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‘Dissemination as intervention’: building local AIDS competence through the report-back of research findings to a South African rural community.

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Abstract

There is much debate about researchers’ ethical obligations to their informants, especially when they study marginalised communities in serious distress. Some say researchers should contribute to interventions to ameliorate the problems they investigate. Within this context, we report on a ‘dissemination as intervention’ exercise developed to report back research findings to a South African rural community -- using a dialogical approach which sought to strengthen participants’ confidence and ability to respond more effectively to HIV/AIDS. Nine workshops were conducted with 121 participants (78 women, 41 men) including religious and traditional leaders, health volunteers, development and sewing groups, scholars, youth out-of-school, traditional healers and teachers. Workshop transcripts, fieldworker diaries and participant debriefing sessions were subjected to thematic content analysis. Workshops provided many with their first opportunity to discuss HIV/AIDS in a supportive context (in a wider climate of fear and denial) and to identify how their individual and collective responses were hampered by gender and age inequalities, stigma, resistance by local leaders and lack of outside support. Workshops alerted participants to the valuable role played by local volunteers and facilitated reflection on how they might support volunteers, assist those living with HIV/AIDS and protect their own sexual health. We highlight variations in the way different groups engaged with these topics in terms of both style of engagement and content of discussions. Workshops provided opportunities for participants to develop critical understandings of the possibilities and limitations of their responses to a pressing social problem, understandings which constitute a necessary (though not sufficient) condition for further action.

Keywords: HIV/AIDS; rural areas; AIDS competence; dialogue; social spaces; community conversations.

INTRODUCTION: ETHICAL OBLIGATIONS TO RESEARCH INFORMANTS?

This paper provides a case study of a ‘dissemination as intervention’ methodology developed to report back research findings to study communities in ways that aim to strengthen community responses to pressing social problems. We report our use of this approach to feedback results of our study of ‘Community Responses to HIV/AIDS’ to residents of Entabeni, a deep rural area in South Africa.

About 65% of people in sub-Saharan Africa, and 45% of South Africans, live in rural areas, which carry a significant weight of the burden of HIV/AIDS in Africa (Kok and Collinson, 2006). In Entabeni, one in four have HIV/AIDS, and the associated death and anguish are features of daily life. Access to medical and welfare support is limited, due to geographical isolation and low literacy and confidence (Wilson and Blower, 2007). Whilst many depend on subsistence farming, recent droughts have undermined this strategy in a hilly and stony physical environment, and chronic poverty is widespread. Various factors – including the domination of women and youth by adult men, in a conservative setting ruled by an unelected traditional chief – combine to undermine effective local responses to HIV/AIDS.

Our study revealed a community steeped in fatalism and bewilderment regarding a condition so deeply stigmatised that many (including some of the dying and their carers) refused to acknowledge its existence (Campbell, Foulis, Maimane and Sibiya, 2005). This atmosphere undermines the collective impact of heroic responses by isolated individuals, families and groups. Within this context, our dissemination workshops were designed not only to report back research findings. They also sought to challenge this fatalism through facilitating a sense of individual and collective agency to respond more effectively to HIV/AIDS. Workshops sought to do this through providing participants with ‘safe social spaces’ in which they could talk about AIDS, develop critical understandings of obstacles to effective prevention and care, brainstorm ways in which they could respond more effectively, both as individuals and in groups, and begin to generate understandings of the types of outside support they would need to optimise the effectiveness of their responses.

The wider context of this paper is an interest in the ethical obligations of researchers to their research informants, particularly when research focuses on marginalised communities in serious distress (Benetar, 2002; Robson, 2001). Three sorts of opinions exist here. At the very least, there is agreement that researchers should follow ethical guidelines in relation to issues such as informed consent and confidentiality (Nuffield, 2002; British Sociological Association, 2002). Secondly, many argue that researchers should go further, feeding back findings to their study communities (Baxter and Eyles, 1997; Flaskerud and Anderson, 1999). Thirdly, some go even further, arguing that researchers should strive to ensure their research contributes to the development of interventions to ameliorate the problems highlighted by the research (Black, 2003; Fuller, 1999), and that researchers should contribute to facilitating the establishment of such interventions (Campbell, 2003, Farmer 2003).

This paper's authors constitute the 'Community Responses to HIV/AIDS Research Project' in the Centre for HIV/AIDS Networking (HIVAN) in Durban. HIVAN is a university-based NGO which specialises in promoting effective networking amongst agencies concerned with HIV/AIDS management, and where possible undertaking social research to support this work[i]. Our HIVAN research programme in Entabeni sought to achieve elements of the 2nd and 3rd levels of input outlined above – by reporting back research findings to community groups using a workshop methodology. We hoped our workshops would in themselves constitute an intervention of sorts, through aiming to achieve two goals.

The first goal of our 'dissemination as intervention' workshops was to go beyond a simple report-back of findings. We sought to present findings in a dialogical workshop format that would promote six features of 'AIDS competence' amongst workshop participants. An AIDS competent community is one where members work collaboratively to support each other in achieving: sexual behaviour change, the reduction of stigma (a key obstacle to prevention, treatment and care), support for people with AIDS and their carers, co-operation with volunteers and organisations seeking to tackle HIV/AIDS, and effective accessing of health and welfare services and grants (Campbell, Nair & Maimane, 2008).

The six dimensions of AIDS competence the workshops sought to promote were: (i) enhanced HIV/AIDS knowledge; (ii) safe social spaces for open dialogue about HIV/AIDS; (iii) critical thinking about obstacles to effective responses; (iv) a sense of local ownership of the problem and responsibility for solving it; (v) the identification of local community strengths and resources for more effective responses; and (vi) the identification of strategies through which local people might contribute to the development of health-enabling social environments (as individuals, as local group members, and through building partnerships with external support agencies).

The second goal of our intervention was to use the workshops for community consultation, where researchers and community members might jointly formulate a strategy for strengthening local community responses to HIV/AIDS – as the first step towards the establishment of a community-strengthening intervention. As it happened, in this particular case, the results of this consultation process fed into an intervention proposal, which was later funded and is currently being implemented. This intervention will be written up elsewhere (Campbell, Nair, Maimane & Gibbs, in preparation). The aim of the current paper is to discuss the extent to which dissemination workshops of the kind we conducted might serve as self-standing interventions – that might constitute a model for researchers who lack the capacity to involve themselves directly in setting up larger scale responses.

CONCEPTUAL FRAMEWORK: 'DISSEMINATION AS INTERVENTION'

The concept of ‘dissemination as intervention’ is rooted in Freire’s notion of critical consciousness, and Fraser’s (1992) critical reformulation of Habermas’ notion of ‘the public sphere’. Freire (1973) argues that a precondition for marginalised groupings to work together to improve their well-being is the development of sound understandings of the causes of their life challenges, and the obstacles that stand in the way of improvements in their living conditions. A critical awareness of obstacles is a necessary precondition for tackling them. Freire’s focus on the way people understand social problems is particularly relevant here because two key obstacles to effective HIV/AIDS management in South Africa relate directly to peoples’ conceptualisations of the problem. The first is the *stigmatisation* of people living with AIDS, leading not only to individuals’ and communities’ unwillingness to take ownership of the problem and to provide appropriate support and help to people with AIDS and their carers, but also to a denial of personal vulnerability and a reduced likelihood that people will take preventive action (Campbell, Nair & Maimane, 2007b). The second is ‘*competing beliefs’* which undermine peoples’ acceptance of biomedical information about the causes of HIV-transmission and the importance of taking appropriate measures to avoid HIV/AIDS infection (these include traditional beliefs ascribing HIV-infection to witchcraft rather than sex, scepticism about the efficacy of condoms, a belief that AIDS is a white plot to decimate the black population and so on).

A key dimension of providing a supportive environment for HIV/AIDS management is the provision of ‘social spaces’ in which people feel safe to discuss the often literally ‘unspeakable’ topic of HIV/AIDS. Such spaces provide contexts within which people can collectively work through their doubts and uncertainties about this new and still unfamiliar disease. Through a process of dialogue they can make this information relevant to their own lives – processing it in ways compatible with their pre-existing frames of reference, vocabularies and social practices.

Drawing on Habermas’ idealised concept of the public sphere, effective dialogue is most likely when participants engage in debate in conditions of equality, and where ideas are evaluated in terms of the sense they make to the participants, rather than the extent they support the status quo (Jovchelovitch, 2001). Fraser (1992) distinguishes between the dominant public sphere (controlled by economically and/or politically influential members of a social group) and subaltern public spheres. The latter are spaces where members of less powerful peer groups (e.g. women or young people) are able to talk about controversial topics in conditions of openness, trust and solidarity. These might include ways in which their interests are undermined by more dominant social groupings (e.g. men, adults or political leaders), and the possibility of challenging the status quo.

The ideals of dialogue and critical thinking in subaltern spaces are implicit in the UNDP's 'Community Conversations' approach – developed in Ethiopia – and regarded by many as an example of 'best practice' in the AIDS arena (Lewis, 2004; UNDP, 2005). Trained local facilitators provide contexts where people can identify the problem of HIV/AIDS in terms that make sense to them, as well as identifying their own solutions. Such groups ideally provide contexts for the development of AIDS competence, providing social spaces in which people can talk openly about taboo topics for the first time; identify the extent to which their own cultural norms and values fuel the epidemic, and brainstorm feasible strategies.

ENTABENI: BASELINE RESEARCH FINDINGS

In Entabeni, 25% of adults and 43% of pregnant women are HIV-positive (HEARD, 2004). Polygamy is widely practiced. Many employed men are migrant workers who engage in multiple relationships, making wives particularly vulnerable to infection (Karim *et al.*, 1992; Lurie *et al*., 2003). Few residents have access to radio, television or other sources of information about HIV/AIDS or how to avoid it (HSRC, 2005). Access to basic health and welfare services is minimal as are clean water and good roads. Poverty, unemployment and illiteracy are rife and TB, AIDS and cholera are common (Barron *et al*., 2006).

Within such a context, informal care – within impoverished households, generally provided by women and young people – is the only support for many dying of AIDS (Robson 2000; Robson *et al*., 2006). The negative impacts of the burden of care include physical and psychological burnout (Baumann *et al*., 2006; Orner, 2006; Thomas, 2006), family breakdown (Campbell & Foulis, 2004) and the destruction of household economies (Rugalema, 2000). Little is known about how people cope, what formal and informal networks are available to help people with HIV/AIDS and their carers, and what factors shape the effectiveness of these community networks (Campbell & Foulis, 2004). These constituted the central topics of our baseline research.

Our detailed case study of local responses to HIV/AIDS was conducted in partnership with Entabeni's traditional chief (*Inkosi*), who facilitated community entry through introducing us to local health volunteers, and authorising them to work with us. At this stage, we emphasised that we had funding only for a research study (including report-back of findings) and not an intervention. The *Inkosi* was concerned about growing numbers of AIDS deaths in Entabeni, and felt 'something should be done'. He hoped our research would eventually be of practical benefit to the community.

Our main research findings related to the existence of a team of around 60 volunteer community health workers who had banded together to assist households nursing dying patients (see Campbell *et al*., 2008 and Maimane *et al*., 2004, for baseline findings). This group had been trained through fragmented inputs from missionaries, government and NGOs. The only group offering care and support to households affected by AIDS, working for no pay, and often travelling long distances by foot, these volunteers helped carers with tasks such as fetching wood and water, cooking, cleaning patients and offering emotional support. Stigma often meant that after long walks to households rumoured to be housing dying AIDS patients, volunteers would be turned away by families denying that this was the case. Without supportive health and welfare systems, with little recognition from local leaders, or the church (the only established informal network in the community), dealing with the severest and most challenging of health problems in a climate of hunger, poverty and often hopelessness, this group was remarkable for their dedication and commitment.

Our research concluded that these volunteers were well-placed and willing to lead an accelerated community response to AIDS, but would need further training, recognition and assistance from local leaders and community members, and strong support from support agencies outside the community, particularly in regional health and welfare departments and relevant NGOs. However, a necessary precondition for achieving such goals would be for local people to develop greater awareness of AIDS, critical understandings of the community's lacklustre response, a sense of ownership of the problem, a recognition of local resources for responding more effectively, and an awareness of potential support partners outside of the community – the dimensions of AIDS competence defined above. Our workshops sought to facilitate the development of these amongst nine key local groups. The remainder of this paper presents our analysis of our successes and failures in this enterprise.

THE DISSEMINATION WORKSHOPS

Our dissemination workshops had four sections: (i) building HIV/AIDS-relevant knowledge; (ii) discussing the impact of AIDS on the local community, and obstacles to meeting patient and carer needs; (iii) identifying and building on existing community strengths; (iv) formulating strategies for individual and group contributions to more effective local HIV/AIDS management. Apart from section (i) where input came from group participants alone (see below), the other three sections began with a brief input from the researchers outlining findings, followed by small group discussions of the implications of the findings for possible local action.

We facilitated workshops with nine groups of local residents, involving a total of 121 participants: health volunteers (15 – 13 women, 2 men), religious leaders (32 – 20 women, 12 men), traditional leaders (9 – 3 women, 6 men), traditional healers (5 men), school learners (14 – 8 girls, 6 boys), young people out of school (9 – 4 girls, 5 boys), members of a local sewing group (6 women), teachers (16 – 13 women, 3 men), and a local development group (15 - 11 women, 4 men). The volunteer leader nominated by the Inkosi to facilitate our research was asked to organise groups of roughly 15 people each. Numbers that attended are reflected in brackets above, as is the gender breakdown of participants (78 women and 43 men).

Workshops were facilitated by the third and fourth authors, experienced in running participatory workshops (Chambers, 1997; Reason and Bradbury, 2001; Gaventa and Cornwall, 2001). Workshop discussions were tape recorded, and each facilitator transcribed his or her workshops. Furthermore (except with traditional healers and teachers who were not available at suitable times) between one and three members of each group were invited to participate in a brief post-workshop evaluation session to discuss their perceptions of the workshops. These were also tape recorded and transcribed. Transcriptions were subjected to thematic content analysis (Attride-Stirling, 2001), coding material according to the dimensions of AIDS competence which frame our presentation of findings below.

FINDINGS

To what extent did workshops promote a sense of AIDS competence in their participants?

General commitment and feedback

Peoples' commitment to workshops was reflected in the fact that many travelled long distances to participate, some walking for up to four hours. With two exceptions discussed below, every group was overwhelmingly positive about the experience, with many saying the researchers had been 'sent by God' to help the community, with the workshops being described as 'an act of God'. The groups that showed the greatest enthusiasm were the school learners and religious leaders. Large numbers of school learners crowded around the workshop entrance, begging to participate. '*Debate was hot*' (Fieldworker diary) and – in a deprived community on a very hot day – participants refused to break for refreshments, saying the discussion was too interesting. Religious groups were asked to send 15 representatives for a two hour workshop. In fact, 32 people arrived, and the workshop went on for five hours, again with people refusing breaks and engaging in lively discussion.

The greatest appreciation was expressed by the volunteers. Three months after the workshops, they said they had played a vital role in raising health volunteers' profile in the community.

> *Before this workshop we were no longer enthusiastic about our work. The level of performance was very low because we were beginning to think no one cared about us, despite the vital role we were playing in this community ………We salute you. God is good for bringing you people from HIVAN into this community. We used to live in darkness. (Volunteers)*

The two exceptions to this rule of enthusiastic participation and positive feedback were the Traditional Healers group – with five participants – and the *Izinduna* – which we refer to as the Traditional Leaders group in this paper. (Whilst the *Inkosi* is the supreme chief in the community, he delegates the day to day management of the community to his headmen or *Izinduna*, who hold significant power in community life, and would be a key constituency for a project seeking to build support for the volunteers). The latter group made it clear that they were reluctant to participate, and in fact derailed our first workshop with them by informing us they were no longer available a few minutes before it was due to start. However, it was impossible for them to refuse in the longer term, given that the *Inkosi* had authorised the workshops. As will be discussed below, the participation of both groups – composed mostly of older, traditional and relatively powerful men – was restricted in a number of ways.

1. Knowledge

The first phase of the workshop focused on building knowledge about AIDS and its causes, through providing opportunities for people to consolidate the fragments of knowledge they had amongst them. For two reasons, workshop facilitators did not ‘correct’ any misconceptions arising in discussions. Firstly, we sought to provide opportunities for participants to discuss HIV/AIDS in ways that made sense to them in the context of their own worldviews and possible worlds. Secondly we sought to facilitate knowledge-building such that participants would feel a sense of personal ownership of any knowledge they acquired – and thus be more likely to retain and use it – than would be the case with knowledge seen as originating from ‘expert outsiders’. Some say this strategy opens up the risk that facilitators will knowingly allow participants to leave with inaccurate knowledge. However in almost every case group members corrected one another when misconceptions were expressed. When some participants lacked knowledge, others were able to fill in the gaps.

> *Volunteer A: Some say condoms spread AIDS because they have a small hole in the tip. Others say the AIDS is in the small worms that develop if you put condoms into warm water. Is there any truth in this?*
> *Facilitator: Can someone respond to this question?*
> *Volunteer B: This is not true because children play with condoms. They blow them up like balloons. They wouldn’t inflate if there were holes in them.*
> *Volunteer C: We once poured warm water into a condom and no worms developed. We also left this water in the sun for some time, and nothing developed either.*

Between them each group pieced together a fairy accurate body of information. In our baseline research, community members repeatedly told us that they lacked knowledge about AIDS. Workshop discussions suggested that when provided with the opportunity in a supportive context, people were able to construct a fairly respectable knowledge base with no input from facilitators. Participants’ problem appeared not so much to be one of lack of knowledge, as of not having had previous opportunities to share and discuss this knowledge and work through their doubts and uncertainties about it.

2. Social spaces for dialogue

Workshop participation represented the first chance many had had to discuss HIV-related issues in a supportive group setting. Whilst some groups took longer to warm up than others, most engaged in animated discussion and debate in a lively and interested way. It was clear that people were taking risks and talking openly about taboo topics in a way they found unusual. The frequent laughter and giggling in small group discussions bore witness to this. But people gradually overcame their reservations, and after a while the laughter stopped as they jointly created a ‘safe space’ to keep on talking.

Silence and stigma had been a key theme in our baseline research (Campbell et al., 2007b). AIDS was a taboo topic, shrouded in denial and avoidance. In this respect, the dissemination workshops were exceptionally successful. Participants – even amongst the more reticent traditional leaders and traditional healers – spoke with great openness, often very movingly, of the deaths of children or family members.

> *My son died of this disease. He never told me the truth. It was the doctor who told me after he had died. (Traditional Leaders)*

A participant in the Religious Leaders workshop spoke about his HIV-positive son ‘living positively’ with AIDS, and the role played by the health volunteers in supporting him.

> *I am talking about my own son who is living with this virus. He is well and sound. He has been living with it for years, but because the health volunteers care for him he is still alive. Even when others don’t want to come near him, they bring him food. He has his own children, and he is alive. (Religious Leaders)*

Such disclosures often stimulated useful discussions of AIDS-related dilemmas currently faced by participants. A carer of a grandchild with AIDS spoke of her fear that she would become infected whilst cleaning the child’s sores, saying she was reluctant to use gloves for fear of stigmatising the child. Another carer in a similar situation said she had solved this problem by using gloves when bathing all her grandchildren, including those who were not HIV-positive.

The workshops also provided spaces for people to share positive options for action in a context where stigma and rejection were common.

> *A woman visited our church and told us she was HIV positive. It was clear she was a deep Christian. The congregation held her and hugged her, wishing her well. They showed her love. She left the church feeling good. (Health volunteer)*

Workshop transcripts showed numerous examples of thoughtful and engaged discussions, as people exchanged views, and challenged one another in exactly the way we had hoped for, as this extract from the school learners discussion suggests (F = female, M = male):

> *F1: Its not easy to abstain from sex, people cannot control themselves.*
> *F2: I think its easy to abstain if you have never had sex, but if you have experienced it I think its not easy to abstain.*
> *F1: The main problem is with boys. They look at girls and think about sex. They say that it becomes painful and they must have it.*
> *M1: This is not true, we <u>are</u> able to control ourselves.*
> *M2: I would like to disagree with [F2] when she says its not easy to abstain if you have already experienced sex. If you have a positive and determined attitude its easy to abstain.*
> *F2: If I steal sugar and I know its nice, I will always go back and steal it.*
> *F3: Its not fair to blame boys. Even girls are guilty. Girls also cant' control themselves. We grab any boy we come across. (Learners)*

Some groups said it was the first time they had been exposed to an unstructured and democratic discussion format. At the start of many groups, women sat separately from men, as is the local custom in a traditional patriarchal setting. In every group but one, facilitators expressly asked men and women to sit together and ensured that small group discussions contained a gender mix wherever possible, with very positive results. The exception here was the traditional leaders workshop, where the facilitators felt unable to intervene in seating arrangements – out of respect for the importance of the participants. This led to a significant reduction in the quality of the small group discussions.

Throughout our dissemination exercise, the general rule was that women and young people of both sexes were enthusiastic and frank participants in discussion. This was not always the case with older men. Male traditional leaders, in particular, made it very clear that they were unwilling to engage in workshop-style discussions, or to express any personal views about sensitive topics. After the first part of the small-group exercises in the traditional leader workshop, female traditional leaders reported back a spirited and engaged discussion about the causes of AIDS. Their male counterparts were not as willing. When asked to feed back the content of their small group discussion, the male rapporteur told the plenary that his group had nothing to say.

> *We couldn't discuss this. You (the facilitators) must tell us about this disease since we know nothing about it. (Male traditional leader)*

The traditional healers were also very unwilling participants in discussions. Furthermore the content of their discussions, as well as their own behaviour, illustrated how they inhabited a world dominated by authority-based interactions rather than dialogical engagement. When a workshop discussion turned to how teachers might best communicate with youth about safer sex, a traditional healer expressed great irritation.

> *This is really disgusting. I don't expect my child to be told about sex at school. All that children need is to be told is that if they have sex they will die, that is all. (Traditional Healers)*

Male traditional leaders and traditional healers are central to any attempts to facilitate more effective community responses to AIDS. Whilst they were often surprisingly open in talking about AIDS deaths in their personal lives, their style of participation in the workshops indicated the challenge that would be faced by a project seeking to engage them in their leadership roles to support the creation of a democratic, supportive and humane environment most conducive to effective community involvement in prevention and care.

The 'problem of men' was not just evident in the style of engagement of the more powerful adult men in the workshops. It was also evident in the *content* of many of the workshop discussions. In every single discussion involving women participants, men were cited as the chief obstacle to HIV-prevention, in terms of refusing to practice safe sex, or even to acknowledge the risks they took if they had many girlfriends. Secondly men were said to respond very negatively to wives or family members who tested positive. This point is taken up in the next section.

3. Critical thinking

As discussed above, a community's ability to improve their chances of health and well-being is strongly enhanced by recognition of obstacles that stand in the way of this goal. Gender, age, stigma, and lack of support from leadership loomed large in peoples' accounts of the challenges to community coping with AIDS.

The strongly patriarchal nature of the community was repeatedly evident to fieldworkers:

> *As we were leaving the Traditional Leaders Workshop, I noticed a woman in her fifties kneeling on all fours (wearing a white scarf to depict respect for the leaders). She was trying to talk to two standing leaders who continued chatting to each other, and only intermittently looked down to give her some of their attention. This sight, for me, epitomised the absolute oppression of women in this community. (Fieldworker diary)*

Male unwillingness to acknowledge or learn about AIDS and unhelpful male attitudes to HIV prevention and AIDS care were themes running throughout every workshop - aside from the Traditional Leaders and Traditional Healers. Women, youth, and some men repeatedly spoke of openly unfaithful men having no interest in learning about HIV/AIDS, refusing to use condoms, and when HIV struck, accusing their wives of infecting them.

> *Women of this community have no power to influence men on HIV prevention. Even those men who do talk about prevention don't include themselves. They refer to young people (Health Volunteers)*

> *I could try and share information from this workshop with my husband, but he would just say there was nothing he could learn from a woman. (Sewing Group)*

Male arrogance and resistance to change was a constant theme. Mrs Y (head of the Sewing Group, and one of the most confident and successful female workshop participants) said that whilst she regularly handed out condoms to women, to give them to men was out of the question.

> *Men don't want to hear a thing about condoms. They think they know a lot about life. They don't want to move along with the times. The problem with men is that they don't want to change. If you talk to a man about change, you are just wasting your time. They think they know everything. (Sewing Group)*

Many women spoke of the terror of knowing that their husbands had multiple partners, yet refused to discuss condom use – saying that they had paid *lobola* (bride-wealth) for their wives, and as such could do as they wanted with them.

> *Volunteer: The rules say you don't argue with your husband, even if it means you will die. (Health Volunteers)*
>
> *Volunteer: Our husbands have affairs, and you suspect they are HIV positive, but you cannot suggest the use of condoms. If you talk about AIDS, they say that there is no AIDS - yet people are dying around us left and right. We married women feel that we are dying whilst we are alive. Its like we might as well hang ourselves, since we have no power to avoid AIDS in marriage. (Health Volunteers)*

In a discussion of sources of advice and support for an HIV positive mother – deciding whether or not to breastfeed her baby, in the absence of money to afford a regular supply of powdered milk – a young man in the Out-of-School Youth workshop was emphatic that it was not an option for a woman to discuss such a problem with her husband. In his view a man's role as household head placed him beyond dialogue, and beyond the possibility of fairness or empathy.

> *Telling her husband would be a stupid thing to do. What if he abandoned her and the baby saying she infected him with the*

> *virus……….. You all know how hard-hearted our fathers are, you can't sit down with them and discuss issues. All that they know is that they are heads of households…….. (Out of school youth)*

In a more general vein, as one (male) health volunteer concluded:

> *I am going to be blunt and say that men have no commitment to helping this community. They think it's a waste of time. Even those that don't drink don't imagine that they have any role in helping other people. They don't have* ubuntu *(humanity). (Health Volunteers).*

Despite this overwhelmingly pessimistic assessment of the intractability of male resistance, there were some exceptions to this trend. These included young men in our Learners and Out of School Youth groups, who despite not using condoms themselves, participated eagerly in the workshop, and expressed a strong interest in becoming involved in any new community project to manage HIV/AIDS. There were also occasional men scattered in other groups, particularly the Religious Leaders, Teachers and Health Volunteers groups, who appeared open to dialogue and new ideas. There was the single woman learner who challenged the stereotypical distinction between sexually uncontrolled men and controlled women. Even the head of the Sewing Group mentioned above suggested that it might be possible to reach men through the involvement of community outsiders. This point is taken up below.

Poor inter-generational communication was cited as another key obstacle to HIV/AIDS management, linked to the refusal of many adults to acknowledge that many young people are sexually active, or to support them in protecting their sexual health.

> *I was at the clinic when one boy took a condom from the box in the waiting room. Everyone who was there started shouting at him, saying 'Hawu, how can such a young person take condoms'. (Adult woman, Development Group)*

Some young people spoke of blanket denial by both mothers and fathers.

> *There is a problem if a young person talks about HIV and sex at home, after attending awareness events at school. Children know that talking about HIV and sex to their parents is not considered right, not allowed. Even if a child has been raped she will be scared to talk about it. (Health volunteers)*

Some youth said that mothers were more accepting.

> *If I started asking my father about sexual issues he would say: 'I am the only man in this house.' There are many issues I would like to discuss with him and its not easy when he is not forthcoming. I don't think I could tell him if I found I was HIV positive, even until I died. Our fathers are very stubborn. (Learners)*

Here again, there were few fragmentary exceptions to this trend. Several adults disagreed that condom availability would cause otherwise abstinent young people to 'indulge in sex'.

> *Condoms are not the reason for youth sex. Youth are already having sex. It's the older people who are not comfortable about sex. (Development Group)*

As discussed below, teachers were particularly positive about young peoples' ability to learn and teach one another HIV/AIDS relevant skills and knowledge, saying that the school should play a role in facilitating this. And some young people went beyond this, saying that perhaps it was they who needed to break the inter-generational silence and that they had a role to play in educating their parents about HIV/AIDS.

> *We should talk to our parents – we know more than they do about these things. They can be educated by us. (Learners)*

Elsewhere we have written extensively on the symbolic and material drivers of AIDS-stigma in Entabeni (Campbell et al., 2005; Campbell et al., 2007). Stigma is exacerbated by poverty, where households and communities lack adequate resources to care for people with AIDS, and where such care is often the last straw for women already over-burdened with the challenges of survival. In health services, stigma is intensified where health workers lack the skills and resources to alleviate the agony of suffering or dying patients. And within patriarchal societies such as Entabeni, where men are often deprived of their traditionally defined roles of political and economic influence (Silberschmidt, 2001), AIDS is a very obvious sign of the breakdown of so-called ‘traditional’ adult male control of the sexuality of young people, especially young women.

In our dissemination workshops, the most frequently mentioned stigma-related issue related to the difficulties of nursing family members who denied that they had AIDS. People repeatedly said that whilst they had been advised to wear gloves when nursing people with open sores or diarrhoea, sick people took offence, accusing their carers of implying they had AIDS.

> *My sick daughter had a baby, which she dumped on me to care for. The problem is that I see symptoms of AIDS in this baby. When I handle the baby I use gloves, because the health volunteers have taught me to do this. But when I do so my daughter shouts at me, asking me why I stigmatise her child. (Religious leaders)*
>
> *Recently I spoke with a woman whose husband has AIDS. I asked her why she doesn’t use gloves whilst cleaning his sores. She said she was afraid he would think she was stigmatising him. (Teachers)*

Volunteers regarded stigma was a key reason for lack of support for their work by other community members. Thus, for example, AIDS stigma meant that families with members living with AIDS frequently turned health volunteers away at the gate denying that they had any such problem in their household.

> *Please can you organise a community-wide meeting to educate everyone in the community who has not attended these workshops. Perhaps this will stop families from allowing their dogs to attack us. When they see a person wearing the red and black uniform (of the volunteers), they know its one of us, and they close all their doors. (Health Volunteers)*

Volunteers said that in households that did accept their help, family members often became lazy, expecting them to do menial tasks of cleaning and cooking for patients. They said their time would be better spent offering specialist help such as nutritional advice, counselling and bed-bathing those with open sores

– with families performing less specialised tasks. This would also enable the volunteers to visit more families.

They complained bitterly about the lack of any payment for their work.

> *People don’t believe we aren’t getting paid, they say we are hiding our earnings from them, even our husbands say that. I like this work that I do, and the sick people depend on us, I wouldn’t abandon them. The only problem is that I don’t bring anything home at the end of the month. This compromises my dignity, and creates conflict with my own family. (CHW)*

They also said that their ability to perform their role effectively was dramatically undermined by lack of support from the Izinduna.

> *Volunteer: The Izinduna are the main obstacle to our work. They don’t accept we are doing this work for the community.*
> *Volunteer: They don’t accept that the Inkosi has given us permission to do our work. They pretend they don’t know who we are.*
> *Volunteer: The welfare asked the Induna’s to provide a list of needy families supporting orphans for grants, and to get advice from us because we work with these families. They didn’t ever consult us, and afterward we found out that they had written down the names of needy families, but also the names of their friends and relatives.*

As was the case in our baseline research, volunteers repeatedly expressed the view that the power-hungry Izinduna were threatened by the positive and growing role that the volunteers played in Entabeni through their invaluable role in supporting the needy.

> *The Izinduna must recognise our role as health workers. They mustn’t think we are trying to take their positions. We as health workers are under our leaders, we respect them. The leaders feel threatened by this, they must be reassured. (Male health volunteer).*

4. Ownership/ responsibility

To what extent did the workshops succeed in increasing peoples’ sense of ownership of the challenge of AIDS rather than passively waiting for outside assistance? Our baseline research suggested that aside from the volunteers, few had been prepared to take such ownership or any responsibility for tackling it. We have already seen how some women and young people insisted there was little or nothing they could do, citing gender and age hierarchies as insuperable barriers.

Such distancing from responsibility was particularly strong in the Traditional Leaders and Out-of-School youth groups. Some Out-of-School Youth said they were powerless to protect themselves because they were prisoners of irrepressible sexual urges. Of the 9 participants in this group, 8 were sexually active, and not one used condoms.

> *M1: When an individual grows up, s/he gets a craving for sexual intercourse, you can't run away from nature, and you can't prevent it from taking its course.*
> *M2: I don't think we should even bother to find out our HIV status – that is just a way of hastening death. You are going to die anyway. I am just saying this because you said we must talk openly. This is how I feel.*
> *Facilitator: Aren't you scared?*
> *F: O God! Personally I am afraid of it. If you could read my heart you could see how much I fear having HIV/AIDS. I am too terrified to go for a blood test. But (giggles) sex happens. (Out-of-School Youth)*

Traditional Leaders distanced themselves from any responsibility for HIV-transmission in their own relationships through blaming it on a combination of women and sick children in an emotionally charged discussion, which carried an undertone of panic.

> *M1: HIV/AIDS leads to a very difficult situation because we all take care of people that are infected and we don't use gloves. This is really a big problem because it causes conflicts in our homes. If my wife discovers she has this virus, the first person she will suspect is me, whereas I am innocent.*
> *M2 (Loudly): As far as I am concerned, I don't have this disease. What if my wife gets infected by caring for her child and then she tells me she has this disease? I wouldn't accept that. She must leave this house. I don't have this disease and she tells me she has it! That will be the end of the relationship. Why should she stick around until I get infected? She should tell me before she infects me! Perhaps she has already killed me!*

> *M3: If I discovered that I had this virus tomorrow, I would tell my family that I am lost. It would be up to me to decide whether to hang myself on a tree or something. Why should I continue living because it means I am now a poison in this world. (Transcriber's note: By now everyone was talking at once, its no longer possible to hear what they are saying.)*

5. Recognition of individual and community strengths

Many workshop participants spoke of the personal confidence they had experienced through workshop participation.

> *As a result of the workshop, I was encouraged to go for an HIV test myself, knowing that if I knew my status I might take special care of myself and live for many years since I am still young. It made me remember the HIV-positive women in the support group who look young and beautiful. (Health Volunteers)*

> *I have always been afraid and embarrassed to talk about sex to other people. This workshop taught me that I must start talking to my children at a very young age because they are told about these things at school and they come back home and ask more questions. This workshop therefore taught me not to be shy to talk to my children about sex. (Development Group)*

> *M: Until now I have been afraid to talk openly. But this workshop makes me feel confident that I can talk to other people without being ashamed of how they will react.*
> *M: I have gained a lot by coming here, what I appreciate most is that we now have people who are working in our community to give us guidance to do things on our own.*
> *F: In this community we young people are not used to being together and discussing matters that concern us and the community. I have learned many things, I have really gained a lot from this workshop.*
> *F: I think that having more meetings like this will develop our capacity to open up.*
> *M: I wish all the young people in this community had been here to gain what we have gained today. This has been a great opportunity. (Out of school youth)*

A key aim of the workshops was to promote recognition of the work of the health volunteers, as a key step towards mobilising greater community support for their efforts. Workshop discussions revealed patchy awareness of the volunteers' work. Out-of-School Youth knew virtually nothing about them. Members of the Development Group knew about them, but complained about their unsystematic coverage of the community, and said the volunteers didn't perform their role very well. Other groups tended to be aware of them, but vague about their role and value. The volunteers were unanimous that the dissemination workshops had increased their profile in the community, and their confidence about what they had to offer.

> *After the workshop I felt confident to challenge the nurses at the clinic when they refused to give nutritional powder to HIV-positive people, saying it was only for tuberculosis patients. (Volunteer)*

People repeatedly referred to the role of our workshop style in building their confidence in what they had to offer. Several informants commented positively on the dialogical style of the workshop, and on the 'humble' role played by the facilitators. The volunteers spoke particularly appreciatively of the facilitators' emphasis that 'there are no right or wrong answers', and their skill in creating a climate of open discussion. They contrasted this with the litany of 'shoulds' and 'oughts' that had too often characterised the few previous discussions of HIV/AIDS that had taken place in the community.

> *You encouraged us to provide information ourselves. You only taught us things which we did not know. This was an excellent approach. (Health Volunteers)*

The health volunteers also commented positively on the facilitators' style of throwing problems back to people in the workshop. They said this effectively challenged peoples' tendency to fatalism and passivity, and their habit of waiting for outsiders to come and tell them what to do. The following extract from a workshop transcript illustrates the way in which facilitators did this.

> *Volunteers: We desperately need a permanent clinic in this community. Facilitator: Who is going to see to it that this clinic is built? Volunteer: I think Mr Mzobe should be our representative but he says he is too busy to action this at present. Facilitator: But you are well aware that Mr Mzobe is overloaded with community work. You need to be involved in these issues yourself and not wait for one person to do all the work.*

> *Volunteer: We are starting to be aware of this in the way that you say.*
> *All: We agree.*

6. Brainstorming of future strategies

The sixth dimension of AIDS competence fostered by the dissemination workshops was to work with people to identify strategies for strengthening community responses to HIV/AIDS. Discussions of strategies touched on different types of activities. These related to both AIDS-care and HIV-prevention, networks for implementing activities, and the need for external support if local activities were to have any chance of success.

We have already referred to punitive and authoritarian strategic thinking by some conservative participants. Rare traces of this were present in the strategy discussions, such as this call for punishment of non-virgin girls:

> *M: We must go back to basics, and all girls must undergo virginity testing. If its is found that they are no longer virgins, they should be forced to marry old men whose wives have long since died. They must be made to feel they have done something shameful.*
> *F: I agree. Virginity testing is the key. If they are no longer virgins they must be chased away from home to go and marry old grey-bearded men. (Religious Leaders)*

However strategies associated with kindness and empathy were advocated more frequently than punishment. People repeatedly called for more education to create a more humane environment for people with AIDS. Everyone highlighted the youth as a group in urgent need of AIDS-related education and support – citing churches, schools and community meetings as possible fora for this. People also referred to peer education as a useful strategy.

Whilst traditional leaders and traditional healers were scathing about young people, other groups – especially teachers, and young people themselves – referred to young people out-of-school as an under-utilised resource, which could be mobilised to support volunteers – both through conducting peer education with each other, and also through assisting the health volunteers with AIDS-care work.

> *Young people should be educated by their peers. They should be given freedom of speech. They are happy for opportunities to discuss sexual health amongst themselves – the teachers needn't say much. When children are given a chance to talk about serious topics, they become comfortable ……….. One of them might be living with the virus and afraid to tell a parent, and find it easier to talk to other peers. Children also understand better when they teach each other. (Teachers)*

Despite having shown a high degree of fatalism and despondency in their discussion of their own sexual behaviour, some members of the Out-of-School Youth group ended by expressing a strong interest in playing a greater role in AIDS-related work:

> *As youth out of school, we have the capacity to play a significant role in tackling AIDS. Youth like us to not have any privileges. If we underwent proper training to do this work, we would feel capacitated and motivated. (Out-of-School Youth)*

Several participants warned against a narrow youth focus, emphasising that adults needed educating as well. As already discussed men were repeatedly singled out as a constituency to target, as were parents and teachers.

> *Before you educate youth in schools you need to educate parents, because I am telling you, if you start telling learners about sex, and giving them condoms, they will go home to parents who are not educated and the reception will be negative. (Religious Leaders)*
>
> *Its not just youth in schools who need information and counselling. There should also be counsellors in schools who counsel teachers. You might find a teacher who is infected with the virus but there is no one to talk to, and they are dying a silent death. Teachers must be open to each other, not just to the learners (Teachers)*

In relation to AIDS-care many spoke generally of the need for trained counsellors to support infected and affected individuals. Furthermore they emphasised that every single member of the community could contribute through being more tolerant and supporting of people with AIDS: showing kindness to them, visiting them, offering them help (with washing, cleaning and so on), fetching water for them, giving them love and, where possible helping them with money, praying for them, and so on.

There was general consensus across the groups that the health volunteers would need to be the core of any strengthened collective response.

> *I don't think there will be any problem in strengthening local responses to AIDS since we already have health volunteers in this community. (Teachers)*

However, participants agreed that volunteers could not carry the whole burden on their own, and that they would need substantial community support. Participants were quick to identify ways they could support the volunteers. These included encouraging the families, friends and neighbours of AIDS-affected households to provide a more supportive context for the volunteers' work. They recommended actions such as welcoming volunteers when they visited, expressing appreciation of their efforts, being more honest/disclosing about the fact that sick family members had AIDS, offering volunteers something to eat or drink if they had walked a long way; helping them perform the simpler aspects of the nursing role (finding wood to heat water, cooking for patients, cleaning their rooms); and wherever possible learning home nursing skills themselves, freeing up volunteers' time to visit more families. Where possible community members with cars should assist volunteers with transport – either to shorten the very long distances they often walked from one patient to the next, or else to assist them in taking seriously ill patients to hospital or to welfare outlets (to date unpaid volunteers had often had to find the money for these journeys themselves).

The volunteers were willing to take on an expanded role, but were clear that they needed training, support from traditional leaders, and from community outsiders. When asked to brainstorm who might offer support from the outside, however, the only network the volunteers could mention was HIVAN (the researchers' organisation) – confirming the absolute nature of this community's isolation.

Pressed by workshop facilitators, traditional leaders expressed a vague commitment to assisting the volunteers, but were unable to give this much content. They persistently engaged with issues raised in workshops as individuals, rather than in their role as leaders. Thus, one traditional leader spoke bitterly about his wife's unpaid work as a health volunteer – but didn't frame this issue beyond the limits of his personal situation. His discussion of this matter took the form of a grumble, rather than framing it as a collective problem that might form the basis for action. Furthermore, he looked to outsiders to tackle this problem.

> *TL: My wife is a health volunteer. She spends most of the time visiting households. I am sitting at home because I am unemployed. At the end of the day, she comes back home and she uses the little soap that I have to wash the clothes she has been wearing. This makes me very bitter. I think you should do something about this. You are from the government, aren't you?*
> *Facilitator: No - we are from an organisation called HIVAN.*
> *TL: I think you should coordinate with the government so that these people get help. They walk long distances. I am not sure whose money the volunteers spend when they take sick people to Esikhawini. I have never asked. This is my main worry. (Traditional Leaders)*

Workshop participants generally referred to narrowly biomedical conceptualisations of prevention and care. Very few discussions linked the fight against AIDS to wider social struggles. In the workshops of Learners, Out-of-School Youth, and Traditional Healers, brief reference was made to links between ill-health and the lack of roads, clinics and clean water. One participant in the Sewing Group linked the community's poor health with the fact that most residents could not speak English, and linked this to the need for poor people, and women in particular, to understand more about voting. But these references were vague.

The most notable exception here was one of three female traditional leaders in the male-dominated group. She expressed a great willingness to support the health volunteers in her leadership role, but specified that her ability to exercise leadership in this or indeed any aspect of her role was limited by her lack of training.

> *Woman leader: Here I am, a traditional leader of this community. I don't have any training. I only use my own experience. I might think I am on the right track whereas I am on a very wrong track. Being in charge of people is a very challenging task. You cannot do it without any training. I am appealing to you in HIVAN to organise training for us. As we are talking of working closely with health volunteers, we need to be able to read their registers, and the notebooks they use when visiting households. I might even go to the extent of signing these books. How can an induna sign if he/she is not educated? (Traditional Leaders)*

She too looked to HIVAN to organise such training. Furthermore, her vision of the possible help that leaders could give the volunteers ('signing their notebooks') was very vague. However, it did represent one example of placing the fight against HIV/AIDS in the context of wider struggles.

CONCLUSION

In line with our interest in the ethical obligations of researchers to communities, our paper has documented our 'dissemination as intervention' approach examining the extent to which it served to build the six dimensions of AIDS competence amongst participants. This strategy was designed not only to report back findings to our research informants, but to do so in a way that would strengthen their confidence and ability to respond to HIV/AIDS in more effective ways.

We believe that our analysis provides a nuanced illustration of the potential of this approach. Our feedback from workshop participants was overwhelmingly positive, with participants repeatedly saying that such vitally needed discussions could not have taken place without outsider impetus and input. Through an analysis of workshop transcripts, we have highlighted ways in which the workshops were extremely effective in providing:

- safe social spaces for many participants to engage in constructive dialogue about the previously taboo topic of HIV/AIDS;
- contexts in which people could engage in critical thinking about the way in which unequal power relations – especially those related to gender,

age and traditional leadership – undermined the effectiveness of local peoples’ responses to the challenges of prevention and care;

- opportunities for people to develop understandings of ways in which they themselves could support the fight against HIV/AIDS; and
- in which they could brainstorm strategies which would be actionable and feasible in the light of peoples’ own understandings of the possibilities and limitations of their lives.

The disappointing results of HIV/AIDS awareness programmes in sub-Saharan Africa have often been ascribed to the fact that programmes are imposed on communities by ‘outside experts’ in ways that often fail to resonate with the worldviews and perceived needs of community members (Campbell, 2003). Freire (1973) refers to this type of engagement as ‘cultural invasion’. By explicitly designing our research feedback in the form of a dialogue between researchers and community members, we believe that our workshop represents one step towards beginning to address this problem.

We also hope to have highlighted the complexities of workshops of this kind – through framing our discussion within a case study of the complexities of tackling HIV/AIDS in deep rural areas where complex configurations of poverty and power shape and limit peoples’ visions of what is and is not possible with complex and varying implications for their health and well-being. With regard to the fight against HIV/AIDS, our workshops highlighted as many causes for pessimism as optimism – as well as highlighting the inherent limitations of such approaches. Both the content of workshop discussions, and the style of engagement of different interest groups, highlighted many of the challenges standing in the way of the development of more effective responses to HIV/AIDS.

Taking account of the critique of those who view communities as homogenous groups (Cornish and Ghosh, 2007), our analysis provides a useful illustration of the way in which very rigid social hierarchies lead to social divisions – between men and women, adults and youth, leaders and subjects – that undermine the likelihood of effective and united local responses even to a crisis as life-threatening and destructive to community well-being as HIV/AIDS. In conditions of geographical isolation and severe poverty, where the wider economic and political power of adult men and traditional leaders is severely challenged at every turn (Silberschmidt, 2001; Beall, 2006), these groups may have a vested interest in preserving the very social relations that fuel the HIV/AIDS epidemic. Furthermore in such settings disempowered groups, such as young people, might collude in behaviours that simply entrench their ill-health and negative social situations.

Furthermore, even in cases where workshop participants were easily able to identify the way in which unequal power relations fuelled the epidemic, they did not translate these more ‘sociological’ understandings into action plans in the ‘strategy’ sections of the workshops. Virtually all the action strategies people suggested were shaped by a conceptualisation of HIV/AIDS as a narrow issue related to promoting the health and welfare of individuals, rather than reflecting participants’ more ‘politicised’ discussions of the role of gender, age and leadership in driving the epidemic. Having said this, however, we have no doubt that the more welfare oriented strategies suggested by participants are vitally needed, and could constitute a very promising first step in the direction of a more ‘sociologically-informed’ social development response over time.

In this particular case study the researchers were in the fortunate position of being able to use the dissemination workshops as the first step towards the development of a funded intervention to build support for community volunteers, and to use the project as a springboard for the more general empowerment/ social development of volunteers, women and young people in Entabeni. However not all researchers have the networks or resources to engage to this extent with their study communities. For those who are unable to do so, we do believe that our dissemination as intervention method still provides a useful way for working with study communities to develop more critical understandings of the possibilities and limitations of their responses to a pressing social problem. Such understandings are a necessary if not sufficient condition for further action.

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[i] Billions of dollars have been poured into disappointing HIV/AIDS interventions in sub-Saharan Africa. Most of these have been biomedical and/or behavioural in focus, seeking to change the physical health or behaviour of individuals. Furthermore well-intentioned efforts have not always resonated with the perceived needs and interests of target communities. There is growing consensus around the need to complement such approaches with parallel efforts to build community contexts that enable residents to make optimal use of such interventions where they are available, and to support positive indigenous responses by local people when they are not. The latter is often the case in rural areas where various factors

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combine to limit peoples’ access to health and welfare support. HIVAN has a particular commitment to research and action seeking to facilitate local community responses – through building support networks both within communities, and between communities and outside support agencies.