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Factors influencing the decision to voluntarily test for HIV: The perceived threats of being HIV positive

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Abstract

This paper investigates voluntary HIV testing behaviour among young adults in two Cape Town townships. Despite exceptionally high HIV prevalence rates, South Africa experiences low rates of HIV testing. Low levels of testing are worrisome because knowledge of HIV status is thought to be a key element in both the prevention of HIV transmission and the provision of care and treatment for those who are infected. Through qualitative in-depth interviews with 15 young adults (9 female, 6 male), this study found that choices regarding the voluntary uptake of HIV testing were strongly linked to the perceived implications of the HIV test. An analysis of the findings illustrates that study participants perceived HIV positive people to experience a number of threats because of their status – namely physical threats, social threats, and psychological threats – and that HIV testing served to either mitigate or expose an individual to these threats. Physical threats posed by HIV, such as opportunistic infections or death, encouraged HIV testing because it was only through testing that these potential threats could be mitigated. Conversely, an HIV test exposed an individual to social threats, such as ostracism and shame, and psychological threats, such as depression and self-rejection. Where social and psychological threats were perceived to be strong, testing was actively avoided. The findings of this study are that the decision to voluntarily test for HIV can be explained through a balance of the physical, social, and psychological threats that one can mitigate or be exposed to through testing for HIV. Using a threat-balance model, the analysis of findings shows that when study participants perceived physical threats to outweigh perceived social and psychological threats of living with HIV, they were biased towards testing. When they viewed social and psychological threats to outweigh physical threats, they were biased against testing. The focus on perceived threats of living with HIV highlights the need to focus on the social and psychological aspects of HIV/AIDS disease and illness, and not simply the clinical diagnosis and treatment of symptoms, both of which focus on physical threats. Because enhanced infrastructural resources for HIV testing and the availability of ARVs for mitigation of the physical threats alone do not encourage HIV testing, a

comprehensive plan to increase HIV testing must also seek to reduce the social and psychological threats presented by HIV infection.

Introduction

Despite high HIV prevalence rates and AIDS-related deaths[1], less than 1 in 3 people in the South African population of 47 million have ever been tested for HIV (Shisana, et al. 2005:80). This means that in a country with an exceptionally high HIV prevalence rate, 70% of people are naive to their status, 2 million of which are estimated to be unknowingly HIV-positive (UNAIDS 2006b:13). UNAIDS/WHO has stated that, "among the interventions which play a pivotal role both in treatment and prevention, HIV testing and counselling stands out as paramount" (2004:1). The South African Department of Health, in recognition of the role of HIV testing in both prevention and treatment, has made increasing the uptake of voluntary HIV testing a key priority in its HIV & AIDS and STIs National Strategic Plan (NSP) 2007-2011 (SANAC 2007:16)[2]. However, while the physiological effects of HIV infection are well established, the circumstances that provoke some people to "prefer death over testing" (Mgcobo 2007:1) are less explored and are consequently silently noxious. This paper analyses the findings of a qualitative study that set out to uncover the determinants of low levels of voluntary HIV testing in South Africa. In light of these findings, this paper proposes a model that demonstrates the interaction of many factors that influence the decision to voluntarily test for HIV.

HIV testing has a long history rooted in a debate between human rights and public health[3]. Primarily concerned with balancing an individual's rights to

[1] National estimates from 2005 predict an HIV prevalence rate of 10.8% in the population 2 years and older (Shisana, et al. 2005:33) and 18.8% in the adult (15-49) population (SANAC 2007:7). UNAIDS estimates show that 5.5 million people are living with HIV in South Africa and that in 2006, an estimated 320,000 people died due to AIDS (UNAIDS 2006b:11; UNAIDS 2006a:445). This brings the total deaths due to AIDS to over 1.8 million (Dorrington, Johnson, Bradshaw, and Daniel 2006:20)

[2] The NSP was drafted in 2007 in an unprecedented collaboration between civil society organisations, AIDS activists, academics, the international community, and select government officials.

[3] This debate was begun in the 1980s by Jonathan Mann, then founder and head of WHO's Global AIDS Programme. At the time, Mann made HIV testing a voluntary practice because he was anticipating the massive stigmatisation that comes with an HIV-positive diagnosis, especially when it affected already marginalised groups (Mann, Gruskin, Grodin, and Annas 1999). This later led to accusations that "HIV exceptionalism" had resulted in high prevalence rates and low testing rates. The argument went that rather than treating HIV like other

autonomy in health care decisions against the public health benefits of the greater society, this debate between voluntary and routine methods of HIV testing has been given renewed attention in recent years with the realization of the importance of HIV testing for treatment and prevention efforts. Still an elective process in most countries including South Africa, it has been theorised that the voluntary nature of voluntary counselling and testing (VCT) is responsible for low testing rates throughout Africa because many people actively choose not to test (De Cock 2005). In response to this, theorists argue for practitioner-initiated testing and counselling (PITC) in an effort to increase rates of testing, normalize HIV, and provide the opportunity for the associated prevention and treatment benefits (Cameron 2005; De Cock, et al. 2002; Heywood 2005). The support for either testing method – PITC or VCT – is predicated on the assertion that *it* will work best to increase the number of people who test for HIV, and thus enhance treatment and prevention of HIV/AIDS.

Strategies for increasing the voluntary uptake of HIV testing in South Africa have most commonly focused either on making infrastructural improvements to increase the number of testing services or have been in the form of AIDS campaigns that encourage testing by emphasizing its function as an entry point to accessing medical services to manage HIV infection and reduce future transmission. In a departure from these strategies, qualitative in-depth interviews conducted with 15 young adults living in Nyanga and Khayelitsha highlight the need to consider the physical, social, and psychological implications of living with HIV in order to understand why people chose or refuse to undergo an HIV test. The results show that testing infrastructure and AIDS awareness-raising campaigns are not enough to encourage voluntary testing; even with the availability of services and knowledge of the health benefits of HIV testing, individuals still need to have an individual "bias towards testing." This study examines the factors that create that bias and "tip" an individual towards or against testing. Provided with access to testing services, it is ultimately a balancing of physical, social, and psychological threats that will determine whether or not someone tests for HIV. A threat-balance model is presented in the findings section to demonstrate the relationship between physical, social, and psychological threats of living with HIV and determine the "testing tipping point."

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infectious diseases, "for which consent for testing is implicitly assumed by virtue of medical consultation, and diagnosis is encouraged, the diagnosis for HIV infection has often been actively avoided" (De Cock, et al. 2002:68).

A Review of Barriers to HIV Testing in South Africa

Research conducted into HIV-related health seeking behaviour has identified a range of factors that may explain why testing levels are low in South Africa. Four significant factors that have been suggested include: 1) a lack of access to HIV testing services; 2) a lack of knowledge of HIV/AIDS-related issues; 3) a lack of treatment for HIV/AIDS; and 4) high levels of HIV-related stigma.

Lack of Access to Testing Services

Low rates of testing in South Africa, and in fact in most of the developing world, have been attributed to a limited access to testing services (Hutchinson and Mahlalela 2006; UNAIDS 2007; Weiser, Heisler, Leiter, Percy de-Korte, Tlou, DeMonner, Phaladze, Bangsberg, and Iacopino 2006). With inadequate material and human resources, many African countries experience weakened health care systems, particularly with regard to HIV-related services (Asante 2007:644). Throughout sub-Saharan Africa, the availability of VCT is "constrained by shortages of skilled service providers, inadequate material resources, poor infrastructure and inadequate procurement and supply management systems" (Matovu and Makumbi 2007:1316). Increasing access to testing services is believed by some to lead to similar increases in the numbers of adults who voluntarily test for HIV (Matovu and Makumbi 2007; Pronyk, Kim, Makhubele, Hargreaves, Mohlala and Hausler 2002).

However, while not all areas have uniform coverage of VCT services, South Africa has a stable and growing health infrastructure. In 2002, there were only 450 VCT centres and 800 trained counsellors around the country (Department of Health 2002b; Kalichman and Simbayi 2003:442). By 2005, the Department of Health reported an increase to over 3,200 designated VCT sites with more than 450 in the Western Cape alone (Department of Health 2005). The impact of the current and growing number of HIV testing sites is shown by a recent South African population survey which reported that 80% of the population could name a place where HIV testing was offered (Shisana, et al. 2005:86). Given the proliferation of testing services and the high level of awareness about them, the low rates of HIV testing in South Africa cannot be explained, solely, by a lack of access to testing services.

Lack of Knowledge about HIV/AIDS Issues

Another common, though increasingly outdated explanation for low rates of testing and continued unsafe sexual practices in South Africa is that there is a lack of awareness about HIV/AIDS related issues among the majority of South Africans. Using cognitive-behavioural theories[4] of human behaviour, limited knowledge about HIV is often suggested as a significant factor responsible for low levels of testing behaviour or poor adherence to prevention and treatment initiatives (Gebrekristos, Lurie, Mthethwa, and Abdool Karim 2005; Kalichman and Simbayi 2003; Kalichman, Simbayi, Cain, Jooste, Skinner, and Cherry 2006; Nachega, Lehman, Hlatshwayo, Mothopeng, Chaisson, and Karstaedt 2005; Smith and Stasson 2000).

The South African Department of Health's communication initiative *Khomanani* is an example of a health campaign that seeks to alter sexual behaviour by addressing issues of poor HIV/AIDS knowledge (Cullinan 2003). The following statement explains the intentions of Khomanani:

> 'The campaign adopted a behavioural change framework that sees individuals and communities progressing along a five-step process from ignorance towards knowledge, approval, intention, practice and advocacy. While some individuals may be further along this process, it begins with ignorance of HIV and AIDS risk and consequences, and then proceeds to knowledge of these...' (Department of Health 2003).

As is evident in the Khomanani campaign, "individual and interpersonal theories (such as the Health Belief Model...) have so far been the ones most influential in the development of HIV prevention interventions" (Mathews 2005:151). Many other campaigns in South Africa also view increased HIV knowledge as the key to practicing protective sex, adhering to treatment, and accessing testing and treatment services[5]. Despite the importance of awareness about AIDS and HIV,

[4] Such theories include the Health Belief Model (Janz, Champion, and Strecher 2002), Social Cognitive Theory (Bandura 1997; Bandura 1977), the Theory of Reasoned Action and Planned Behavior (Fishbien and Ajzen 1975; Azjen 1988), and Knowledge Attitudes Practices (KAP) (WHO 2008).

[5] Other campaigns in South Africa that have focused on changing knowledge and attitudes include *loveLife* and Soul City, as well as the age-appropriate HIV/AIDS education that has been included in South African school-based life orientation programmes. loveLife advocates abstinence, partner reduction, and increased condom use by attempting to "change the pervasive values and attitudes among young people to sex, sexuality, and gender relations" (loveLife 2004:2). Soul City makes part of its widespread television, radio, print media, and

there are two primary objections to the view that low levels of knowledge about HIV/AIDS or the benefits of HIV testing are the cause of such low testing rates. Firstly, "whilst there appears to be a logical connection between concepts of health, beliefs about health maintenance, and health-related behaviours, empirical evidence suggests that their importance may in fact have been overestimated, and that the relationship between knowledge and action is a problematic one" (Williams 1995:580). In the case of prevention, for example, it is a harmful misconception that lack of knowledge about the ways HIV is transmitted and the methods for HIV prevention is the cause of unsafe sexual practices. To the contrary, it has been found that people "knowingly engage in sexual behaviour that could lead to a slow and painful premature death" (Campbell 2003:1). Likewise, the expectation that "knowledgeable and empowered HIV-positive clients" will take responsibility for correctly adhering to life-long antiretroviral treatment does not account for the actual experience of living with HIV, which can often be traumatic in the alienating and sometimes hostile environment of HIV/AIDS in South Africa (Robins 2006:313). This enviroment has been shown to discourage ARV treatment uptake and adherance, even where awareness of its health benefits was strong (Gilmore and Somerville 1994; Skhosana, Struthers, Gray, and McIntyre 2006; Simbayi, Kalichman, et al. 2007). Similarly, it has been shown that many people chose not to test despite knowing the benefits of learning one's status early. By looking at examples of prevention, testing, and treatment of HIV, it is evident that the relationship between knowledge and behaviour is tenuous and thus cannot solely account for low levels of testing.

Secondly, the notion that South Africans are unaware of HIV-related issues and the importance of HIV testing is unfounded. In 2005, a South African national HIV population survey found proficient knowledge in various areas of HIV, ranging from its transmission to the ways it is treated or prevented. For example, the survey reported that 93.9% of 15-24 year-olds and 95.7% of 25-49 year-olds correctly believed that HIV could be transmitted through unprotected sex. More than 80% reported that there was no cure for AIDS and 84.6% said they would seek ARV treatment in order to "extend life or live longer" (Shisana, et al.

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government lobbying campaign the reliance on imparting "information and impacting on social norms, attitudes and practice" (Soul City 2008). HIV/AIDS curricula has been included in South African schools since 1998 (Nattrass 2007) and has nationally-defined but province-regulated subject matter (Department of Health 2002a). The Western Cape school system uses its position "as the primary transmitter of knowledge, skills and values to the youth of society – to raise HIV-awareness, to disseminate information about HIV and its transmission, and to help change the attitudes of young people to inhibit the spread of the epidemic" (Western Cape Education Department 2002).

2005:89). The survey stated that while knowledge varies across age groups, “overall, implicit knowledge is high” (Shisana, et al. 2005:86-87), suggesting that low levels of testing are not necessarily due to a lack of knowledge about HIV/AIDS or ARVs. A study of HIV testing knowledge and practices in South Africa found no difference in HIV knowledge between those who had and those who had not tested for HIV (Kalichman and Simbayi 2003). In fact, studies have consistently shown that “HIV testing history [is] not associated with AIDS related knowledge” and that “factual based education about HIV transmission is necessary but insufficient in promoting HIV antibody testing” (Kalichman and Simbayi 2003:446).

Lack of Treatment for HIV/AIDS

A third explanation for the low rates of testing in South Africa has been linked to the availability of ARVs. Support for HIV testing has historically been compromised by the lack of an effective treatment response once an individual was diagnosed HIV-positive (De Cock, et al. 2002). In the absence of highly active antiretroviral treatment (HAART) in South Africa, resistance to getting tested or to knowing one's status has been attributed to fear of being HIV-positive caused by the association between AIDS and death (Shisana, et al. 2005). For example, one study from South Africa explicitly demonstrated that a "fear of death" is the reason for some individuals' refusal to take an HIV test (Day, Miyamura, Grant, et al. 2003:668). Another study showed that a group of youth from Durban, South Africa viewed an HIV-positive diagnosis as *equivalent* to death and as a result, many chose not to test for HIV, donate blood, or use the same clinic twice simply to avoid ever finding out if one was infected (Leclerc-Madlala 1997:368).

Sontag (1978) argues that diseases which are not fully understood, and more importantly, are without effective treatment, are the most feared. Her earlier work draws on examples primarily from tuberculosis (TB) and cancer, citing that “not so many decades ago, learning that one had TB was tantamount to hearing a sentence of death – as today, in popular imagination, cancer equals death” (Sontag 1978:7). The language linking death to a diagnosis, rather than to the chronic illness itself, is repeated in the current discourse around HIV/AIDS. A study conducted with mineworkers in South Africa found that many believed a lack of a future and the cessation of "everything" follow a positive diagnosis and therefore many refused to take an HIV test (Day, et al. 2003:668). Sontag went further to suggest that the development of treatments for TB facilitated the reduction of fear associated with the disease (1978:35). In

her later work, Sontag suggested that AIDS had replaced cancer as the most feared disease, in part because it was "extremely recalcitrant to treatment" (Sontag 1989:16)[6]. Consistent with Sontag's observation that tuberculosis treatments reduced fears associated with the disease, it has been speculated that improved and widely available antiretroviral therapy could similarly reduce fear of AIDS and potentially encourage HIV testing.

Lessons from other countries that are also battling with AIDS epidemics demonstrate this, showing that increased access to ARVs encourages testing evidenced by substantial increases in VCT. In Brazil, for instance, when the national government announced in 1996 that it would provide antiretrovirals free through the public health care system, people "who had not yet been diagnosed decided to be tested on the basis of information about the effectiveness of the drugs and their availability free of charge" (Galvão 2002:1863). In Botswana, a survey about the benefits of routine HIV testing showed that 67% of those who had not been previously tested for HIV would do so "knowing that they could get treatment for HIV/AIDS" (Weiser, et al. 2006:1018). Knowledge that ARV treatment was available was also one of the most common motivational factors for testing cited by those who had already participated in VCT. Similarly, "the advent of therapy in industrialised countries has greatly increased motivation for people to be tested" (De Cock, et al. 2002:68).

Following the South African government's commitment to providing HAART nationally in 2003 and the commencement of the rollout in 2004 (Butler 2005; Heywood 2004; Leclerc-Madlala 2005; Nattrass 2007), the increasingly viable option of providing treatment following an HIV positive diagnosis has the potential to increase the voluntary uptake of HIV testing. This is because it is widely speculated that the knowledge that ARV treatment is available in the event of a positive test result will function to allay the fears of those who would normally choose not to test for fear that they would be positive (Nattrass 2003:10). Researchers within South Africa have found correlations between knowing someone on ARVs and likelihood of being tested, suggesting that "the availability of ART may lead to an increase in the uptake of counselling and testing services" (Mfundisi, et al. 2005:485). Thus, the scale-up of ARV treatment has been viewed as a "vital step towards encouraging testing in sub-Saharan Africa" (Asante 2007:644).

[6] Indeed, in 1989 when Sontag was writing about HIV/AIDS, effective ARV treatment had not yet been developed. A combination of drugs now known as HAART was finally approved for use approval in 1995 (Merson 2006) and has been available worldwide since 1996 (Wood 2005:505). HIV/AIDS is no longer considered "extremely recalcitrant to treatment."

High Levels of HIV/AIDS-related Stigma

Lastly, stigma is believed to contribute to low levels of voluntary testing. According to UNAIDS and WHO, while access to HIV testing services is limited in lower- and middle-income countries, "the reality is that stigma and discrimination continue to stop people from having an HIV test" (UNAIDS/WHO 2004:1). This has been found in South Africa, with studies showing that "stigmatising beliefs about AIDS and their associated fears of discrimination can influence decisions to seek HIV testing and HIV treatment services" (Kalichman and Simbayi 2003:442).

Throughout history, stigmatisation has negatively affected the health and well-being of individuals affected by stigmatised conditions. Infectious diseases (especially sexually transmitted diseases) are particularly stigmatised, and often result in

> 'exclusion and disempowerment [that] can impede access to prevention and care services, in particular access to treatment that can cure or suppress infection. [Stigmatisation] can also increase vulnerability to being exposed to infection or becoming infected because precautions cannot be implemented' (Gilmore and Somerville 1994:1343).

In the context of the AIDS epidemic, "stigma is perhaps the greatest dread of those who live with AIDS and HIV – greater to many even than the fear of disfiguring, agonising and protracted death" (Cameron 2005:53). Stigma is considered to compromise the effectiveness of HIV awareness and prevention initiatives and discourage individuals from testing for HIV, accessing treatment and care services, and disclosing their status to friends or family members (Almeleh 2006; Daftary, Padayatchi, and Padilla. 2007; Hutchinson, Mahlalela, and Yukich 2007; Kalichman and Simbayi 2003; Kalichman, et al. 2006; Parker and Aggleton 2003; Skhosana, Struthers, Gray, and McIntyre 2006; Simbayi, Kalichman, et al. 2007). The UNAIDS Reference Group (2005:43) explains that "reducing HIV/AIDS-related stigma and discrimination at all levels, notably within health care settings" is a key factor for increasing the demand for voluntary HIV testing.

A Biopsychosocial Approach

In light of the above factors that may explain low levels of testing in South Africa, a biopsychosocial approach will be taken in this paper to understand disease and illness and the associated health-seeking behaviours. A biopsychosocial approach to disease and illness has arisen out of the criticisms directed at narrowly-focused biomedical approaches commonly used in clinical medicine and the subsequent polarization of "patient" and "practitioner" understandings of disease and illness that were created to combat these approaches. Until recently, and still to a large extent,

> 'the dominant model of disease... is biomedical, with molecular biology its basic scientific discipline. It assumes disease to be fully accounted for by deviations from the norm of measurable biological (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioral dimensions of illness' (Engel 1977:130).

In an effort to debunk purely biomedical models of disease, theorists have sought to differentiate between disease and illness by demonstrating how patients and practitioners view ill-health differently in the body. In particular, Kleinman differentiates between disease and illness by saying that the former is a biomedical practitioner's understanding of pain or bodily malfunction while the latter is the patient's "psychosocial experience and meaning of [the] perceived disease" (Kleinman 1980:72). Similarly, Hahn explains that

> 'when physicians consider symptoms, they focus on the pathophysiologic processes of the disease that produces them. But when patients have a symptom, they are often most concerned with its effect on health-related quality of life and the objective experience of illness' (Hahn 2001:903).

Highlighting these differences between patients and practitioners has helped to forge the way for expanded understandings of disease that consider not just the physical symptoms of disease, but also the social, financial, or emotional impacts of illness. The biopsychosocial model merges patient and practitioner understandings of disease and illness and thus enables a fuller understanding of HIV and AIDS. To this end, the biopsychosocial model (Engel 1977) is useful for understanding HIV testing because it illuminates the multiple and varied

experiences of living with HIV and how an HIV test – the gateway to discovery of status – may contribute to or facilitate undesired illness.

HIV/AIDS is still a heavily medicalised condition (Tarantola 2005) and the separation between AIDS disease and AIDS illness has created problems for prevention, diagnosis, and treatment in South Africa. Biological-based AIDS education, behavioural change prevention messages (such as abstinence and condom usage), regular testing and early detection, and provision of HAART are all strategies that have focused on AIDS disease. They prioritise containing the HI-virus, diagnosing opportunistic infections and positive HIV-status, and managing disease with medical drugs.

However, as this thesis demonstrates, "low use of HIV testing is also largely understood to result from individuals' fears of the health and social consequences of a positive diagnosis. Incidents of social rejection, loss of employment, family disruption, and violence continue to fuel these fears, as they have since the beginning of the epidemic" (Tarantola 2005:40). Additionally, low levels of testing are associated with the "internal dimension of stigma – the fear, self-disablement, feelings of contamination, self-rejection and self-loathing experienced by people with HIV" (Cameron 2007:100). Thus, "addressing the *implications of a positive test result,* including non-discrimination and access to sustainable treatment and care for people who test positive" is a crucial factor for increasing the demand for voluntary HIV testing (UNAIDS Reference Group 2005:43).

Methodology

This study was conducted during 2007 with 15 young adults (between 19-31 years old) from two African townships surrounding Cape Town in the Western Cape province of South Africa. Purposive sampling was used to recruit the 15 participants, for reasons explained below. The majority of participants (10) were drawn from a group that attended a UCT-based health and life skills workshop that I led during 2006 and 2007. The additional participants (5) were recruited from other sources through university and work. All respondents were employed or participated in HIV/AIDS-related activities (refer to table 1 for details). The close relationship I held with each of the participants before the study, and more importantly a relationship that already involved discussions of HIV/AIDS-related issues, facilitated immediate rapport with participants and allowed for intimate discussion of taboo subjects about sex, condom usage, HIV/AIDS, and death.

In addition to my close relationship with each of the participants in this study, a primary motivation for sample selection is reflected in the demographics of the population group (age, population group, residential area), which were kept constant across the sample group to allow for meaningful analysis. Young people between the ages of 25 and 34 have the highest HIV prevalence rates in South Africa (Shisana 2005:34) and "more than half of all new infections globally are in the young people aged 15-24" (Harrison 2005:264). When age is combined with population group (African) and locality type (urban informal), the incidence and prevalence rates for the participants' population groups are incredibly high[7]. Furthermore, the rate of HIV testing among 15-24-year-olds, the age group in which the majority of participants fell, is at 20.8%, well below the national average of 30.3% (Shisana 2005:80). Importantly, however, 14 of the 15 participants in this study had been tested at least once for HIV making them a unique and crucial population. Studying this group can help point to factors that may encourage the uptake of HIV testing.

The semi-structured qualitative interview format enabled the collection of in-depth information about seven main themes: 1) demographic and historical information about each participant; 2) the participant's first encounter with HIV/AIDS; 3) factors leading to the development of their current feelings towards HIV/AIDS; 4) sources where information about HIV/AIDS was obtained; 5) participant's personal testing experiences; 6) participant's ideas about what happens after an HIV test; and 7) participant's evaluation of how to encourage voluntary HIV testing.

The qualitative in-depth interviews elicited a wealth of information regarding HIV and testing. Modified grounded theory (Glaser and Strauss 1967) was used for data analysis and allowed for the generation of new theory on HIV testing behaviour. The information collected in the interviews was grouped thematically and is presented below to structure the new theory. This method of data analysis allows for the generation of theory because "one generates conceptual categories or their properties from evidence; then the evidence from which the category emerged is used to illustrate the concept" (Glaser and Strauss 1967:23). Many of the participants' comments used to form the argument are crosscutting and could fall under several themes.

[7] Prevalence rates for the study population are as follows: for 20-24-year-olds it is 15%, for 25-29-year-olds it is 23.2%, and for 30-34-year-olds it is 24.9%; for Africans the prevalence rate is 13.3%; for urban informal populations it is 17.6% (Shisana 2005:34, 36).

Table 1: Participant Biographical Information and HIV Testing Behaviour

Name	*Gender*	*Age*	*First Language*	*Residential area*	*Hometown/Grew Up*	*Employment status at time of interview*	*Schooling*	*Testing Behaviour*	*Reported HIV status*
Yola	Female	25	Xhosa	Delft/ Belleville	Eastern Cape	Employed	Did not finish high school; failed grade 12	Yes	Negative
Chuma	Male	25	Xhosa	Guguletu	Umtata, Eastern Cape	Employed	Matric 2003; some tertiary	Yes	Negative
Asanda	Male	20	Xhosa	Khayelitsha	Cape Town, Khayelitsha	Employed	Matric; Cape Technikon	Yes, 2 times	Negative
Nondumiso	Female	31	Xhosa	Khayelitsha	Eastern Cape	Employed	Matric; adult education classes	Yes, 1 time	Positive; on ARVs
Thandi	Female	25	Xhosa	Khayelitsha	Eastern Cape	Employed	Langa Finishing School	Yes, 2 times	Negative
Xolisa	Male	20	Xhosa	Lower Crossroads	Pritchard West, Eastern Cape	Unemployed	Matric 2004	Yes, 1 time	Negative
Lebohang	Female	24	Xhosa/ Afrikaans	Mitchell's Plain	Cape Town	Unemployed	Did not finish high school; left in grade 9	Yes, 2 times	Positive, not on ARVs
Nomvano	Female	19	Xhosa	New Crossroads	Cape Town	Unemployed	Matric 2006	No	Hasn't tested
Odwa	Female	19	Xhosa	New Crossroads	Cape Town	Unemployed	Did not finish high school; left in grade 10	Yes, 1 time	Negative
Isaac	Male	23	Xhosa/ Afrikaans	Nyanga	Kimberly, Northern Cape	Unemployed	Matric 2005	Yes, 1 time	Negative
Lihle	Male	20	Sotho	Nyanga	Cape Town, Nyanga	Employed	Did not finish high school	Yes, 4 times	Negative
Lundi	Male	21	Xhosa	Nyanga	Port Elizabeth, Eastern Cape	Employed	Matric 2004; classes at Damelin	Yes, 3 times	Negative
Thobeka	Female	20	Xhosa	Nyanga East	Cape Town	Employed	Matric 2004	Yes, 1 time	Negative
Nopinki	Female	23	Xhosa	Nyanga/ Zwelitsha	Cape Town	Unemployed	Matric 2005	Yes, 1 time	Negative
Philiswa	Female	21	Xhosa	Nyanga/ Zwelitsha	Cape Town	Unemployed	Matric 2004	Yes, 3 or 4 times	Negative

Findings

The perceived consequences of living with HIV, as defined by the study participants, are discussed in the first part of this section. The link participants made between these perceived consequences and the role an HIV test plays in mitigating or exposing one to these consequences is also shown. The second part of this section presents a model that has been developed to explain how an individual balances these consequences in order to make a decision about testing for HIV. The model shows that, provided with an opportunity to test, an individual must be "biased towards testing" in order to voluntarily test for HIV.

The Threats

Analysis of the empirical data identified three different perceived consequences of testing HIV positive and, thereafter, living with the illness. Firstly, participants spoke of the disease-oriented symptoms, the visual and functional changes in the body, and the eventual death due to AIDS. Secondly, they discussed their perception that HIV positive people experienced harmful social reactions from family members, friends, neighbours, and other members of their community. Thirdly, they described the mental collapse, self-rejection, isolation, and depression that they believed was felt by people who learned they were HIV positive. The participants saw these three perceived implications of living with HIV as undesirable, and for this reason, the paper refers to them as "threats." Drawn from the list above, the three threats experienced by an HIV positive person can be conceptualised in the following way:

1. physical threats (physical impact on your body and your functioning organs and the consequences this causes for your life);
2. social threats (social impact of other people knowing you are HIV positive and the negative treatment you receive because of this);
3. psychological threats (psychological impact caused by knowing you are positive and the harmful consequences and realities you believe come with this new identity).

The participants explained how an HIV test served to either mitigate or expose a person to the threats of living with HIV. Participants believed that physical threats were mitigated by an HIV test because the test served as an entry point

for the uptake of HAART and the adoption of healthy living practices that would otherwise be neglected. Conversely, participants also believed that an HIV test exposed an individual to the social and psychological threats that were born out of living with HIV because both public disclosure and private awareness of status resulted from an HIV test. Thus, perceived physical threats can be seen to encourage HIV testing while perceived social and psychological threats can be seen to discourage HIV testing. An individual's bias towards testing is a reflection of which threats are most salient and influential.

Physical Threats

Participants identified a number of physical threats that they perceived to accompany a positive HIV status. Most prominently, they identified death as an outcome of living with HIV. In some instances, this outcome was seen as an inevitable – and final – stage in the progression of infection.

> 'I think, they say there are stages. You've got stage 1, stage 2, there's stage 3, and then if you in stage 4 then you're in AIDS and then you die' (Odwa, 19-year-old female).

Also speaking to the sureness of death, one participant explained the root of her fear of HIV.

> 'I don't want to lie. I'm scared of HIV. [Because] you know every time that one day you are going to die because there is something…you've got virus in your blood' (Yola, 25-year-old female).

Many participants used the topic of death to emphasize the enormous impact of HIV. They did this by explaining who was infected and how many people died due to the disease.

> 'A lot of people are dying because of HIV' (Yola, 25-year-old female).

> 'HIV is destroying what we have, you see. The youth is dying because of it. And what I can see, most of the people who are infected is the youth' (Xolisa, 20-year-old male).

> ‘HIV, what can I tell about HIV? HIV, what can I say, is a serial killer’ (Odwa, 19 year-old female).

Although all 15 participants discussed the link between HIV infection and mortality, death was not the only physical threat that they perceived to be presented by a positive HIV status. Participants were also acutely aware of the opportunistic infections and disease that accompanied advanced HIV infection.

> ‘When you saw people who are positive, some of them, like those they are serious, maybe they are ill. Some of them their feet, they can’t even walk because their feet are painful’ (Yola, 25-year-old female).

> ‘I used to [see] somebody with HIV/AIDS and it was difficult for him even to eat because... his throat was sore. So at that time everybody, everybody if you got HIV/AIDS, we know the symptoms, your hair look lighter and you become thinner’ (Lundi, 21-year-old male).

In two instances, participants equated the experience of living with advanced HIV infection to images of a small baby. In each case, the image conveyed frailty and vulnerability. One participant described the experience of her aunt’s HIV infection.

> ‘I remember when we left her; we were in south western [Namibia], in Windhoek. She was so fat but when she came here she was so thin... She’s almost looking like a small baby in the bed. And she was sweating and got lots of spots on the body... and started being couldn’t take care of herself. She was like a small baby’ (Lebohang, 23-year-old female).

Another participant talked about pictures he had seen while participating in a community project about HIV/AIDS.

> ‘But I remember the picture. This girl was in between 16 and 14. She was as small as a baby. A newly born baby, you see. They were showing a picture before and then they were showing a picture after, when she had this virus. And she was small in the bed’ (Lihle, 20-year-old male).

Death, disease, and helplessness due to opportunistic infections were acutely felt physical threats that participants associated with HIV infection. Virtually all participants had experienced the death or sickness of a family member or friend

due to AIDS, and therefore the prevailing association between death and HIV held true despite the fact that only two participants were HIV positive, only one of which had experienced opportunistic infections.

Significantly, participants responded to these perceived physical threats by stressing the importance of routinely testing for HIV.

> 'People must go test. I think you test twice a month, I mean, twice a year... every six months' (Odwa, 19-year-old female).

On one hand, HIV testing was widely viewed as a crucial part of living a healthy lifestyle and provided both infected and uninfected individuals with the opportunity to make informed choices about their own health.

> 'Go there and check your status knowing that, if you are positive or negative, this is the precaution that I have to take now that I know my status. Regardless of negative or positive. Now I know my status. This is what I have to do now in order for me to live a good life regardless of the status. Negative or positive' (Isaac, 23-year-old male).

More importantly, however, an HIV test was seen as a direct way of combating the physical threats that participants attached to HIV infection. Testing sometimes initiated safer sexual behaviours such as condom usage and, in the case of a positive diagnosis, could encourage an individual to eat healthily, stop drinking or taking drugs, and start exercising. An HIV test also mitigated disease and death because ARVs, which garnered huge support among the participants, were available for those who tested positive but could only be accessed if one knew his or her status.

> 'Because the thing that is happening now, you know, because there are many people that is HIV and AIDS; if you go to the clinic you will get some treatment and will go to be better' (Nopinki, 23-year-old female).

Antiretrovirals were overwhelmingly advocated by the participants and accounted for their assertion that AIDS was not inevitably a fatal illness. While HIV was sometimes associated with death, HIV testing was seen as a way to empower people against death particularly because of the availability of ARVs. One participant went so far as to suggest that not testing for HIV was dangerous to one's health because it meant that one could not access ARVs.

> ‘Not knowing your status is very dangerous. You just find yourself you’re already AIDS. And then not HIV now. [If you know your status, you can] go to the clinic and ask for ARVs or the pills that just can, [help you] stay normal, you see? Not get sick’ (Xolisa, 20-year-old male).

Participants perceived the physical threats of living with HIV to include death, disease, and helplessness due to opportunistic infections. In order to avoid these outcomes, they stressed the importance of regular HIV testing because knowing one’s status allowed for the management and treatment of sickness and the prolonging of life. Across the board, an HIV test was associated with increased physical health and the reduction of physical threats caused by HIV infection.

Social Threats

In addition to physical threats, participants perceived a number of social threats that an individual experienced when he or she was HIV positive. One prominent theme that surfaced in the interviews was the perception that HIV positive individuals were avoided and isolated by other members of their family or community.

> ‘Many people from where I live, the thing is, when you have the disease, they tend to isolate you. They don’t want to associate themselves with you… [They do that] by trying to avoid you. Like, when you come, they will go away. They don’t want to talk with you’ (Asanda, 20-year-old male).

Sometimes participants explained that this avoidance was due to fears that one could contract HIV by sitting next to someone who was infected[8]. Other participants stated that there was a belief that HIV positive people were “dirty” or “wrong” and were therefore labelled as “HIV positive” and subsequently avoided.

> ‘What I've seen happening, like where I live in, there are some people who are labelled as a flag ... they have HIV…It’s like you are wrong; you are dirty or something. There’s something wrong with you; you are not as equal as some other person’ (Thobeka, 20-year-old female).

[8] Many participants maintained that this view was still prevalent in the areas where they lived, although all would agree that it was an “uneducated” view and incorrect.

Linked to avoidance and isolation, participants also explained the rejection that HIV positive people could experience. This usually happened when someone disclosed his or her status to a sexual partner, but someone could also be rejected by family members.

> 'So you try to tell your partner [you have HIV]. It's hard. It's very hard. Just because they kick you, they could kick you out of the house, you see' (Xolisa, 20-year-old male).

> 'And some of the people don't feel comfortable being HIV [positive]. They are afraid... to speak to others 'cause they think they would be judged by others…The thing that you'd be scared of is being laughed at by those ones you told that you are HIV positive. And maybe dumped by your family. Yeah. And being alone' (Nomvano, 19-year-old female).

Fear of rejection and of being alone was compounded by the fear of being personally blamed for contracting HIV. Blame and judgement were social threats not only because they reinforced labelling and rejection, but also because they dismantled necessary care or support that could come from others.

> 'Like in most cases people they don't, [people are] still blaming those people who are HIV positive. They were not faithful enough to their partners. If they saw somebody positive, maybe some of them they are laughing at them and they're saying nasty things about them' (Yola, 24-year-old female).

> 'Some, they are afraid of the community. Some of them, they talk a lot... For example, if you've got TB, yeah, TB is also dangerous, serious. If you've got TB, they thought that you have AIDS. That is why some people don't want to get tested. Yeah, some be judging you. Yeah, they didn't console you' (Chuma, 25-year-old male).

Participants expressed the social damage caused when one's HIV status was public knowledge. They also described the desires of many people to avoid the isolation, gossip, rejection, and blame for being HIV positive. Thus, unlike the physical threat posed by HIV, the social threat experienced by HIV positive individuals discouraged testing. It would be reasonable to assume that HIV testing itself does not expose individuals to the social threats associated with being HIV positive because VCT is presumed to be confidential. However,

participants often perceived disclosure of status as an inevitable consequence of HIV testing and thus believed an HIV test exposed one to social threats.

Participants demonstrated two main reasons why voluntarily testing for HIV exposed an individual to the social threats of being HIV positive. Firstly, participants spoke frequently about the experience of being tested and how counsellors or nurses at clinics gossiped and judged HIV positive people. This meant that even if HIV positive individuals did not disclose to other people such as friends or family members, they were still blamed for contracting the virus, their status was not kept confidential, and the community often found out they were HIV positive.

> 'They don't want to [get tested], some of them. Maybe they go test, you see, and then they go to the clinics [in Cape Town], you see, because if they're in the clinics here in KTC, maybe some of them know the nurses there that [are] going to [test you], you see, and they ashamed of themselves. They say... that nurse will tell the people that "oh, she's HIV positive"' (Odwa, 19-year-old female).

Participants perceived health care workers administering HIV tests to be untrustworthy. They were afraid of being judged and they feared that if they were diagnosed with HIV, the nurses would gossip about them at the clinic or in the communities where they lived. This judgement and gossiping by the VCT nurses meant that testing could expose one to social threats even if they did not disclose their own status to friends, family, or the community.

Secondly, even in instances where nurses or counsellors did not judge or gossip about their clients, a person who was testing for HIV risked being seen by others at a local clinic, and this would also expose him or her to social threats.

> '[My friends said], "I'm not going to do it in our local clinic. I'd rather go pay," because the people here, they will tell you that you are HIV positive, and then when you get home, everyone knows about your status. That you are HIV positive' (Lihle, 20-year-old male).

Participants explained that clinics had a special area for people who were testing for HIV or receiving ARV treatment and this meant that even if one did not disclose his or her status, the community would eventually find out anyway.

> 'I think they are scared about some other people seeing them go to the clinic and take some tablets because in Nyanga clinic, here, there is a

> side for people that have HIV/AIDS. And everybody is knowing that side. So I think some of them they are scared to see that' (Nopinki, 23-year-old female).
>
> 'People who go for HIV, they know the rooms which they are going [to]. And then if someone sees me that I'm going through that room, I'm going for my HIV treatment and they know from that day that I'm HIV positive… And some, they don't want to go for a treatment, like, they will be sharing their status to the whole world if they go to a clinic and go for ARVs' (Thobeka, 20-year-old female).

The social threats of living with HIV involved those consequences of sharing one's status with others. Isolation, rejection, and blame were associated with being HIV positive, and an individual could be exposed to each of these consequences after testing for HIV.

Psychological Threats

The third perceived threat that was found through an analysis of the empirical data was the psychological threat associated with learning that one was infected with a highly stigmatised disease. The clearest indication that HIV infection was perceived to lead to psychological damage was the witnessing by many participants of the mental, rather than physical, destruction that HIV positive people experienced.

> 'I don't know how to put this, but, the impact that AIDS is making in a lot of people's lives is it's destroying them, like mentally more than physically, so that's why they are demotivated' (Asanda, 20-year-old male).

The mental impact of HIV infection was also demonstrated through the participants' perception that many HIV positive people lacked a personal acceptance of their status. Personal acceptance was perceived by participants to be different from acceptance by family members and friends.

> 'I think HIV... it's a very big problem in our community where I live in because... there are many people who are infected with it and some of them do know that they have HIV but it's hard for them to accept it' (Thobeka, 20-year-old female).

One participant spoke about his two HIV-positive uncles and explained how the difference in their reactions to an HIV positive diagnosis affected their survival outcomes. This example is discussed in greater detail below as a case study.

> 'The [uncle] who is still alive, the main reason he's still alive is he did accept that he's gotten AIDS. And he used to drink but he stopped. He didn't smoke. He didn't smoke. The other uncle, he didn't accept it. And he ended up dead' (Chuma, 25-year-old male).

Living with HIV was also perceived to bring internal shame – a psychological threat – on those who were infected. Three participants explicitly suggested that people were afraid to find out they were HIV positive because they were afraid to admit that they had knowingly exposed themselves to HIV.

> 'Maybe she was fooling around and ... [her] parents, they are trying to stop her on that, for doing that. So... she will be afraid... to came back to tell [her] parents "I'm HIV." She will know that [her] parents will say to her you, "now we told you that you must stop doing this." So I think that's one of the reasons for people to hide this' (Lundi, 21-year-old male).

> 'Some of the parents are strict, like "Don't do this, do this," but when you're older now you say "I'll do this, I'll do this." But your father *did* tell you not to do this or you will get HIV and AIDS. Sometimes you are going to be too afraid to tell your parents [that you have HIV], you see' (Xolisa, 20-year-old male).

In these two instances, parents are perceived as chastising rather than supportive, with punitive statements like "I told you so" when they learned of their child's HIV-positive status. Rather than merely demonstrating a social threat, however, these instances demonstrate the psychological impact of internal shame from having knowingly made an unwise decision.

Like the social threats of being HIV positive, perceived psychological threats also discouraged HIV testing. This is demonstrated in the participants' perceptions of the reactions HIV positive people had to their positive diagnosis. Participants frequently stated that, upon learning their status, many HIV positive people subsequently engaged in unhealthy behaviour. For instance, Lebohang suggested that HIV positive people would choose to spread the disease for fear of dying alone.

> ‘When you talk to most of the people, they think... “I’m HIV, I’m going to die soon so let me rather spread this disease and not use condoms…” Most of the people do that. They tell you they won’t die alone and we will all die together’ (Lebohang, 23-year-old female).

It was also believed that many people committed suicide after learning that they were HIV positive.

> ‘And they are afraid of their results too. Some of them, [when they get tested] they just commit suicide. Commit suicide’ (Xolisa, 20-year-old male).

> ‘But some, they don’t want to find out. They know that if they find out they got AIDS, they [will] just kill their selves’ (Chuma, 25-year-old male).

Furthermore, personal knowledge of an HIV positive status was perceived to be very stressful and could lead to further health problems and even death.

> ‘Most of the time your CD4 count is also about stress, stress makes your CD4 count drop’ (Lebohang, 23-year-old female).

> ‘My brother and sister passed away at an early age… they had too much on their mind, worries, things that they could have wished to have done in their lives but now they will never be able to do it again. I think that’s one of the ways that made it worse for them to pass on. [On an] actual physical level. It was... hurting them emotionally, there was no way they could have things straight... In that way, they lost weight and all that stuff, like, all the symptoms can gather on one position’ (Isaac, 23-year-old male).

Participants stressed the damaging, often deadly, impact that negative thinking had on the prognosis of HIV and AIDS. For this reason, many participants suggested that the damage due to the psychological threats of knowing one was HIV positive was great enough to discourage HIV testing and knowledge of status. To cement the fear of the psychological damage of learning one’s status, one participant explained that it was impossible to know how one would react to the HIV test result. This reinforces the beliefs of many participants who stated that sometimes it was “better not to know” that one was HIV positive.

> ‘I don’t know whether it is easy to tell somebody else... Right now, I don’t know whether I am positive or I am negative. Maybe right now I think I am strong. I think that if maybe tomorrow I can find out that I am positive, I thought I [was] going to tell my family but when that time comes I don’t know whether I am going to be strong… That it is why I am saying that we are expecting too much from those people and we don’t know the pain’ (Yola, 25-year-old female).

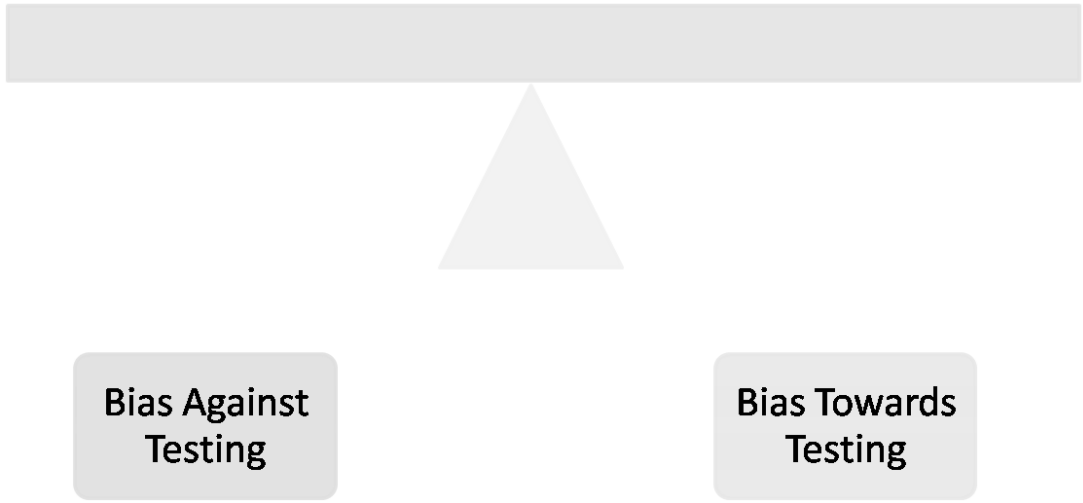
The psychological threats of living with HIV included mental collapse, lack of personal acceptance leading to ill health and death, and internal shame. Once individuals were tested for HIV, they became aware of their status and were exposed to these threats. Ill health caused by stress, desires to spread the disease, and thoughts of suicide were consequences of the psychological threat presented by living with HIV.

In summary, the findings indicate participants believed that physical threats of HIV/AIDS (such as opportunistic infections and death) could be managed through healthy living and the commencement of ARVs, both of which were initiated only after an HIV test. Conversely, participants perceived the act of testing to expose HIV positive individuals to the social and psychological threats associated with AIDS, created through the public or private acknowledgement that one was infected.

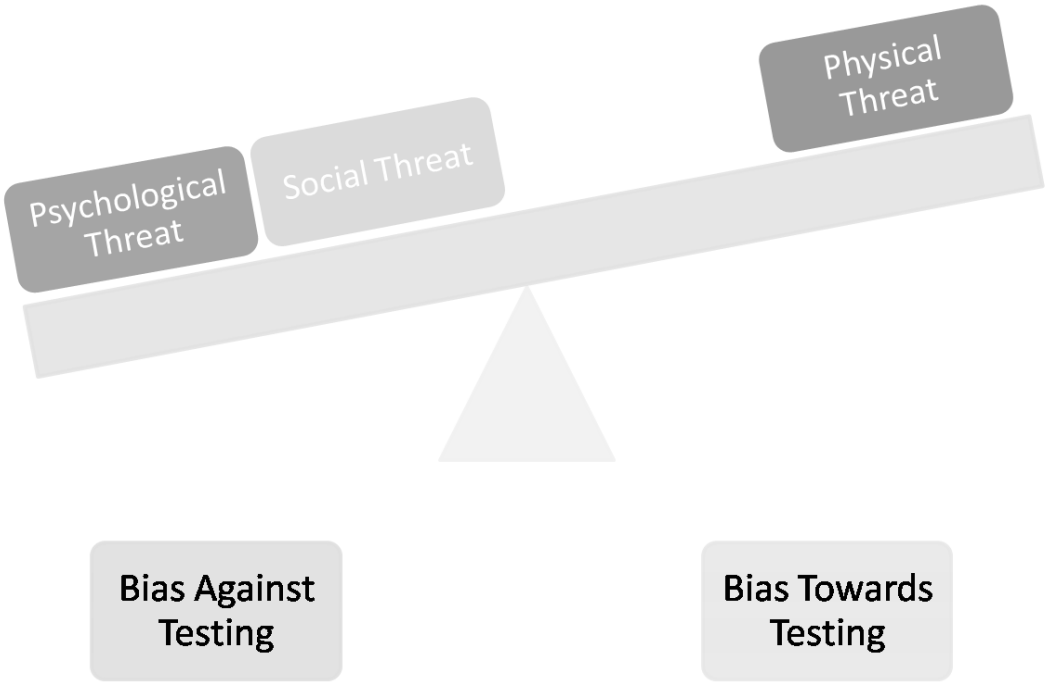
The Threat-Balance Model: Finding a Bias Towards Testing

This section proposes a model for understanding the relationship between the perceived physical, social, and psychological threats of being HIV positive and the impact HIV testing has on mitigating or exposing one to these threats.

Using the visual image of a balance, the threat-balance model shows how the differing weights of each threat tip the balance in one direction or the other, either biasing an individual towards testing or against testing for HIV. When an individual has a bias towards testing, and testing services are available, he or she will test for HIV.



To echo the empirical data collected in this study, this model places social and psychological threats on one side of the balance and physical threats on the other. This is because social and psychological threats have a similar effect on testing behaviour, and both have an opposite effect to physical threats. For example, when the balance is tipped to the social and psychological threats, signifying that the damage due to social and psychological threats is perceived as greater than the damage due to the physical threats, an individual will be biased against HIV testing. This is illustrated in the diagram below.



When the model is tipped towards the physical threats on the right, suggesting that the individual perceives the damage due to physical threats to outweigh the perceived social and psychological threats, an individual will be biased towards testing for HIV.

An individual's perception of the likelihood and severity of each of these three threats in their own lives determines whether or not they will be biased towards testing. Thus, testing behaviour can be conceptualised as a balancing act, a weighing of risks and benefits, between the physical, social, and psychological threats that are perceived to affect people living with HIV.

Understanding the interplay between physical, social, and psychological threats requires two related processes. The first process focuses on an individual's perception of each threat. Individuals will vary in their perception of the likelihood and severity of the physical, social, and psychological threats, as well as the impact that an HIV test will have on either mitigating or exposing them to damage. The variations in perception of the threats, when viewed in relation to one another, serve to explain the initial position of the balance, biased either towards or against testing. The second process observes the point at which the balanced shifts from a bias against testing to a bias towards testing, caused by a change in perception of one or all of the threats, understood here as the "tipping point." Thus, it is the *change* in perception of threats over time that fuels the tipping point. The sample group used in this study is particularly well suited for exploring this 'tipping point' because 93% of the group had 'tipped' towards testing at a particular point in their lives, as explored in each of the interviews.
To illustrate the variation in perception of the three threats of being HIV positive, as well as the point at which an individual becomes biased towards testing, participants' individual testing stories will be examined through two case studies.

Case Study #1: Thobeka

Thobeka is a 20-year-old female from Nyanga East. She was born in Cape Town and has lived in Nyanga all her life. She lives with her mother, uncle, sister, and cousin. Her mother's sister and two children sometimes come to visit Thobeka and her family in Nyanga.

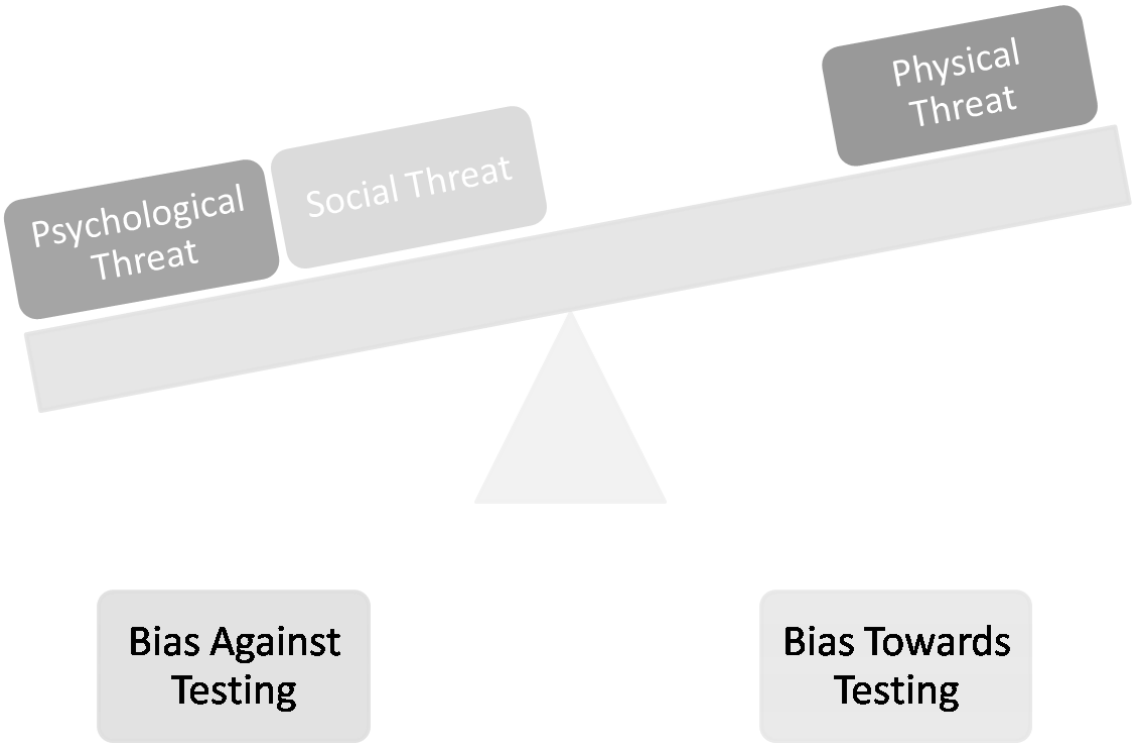
Two of the five people in Thobeka's house are HIV positive. She also has an aunt who is infected and an uncle who recently died due to AIDS. Considering this experience, she describes her feelings about HIV/AIDS below:

> ‘Like for me, I don’t judge anyone who is HIV positive because I had an uncle who died in January with HIV/AIDS and I could not, I did not insult him at home... There was some people who did not want to accept [him]. And now I’m living with two people at home who are HIV positive... They are still the same person as you are it's just that they have the virus… nothing changed with them.’

In addition to having an intimate experience with AIDS in her home and with her family, Thobeka was optimistic about the outcome for those who were living with AIDS. She believed that with personal acceptance of status, healthy living, and ARVs, an HIV positive person could survive a long time and sometimes even outlive an HIV negative person. Part of Thobeka’s acceptance of HIV/AIDS and her strong belief in HIV testing may have resulted from her uncle’s death. Thobeka described what her uncle told her before he died.

> ‘My uncle, before he died, he said to us, he told us not to be ashamed of him and we must tell everyone why, what caused his death. We must explain what HIV is and talk and that he died of HIV and that he is not ashamed of it himself so that he can die happier and willingly.’

Thobeka’s perception of the social and psychological threats that one was exposed to by being HIV positive were considerably low. She had an accepting family that openly discussed HIV/AIDS-related topics. She believed that HIV positive people were no different from HIV negative people. Her knowledge of the physical threats presented by HIV, and subsequent benefits of testing, was also high. However, it is clear from Thobeka’s testing story, shown below, that her perception of the physical threats was not strong enough initially to outweigh the perceived social and psychological threats also associated with having HIV. The threat-balance model representing Thobeka’s initial state is represented in the figure below:



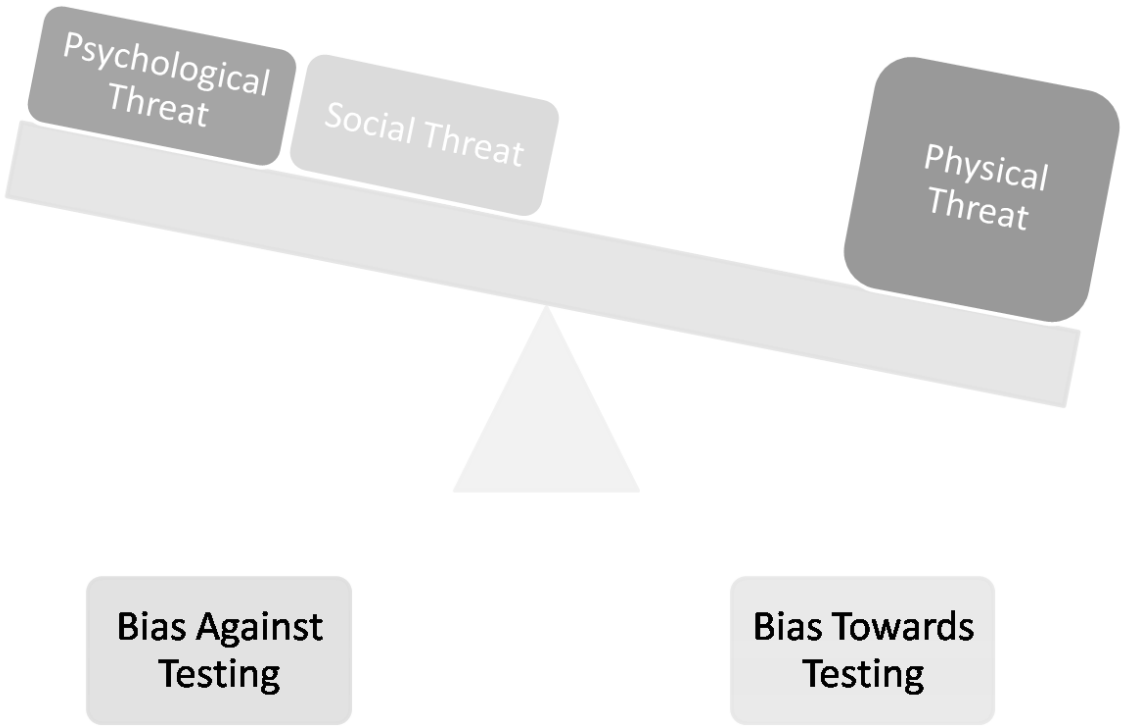
Thobeka describes the moment when this changed for her.

> 'The reason why I choose to go get tested… When I found out that my uncle was HIV positive there was nothing great for me to go get tested. But when my sister, my mother's sister told me that she was HIV positive and her kids were HIV negative, then I thought, if the kids were also HIV positive, what would [that] put me in? That is, what would my status be? Then from that day when she told me, explained to me that she is HIV positive and she is happy that her kids are not HIV positive, I decided to go get tested so that I had to know my status.'

Although she was aware of the physical threats of being HIV positive and she had low perceived social and psychological threats because of the strength and acceptance of her family, it was not until she felt a personal likelihood of infection that she decided test for HIV. The likelihood of infection increased for Thobeka when she considered the possibility that someone her age could also be infected with HIV. This highlights that Thobeka may have perceived generational differences for the physical threat of HIV infection. In her reactions to the negative test result, it is clear that Thobeka perceived a very high likelihood of the physical threat for herself at the time she decided to test.

> ‘I was very scared, I was very scared… I thought, like, what if I’m HIV positive? Like already, let’s say, half of my family is HIV positive and there is a possibility that I might be HIV positive too. I was very scared really. I won’t lie. Even when the counsellor told me my results I was very shocked, I was very shocked.’

Thobeka’s tipping point from an individual bias against testing to an individual bias towards testing resulted from the heightened likelihood of the physical threat posed by HIV infection. The model below represents the change in her perception of the physical threat:



This is the point when Thobeka chose to test. Her perception of the physical threat increased to a point where it outweighed any social or psychological threats that she may encounter if she were HIV positive.

A second case study shows a different testing tipping point. Unlike Thobeka’s tipping point, which happened through a change in the physical threat, the next case study shows the impact of a reduction in the perceived social threats of living with HIV.

Case Study #2: Chuma

Chuma is a 25-year old male who grew up near Umtata in the Eastern Cape. He defines his hometown as a "rural area." Chuma moved to Guguletu, Cape Town a year ago and lives now with his brother. Some of his sisters live in Cape Town but the majority of his large extended family still lives in the Eastern Cape. He goes back to visit them a few times a year, particularly during the holidays. His girlfriend also lives in the Eastern Cape.

Many of the members of Chuma's family are nurses. At least four of his sisters or aunts are nurses, which he stated while explaining that he had learned a lot about HIV/AIDS at home from his family. Chuma has also had family members who were infected with HIV. In particular, Chuma spoke of two uncles who had contrasting stories of HIV infection. He described why he believed one of his uncles died.

> 'I had an uncle who had AIDS. But he died. Yeah. I spoke to him how easy [it] is, you know, and my uncle, he didn't want to accept that he had AIDS. He ended up using alcohol, smoke cigarettes, and used to smoke dagga. Also he didn't want to eat his treatment. And he ended up dead.'

Despite claiming that he did not know very much about HIV/AIDS before moving to Cape Town because he grew up in a rural area that had limited access to information, Chuma was aware of the methods of HIV prevention and believed in the possibility for survival through using ARVs and practicing healthy living. These healthy behaviours included using condoms during sex, going to the clinic or to get counselling, "talking about it," and "accepting it." From witnessing one uncle die of AIDS, he was aware of the opportunistic infections that were associated with the advanced stages of HIV. However, he also witnessed an uncle survive with HIV over an extended period of time so he was optimistic that HIV infection did not always signify death.

Chuma's experience of getting tested highlights a different shift in perception from the tipping point observed in Thobeka's story above. He first explains that he did not personally choose to get tested for HIV, but rather was forced to go to the clinic by his girlfriend.

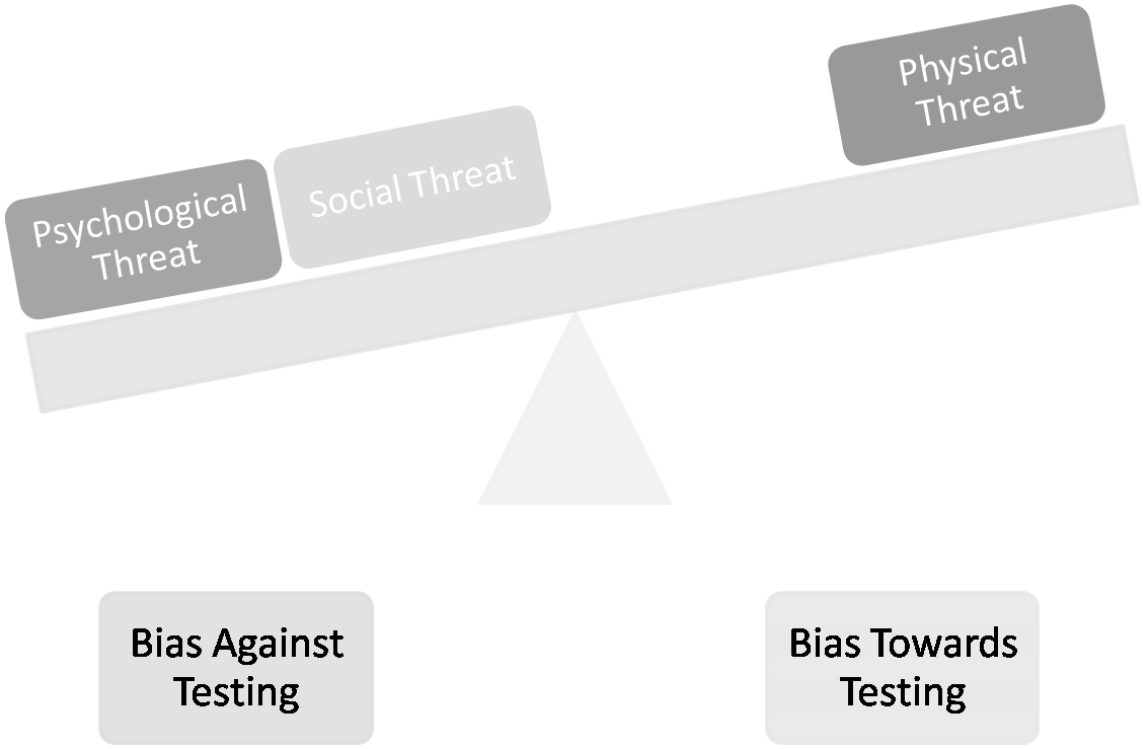
> Chuma: Firstly, I didn't want to. But I've got a girlfriend. So she forced me to go test with her. So that is why I went. But I didn't want to.

> Hannah: [How] did she force you to [test]?
> Chuma: She said if I really love her, I should go with her to get tested. So I thought about that... [In the waiting room of the clinic], I thought to change my mind. To not get tested. Yeah. But for the sake of my girlfriend...

When he reflected on why he did not want to be tested, he cited his fear of acknowledgement of a positive status, driven, in part, because he did not know whether or not he was infected with HIV. He had also explained during his interview that he had had concurrent sexual partners, in addition to having sex with his girlfriend, and that he did not always use condoms. Chuma explained that he would be ashamed if he were diagnosed with HIV after knowingly engaging in unprotected sexual behaviour. Below, Chuma talks about his fear of acknowledging he could be HIV positive.

> 'I was afraid. I was afraid of getting tested because I didn't know that I had [HIV or not]. I didn't know about my status.'

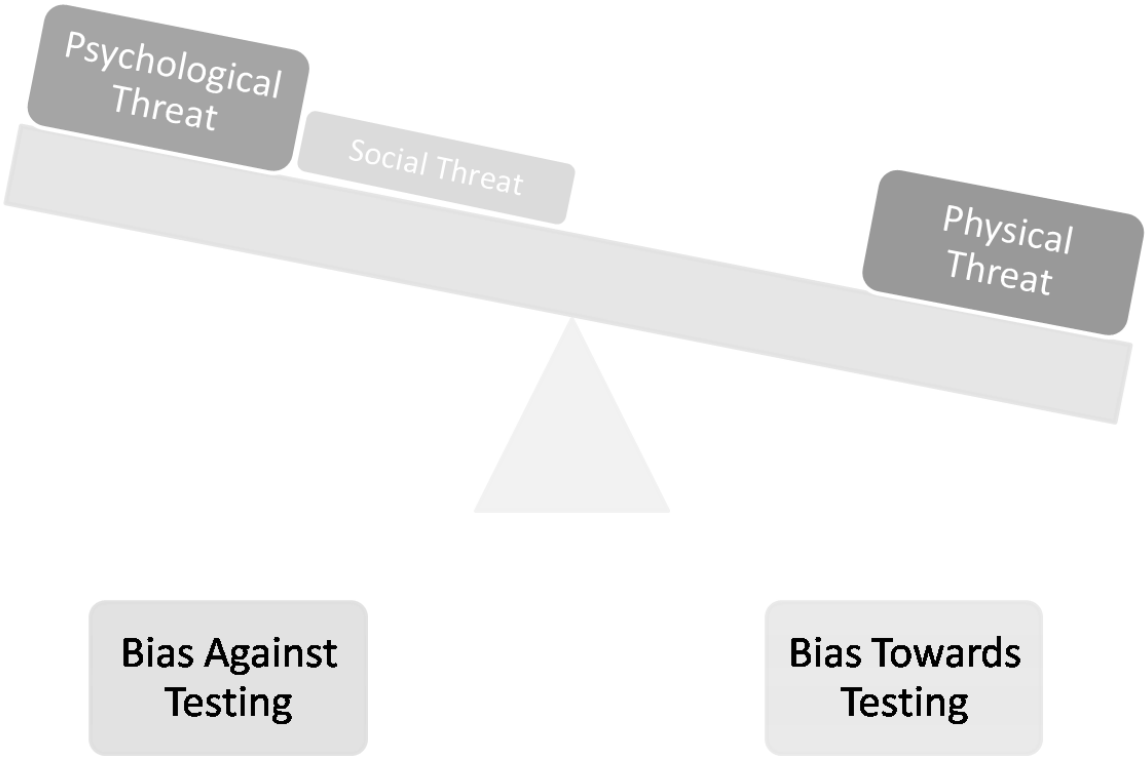
From Chuma's story, it appears that his perception of the physical threat was strong, given his experience of a dying uncle and the knowledge he gained from the nurses in his family. It also appears that Chuma perceived a strong psychological threat to being diagnosed with HIV, learned from his experience with his HIV-positive uncle who did not accept his status and died as a result. Although he also perceived a physical threat associated with living with HIV, it was not strong enough to bias him towards testing for HIV. Here is a model representing Chuma's perception of the threats before he tested for HIV:



Only through his explanation of what allowed him to go through with the HIV test does Chuma's tipping point become clear. In the waiting of the clinic, Chuma describes what happened just before he tested.

> '[My girlfriend] was close to me. She sat next to me. Wow. And put [her arms around] my body. She hug me… Also, [she said] it doesn't matter if we have AIDS 'cause she will always be there for us.'

The expression of love and support from his girlfriend, regardless of the outcome of his HIV test, reduced Chuma's perception of the social threats of living with HIV. The lifting of perceived social threats, while his perceptions of the psychological and physical threats of HIV remained the same, was enough to shift Chuma's threat-balance in the direction of a bias towards HIV testing. The model below represents Chuma's change in perception of the three threats at the time he chose to test for HIV.



As is evident from both of Chuma's models, a reduction in the social threat of being HIV positive enabled Chuma to voluntarily test for HIV.

Discussion

This section explores the three threats discussed above – physical, social, and psychological – and the variable effects they have on HIV testing. Physical threats, which are mitigated through testing, encourage VCT. Social and psychological threats, which are presented through testing, discourage VCT. The findings are discussed through the lens of the body of work on HIV testing and health seeking behaviour.

First, the findings are considered in light of the literature on the potential barriers to HIV testing – lack of access to testing services, lack of knowledge about HIV/AIDS, lack of ARV provision, and high levels of HIV-related stigma – discussed at the beginning of this paper. Thereafter, the value of a biopsychosocial approach to HIV testing is complemented with a review of the threat-balance model.

The participants from Nyanga and Khayelitsha suggested that lack of access to VCT was not an inhibiting factor in their own choices around testing. In addition to citing numerous places where HIV testing was offered, 14 of the 15

participants had tested at least once (and some participants had tested up to four times) before the time of interview. While this study cannot support "limited access to VCT" as a useful explanation for low testing rates in South Africa (Matovu and Makumbi 2007; Weiser, Heisler, et al. 2006), it is evident that individuals must have the ability to test for HIV so that when the balance tips from being biased *against* to being biased *towards* testing, they can carry out this action.

Contrary to literature suggesting that there is a lack of awareness regarding HIV/AIDS and HIV testing (Department of Health 2003), participants in this study showed they had detailed and comprehensive knowledge of the physical threats and the clinical implications of HIV infection. High levels of knowledge about HIV were also evident in the participants' descriptions of opportunistic infections, their knowledge of how to take ARVs and why they worked, and the important role that early and regular testing had on disease prognosis.

Importantly, participants also revealed a great deal of knowledge regarding the perceived negative social and psychological consequences of being infected with HIV. They witnessed or had heard about the social isolation that sometimes followed an HIV positive diagnosis. Siblings or relatives had been "dumped" by their partners after revealing their HIV status. Participants experienced the depression or mental "destruction" of family members who could not cope with the psychological stresses of living with HIV. One participant described how his uncle "ended up dead" because he did not accept his own status and another described how her sister's life was "just miserable" because she could not come to terms will her illness. They observed the frailty and helplessness of people suffering from opportunistic infections. The image of a "small baby" surfaced repeatedly and was used to describe aunts, teenagers, and friends. This caused the participants to feel an acute sense of vulnerability attached to HIV infection and they acknowledged the shame associated with not being able to care for one's self or having to rely on others for life support.

The nuanced understandings of HIV prevention and the dual role that ARVs have in mitigating physical threats and exposing one to social and psychological threats demonstrate that participants, in fact, had *multiple* kinds of knowledge. Findings from this unique sample group, with an exceptionally high rate of VCT, critique the link between increased biological and clinical knowledge of HIV and increased levels of HIV testing. As demonstrated above, the participants' decisions to test for HIV were not a response to increasing levels of knowledge regarding AIDS or ARV treatment but rather a decision based on their cumulative experience of the perceived physical, social, and psychological consequences of living with HIV. Certain types of knowledge may encourage

uptake of HIV testing, while others can discourage testing. Thus, rather than a lack of knowledge, low levels of testing may be due to conflicting types of knowledge.

In corroboration with the literature, provision of ARV treatment was not only a crucial benefit of, but also as a motivation for, VCT, as treatment was seen as the primary method for mitigating the physical threat of being infected with HIV (Asante 2007; Galvão 2002; Mfundisi, et al. 2005). Furthermore, participants stressed the importance of testing early and regularly for HIV, as they were aware that the effectiveness of ARVs was dependent on the stage of HIV infection during which individuals were initiated on treatment. Recognition by the study participants that HIV testing could lead to ARV treatment interventions illuminates the potential barrier to testing that is created through a lack of access to treatment, as discussed in the literature (Day, et al. 2003; Nattrass 2003). The frequency with which participants incorporated the topic of HAART into discussions of the benefits of voluntarily testing for HIV suggests that availability and access to ARVs are important for encouraging HIV testing and that lack of access may indeed be a barrier to the uptake of VCT. However, as supported in the literature, it was clear from discussions of the social and psychological threats presented by HIV testing that the provision of antiretroviral treatment did not simply function to mitigate the physical threat and therefore cannot necessarily be seen to encourage the uptake of testing (Gilmore and Somerville 1994; Kalichman and Simbayi 2003). Attending public health care facilities and standing in designated "ARV treatment queues" at the clinic transformed ARVs as way to mitigate the physical threat into a means of exposing an individual to the social threats also attached to living with HIV. It is for this reason that tasking HIV positive clients with the responsibility of adhering to ARV treatment in the absence of efforts to reduce the social and psychological threats associated with being positive amounts to "unsound public health practice" (Tarantola 2005) and will ultimately be unsuccessful (Robins 2006). Furthermore, it highlights how important it is to consider personal experiences when understanding an individual's choices and motivations for managing their health.

The importance of addressing stigma surrounding an HIV positive status surfaced frequently in the interviews and was depicted by the social and psychological threats one could be exposed to after a positive HIV test result. As is consistent with the literature, fears of discrimination, social isolation, rejection and abuse were motivations not to test for HIV (Hutchinson, Mahlalela, and Yukich 2007; Kalichman and Simbayi 2003). So, too, was the psychological threat, echoed in the literature, of the "paralyzing dread of

confronting HIV" within one's self that exists even when there is no fear of discrimination or rejection by friends and family (Cameron 2007:100). The perceived threats resulting from public exposure and private awareness of status suggest that stigma is, in fact, a deterrent to VCT. However, the sources of this stigma highlight the complexity of the issue. Social stigma was perceived to come not only from neighbours, community members, and sometimes family, but also from the health care workers administering HIV tests, calling into question the proposed benefits of increasing confidentiality, and therefore protection from public exposure, of the testing process. VCT, then, also exposes one to the social threats – discrimination and blame, spurred on by gossip – which originate from health care practitioners. Furthermore, the psychological threat that was identified by participants describes a personal or internal stigma, the source of which is less understood and may be harder to combat.

> 'The most inaccessible, the most intractable element of stigma is the disfiguring sense of shame that emanates from the internal world of someone with HIV or AIDS. This sense colludes with external shame, overcoming efforts to deal with the disease rationally, keeping those with AIDS or HIV in involuntary self-imposed isolation, casting a pall of contamination and silence over the disease' (Cameron 2005:70).

Thus, the difficult task of combating stigma within communities affected by AIDS and HIV must extend beyond community relations to the health care sector and others who define disease and illness, as well as reach HIV-positive individuals on a personal level by challenging their internal devaluation.

Because analysis of the findings highlights three threats associated with HIV infection (physical, social, and psychological), a biopsychosocial approach to health (Engel 1977) is a useful model for understanding HIV testing behaviour. When deciding to test for HIV, the participants in this study did not simply consider the effects that HIV infection had on their physical health. Thus, unlike the biomedical model which "views the body as a machine and the disease as damage to it, the doctors' function being to repair the injuries caused" (Nascimento-Schulze, Garcia and Arruda 1995:2), a biopsychosocial model of health takes into consideration social and personal experiences when understanding testing behaviour. Given that participants *did* perceive a physical threat to living with HIV, the threat-balance model demonstrates that individuals use multiple paradigms of disease and illness, including biomedical understandings, to create a more holistic approach to health. This disrupts the notion that HIV infection can be polarised into "biomedical disease" and "social

experience of illness," a finding supported by the literature (Hahn 2001; Kleinman 1980; Tarantola 2005). Individuals are nuanced, complex, and varied in the ways they think about their own health.

The value of the threat-balance model is not simply its recognition of the multiple factors that affect the decision to test for HIV, but the interplay *between* these factors, the balance – the tug-of-war, so to speak – for and against testing as a form of health-seeking behaviour. Examples of this balance are evident in other literature about HIV testing; a report from Botswana shows the battle between stigma (which deters testing) and ARVs (which encourage testing):

> 'Many of them – most still, it will seem – are deeply reluctant to [get government-supplied drugs]...because they fear they will be identified as having AIDS. So they postpone it for as long as possible. They fall sick first. Even then they delay. They eventually go and stand in the clinic's queues. But mostly they do so only when they are approaching the point of death' (Cameron 2005:67).

As consistent with this report, testing was a crucial in each participant's mind for mitigating physical threats, but it also had the potential of initiating social and psychological threats. When these latter threats were strongly felt, testing was no longer viewed *only* as a way of mitigating potential dangers of HIV infection but rather came as an unwanted pathway to undesirable outcomes. Especially in circumstances where an HIV positive person was not physically ill with opportunistic infections, HIV testing was seen to create more dangers than it mitigated. Only when the physical threat was absolutely unavoidable did patients seek medical assistance.

The threat-balance model is significant because it demonstrates that interventions targeted at only one part of this model, such as expanded ARV treatment that promises to mitigate the physical threat, do not consider the weight of other threats that also influence an individual's decision to test. Similarly, efforts to increase confidentiality within testing services must also understand the social threat presented by the relationship between nurse and patient or the psychological threat to which one is exposed merely through learning of one's HIV status, neither of which is reduced through increased confidentiality.

Importantly, this model also helps to highlight a missing link in the debate between VCT and PITC as a means to increase rates of HIV testing (Cameron 2005; De Cock 2005; Heywood 2005), and that is whether testing itself is the

marker of future prevention, care, and survival. Statistically, "if the end goal of [routine HIV testing] is to test a larger proportion of the population, it has succeeded" (Kenyon 2005:22). However, it is not the test *per se* that allows for prevention and treatment interventions to take place, but the personal and social environment for the individual after he or she receives a positive test result. It is thus important to understand not only the effects of different testing methods (voluntary or routine), but the various threats that a person may face following an HIV-positive test result.

Conclusion

This paper has explored HIV testing behaviour among a group of young adults from Cape Town, South Africa. The participants interviewed for this study comprised a unique study sample, with 14 of the 15 (93%) participants having tested for HIV in a country where the population average for those who have been tested is roughly 30% (Shisana et al. 2005). By interviewing young South Africans who had chosen to voluntarily test for HIV, this study has been able to explore participants' understandings and experiences of HIV/AIDS in their daily lives both before and after they had tested for HIV and is thus able to demonstrate the relevant factors that contributed to their uptake of VCT.

This study found that individuals considered a range of factors (not limited to ARV treatment) when deciding whether or not to test for HIV. As shown above, participants identified a number of threats that they perceived to be associated with HIV infection. Their decisions of whether or not to test can be explained by observing how an HIV test impacted upon each of these threats. Participants identified physical threats presented by HIV infection. They perceived death to be closely linked with AIDS and all but one participant had experienced a family member or close friend die of AIDS. Many participants also listed opportunistic infections in their description of HIV infection. These, too, had often been experienced by people close to the participants. Study participants identified social and psychological threats that one may be exposed to when living with HIV. Social isolation, rejection, and blame were perceived by participants to follow an HIV positive diagnosis. Many gave anecdotal evidence of people they knew who had been rejected by sexual partners after revealing their HIV positive status. The participants were acutely aware of the gossip that circulated around their communities. Although many disputed the rumours that were spread about HIV positive people, gossip was viewed as a negative and damaging consequence of living with HIV. In addition to these social threats, participants identified mental destruction, lack of personal acceptance, internal

stigma, and shame to be psychological threats that a person was exposed to when living with HIV. They often attributed the death of family members from AIDS, in part, to the stress and depression that accompanied personal awareness of an HIV positive status. Psychological threats were personally significant to some participants even though they had not tested positive for HIV because they were aware that it was difficult to predict how one would react to a test result. For this reason, it was the possibility of mental destruction, self-rejection, thoughts of suicide, and loneliness that guided their decisions around testing.

Observation of the impact that testing had on either mitigating or exposing one to these threats adds depth to the experience of HIV testing. Participants had a strong sense that VCT was a way of reducing the physical threats associated with HIV infection. They were well versed in the details of ARV treatment and gave powerful stories of the possibility of survival and optimism in spite of HIV infection. Testing was a crucial factor in each participant's mind for mitigating physical threats. Conversely, testing had the potential of initiating the social and psychological threats they associated with living with HIV. This dynamic meant that testing did not always mitigate the potential dangers of HIV infection. It could also serve to create social and psychological dangers, which were sometimes perceived as greater than the physical consequences of the infection itself.

The threat-balance model illustrates three threats perceived by study participants and the impact that an HIV test had on either mitigating or exposing an HIV positive person to these threats. It also demonstrates how individuals view health and illness. Unlike biomedical models of health that function to separate the physical body from the social and psychological experience of illness, the threat-balance model incorporates both disease and illness-oriented factors when understanding health-seeking behaviour. This model was born out of the experiences and stories of the participants in this study.

This paper recommends that in order to increase the rates of voluntary testing and counselling and, more importantly, the subsequent opportunities for HIV prevention and provision of ARV treatment, all three perceived threats posed on HIV positive people must be addressed. While continued reduction of the physical threat through HIV testing (ARV treatment, healthy living, condom usage, etc) must be emphasised, this study has shown that similar attention should be spent on reducing the social and psychological threats that one is also exposed to when living with HIV.

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