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

Abstract

What ethical obligations do researchers have to research informants in marginalised communities in serious distress? Our ‘dissemination as intervention’ exercise reported research findings back 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 people. Workshops provided opportunities for participants to start developing critical understandings of the possibilities and limitations of their responses to HIV/AIDS, understandings which constitute a necessary (though obviously not sufficient) condition for further action. Workshops alerted participants to the valuable role played by local HIV/AIDS volunteers, facilitating reflection on how local people might better support the volunteers. These discussions served as the impetus for the establishment of a three-year community-led intervention to further these goals.

Keywords: Knowledge transfer; research ethics; HIV/AIDS; AIDS competence; dialogue; social spaces; community conversations.

INTRODUCTION: ETHICAL OBLIGATIONS TO RESEARCH INFORMANTS?

We provide a case study of a 'dissemination as intervention' methodology to report back research findings to study communities in ways that seek to facilitate community responses to pressing social problems. We used this approach to feedback results of our research into community responses to HIV/AIDS to residents of Entabeni, a deep rural area in South Africa. Our dissemination paid particular attention to (i) building greater recognition of and support for the work of largely invisible female health volunteers, often the only support available to people dying of AIDS in desperate conditions, and (ii) increasing local level 'AIDS competence'.

About 65% of people in sub-Saharan Africa, and 45% of South Africans, live in rural areas, which carry a significant burden of the HIV/AIDS epidemic in Africa (Kok & Collinson, 2006). Entabeni has a high HIV-prevalence (36% of pregnant women) and poor access to formal health and welfare services. Whilst many depend on subsistence farming, recent droughts have undermined this and chronic poverty is widespread.

Our study revealed a community steeped in fatalism and bewilderment regarding an affliction so deeply stigmatised that many (including some of the dying and their carers) refused to acknowledge its existence (Campbell, Foulis, Maimane and Sibiyi, 2005). This atmosphere undermined 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 make a small contribution to the long-term challenge of confronting such fatalism through a workshop style which aimed to promote the recognition and valuing of existing community responses to the epidemic, particularly the work of the unpaid health volunteers. We hoped this would serve as a starting point for facilitating a widespread sense of individual and collective agency to respond more effectively to HIV/AIDS. By increasing this recognition and support, the project

also sought to enhance the capacity of the health volunteers, many of whom were exhausted and demoralised by the burden of the work they engaged in – conducted in a highly male dominated context, where they felt their gender was a key barrier to appropriate community respect for and support for their work.

Our workshop philosophy was informed by Billig (1987), Freire (1973) and Jovchelovitch (2007) who emphasise the key role of debate and dialogue in the processes through which peoples' sense of their possibilities for action are reproduced or transformed. Workshops sought to provide participants with 'safe social spaces' where they could talk about AIDS, develop critical understandings of obstacles to effective prevention and care, brainstorm ways they could respond more effectively, both as individuals and in groups, and generate awareness of the types of outside support they would need to optimise the effectiveness of their responses. As will be emphasised repeatedly below, it would be naïve and incorrect to suggest community-level dialogue could, in and of itself, bring about significant social change in the social inequalities (poverty, gender) that drive the epidemic. The aims of the workshops were more modest: to provide people with opportunities to reflect on and develop feasible and actionable strategies within the constraints of their own lives.

The wider context of this paper is two-fold. Firstly the rapidly expanding literature on Knowledge Transfer and Exchange (KTE), (Mitton, Adair, McKenzie, Patten, & Perry, 2007; Ward, House, & Hamer, 2009a), and the growing institutional pressure on researchers to produce findings that have 'impact' on 'research users' (Ward, House, & Hamer, 2009b; WHO, 2004). In the health field, users are typically defined as health policy-makers (e.g. Jack, Brooks, Furgal, & Dobbins, 2010; Start & Hovland, 2007) and professionals (e.g. Ward, House & Hamer, 2009b), with few studies regarding marginalised communities themselves as 'research users'. Our work is motivated by a vision of 'research impact' that recognises communities as key participants in debates about the implications of research findings. This puts some

responsibility on researchers to develop strategies and case studies of different models of researcher-community engagement.

The second context of our work is an interest in ethical obligations of researchers to their research informants, particularly when research focuses on marginalised communities in serious distress (Benatar, 2002; Robson, 2001). Three sets of views exist here. At minimum, 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). Many argue researchers should go further, feeding back findings to study communities (Baxter & Eyles, 1997; Flaskerud & Anderson, 1999). Some go even further, saying 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 promotes networking amongst HIV/AIDS agencies, undertaking social research to support this work. Our HIVAN research programme in Entabeni sought to achieve elements of the 2nd and 3rd levels of input outlined above – reporting back research findings to community groups using a workshop methodology. We hoped our 'dissemination as intervention' workshops would, in themselves, constitute a modest intervention of sorts, through aiming to achieve two goals.

The first goal was to go beyond a simple report-back of findings, by presenting findings in a dialogical workshop format that aimed to facilitate 'AIDS competence' amongst participants (Nhamo, Campbell & Gregson, in press). 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 living 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, 2007).

The six dimensions of AIDS competence we 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 the intervention was to use the workshops for community consultation, where researchers and community members might begin to discuss the shape of a potential community-strengthening intervention. In our particular case, the workshops informed the proposal a three-year intervention to strengthen local responses to HIV/AIDS, which was later funded and implemented. This intervention has been written up elsewhere (Campbell, Nair, Maimane & Gibbs, 2009). The aim of the current paper is to discuss the extent to which our 'dissemination as intervention' workshops might serve as a model for self-standing, if very modest, interventions that could be implemented by researchers lacking 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' idealised notion of 'the public sphere'. Freire (1973) argues that a precondition for marginalised groups to improve their lives is the development of understandings of the obstacles that stand in the way of their well-being. A critical awareness of obstacles is a necessary precondition for tackling them – either through learning how to predict and ameliorate their impacts (the goal

of our Entabeni workshops), or in more ideal conditions, working collectively to resist negative relations and bring about transformative social change. Freire's focus on how people understand social problems is particularly relevant here because two key obstacles to effective HIV/AIDS management in Entabeni related directly to peoples' conceptualisations of the problem. First the *stigmatisation* of people living with AIDS, leading to an unwillingness to 'take ownership' of the problem and provide appropriate support and help to people living with AIDS and their carers, and a denial of personal vulnerability reducing the likelihood of taking action to prevent HIV. The second were '*competing beliefs*' which undermined people's acceptance of biomedical information about the causes of HIV-transmission and how to prevent it, discussed below (Campbell, Foulis, Maimane & Sibiya, 2005).

A key dimension of building a supportive environment for HIV/AIDS management is the provision of 'social spaces' in which people feel safe to discuss the 'unspeakable' issue of HIV/AIDS. Such spaces provide contexts where people can collectively work through doubts and uncertainties about taboo topics. 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 participants, rather than the extent they support the status quo (Jovchelovitch, 2007). In her feminist critique of Habermas, Fraser (1992) distinguishes between the dominant public sphere (controlled by economically and/or politically influential members of a social group) and 'counter-public spheres'. The latter are spaces where members of less powerful peer groups (e.g. women or young people in the case of Entabeni) are able to talk about controversial topics in conditions of openness, trust and solidarity. These discussions might include ways in which their interests are undermined by dominant social groupings (e.g. men, adults or political leaders in the Entabeni context), and the possibility of challenging the status quo. Ideally

such debates form the starting point of brainstorming sessions in which people formulate action plans about ways in which they might start ameliorating the impacts of negative social relations on their health and well-being.

The challenges of creating 'safe social spaces' where marginalised groups can develop critical understandings of the social circumstances that undermine their well-being have been extensively debated by critical, feminist and participatory geographers. Cornwall (2004) discusses the potential of participatory interventions to build 'spaces for transformation' with marginalised groups. Rose (1997: 315) refers to the role that participatory research engagements can play in drawing attention to what may previously have been invisible 'landscapes of power'.

Participatory geographers have been appropriately sceptical of the potential one-off, short-term participatory engagements between researchers and marginalised community members to achieve lasting social change in the power structures that oppress people. Jones (2001), for example, criticises this expectation. Using Foucault's (1967/1997) notion of 'heterotopian spaces' (understood as those 'other spaces' in which marginalised people are able to engage in unusually empowering dialogue about their potential for agency), she emphasises that one-off empowering interactions and insights developed in workshops would need to be 're-performed' or repeated in other settings over time before they were likely to impact on peoples' daily social relations. In his study of the Stepping Stones HIV empowerment programme in Zimbabwe, Kesby (2005) similarly emphasises that one-off workshop experiences seeking to conscientise poor people in the interests of promoting a 'reflection-action change cycle' need to be 'rehearsed for reality'. This would require people being able to practice newly learned and potentially empowering thinking styles and social interactions in repeatedly facilitated 'safe (heterotopian) spaces' before putting them into action in dominant public spheres. Vaughan (in press) argues there is a need for participatory activists to facilitate the development of 'in-between' spaces, which serve as bridges between the counter-public and public spheres.

Nagar (2000) is similarly cautious in her case study of a street theatre initiative seeking to provide spaces for poor Indian women to publically name and condemn the life-threatening violence against married women by their in-laws. Theatrical performances generated a deep sense of public unease and discussion amongst theatre audiences in many small communities. However, audience members in the village that had been the site of the recent wife-killing that had provoked the theatre production were too frightened to discuss the issue in a public setting, for fear of reprisals from the very men and families that had been involved in the murder.

In our own work we have repeatedly emphasised the problematic nature of assuming significant social change can result from local community interventions *per se*. Positive changes in the lives of the most marginalised are unlikely without significant support by powerful social actors and groups from both within and outside of communities, as well as their 'political will' to assist the most marginalised in improving their opportunities for well-being (Campbell, Cornish, Gibbs & Scott, 2010). In this regard, we emphasise the relatively limited goals of our own workshops. In contrast to the more ambitious 'social change' agenda's of many of participatory feminist scholars, our aims were not to bring about changes in gender or economic relationships, but more modestly to try and increase levels of AIDS competence in Entabeni, through increasing local peoples' recognition of the value of, and support for, unpaid female health volunteers, who were often the only support available to AIDS-affected households.

Wieck (1984) cautions that defining social problems (e.g. HIV/AIDS) in wide terms (e.g. patriarchy, economic inequalities) is not particularly useful for local community workers dealing with the immediate daily impacts of large-scale social problems (e.g. nursing a dying AIDS patient, who has diarrhoea 15 times a day, with no running water or bed linen). He argues that frontline community programmes should focus on achieving 'small wins' (e.g. building the capacity of previously marginalised women to cope with a very immediate problem) as early stepping stones to long-term and more ambitious changes

(Wieck, 1984). With this in mind, the goals of our two hour dissemination workshops were, at most, to promote recognition of, and support for, the value of the work of the health volunteers, rather than empowering female health volunteers to go home and reconstruct their relationships with previously oppressive male partners, or openly tackle Traditional Leaders that belittled their efforts. Alinsky (1974) argues that small steps of this nature should be viewed as very tiny contributions to the gradual, long term and non-linear process of achieving goals such as redistribution of wealth and power.

Williams (2004) argues against the tendency for some western gender theorists to assume that pro-women participatory social development programmes are only successful to the extent that they effectively tackle structural gendered inequalities. He argues that women might often achieve more through working *within* existing male-dominated power structures than through seeking to challenge them. Similarly Scheyvens (1998) argues that the long-term goal of women's empowerment in heavily male dominated settings may often be better advanced through 'subtle strategies' that increase women's agency through 'small steps' providing women with opportunities to learn and grow without alerting possible antagonists (husbands, elders, church leaders). In our own work in other contexts in South Africa (Campbell, Maimane & Nair, 2006) we found that even though women diagnosed gender inequalities as the root of their inability to respond effectively to HIV/AIDS, they invariably preferred to 'work around' men, rather than tackling them directly.

Our modest 'small wins' interpretation of the potential of dialogue and critical thinking in safe counter-public spheres 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, and brainstorm solutions that are practically achievable in the contexts of their own lives.

CONTEXT OF THE RESEARCH

Entabeni is a rural community in KwaZulu-Natal, South Africa, 30km from the nearest town and 150km from Durban. The nearest hospital is 30km away, with poor roads and transport unaffordable by many. A mobile clinic visits the area once a month. Poverty is widespread, due to its relative isolation, poor quality, rocky land, and frequent droughts, which make subsistence farming difficult. Despite the expansion of social grants in South Africa, many in Entabeni struggle to access these.

In South Africa, 28 percent of pregnant women are HIV-positive, rising to 36 percent in the Health District where Entabeni is located (South African Government, 2008). In our research, conducted prior to the roll-out of anti-retroviral therapy, an HIV/AIDS diagnosis was effectively a death sentence. A complex range of factors drive the HIV/AIDS epidemic and undermine local responses to HIV/AIDS. Migration to towns in search of jobs is a major driver of HIV/AIDS in this particular community (Karim *et al.*, 1992). Gender inequalities play a key role in shaping HIV/AIDS in Africa, limiting women's agency in relation to safeguarding their health and well-being (Kalipeni, Oppong & Zerai, 2007). In Entabeni the concept of bride-wealth "*lobola*" (paid by a man to his new wife's parents) is often used to reinforce women's unequal status, limiting their ability to negotiate condom use with unfaithful partners and to assert their gendered needs and interests in the private and public spheres, further undermining their ability to act in ways that protect their health (Campbell, Nair, Maimane & Gibbs, 2009). Women health volunteers repeatedly cited the low status of women in the community as an obstacle to recognition of the value of, and support for, their work.

HIV-related stigma is increasingly described as a major driver of HIV/AIDS across Africa, and in Entabeni, limiting people's access to prevention and care (Deacon *et al.*, 2005; Ogden & Nyblade, 2005). Another important factor undermining effective local responses to HIV/AIDS in Entabeni are 'competing beliefs', which may contradict biomedical understandings of the disease and how best to respond to it. Understandings of HIV/AIDS were rooted in local interpretative frameworks including witchcraft (Ashforth, 2002) and doubts about the efficacy of condoms (HSRC, 2005).

Entabeni is a traditional authority area, a legacy of apartheid, which sought to place 'surplus' populations in 'tribal homelands' (Platzky and Walker, 1985). Traditional authorities continue to wield significant power. The area is governed by the autocratic *Inkosi* (Chief), who delegates day-to-day running of the area to *Izinduna* (referred to as Traditional Leaders in this paper) who hold significant authority over the local population. Overlapping the *Inkosi's* authority is the democratically elected Municipality, a branch of the Provincial Department of Local Government and Traditional Affairs. Despite the ideal of two complementary forms of government, *de facto* the *Inkosi's* power remains strong, controlling vital access to land (Ntsebeza, 2006), and positioning himself as 'guardian of (male and adult dominated) traditional culture', a role warmly supported, particularly by adults and men, in this very traditional rural community. The *Inkosi* has sought to limit increased access to municipal services such as water and electricity, for fear of losing authority, drawing on notions of tradition to achieve this. HIV/AIDS has provided another fertile arena to pursue his personally empowering 'traditionalist' role. He has actively promoted a return to tradition – including virginity testing of young girls, and reaffirmed norms of female fidelity to polygamous husbands – to 'stop' HIV/AIDS (Campbell, in press).

In many ways Entabeni is not representative of South African rural areas. It has particularly poor access to health and welfare services, unusually high levels of poverty and HIV/AIDS and is governed by a particularly autocratic *Inkosi*. All these combine not only to undermine effective local responses to HIV/AIDS, but also provide a particularly stark illustration of the dynamics shaping responses to HIV/AIDS in South Africa. We are guided by Flyvberg's (2001) argument that the generalisability of case studies to other communities needs to be assessed by skilled social observers on a case-by-case basis.

ENTABENI: RESEARCH FINDINGS

Our workshops sought to disseminate our research findings about local responses to HIV/AIDS. This research had been conducted in partnership

with Entabeni's *Inkosi*, introduced to the researchers through a university colleague born in the area. The *Inkosi* facilitated community entry through introducing researchers to the health volunteers, giving the researchers permission to enter the community, and authorising the volunteers to assist us in conducting the research. At this stage we emphasised we had funding for research and not for intervention. Concerned about growing numbers of AIDS deaths, the *Inkosi* felt 'something should be done', and hoped our research would eventually lead to practical benefit for the community.

Our study found health 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 (Campbell, Nair, Maimane and Sibiya, 2008). A necessary precondition for achieving this 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 key local groups.

The 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 local groups involving 121 participants (78 women and 43 men):

- 15 health volunteers (13 women, 2 men),
- 32 religious leaders (20 women, 12 men),
- 9 traditional leaders (3 women, 6 men),
- 5 traditional healers (all men),
- 14 school learners (8 girls, 6 boys),
- 9 young people out of school (4 girls, 5 boys),
- 6 members of a local sewing group (all women),
- 16 teachers (13 women, 3 men),
- 15 members of the local development group (11 women, 4 men).

The leader of the health volunteers was nominated by the *Inkosi* to facilitate our research was asked to organise groups of roughly 15 people each.

Numbers that attended are reflected above.

Workshops were facilitated by the third and fourth authors, an older woman and a younger man, both African Zulu-speaking fieldworkers experienced in running participatory workshops. They were tape recorded, and each facilitator transcribed and translated their workshops. Furthermore (except with traditional healers and teachers who were not available at suitable times) between one and three members of each group participated in a post-workshop evaluation session to reflect on their experiences 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 participants?

GENERAL COMMITMENT AND FEEDBACK

Many participants travelled long distances, some walking for up to four hours to attend workshops. With two exceptions discussed below, every group was overwhelmingly positive about the experience, with workshops being described as 'an act of God'. Most enthusiastic were 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 health 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 communityWe salute you. God is good for bringing you people from HIVAN into this community. We used to live in darkness. (Volunteers)

Two exceptions to enthusiastic participation were the Traditional Healers and the Traditional Leaders groups. The latter were openly reluctant to participate, derailing their first workshop by saying they were no longer available 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 workshop phase asked participants to discuss the causes of AIDS and how to prevent it, providing opportunities for people to consolidate fragments of knowledge they had amongst them. Workshop facilitators did not

'correct' misconceptions arising in discussions, seeking to provide opportunities for participants to discuss HIV/AIDS in ways that made sense to them in the context of their own worldviews. We hoped 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 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 participants lacked knowledge, others were able to fill in the gaps.

Health 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?

Health 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.

Health 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.

In our research, community members had repeatedly said they lacked knowledge about AIDS. Yet workshops suggested that when provided with the opportunity and supportive context, people were able to construct a fairly comprehensive knowledge base with no input from facilitators. Rather than lack of knowledge, participants appeared to have suffered from lack of supportive 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. Some groups took longer to warm up than others, but most engaged in animated discussion and lively debate. It was clear people were taking risks and talking openly about taboo

topics in a way they found unusual. Frequent laughter and giggling in small group discussions bore witness to this. But they gradually overcame their reservations, and after a while the laughter stopped as they co-constructed a 'safe space' to keep on talking.

Silence and stigma had been a key theme in our research (Campbell, Foulis, Maimane & Sibiya, 2005; Campbell, Nair & Maimane, 2007). AIDS was a taboo topic, shrouded in denial and avoidance. In this respect, workshops were exceptionally successful. Participants – even amongst more reticent Traditional Leaders and Traditional Healers – spoke with 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 son 'living positively' with AIDS, and the role of 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. A carer of a grandchild with AIDS spoke of her fear of becoming 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 tackled 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 interactions, 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: It's not easy to abstain from sex, people cannot control themselves.

F2: I think it's easy to abstain if you have never had sex, but if you have experienced it I think it's 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 are able to control ourselves.

M2: I would like to disagree with [F2] when she says it's not easy to abstain if you have already experienced sex. If you have a positive and determined attitude it's easy to abstain.

F2: If I steal sugar and I know it's nice, I will always go back and steal it.

F3: It's not fair to blame boys. Even girls are guilty. Girls also can't 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 every group but one, facilitators expressly asked men and women to sit together and ensured that small group discussions contained a gender mix, with positive results. The exception was the Traditional Leaders' workshop, where facilitators felt unable to intervene in seating arrangements – out of respect for the participants' status. This reduced the quality of small group discussions.

Across all workshops, women and young people of both sexes were enthusiastic and frank participants. This was not always the case with older men. Male Traditional Leaders, in particular, were unwilling to engage in discussions, or express personal views about sensitive topics. After the first set 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 less willing. When asked to

feedback the content of their small group discussion, the male rapporteur told the plenary 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)

Traditional Healers were also 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 often surprisingly open in talking about AIDS deaths in their personal lives, their style of workshop engagement 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 adult men in the workshops. It was also evident in the *content* of many discussions. In every single discussion by women, men were cited as the chief obstacle to effective responses to HIV/AIDS, as discussed below.

3. CRITICAL THINKING

As discussed above, a community's ability to work towards improving their health is strongly enhanced by recognition of, and reflection on, the 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 faced by the Entabeni community in coping with AIDS.

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

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/AIDS prevention and care, were themes running throughout every workshop - aside from those of 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 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 their husbands had multiple partners, yet still refused to use condoms with them because they had paid *lobola* for their wives and could do as they wanted with them.

The rules say you don't argue with your husband, even if it means you will die. (Health Volunteers)

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. It's like we might as well hang ourselves, since we have no power to avoid AIDS in marriage. (Health Volunteers)

In discussing sources of help for an HIV positive mother – concerned about breastfeeding her baby, yet unable to afford powdered milk – a young man in the Out-of-School Youth workshop insisted such a woman should not discuss the problem with her husband if it meant disclosing her HIV status. He said 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 boy)

Health volunteers regarded AIDS stigma as a key reason for lack of community support for their work. Families with members living with AIDS frequently turned health volunteers away at the gate denying that they had any such problem in their household.

Health volunteers also 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 (volunteer) 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. (Health Volunteer)

They also said that their ability to perform their role effectively was dramatically undermined by lack of support from the *Izinduna*. Volunteers repeatedly said power-hungry *Izinduna* were threatened by the positive and growing role that the health 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. (Health Volunteer)

4. OWNERSHIP/ RESPONSIBILITY

To what extent did workshops increase peoples' sense of ownership of the challenges of HIV/AIDS rather than passively waiting for outside assistance? Our baseline research suggested that aside from the health volunteers, few had been prepared to take ownership or 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.

Distancing from responsibility was particularly strong in the Traditional Leaders and Out-of-School Youth workshops. 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?

F1: 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 also distanced themselves from any responsibility for HIV-transmission in their own relationships. They blamed transmission on factors such as unreliable women, or infection via nursing 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, it's no longer possible to hear what they are saying.)

5. RECOGNITION OF INDIVIDUAL AND COMMUNITY STRENGTHS

In follow up interviews and discussions many workshop participants spoke of the personal confidence building 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 Volunteer)

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)

M1: 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.

M2: 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.

F1: 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.

F2: I think that having more meetings like this will develop our capacity to open up.

M3: 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)

As discussed above, a central aim of the workshops was to promote recognition of the health volunteers' efforts, as a key step towards mobilising greater community support for them. Workshop discussions revealed patchy awareness of the health 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, saying the health volunteers didn't perform their role very well. Other groups tended to be aware of them, but vague about their role and value. The health volunteers were unanimous that the 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. (Health Volunteer)

People repeatedly referred to how the workshop style had built 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.

Health Volunteers: We desperately need a permanent clinic in this community.

Facilitator: Who is going to see to it that this clinic is built?

Health Volunteer 1: 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.

Health Volunteer 2: 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 the workshops sought to foster was the identification of local strategies for strengthening community responses to HIV/AIDS. Discussions of strategies touched on activities relating 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 workshop participants. This was present in some of the discussions of possible strategies, such as a call to punish non-virgin girls:

M: We must go back to basics, and all girls must undergo virginity testing. If it 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 living with AIDS. Everyone highlighted youth as a group in urgent need of AIDS-related education and support – citing churches, schools and community meetings as potential networks. 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 youth themselves – referred to Out-of-School Youth as an under-utilised resource, which could be mobilised to support health volunteers – through conducting peer education and assisting the 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 Out-of-School Youth 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 do 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 key target group, 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)

It's 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 member of the community could contribute through being more tolerant and supportive of people with AIDS: showing kindness to them, visiting them, offering them help (with washing, cleaning and so on), fetching water, giving love and, where possible, helping with money.

There was consensus across the groups that the health volunteers should 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 health volunteers could not carry the whole burden, and would need substantial community support. People were quick to identify ways they could support the volunteers, including encouraging families, friends and neighbours of AIDS-affected households to provide a more supportive context for the health volunteers' work. They recommended actions such as welcoming volunteers when they visited and expressing appreciation of their efforts; being more willing to disclose family members living with 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. Other suggestions included, where possible community members with cars should assist volunteers with transport – either to shorten the 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 (unpaid health volunteers often had to find the money for these journeys themselves).

The health volunteers were willing to take on an expanded role, but were clear 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 helping the volunteers, but were unable to suggest concrete ideas. 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 an example of a participant conceptualising HIV/AIDS challenges in the context of wider struggles.

CONCLUSION

Our paper has documented our 'dissemination as intervention' approach in the interests of our commitment to regarding communities as 'research users',

and to promoting debate about researchers' ethical obligations. Both these commitments imply the need for debate about possible methods for reporting findings back to research communities in ways that facilitate local debate and discussion about possible action. Our feedback from workshop participants was overwhelmingly positive, with participants repeatedly saying that what they regarded as vitally needed discussions could not have taken place without outsider impetus and input. As emphasised above, unlike many researchers and activists in the 'dialogue and critical thinking' arena, we did not expect the workshops to lead to fundamental challenges to gender inequalities or poverty. Our workshop aims were more modest: to increase peoples' recognition of and support for female health volunteers and promote local AIDS competence. In this regard, we have highlighted how the workshops provided:

- safe social spaces for many participants to engage in constructive dialogue about the previously taboo topic of HIV/AIDS;
- contexts where they could critically discuss how unequal power relations undermined the effectiveness of local responses to prevention and care;
- opportunities for people to develop understandings of how they themselves could support the fight against HIV/AIDS; and
- opportunities to brainstorm strategies which would be actionable and feasible in the light of peoples' own understandings of the possibilities and limitations of their lives.

We have also highlighted the limitations of these workshops – showing how in many ways they serve as a microcosm of the complexities of tackling HIV/AIDS in contexts where configurations of poverty and power shape and limit peoples' visions of the possibility of health and well-being. What we referred to above as the counter-public sphere or heterotopian spaces opened up by the workshops were far more enthusiastically embraced by women and young people – the groups who would have the most to gain from the social change – than older men and traditional leaders, who would have the most to lose from any redistribution of power.

Contrary to Freire's (1973) argument that reflection on the social roots of problems opens up spaces for people to formulate politicised action to tackle problems at their social roots, even where workshop participants were easily able to identify how unequal power relations fuelled the epidemic, they did not translate these 'sociological' understandings into action plans in the strategy sections of the workshops. Virtually all the action strategies people formulated were shaped by a conceptualisation of HIV/AIDS as an immediate health and welfare problem, rather than reflecting their more 'politicised' discussions of the role of gender, age and leadership in driving the epidemic. We have no doubt that the more welfare oriented strategies suggested by participants are vitally needed given the immediacy and the degree of the suffering of those dying of AIDS with little or no medical support, however, we believe that these might conceivably constitute a promising first 'small wins' step in the direction of a more 'sociologically-informed' social development responses over time.

As discussed above, the expectation that one-off workshops might lead to significant challenges to complex social relations are clearly unrealistic. However Lewis and Mosse (2006) warn against attempts to discuss the impacts of participatory interventions using simplistic linear models – which would suggest that the 'input' of participatory dialogue should lead almost immediately and visibly to the 'output' of significant resistance by, or social or economic advancement of, the powerless. They argue that reality is messy, and that the impacts of participatory interventions may often be far more diffuse, complex and long-term than meets the eye. This comment is echoed in Eyben's (2005, p 99) critique that the 'managerialist' input-output model implicit in many discussions of participatory interventions ignores the often chaotic, unpredictable, long-term and improvisational nature of successful participatory projects, and of the social change processes more generally.

We have no doubt that our workshops opened up new spaces for women and young people to engage in dialogue about a devastating social problem that many local people had often been too terrified to think about or discuss openly, and to brainstorm locally realistic and feasible ways they might

respond to AIDS, even within the contexts of the limitations of their existing lives and social relations. It is not completely inconceivable that workshop participation planted the seeds of new ways of being and seeing by some participants, which they might have opportunities to 'rehearse' in other social spaces at some future stage of their lives. Furthermore, as already stated, workshop discussions *did* form the basis of a three-year funded intervention in Entabeni, which led to a significant increase in the ability of volunteers to deliver help to many AIDS-affected households over this period. As we have discussed elsewhere (Campbell, Nair, Maimane & Gibbs, 2009), the achievements of the three year programme were perhaps more of a short-term 'welfare' success than a long-term 'social development' outcome, but a significant achievement nevertheless, particularly bearing Lewis and Mosse's caveats in mind, as well as Wieck's (1984) small wins approach discussed above.

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 large-scale funded intervention to build the skills of, and support for, community volunteers. However not all researchers will have the networks or resources or practical skills to engage to this extent with their study communities. For those who are unable to do so, we believe our 'dissemination as intervention' method provides a useful way for researchers to engage with and enable study communities to begin to think through realistic and actionable ways they can respond to pressing social problems – in relation to actions they might take, and alliances they might build, even within the contexts of their existing social and resource constraints. In this regard – and in the light of our interest in furthering debate about ethical research practice – we believe our experiences of 'dissemination as intervention', although modest, serve as a useful example of one way in which researchers might routinely be expected to report back research results – through dissemination workshops which we argue should be routinely costed into all research funding proposals as a matter of course where research is conducted with communities facing pressing social problems.

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