’s key co-ordinating body:

Interviewer: I am asking if people are aware of the Entabeni Health Partnership and what they stand for?

Makhosi: I think those who know this organisation are those that work closely with them. Otherwise the rest of the community does not know about them ...That is why I am saying the partnership must introduce itself to the community.
(TRADITIONAL COUNCILLOR)

From our point of view as Project facilitators, the local councillor’s view that the partnership should ‘introduce itself to the community’ was extremely surprising, given the Project’s very energetic and on-going efforts to inform local leaders about every aspect of its functioning over a three-year period, and to keep them informed about partnership activities.

Some uninvolved women suggested that their lack of awareness of this partnership and its efforts was symptomatic of the nature of the community, where uninvolved people were excluded from current areas of interest and activity, with community leaders refusing to give them information, or else not explaining things in ways that local people could comprehend:

Gugu (F): Ay, we haven’t heard about that Partnership. Nobody has told us. Even if they had tried to tell us about it, at times our leaders don’t explain things well enough for us to understand what they are talking about. (UNINVOLVED WOMAN)

As discussed above, the Project worked hard to involve *Indunas* in HIV/AIDS management, with little success. The *Inkosi* was the one person who might have been able to address this, through encouraging *Induna* participation. However, whilst he allowed HIVAN access to the community, and supported the Project from a distance, he did not intervene directly to ensure that the Project succeeded in meeting its goals. This lack of support from local leadership was a key factor undermining the Project's success.

One bridging relationship that did improve because of the Entabeni Project was people's access to government health and services. Discussants identified the health volunteers' training and the resulting increase in volunteer and community confidence as central to this.

Makhosi: People have now started using the clinics, even though they are a distance away. The volunteers have played a major role in educating people on coping with illnesses. When they feel unwell, they don't sit around and hope the illness will go away on its own. They consult the volunteers who advise them to go to the clinic or even go to the extent of accompanying the sick person to the clinic themselves. (TRADITIONAL COUNCILLOR)

DISCUSSION

Recent discussions have emphasised the need for health volunteers to play a greater role in the provision of HIV/AIDS services and support, especially in the light of the shortage of trained medical professionals in sub-Saharan Africa. As discussed earlier, Rifkin (1996) has criticised such programmes for using health volunteers to provide cheap health and welfare services. She argues that programmes fail to facilitate the wider empowerment of volunteers through involving them in Project decision-making and leadership, increasing their ability to participate more meaningfully in wider community affairs, and to exercise leadership in areas beyond HIV/AIDS.

The Entabeni Project sought to create a context in which volunteers not only improved their AIDS-related skills, knowledge and training, but also attained more general empowerment through participation in every aspect of Project functioning. This was to be done through ensuring they were actively included in Project planning, implementation and evaluation, and that they were active participants in supportive social networks, both within the community and with external support agencies.

Ironically – although the Project specifically worked to address Rifkin’s concerns - community members’ evaluation of the Entabeni Project echoes Rifkin’s (1996) critique. While the Entabeni Project succeeded in achieving what Rifkin would call ‘target-oriented goals’ (the expanded delivery of home nursing support by volunteers), the empowerment goals of the Project (to prepare female volunteers to sustain the activities once the formal life of the three-year Project had ended, and to play a more active and empowered role in improving the more general well-being of themselves, their families and the community) were not met.

What did the Entabeni Project succeed in doing? According to community members’ perceptions, it succeeded in building volunteers’ confidence, community confidence in the volunteers, and increasing people’s knowledge about HIV/AIDS. It also facilitated the participation of religious leaders in HIV/AIDS management, which led to increased social spaces to discuss HIV/AIDS in churches. Finally, the Project also achieved increased access to government services for some previously marginalised people. All of these are real successes and demonstrate significant Project achievements.

A key issue that emerged from our analysis of the discussions was the lack of a unified and coherent Project image in the community as a whole. As Table 2 demonstrates, the range of topics mentioned across our data corpus covered a wide area – with many topics being mentioned only in 4 or 5 of our total of 17 discussions.

Although the image of the Entabeni Project was not coherent, there was some consistency in the general ways in which people perceived HIV/AIDS and the solutions to it. Discussants were in agreement that it was the Project’s training workshops that had yielded positive benefits for the community. The heavy emphasis on the training courses in community perceptions of the Project reflects a more general community view of HIV/AIDS as a technical issue to be resolved through further training. While training *is* important, one of the aims of the Project had been to develop people’s sense of HIV/AIDS as a community-level problem, one to be tackled through collective action by community members, a sense of solidarity amongst community leaders and health volunteers, and strong support structures from external partners. Understandings of the need for more collective community-level responses tended to be absent from our discussions with informants.

While people focused predominantly on technical aspects of the Project’s success, some did have broader views of the social factors undermining the Project’s aims of

empowerment and sustainability. Thus some, for example, emphasised the role of stigma in limiting social spaces and action. While the Project had made substantial efforts to challenge stigma, not only through building general HIV awareness, but also through increasing access to health care and seeking to provide a humane and respectful environment for PLWHA, as well as the involvement of a wider range of community actors in supporting PLWHA, AIDS-related stigma was still perceived as a major barrier after three years of the Project. In relation to poverty, another factor that featured was that, despite the fact that large project efforts had gone into securing health stipends for volunteers through the Department of Health, and into increasing access to welfare grants for the wider community, people still faced huge problems in accessing stipends and grants.

Another problem articulated by discussants was the lack of buy-in to the Project's democratic ethos from key leaders – specifically the *Indunas* and the male leaders of the health volunteers. Poor communication between *Indunas* and the community, and between the male volunteer leaders and the female majority of volunteers, limited not only the diffusion of knowledge, but also the potential for widespread volunteer ownership of the Project to emerge.

HIVAN worked hard to position themselves as equals to the grassroots community in driving the Project forward, rather than taking the role of 'outside experts' and imposing their views too heavily on local Project members. Because of this, the HIVAN Project team were determined not to interfere in the internal management of the volunteer team. This team had been set up and successfully run against incredible odds before HIVAN arrived in the community. Whilst HIVAN was willing to work hard to create the possibility of positive growth and change in the Project – through supporting female health volunteers and quietly suggesting on many occasions that male leaders should allow female leaders to emerge – we were unwilling to interfere more heavy-handedly. Yet in retrospect, difficulties internal to the volunteer team, especially around communication between leaders and members, were a key factor in undermining a broad sense of Project ownership by the female health volunteers, and in reinforcing the position of the male leadership of the volunteers. This dynamic undermined the broader empowerment of the female majority of volunteers to play a significant role in Project management and decision-making, or to use their project involvement as a springboard for wider personal or community improvements.

The Project had also operated with the tacit assumption that, through running itself on democratic principles and ensuring involvement by a wide range of community members (especially those traditionally excluded, young men and young women, health volunteers and women), this would lead to wider improvements in the community status of these groups. Yet as our discussions with participants demonstrated, such attempts had been ineffective insofar as community leaders failed to support the Project in the way we had hoped, and the male leaders of the health volunteers had not developed new and more gender-neutral ways of sharing power and decision-making in the team. Project structures - like wider community structures – remained resolutely undemocratic, despite HIVAN's efforts to challenge these. This has hindered the empowerment of health volunteers and the potential long-term sustainability of the Entabeni Project.

The final major barrier that discussants raised to the aims of sustainability and empowerment – mainly through their silence on the topic – was the limited role played by external agencies in supporting the Project. Elsewhere we have documented the often fruitless attempts made by the HIVAN Project team to encourage greater involvement of external agencies in the Entabeni Project (Nair & Campbell, 2008). Without such support and involvement, the sustainability of such a project was questionable.

Our findings suggest that whilst there is a pool of committed women keen to contribute to tackling HIV/AIDS within communities, there needs to be a high dose of realism regarding what can be achieved without the provision of sustainable stipends for health volunteers, without 'buy-in' from community leaders to democratic projects aims and ideals, and without substantial support from external agencies. We believe that our findings have important implications for those promoting and implementing the 'task shifting' of certain health responsibilities from health professionals to grassroots community members. We are in full agreement that local people could play an increased role in the care and support of people with AIDS – or indeed people with tuberculosis or diabetes, or the elderly or the very young. However, the ability of volunteers to deliver optimally effective services will be dramatically limited unless proper remuneration arrangements and support structures are put into place.

References

Akintola, O. (2006). Gendered home-based care in South Africa: more trouble for the troubled. *African Journal of AIDS Research*, 5(3), 237–247.

- Attride-Stirling, J. (2001). Thematic networks – an analytical tool for qualitative research. *Qualitative Research*, 1(3), 385-405.
- Barron, P., Day, C. & Monticelli, F. (2007). *The District Health Barometer – Year 2006/07*. Durban, South Africa: Health Systems Trust.
- Bauer, M. & Gaskell, G. (2000). *Qualitative researching with text, image and sound*. London: Sage.
- Campbell, C. (2003). *'Letting Them Die': Why HIV/AIDS programmes fail*. Oxford: James Currey.
- Campbell, C. & Foulis, CA. (2004). Creating contexts for effective home-based care of people dying of AIDS in South Africa. *Curationis*, 27(3), 5-14.
- Campbell, C., Gibbs, A., Maimane, S. Nair, Y. & Sibiyi, Z. (2008, forthcoming) Youth participation in the fight against AIDS in South Africa: from policy to practice. *Journal of Youth Studies*.
- Campbell, Y., C., Gibbs, A., Maimane, S. & Nair (2008). Theorising pathways between participation and behaviour change: A case study of health volunteers in rural South Africa. Presentation to the *XVIIth International AIDS Conference*, Mexico City, 3-8 August 2008.
- Campbell, C., Nair, Y. & Maimane, S. (2007). Building contexts that support effective community responses to HIV/AIDS: A South African case study. *American Journal of Community Psychology*, 39, 347-363.
- Campbell, C., Nair, Y., Maimane, S. (2007). 'Dying twice': towards an actionable multi-level model of the roots of AIDS stigma in a South African community. *Journal of Health Psychology*. May 2007, 12:3.
- Campbell, C., Nair, Y., Maimane, S. & Gibbs, A. (2008). Strengthening community responses to AIDS: possibilities and challenges. In P. Rohleder, L. Shwartz, & S.Kalichman (Eds) *HIV/AIDS in South Africa 25 years on*. Forthcoming.
- Campbell, C., Nair, Y., Maimane, S. & Sibiyi, Z. (2005). Building 'AIDS competent communities.' *AIDS Bulletin*, 14(3), 14-19.
- Campbell, C. Nair, Y. Maimane, S. & Sibiyi, Z. (2008a). Supporting people with AIDS and their carers in rural South Africa: Possibilities and challenges. *Health and Place*, 14(3), 507-518.
- Campbell, C., Nair, Y., Maimane, S. & Sibiyi, Z. (2008b). Dissemination as intervention': building local AIDS competence through the report-back of research findings to a deep rural community in South Africa. *Antipode*. Forthcoming.
- Chambers, R. (1994). Participatory Rural Appraisal; (PRA): Analysis of experience. *World Development*, 22(9), 1253-1268.
- Clemens, M. & Pettersson, G. (2008). New data on African professionals abroad. *Human Resources for Health*, 6(1), 1-25.
- Eyben, R. (2006). Relationships: A new perspective on international aid. In: R. Eyben (Ed.), *Relationships for aid*. London: Earthscan.
- Flick, U. (2002). *An introduction to qualitative research*. (2nd ed.) London: Sage.
- Flyvberg, B. (2001). *Making social science matter: why social inquiry fails and how it can succeed again*. Cambridge: CUP.
- Gaskell, G. & Bauer, M (2000). *Qualitative researching with text, image and sound*. London: Sage.
- Geertz, C. (1983) *Local knowledge: further essays in interpretative anthropology*. New York: Basic Books.
- Gergen, K. (1999). *An invitation to social construction*. London: Sage.
- Gregson, S., Adamson, A., Papaya, S., Chimbadzwa, T., Mundondo, J, Nyamukapa, C., Mason, P., Garnett, G., Chandiwana, S., Foster, G. & Anderson, R. (2007). Impact and process evaluation of integrated community and clinic-based HIV-1 control: a cluster-randomised trial in eastern Zimbabwe. *PLoS Medicine*, 4(3), 0545-0555.
- Gruber, J. & Caffrey, M. (2005). HIV/AIDS and community conflict in Nigeria: Implications and challenges. *Social Science and Medicine*, 60(6), 1209–1218.

- HEARD (2005) *HIV/AIDS Statistics, September 2004*. Retrieved January 2005, from <http://www.ukzn.ac.za/heard/resources/ResourcesStatistics.htm>
- Hunter, M. (2006). The changing political economy of sex in South Africa: The significance of unemployment and inequalities to the scale of the AIDS pandemic. *Social Science and Medicine*, 64(3), 689-700.
- Kvale, S. (1996). *InterViews*. London: Sage.
- Lurie, M., Williams, B., Zuma, K., Mkaya-Mwamburi, S., Garnett, G., Sturm, A., Sweat, M., Gittelsohn, J. & Abdool Karim, S. (2003). The impact of migration on HIV-1 transmission in South Africa: A study of migrant and nonmigrant men and their partners. *Sexually Transmitted Diseases*, 30(2), 149-156.
- Mqadi, N. (2007) *External evaluation of the community responses to HIV/AIDS project – evaluation conducted for the Centre for HIV/AIDS Networking (HIVAN)*. Durban: HIVAN, UZKN.
- Nair, Y. & Campbell, C. (2008). Building partnerships to support community-led HIV/AIDS management: a case study from rural South Africa. *African Journal of AIDS Research*, 7(1): 45-53.
- Ogden, J., Esim, S. and Grown, C. (2006). Expanding the care continuum for HIV/AIDS: Bringing carers into focus. *Health Policy and Planning*, 21(5), 333-342.
- Pang, T., Lansang, M. & Haines, A. (2004). Brain drain and health professionals: A global problem needs global solutions. *British Medical Journal*, 324(7336), 499–500.
- Reason, P. & Bradbury, H. (2001). Introduction: inquiry and participation in search of a world worthy of human aspiration. In P. Reason & H. Bradbury (Eds), *Handbook of action research: Participative inquiry and action*. London and New York: Sage.
- Rifkin, S. (1996). Paradigms lost: toward a new understanding of community participation in health programmes. *Acta Tropica*, 61, 79-92.
- Rugalema, G. (2000). Coping or struggling? A journey into the impact of HIV/AIDS in Southern Africa. *Review of African Political Economy*, 86, 527-545.
- Samson, M., MacQuene, K. & van Niekerk, I. (2005). *Social grants, South Africa*. Inter-Regional Inequality Facility, Policy Brief No. 1. London: ODI.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing and Health*, 8(3), 179-183.
- Schneider, H., Hlophe, H. & van Rensburg, D. (2008). Community health workers and the response to HIV/AIDS in South Africa: Tensions and prospects. *Health Policy and Planning*, 23(3), 179-187.
- Silverman, D. (1993). *Interpreting qualitative data: methods for analysing talk, text and interaction*. London: Sage.
- UNAIDS (2004). *National AIDS Programmes: A guide to monitoring and evaluating HIV/AIDS care and support*. Geneva: UNAIDS
- Van Damme, W., Kober, K. & Laga, M. (2006). The real challenges for scaling up ART in sub-Saharan Africa. *AIDS*, 20, 653-656.
- Walt, G (Ed.) (1990). *Community health workers in national programmes: Just another pair of hands?* Milton Keynes: Open University Press.
- WHO (2008). *Task shifting: Global recommendations and guidelines*. Geneva: WHO.

Table 1: Research Informants

Those involved in the Entabeni Project

Designation	Type of interview	Number of participants	Breakdown by Ssx (F = Female, M = Male)
Health volunteers	Focus group discussion	5	4F and 1M
Health volunteers	Focus group discussion	7	7F
Health volunteer	In-depth interview	1	1M
Health volunteer	In-depth interview	1	1F
Out-of-school youth	Focus group discussion	2	2F
Traditional leaders	Focus group discussion	5	2F and 3M
Traditional leader	In-depth interview	1	1F
Traditional leader	In-depth interview	1	1F

Those uninvolved in the Entabeni Project

Designation	Type of interview	Number of participants	Breakdown by sex (F = Female, M = Male)
Teacher	In-depth interview	1	1F
Youth	In-depth interview	1	1F
Youth	In-depth interview	1	1M
	In-depth interview	1	1M
Adults	Focus group discussion	3	3F
Adult	In-depth interview	1	1F
Adult	In-depth interview	1	1F
Adult	In-depth interview	1	1F
Adult	In-depth interview	1	1F

Table 2: Coding frame and data analysis

Dimension of AIDS competence	Themes	Number of discussions that agree/disagree	Definition of theme
Knowledge	Training has led to an increase in knowledge	9 agree, 4 disagree	Training by health volunteers and HIVAN has increased knowledge about HIV/AIDS in the community
	Witchcraft hampers learning	4 agree, 1 disagrees	Traditional beliefs about illness causation provide alternative interpretive frameworks to biomedical explanations of HIV/AIDS with which the Entabeni Project aligned itself
	Male resistance undermines female efforts to practice safe sex	4 agree	Men stop women acting on HIV/AIDS knowledge gained from the project by insisting on unsafe sex
Social spaces, dialogue and critical thinking	Project has encouraged open discussion about HIV/AIDS in churches	5 agree, 2 disagree	Through project activities, HIV/AIDS is talked about more in churches, by church leaders and in church organisations
	The project has resulted in increased openness in community to talking about HIV/AIDS	4 agree	As a result of the project, people talk about HIV/AIDS increasingly in general spaces in the community including between adults and children
	Stigma has undermined project efforts to create social spaces and dialogue	6 agree	Stigma has hampered project attempts to promote social spaces, leading people to refuse to talk about either themselves or others living with HIV/AIDS
	More training is seen as the way to challenge HIV in the community	4 agree	People expressed the view that with further training everyone would know about HIV and the community could tackle the epidemic
Confidence	Participation in the project has led to an increase in confidence amongst home-based carers	4 agree	As a result of the project and its activities health volunteers are more confident in their skills as carers and in their knowledge about HIV/AIDS
	Community	7 agree	Due to the project

	members have confidence in home-based carers		community members have more confidence in the health volunteers and the work that they do
Ownership and responsibility	Health volunteers feel unconfident about their ability to carry on the project once HIVAN leave the community.	9 agree	Health volunteers worry about HIVAN leaving the community and the chances that the project will continue
	HIVAN's way of working with the health volunteers was appreciated	3 agree – minority view	Health volunteers express the view that the way HIVAN interacted with them made them feel they had a say in the project and felt ownership
	Project efforts to promote ownership undermined by people's perceptions of the scale of HIV/AIDS epidemic	5 agree	People in the community express an inability to deal with HIV/AIDS because of the scale of epidemic in their community
	Lack of interest amongst leadership undermines project efforts	5 agree, 2 disagree	Community leaders show little interest in HIV/AIDS in their community and this undermines people's ownership of HIV/AIDS and the project
	Poverty undermines people's involvement in HIV/AIDS management in the community	5 agree	High levels of poverty undermine ownership and involvement in the project amongst community members
Bridging relationships	During the project there has been an increase in access to government services	5 agree, 3 disagree	Increased access to government health and welfare services has emerged in the community because of the project and the home-based carers
	Knowledge about Entabeni Health Partnership is limited	6 agree	Community members have little knowledge about the Entabeni Health Partnership and what it is doing

Appendix A: Topic Guide

1. What challenges does HIV/AIDS pose this community at this stage of the epidemic? Elicit concrete examples of real case studies of real people rather than only generalised comments. (General ice-breaker question to get people thinking about AIDS in a very general way.) 15 MINUTES

2. Is there more that this community could be doing to respond to HIV/AIDS than is currently the case? (General question about possible community responses - ask this question in a general way, out of the context of the project.) 20 MINUTES

3. Are you aware of any role that the project has played in this community? (Leave this open ended and see what people come up with - don't give any leading questions) Please give us concrete examples if you can. 20 MINUTES

5 MINUTES TO STAND UP AND STRETCH AND REST

4. What are the main achievements of this project? 20 MINUTES

5. With the wisdom of hindsight, what could the project have done better/differently? 20 MINUTES

6. What are the chances that this work will be sustained once HIVAN has left? What factors will encourage sustainability? What factors will discourage sustainability? 20 MINUTES

Try at all times to get people to talk about examples of individual people/ individual situations, and to go beyond generalised platitudes wherever possible (e.g. If someone says: 'The children are dying' probe with: 'Can you tell us about particular situations where children have died, how have people coped with this?')

Appendix B: Three stages of data analysis

Stage one

The data were read and re-read in terms of the guiding question:

‘What factors do discussants think have facilitated or hindered the Project?’

Working through each discussion, we identified themes that emerged across one or more discussions as factors discussants perceived as either facilitating or hindering the Project (e.g. ‘Project training has led to an increase in AIDS-related knowledge in this community’ and ‘Lack of interest by local leaders has undermined Project efforts’).

Stage two

These themes were then clustered according to their relevance to the five dimensions of AIDS competence (e.g. the theme of ‘Lack of interest by local leaders has undermined Project efforts’ was grouped under the dimension of ‘Community ownership of AIDS’). Each dimension of AIDS competence was associated with between 4 and 7 themes. A record was kept of how many of the individuals or groups referred to each theme.

Stage 3

The long-list of 36 themes was reduced to 16 themes (listed in Table 2 below) through our elimination of any theme that was referred to in less than 4 discussions. In some ways the choice of 4 discussions as a cut-off point was an arbitrary act of convenience to reduce the data set to a manageable size for this particular academic paper.

In addition, most themes raised in less than four discussions tended to be vague and under-developed. For instance the theme ‘Involvement in Project structures has increased people’s confidence’ fell under the dimension of ‘Community confidence to respond to AIDS’. This issue was raised in only one discussion with a young woman who was out-of-school. She emphasised how her involvement in the Project had boosted her confidence:

Gladys (F): I used to be very frightened to talk to people. What has developed my confidence more than anything is my involvement in the Entabeni Health Partnership. (OUT OF SCHOOL YOUTH)

This quote was not detailed and this point was not raised in any of the other discussions. In the single case where a theme appeared particularly important, even though it was only mentioned in three and not four discussions, we included it in our analysis, as will be flagged up in the text.