

EVALUATING HIV-PREVENTION PROGRAMMES: CONCEPTUAL CHALLENGES

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Abstract. Within the context of HIV prevention in sub-Saharan Africa there is a growing move away from information-based health education towards the development of community-based participatory interventions. This progress has not been matched by the development of conceptual tools and indicators for evaluating the psycho-social and community-level changes which such programmes seek to bring about. Programme evaluators still rely overwhelmingly on individual behavioural and biomedical outcome measures, paying less attention to the processes underlying such outcomes. This paper outlines the rationale and conceptual framework underlying the planned evaluation strategy of a recently implemented three-year HIV-prevention project in the gold mining district of Carletonville. This evaluation seeks not only to measure the extent to which the programme succeeds or fails in having an impact (on levels of HIV and STDs as well as levels of perceived risk and condom use), but also to document the psycho-social and community-level dynamics underlying project outcomes.

HIV-prevention programmes have generally conceptualised HIV-transmission at the biomedical or behavioural levels of analysis, and as a result have focused on interventions such as STD management, condom distribution and traditional information-based health education approaches. These approaches have been evaluated using a range of biomedical and behavioural outcomes at the individual level of analysis. Such outcomes have included changes in the prevalence and incidence of HIV or other STDs over the course of the intervention, various individual behavioural indicators (such as changes in knowledge, attitudes and reported behaviour), or indirect measures of behaviour change such as the number of condoms distributed in a community (MacPhail, 1998).

A considerable amount of evidence reveals the limitations of such individualistic approaches to HIV-management with a growing body of literature demonstrating the

role played by social, cultural and economic factors in HIV-transmission (see Gillies, 1996). This has prompted a trend towards more community-based, participatory health promotion models, which aim not only to treat STDs, and promote individual behavioural change (e.g. increased condoms use, reduced number of partners) through the provision of information about health risks, but also to encourage the development of social and cultural environments that enable desired behaviour changes to take place (Tawil, Verster & O'Reilly, 1995).

These developments are based on the understanding that sexual behaviour – far from being the result of rational individual choices based on the possession of factual knowledge – is nested within a complex range of psycho-social processes, including the collective negotiation of sexual identities, as well as self-efficacy or empowerment at the personal, small group, community, cultural, economic and social levels of analysis (Campbell, 1998a). Health promotion programmes which include a peer education and community development thrust attempt to take into account some of the broader dynamics which shape and constrain sexual behaviour by emphasising processes such as grass-roots participation in programme implementation and the creation of partnerships or alliances between a range of stakeholders in project management (Gillies, 1998).

The progress that has been made in the design of community-based interventions has not been matched in the development of appropriate community-level indicators. Such indicators are needed for evaluating the psycho-social and environmental processes which community-level HIV prevention programmes seek to encourage so as to promote health-enabling environments, i.e. environments which reduce the likelihood of people engaging in unsafe sexual behaviour.

Aggleton et al (1992) distinguish between outcome evaluation and process evaluation. Outcome evaluations are usually quantitative in nature, and aim to measure whether and to what extent the goals associated with a particular health intervention programmes has been met. Process evaluations are usually qualitative in nature, and aim to examine how programme outcomes have been achieved. "Process evaluation aims to interpret and illuminate how and why particular health outcomes were brought about. It is important in HIV work since, without it, health promoters run the risk of identifying the outcomes of particular health promotion activities without knowing how and why they were achieved." (Aggleton et al, 1992:2)

While Aggleton et al (1992) make an important point in drawing attention to the need to study the processes whereby a particular intervention might or might not have succeeded, their conception of the scope of process evaluations is unduly narrow. They recommend that such evaluations should focus on "the communication that takes place between health educators and health promoters and those they are working with" (Aggleton et al, 1992:10). It is our view that understanding the success or failure of HIV-prevention programmes goes beyond the narrow confines of communication between health promoters and target audiences. Attention should also be given to factors such as the extent to which target groupings identify with and trust the programme and feel that it is representative of their needs and interests; the extent to which wide-scale and sustainable transformation of sexual identities and norms takes place at the group level (peer or community groups); and the extent to which project stakeholders are adequately committed and motivated to participating as fully as

possible in making the project a success, as well as the extent to which their efforts are optimally co-ordinated.

SOCIAL CAPITAL AS A USEFUL CONCEPTUAL TOOL FOR EVALUATORS?

Kreuter (1997) has suggested that the concept of social capital provides a promising conceptual framework for developing broader measures of the effects of health promotion, which move beyond individualistic biomedical and behavioural measures. He argues that one important determinant of the success of health promotional interventions lies in the extent to which target communities have organisational systems that support the intervention, and the extent to which these are activated. The activation of these organisational entities depends partly on the extent to which people are aware of them, identify with them, value them and trust them. Kreuter (1997:2) defines social capital as "those specific processes among people and organisations, working collaboratively and in an atmosphere of trust, that lead to the accomplishment of goals of mutual social benefit", further specifying that social capital is "a relational term which connotes interactions among persons through systems that support and enhance that interaction".

Wide-ranging research has suggested that high levels of social capital are associated with a range of political benefits such as more effective and democratic governments (Putnam, 1993) and economic benefits (Narayan & Pritchett, 1997; Moser 1998). More recently researchers have begun to argue that high levels of social capital might be associated with a range of positive health outcomes (Gillies, 1997). Several authors hypothesise that health promotion projects will succeed or fail to the extent to which they are able to enhance levels of social capital in their target communities (Wallace, 1993; Higgins & Gillies, 1996; Wilkinson, 1996).

Putnam (1993) operationalises the concept of social capital in terms of five characteristics. He characterises social capital as the community cohesion that is associated with:

- a strong sense of *community identity*, coupled with a sense of solidarity and equality amongst community members;
- dense networks of associations and organisations in the voluntary, state and personal spheres, ranging from networks at the informal level of peers and neighbours, to voluntary networks and NGOs, to provincial and national networks, organisations and government ministries;
- strong *community norms of co-operation, reciprocity and trust*;
- positive attitudes to community networks
- levels of *civic engagement* i.e. widespread participation of community members in the process of setting up, sustaining and drawing on community associations and networks.

Gillies, Tolley and Wolstenholme (1996) and Gillies (1997) argue that social capital provides an important new framework for organising our thinking about the broader social and community determinants of health. They argue that it could form the conceptual basis for the development of measures which would assist in investigating the extent to which health promotion programmes succeed in achieving broader objectives than the changes in individual behaviour, beliefs and disease states that have been the focus of conventional health intervention evaluation. They suggest that projects succeed or fail to the extent to which they serve to promote health-enhancing

levels of social capital (civic engagement, trust, reciprocity, local identity) in their target communities. The concept of social capital provides the possibility of operationalising those aspects of the social and political contexts of community-based interventions which (despite being crucial from a theoretical and an intuitive point of view) have hitherto evaded measurement.

In a review of the relevance of the concept of social capital to practice and research in health promotion, Campbell (1998c) argues that further development of the concept could serve to pull together large amounts of fragmentary existing research in the social psychology and sociology of health literature linking positive health outcomes to levels of positive community identity (e.g. Freire, 1970; Wilson, 1995), self-efficacy (e.g. Bandura, 1977), social support (e.g. Gottlieb, 1981), social networks (e.g. Berkman, 1995), perceived relative deprivation (e.g. Wilkinson, 1996) and social power relations (e.g. Blane, Brunner and Wilkinson, 1996). Furthermore, pilot research both in South Africa (Campbell, Meth & Williams, 1998) and England (Campbell, Wood & Kelly, 1998) has found tentative preliminary evidence for a health-social capital link. However, much work remains to be done in fleshing out exactly what is meant by social capital; in conducting further research to substantiate these tentative pilot findings; in unpacking the meaning of the concept in our particular context; and in developing theories of the processes that mediate between social capital and health.

In the remainder of this paper we provide an account of our on-going research into HIV prevention on the South African gold mines, and our planned evaluation of the recently initiated STD/HIV management programme in the Carletonville gold mining area near Johannesburg which will be implemented over the next three years (Williams & Campbell, 1996). Carletonville is a community of about 250 000 people, 75 000 of whom are mineworkers mostly living in single sex hostels, with the remainder living in a range of residential areas – including the city centre and a number of formal and informal townships and squatter settlements. One of our goals in this paper is to emphasise the role we believe the concept of social capital could play in guiding our attempts to synthesise and make sense of the multiple data sources which the evaluation will generate.

HIV TRANSMISSION ON THE SOUTH AFRICAN GOLD MINES: BEYOND THE BIOMEDICAL AND BEHAVIOURAL.

A pilot survey conducted in January 1998 showed that the prevalence of HIV/AIDS amongst gold mine workers in Carletonville was 22% (Williams & Campbell, 1998a). In their analysis of the way in which HIV has been managed on the gold mines in South Africa, Campbell and Williams (1998) look at the great effort that has been put into HIV-prevention by mine managements who responded to the epidemic several years before the government. In that paper they consider a number of reasons why such efforts have made so little impact on HIV transmission. Firstly, while mines have provided high quality, free treatment for STDs to miners, the quality of their health educational programmes has been technically weak, depending on information-based health education programmes which are known to have limited impact in promoting sexual health (see also Crisp, 1996). Secondly, there has been a lack of unifying vision amongst the major stakeholders (management, unions and government) which meant that those prevention activities that did exist on the mines, or in provincial clinics, for example, were piecemeal and poorly co-ordinated. Historically, the government has not always provided strong leadership in the area of HIV-control, so that mine-based

attempts to slow down HIV transmission were often been conducted in a policy vacuum, without the support of effective national policies and programmes to support the work people were trying to do in particular industrial contexts. Finally, levels of fatalism and despondency have reduced the potential efficacy of various stakeholder's efforts across a range of levels and sectors. Issues relating to misunderstandings, fear and stigma have driven the disease underground amongst mineworkers – so there has been no ownership of the problem at the grassroots level.

In addition to all the factors outlined above, and possibly most importantly, efforts to fight HIV on the mines have been hindered by the tendency to view HIV almost exclusively as a biomedical, behavioural or human rights problem at the individual level of analysis (Williams & Campbell, 1998b). While it cannot be denied that HIV involves biomedical and behavioural as well as important human rights issues, inadequate attention has been paid to the social and developmental dimensions of HIV-transmission.

Mine-based HIV prevention interventions have traditionally concentrated on promoting early detection and treatment of STDs and condom use, through HIV education programmes or counselling at clinics. These interventions have sought to bring about behaviour change – either sexual behaviour change (in particular increased condom use) or health-seeking behaviour change (the seeking of early and appropriate treatment of STDs) – through the provision of information. Underlying these approaches is the assumption that health-related behaviour is the product of individual rational choice, and that people will act in ways that enhance their health if they are in the possession of accurate information about health risks.

The Epidemiology Research Unit in Johannesburg is currently engaged in a number of studies which aim to explore why these biomedical and behavioural programmes have had so little impact on the HIV epidemic on the mines. In one study, Campbell (1997a) asks why many mine workers continue to have unprotected sex, often with multiple partners, and often with commercial sex workers, despite exposure to HIV education and STD management programmes, which have succeeded in instilling high levels of awareness of the risks of HIV amongst mineworkers. Starting from the assumption that sexual identities are shaped by peoples' working and living conditions, as well as the interpretative repertoires they construct for making sense of relationships, health and healing, her research seeks to illustrate how a mine worker's risk of contracting HIV is affected by a range of social and psycho-social circumstances which the narrow biomedical/behavioural perspective fails to take adequately into account.

Mine workers generally come from impoverished rural areas in southern Africa, including several neighbouring countries, where levels of unemployment are high, and where work on the mines, despite its hardships and dangers, is one of their few options for economic survival. They travel to the mines as migrants, where most of them are housed in single sex hostels, generally far away from their families, in an environment that offers only restricted opportunities for social support and few opportunities for the development of stable intimate social relationships. Large numbers of impoverished women flock to the mines to make a living selling sex and alcohol. Amongst mineworkers, perceived levels of self-efficacy are low, reducing the likelihood of health-promoting behaviours, in a context where diseases such as tuberculosis are common and the risk of death or injury in a work-related accident is high (Williams et al, 1998).

In a context where death, injury and illness are the norm, HIV is simply one additional threat to health. The normative context in which workers live views regular "flesh-to-flesh" sex as essential for a man's good health, a view which militates against the use of condoms (Macheke & Campbell, 1998). Norms of masculinity, associated with physical strength and bravery, serve as a key coping mechanism whereby miners deal with their harsh and dangerous working conditions. Given that masculinity is also associated with high levels of sexual activity, the very norms that play a key role in the adjustment to the rigours of the working environment also serve to increase the risk of HIV transmission. The combined effect of all these contextual factors is that miners are reluctant to use condoms.

In another study, Campbell (1998b) found that sex workers often agreed to unprotected sex despite fears of HIV-infection because men refused to pay for sex with condoms. Given that clients were in short supply, sex workers feared that if they became too insistent about condom use miners would simply take their business elsewhere. Low levels of social cohesion amongst sex worker colleagues meant that women were unlikely to present a united front in insisting on condom use. Furthermore, the conditions of poverty and violence that had characterised the lives of most of the sex workers in this study had undermined the development of a sense of confidence and assertiveness which would have empowered women to be more insistent in protecting their sexual health through condom use.

CONCEPTUALISATION OF THE CARLETONVILLE PROJECT.

Studies such as those outlined above show that the process of sexual behaviour change involves far more than simply giving people information, making condoms freely available and improving STD services. Sexual behaviour is not determined merely by the free choice of rational individuals but by a range of complex community and social processes. Against the background of such arguments, the Carletonville HIV-prevention programme is designed to conceptualise HIV/AIDS in a way that moves beyond traditional individualistic perspectives. Some of the activities of this project are fairly typical – aggressive syndromic management of STD's, health education and condom distribution. However this project aims to improve on existing interventions in the southern African context in a number of ways that take account of the context of sexual activity in ways that are broader than traditional HIV management programmes on the mines.

Firstly, the project will be aimed not just at mineworkers, but also at members of the communities surrounding the mines within which miners conduct their social and sexual lives. Secondly, the project will be managed not only by mine managements as is usually the case, but by an alliance of management, trade unions, grassroots community organisations, and representatives of the provincial and national health services. Thirdly, attempts will be made to involve a wide range of traditional and biomedical practitioners in the project's activities to ensure that the project is not dominated by the biomedical world view, which might not be the chosen perspective of many members of the target community. Fourthly, rather than relying on information-based HIV-education, community-based outreach and peer education strategies will be used and every effort will be made to ensure that target audiences participate as fully as possible in the design and implementation of these strategies, increasing people's sense of self-efficacy in relation to their health through maximising their leadership and participation in health-related projects.

Furthermore community-based peer education programmes, which are designed in explicit opposition to information-based education programmes, aim to provide the enabling conditions for people to renegotiate sexual cultures collectively rather than to persuade individuals to make individual decisions to change their behaviour by providing them with information about health risks (Dube & Wilson, 1996). The project will make every effort to conceptualise and design its interventions in a way that views HIV-transmission as a community problem rather than an individual problem, and to maximise networking between this local initiative and HIV-prevention initiatives at a provincial and national level, with the latter having a crucial role to play in providing a supportive context for efforts in our particular community of interest.

Campbell (1998) argues that the inter-related concepts of social identity and self-efficacy are potentially important conceptual tools for beginning to understand the processes underlying successful health promotion programmes. Drawing on her adaptation of social identity theory as a tool for understanding the way in which behaviour is shaped by social context, she summarises her argument in three points:

- "1: Social identities play a key role in the performance of sexual behaviours. Our identities consist of a series of frequently shifting affiliations with a series of loosely defined group memberships (e.g. family, peers). Different group memberships are associated with a range of socially negotiated recipes for living (discourses and practices) which shape and constrain our experience and behaviour.
- 2: In the process of social identity construction, people are motivated by a fundamental human need for positive self-esteem, self-efficacy or empowerment.
- 3: Social and sexual identities are negotiated within the particular social, community and cultural contexts in which people and their families live and work. These contexts often determine the extent to which people have access to opportunities for empowerment/ self-efficacy. Here empowerment must be regarded as both a subjective state (referring to the subjective sense that one is in control of important aspects of one's life) as well as an objective state (given that a range of social, material and economic factors will constrain the extent to which one is indeed in control of important aspects of one's life or not)." (Campbell, 1998:73).

Against this background, it is our belief that changes in sexual behaviour (increased condom use) and health-seeking behaviour (increased STD treatment) are unlikely to be generalised or sustained without the following:

- i) *The widespread renegotiation of the social and sexual identities of people in high risk situations for HIV.* The programme's starting assumptions about sexual behaviour are that sexuality consists of a complex of actions, emotions and relationships "whereby living bodies are incorporated into social relations" (Kippax & Crawford, 1993:257); and that "sexual behaviour is inextricably linked with the norms characteristic of the social groups with which we identify" (Stockdale, 1995:46). Thus the project aims to bring about not only individual behaviour change, but also wider changes in the social identities of people in high risk situations - especially mine workers and sex workers - through peer education programmes which seek not merely to provide individuals with information, but also seek to provide people with the opportunity to collectively renegotiate peer norms.

ii) *Increased self-efficacy amongst members of target groupings through participation in programme planning and implementation.* It is now well accepted that the degree to which one feels that one has control over important aspects of one's life is an important determinant of one's health-related behaviour (Bandura, 1996). The greater one's sense of self-efficacy, the more likely one is to engage in health promoting behaviours. In many HIV interventions increases in self-efficacy are now regarded as one of the most important outcomes. But here again, changes in self-efficacy tend to be measured as individual-level outcomes, with inadequate attention to the processes whereby participation in health interventions are hypothesised to increase peoples' sense of control over their lives and health. The concept of participation is still poorly theorised and understood in view of the central role that it plays in the enterprise of development in general, and in health promotion projects in particular. In a review of a large number of health promotion alliances in a range of industrialised and non-industrialised countries, Gillies (1997) argues that the stronger the representation and the participation of grassroots community structures in practical aspects of health promotion, the greater the impact of the project is likely to be. However others (e.g. Madan, 1987; Stone, 1992; Asthana & Oostvogels, 1996) are more skeptical about the supposed benefits of participation and much conceptual and empirical work remains to be done in this regard, if we are to begin to understand how HIV prevention programmes do or do not have their desired effects.

iii) *The promotion of community contexts that enable health.* The first step in creating health-enabling communities involves the active participation not only of people in high risk situations, such as mineworkers and sexworkers, but also members of the broader communities in which they live their lives. The Carletonville project is based on the assumption that health enabling communities can only be created through alliances between a wide range of stakeholders (grassroots community groupings, mine managements, trade unions, provincial and national health representatives and so on) as well as healers (traditional and biomedical). It is through such alliances that the project hopes to be able to influence the wider context of behaviour change and health. However, a range of factors will influence the extent to which such alliances achieve their intended goals, including levels of motivation and commitment of various stakeholders, the extent to which national policies are supportive of such goals, and so on.

Given that the project aims not only to increase HIV-preventive behaviour and to reduce levels of STDs, but at the same time to bring about changes in identity, self-efficacy, and community and political contexts, there is a need to develop new indicators which will make it possible to measure the processes underlying successful health promotion. Existing outcome indicators that measure the beneficial effects of programmes in relation to individuals, such as changes in STD rates and levels of reported condom use, cannot capture the extent and impact of the multi-layered processes going on in projects such as the one in Carletonville. Currently we lack sociologically and politically sophisticated theories of behaviour that can cope with the complexity and diversity of the social contexts of behaviour change (Gillies, 1998).

EVALUATION OF THE CARLETONVILLE PROJECT.

The evaluation of the project will draw on a number of inter-locking data sources including:

- *Biomedical surveys.* A sample of 2000 people will be tested for STDs and HIV at the beginning and end of the three-year intervention.
- *Behavioural surveys.* The 2000 people tested in the biomedical surveys will also take part in a linked survey consisting of amended version of the UNAIDS multi-site questionnaire which seeks to measure partner relations and sexual networking patterns, HIV-related knowledge, attitudes and practices, patterns of migrancy, socio-economic factors and levels of community cohesion.
- *STD monitoring.* STD levels will be monitored throughout the project by a system of reporting which should include all health service providers.
- *Epidemiological modelling.* Epidemiological models of HIV-transmission will be constructed on the basis of the data outlined above.
- *In-depth ethnographic interviews and focus groups.* These will be conducted with sub-samples of informants to generate explanations of the processes underlying the impact of the intervention as measured by both the behavioural survey and biomedical tests. Such interviews and focus group discussions will be carried out periodically throughout the life of the project, and will attempt to explore, in particular, the extent to which the project impacts on peoples' social and sexual identities, on their senses of perceived self-efficacy and on their perceptions of health, healing and sexual health.
- *Participant observation.* Participant observation of STD treatment settings and peer education settings will seek to evaluate the extent to which health education and health services are delivered in a way that combines state-of-the-art practices, as well as being congruent with the social identities and health beliefs and practices of members of the communities of interest – these factors being combined in ways that are likely to minimise the likelihood of STD and HIV transmission.
- *Operational evaluation.* The management of the project will be evaluated through detailed analysis of minutes of key meetings, project monitoring records kept by the project management team, and interviews and workshops with key representatives of all of the stakeholders in the Carletonville mining community. This stage of the evaluation will focus on the effectiveness of the project's implementing organisation, its personnel, its operating procedures, its relationships with other key organisations at the community, provincial and national level, the extent to which funding and resources are adequate for the project's goals and so on.

The evaluation will seek to determine the biomedical and behavioural impact of the programme as traditional evaluators have sought to do. In addition it is hoped that this multi-faceted body of data will provide the basis for well-informed hypotheses about the processes underlying the presence or absence of the behavioural and biomedical outcomes we hope for. These hypotheses will form the basis of the development of social and community-level indicators which begin to capture information regarding the kinds of co-operation, and the processes of community development and identification which we believe will be closely related to the success or failure of the project. The concept of social capital, which highlights the potentially health-enhancing effects of the active participation of citizens in local community networks and organisations which they trust, and with which they can identify, as well as emphasising the importance of stakeholders' alliances or partnerships in effective health promotion, could serve as a

promising framework for synthesising this array of findings in a way that highlights the processes underlying the project's success or failure.

CONCLUSION: MORE QUESTIONS THAN ANSWERS.

We are aware that this paper has raised more questions than it has provided answers. We hope, however, to have made a convincing case for the limitations of existing approaches which attempt to evaluate the impact of HIV prevention programmes in terms of biomedical and behavioural outcomes, without reference to the social, political and environmental factors that enable or constrain programme successes or failures. Our own thinking as to how to develop concrete and actionable indicators of these factors is still in its infancy. In our attempt to contextualise the conventional biomedical and behavioural outcome indicators of the Carletonville project we will often be feeling our way, and the conceptual tools that currently exist for this task still require development and refinement. We hope that the concept of social capital will provide us with a starting point for some of our explorations. If health programme evaluators are to increase our understandings of the mechanisms underlying the success or failure of HIV interventions, and the extent to which such interventions can be generalised and are sustainable, then the task of developing and refining social and community-level conceptual frameworks and indicators of programme success needs to be pursued as a matter of urgency.

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