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The impact of social environments on the effectiveness of youth HIV-prevention: a South African case study.

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Abstract

Few would disagree that 'social context' shapes the effectiveness of HIV-prevention programmes. However much work remains to be done in developing systematic conceptualisations of HIV/AIDS-relevant aspects of social environments in vulnerable communities. This paper contributes to this challenge through a case study (44 interviews, 11 focus groups with 55 people and fieldworker diaries) of the impact of social context on a participatory peer education programme involving young people in a peri-urban community in South Africa. Three interacting dimensions of context undermine the likelihood of effective HIV-prevention. *Symbolic context* includes stigma, the pathologisation of youth sexuality (especially that of girls) and negative images of young people. *Organisational/network* context includes patchy networking amongst NGOs, health, welfare and education representatives and local community leaders and groups. This is exacerbated by different understandings of the causes of HIV/AIDS and how to manage it. These challenges are exacerbated in a *material-political context* of poverty, unemployment and crime, coupled with the exclusion of young people from local and national decision-making and politics. HIV-prevention initiatives seeking to promote health-supporting social environments should work closely with social development programmes -- to promote young peoples' social and political participation, increase opportunities for their economic empowerment, challenge negative social representations of youth, and fight for greater recognition of their sexuality and their right to protect their sexual health.

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Introduction

One in ten South Africans aged 15 to 24 are HIV positive, despite numerous HIV-prevention interventions through the media, schools and local community groups (Dept Health, 2003). Existing research tends to explain the disappointing effectiveness of HIV-prevention efforts through technical details of interventions (e.g. the appropriateness of educational messages), or individual characteristics of target audiences (e.g. their attitudes or behaviour). Our research seeks to expand this lens by examining the extent to which social environments are supportive of HIV-prevention efforts.

In this paper, we highlight three dimensions of social context which undermine the effectiveness of youth HIV-prevention efforts in the marginalized South African communities in which the epidemic flourishes. *Material-political context* includes young peoples' access to money, jobs and political influence. *Symbolic context* refers to the web of social representations into which young people insert HIV prevention messages (e.g. their understandings of age- and gender-appropriate sexual behaviour). *Institutional-network context* includes the extent to which public sector, private sector and civil society networks are supportive of the well-being of young people in general, and of HIV prevention efforts in particular.

This work takes the form of a descriptive case study conducted in the peri-urban community of Ekuthuleni in the KwaZulu-Natal province. It has a population of 20 000 people. Unemployment stands at 40%; many live in severe poverty. HIV prevalence is high – 16% of adults and 36% of pregnant women (Shisana 2002). Yet levels of disclosure are minimal due to the vicious stigmatisation of people living with AIDS (PLWAs). People with AIDS

and their families generally collude in passing off their illness as a more socially respectable one such as tuberculosis. So successful is this, that most of our research informants said they were not aware of any HIV positive people in the community.

Methodology

Our research was conducted in partnership with the Christian Youth Alliance[1], an internationally funded NGO which seeks to prevent HIV through youth peer education, backed up by support groups and counselling for PLWAs. Peer education involves the participation of young people in youth-led programmes. Ideally such programmes facilitate contexts in which youth can engage in debate and dialogue about high risk sexual behaviours and the possibility of changing them (Campbell and MacPhail, 2002). The underlying assumption is that people are most likely to change their behaviour if liked and trusted peers are seen to be changing theirs (Rogers, 1995). Our research goal was *not* to evaluate the CYA's peer education activities but rather to focus on the context in which this work was being conducted, in the light of the organisation's on-going debates about how best to promote social environments most likely to support their HIV-prevention efforts.

In justifying our choice of the case study method, we distinguish between two forms of research. Hypothesis-testing research is conducted when one knows exactly what one is looking for, and able to tightly define and measure one's variables of interest prior to the study. Hypothesis-generating research is preferred when one is working in an under-explored area, where one doesn't know exactly what one is looking for, or how best to define one's variables of interest (in this case those features of social context that might influence the success of youth HIV-prevention efforts). The goal of such research is to describe the case in as much detail as possible, in the interests of mapping out areas for future research (Bromley, 1986).

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[1] The names of our study community and our partner organisation have been changed to protect the anonymity and confidentiality of research informants.

It was against this background that we sought to interview a wide range of people living or working in Ekuthuleni, drawing from those groupings whose views and actions might impact on the lives, health and sexuality of young people. These included teachers, a school principal, community health workers, community leaders, CYA staff, school learners and peer educators in and out of school, traditional healers, clinic nurses, parents, people living with HIV/AIDS, church ministers, local government officials and representatives of a multi-national company which employed local people.

The case study took the form of interviews with 44 individuals, 11 focus groups involving 55 people, with fieldworker diaries recording observations of the data collection process. An open-ended topic guide elicited information we believed which might be relevant to understanding the context of youth HIV prevention, including informants' views of: the South African political context; local community life; the causes of HIV/AIDS; its impact on the community; the role of different groups in HIV/AIDS management; and the potential of peer education, grassroots participation and multi-stakeholder partnerships as strategies for HIV prevention.

Our research was informed by Campbell's (2003) account of six factors that facilitate participatory peer education programmes which seek to challenge health-damaging social/ sexual norms and promote health-enhancing behaviour change. These factors include: accurate knowledge about sexual health risks, the facilitation of critical thinking about obstacles to behaviour change and how these might be challenged, a sense of identity and solidarity amongst peer participants, the empowerment of participants, and the existence of bonding and bridging social capital in the community in which the programme is implemented. Taking this conceptual framework as a starting point, our research examined the extent to which the social environment of Ekuthuleni was likely to support or undermine each of these factors. Our interview data were subjected to thematic content analysis (Flick, 1992), using these six dimensions as the core categories of our coding frame. They constitute the section headings under which our findings are presented and are discussed further below.

Results and discussion

<u>Knowledge</u>

Accurate knowledge about health risks is an important precondition for health-enhancing behaviour change (Crossley, 2000). Young people in our study had accurate knowledge about HIV transmission and prevention. However, various factors prevented them from acting on this information. They were often driven by motivations which competed with safe sex messages. Curiosity was one: "*All of us want to experiment with this thing called sex which we are told is very nice. Our parents went across the border of flesh-to-flesh when they were young. Why can't we?" (Boy, 14)*

Fatalism and bravado was another: "*Young people are stubborn, they want to prove they are not afraid to die. They say to each other: We will die in the same ship (sex) that we came in." (Girl, 13)* Youth also spoke of information overload: "*The youth tell us – 'If you are going to tell us about HIV/AIDS, we know that already. Tell us something new. We are tired of all this AIDS talk all the time'* ". *(Community health worker).*

Young people were often driven by alternative rationalities to those underpinning HIV prevention programmes. In conditions of poverty, girls often depended on sexual partners for gifts such as money or clothing, and had limited power to insist on condoms in such contexts. Some were willing to risk HIV in order to have a baby to access child support grants, or to establish a stronger connection with a desirable boyfriend.

<u>Critical thinking</u>

A key facilitator of behaviour change is the ability to think critically about social obstacles to behaviour change (e.g. gender norms and/or poverty), and to engage in dialogue about ways to overcome them. Ideally critical thinking motivates debate about alternative behavioural norms, serving as a precursor

of collective action to challenge social conditions that promote high risk behaviours (Freire, 1973).

Whilst people often referred to social determinants of HIV-transmission, including poverty, peer pressure and gender norms, there tended to be a mismatch between these social explanations and the individual-level solutions people advocated to reduce HIV/AIDS. People repeatedly cited awareness-raising and abstinence as solutions, and demarcated HIV-prevention as the province of health departments – without advocating the need for parallel efforts to address the social roots of the epidemic.

There was also a lack of critical thinking about the stigmatisation of youth sexuality, which was often referred to in judgemental language as 'bad behaviour', 'immorality', 'wrong-doing' and 'evil'. Few adults acknowledged the reality of young peoples' sexual desire, especially in relation to girls. They said adults had taught them to associate sex with shame and danger, rather than teaching them to be discreet about their sexual activities and to use condoms: "*Mother says if you sleep with a boy you get a baby, he dumps you, and your life is destroyed.*" (Girl, 12)

Yet, as a minority of adults said, youth sexual activity had long been common: "*In my time I could sleep with seven men and only get an STI. I would go to the hospital or traditional healer and be cured in no time. The only difference now is that HIV has no cure.*" (Mother, 50)

However such adults were in a minority in our sample. There was little analysis of the hypocrisy or double standards underlying adults' attitudes to youth sexuality. There was also no evidence for critical thinking about the way in which these attitudes made it unlikely that young people would talk openly about their sexual relationships, or feel comfortable in seeking out information about their sexual health.

Identity and solidarity amongst youth

Peer influence is often an important determinant of sexual behaviour, and peer education seeks to provide a context for the collective renegotiation of peer sexual norms. Furthermore critical dialogue about topics such as intimacy and sexuality is most likely to occur in an atmosphere of trust and solidarity amongst young people who feel they have common life goals and face common life problems (Campbell and MacPhail, 2002).

A range of divisions undermined the likelihood of such solidarity amongst youth in Ekuthuleni: *"Before they can try and change our behaviour, they need to do something to unite the youth, because we do not work hand in hand."* *(Youth Leader)* Strong divisions existed between different groups of young people, undermining the likelihood of a common identity. There was lack of solidarity between the few who attended schools outside the community, those attending what were regarded as second rate local schools, and school drop-outs. There was hostility between more 'respectable' young people and those engaged in crime and drug-use. There was lack of common identity between Christian youth who tried to abstain from sex, and more secular youth who had a more relaxed approach to life.

Psycho-social empowerment and confidence

People are most likely to feel they can take control of their sexual health if they have experiences of being effective in other areas of their lives, and if they have a sense of self-respect and respectful recognition from others (Wallerstein, 1992). Most young people in Ekuthuleni had little education and few skills, and job prospects were poor. There was often inadequate support and guidance for young people from the family unit. Some parents lacked confidence to advise children with more education than they had. Others feared children involved in crime and drugs. Others had died or left home. As one teacher said: *"When some parents come to meetings with teachers, its clear they know nothing about the child. Other young people live with grandparents, its so sad, they come to school without having eaten, they cry, they have problems. They don't have the books they need …."*

Adults frequently described young people as 'mad, bad or deviant', a nuisance to be controlled though harsh discipline, corporal punishment and firm rules. Many adults struggled to see youth as having anything of value to offer the community. There was little recognition of young people as a constituency. They had little representation on local political or community development structures, and played virtually no role in community decision-making. That youth representation that did exist on the School Governing Body was ineffective. The school principal himself regretfully described youth representatives as over-compliant to their elders, as well as competitive and elitist in their role, showing little support or understanding for their less successful or wayward peers.

Bonding social capital

The health-enhancing processes of solidarity, critical consciousness and empowerment outlined above are most likely to take place in communities characterised by high lives of bonding and bridging social capital (Baron et al., 2002). Bonding social capital refers to the existence of trusting and supportive relationships within a local community, which form the context within which people can work collectively to achieve goals of mutual interest (in this case the reduction of HIV-transmission).

Bonding social capital is also important because people who live in trusting and cohesive communities, where their voices are heard and they are able to articulate their views, are more likely to take ownership of the problem of HIV/AIDS, than to passively regard it as the responsibility of professionals or distant government officials (Campbell and Jovchelovitch, 2000). It is also within such communities that people are most like to challenge the stigmatisation of people with HIV/AIDS and to treat them and their families with respect and dignity. In such humane conditions HIV vulnerable people are less likely to respond to the epidemic with fear and denial, and more likely to feel confident to seek out information about prevention or testing for example.

In Ekuthuleni, people helped each other in very effective informal emergency networks when they were short of food or money. They were usually adult-dominated, however, with minimal opportunities for youth involvement or development. Furthermore, these networks were narrowly focused on physical survival ('getting by' rather than 'getting ahead'), and extremely small-scale. As such, they did not provide a platform on which Ekuthuleni residents could come together and pool their collective resources in the fight against HIV/AIDS.

There was absolutely no sense of local 'ownership' of HIV/AIDS management, which people repeated said was the responsibility of the government (yet at other stages of their interviews people repeatedly described the government as distant and unresponsive to their needs). Grassroots passivity was exacerbated by the contradictory tendencies of local leaders. The 'dual leadership' system involved the uneasy co-existence of elected party political leaders and hereditary traditional chiefs. These two groups pulled in different directions, with the former tolerating condoms, but the latter calling for youth abstinence backed up by virginity testing (Scorgie, 2002).

There is little support or solidarity for PLWAs. The stigmatisation of HIV/AIDS often results in lack of support for AIDS sufferers by parents, teachers and the church. As a youth worker told us: *"Children are not comfortable to disclose their HIV status to their parents. Their mothers gossip, saying: "I have an evil child at my house who has contracted this disease." (Youth worker)* In some cases, family members hide sick relatives away, depriving them of health care and support. Where there are few opportunities for achieving social status through money, sexual respectability is highly valued (Campbell, Foulis, Maimane and Sibiya, 2004).

The stigmatisation of PLWAs, together with adult intolerance of youth sexual activity, makes many young people unwilling to associate themselves with HIV prevention efforts. Youth workers from the CYA spoke of how parents punished their children for attending HIV prevention activities, saying that their involvement 'proved' that they were sexually active. They spoke of a school

principal who terminated a peer education programme in his school when he discovered peer educators using sexual health brochures which he described as 'pornography', and a local minister who had told youth parishioners that they would be 'demoted' from the church if they attended an HIV prevention workshop.

<u>Bridging social capital</u>

Attempts to promote contexts that support HIV-prevention efforts are most likely to succeed where it is possible to build 'bridges' between small local projects and more powerful local and extra-local actors or agencies in the public sphere (e.g. health and education departments), the private sector (e.g. employers and funding agencies) and civil society (e.g. national youth organisations or activist groupings such as the Treatment Action Campaign[2]) who have the political or economic influence to assist in achieving programme goals (Woolcock, 1998). Bridging social capital is particularly important for a challenge such as HIV/AIDS because the problem of HIV/AIDS, with its complex mix of biomedical, behavioral and social roots, is too complex for any one constituency to deal with, particularly the poorest and most marginalized communities which are the most vulnerable to the epidemic.

In Ekuthuleni, local HIV/AIDS workers frequently referred to the total lack of support from any outside people or agencies of any sort at all, locally, regionally or nationally. In particular government departments of health and welfare were regarded as ineffective in relation to HIV/AIDS management. As one volunteer community health worker said: *"There are so many PLWAs who need help, but when we complain or make suggestions to the hospital, we don't get any response. Lines of communication are very poor. Social work referrals are even worse. Sometimes I have to hide from my patients in the street because the response from the social workers is so slow I no longer know what to say to them."*

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[2] An activist group concerned with the rights of PLWAs.

People spoke of hospital nurses openly discriminating against AIDS patients, and government grants for PLWAs seldom materialising before the patient had died. The CYA commented that far from receiving help from the government, the situation tended to be the exact reverse. For example, the CYA was running unpaid training courses in AIDS counselling for government social workers, and were providing the only HIV/AIDS education and support available to pupils at the local high school.

Conclusion

In the HIV/AIDS field there is now general recognition that HIV-prevention efforts need to go hand in hand with parallel efforts to promote social environments that are supportive of safer sexual behaviour (Beeker et al., 1998). Details of the social changes that are needed nearly always refer to the need to mitigate the more general impacts of *poverty* and *gender* inequalities, in the interests of providing contexts which increase peoples' power to protect their sexual health. Whilst our case study is certainly supportive of such recommendations, we argue that there is an urgent need to specify *youth* as an additional dimension of social marginalisation, and one that is central to HIV prevention efforts. Youth need to be singled out as a marginalized group in addition to women and the poor in talking about the role of social exclusion in both facilitating HIV-transmission and undermining prevention.

Our findings have shown how young people in Ekuthuleni are excluded from access to education and work; political representation; respect and recognition; and participation in informal and formal community networks. We have highlighted how these forms of exclusion undermine the likelihood of effective HIV prevention–on the assumption that sexual behaviour change is facilitated not only by knowledge about HIV/AIDS, but also by youth solidarity, empowerment, critical thinking, and the presence of bonding and bridging social capital. There is much scope for youth HIV prevention initiatives to work hand in hand with community development programmes that promote young

peoples' social and political participation, increase opportunities for their economic empowerment, challenge negative social representations of young people, and work towards greater recognition of their sexuality and their right to protect their sexual health. Our findings point to such efforts as important components of the challenge of creating social environments that enable young people to protect their sexual health.

Acknowledgements

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