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Dr Emilie Venables

Reproductive Health and HIV Research Unit
University of the Witwatersrand

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Gendered Hillbrow, Healthy Hillbrow? Men's involvement in clinical trials in Johannesburg, South Africa[1]

Dr Emilie Venables,
Senior Researcher, Reproductive Health and HIV Research Unit (RHRU)
evenables@ rhru.co.za

Introduction

This paper offers an introduction to male participation in clinical HIV prevention research in Johannesburg, South Africa, and is based on background research conducted for a feasibility and acceptability vaccine study beginning in Hillbrow in May 2010. Within this paper, I demonstrate the importance of social research within clinical HIV prevention research, and frame this discussion with the idea that one cannot conduct clinical studies without studying the social backgrounds of research participants. In order to understand participation and retention in clinical trials, one must understand the context in which one is working and the backgrounds of those who choose to participate (or not to participate) in research. The more we can learn about those who take part in research, the easier it is to involve communities in further HIV prevention initiatives.

I demonstrate the need to involve men in HIV prevention studies and discuss some of the problems linked to their participation, asserting that the issues surrounding male participation in clinical research go beyond those of gender. I argue that "masculine" behaviours which may have a negative impact upon men's health are not necessarily caused by gender, but by environmental factors and the spaces in which men live, work and

[1] This paper is a draft, intending to offer a broad introduction to some of the main issues involved in conducting clinical research with men. These will be raised in more detail during the seminar presentation and with further research.

socialise. Gendered identities and spatial identities are very much intertwined and should not be separated. The issues surrounding male participation in clinical research, and in health more generally, go beyond physiological differences. This paper focuses on how our environments shape identities, access to health and willingness to participate in research.

Introducing AfrEVacc

The vaccination study (part of the African-European HIV Vaccine Development Network, known as AfrEVacc) which acted as the catalyst for thinking about these issues is a prospective, randomised pilot study that intends to recruit 150 HIV negative men from the Hillbrow area.[2] The study is not a trial of an HIV vaccine, but rather preparatory work to learn more about a population amongst whom future HIV vaccination trials may take place. It is important to stress that although the Hepatitis B vaccination will be administered to randomised participants during the research, no new drugs are being tested and instead the focus of the study is male *attitudes* towards vaccines and vaccine trials.

There is limited research on vaccine acceptability in the context of Sub-Saharan Africa (Sayles et al. 2009) and few vaccine acceptability studies address the issue of gender (Kakinami et al. 2009). Research on vaccine acceptability and feasibility tends to focus on hypothetical questions around dosage, cost, cross-clade protection and duration of protection (Lee et al. 2008), but in this study, the Hepatitis B vaccination will be administered to participants in order to understand their experiences of a *real* vaccine.

[2] The study is funded by the European and Developing Countries Clinical Trials Partnership (EDCTP). The study has received ethical approval from the University of the Witwatersrand HREC.

Recruitment of men to the study will take place through a combination of community outreach, clinic referrals, posters and flyers displayed and distributed throughout the Hillbrow area and discussions on local radio shows. Participants are asked to give their informed consent before taking part, and whilst they are not paid for their participation, they are reimbursed to cover transport costs and other out-of-pocket expenses. The study requires men to commit to a year of participation, with visits every month, which will be a problematic aspect of conducting research in a mobile and transient male population such as this one.

Introducing Hillbrow

The environment in which research is conducted undoubtedly affects who is recruited, how they are recruited and their retention in the particular research. What, therefore, are the implications of conducting clinical research in an urban locus such as Hillbrow?

Hillbrow, located in the inner-city of Johannesburg, is known for high unemployment levels, crime, violence, sex-work and drugs, and has earned itself the reputation as one of the most dangerous areas of the city. Hillbrow also has a poignant space in the media and has become the backdrop for films such as *Jerusalema*, scenes in local soap operas[3], short stories (Holland and Roberts 2002), newspaper articles and magazine features as well as in academic literature. The most significant scholarly contribution to research on Hillbrow has been made by Morris (1999).

[3] The eTV soap opera "*Scandal*" recently featured a storyline involving drugs, sex and violence in Hillbrow.

Hillbrow covers approximately one square kilometre and has a population estimated at 100,000 inhabitants, and its high-rise apartment blocks are a prominent feature of Johannesburg's skyline. In amongst these towering blocks of flats are crumbling and faded examples of Art Deco buildings; poorly apostrophised "*Bad Boyz*" security signs and heavy grilled doors armed by guards act as a reminder that this is an area where crime is rife. Rent is cheap and many buildings in the area are inhabited by squatters.

During the day, and at night, Hillbrow's shebeens are full of men drinking, smoking and playing pool and the smell of stale beer and smoke lingers in the air. As much as it is a place that is feared, Hillbrow's vibrancy gives it an ambience that other areas of the City of Gold do not have. In comparison to the sterile and isolated quiet of the city's northern suburbs, Hillbrow's streets are full of life. Street vendors hawk their wares and local shops spill out onto the pavement, a mix-match of imported Chinese products, local *muti*, take-aways and hair-braiding salons enticing passers-by.

Gender and HIV Prevention Research

Thinking about gender and HIV prevention is not new, and in South Africa there is a particular concern over women's ability to negotiate condom use with their partners and how this impacts upon their health. Research on men and HIV/AIDS and preventative strategies is often limited to the study of migrants and long distance lorry drivers, those in high-risk professions such as mining and men who have sex with men (MSM). So why focus a vaccine study on men when statistics show that the HIV epidemic affects women? Heterosexual relationships remain the most common way that HIV is transmitted in South Africa, and women are socially and physiologically more at risk than their male partners

(UNAIDS 2005). Men, as Barker (2000) has argued, in taking responsibility for their own health and knowing their HIV status, also take responsibility for their partners and families.

Men's Involvement in Research

Literature about men's health suggests that they are disinterested, unwilling or unable to seek health care, which would also suggest a disinterest in taking part in clinical research. It is interesting to note that in a published literature review on clinical trials (Lovato et al. 1997), men were not considered a group of people needing specific targeting, whereas in South Africa, it is the recruitment of men to trials which has been deemed problematic. There are many reasons for this, including lacking access to a male-friendly clinic environment, engaging in employment which leaves them short of time to dedicate to their health, or being ashamed or embarrassed to seek medical advice.

Barker writes that men have the tendency to see women, but not themselves, as procreative – women are therefore given the primary responsibility for reproductive health, meaning that men's access to health care information and facilities is limited (Barker 2000). The link between family planning and sexual reproductive health is also a problematic one when thinking about involving men in HIV prevention research, as family planning is not an area that men have typically been involved in and can make men reluctant to test for HIV because of the perception that it is a "woman's issue".

Notions and ideas about masculinity (or masculinities) and what it means to "be a man" can cause men to become caught up in damaging and unhealthy behaviours, and health-related behaviours, like many other social practices, can be a way of demonstrating femininities and

masculinities (Courtenay 2000). Drinking, smoking, drug use, multiple sexual partners, sexual violence and not consulting health-care providers or knowing ones HIV status are some ways in which stereotypical masculine behaviour can manifest itself as unhealthy. We must also be aware that men may also be consulting *sangomas* or traditional healers rather than biomedical practitioners.

By describing these stereotypical attributes of masculine behaviour, I am not trying to imply that all men in Hillbrow are passive, disinterested or unwilling to take steps to improve their health and that of their partners: I am showing some of the generalisations about men and health that exist, and some of the challenges that are involved when trying to recruit and retain men in clinical trials.

Whilst masculinity can be a useful framework to think with, in many cases it actually leads us into making false assumptions about men and their unwillingness to engage actively in improving their health; not all men in Hillbrow are passive or disinterested in taking steps to improve their health and take part in research. As much as masculinity and the values associated with it affect men's experiences of health and sickness and inform decisions that they make about HIV prevention, health seeking behaviour is also influenced by one's environment. Men are not a single group with an easily defined set of characteristics, and there is no one male identity or masculinity, particularly when working in a diverse community such as Hillbrow. Identity is more than just gender.

In fact, despite the issues discussed above, men in Johannesburg and in South Africa more widely, have been, and continue to be, involved in research. Their engagement in HIV

prevention ranges from the role that they have played in microbicide research (Ramjee et al. 2001), their involvement in behavioural HIV prevention research aimed specifically at men (Peacock and Levack 2005) and their participation in circumcision trials (Auvert et al. 2005). The circumcision trial in Orange Farm, a peri-urban area on the outskirts of Johannesburg, recruited 3,274 men, showing that men were willing to take part in clinical research that involved surgery and follow-up visits. Another circumcision trial in Uganda recruited 4,996 HIV negative men, again demonstrating that it is possible to recruit men into clinical studies, even when the intervention requires surgical interventions (Gray et al. 2007).

Research Participation

A successful clinical trial needs participants, yet the decision to take part in research is clearly not an obligation, and involves a process of informed consent which allows potential participants to decide if they do or do not want to volunteer.

Some people take part in research because they want to help others: altruism is particularly poignant in HIV prevention research, where people participate because they have a genuine desire to help others (Mills et al. 2004). In the case of new drugs or treatments, people are likely to participate because of the perceived benefits taking part in a trial may bring. Others are enticed by improved and increased health care and the benefits of regular HIV and STI testing (which may deter some). "Sensation seeking", or enjoying the attention and regular support that accompanies trial participation has also been documented as a reason for research involvement (Grady 2005: 1682). Whilst reimbursements should not be used to

"entice" people to take part in research studies, for many, they are a factor contributing to their decision to be involved.[4]

There are many barriers to enrolling volunteers into HIV research, particularly clinical trials. Stigmatisation is a barrier to HIV testing, the seeking of treatment for HIV/AIDS and to taking part in medical trials (Macphail et al. 2006). The fear of being seen in a clinic known within a community for the testing and treating of STIs and HIV is a deterrent for men and women alike.

A mistrust of science, the government, medical or technological interventions can also make it difficult to recruit people to clinical research, particularly trials involving a new drug (Barsdorf and Wassenaar 2005; Niehaus and Jonsson 2005). Gossip and rumour may also prevent initial recruitment and continued participation into clinical research (Geissler and Pool 2006). AIDS and any interventions surrounding it are subject to people constructing them in their own ways, and rumour and gossip spread quickly and can be extremely detrimental to research studies (Stadler 2003; Niehaus and Jonsson 2005). There are also fears about the side-effects of new drugs or medications that are being trialled, and participation in different phases of clinical trials undoubtedly differs. Myths surrounding vaccines, including the fear of being injected with HIV, or the belief that an HIV vaccination could cause infection, also act as barriers to trial participation (IAVI 2008).

[4] In South Africa, the rate of reimbursements for clinical trial participants is set by the MCC.

Recruiting men: employment and mobility

Many of the issues discussed above affect both men and women, but what are the specific issues involved in recruiting men in inner-city Johannesburg to research?

Medical settings can appear to be feminine spaces; they may be considered unknown spaces which men are fearful, ashamed or embarrassed about entering. Sexual and reproductive health can be wrongly equated with maternal health, and men subsequently do not see it as relevant to their own needs. Those who have not been exposed to information about HIV or other health issues are also less likely to want to take part in research – clinical studies recruit through clinics and hospitals as well as in the wider community, so if men are not attending clinics, they are not going to know about research opportunities. Clinical studies around vaccines and vaccine acceptability are particularly interesting when considering male participation because women are often responsible for the immunisation of their children, and vaccines may not be something which men are knowledgeable about.

Another barrier to recruiting men into clinical research is closely linked to employment: men are more likely than women to be employed outside of the home and thus do not have the time to commit to a research study, or, as in Hillbrow, form part of a transient and informal workforce and understandably prioritise work or the search for it over other activities. Unemployment is often linked to anti-social and "unhealthy" masculine behaviours: this is not unique to Hillbrow, and young, urban men across the globe find themselves disillusioned and disenchanted with their economic situations and lack of earning power, whether in Ireland (Howe 1990), Ethiopia (Mains 2007) or India (Jeffrey, Jeffery, and Jeffery 2004). Losing their status as breadwinners through being unemployed has caused many men to feel

increasingly vulnerable; economically they are unable to provide an income for themselves and their families which psychologically can cause feelings of lost self-esteem and frustration. Increasing numbers of women searching for employment outside the domestic sphere also threaten the assumed status of men as household heads.

Much has been written about such urban, unemployed men who have 'nothing to do' and are involved in a constant cycle of informal and insecure employment. Jeffery et al. working in India have described this sense of disenchantment as 'time-pass' – men are engaged in an eternal state of waiting and hoping for better conditions and improved life chances that do not always materialise (Jeffrey, Jeffery, and Jeffery 2004). Mains (2007) has investigated a similar phenomena known in Ethiopia as *yiluñña* – this is a state in which men feel pressurised to meet other people's expectations of them but are increasingly unable to meet the economic demands placed on them due to wider scale socio-economic circumstance.

I suggest that men in Hillbrow have similar experiences to those described by Jeffery and Mains, and that participation in research can in fact be seen as a positive intervention that provides unemployed men with structure. It can be viewed as something to commit to and something that offers increased health education and information. Taking part in a research study could be a way of combating feelings of "doing nothing". Participation in clinical studies has many of the same characteristics of employment – a contract is signed, terms and conditions must be understood and adhered to, regular attendance is required, as is "homework" in the form of adhering to condom use, as all participants in HIV prevention research are asked to do. Whilst research participants are not being remunerated in the same way that they would if they were employed, and the issue of reimbursements is not

something to be promoted, there are similarities between employment and research participation. I am not suggesting that participation in research should be seen as a full-time occupation, but that there are similarities between the two which need to be considered.

Thinking about Gender and Space

I now turn to thinking about space, and how recruiting men to clinical trials is linked to spatial and environmental factors, not just gender. Living in a neighbourhood such as Hillbrow can contribute to unhealthy and risky behaviours because of the environment in which men find themselves, not because they are men. Space can construct identities and demonstrate that so-called "male" and "unhealthy" behaviours are linked to ones' environment.

Our environments influence behaviour and reaffirm, question and create identities. In the case of Hillbrow, it is clear from the children walking to school, the washing hanging on balconies and the people talking on the pavements that communities, daily routines and relationships exist. For research to be successful, the layers and networks that lie beneath what appears a fragmented migrant community need to be discovered for us to understand people's lives and their attitudes towards health.

We must consider the ways in which people construct and navigate the environments around them, as well as how one's surroundings equally may dictate the way that someone's life is lived. People may be active participants of a city and may create and reshape landscapes and environments to suit their own needs, or the urban environment of the city

may impose itself upon its residents, making them passive or defenceless to the powers of infrastructure, architectural planning or divisive and enforced boundaries. Spaces may be contested and disputed. Land claims, hijacked buildings and graffiti on pavements are all examples of how buildings, neighbourhoods and land become spaces that people compete for.

In thinking about clinical trials in the context of Hillbrow, I am interested in how male research participants may consider places to be "healthy" or "unhealthy".[5] Is Johannesburg laid out in such a way that encourages its residents to access health care facilities? How do people navigate the city and how does the "(un)healthiness" of a neighbourhood such as Hillbrow contribute to the health status of its residents? How do these factors relate to research participation? As Lynch (1960) has argued, the way in which a resident see their city is not the same as that of a cartographer or town planner and the perspectives of Hillbrow's male residents are very different from those who do not experience the neighbourhood from within.

Gendered spaces within and beyond the household

> "The construction of gender and space are mutually constituting processes that find expression over time."
>
> Low and Lawrence-Zúñiga (2003: 12)

Spaces, as the title of this presentation suggests, are invested with gendered meanings. Space is given meaning by those who reside within or around it, those who travel through it and

[5] These themes will be explored further in a cognitive mapping and photography project entitled "Visual
Hillbrow", which is due to begin in April 2010. The project will involve 10 men from the Hillbrow area.

those who utilise, challenge and accept it. We can study the management, negotiation, adaptation and evolution of public and private spaces, as well as usage of and access to them. Hillbrow's residents, Hillbrow's employees, Hillbrow's decision makers and those who once resided here all affect the neighbourhood, its ambience, and its healthiness.

The gendering of space occurs within the household in the form of divided spaces and labour (Carsten and Hugh-Jones 1995; Bourdieu 1973), but also occurs beyond it. Although the house is an oft-studied subject because of its centrality to production and reproduction, theories of space are taken outside of the household and become applied to the space around the home. Anthropological discussions of spaces outside of the domestic sphere have considered the gendered dynamics of spatial relationships and interactions within schools, workplaces, hospitals and clinics (Venables 2007; Nencel 2001) and social spaces such as bars (McDonogh 2003), restaurants or football stadiums. Another example of the gendering of space outside of the household occurs in the Casamance region of Senegal, where Jola women are forbidden from entering the sacred forest where *circumcision* rituals take place (de Jong 2007). Within the context of South Africa, informal hostels have typically been "male spaces", leading women to reside in informal settlements outside the hostels themselves (Vearey 2010: 49).

Conclusions

Whilst gender is undoubtedly one of the things at the heart of a clinical study aiming to recruit men and is an area in need of further research, it is necessary to think beyond the confines of masculinity and realise that men do not participate (or refuse to participate) in clinical research simply because they are men. Living in an area such as Hillbrow can

contribute to men engaging in unhealthy and risky behaviours because of the environment in which they find themselves, not just because of their gender. Environments do affect health, but living in an environment that may be considered "unhealthy" does not necessarily make men disengaged or disinterested; so-called "male" and "unhealthy" behaviours are actually linked to environment and can be challenged.

For clinical trials, and research in general, to be successful, the layers and networks that lie beneath what can appear as fragmented inner-city communities need to be discovered for us to understand people's lives and their attitudes towards health. The vaccine study on which this draft paper is based will help us to learn more about these different layers, and participants will help to question the negative stereotypes surrounding men and health, and men's involvement in HIV prevention research.

The complex dynamics of Hillbrow's shifting and mobile population mean that migrant identities combined with male identities make recruitment, participation and retention in clinical research difficult. Understanding the background to men's lives means that the study of clinical trials goes beyond the epidemiological and biomedical and helps us to understand the lives of those who participate and may participate in future, which in turn could impact upon HIV in South Africa.

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