

**Alternative Beliefs about HIV/AIDS:
Re-examining Distrust among Young Adults in Cape Town, South
Africa**

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Declaration of Authorship

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Abstract

Alternative beliefs about HIV – such as the man-made origins of the virus or the secret existence of a cure - can undermine trust in, and engagement with HIV prevention and treatment initiatives. These effects make understanding such beliefs an important component of responding to HIV/AIDS in South Africa. Echoing Robins' observation that the current era allows for "the possibility of critical reflection on the ways in which contestations over scientific truth unfold under particular historical conditions" (2009a), this thesis seeks to reconsider dominant explanations for alternative beliefs about HIV/AIDS in South Africa.

Previous studies maintain that the experiences of apartheid, the transition to democracy, and the early years of the new government have had permanent implications for the public's trust in biomedical claims. In this thesis I argue that in addition to these explanations, individuals express distrust about HIV science because certain aspects of these scientific explanations do not 'add-up', particularly when considered in light of their everyday observations and experiences. These disjunctures in information do not simply reflect a lack of HIV knowledge or rejection of scientific principles. Rather, in drawing on past and present experiences, individuals demonstrate their commitment to "street-level epistemologies of trust" (Hardin 1992), an informal manner of empirically engaging with science's rationale.

Employing the Public Understandings of Science (PUS) framework to analyze these beliefs, this study conceptualizes trust and mistrust of scientific and official claims about HIV along a spectrum. Study participants endorse a range of alternative beliefs and knowledge about HIV/AIDS. They cite experiential and observational reasons to justify why they trust some authority figures and not others. In their role as trusted sources of information about HIV, peer educators with the Treatment Action Campaign draw on various "rhetorics of persuasion" (Robins 2009b) in order to lend practical plausibility to their claims. Ultimately, this study argues that respondents' distrust of HIV science should be seen less as a rejection of scientific principles and more as a form of skeptical engagement with certain aspects of these scientific claims.

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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ANC	African National Congress
ARV	antiretroviral
AZT	Azidothymidine
CAPS	Cape Area Panel Study
CHA	Community Health Advocate
CSSR	Centre for Social Science Research
FGD	Focus Group Discussion
HAART	Highly Active Antiretroviral Treatment
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council (South Africa)
MK	<i>umkhonto we Sizwe</i>
MMR	measles, mumps, rubella
MSF	Medicins Sans Frontieres
MSM	Men who have Sex with Men
NGO	nongovernmental organization
PEP	post-exposure prophylaxis
PreP	pre-exposure prophylaxis
PMTCT	Prevention of Mother-to-Child Transmission
PUS	Public Understandings of Science
SANCO	South African National Civic Organization
TAC	Treatment Action Campaign
TLP	Treatment Literacy Practitioner
TLP	Treatment Literacy Programme
TRC	Truth and Reconciliation Commission
UCT	University of Cape Town
USPHS	United States Public Health Service

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Chapter One: Introduction

HIV/AIDS in South Africa

South Africa remains the second worst affected country in the world with regards to HIV/AIDS. National antenatal prevalence is approximately 30% (UNGASS 2012). The 2012 Human Science Research Council (HSRC) Household Survey reported that national prevalence has increased, from 10.6% in 2008 to 12.3% in 2012 (Malan 2013) and that approximately 6.4 million people are currently living with HIV and AIDS in the country. The HSRC study also estimated that approximately 2 million people are now on ART, up from around 1.8 million people who were estimated to be taking antiretrovirals in 2011 (Mayosi et al. 2012). The increase in prevalence is attributed to the government's expansion of the antiretroviral programme (Malan 2013).

As the epidemic has spread, so governments, international non-governmental organizations (NGOs) and civil society groups have implemented interventions to tackle prevention, treatment, and care. Inevitably, while some interventions have succeeded in their objectives, others have not, raising questions about barriers to success. In the early years of the epidemic, access to treatment and clinical care was clearly a factor, with services largely concentrated in the urban centers and a chronic shortage of health care workers. The challenges of accessing services could be viewed as symptoms of "an unlucky geography" (Steinberg 2008a, 199). However, in recent years, increasing numbers of health centers offer HIV testing and antiretroviral (ARV) treatment and support (Mayosi et al. 2012; UNGASS 2012).

Even with these improvements, there are those who do not access prevention or treatment services (Cornell et al. 2011; Steinberg 2008a; Campbell 2003). Though myriad reasons exist to explain poor uptake or loss to follow-up, a recent *Lancet* article stated that, "One of the biggest obstacles to HIV prevention and treatment is poor knowledge or denial about HIV status and the associated risk (Mayosi et al. 2012, 2030). The *Review of the South African AIDS Epidemic* found that correct

knowledge about preventing sexual transmission of HIV and correct identification of misconceptions about HIV transmission actually decreased significantly between 2005 and 2008 (Shisana et al. 2009). These misconceptions included the existence of a cure for AIDS, the role of witchcraft, the link between HIV and AIDS, and the idea that sex with a virgin can cure AIDS (Shisana et al. 2009). A number of studies have highlighted these challenges, suggesting that a range of alternative beliefs about HIV/AIDS, including the possible conspiratorial origins of the virus or the existence of a cure, are endorsed by certain segments of the population (Bogart, Skinner, et al. 2011; Grebe and Nattrass 2012; Nattrass 2012a; Tun et al. 2012). The prevalence of these beliefs raises the question of whether alternative beliefs or misconceptions about HIV/AIDS are undermining South Africans' participation in these programmes.

To the extent that alternative beliefs have been measured, the evidence to date suggests that certain alternative beliefs about HIV/AIDS in South Africa are associated with lower likelihood of condom use (Bogart, Skinner, et al. 2011; Tun et al. 2012; Grebe and Nattrass 2012), lower likelihood of HIV testing (Bogart, Kalichman, and Simbayi 2008; Tun et al. 2012; Skinner et al. 2012), and lower rates of uptake of antiretroviral medication (Lennon and Kalichman 2012). In light of these findings, Skinner and colleagues remarked that alternative beliefs about HIV/AIDS "need to be considered in the development of HIV interventions" (2012).

In the context of these findings, this thesis focuses on understanding the reasons why these beliefs are plausible to some South Africans, offering a reinterpretation of alternative beliefs in the context of contemporary South Africa. My own interest in this question arose during my master's programme at the LSE. My MSc dissertation focused on the origins and impacts of the polio vaccine boycott in northern Nigeria, and concluded that communities' previous experiences of neglect by the government and exploitation by western pharmaceutical companies influenced their current distrust of polio vaccination campaigns (Rubincam 2008). I became

interested in exploring the underlying roots of distrust in health programmes such as HIV/AIDS, as well as how best to respond to such distrust.

Following the completion of my MSc programme in Fall 2007, I spent a year as a visiting research fellow at the Health Economics and HIV/AIDS Research Division at the University of KwaZulu Natal in Durban, South Africa. While conducting research and living in South Africa, I became curious about what Fassin calls “the exceptionality of AIDS in South Africa” (Fassin 2002). To Fassin, this exceptionality refers to the high prevalence of the virus in South Africa as well as the manner in which the former head of state, Thabo Mbeki, had become a pariah in the eyes of the domestic and international AIDS community for his stance on HIV/AIDS. Mbeki infamously questioned the link between HIV and AIDS and implied that the scientific consensus about HIV was suspect because of its association with western power and pharmaceutical profit (Nattrass 2007; Geffen 2010). Mbeki’s stance motivated a powerful challenge from AIDS activists and organizations both within the country and abroad (Geffen 2010). Also notable was the way in which this stance, and the polarization between the AIDS dissident and biomedical communities it engendered, rendered many research topics about HIV/AIDS unusually sensitive. Such sensitivities make up part of what Robins means when he refers to the “other less visible casualties” (Robins 2009a) of the struggle over the scientific governance of HIV/AIDS in South Africa.

As one might expect, the country’s unique experience with political AIDS denialism has had several lasting legacies for the practice of HIV research. First, it introduced a nervousness in relation to research on alternative and traditional treatments for HIV that might not have existed to the same extent without this historical backdrop (Nattrass 2008). This arose because the Minister of Health until 2009, Manto Tshabalala-Msimang, openly supported traditional treatments for HIV and denigrated the efficacy and safety of antiretroviral medication. Robins describes how activists adopted a “techno-fundamentalist” position towards HIV science as a direct consequence of “government lethargy in relation to supporting AIDS

treatment, as well as the actions of AIDS dissident thinkers within government and unsubstantiated claims by traditional leaders that they could cure AIDS” (2009b, 100). The second legacy of political AIDS denialism is that it made research on public distrust and skepticism about HIV science uniquely fraught. At times, there seemed to be an implication that those trying to comprehend AIDS denialism or distrust of the scientific consensus were in danger of losing objectivity and were themselves appearing to endorse (or at the very least, apologize for) denialism¹.

When I was first living in South Africa in 2008, I became aware that this was a country where these sensitivities were starting to change. Writing in 2009, Robins’ notes how the shift from Mbeki’s to Zuma’s administration offered “the possibility of critical reflection on the ways in which contestations over scientific truth unfold under particular historical conditions” (2009a). Thus this study was conceptualized and undertaken in a period of particular significance for the study of alternative beliefs about HIV/AIDS – both conspiratorial beliefs as well as those merely distrusting or questioning the scientific consensus about HIV/AIDS.

The international community’s preoccupation with Mbeki’s stance has influenced how subsequent doubts and distrust among the South African public are interpreted and studied. When studies are published showing that alternative beliefs about HIV/AIDS remain prevalent in post-Mbeki South Africa, these beliefs are often attributed, at least in part, to his poor political leadership when in power (Geffen 2010; Tun et al. 2012; Bogart, Skinner, et al. 2011). As Tun and colleagues observe, “with messages from high-profile public figures contradicting evidence-based information from HIV researchers and the medical community, it is hard for the average South African to glean accurate HIV prevention information” (2012, 459).

¹ As an example of both of these legacies in action, a roundtable discussion in mid 2010 at the University of Cape Town focusing on the topic of traditional medicine and HIV treatment swiftly became a hotly contested debate between an activist from the Treatment Action Campaign (TAC) and several anthropologists about the appropriate way to study alternative beliefs (University of Cape Town 2010).

Distrust among the South African public is also interpreted in the context of the country's unique historical experience. Given the 46-year history of enforced racial segregation under the apartheid system, with associated laws governing freedom of movement, access to education, voting and basic services, one group of researchers concluded that alternative beliefs are "not surprising particularly in light of the history of apartheid" (Tun et al. 2012, 463). Fassin points to the manner in which South African history is "embodied", meaning "the way in which individual and collective histories are transcribed into individual and collective bodies" (Fassin 2007, 65). "This history", Fassin and Schneider assert, "still remains deeply present to many South Africans and explains much of the mistrust towards Western science, medicine and public health" (2003, 497).

South Africans are thus often represented as dominated by the long shadow of apartheid, as victims of President Mbeki's campaign of obfuscation and denial while in power, or as bit players in the "David and Goliath narrative" in which "heroic AIDS activists successfully fought against the might of the South African state and the global pharmaceutical industry" (Robins 2009a). This account makes the majority of the South African population largely passive participants in interpreting and responding to the HIV epidemic in their country.

This thesis offers a reinterpretation of these conceptualizations by examining the reasons for alternative beliefs about HIV/AIDS in a field site in contemporary South Africa. In using a Public Understanding of Science framework rather than the more dominant tradition of conspiracy belief studies, it also explores alternative beliefs that extend beyond the narrower frame of 'conspiracy beliefs', to include beliefs that express distrust, skepticism, open-mindedness, confusion and doubt. I adopt this frame of reference as a way of describing the problematic with which I am engaged for the following reasons: (a) it avoids the epistemological problem of identifying a body of knowledge or an idea as a conspiracy – which would itself have to be researched as an empirical question rather than assumed and which is not the focus of this study, and which raises further questions about the way such language can be

used to discredit those who hold certain alternative beliefs; (b) it uses the terms “public” and “understanding” to recognize that the empirical problem here is that there is a truth – albeit scientific, peer reviewed, open to constant examination and therefore always only provisional – about which “understanding” by a “public” for whom it has health and welfare implications is the research problem.

Research aims and questions

Echoing Robins’ observation that the current era allows for “the possibility of critical reflection on the ways in which contestations over scientific truth unfold under particular historical conditions” (2009a), this thesis seeks to reconsider dominant explanations for alternative beliefs about HIV/AIDS in South Africa. This is not intended to obscure or negate the role of Mbeki’s denialism or of the history of apartheid but rather to situate these two bodies of explanation in the context of contemporary South Africa; in other words, if apartheid continues to exert an influence on distrust of the scientific consensus around HIV/AIDS, why and how is this experience articulated? How do South Africans make sense of Mbeki’s stance now that he has left office? And what other sources of distrust exist for South Africans in a post-Apartheid, post-Mbeki era?

I argue in this thesis that in addition to the experiences listed above, individuals express distrust about HIV science because certain aspects of those scientific explanations are not ‘adding-up’, particularly when considered in light of their everyday observations and experiences. These disjunctures in information do not simply reflect a lack of HIV knowledge or rejection of scientific principles. Rather, in drawing on past and present experiences, individuals demonstrate their commitment to “street-level epistemologies of trust” (Hardin 1992), an informal manner of empirically engaging with science’s rationale.

Previous studies have conceptualized certain forms of distrust about HIV science as “conspiracy belief” (Lennon and Kalichman 2012; Tun et al. 2012; Grebe and Natrass 2012; Natrass 2012a; Clark et al. 2008; Hutchinson et al. 2007; Ross,

Essien, and Torres 2006; Russell et al. 2011). This thesis argues that by focusing on expressions of distrust as “conspiracy beliefs”, researchers have obscured the extent to which most individuals express doubts about HIV science as agnostics rather than as conspiracy theorists. The aim is thus to highlight the spectrum of distrust and trust among the study population rather than to regard all expressions of distrust as conspiratorial and somewhat static.

This conceptualization has important implications for how one responds to distrust. If those who distrust the scientific consensus about HIV/AIDS are viewed as all committed AIDS conspiracy theorists and denialists, unlikely to concede and uninterested in alternative viewpoints, there are few opportunities or incentives for policy makers, researchers, and activists to engage with them (Sunstein and Vermeule 2009). If, however, individuals are open to new information and express ambivalence and skepticism about HIV science rather than outright rejection, it opens up the possibility for such individuals to be engaged by programmes, interventions and other people. Therefore, a further aim of this study is to explore what sources of information about HIV/AIDS are most highly trusted by respondents.

Once these trusted sources of information and the mechanism by which trust is built have been identified, the question remains: what type of intervention is best suited? A range of possible strategies has been suggested, from basic knowledge enhancement to culturally-appropriate outreach (Bogart, Skinner, et al. 2011). This study aims to highlight the strengths and limitations of a particular form of engagement used by the Treatment Action Campaign’s peer educators. These individuals work in their own communities to increase health literacy about basic HIV concepts and boost public trust in HIV prevention and treatment programmes.

This thesis makes several empirical contributions. First, to the Public Understandings of Science corpus of scholarship: there is a dearth of research situated in the developing world on how people judge the plausibility of scientific

claims. This study contributes to a more detailed understanding of the factors shaping a particular public's engagement with and trust of HIV prevention and treatment programmes. Second, this study contributes to scholarship on contemporary South Africa. As noted above, most studies of public distrust of HIV/AIDS in South Africa have drawn on two dominant explanations: public distrust is a reflection of the experience of Apartheid and/or the confusion sown by Mbeki and his administration. This study draws attention to the ways in which these explanations continue to play a significant role in public distrust, as well as highlighting additional factors, such as disjunctures in information. Third, in relation to conceptualizations of distrust: this study highlights how most individuals are not committed AIDS denialists or conspiracy theorists but rather 'HIV/AIDS agnostics', searching for indications of trustworthiness in the world around them.

In order to accomplish these aims and make these contributions, this study asks three main research questions:

1. What are the reasons for the plausibility of alternative beliefs about HIV/AIDS among the South African public?
2. What individuals and organizations are trusted sources of information about HIV/AIDS in contemporary South Africa?
3. What sorts of strategies are being employed, on the ground, to advocate on behalf of HIV science to a population without high levels of scientific literacy?

Examination of these questions form the main content of chapters 4, 5, and 6 of the thesis.

Thesis outline

This thesis is divided into 7 chapters. Chapter two outlines the empirical and theoretical literature on alternative beliefs, highlighting the benefits of using the

Public Understandings of Science (PUS) framework to explore how trust and distrust are formed with reference to historical and contemporary observations, and in relation to individuals and institutions.

Chapter 3 details the methodological considerations underpinning the approach taken and the methods used to collect, analyze and interpret the data in this study, particularly the use of multiple and mixed methods to access various complimentary and contradictory viewpoints.

Chapter 4 is the first of three empirical chapters. It focuses on the nature of, and reasons for alternative beliefs about HIV/AIDS among respondents. This chapter argues that alternative beliefs are rarely expressed in purely conspiratorial terms, and that these beliefs can be better understood as reflections of daily experiences, past history, endorsement of alternative explanations about HIV by members of the elite, and disjunctures in information about the virus. Chapter 5 explores trusted sources of information about HIV/AIDS for this population. Findings suggest that those in public service roles – doctors and nurses, as well as activists – are the most trusted, whereas those seen to possess self-interested motives – traditional healers and politicians – are least trusted. Political reputations are explored in more detail and contradictions between academic/activist and the South African public's view of certain politicians are discussed. The final empirical chapter – Chapter 6 – presents an analysis of the strategies used by of one specific trusted group – peer educators from the Treatment Action Campaign (TAC) - to advocate on behalf of HIV science. These data reveal that peer educators face challenges in communicating with members of the public and are forced to employ various “rhetorics of persuasion” in their discussions.

Lastly, Chapter 7 concludes with a discussion of key policy and practice recommendations, focusing on the importance of clear, concise information that addresses historical abuses and present-day disjunctures in information. It highlights the potential for political leaders to either worsen or helpfully address

alternative beliefs about HIV/AIDS as well as outlining how the internet can be used by activist and academic communities to reinforce the scientific consensus about HIV/AIDS.

Chapter 2: Approaches to alternative beliefs about HIV/AIDS

Introduction

This chapter introduces theoretical and empirical approaches to the study of alternative beliefs about HIV/AIDS. It is divided into four sections. Section 1 begins by outlining the existing research on alternative beliefs about disease in general and HIV/AIDS specifically. Section 2 highlights the predominance of certain explanations for alternative beliefs in South Africa, hinging particularly on the ‘embodied’ memory of the apartheid state and the more recent obfuscation and AIDS denial by Thabo Mbeki and his supporters. Section 3 identifies conspiracy theory as a dominant approach to the study of alternative beliefs and specifies why it is less useful for this research than an alternative. Section 4 introduces Public Understandings of Science (PUS) as the analytical approach taken in this study, and highlights its advantages as an approach to view mistrust in health care providers, the health care system, and the state.

Section 1: Studying Alternative Beliefs

In his book *Bad Science*, Ben Goldacre asserts, “If the scientific method has any authority – or as I prefer to think of it, value – it is because it represents a systematic approach, but this is valuable only because the alternatives can be misleading” (2010, 172). These alternatives involve perceiving patterns where there are none, and using intuition to reason informally. As Goldacre observes, detecting patterns and drawing from intuitions are perfectly adequate for assessing issues in the social domain, such as whether one’s business or romantic partner is trustworthy. “But for mathematical issues, or assessing causal relationships, intuitions are often completely wrong, because they rely on shortcuts that have arisen as handy ways to solve complex cognitive problems rapidly, but at a cost of inaccuracies, misfires and oversensitivity” (2010, 185).

After identification of the problem to be explored, the scientific method involves systematically searching for evidence in the most unbiased manner possible.

Scientists strive for rigorous, replicable results by including certain safeguards against bias in their experiments. In the classic double blind experimental design, scientists blind their studies by concealing from both participants and researchers the identities of those who have received an intervention from those who have not. They also randomize their participants by recruiting people for treatment without reference to their personal characteristics or health status. In doing so, they ensure that any differences observed in the experiment are the result of the treatment and not of the researchers' or participants' bias.

Evidence-based medicine uses the scientific method to determine the best treatment for a given disease. For all the seeming simplicity and straightforwardness of this approach, the scientific method and its applications for human health are difficult to understand. It involves setting aside one's biases, even those of which one is barely conscious (Banaji and Greenwald 2013). It involves trusting the expertise of others who have conducted the experiments and tests on one's behalf. In his study of one man's reluctance to test for HIV in South Africa, Steinberg writes about a conversation he has with his protagonist about HIV science. When asked for his account of where HIV comes from, he describes an endemic animal virus called SIV that spread to humans, and the social and economic conditions that make southern and eastern Africa disproportionately affected. In his next remark, he acknowledges how much of this account is based on trust in others' expertise:

I tell him that this is the story I have accepted for the moment, that it comes from a reservoir of knowledge I have passively inherited rather than chosen, something that is just in the air around me, as witchcraft is in the air around him, that I myself have next to no expertise in these matters, and that the story is by no means adequate, that almost everything about it is provisional" (2008a, 230).

Steinberg highlights how trust in this context requires believing in claims that are often difficult to comprehend and seemingly counter-intuitive for a non-scientific audience. Concepts such as causality and risk are difficult to convey. Causality (*a* causing *b*) is often conflated with association (*a* and *b* occurring at the same time). Risk can be difficult to communicate and easily misconstrued, with words such as “rare”, “unlikely”, and “common” signifying different levels of risk to patients and physicians (Lipkus and Peters 2009; Berry et al. 2003).

Trust in medical experts, such as doctors and scientists, is essential if one is to accept their proposed treatments such as pills, vaccines, or surgery. However, past abuses within health care have impacted negatively on public trust in medical interventions and health care professionals: Examples include the Tuskegee Syphilis Study, in which 399 African American men with syphilis were left untreated for 40 years by the US Public Health Service (Thomas and Quinn 1991; Freimuth et al. 2001; Jones 1981); and the Vioxx scandal, where data that a painkiller found to increase patients’ risk of heart attack was hidden from the public by the pharmaceutical company Merck (Nattrass 2012a; Goldacre 2010). These are but two prominent examples illustrating that the testing and delivery of biomedicine is, at times, far from evidence-based and less than ethical.

Whether people experience poor treatment at the hands of a specific physician, learn about unethical medical trials from a newspaper or history book, or simply encounter confusing or contradictory explanations for scientific phenomena, the effect can be similar: individuals often approach science and medicine with a certain degree of skepticism or doubt (Corbie-Smith, Thomas, and St. George 2002; Thrasher, Earp, and Golin 2008; Hoyt et al. 2011; Ford et al. 2013; K. J. Roberts et al. 2005; Kaler 2009). The danger, of course, is that certain historical experiences can become such a pervasive and all-encompassing part of the way a population thinks about its own history that they create an a priori expectation of conspiracy, abuse, or neglect where none might actually exist. Goldacre argues that though mistakes and abuses exist, they should not undermine one’s trust in the scientific method:

“Terrible things happen in medicine, when it goes right as well as when it goes wrong... Doctors can be awful, and mistakes can be murderous, but the philosophy driving evidence based medicine is not” (2010, 147–8). With any health intervention, however, there is a balance of risks between benefit and harm, and people make decisions about their own health based on experiences, observations, and interpersonal trust as much as a careful review of, or trust in, the scientific evidence.

The difficulty of approaching a health issue from a purely scientific perspective is even greater when that issue is an incurable disease that can only be managed and controlled with long-term therapeutic interventions. Though HIV is not alone in stimulating alternative explanations of disease, the HIV virus and resulting epidemic have spawned distinct and powerful meanings and interpretations around the world. Indeed, Paula Treichler suggests that HIV/AIDS has spawned two epidemics, “simultaneously an epidemic of a transmissible lethal disease and an epidemic of meanings or signification” (1999, 11). While the first epidemic is understood to spread through blood, through needles, between lovers, and between mothers and their children, the second epidemic is expressed in people’s beliefs and explanations about where HIV comes from, how it spreads, what is the best form of treatment, and whether it can be cured. These meanings include AIDS as “an irreversible, untreatable, and invariably fatal infectious disease that threatens to wipe out the whole world”, “a creation of biomedical scientists and the Centers for Disease Control to generate funding for their activities”, “a CIA plot to destroy subversives” and “an imperialist plot to destroy the Third World” (Treichler 1999, 12).

These alternative perceptions and beliefs about HIV are not uncomplicated, innocuous ideas without consequences. Indeed numerous studies have found that individuals who distrust the biomedical consensus may be less likely to adopt recommended public health behaviours promoted in HIV prevention and treatment programmes. For example, individuals who believe that HIV is a man-made virus are less likely to use condoms (Grebe and Nattrass 2012; Bogart, Skinner, et al. 2011),

less likely to have an HIV test (Steinberg 2008a; Tun et al. 2012; Bogart, Kalichman, and Simbayi 2008), less likely to take-up antiretroviral medication (Lennon and Kalichman 2012), and less likely to adhere to anti-retroviral treatment (Bogart et al. 2010). The belief that “vitamins and fresh fruits and vegetables can cure AIDS” was associated with lower intentions to use condoms among men (Bogart, Skinner, et al. 2011), while those who held a range of alternative beliefs about HIV had a lower likelihood of reported condom use (Tun et al. 2012).

Alternative beliefs about HIV are not endorsed solely by members of the public in developing countries. In several countries around the world, individuals with social and political clout have supported views differing from the biomedical consensus, lending these beliefs “additional purchase in the public imagination” (Nattrass 2012a). Wangari Maathai, a Kenyan Nobel Peace Prize winner, publically declared that the virus was created by “evil minded scientists” as an act of “biological warfare” to kill black people (The Economist 2004). During the 2008 US presidential elections, a tape was aired showing Jeremiah Wright, Barack Obama’s pastor, condemning the US government for deliberately spreading the virus among marginalized groups (Wright 2003). President Yahya Jammeh in the Gambia claims he possesses a cure for AIDS and treats infected individuals in the Presidential Palace (Cassidy and Leach 2009). But perhaps the most destructive instance of elite endorsement of alternative beliefs about HIV occurred in South Africa, under former President Thabo Mbeki. Several publications have outlined the contentious history of Mbeki’s HIV/AIDS policies in South Africa (Nattrass 2007; Nattrass 2008; Nattrass 2012a; Geffen 2005; Geffen 2010). What follows is a brief summary of these more comprehensive studies.

Political Denialism in South Africa

In 1996, Anthony Brink, an attorney and employee of the German ‘AIDS cure’ manufacturer Matthias Rath², drew former President Mbeki’s attention to AIDS dissident websites (Sparks 2003, 286). Beginning in 1997, former President Mbeki and then-Minister of Health Dr. Mantombazana Tshabalala-Msimang began endorsing pseudo-scientific theories about HIV and AIDS. They also supported unethical research on an industrial solvent to treat HIV (Geffen 2010; Natrass 2012a) and convened a Presidential AIDS Advisory Panel in 2000 with equal numbers of AIDS denialists and orthodox scientists (Geffen 2005; Natrass 2007). Mbeki delivered a controversial speech at the opening ceremony of the 12th International AIDS Conference in Durban 2000 where he restated that not everything could be “blamed on a single virus” (Mbali 2004, 105).

Subsequently, Mbeki made several public statements questioning the link between HIV and AIDS, claiming that HIV could not cause AIDS because “a virus cannot cause a syndrome” (Mbali 2004, 105), and suggesting that AIDS is a CIA and pharmaceutical industry plot to sell toxic AIDS drugs and discredit his government (Barrell 2000). Even after Mbeki formally withdrew from the public debate about AIDS denialism in April 2002, Tshabalala-Msimang continued voicing AIDS denialist views, warning about the harmful toxicity and side effects of antiretrovirals. She advised that instead of antiretrovirals, HIV positive individuals should take natural remedies, traditional medicines, or foods such as garlic and beetroot (Geffen 2005; Geffen 2010), suggestions that have been widely criticized and lampooned in South Africa and abroad³.

² Rath is a German vitamin manufacturer who claims to be able to cure HIV and AIDS. He conducted unethical trials on residents of Khayelitsha, was taken to court by the Treatment Action Campaign, and is now banned from advertising his remedies in South African newspapers (Geffen 2010; Goldacre 2010).

³ One of the best-known critics of Tshabalala-Msimang’s stance is the political cartoonist Jonathan Shapiro aka Zapiro. His representations of Tshabalala-Msimang were published in several weekly publications in South Africa including the *Mail and Guardian*, the *Sowetan*, and the *Sunday Times* newspapers. For some examples, see: (Zapiro 2004; Zapiro 2003).

Numerous studies attempt to make sense of Thabo Mbeki's controversial position on HIV and AIDS (Mbali 2002; Mbali 2004; Fassin and Schneider 2003; Posel 2005; Natrass 2007; Natrass 2008; Natrass 2012a; Kenyon 2006; Gumede 2005; Gevisser 2007; Youde 2005; Butler 2005), questioning whether his beliefs are a product of 'cognitive dissonance' arising from incompatibilities between science and government priorities (Kenyon 2008), a continuation of his African Renaissance project of 'self-determination' (Gevisser 2007), an expression of deeper anxieties and uncertainties about South African nationalism (Geffen 2010; Natrass 2012a), an instrumental calculation of what kind of health care the government could afford (Natrass 2007; Fourie 2006; Butler 2005; Mbali 2004; Mankahlana 2000 in J. Cohen 2000), or a response to the history of racist colonial and apartheid discourses concerning African sexuality (Mbali 2004; Fassin 2007; Cassidy and Leach 2009; Youde 2005; Cameron 2005). Certainly, it seems evident that Mbeki and his supporters did not view orthodox HIV science "as the product of neutral, rational and universal scientific inquiry, but rather understood HIV science as the products of historically constructed and politically-driven processes embedded in specific histories of colonialism, apartheid and capitalism" (Robins 2005, 114).

Beyond exploring Mbeki's rationale for HIV denialism, scholarly inquiries have interrogated the impact of Mbeki's denialism on South African public trust in HIV science. These impacts should be judged in addition to the primary impacts of Mbeki's denialism, namely, the evidence that approximately 365,000 lives were unnecessarily lost because of his intransigence about HIV and AIDS (Chigwedere et al. 2008; Natrass 2008). In Mamphela Ramphele's⁴ words, Mbeki's denialism was "irresponsibility bordering on criminality" (Schoofs 2000).

⁴ Ramphele is a South African activist, doctor, academic and former Managing Director of the World Bank. She helped to found the Black Consciousness Movement alongside Steve Biko, and in 2013, she launched a new political party *Agang* to contest the national elections against the African National Congress.

Speculating about the extent of the 'long shadow' cast over AIDS science by the stance of Mbeki's administration, Tun and colleagues suggest that, "although these denialist positions have been retracted, the messages have already spread and continue to spread" (2012, 459). Recent studies showing that some members of the South African public are distrustful of HIV science and find certain conspiracies plausible (Tun et al. 2012; Grebe and Natrass 2012; Bogart, Kalichman, and Simbayi 2008; Bogart, Skinner, et al. 2011). This casts doubt on the former Minister of Health, Barbara Hogan's pronouncement upon Mbeki's departure from office that "The era of denialism is over completely in South Africa" (Dugger 2009).

That alternative beliefs about HIV can affect public health behavior has made understanding such beliefs an important component of responding to HIV/AIDS in South Africa. This study explores how and why alternative beliefs about HIV/AIDS have emerged in South Africa, a country with a unique experience of both the virus and HIV science. It uses the Public Understandings of Science (PUS) literature to analyze these beliefs, conceptualizing trust and mistrust of scientific and official claims about HIV along a spectrum, and drawing attention to the ways in which trust shifts and evolves in response to dynamic life events. In doing so, this framework encompasses a range of alternative beliefs and knowledge including those that express doubt or skepticism, those that profess ignorance, those that claim authority, those that make a conspiratorial claim, and those that express uncertainty.

Section 2: Alternative Beliefs about HIV/AIDS in South Africa

In South Africa as elsewhere, HIV has long been viewed and interpreted through the experiences and observations of its citizens. What is unique about the South African experience is that this deadly epidemic arrived at precisely the same moment as political emancipation. Posel observes that, "during the apartheid era, the spread of the disease within South Africa remained relatively low; its acceleration occurred in the wake of transition" (2005, 133). In 1990, the HIV prevalence rate among pregnant women had been about 1%; by 2009, it had risen to 29% (South African

MRC 2007). This coincidence between the epidemic and the advent of democracy was not lost on South African citizens (Posel 2005). “When the dead were voters in a brand-new democracy”, Steinberg observes, “sons and daughters of a people just liberated from a white dictatorship, the spectacle appears cynical in the extreme, as if guided by an evil hand (2008a, 6). His protagonist is also sensitive to this parallel, asking, “Tell me, why did people start dying of this thing after democracy came in 1994?” (2008a, 308).

This difficult parallel - between the emergence of a deadly virus and the dawn of political and social freedom in South Africa – seems to have affected the way in which HIV/AIDS has been viewed and interpreted. Some people became convinced that the departing Apartheid administration or its cadres of scientists and doctors were somehow to blame. Indeed, one did not have to look farther than the National Party’s own politicians to find expressions and sentiments which could have given credence to these beliefs. In one 1990 parliamentary debate, a Conservative member of parliament claimed that the National Party was dismissing the threat of majority rule because “AIDS will be responsible for the large-scale elimination of the Black population, to such an extent that Blacks will in reality become a minority in South Africa within five years”. The Minister of National Health and Population Development denied these accusations, responding that the Conservative Party was actually hoping for this outcome, citing Conservative MP Clive Derby-Lewis, who stated: “If AIDS stops Black population growth, it would be like Father Christmas” (Republic of South Africa, 9797).

Certain revelations about state-sponsored violence that emerged in the post-apartheid era may have fuelled public distrust and lent credibility to alternative and conspiratorial beliefs about the origins and spread of the virus (Niehaus and Jonsson 2005; Natrass 2012a). During both the Truth and Reconciliation Commission (TRC) hearings, where victims and perpetrators of apartheid crimes were able to testify publically, and the murder trial of Wouter Basson, a doctor who ran Project Coast, an apartheid government-sponsored biological and chemical weapons programme,

the South African public learned about experiments to create a virus that would kill, sterilize and/or weaken the black population (Truth and Reconciliation Commission 1998; Gould 2005; Gould and Folb 2002). Dr. Daan Goosen, one of Dr. Basson's closest collaborators, reported to the TRC that they had had the following exchange:

I asked Dr. Basson: 'Wouter, why are you involved in this? Why are you involved in this?....And he said: I've got one daughter and one day, and he said we don't really have any doubt that the black people will take over the country, but one day when black people take over the country and my daughter asks me, Daddy, what did you do to prevent this, my conscience would be clean" (Truth and Reconciliation Commission 1998, 14).

These public disclosures may have made mistrust about HIV science more plausible for South Africans, as Fassin contends, "What could be seen elsewhere as unfounded suspicion was in South Africa plain reality, historically attested" (Fassin 2007, 496-7).

Other, more dramatic exploitation of the poor by the powerful have also been documented. Evidence exists that South African doctors have harvested organs from cadavers in public morgues without families' permission, only to provide the organs to wealthy clients who could afford to pay (Scheper-Hughes 2000). As Scheper-Hughes notes, it is impossible to ignore "the directionality of the exchanges: organs moving from poor and black bodies - representing the majority of the population in South Africa and accounting for a grossly disproportionate number of violent and accidental deaths - for transplantation into more affluent white bodies" (Scheper-Hughes 1996, 10).

Even when no actual wrongdoing has occurred, the perception of wrongdoing can persist when current practices map onto previous experience. Numerous medical trials for new pharmaceutical products have been conducted on African subjects over the past half-century in line with ethical guidelines. However, "bracketed by a continuing history of inequality, economic domination, and repressive public health" (Saethre and Stadler 2013, 108), certain perceived inequities or disjunctures

about these trials have fuelled beliefs that these studies steal blood or body parts (White 2000; Geissler 2005; Fairhead, Leach, and Small 2006; Saethre and Stadler 2013; Geissler and Pool 2006), or otherwise exploit African research subjects (Rothman 2000). For example, in a microbicide trial in South Africa, the fact that participants are reimbursed more money than is required for transport costs (the stated purpose of the reimbursement) has led some to view these payments as bribes “intended to discourage participants from complaining about any “side effects” that results from gel use”. Others have perceived this disparity in starker terms; trial participants warn each other that reimbursement will be used to “buy your coffin” (Saethre and Stadler 2013, 107).

Beyond these historical and contemporary perceptions of abuse and exploitation, the South African public has also been exposed to an additional influence on public skepticism and conspiratorial beliefs about HIV/AIDS in the form of state-sponsored HIV/AIDS denialism during former President Thabo Mbeki’s administration. Given his prominence in the political sphere, numerous studies have argued that Mbeki’s denialism while in office has had a direct influence on the public’s doubts about HIV science in the present. As a national leader who made explicit statements endorsing denialist views, studies suggest that Mbeki led the South African public to doubt HIV science in enduring ways (Geffen 2005; Geffen 2010; Tun et al. 2012; Bogart, Skinner, et al. 2011; Grebe and Nattrass 2012). These doubts could be expressed as “misinformation about the causes and treatment of HIV, including the belief that AIDS is not caused by HIV” (Bogart, Kalichman, and Simbayi 2008, 115). Government denialism may also make it difficult for individuals to distinguish “between accurate HIV/AIDS information and the misconceptions about HIV present in communities” (Bogart, Skinner, et al. 2011, 182).

In all these accounts, denial, questioning and obfuscation within the political leadership has translated to confusion, doubts and skepticism among the public. Robins points to personal communication with Dr. Hermann Reuter, a doctor working for *Medicins Sans Frontières* in South Africa to suggest, “There seems to be a

strong link between national level AIDS politics and the obstacles encountered by activists and health workers at the clinic level” (Robins 2009b, 85). “This presidential ambivalence has left many South Africans both confused and scared”, Willan (2004) argues. Citing discussion in the *Mail and Guardian* in April 2003, she states, “They are experiencing doubts sown by confusion and a lack of political leadership to fight this epidemic. The confusion lies at the core of questions about how HIV/AIDS is spread, and the need to use condoms, through to a very real fear about the safety of using ARVs” (2004, 112).

In short, previous research in South Africa has explained the prevalence of alternative beliefs by pointing to the role of historical experiences and elite endorsements of AIDS denialism. However, the extent to which these factors remain plausible influences in current acceptance and endorsement of alternative beliefs requires further investigation.

Section 3: Explanations for alternative beliefs

Previous studies maintain that the experiences of apartheid, the transition to democracy, and the early years of the new government have had permanent implications for the public’s trust in biomedical claims. Scholars point to the manner in which South African history is “embodied”, meaning “the way in which individual and collective histories are transcribed into individual and collective bodies” (Fassin 2007, 65). In practice, this refers to experiences of colonial abuse, the racist, essentializing language of the early HIV years, the Sarafina II and Virodene controversies within South Africa’s newly elected government⁵, and countless small acts of discrimination and marginalization (Mbali 2002; Mbali 2004; Fassin 2007; Fassin and Schneider 2003). “This history”, Fassin and Schneider assert, “still

⁵ Sarafina II refers to a “badly conceived and inappropriately funded” AIDS awareness play, sponsored by the government (Natrass 2008). Virodene was an ‘AIDS cure’ discovered by South African researchers that was endorsed by government officials before being discredited as an industrial solvent containing dimethyl-formamide (Natrass 2008). Both of these experiences led the ANC to harden in its relationship with civil society and the media (K. Johnson 2004).

remains deeply present to many South Africans and explains much of the mistrust towards Western science, medicine and public health” (2003, 497). These studies, however, often fall short of identifying exactly how the experience of apartheid or of historical inequity continues to account for current distrust. Most take the fact of apartheid in the past and of distrust in the present as sufficient evidence for such assertions⁶. For instance, Fassin affirms, “Even though people do not necessarily refer in an explicit way to historical episodes such as these – they sometimes do so spontaneously – such past events do come to the surface in terms of denial and perplexity, doubt and accusation in public debate” (2002, 66). The absence of specific evidence underpinning this claim makes it difficult to assess its accuracy. This is not to suggest that certain historical experiences do not continue to exert a degree of influence on South Africans’ perceptions of HIV science. Rather it is to insist that assertions of this kind need to more specifically identify the mechanism by which these experiences become manifest.

Some studies of public distrust suggest that official denialism under Mbeki has “sown confusion” (Geffen 2005, 184) and “sent very mixed messages concerning the efficacy of condoms and testing, and in particular, the role of treatment” (Jones 2005, 428). Few scholars, however, have empirically investigated the influence of the former president and his health minister in influencing the public’s uptake of HIV science. McNeill (2009) problematizes the notion that the president’s denialism

⁶ A similar instinct exists in US scholarship on mistrust in the African-American community. Studies attributing African-American mistrust to the legacy of the Tuskegee Syphilis Study are ubiquitous (Bogart et al. 2010; Suite et al. 2007; Mackenzie 2011; Roberts et al. 2005), though empirical investigations have at times indicated a more nuanced connection between past experience and present mistrust (Brandon, Isaac, and LaVeist 2005; McCallum et al. 2006). For instance, McCallum and colleagues conclude their study on the legacy of Tuskegee by observing that, “although minorities may generally mistrust medical research, are aware of the USPHS Syphilis Study at Tuskegee, and express an unwillingness to participate in medical research, they may participate at the same rates as Whites if recruited to participate”. Brandon and colleagues argue, “It is time that we move beyond Tuskegee as a catch-all for why African Americans mistrust medical care and begin to address the root causes” (2005, 956).

is a major influence on public discourse about HIV/AIDS. He suggests a key distinction should be drawn between the “state denialism” of the President and members of his administration, and the “consensus” among the citizenry to deny AIDS or refuse to speak about it; in his view, “to assume a causal relationship between them obscures more than it reveals” (2009, 354–355). Similarly, Steinberg questions the impact of Mbeki’s policies rather than drawing firm conclusions about them: “If South Africa’s government had felt unequivocal about ARV treatment and had rallied behind it, what would Sizwe have thought of Hermann’s needle? Would people have asked in quiet tones whether their government was killing them?” (Steinberg 2008a, 153). Particularly as more years elapse since the end of the apartheid era and Mbeki’s time in office, assumptions about the current roots of distrust and suspicion should be questioned and if necessary, updated⁷.

This study echoes the position taken by McNeill (2009) that the question of the influence of historical experience and Mbeki’s ‘long shadow’ must not be assumed to be settled. As Robin’s argues, “it has become apparent that people’s interpretations of the AIDS pandemic are far more complex and differentiated than either government or TAC originally anticipated” (2005, 129), raising the question of what truly underlies public distrust of HIV science. Rather than presume that the abuses of the apartheid state or Mbeki’s pronouncements have influenced members of the public to express suspicion and distrust, this study explores the extent to which the South African public is influenced by an awareness of historical events, and the degree and nature of influence of the state on the South African public’s distrust.

⁷ For instance, Steinberg describes a recent visit to a high school in Durban where he spoke with a group of 15 year olds. This age-range is often called the “born-frees” for having been born after the end of apartheid. This is often interpreted to mean that Apartheid, the ANC, and the fight for freedom will not play as significant a role in their political outlook. Steinberg asked them the question: “Is the past still alive here in this school?” Their answers reflected how race remains a salient category of meaning for them and how the past has undeniably shaped their current understandings of race. He concludes that theirs “is a distinctively post-apartheid identity but it is nourished by the apartheid past” (Steinberg 2013).

Thus, this study focuses on understanding public distrust in the post-apartheid, post-Mbeki era with an emphasis on identifying precisely how (and if) either historical period has had a significant influence on distrust among the South African public.

This section has summarized the specific context of South African research on alternative explanations about HIV/AIDS, highlighting how explanations of public distrust often hinge on both the history of apartheid-era abuses and the 'long shadow' of Mbeki's state denialism about HIV/AIDS. The next section will discuss the tendency to frame alternative beliefs as 'conspiracy theories'. This conceptualization has important implications for how alternative beliefs are studied and responded to by public health organizations.

Conspiracy theories

Conspiracy theories have been defined alternately as "a skeptical, paranoid, obsessive practice of scanning for signs and sifting through bits of evidence for the missing link" (Stewart 1999) and as "historically contingent propositions formed in response to events or conditions that serve as explanations for disjunctures or gaps in information" (Wilson 2008). The former definition is illustrative of the more traditional focus on the individual psychological and cognitive characteristics of people who endorse alternative explanations. These studies seek to better understand the particular psychological "needs" of individuals that conspiracy theories accommodate or express (Swami, Chamorro-Premuzic, and Furnham 2010; Swami et al. 2011), and originate with Hofstadter (1965), who defined conspiracy theorizing as "the paranoid style in politics". Though Hofstadter's use of the word 'paranoid' was intended metaphorically rather than clinically, his work has inspired subsequent exploration of the topic as an individual or collective pathology⁸.

⁸ At the extreme, the pathological conceptualization of conspiracy beliefs has led to unfortunate polemics about the nature of alternative beliefs. For instance, Thompson writes: "Some bogus material is easily spotted: its theories are clearly

Observations about the stigmatizing effect of viewing conspiracy beliefs in primarily psychopathological terms have fuelled an opposing tradition, conceptualizing conspiracy beliefs as 'counter narratives' (Farmer 1992; Mackenzie 2011). These accounts emphasize how contextual factors – particularly previous experiences of marginalization, racism or discrimination - have shaped current perceptions of trust in official narratives (Waters 1997; Briggs 2004; Nations and Monte 1996). In doing so, they place their emphasis on the experiences and observations of individuals and communities.

Conceptualizing conspiracy beliefs as counter-narratives highlights the important historical and contemporary roots of mistrust in official accounts and directs our attention as scholars to the strategies employed by marginalized peoples to make their version of events heard. However, several fundamental weaknesses accompany this scholarship, which taken together, serve to undermine the usefulness of this framework for the current study.

By framing conspiracy beliefs as counter-narratives, scholars attempt, in effect, to exonerate the term 'conspiracy theory', purging it of its traditional negative connotations by turning it into a tool to challenge power "through the articulation of oppositional ideas about dominant scientific knowledge" (Mackenzie 2011, 492). This pejorative connotation is in keeping with Hofstadter's original conceptualization: "Of course this term is pejorative, and it is meant to be; the paranoid style has a greater affinity for bad causes than for good (1965, 3). For scholars in the 'counter-narrative' tradition, it is desirable to eliminate any undertone of judgment and paranoia, focusing instead on the experiences and perspectives of respondents that make such beliefs "thinkable"⁹.

outlandish and the individuals who champion them are dishonest or gullible" (2008, 3).

⁹ Natrass 2012a argues that certain alternative beliefs are "thinkable" even if they are ultimately untrue.

It is questionable, however, whether the concept has ever completely lost its negative association with the judgments and stigma of psychopathology. Studies examining the contextual factors underpinning conspiracy beliefs must contend with these negative connotations, at times bending over backwards to argue that such beliefs are justified though ultimately wrong, “paranoia within reason” (Marcus 1999). This justification often involves the inclusion of caveats outlining the plausibility of such beliefs. One study explains, “The Jim Crow era of racial apartheid required covert, conspiratorial acts – indeed, given the history of both overt and secret state-sponsored racial subordination in America, African-Americans frequently have a defensible claim that someone is out to get them” (Fenster 1999, 11). Another accounts for a high prevalence of conspiracy beliefs among the Latino population by observing: “A class action suit in Los Angeles revealed that Chicano women were being sterilized immediately after giving birth...Suspicion of health-related motives in Latinos, while speculative, are thus not hard to account for” (Ross, Essien, and Torres 2006, 344). By calling such beliefs ‘conspiracy theories’ while simultaneously expressing sympathy for their roots in discrimination and marginalization, scholars may inadvertently undermine their own best intentions and arguments.

These analytical weaknesses are further challenged by the fact that some of the beliefs typically characterized as ‘conspiracy theories’ lack key definitional qualities, such as a belief in the existence of deliberate and secret plots. Turner (1993) and Sasson (1995) both identify two distinct groups of conspiracy beliefs, those that reflect the ‘malicious intent’ of government or powerful institutions to harm or exploit others, and those that reflect the ‘benign neglect’ of public institutions and people towards marginalized groups. Surveys questions such as “Is the government telling the truth about AIDS?” (S. Parsons et al. 1999) or asking respondents to rate their agreement with the statement “I trust federal government reports on AIDS” (Thomas and Crouse Quinn 1993) or “AIDS information is being held back from the general public” (Tun et al. 2012) are characteristic of ‘benign neglect’ studies.

Strictly speaking, theories of 'benign neglect' lack any serious assertion of a deliberate or secret plot to harm others. Rather, people are harmed precisely because those in power lack interest in organizing to improve marginalized peoples' lives. Thus, this second category of so-called 'benign conspiracy theories' are not conspiracy theories at all, but rather theories expressing mistrust of official intentions and discrimination in official policies.

Several subsequent studies have utilized variations of the term "conspiracy theories of benign neglect" (Simmons and Parsons 2005; Mackenzie 2011) to refer to "conditions that are allowed to persist due to societal racism, such as racial bias of the court system and the police harassment of African Americans" (Simmons and Parsons 2005, 584), or to claims that "the inaction of government agencies constitutes genocide" (Mackenzie 2011, 491). In doing so, scholars usefully emphasize instances when neglectful inactivity can be as harmful as malicious action. Indeed, Epstein (1997) highlights how AIDS treatment activist organizations in the US used the 'genocide as a byproduct of inaction' frame to mobilize supporters in the late 1980's¹⁰. However, in using the term 'conspiracy theory', the authors yoke these justifiable grievances of neglect and mistreatment to the pejorative connotations of the term discussed above in ways that may not strategically advance the interests of marginalized populations or accurately represent the range of their beliefs.

This is not to suggest that no respondents in any study posit truly conspiratorial explanations; there is ample evidence to suggest that conspiratorial beliefs do exist and importantly, have an impact on public health behavior (Bogart et al. 2010; Bird and Bogart 2003; Grebe and Nattrass 2012; Kalichman, Eaton, and Cherry 2010; Lennon and Kalichman 2012; Hutchinson et al. 2007). It is rather to argue that

¹⁰ The genocide frame is also still used by the US AIDS activist and playwright Larry Kramer. Audience members for his play *The Normal Heart*, which played on Broadway in 2011, were handed a pamphlet entitled "Please Know" upon exiting the theatre, which outlined his views on the cost of governmental neglect of AIDS funding (Kramer 2011).

studying alternative explanations about HIV/AIDS as ‘conspiracy theories’ alone can limit one’s ability to explore and understand this phenomenon. By representing alternative beliefs as conspiracy theories, scholars are either narrowing the focus of study to a small sub-section of alternative beliefs that explicitly speak to malevolent plots, or are broadening the focus of study to include observations about mistrust in doctors, the health care system, or the state as ‘conspiracy theories of benign neglect’.

Furthermore, an alternative framework – of Public Understandings of Science (PUS) - outlined below can incorporate discussions of conspiracy theory as one sub-set of alternative beliefs. For instance, in their study of parental distrust of childhood vaccination, Brownlie and colleagues recount parents’ beliefs that “professionals’ claims to impartiality were undercut by perceptions of a relationship with the pharmaceutical companies responsible for producing vaccines and of payback through the target system”, a clear insinuation of cover-up and hidden profit (Brownlie and Howson 2005). The interviews in Wynne’s (1992) study with sheep farmers’ distrust of the UK government captured “many farmers bitterly accusing the scientists of being involved in a conspiracy with a government which they saw as bent on undermining hill farming anyway” (1992, 286). The distinction between these frameworks lies in PUS studies’ broader investigation of alternative explanations, including but not limited to, conspiracy beliefs, rather than the exclusive focus on conspiratorial explanations. In doing so, PUS studies avoid reifying conspiracy beliefs as an exotic category of belief, a risk that accompanies even the most historically-sensitive and contextual conspiracy belief studies. Having outlined the limitations of viewing alternative beliefs solely through the framework of conspiracy theories, this alternative corpus of literature focusing on the Public Understandings of Science, will be discussed below.

Section 4: Public Understandings of Science framework

The PUS literature in relation to health is vast and draws from various disciplines including: sociology, political science, history, philosophy, anthropology, public

health, and interdisciplinary science and technology studies and development studies. PUS studies were originally conceptualized around a 'deficit model', whereby negative public attitudes and perceptions or scientific claims were traced to a lack of information or awareness – a cognitive and informational deficit (Wynne 2006)¹¹. The deficit model has been criticized for focusing excessively on the personal attributes of individuals as deficiencies rather than recognizing how trust and credibility in science is “a non-linear function of scientific awareness, coupled with various socio-economic and historical specificities” (Bhaduri and Sharma 2012, 2). Science is, of course, “partial, provisional, and even on occasions, deeply controversial (Durant 1999, 315). Rather than characterizing lack of science uptake as the result of ignorance, critics point to how trust deficits arise when ‘errant data’ fail to be credibly accounted for in official explanations (Wynne 1992). Wynne (2006) highlights the ways in which sources of scientific authority are themselves implicated in the dearth of trust in science.

Observations about the inadequacies of the deficit model led to the development of the 'dialogue', 'democratic', 'contextual' or 'reflexive' model (Bhaduri and Sharma 2012; Durant 1999; Irwin and Wynne 1996; Miller 2001), which de-emphasize the cognitive dimensions of public understandings of science in favour of the relational dimensions (Wynne 2006). Thus, a two-way dialogue is undertaken between scientific institutions and the public about issues of scientific concern. This conceptualization of PUS has several important components, which will be outlined below. These include: 1) viewing alternative beliefs in the context of everyday experiences and observations, 2) examining how trust and distrust is formed through relationships between people and institutions, and 3) exploring the underlying meanings of uncertainty.

¹¹ Beginning with the Royal Society report in 1985, the 'deficit model' of PUS represented the public as fundamentally misunderstanding some aspect of scientific knowledge, as indicated, for example, in surveys of public comprehension about GM foods or nuclear energy (Wynne 2006). The deficit model reflects the view that the public has selectively withdrawn trust in recent decades; the presumption being that as science becomes more complex, the public cannot keep up.

Practical experiences and observations

First, contextual studies treat alternative beliefs as understandings arising from practical experiences as opposed to irrational or ignorant assertions, and draw attention to how these understandings fit together with scientific accounts (Irwin and Wynne 1996, 9). In doing so, these studies recognize the existence of other forms of expertise (Durant 1999) and observe how people reflect upon the epistemological status of these multiple forms of knowledge (Michael 2002; Wynne 1992). Hardin calls this the “street-level epistemology of trust...a theory that focuses on the individual and on the ways the individual comes to know or believe relevant things, such as how trustworthy another person is” (Hardin 1992). Steinberg highlights how people in his field site judged the trustworthiness of biomedical interventions based on such street-level epistemologies. When faced with a number of villagers who are publically diagnosed with HIV, some of whom go on ARV treatment and some who do not, the rest of the community is conflicted about what to believe:

As for the rest of the village, they are not sure. They will watch both groups keenly. They will observe who lives and who falls ill and dies. The outed are the unfortunate subjects of an empirical experiment (2008a, 192).

Salient experiences and observations can be drawn from both the present and the past. Some past experiences, particularly those of racism, marginalization, and discrimination, may inform mistrust in the present. Lain and colleagues found that negative past experiences with medical providers was associated with late entry into HIV care (Lain, Valverde, and Frehill 2007). Another study found that African-Americans were more likely to hold current alternative and conspiratorial beliefs if they had knowledge and awareness of past, historically documented events targeting African-Americans (Nelson et al. 2010). A central theme of this literature in relation to health and disease is that trust in doctors, the health care system, medications and the state is essential, yet such trust can be undermined by harmful past experiences and observations.

For instance, there is widespread discussion of certain contemporary health controversies or crimes that may have impacts for public trust (MW Calnan and Sanford 2004), some of which are country-specific while others resonate internationally. Alternative explanations about health and disease are tied to tangible observations about these events. Oft-cited incidents in the UK include: the mad-cow disease outbreak in 1996 and subsequent controversy about public safety and farmer's livelihoods; the trial and conviction for murder of the GP Harold Shipman; and the removal of children's organs from Alder Hey hospital in Liverpool (Michael Calnan and Rowe 2004). Aboriginal Canadians are believed to distrust the medical system in Canada because of the relocation of Aboriginal children in the residential school system and removal of Northern patients to TB sanatoria (Macdonald, Rigillo, and Brassard 2010; Health Council of Canada 2012). Farmer highlights how Haitians have articulated their history in the form of alternative beliefs about the origins of HIV/AIDS: such beliefs "contain considerable amounts of truth when examined not as isolated anecdotes, but as lessons drawn from the last five hundred years of Caribbean history" (1992, 247). US studies, particularly those focusing on African-American populations' loss of trust, emphasize the "long-shadow" cast by the US Public Health Service (USPHS) Syphilis Study at Tuskegee, where 399 African-American men were systematically withheld from syphilis treatment so that researchers could study the natural progression of their disease (Thomas and Quinn 1991). In this way, a single historical event, such the Tuskegee study can progress "from science, to conspiracy, to metaphor" (Thomas and Curran 1999). At times, such events can come to symbolize an entire history of discrimination and marginalization and contribute to an *a priori* expectation of abuse or discrimination¹².

¹² The progression, "from science, to conspiracy, to metaphor" is, of course, what Goldacre warned of when he cautioned against allowing specific failures and abuses in the practice of biomedicine to undermine public trust in biomedical science in general (Goldacre 2010). Evidence that Tuskegee has entered the 'metaphor' stage is provided by Brandon and colleagues: they show that respondents lacked actual knowledge of the details of Tuskegee and that rather, "the Tuskegee study represents another example of why the medical system cannot be trusted" (2005,

The MMR vaccine debate has been accorded international significance, arising in 1999 following the publication in the *Lancet* of a study by Andrew Wakefield and colleagues venturing a putative link between childhood vaccination for measles-mumps-rubella and autism (Campbell 2011; Brownlie and Howson 2005). Speaking more broadly, Larson and colleagues highlight how perceptions of trust and risk in relation to vaccines are now “converging, evolving and having impacts well beyond specific geographic localities and points in time” (2012, 1053).

In addition to the experience of state-sponsored racism and discrimination, scholars have observed that mistrust and skepticism may be indicative of wider global distrust brought about by the uncertainties and ambiguities of the modern era (Giddens 1990; Beck 1992; Lyotard 1984; Sanders and West 2003). Scholars see the modern era as characterized by “existential insecurity”, leading people to seek alternative explanations (Giddens 1990; Beck 1992; Knight 2002; Sanders and West 2003; Lyotard 1984). Even as the public is promised a more open and transparent experience of state power, they observe that much remains shrouded in secrecy (Sanders and West 2003). In contrast to pre-modern systems, where authority and knowledge resided in elders, argues Giddens (1991), insecurity in the modern era is derived from our reliance on ‘expert systems’ that have no direct relationship to us yet in which we must trust. As the public increasingly recognizes its existence in this “risk society”, trust and credulity in science is stretched, sometimes to the breaking point (Beck 1992).

In this vein, studies have examined the relationship between alternative beliefs and the accelerated processes of globalization. When a young boy of African descent was found dead in the River Thames in London, Sanders explored how subsequent

955). Similarly, McCallum and colleagues found that familiarity with the Tuskegee study “did not necessarily ensure accurate knowledge of it” (2006, 716). Tuskegee has become “the quintessential motif of how the medical and scientific communities abuse, neglect and silence African Americans” (Suite et al. 2007, 881).

alternative beliefs underscored modern-day Britons' anxieties about the forces of globalization and the consequent "unraveling [of] the moral fabric of British society" (2003, 53). Research in Indonesia suggests that alternative beliefs about HIV highlight specific concerns that urban Indonesians have about modernity and the power of the Indonesian state (Kroeger 2003, 243). Rodlach connects Zimbabweans' unease about lowering standards of sexual morality to alternative beliefs about the origins of HIV (Rodlach 2006). Contemporary legends about HIV/AIDS in Newfoundland, argues Goldstein, articulate a collective island anxiety about danger from the mainland and fear of the stigma of being branded 'the AIDS capital of Canada' (2003, 53).

Mistrust and alternative beliefs about HIV/AIDS in South Africa can also be connected to wider global distrust brought about by the uncertainties and ambiguities of the modern era (Niehaus and Jonsson 2005; Steinberg 2008a; Natrass 2012a). Niehaus and Jonsson observe that men in the South African lowveld discuss alternative beliefs about the origins of HIV, blaming trans-local agents such as Dr. Wouter Basson, Americans, and soldiers as a response to their humiliating experiences of job losses and deindustrialization in the global labour market (2005).

The specificity of these concerns highlights the importance of considering each context independently, rather than assuming that sources of anxiety or distrust are universal. As Gray argues, "There is no single theory of conspiracism that simply and neatly can explain conspiracism, much less one that can be taken from the Western experience and superimposed onto [other cultures] to explain both the breadth and frequency of conspiracy discourse" (2008, 167). It also illustrates the manner in which South Africans' anxieties express concerns specific to the unique political and historical landscape while simultaneously sharing characteristics and themes with other theories and explanations from around the world (Fassin and Schneider 2003; Fassin 2007; Goldstein 2004; Farmer 1992) - a concept that folklorists refer to as 'ecotypification' (Fine 1992).

Relational trust

A second feature of contextual PUS studies is the recognition that scientific knowledge builds upon relational processes of trust and credibility (Irwin and Wynne 1996, 3). Rather than regarding a dearth of trust merely as the public's rejection of scientific claims, the emphasis on trust points to the ways in which PUS is unavoidably interactive. As Gilson has observed, "trust is a relational notion: it generally lies between – people, people and organizations, people and events" (2003, 1454). Thus, contextual PUS studies examine not only how lay understandings of scientific processes are negotiated and constructed, but also how scientific authorities and those in power influence these processes with their own actions, rhetoric, and reputations. These reputations are often formed in reference to past experience; as Fine observes, "In considering the credibility of the speaker, we are likely to ask whether there is something to gain or hide, and whether the person has provided poor information in the past...Deceptiveness can become embedded in a reputation" (2007, 11). When those in authority fail to credibly address wrongdoing or resolve confusion, further distrust can result. Wynne points to the failure of scientific authorities, at times, "to recognize the ever-increasing demands which are being imposed on public credulity by science" (Wynne 2006, 213).

By focusing on how social identities and relationships inform trust, scholars extend their analysis beyond health-specific dimensions, to examine how interpersonal and system-related trust are inseparable from trust in wider structures, such as the government. Ward and Coates' study of trust in a materially deprived community in the UK described how participants' lack of trust in local GPs could not be separated from their mistrust of the local and national health care system (2006, 297). Similarly, in their study of African-Americans' trust in medical care, Brandon and colleagues (2005) found that mistrust was more related to general suspicion of societal institutions than a particular episode of historical health care-related discrimination. Among UK parents considering MMR vaccination for their children, trust "cannot be understood outside interactions and relationships nor isolated

from the systems or institutions within which these unfold” (Brownlie and Howson 2005, 225). Studies such as these encourage a broader contextual examination of multi-dimensional trust and mistrust than that investigated by solely health-specific measures.

In viewing trust and mistrust along a spectrum, drawing attention to the ways in which trust shifts and evolves in response to dynamic life events, PUS studies explore how trust is shaped in the context of respondents’ experiences, relationships and identities. Such an approach enables the study of alternative explanations for HIV/AIDS in South Africa to be interrogated in the context of trust in health care providers, the health care system, HIV medications, politicians, and the state. It also emphasizes how relationships of trust are shaped by wider processes, including past and present views of national and trans-national controversies.

Uncertainty

A third feature of contextual PUS studies is the consideration of underlying meanings related to ‘uncertainty’. Some posit uncertainty as an inseparable component of trust, since trust without risk is merely confidence. Kramer defines trust as entailing “a state of perceived vulnerability or risk that is derived from individuals’ uncertainty regarding the motives, intentions, and prospective actions of others on whom they depend” (1999, 571). Building on this, Luhmann (2000) suggests conceiving of trust “as a practice which becomes significant in the context of uncertainty”. Misztal argues that “to ‘trust is to believe despite uncertainty” (1996); and Mollering (2000) proposes that it is this “bracketing of the unknown which is the defining aspect of the nature of trust” (2001, 417). Put another way, trust always involves “leaps of faith” of some kind (Brownlie and Howson 2005). Viewing trust and uncertainty as interconnected concepts has important implications for studying public trust in science. Rather than dichotomizing the public’s reactions to science as either ‘trusting’ or ‘doubting’, this approach views

beliefs about trust along a spectrum, with uncertainty or ambivalence as a meaningful category of analysis in its own right.

Indeed, uncertainty among respondents can convey significant information. The public may express uncertainty about science if scientific claims seem simplistic, contradictory, or makes projections into the future that are difficult or impossible to predict (Brownlie and Howson 2005; Wynne 1992; Wynne 2006). This is in contrast to deficit model or conspiracy belief studies, where ‘uncertainty’ “is usually treated as intellectual feebleness” (Wynne 1992, 301)¹³. In quantitative surveys, ambivalence is often simply coded as “don’t know” or “undecided”, and then recoded into other categories or excluded from analysis altogether (for instance, Russell et al. 2011). Wynne notes the ease by which the “richness” of ambivalence could be marked down as “mere ‘don’t knows’ in a more efficient attitude survey”, an approach he calls “a grotesque distortion of the true position” (1992, 300).

Thus, PUS studies highlight the dialectic nature of trust and uncertainty, and emphasize how respondents make decisions about health and disease in contexts of everyday uncertainty. Alternative beliefs about HIV/AIDS in South Africa can be seen in the context of competing explanations and uncertainty about the virus, to be adopted and discarded accordingly. Steinberg highlights how his subject changed his mind about a foreign doctor’s motives over the course of his fieldwork:

‘You no longer believe, then,’ I asked, ‘that he is part of the conspiracy of the *umlungus* to kill the blacks? He is not one of those who knows of the cure for AIDS but holds it back?’. ‘No’, he replied. ‘He wants to do good with those pills. He is not part of the plot. He doesn’t even know about it.’ (2008a, 371).

¹³ A recent exception is Van Prooijen and Jostmann (2013) who measured how perceived morality among authorities interacts with belief in conspiracy theories under conditions of uncertainty, finding that when respondents were made to feel aware of uncertainty, they became hyper-vigilant about the morality of authorities in determining the plausibility of conspiracy beliefs. ‘Uncertainty’ in this study is conceptualized as “lacking control”, a concept with roots in psychological and cognitive theory.

Steinberg further observes how his subject suspects that HIV originated in the “vividly imagined laboratories of Western science”, while also noting that he was “entirely open” to other explanations (2008a, 21). Natrass echoes this, suggesting ambivalence and fluidity underlying alternative beliefs about HIV/AIDS (2012a). In his study of the democratization of HIV science in South Africa, Robins observes, “Those who are not ‘true believers’ of medical science may indeed experience profound ambivalence and uncertainty towards scientific explanations of HIV and ARV treatment” (2009b, 102).

In short, the Public Understanding of Science framework can illuminate the evolving, relational, and multi-dimensional nature of trust as a function of the social identities and relationships in a particular society. In doing so, the PUS framework highlights the spectrum of trust and doubt underlying public uptake of scientific claims and will be used to guide analysis in this study. The following chapter will outline how the PUS framework informed the methodological approach to this research.

Chapter 3: Methodology and Methods

“The validity of a study on sorcery beliefs and conspiracy theories heavily depends on the right selection of methods” (Rodlach 2006).

Introduction

In order to achieve the research aims outlined in Chapter 1, it is necessary to employ an iterative methodology that is semi-structured to allow for focused exploration of particular topics of interest, while also enabling insights to emerge in more naturalized settings. Given the potential for some respondents to feel intimidated or stigmatized by open discussions about alternative beliefs about HIV/AIDS, triangulation techniques were employed to gain a fuller perspective on the worldview of respondents. Multiple data collection methods also aimed to capture the dynamic nature of these beliefs.

This chapter contains 7 sections. The first section provides the rationale for using mixed and multiple methods to study alternative beliefs about HIV/AIDS. The combination of a survey, focus group discussions, and interviews with peer educators provides a unique perspective on these data, enabling the triangulation of findings to ensure greater data validity. The second section outlines the research sites and duration of fieldwork, and highlights the specific and unique attributes of South Africa, the Western Cape, the City of Cape Town, and Khayelitsha township that have shaped the research processes and outcomes. Section 3 provides details on participant recruitment and the study instruments, including the CAPS survey, focus group discussions, and in-depth interviews. Section 4 outlines the study participants from each round of fieldwork and discusses the extent to which participants are representative of the larger CAPS sample. Section 5 highlights important ethical and practical issues relating to the research, including ensuring informed consent, safety concerns, and compensation arrangements. In section 6, I discuss the methodological limitations of my approach, including reflection about how my own personal characteristics may have affected data collection, and the use

of translators. The final section outlines my plan of analysis of quantitative and qualitative data.

Section 1: Rationale for mixed- and multiple- methods

There is a dearth of mixed-methods studies of alternative beliefs about HIV/AIDS, with most studies favoring either regression analysis of set variables through a quantitative survey (Grebe and Natrass 2012; Bogart, Kalichman, and Simbayi 2008; Bogart, Skinner, et al. 2011) or ethnographic investigation of beliefs within a specific community (Rodlach 2006; Steinberg 2008a; McNeill 2009). Each approach has its own advantages and limitations, specifically conclusions that cannot be drawn from certain types of data. For instance, researchers employing qualitative methods are often required to conclude at the end of their research that while it is highly unlikely that there is *not* an association between alternative beliefs and health behaviours, they are unable to establish this association statistically. Kaler (2004) concludes her fascinating study of the 'long shadow' of population control programmes with this caveat:

That these stories directly influence decisions to use condoms is not clear. Although some people end their recounting of condom/AIDS/population control stories with some version of "...and that's why I don't use condoms", not everyone made a connection with their own practices (2004, 113).

Rather than establishing a statistical association between alternative beliefs and behaviour, researchers rely on interview transcripts, field notes, and observations. While rich in information, these are rarely sufficient to persuade quantitatively-minded academics or policy makers. Dismissed as "mere anecdotes" by many, policy makers in particular express frustration with anthropologists and other qualitative researchers for their lack of clear, statistically-demonstrated, policy prescriptions (Nichter 2008, 69).

Distinct limitations also exist in solely quantitative studies of this topic. Bogart and Bird (2003), Bogart and Thornburn (2005) Ross et al (2006), Bogart et al (2011), and Gillman and colleagues (2013), among others, show quantifiable associations

between endorsement of conspiracy beliefs and HIV behaviour, after controlling for HIV knowledge, suggesting that lack of knowledge about HIV is not the root cause of respondents' suspicions. However, none of these studies explore the explanations for these suspicions with qualitative follow-up investigation. The contextual analysis that does exist is often superficial. For instance, Bogart and Thorburn (2005) point to the wealth of existing research on the roots of suspicions of the medical establishment among African-Americans, specifically the Tuskegee syphilis experiment. Similarly, Bogart and colleagues point to the "context of historical oppression under apartheid and some South African policy makers' inconsistent prevention messages" as an explanation for their findings (2008, 116). More detailed study of these origins is, however, essential to inform appropriate responses. In their conclusion, Ross and colleagues echo this: "More detailed investigation into the sources of such beliefs, using qualitative approaches, are warranted, and further research into the origin of this belief is appropriate" (2006, 344). In short, previous studies have undertaken only one part of the analysis necessary to comprehensively understand this phenomenon and how best to respond to it.

This study combined quantitative measurement of alternative beliefs with qualitative exploration of these perspectives in focus group discussions and interviews. The validity and reliability of this research was enhanced by alignment with Tong and colleagues' checklist for qualitative health research (Tong, Sainsbury, and Craig 2007). It includes 32-items that qualitative health studies should consider, including a strategy to triangulate findings. One method to triangulate findings is by combining methods (Golafshani 2003). Triangulation is defined as "a validity procedure where researchers search for convergence among multiple and different sources of information to form themes or categories in a study" (Creswell and Miller 2000, 126). The 'what' quantitative portion of this study – exploring which alternative beliefs are endorsed by individuals in the target community – is coupled with the 'how' and 'why' qualitative element – exploring how individuals make sense of these narratives (Tashakkori and Creswell 2007). Given the differing

strengths and advantages of certain methods, I expected that some information would be more readily available in either qualitative or quantitative data collection. As noted by Rodlach (2006), people may be much more willing to endorse alternative beliefs about HIV/AIDS in focus group discussions or interviews, and much less likely to seem sympathetic to these beliefs in surveys. Similarly, Steinberg found that when his respondent discussed certain alternative beliefs about HIV, he was acutely sensitive to being judged. When Steinberg expresses incredulity about the hidden existence of a cure for HIV, Sizwe remarks, "I have told you a black people's secret. I am sorry I have told you that" (2008a, 139).

Focus group discussions were also selected because they reversed the traditional power dynamics of research, more prevalent in survey and interview-based research, allowing greater control over the process to be exercised by respondents themselves. By directing the conversation and exploring key topics of interest, focus group participants can "develop the themes most important to them" (Cooper, Diamond, and High 1993), and thus, provide insight into "participants' conceptual worlds" (Broom and Dozier 1990). Focus groups can also mirror, more closely, "everyday social interchange in a relatively naturalistic way" (Wilkinson 1999, 226). In doing so, these exchanges produce insights about the way certain beliefs are represented, debated, and contested within a specific segment of society as a whole (Kitzinger 1994; Wilkinson 1999):

Participants do not just agree with each other, they also misunderstand one another, question one another, try to persuade each other of the justice of their own point of view and sometimes they vehemently disagree (Kitzinger 1994, 170).

The interactive nature of the focus group discussion can thus provide insight not available outside of the group context. These advantages of focus groups – reversing power dynamics between researcher and researched, capturing 'naturalistic' interactions, and highlighting the importance of the social context in constructing meaning, has led some researchers to argue focus groups are an inherently feminist method (Maynard and Purvis 1994, 3).

In-depth interviews with peer educators from the Treatment Action Campaign (TAC) office in Khayelitsha complemented the survey and focus group discussions, and were designed to explore this topic from a distinct perspective. These interviews provided insight into alternative beliefs about HIV/AIDS from the perspectives of those who are entrusted with publically disseminating scientific information about HIV/AIDS and responding to doubts or confusion 'on the ground' in Khayelitsha. Geffen highlights the centrality of local TAC branches, particularly in their treatment literacy programme, in combating misinformation about HIV science: "It is here that a critical mass of working-class people in townships learnt enough of the science of HIV to be able to realize that the denialist message, promoted by Mbeki and filtered down through the ANC's structures, was wrong" (2010, 192). As a means of ascertaining the extent to which alternative beliefs about HIV/AIDS were still pervasive in Khayelitsha, the TAC peer educators were some of the best people to consult. Not only could they describe the beliefs and questions about HIV that they heard on a daily basis, but they could also explain the strategies they used to overcome doubts or confusion about HIV/AIDS.

These interviews with peer educators were also a means of triangulating the data from the other two methods of data collection. By exploring these topics using a third method with a group of key interlocutors – those who are most likely to hear about alternative beliefs about HIV/AIDS circulating within the community – these interviews provided a check on data validity from the other two methods.

Using mixed methods also opens up the possibility that the data from these different sources will be in conflict with each other. When divergent data arises from different methods, it forces the researcher to explore why this might be so (Slonim-Nevo and Nevo 2009). Barring the existence of an obvious methodological flaw in the derivation of one set of findings, which would justify its dismissal, the discovery of this type of discrepancy should be regarded as an opportunity to explore the potential complementarity of the data sets rather than viewed as an inconsistent

contradiction. Teddlie and Tashakkori assert that these results provide “information that might otherwise be lost, including possibly new theoretical perspectives on the phenomena under investigation” (2008). Mixed methods may thus reveal “different aspects of the phenomena under investigation and thus provide an enhanced and more complete view of reality” (Slonim-Nevo and Nevo 2009, 124). Incongruities arising from different methods are discussed in more detail in Chapter 4 and 5.

Section 2: Research sites and duration

The fieldwork for this research took place over two different periods of roughly 12 weeks each, from June to September 2010, and September to December 2011.

Research for the first field visit was undertaken in Cape Town, where I was based at the Centre for Social Science Research (CSSR) at the University of Cape Town. While I maintained my affiliation with the CSSR during my second field visit, I conducted research in Khayelitsha (Image 1), a township located approximately 30 km outside of Cape Town.

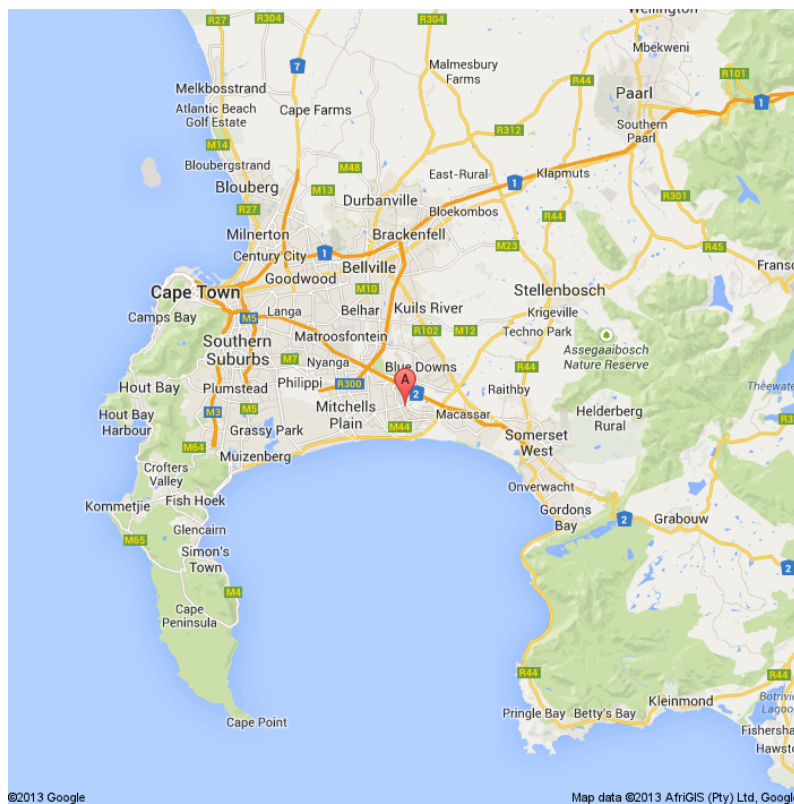


Image 1: Location of Khayelitsha, South Africa (Google Maps 2013)

These research sites were chosen for several specific reasons. First, South Africa as a country has the highest absolute number of people living with HIV and AIDS. It is also the wealthiest and most industrialized country in the region and thus, failure to effectively implement testing, prevention and treatment programmes cannot be blamed solely on economic imperatives. The burden of HIV/AIDS prevalence in South Africa, combined with the history of political denialism of HIV science at the highest levels of the political administration, has led to more existing studies on the origins and impacts of HIV/AIDS conspiracy and mistrust than other highly-affected countries in sub-Saharan Africa (Bogart, Kalichman, and Simbayi 2008; Bogart, Skinner, et al. 2011; Grebe and Nattrass 2012; Steinberg 2008a; Niehaus and Jonsson 2005; McNeill 2009; Tun et al. 2012). These existing studies provide a useful background to the current research.

Second, I narrowed my focus within South Africa because, in mid 2008, I was given the opportunity to put several question modules onto a large quantitative survey being conducted in the Cape Town Metropolitan Area. This quantitative survey – the Cape Area Panel Study (CAPS) - was a unique opportunity to measure endorsement of various alternative beliefs about HIV/AIDS across different demographic and socio-economic groups in the same geographic area. The CAPS survey was a far larger endeavour than I could have funded, organized or implemented with my own resources, and I thankfully accepted the offer to participate.

Third, my own background in South Africa provided me with useful experience and knowledge about the research context. Upon graduating from my MSc programme in 2007, I worked for a year as an HIV researcher in Durban, South Africa. I have maintained my affiliation with the research organization as a research associate since 2008. Contacts made through my time in Durban proved invaluable for developing my research project and negotiating my affiliation with the University of Cape Town.

Research in Cape Town and the Western Cape province

The decision to base my research in the Western Cape province, and in particular, the Cape Town area, came with certain opportunities and limitations. One of nine provinces in the country, the Western Cape province enjoys the highest Human Development Index score in South Africa. It also has the second-highest average annual household income after Gauteng province and the highest overall level of education in the country. It is the joint second largest contributor to South Africa's total GDP at 14.3%. The province is more equal than the rest of South Africa¹⁴, though it remains extremely unequal by international standards. Its population distribution is also unique within South Africa, with 48.8% of its residents identifying themselves as from the Coloured community, 32.8% from the Black African community, 15.7% from the White community and 1% from the Indian or Asian community. Just under half of all residents speak Afrikaans as a first language, 24.7% speak Xhosa and 20.2% speak English (Statistics South Africa 2012).

Politically, the Western Cape is also distinct from other parts of the country, being only one of two provinces that did not elect the ANC in the 1994 elections (the other being KwaZulu-Natal). It is still administered by a non-ANC party, the Democratic Alliance, led by Premier Helen Zille.

The Western Cape is exceptional also in its response to HIV/AIDS as compared to the rest of the country. The province is sometimes contrasted with the country as a whole for having a health service that "runs parallel to the First World" (Richey 2008, 2), and for creating a policy environment that "embraces science while the rest of the country lags behind" (Richey 2008, 3). Critics point out that the Western Cape has a lower disease burden than other provinces in South Africa and that its HIV prevalence rate among antenatal clinic attendees was half of the national average, at 15.4% compared to 29.5% (Richey 2008, 10). This makes a comprehensive response to HIV/AIDS significantly easier to implement. The

¹⁴ The province's Gini coefficient of 0.63 is lower than South Africa's coefficient of 0.7.

Democratic Alliance has implemented a well-funded and comprehensive programme to test, prevent and treat HIV/AIDS in the Western Cape that has almost universally better indicators than the other provinces in South Africa.

In short, though poverty and inequality is pervasive in Cape Town, my field site was situated in a province of relative privilege compared to the rest of the country. In doing research on alternative explanations about HIV/AIDS in the Cape Town metropolitan area, I chose a city within a province where the political response to HIV/AIDS has been deliberately juxtaposed with the intransigence of the Mbeki administration. Thus, Cape Town is not representative of a 'worst-case scenario' when it comes to political denialism. By not focusing deliberately on a context where HIV/AIDS science had been questioned openly by the political elite¹⁵, I aimed to capture a more general sense of public beliefs about HIV/AIDS. These particularities of my field site undoubtedly shaped my findings and will be explored in more detail in my results and discussion chapters.

Research in Khayelitsha

The site for my second round of fieldwork, Khayelitsha is an urban township located on the Cape Flats within the Cape Town municipality, located about 30 kilometers from the city of Cape Town. It was created artificially in the 1980s by the apartheid government, separated by distance and poor transport links from the white suburbs and the city bowl. Often said to be the fastest growing township in South Africa, it has a population of 406,779 (as of 2005), making it the 20th largest city in the country. Over 95% of its inhabitants identify themselves as Black African and 96.8% speak Xhosa as their first language. Approximately 62% of its residents originate from the Eastern Cape province, making Khayelitsha a city of people who have made

¹⁵ For example, a study of public distrust about HIV science would be quite different in a province such as Kwazulu-Natal, where in 2006, the political executive in charge of health, Peggy Nkonyeni, criticized the Treatment Action Campaign's support of ARVs and praised the use of traditional medicines to treat the virus (Mcetywa 2006).

the rural to urban transition¹⁶. Economically, Khayelitsha remains very poor, with approximately 70% of its residents still living in informal houses, and over 50% of residents being unemployed.

Khayelitsha was chosen as the site for my second round of fieldwork for three main reasons. First, the majority of participants in the focus group discussions came from Khayelitsha. My aim in returning to Khayelitsha for an additional round of data collection was to interview peer educators from the same community as the FGD respondents, in order to develop a sense of what challenges they faced in disseminating HIV science to the public on a daily basis.

Second, in results from the CAPS survey on ‘trusted sources of information about HIV’, the Treatment Action Campaign regularly received high scores. I wanted to explore how TAC worked with the public to develop trust in their scientific dissemination activities, particularly the Treatment Literacy Programme (TLP) conducted by peer educators. TAC’s TLP is one of the most prominent and developed programmes of its kind¹⁷, and Khayelitsha is the location of TAC’s flagship office. My base at the TAC Khayelitsha office enabled me to observe the day-to-day running of the organization, speak informally with peer educators as well as conduct formal interviews, sit in on meetings and discussions, participate in demonstrations, as well as contribute in small ways to the publicity and advocacy efforts of the organization.

Third, Khayelitsha was chosen as a site to explore alternative beliefs precisely because – as will be discussed in more detail below - it is an exemplary environment, where HIV services and support are readily available, active and well-

¹⁶ Many residents of Khayelitsha reverse this process temporarily over the holidays, returning to the Eastern Cape for several weeks in December.

¹⁷ Nathan Geffen, former Treasurer of TAC, has attributed TAC’s success to the Treatment Literacy Programme, calling it “an almost unsung programme that consumed about half of our budget” (2010, 188) as well as “pioneering and crucial to the success of the first large HAART projects” (2010, 191).

known. The exceptionality of Khayelitsha will be discussed in more detail below.

TAC Khayelitsha

Situated in the same building as the *Medicins Sans Frontieres* office and around the corner from the *Ubuntu* clinic providing comprehensive HIV services, the TAC Khayelitsha office is a hub for a host of activities relating to HIV service delivery, advocacy and education, including: organizing protests and demonstrations in the area and in the city of Cape Town, disseminating information about HIV/AIDS online and in written publications to the community, and operating the treatment literacy programmes with community health advocates and peer educators. The office is small, composed of three rooms, connected by a hallway, and is frequently full of people (Image 3). Community members sometimes come into the hallway in order to use the computers or talk to TAC members, and there is a constant flow of people in and out of the office.



Image 2: TAC Khayelitsha office (Author photo)

The TAC Khayelitsha office has been called the “strong-hold” of TAC’s work and “the only site in the nation where TAC has such a base” (Decoteau 2008, 200). TAC

became involved in Khayelitsha shortly after its founding on the steps of Cape Town's St George's Cathedral in 1998. The intention was "to establish volunteer-run branches in Cape Town's poorest townships to educate people about Aids and alert the rest of the organization to problems at their local clinics and hospitals" (Geffen 2010, 52). Khayelitsha's clinics, in partnership with MSF, piloted ARV treatment in South Africa in 2001¹⁸. By 2011, over 20,000 people had been put on ARV treatment in Khayelitsha (Treatment Action Campaign 2012). The attention devoted to Khayelitsha's ARV programme and the resources from MSF make the public health facilities in Khayelitsha better than in most public clinics in other areas, though long queues and wait times are still part of the norm (Geffen 2010).

In many ways, Khayelitsha, and by extension, the TAC/MSF Khayelitsha office is the stage on which the country's debate and controversies about HIV science have been played out. As mentioned above, Khayelitsha's clinics were the first to roll-out ARV treatment in 2001. In 2002, making a distinctive break with the Mbeki administration's stance on HIV, Nelson Mandela attended the MSF pilot programme in Khayelitsha, wearing TAC's trademark HIV-positive shirt¹⁹. Nathan Geffen, Treasurer of TAC at the time, recalls, "The symbolism was profound: the world's and the country's most beloved hero had aligned himself with our struggle" (2005, 62).

In 2005, a less positive episode drew attention to the township. Matthias Rath set up clinics in Khayelitsha to distribute multivitamins as an alternative treatment for AIDS and conduct a so-called 'clinical trial' to measure their efficacy. Geffen

¹⁸ Zackie Achmat, one of the founders and former Chairperson of TAC, was instrumental in bringing the MSF clinic to Khayelitsha. In 1999, a doctor with MSF, Eric Goemaere, came to South Africa to set up a treatment programme in Johannesburg. After being turned away by government officials, he met with Achmat, who persuaded Goemaere to stay and set up the clinic in Khayelitsha (Power 2003; Geffen 2010; Grebe 2011).

¹⁹ This shirt, featuring the words 'HIV positive' on the front, was conceived by TAC as a way of showing solidarity to those living with HIV. It was based on the apocryphal story of the King of Denmark who wore a Star of David in solidarity with Danish Jews and asked all his countrymen to do the same when Hitler invaded the country (Power 2003).

marveled at the audacity of this act: “This is probably TAC’s most active area in the country. It is where we helped MSF, the City of Cape Town Municipality and the Western Cape provincial government implement the country’s first community-based, public-sector PMTCT and HAART programmes. Here people had seen the benefits of ARVs first-hand and now Rath had moved in to try to undo this work” (Geffen 2010, 139). Numerous people died as a result of Rath’s “clinical trial” although final numbers have never been confirmed (Geffen 2010, 141). In April 2005, the Department of Health held a public meeting in Khayelitsha, attended by Matthias Rath. Some activists hoped that Health Minister Tshabalala-Msimang would use this opportunity to publically oppose Rath’s unethical activities in the township. Instead, she famously stated, “I am not for TAC and I am not for Rath, I am for the ANC” (Cullinan and Thom 2009; Geffen 2010). Yet, as has been well documented, she openly supported Rath’s work (Geffen 2010, 143).

By choosing to conduct interviews with activists and volunteers at the TAC Khayelitsha office, I thus situated myself in a rather exceptional environment in South Africa. The success of TAC and MSF in Khayelitsha is often said to have inspired a sort of challenge. As Hermann Reuter, the MSF doctor in charge of the Lusikisiki project explained:

Everybody started saying, ‘Ja, you can do it in Cape Town, but Cape Town is not the rest of South Africa. Cape Town has a lot of academic doctors. If there are complications, there is Groote Schuur and Tygerberg hospitals, two of the best hospitals in the country, just around the corner. Why don’t you go somewhere where the drug supplies arrive once every three months when you are lucky? Go somewhere where there are no doctors and half the nurses’ posts are unfilled. See if you can put people on ARVs there’. So we came to Lusikisiki (Steinberg 2008a, 86)

Khayelitsha was thus framed as ‘too easy’ and contrasted with the challenges of the rural site of Lusikisiki. Lusikisiki was a challenge, not only because of limited personnel and poor drug supply, but because, as Robins notes, “alternative conceptions of illness, beliefs in witchcraft, and AIDS stigma and denial seemed much more entrenched in these rural settings” (Robins 2009c).

In short, Khayelitsha is often viewed as a run-away success story, lacking many of the challenges facing rural HIV programmes. Thus, to study alternative beliefs in Khayelitsha is to study them in a place they are least expected to exist – if TAC’s stated mission to convert members to “a scientific worldview”²⁰ has succeeded. However, this characterization of Khayelitsha as a site of overwhelmingly success can obscure persisting uncertainty and distrust of HIV science among some urban South Africans. Steinberg observes that when people start coming for treatment, it is sometimes seen as a signal that doubts about HIV science have been replaced with confidence and certainty:

Those involved in the treatment programme assumed that the doubts had gone; they spoke of them only in the past tense. In truth, the doubts had retreated into a zone of deep privacy. They were not in the heads and the hushed conversations of people like Sizwe: neutral people, agnostic people, neither in one camp nor another (2008a, 149).

If alternative beliefs continue to circulate in Khayelitsha, the location of the flagship TAC office and MSF-staffed clinic, the site of so many battles and successes in early ARV treatment, what can this tell us about the nature of alternative beliefs in South Africa today?

My interviews with TAC peer educators were conducted with reference to the unique history of the township and of the organization. In our discussions, I probed their experiences during Mbeki’s administration, their current activities in disseminating HIV science to the public, and the connection (if any) that they saw between the two.

Section 3: Participant recruitment and study instruments

This study employed a mixed-methods sequential explanatory design (Ivankova, Creswell, and Stick 2006) characterized by collecting and analyzing first

²⁰ This is a reference to a comment made by a veteran AIDS activist to Steven Robins, that the “fundamental goal of TAC was to convert members to a scientific world view” (Robins 2009b, 95)

quantitative and then qualitative data in three consecutive phases within one study. The different phases of the research design, along with the criteria for participant recruitment and the study tools are outlined below.

CAPS survey

Quantitative data collection was completed in October 2009 through the Cape Area Panel Survey (CAPS), a Cape-Town based longitudinal survey. This was the fifth wave of the survey, involving 2905 respondents aged between 19 and 29, from a representative sample of all racial groups and income classes. Original recruitment for the first wave of CAPS occurred in 2002, using a two-stage sample, stratified by the three main population groups in South Africa²¹ (African, Coloured and White). The first stage involved selecting clusters, categorized by predominant population group, and in the second stage, households were randomly selected from clusters to achieve a representative sample (Grebe and Natrass 2012). In total, 4752 young adults were interviewed from these households (Cape Area Panel Study 2006). In subsequent waves, teams of research assistants follow up on respondents' locations year after year for inclusion in the next round²². Grebe and Natrass note that,

²¹ The 1950 Population Registration Act enshrined these three racial categories for classification of the South African public (subsequently adding the fourth – Indian). In practice, the classification system was somewhat arbitrary in that census enumerators would determine the appropriate category despite lacking formal training. The post-apartheid government has maintained these categories and as Seekings' observes, "there remains a close correlation between official apartheid-era racial classification, post-apartheid self-classification and post-apartheid classification by other people" (2007, 9).

²² Wave 1 also collected information on all members of these young people's households, as well as a random sample of households that did not have members age 14-22. A third of the youth sample was re-interviewed in 2003 (Wave 2a) and the remaining two-thirds were re-visited in 2004 (Wave 2b). The full youth sample was then re-interviewed in both 2005 (Wave 3) and 2006 (Wave 4). Wave 3 also includes interviews with approximately 2000 co-resident parents of young adults. Wave 4 includes interviews with a sample of older adults (all individuals from the original 2002 households who were born on or before 1 January 1956) and all children born to the female young adults. The study covers a wide range of outcomes, including schooling, employment, health, family formation, and

although there has been a decreasing sample size in subsequent waves of the CAPS survey, due to attrition, and that this has affected the representativeness of the sample, the sample is still “broadly representative of urban Africans and Coloureds” (2012, 764).

I included seven questions about conspiracy beliefs and fifteen questions about trust in HIV-related information in the 2009 CAPS survey. These questions were derived from similar studies conducted in the US and modified to the South African context in a pilot. Conducted in January and February 2009, the pilot involved 28 individuals, both male and female, who represented the target population. In total, African (n=8 male, n=8 female), Coloured (n=4 male, n=4 female) and White (n=2 male, n=2 female) respondents yielded important information about these two sections. No major adjustments were made to the questions on trust as a result of the pilot.

More substantial modifications occurred in the questions about alternative beliefs. A significant group of people responded “Don’t know” to the original questions, prompting discussions about how to modify the possible response options. It was felt that some respondents may be answering “Don’t know” when in fact they are undecided about their feelings towards the given statement. Given the strongly worded nature of the statements, it is possible that respondents were not certain enough of their opinions to answer ‘agree’ or ‘disagree’. It is also possible, as Rodlach (2006) suggested in his own attempt to quantify conspiracy beliefs, that respondents were cued into the political significance of endorsing conspiracy beliefs, and answered in an indefinite way in order to avoid being judged. In all cases, it was deemed necessary to create an additional response option, which is how the ‘neither agree nor disagree’ option came to be included. Respondents were told only about the five main response options, but would be able to answer “Don’t know” only if they themselves volunteer this response. The other modifications

intergenerational support systems. For more information, see:
<http://www.caps.uct.ac.za/index.html>

resulting from the pilot were to the conspiracy belief questions themselves. Several questions had confusing or misleading wording that respondents flagged to interviewers. For example, an original questions read: “There is a cure for AIDS, but it is being withheld from the poor” and due to confusion (people questioned why it was being withheld from only “the poor” and did not always understand the word “withheld”) was changed to “There is a cure for AIDS but it is being kept a secret from some people”. Several questions were also cut due to time and space constraints (the first survey took over 2 hours to administer). The modules as they appeared in the final survey are shown below.

Table 1: CAPS survey questions on alternative beliefs about HIV/AIDS

G.53	How strongly do you agree or disagree with the following statements: SHOW CARD B	Strongly agree	Agree	Neither agree/disagree	Disagree	Strongly disagree	Don't know
G.53.1	A lot of important information about AIDS is being kept from the public.	1	2	3	4	5	9
G.53.2	You can get HIV from condoms.	1	2	3	4	5	9
G.53.3	HIV was deliberately created by humans.	1	2	3	4	5	9
G.53.4	There is a cure for AIDS but it is being kept a secret from some people.	1	2	3	4	5	9
G.53.5	AIDS was created by scientists in America.	1	2	3	4	5	9
G.53.6	AIDS was invented to kill black people.	1	2	3	4	5	9
G.53.7	HIV is harmless and does not cause AIDS.	1	2	3	4	5	9

Table 2: CAPS survey questions on trust in HIV information sources

G.49	How much would you say you trust HIV information from the following sources? Would you say not at all, not really, somewhat or a lot? SHOW CARD F	Not at all	Not really	Somewh at	A lot	Don't know
G.49.1	Nurses	1	2	3	4	9
G.49.2	Doctors	1	2	3	4	9
G.49.3	Sangoma or Inyanga (Traditional healer)	1	2	3	4	9
G.49.4	Government Pamphlets	1	2	3	4	9
G.49.5	Radio	1	2	3	4	9
G.49.6	Newspaper	1	2	3	4	9
G.49.7	Community leaders	1	2	3	4	9
G.49.8	Religious leaders	1	2	3	4	9
G.49.9	Treatment Action Campaign (TAC)	1	2	3	4	9
G.49.10	South African National Civic Organisation (SANCO)	1	2	3	4	9
G.49.11	Our former Health Minister Manto Tshabalala-Msimang	1	2	3	4	9
G.49.12	Our current Health Minister Barbara Hogan ²³	1	2	3	4	9
G.49.13	Our former President Nelson Mandela	1	2	3	4	9
G.49.14	Our former President Thabo Mbeki	1	2	3	4	9
G.49.15	ANC leader Jacob Zuma ²⁴	1	2	3	4	9

Focus group discussions

Following the initial analysis of CAPS 2009 data, focus group discussions were organized with a sub-group of CAPS respondents. These took place from July-September 2010.

Four of the questions about alternative beliefs from the CAPS survey were used to inform the sampling for the focus groups (Table 1):

1. HIV was deliberately created by humans
2. There is a cure for AIDS but it is being kept a secret from some people
3. AIDS was created by scientists in America

²³ This survey was created before Barbara Hogan had been replaced as Minister of Health by Aaron Motsoaledi.

²⁴ This survey was created and administered before Jacob Zuma was elected President of South Africa in April 2009.

4. AIDS was invented to kill black people

Based on their answers to the above questions, respondents were grouped into one of four different focus groups. Group one included respondents who answered ‘strongly agree’ or ‘agree’ to all of these questions and was categorized as ‘endorsers’. Group two was made-up of respondents who answered “strongly disagree” or “disagree” to all the questions and labeled ‘non-endorsers’. Group three was composed of a blend of these two groups and called “mixed”. The fourth group was composed of people who answered “neither agree nor disagree” to the conspiracy belief questions and categorized as “uncertain”.

In addition to these recruitment criteria, focus group discussions were limited to African respondents living in Khayelitsha. While a significant minority of all CAPS respondents endorsed these conspiracy beliefs, African respondents disproportionately endorsed these statements as plausible. Figure 3 shows these results.

Table 3: Percentage of respondents answering “strongly agree” or “agree” to alternative belief questions on 2009 CAPS survey

	HIV was deliberately created by humans	There is a cure for AIDS but it is being kept a secret from some people	AIDS was created by scientists in America	AIDS was invented to kill black people
African	21.1	18	15.7	16
Coloured	11.9	3.3	3.5	0.8
Indian²⁵	9.1	18.2	9.1	0
White	7.9	0.7	0.7	0

²⁵ The percentage of Indian respondents endorsing these beliefs is slightly misrepresentative since there were only 11 Indian respondents in the 2009 CAPS sample.

The restriction of focus group participants to African CAPS respondents was made both because African respondents were more likely to endorse conspiracy beliefs than other groups, and also because the African population in South Africa has a far larger HIV prevalence than others, making obstacles to reaching this group, such as distrust of HIV science, of special concern. Recruitment was limited to residents of Khayelitsha in order to explore how alternative beliefs about HIV/AIDS were discussed by individuals from the same social context. Additionally, and more pragmatically, recruiting solely from Khayelitsha facilitated the transportation of respondents to the research site, at the Centre for Social Science Research at the University of Cape Town.

The stratification of focus groups into the sub-categories listed above was designed to capture the way alternative beliefs about HIV/AIDS were represented and received collectively in peer groups. Underlying questions that guided the design of the focus group discussion guide included: Is the expression of suspicion or doubt about the official wisdom on HIV and AIDS stigmatized, given the recent history of controversy surrounding Thabo Mbeki's intransigence? Or is such mistrust normalized? Will there be visible differences between 'strong endorser' and 'strong non-endorser' focus groups? Is mistrust about HIV science widely shared among people, or kept private? Will people openly disagree about HIV science and alternative explanations for HIV/AIDS? Such information could only be yielded through guided group discussions.

As outlined in the literature review, many quantitative studies have examined the topic of alternative beliefs and mistrust about HIV/AIDS on an individual level – what characteristics, beliefs, experiences are associated with these beliefs. In contrast, qualitative studies of alternative beliefs about HIV/AIDS have often focused on the macro dynamics of such beliefs, by examining perspectives and experiences at the level of a cultural phenomenon. These studies suggest that beliefs might be similar among all peoples of similar experience. Aiming to situate my analysis between the individual and cultural level, these focus group discussions

explored individual variation within a cultural and ethnic group while also exploring collective experiences.

The focus group guide was designed to allow alternative beliefs about HIV/AIDS, including conspiracy theories, to emerge naturally in conversations, before probing further about specific beliefs (Albrecht, Johnson, and Walther 1993; Wilkinson 1999). The guide was also intended to explore whether endorsement of conspiracy beliefs was stigmatized, openly supported, or contested. The potential for focus groups to lead to 'censorship' or 'conformity' within the group has been well-documented (Carey 1995). The four different focus group categories was seen as a way of observing how alternative beliefs are represented, debated, and discussed, and in particular, whether individuals seemed swayed by these dual pressures. The focus group discussion guide is included in Appendix A.

After CAPS respondents were identified as fitting into one of the four categories of interest and meeting demographic criteria (African and living in Khayelitsha), they were contacted by a male or female research assistant employed at the Centre for Social Science Research. The aims of the study were explained and the respondent was asked if they were interested in participating. Though every effort was made to keep the composition of focus groups as unbiased as possible, it should be noted that some of the initial people contacted did not end up participating in this study, either because their contact details had changed or because they refused. Thus, these focus groups may not be representative of the entire African CAPS sample; it is certainly possible that people with the most strongly conspiratorial beliefs avoided participating in a university-sponsored study.

All focus groups were conducted in Xhosa by a male or female research assistant, digitally recorded, and thereafter transcribed and translated. A random sample of transcripts were back translated by research assistants in order to ensure good translation validity. Focus group participants were assigned a number at the beginning of the session, and asked to refer to themselves by that number before

making a comment. While this introduced a somewhat artificial quality to people's remarks (and when discussions became more animated, participants sometimes forgot to note their number), this method enabled a reader of the FGD transcripts to follow the specific remarks of different FGD participants over the course of the discussion. The tendency among some analyses of focus groups to decontextualize comments and view individual remarks on their own, outside of the group interaction, has been heavily critiqued by qualitative researchers (for example, Carey 1995; Kitzinger 1994; Wilkinson 1999; Duggleby 2005; Morgan 2007). The numbering of respondents permitted an analysis of group interaction and how individual respondent views evolved in response to others' comments.

Longitudinal Design Considerations and Peer Educator Interviews

Steinberg's (2008; 2010) observation that alternative beliefs about HIV/AIDS evolve over time was a significant consideration in this study. It would have been useful to conduct repeated focus group discussions with 2009 CAPS respondents in order to explore how these beliefs change in response to current observations and events. However, it would have been difficult to recreate the same composition of the focus group discussion for a second or third conversation. Furthermore, given that these respondents have been participating in a longitudinal study since 2002, and have regularly been accessed for follow-up studies, it was also deemed important not to burden these respondents with repeated requests for interviews.

Rather than attempt repeated focus groups, therefore, a complementary method was utilized. Peer educators from the Treatment Action Campaign's Khayelitsha office were interviewed to explore the alternative beliefs about HIV/AIDS that they hear on a daily basis. In working in the same community as FGD respondents, TAC peer educators could reflect the concerns, queries and views of their clients, and comment on the changing nature of alternative beliefs in the community.

TAC peer educator interviews

Both Community Health Advocates (CHAs) and Treatment Literacy Practitioners (TLPs) – hereafter referred to collectively as peer educators - who work for the Treatment Action Campaign (TAC) in Khayelitsha township were interviewed for this phase of fieldwork. The aim of TAC’s work with CHAs and TLPs is to empower patients with information about HIV and antiretroviral treatment. TAC communicates information about HIV in a straight-forward biomedical manner, with answers to questions such as “What is a CD4 count?” and “How do we know HIV tests are accurate?” in their newsletters and pamphlets. Working in conjunction with Mary-Jane Matsolo, Head of Policy and Research, and Amelia Mfiki, Coordinator of Peer Educators involved in the Treatment Literacy Group, I engaged in participant observation and in-depth one-on-one interviews from September – December 2011. During this time, I volunteered at the Treatment Action Campaign’s Khayelitsha office, performing various functions in the communications department (for example, drafting newsletter content and updating the TAC blog), while conducting data collection. This was done both in order to contribute to the organization as a reciprocal gesture, as well as to observe the day-to-day operations of TAC in one of its flagship offices.

The range of questions covered in one-on-one interviews included:

- What kinds of challenges to HIV science, in the form of doubts, mistrust or conspiracies, have peer educators heard in the course of their work?
- How have they responded to any issue of mistrust, doubts or confusion?
- What techniques have they used to make their job of communicating complex scientific facts easier?

The use of this method brought additional benefits, in that it enabled exploration of the strategies employed by peer educators to counter alternative beliefs about HIV/AIDS. These findings are discussed in Chapter 6.

In total, 20 in-depth interviews with peer educators were undertaken, including two with the leaders of the Treatment Literacy Programme and the Community Health

Worker programme. All participants were given the opportunity to select a pseudonym in order to shield their identity. Interviews were tape recorded, transcribed and, if conducted in Xhosa, translated into English.

Section 4: Description of research participants

Focus group discussions

In total, 10 focus group discussions (FGDs) with African respondents (n=47), five with men and five with women, were conducted. All FGD participants came from Khayelitsha township. Focus group discussions lasted from 40 minutes to 2 hours, depending upon the respondent. The composition and description of each focus group is seen in Table 4.

Table 4: Focus group discussion participants

Number	Gender	Type	Date	No. of Ppl
1	Female	Mixed	July 8 2010	4
2	Male	Endorse	Aug 11 2010	4
3	Female	Non Endorse	Aug 12 2010	5
4	Male	Non Endorse	Aug 13 2010	4
5	Male	Mixed	Aug 15 2010	6
6	Female	Mixed	Aug 18 2010	5
7	Female	Mixed	Aug 21 2010	5
8	Female	Non Endorse	Aug 25 2010	3
9	Male	Uncertain	Aug 27 2010	5
10	Male	Mixed	Aug 28 2010	6
TOTAL				47

Bias and representativeness in the focus group discussions

Five out of 10 focus groups ended up being 'mixed' because of the difficulty of recruiting specific participants for particular dates. This complicated the aim of distinguishing between participants from different sub-groups of the CAPS survey and contrasting their responses in the analysis, as there was only 1 focus group entirely composed of 'endorsers'. This is partly because there are comparatively fewer female endorsers in the CAPS sample in Khayelitsha in particular, making recruitment difficult from this small group. Women also cited more childcare responsibilities that restricted their ability to attend a focus group in the city of Cape

Town. However, there were three groups composed entirely of non-endorsers, allowing for observations about what these individuals believe about HIV/AIDS. Furthermore, the 'mixed' groups enabled insights into how alternative beliefs about HIV/AIDS are discussed in the public sphere. As will be discussed further in Chapter 4, similarities and differences across focus group categories yielded important insights into the nature of alternative beliefs.

TAC Interviews

Twenty interviews were conducted with peer educators, 13 were with female peer educators and 7 with male peer educators. Five were current or former Community Health Advocates (CHA), 14 were current or former Treatment Literacy Practitioners (TLP), and 1 worked as a condom distributor. They ranged in age from 24 to late-40s and had worked at the Treatment Action Campaign for between 1-7 years. The characteristics of the peer educators in this sample are set out below.

Table 5: Peer Educators from TAC Khayelitsha Office

No.	Name	Type of peer educator	Date	Language of Interview
1	Lina	CHA	Nov 25 2011	English
2	Velile	CHA	Nov 30 2011	English
3	Sobza	CHA	Nov 30 2011	Xhosa
4	Sonia	Trainer CHA	Nov 30 2011	Mixed
5	Abongile	CHA	Nov 30 2011	Xhosa
6	Nthabiseng	TLP	Dec 6 2011	Mostly English
7	Snax	TLP	Dec 6 2011	English
8	Pretty	TLP	Dec 6 2011	Xhosa
9	Andile	TLP and Trainer	Dec 7 2011	English
10	Pemeido	TLP	Dec 7 2011	English
11	Nomandithini	TLP	Dec 7 2011	Xhosa
12	Lloyd	TLP	Dec 7 2011	English
13	Neliswa	Former TLP, now District Coordinator	Dec 9 2011	English
14	Chunyiswa	TLP	Dec 9 2011	English
15	Bonelwa	TLP	Dec 12 2011	Xhosa

16	Nonqaba	TLP	Dec 12 2011	Xhosa
17	Poppy	TLP	Dec 12 2011	English
18	Isaac	Condom distributor	Dec 13 2011	English
19	Ntombekhaya	TLP	Dec 13 2011	Xhosa
20	Amelia	Coordinator of TLP	Dec 13 2011	English

Section 5: Ethical and Practical Considerations

Research ethics for this project were reviewed and approved by the Centre for Social Science Research at the University of Cape Town and the London School of Economics (see Appendix B for ethics document). Specific ethical and practical issues are outlined below.

Informed Consent

Informed consent was sought by providing written and oral information about the goals of the study prior to the commencement of focus groups and in-depth interviews²⁶. After having a discussion with a trained research assistant over the phone before arranging to participate in the focus group discussions, respondents were provided with an information sheet about the project explaining its implications and also had the project aims and objectives verbally explained prior to the commencement of the focus group discussion. Respondents' oral and written consent was sought to tape record the discussion.

The content of the focus group discussions and in-depth interviews were not intended to be disturbing or overly personal. Had the discussions proved unsettling for any participants, the focus group discussion facilitator was also a trained HIV counsellor and had experience providing counselling and advice to similar groups. However, in the course of several interviews with TAC peer educators, personal

²⁶ See Appendix C for the informed consent form for the focus group discussions.

issues and experiences were revealed, including HIV status. These disclosures are not included in this dissertation and are only alluded to in a general manner in order to illustrate how certain peer educators make use of their HIV status to garner credibility with clients; this is discussed in more detail in Chapter 6.

Anonymity and Confidentiality

Anonymity and confidentiality was fully protected, as no reference to specific information reported on the CAPS survey was discussed in reference to any FGD participants. As discussed above, participants in the FGD were assigned a number in order to avoid using names as identifiers (for example: FGD participant #2). Data analysis on the content of focus groups used the identification numbers as reference points. The transcripts of all focus groups were made available only to a small number of individuals in the CSSR office who were involved in discussing the FGD content (Nicoli Nattrass and Eduard Grebe). Peer educators were also provided verbal explanations about the nature of the research and given the option of selecting a pseudonym in order to avoid being identified in quotations.

Compensation

Whether to pay respondents for participation in research is contentious. Paying respondents has been shown to increase participation and reduce attrition in longitudinal studies, particularly among low-income respondents (Goritz 2008; Van den Brakel, Vis-Visschers, and Schmetts 2006). Some researchers, however, argue that introducing incentives will reinforce “paternalistic roles” and the inequality of relationships between the researcher and the researched (Yancey and Rainwater 1970). “Researchers may become accepted for what they provide, not for what they are”, and in this process “the relationship may become commodified and instrumental” suggest Fine and Sandstrom (1988, 25).

Fine and Sandstrom’s reference to instrumentality is noteworthy, in that they frame it as something to avoid – and by extension, something that *can* be avoided if research relationships are managed properly. However, Weinreb and colleagues

suggests that *all* research relationships are inherently instrumental; essentially, the researcher needs the researched (as sources of data collection) far more than the reverse. A failure to recognize this innate dynamic can lead to exploitation by the researcher, a risk that increases when researchers “use more intimate methodologies”, as respondents who became close to researchers during participant observation or in-depth interviews can feel deserted when researchers leave the field (Weinreb, Madhavan, and Stern 1998). The risk of exploitation is also particularly present with low-income respondents.

In recognition of these considerations, compensation was provided to all focus group participants in the form of both monetary and in-kind contributions. In addition to being provided with transportation to the focus group venue (using a privately hired van to pick up participants at their homes), participants were given a contribution for the cost of their return transportation and a 75 Rand voucher to Checkers, a local grocery store. Participants were also provided with lunch and a hat or scarf from the CAPS survey. It was seen that these incentives would adequately compensate participants for their time while not creating excessive inducement to participate in the research (Porter and Whitcomb 2003). Furthermore, these incentives were in line with previous CAPS and CSSR protocol with regards to research participation.

Compensation and reciprocity was more complex in my interviews with the peer educators at TAC. I was mindful of the fact that peer educators were taking time out of their busy daily schedule to find time to speak one-on-one with me. However, after discussion with Amelia, the coordinator for the Treatment Literacy Programme, it was not deemed appropriate to formally compensate peer educators for speaking with me about their work during office hours. I did make small snacks and drink available during interviews and occasionally would take a respondent out for lunch with me if we were conducting our interview over their meal-break.

Beyond these small in-kind gestures, I volunteered at the TAC Khayelitsha office. I

worked mainly with Mary-Jane Matsolo, Head of Policy and Research, assisting with various functions in the communications department such as drafting newsletter content and updating the district blog. My intention in this work was partly what Knox calls “imitative participation” (2005), that is, participation for the purposes of gathering data for research, and partly an attempt to ‘give back’ to the organization, whose aims and objectives I respect and admire.

During this research the Khayelitsha office did not have a working camera, so it rested on staff members to use their own equipment and phones to provide photo documentation. As an additional gesture towards recognizing the importance of reciprocity in research relationships, my husband, Scott Naysmith visually documented TAC protests and demonstrations during the course of my fieldwork. When TAC Khayelitsha members were captured in these photos, I had them printed and distributed to TAC peer educators and staff. Several of Scott’s photographs were included in *Equal Treatment*, TAC’s newsletter, and in blog posts²⁷.

Safety

No major safety concerns existed for the survey or the focus group component of this research. As the Centre for Social Science Research team conducted the CAPS survey, I was not physically involved in data collection activities. All focus group discussions took place at the Centre for Social Science Research at the University of Cape Town.

Of greater concern was the portion of research focused on interviewing peer educators at the Treatment Action Campaign office in Khayelitsha township. Undertaking this data collection involved driving to and from Khayelitsha township several times a week. The route from Cape Town to Khayelitsha along the N4 highway is notoriously dangerous. I saw several multi-car accidents, usually involving public taxis, during the course of fieldwork. I mitigated this risk by driving

²⁷ Blog posts can be accessed here: <http://www.tac.org.za/district/world-aids-day-2011/>

only during daytime hours. Alternative means of transport, using either public taxi or train, were not seen as appropriate to mitigate risk.

As has been discussed in more detail above, Khayelitsha township experiences high rates of crime and violence. I was mindful that I would stand out from other people and might be a target for robbery due to a perception of wealth. Another researcher affiliated with the CSSR at UCT had been attacked with a knife in Khayelitsha earlier in 2011, due to an altercation over her cellphone (Personal communication). The majority of my time in Khayelitsha, however, was spent within the TAC office. When I did venture around the township, it was always in the company of several members of TAC and my research assistant, all of whom were well known in the community. Several times, I accompanied TAC members to protests at the District Courthouse and once to an informal settlement where there had been several unsolved cases of sexual violence against young girls. In these cases, I trusted my research assistant and other TAC members to tell me which areas were unsafe and if a situation seemed to be becoming more combative.

Section 6: Limitations of the methodological approach

There are several limitations of the methodological approach taken in this study. First, the generalizability of results may be limited by the specificity of my research site. As discussed above, the Western Cape in general - and specifically Khayelitsha - is an exceptional environment in many respects, and studying alternative beliefs about HIV/AIDS in this context may not offer insights into such beliefs in other urban centres in South Africa. My interviews with peer educators from the Treatment Action Campaign are also not generalizable for a similar reason; TAC is a high profile, extremely well-coordinated organization that has achieved international and national recognition, and as such, the experiences of peer educators working for TAC may not represent the experiences of other peer supporters in South Africa.

Second, I relied on research assistants for translation throughout the research

process. Though I took Xhosa classes in Cape Town prior to beginning fieldwork, I did not reach a level of competence to operate autonomously in data collection activities. As a result, all focus group discussions were conducted in Xhosa by two trained research assistants from the CSSR, Ncedeka Mbune and Thobani Ncapayi. Both Ncedeka and Thobani had previous experience conducting focus group discussions and were trained in advance on the specific content of this research. They both live in Khayelitsha and offered valuable insight into the formation of focus group topics and the interpretation of data following the FGD.

At times, transcripts of these discussions reveal lines of inquiry that were regrettably dropped, or an abrupt change of questioning that may have affected the overall tone of the discussion. Such omissions or missteps were, of course, only visible after the focus group discussion had been completed. When such a situation was noted, it provided an opportunity to improve future focus group facilitation. Thus, the process of conducting the focus groups was highly iterative and the quality over time of these discussions improved.

Only in two instances did respondents raise an issue in the focus groups that, in retrospect, should have been addressed before the data collection process was complete. Both of these concerned requests for further information. When discussing the origins of HIV in a mixed female focus groups, one respondent asked, "Could you tell us about it yourself?" A male respondent echoed this question, inquiring, "In all these questions you have asked us – at the end you are going to give us answers when we are done here?" As these two requests occurred near the end of data collection, they only came to my attention after this process was complete. Thus, I was not able to formulate an appropriate response.

Upon reflection, this raises an issue relating to how the research was conceptualized. Asking people about alternative explanations involves creating a safe space to discuss a range of thoughts, beliefs and experiences. The facilitators were, of course, trained to keep the focus group discussions open-ended and not

identify a particular 'correct' scientific perspective. However, this clearly created tension with some respondents who wanted to use the opportunity to gain further clarity on key scientific issues. Had we modified the study design to include an element of debriefing and education at the end, we might have inadvertently shamed those people who had raised beliefs that differed from the scientific consensus. And yet, not providing this clarity when it was requested may have left respondents with further questions. If undertaking this type of research project again, I would endeavor to provide additional resources at the conclusion of the focus group discussion to those who requested it.

Interviews with peer educators were conducted in whichever language the respondent preferred; both Thobani and myself were present for all interviews. As discussed, Thobani is a skilled and knowledgeable research assistant, and frequently brought insights into the interview that I would not have been able to capture otherwise. As a resident of Khayelitsha with prior experience as a peer educator with TAC, Thobani was uniquely situated to question current peer educators about their experiences. As a result, I felt his presence facilitated the research process rather than hindered it. There were undoubtedly situations when fluency in Xhosa would have allowed me to grasp or perceive more of what was going on – my dependency on a translator or accommodating colleagues meant that important interactions may have occurred right in front of me without my taking notice.

Third, my nationality and race unquestionably influenced my data. Previous researchers have noted how difficult it is to conduct research on politically sensitive issues, particularly when the researcher's country of origin and identity comes with certain associations (Scheyvens and Storey 2003, 7). In this case, I was conscious of the fact that a North American asking about the perceived origins of HIV and AIDS may be seen to speak from a position of scientific privilege. Rodlach noted similar limitations in his 2006 study in Zimbabwe and eventually concluded that a quantitative survey on this topic was made difficult, in part, for these reasons.

I was acutely aware of these potential sensitivities during the pilot of the focus group discussion. The group was arranged in a conference room at the University of Cape Town and I had originally intended to introduce myself, explain that I did not speak sufficient Xhosa to participate or facilitate the discussion, and then sit quietly to the side taking notes about the general mood and non-verbal activities taking place. Although all participants agreed to this arrangement, and despite my assurances that I did not understand what was being said, it became clear from sideways glances and awkward pauses during the discussion that my presence was noted throughout. Thereafter, I decided to introduce myself to the group, explain the study, seek agreement for the discussion to be recorded, and then retreat to an adjacent room for the rest of the discussion. This enabled me to be on-hand if needed, such as if there was a malfunction with the digital recorder, but not present in the room during the focus group. All subsequent discussions occurred in this way and both research assistants reported that people spoke much more freely as a result.

During my time spent at the TAC Khayelitsha office, I was often the only white foreigner in the TAC office, although TAC has extensive contacts with international organizations and the neighbouring MSF office employed several white South Africans and foreigners who were sometimes present at meetings or demonstrations. Being mindful of the ways in which my foreign identity affected my research relationships did not prepare me for the revelation one day upon discovering that at least one of the TAC peer educators thought I was a white South African. I had thought my accent would 'give me away' as a foreigner but this was not the case. This recognition forced me to reflect on what it might mean to be perceived as a fellow South African citizen during my activities at TAC rather than as a foreigner. I had assumed my foreignness would allow me to ask certain questions about South African history and politics that might have been strange or naïve for a South African to ask. When I was made aware that some perceived me as a South African, I made sure to clarify this in future encounters, as I thought this would enable me to ask questions about context and history that a South African would be

perceived as already knowing.

Section 7: Analysis, interpretation and representation

Analysis of the quantitative data from CAPS is used in this dissertation in purely descriptive form, using SPSS statistical software (IBM Corp 2010). More complex regression analysis has been undertaken with these variables of interest by Eduard Grebe and Nicoli Nattrass (Grebe and Nattrass 2012; Nattrass 2012). These publications were used to help situate this study and to compare and contrast against qualitative findings.

Qualitative data analysis of the focus group discussions, interviews with peer educators and fieldnotes, has been facilitated by the use of Nvivo software (Nvivo 2009). Data was analyzed using open-coding (i.e., identification and categorization of recurring patterns), and axial coding (i.e., re-examination of categories to see how they are linked), marginal remarks, comparisons, and memo-writing (Strauss and Corbin 1990). I approached initial analysis as an interactive process, with data abstracting, coding, and categorization as a simultaneous enterprise for the purpose of identifying and/or confirming major themes and patterns to validate my conceptual framework. As soon as several interviews were transcribed, I met with my research assistants to review the transcripts, discuss emerging concepts, and triangulate across perspectives to compare their interpretations and impressions of the data (Denzin and Lincoln 1998).

Saturation

Preliminary analysis of the content of interviews began when I was still collecting data, allowing for an iterative process between investigation and analysis. Once a topic had presented itself – what Glaser (2002) calls “earning its way” – data collection and analysis continued until no new insights emerge. Though each peer educator’s experiences and perspectives were unique in their own way, I found that general thematic saturation occurred by the 15th interview. Nonetheless, I continued with five additional interviews in order to ensure theoretical saturation and to

capture unique roles in the peer education programme, such as Amelia, the TLP trainer.

Conclusion

This chapter has outlined the methodological approach taken in this study, highlighting the rationale for a mixed-method study to explore the topic. It discussed the research sites, tools, recruitment and description of participants, and considered various ethical and practical implications for this research. Finally, this chapter highlights the limitations of the methodological approach and outlines the framework for analysis.

The next chapter is the first empirical chapter and will examine the plausibility of alternative beliefs about HIV/AIDS among the study population.

Chapter 4: Alternative beliefs about HIV/AIDS in post-apartheid Cape Town

“The willingness to accept rumors that others dismiss is grounded on the politics of plausibility, tied to knowledge of historical circumstance” (Fine 2007, 15).

Introduction

As discussed in Chapter 2, alternative beliefs about HIV/AIDS have the power to challenge the implementation of prevention and treatment programmes, by weakening public understanding of, and trust in, HIV science. It is therefore crucial to study the extent to which alternative beliefs are endorsed, why they continue to resonate, and how we might better address them in future campaigns.

This chapter explores alternative beliefs about HIV/AIDS endorsed by African respondents in Khayelitsha Township, highlighting findings around two dominant themes: Speculation about the origins of HIV/AIDS as a deliberately man-made virus, and confusion or distrust surrounding the existence of a cure. It also draws on insights from peer educators from the Treatment Action Campaign who, in their role as “antennae” within their communities (Dickinson 2011), are able to report on key questions and doubts encountered as part of their daily routine. By focusing on alternative beliefs about HIV/AIDS from the perspectives of both respondents and a group of key interlocutors, this chapter provides a comprehensive view of prevalent beliefs and the rationale of those who hold them. Notably, most respondents avoided attributing the origins of the virus or the withholding of a cure to the deliberate malevolence of scientists, doctors or foreigners. Rather, respondents viewed these aspects of HIV science as inconsistent given their experiences and observations of past and present inequalities and disconnects in logic with scientific facts.

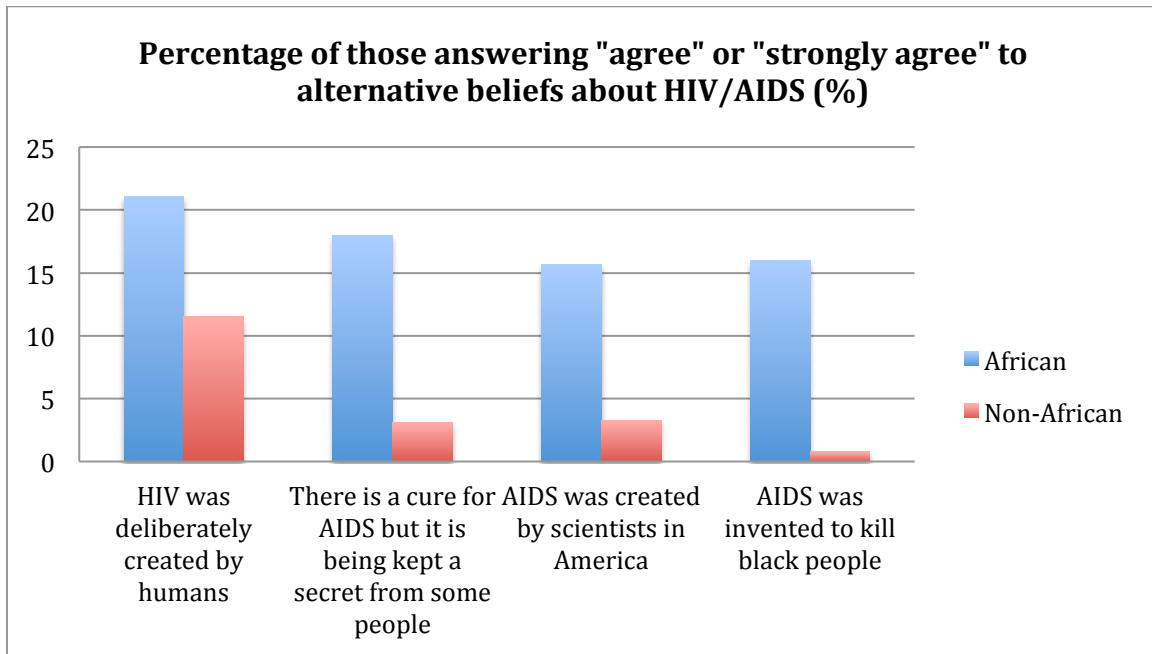
This chapter is divided into 5 sections. Section 1 reports on the quantitative results from the CAPS survey, which shows higher levels of alternative and conspiratorial beliefs about HIV/AIDS among African respondents. Section 2 addresses the question of whether respondents simply lack knowledge about HIV/AIDS, and

points to the high prevalence of African respondents who feel that important information about HIV/AIDS is being withheld from the South African public. Section 3 and 4 examine respondents' beliefs about the origins of HIV/AIDS and the existence of a cure, highlighting how these beliefs arise from a combination of apartheid-era experiences of racism, obfuscation and denial among political elites, and present-day disjunctures in information between observable evidence and scientific facts. Section 5 reviews the possible explanations for divergence between quantitative and qualitative data in this study, drawing attention to the ways in which alternative beliefs about HIV/AIDS may be more fluid and contingent than typically represented in quantitative surveys. Chapter 4 concludes by highlighting the potential importance of trusted sources of information about HIV, leading into Chapter 5's discussion of trust and leadership.

Section 1: Results from the CAPS survey

In order to explore the prevalence of alternative and conspiratorial beliefs among the CAPS sample, simple descriptive statistics were generated for the relevant questions, as illustrated in Chapter 3. Below is the overall percentage of the CAPS sample that endorsed certain alternative beliefs about HIV/AIDS in the 2009 survey.

Figure 1: Prevalence of alternative beliefs about HIV/AIDS



Compared to all other population groups (Coloured, Indian and White), a significantly larger percentage of African respondents answered either ‘strongly agree’ or ‘agree’ to questions about the possibility of a deliberate, man-made origin of the virus, as well as the secret existence of a cure. If those answering “neither agree nor disagree” are included in this analysis, the percentages are significantly higher. On average, 10% of African respondents answered in this manner, raising the question of what it means to answer ‘neither agree nor disagree’ to questions as politically loaded as those above. As has been suggested by others, one of the legacies of Mbeki’s denialism may be to create a deep-seated sense of uncertainty and confusion among the public. This raises the question: should uncertainty in this context be seen as indicating a subtle form of endorsement of alternative beliefs? Alternately, uncertainty may simply suggest that respondents have not yet made up their minds and remain open to either possibility. Further reflections on uncertainty apparent in the qualitative data will be discussed throughout the chapter.

Some of the characteristics associated with alternative and conspiracy beliefs in this population have been explored elsewhere, and point to the importance of cognitive,

cultural, and demographic traits. These include: being African; coming from a poorer household; not having tertiary education; not having voted in the last election; believing in witchcraft and holding traditional values (defined as supporting the statement “A man is not a man unless he is circumcised”). Additionally, those who had never heard of the Treatment Action Campaign and who trusted Manto Tshabalala-Msimang more than her successor, Barbara Hogan, were more likely to endorse these statements, suggesting that political leadership may be an important dimension of such beliefs (Grebe and Nattrass 2012; Nattrass 2012a). To further explore the prevalence and rationale for alternative beliefs, focus groups were convened with African respondents only. The results from these focus group discussions are highlighted below.

Section 2: Alternative beliefs about HIV/AIDS

Though some conceptualizations of alternative beliefs have suggested that such beliefs constitute a rejection of scientific principles (Hofstadter 1965; Thompson 2008; Sunstein and Vermeule 2009), the alternative beliefs discussed below do not stem from lack of knowledge about basic HIV information or from an anti-scientific mindset. Rather, they reflect careful observations about the way politics, the economy and public health are experienced in South Africa today. Seen through the lens of Public Understandings of Science, respondents are actively engaging with science’s logic and rationale by drawing from their own observations, experiences and sense of consistency and plausibility (Waters 1997).

In order to further explore the extent to which HIV/AIDS information could be a factor in respondents’ beliefs and doubts, Table 6 shows respondents’ answers to questions measuring their knowledge about HIV/AIDS from the CAPS survey. It is striking that only a very small minority of respondents in the survey incorrectly believed that HIV could be transmitted through non-sexual contact, such as a handshake or kissing. There was, however, significant room for misinformation or confusion surrounding the more complex questions about HIV science, such as whether an HIV-positive mother could have an HIV-negative baby.

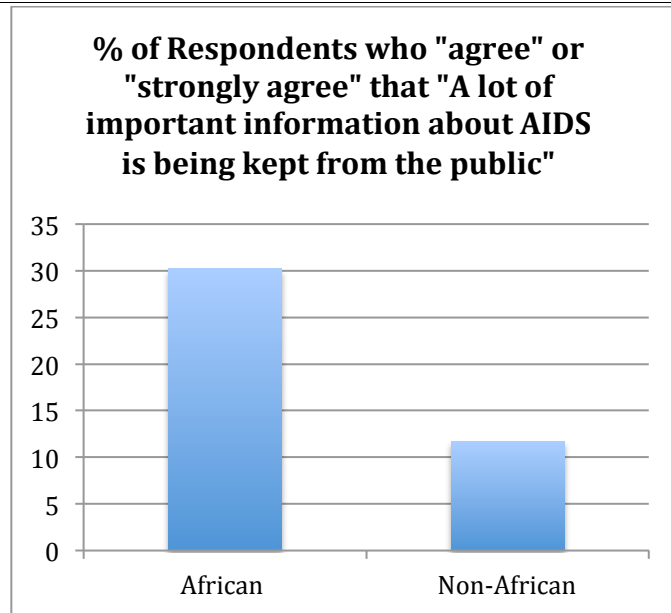
Table 6: Percentage of African respondents answering correctly to HIV knowledge questions on 2009 CAPS survey

HIV/AIDS Knowledge Questions	% answering correctly
Do you think you can get HIV by shaking hands?	96.3%
Do you think you can get HIV by using a public toilet?	92.8%
Do you think you can get HIV by sharing a bath?	92.5%
Do you think you can get HIV by sharing a bottle of water?	92.1%
Do you think you can get HIV by kissing on the lips?	86.0%
Is it possible for a healthy looking person to have HIV?	69.8%
Do you think you can get HIV by deep kissing?	66.0%
Do you think you can get HIV by touching someone's genitals (penis or vagina?)	64.8%
Can HIV/AIDS be transmitted from mother to her child?	54.8%
Do all children born to HIV positive women get HIV?	61.2%

These results suggest that while the population has absorbed the basic facts of HIV transmission, more complex aspects of HIV science remain perplexing or unclear. These findings are consistent with other studies measuring knowledge about HIV/AIDS in South Africa (Shisana et al. 2009). For instance, in Makongoza and colleagues' study with South African adolescents' knowledge about the origins of HIV, only 21% could answer correctly, while 47.6% were unsure (2012).

Beyond the question of HIV knowledge, a further question on the CAPS survey asked respondents to indicate their agreement with the statement "A lot of important information about AIDS is being kept from the public" (Figure 2).

Figure 2: Beliefs about withheld information about HIV within CAPS sample



This received the highest levels of endorsement among the African sample, with slightly more than 30% of Africans in the CAPS survey agreeing or strongly agreeing with this question. This survey item highlights a pervasive sense of being excluded from access to important information about the virus, its prevention and its treatment. It reflects the perception that there are discussions, studies and experiments taking place, to which the certain segments of the South African public is not privy. This theme of exclusion and of feeling as though one has insufficient information was also raised during the focus group discussions and will be discussed throughout the chapter.

In the focus group discussions and interviews, both respondents and peer educators discussed alternative beliefs about HIV/AIDS, particularly beliefs about a man-made origin of the virus and/or the existence of a cure. These beliefs seem to stem from both past experiences of, and knowledge about, historical abuses and inequalities as well as disjunctures in information between everyday observations and scientific facts. Respondents also discussed the role of unscrupulous agents who actively promoted misinformation about HIV/AIDS. Viewed through the Public Understandings of Science lens, these results suggest that respondents gauge the

plausibility of certain official claims about HIV against their own observable evidence and sources of information. When evidence arising from these “street-level epistemologies of trust” (Hardin 1992) clash with scientific assertions, respondents were often uncertain about what to believe.

The importance of lay observations has been noted in other work on the interpretation of scientific claims about HIV (Connors 1995; Steinberg 2008a), and other diseases (Parker and Allen 2011; Campbell 2011; Fischer 1999). Steinberg highlights how residents of an Eastern Cape village carefully watched HIV-positive women throughout the advent of their ARV treatment as “a silent empirical test. People wanted to know whether ARV medicine would cure them or kill them, or do something in between. And quite quickly people learned a great deal” (Steinberg 2011). These observations are not always discarded in the face of official pronouncements. Rather, consistent with Hitchens’ definition of conspiracy beliefs, as “the white noise which moves in to fill the vacuity of the official version” (Hitchens 1991), when people observed a gap in logic between HIV science and personal observations, they often expressed sincere doubts about what to believe. Sasson suggests that mistrust among African-Americans is due to similar gaps in logic between official claims and personal observations. His respondents’ rejection of standard explanations for high crime rates in black neighborhoods “stemmed from a basic incompatibility between the “official” accounts and African American popular wisdom”, making alternative explanations rooted in everyday experiences more “compelling” (1995, 274). In her work with intravenous drug users in the US, Connors presents an analysis of this mindset in one of her respondents. In Connors’ words, this respondent is considering

a multiplicity of possible realities, all of which make sense to him on some level. In sorting through these realities, the knowledge grounded in personal experience often wins out in the final discernment of the meanings of AIDS (1995, 437).

‘Disjunctures’ or ‘confusion’ about HIV science often occupy a peripheral position in studies of alternative and conspiratorial beliefs. Though some studies document

“questions and confusion” (K. J. Roberts et al. 2005), “confusion and disagreements” (Niehaus and Jonsson 2005), and “doubts” (Posel, Kahn, and Walker 2007) about aspects of HIV pathogenesis, prevention, and treatment, few have explicitly recognized the link between these disjunctures about biomedical claims and the formation of alternative and conspiratorial beliefs. In contrast to many of these studies, this chapter situates these disjunctures at the center of alternative beliefs. In many respects, as discussed below, the official story about HIV often does not align with respondents’ observed reality. The first theme to be examined in this light is respondents’ beliefs about the man-made origin of the virus.

Section 3: Origins of HIV/AIDS

Respondent’s beliefs about the natural or man-made origin of the virus are discussed below in the context of a range of explanations for the cause of the epidemic. Peer educators confirmed that they regularly found themselves being questioned by clients²⁸ about the origins of the virus.

Interviewer: Do you have people ask you about where HIV came from?

Pemeido: Yah, a lot! [laughing] A lot²⁹.

Another peer educator confirmed the salience of this topic.

Nomandithini: They ask us a lot [laughing]. Yes, they ask us where HIV comes from.

²⁸ ‘Clients’ is the preferred term among Treatment Action Campaign peer educators for those members of the public who are educated or otherwise assisted by the organization staff. Although some have problematized the term ‘client’, suggesting that people prefer the term ‘patient’ (Deber et al. 2005), TAC peer educators use the term out of respect for those to whom they provide services. Though the term ‘client’ among peer educators and ‘respondent’ in relation to the focus group discussions are referring to a similar demographic (young adults living in Khayelitsha, South Africa), the two terms are used distinctly to differentiate these sources more clearly and to reflect the research process.

²⁹ See Chapter 3 for a list of all peer educators and the interview dates.

And another educator said the questioning about the virus' origins extended to within her own family, exclaiming, "Yah! Even my daughter, even my son!! Even our cousins!!" (Neliswa).

When discussing the origins of HIV among focus group respondents, some of these informants focused on Biblical prophecies, suggesting that HIV was invented by God to punish people. As one female non-endorser explained,

And then some people once said HIV is some punishment from God, it's the way we are being punished. And I would believe that. Because maybe he wants to see your faith in him and he will give you miracles to prove – to show people that if he so wishes he could cure it (N1 Female Non-Endorser 12/08/2010).

A male non-endorser echoed this viewpoint:

The way I think about it is that it seems like a punishment that is being meted out on human beings by God – because human being aren't honest and that is the way in which they get punished by getting HIV and AIDS (N2 Male Non-Endorser 13/08/2010).

Others blamed foreigners for bringing it to South Africa. One female endorser stated,

No, I just want to say it came from these foreigners – these Zimbabweans and Nigerians – because it's just become rife ever since these Zimbabweans and Nigerians came here (N1 Female Mixed 21/08/2010).

To this, a fellow endorser respondent questioned, "But where did they get it from? The Nigerians themselves where did they get it from?" (N5 Female Mixed 21/08/2010). As the following quotes suggest, this was also echoed by peer educators, who report that their clients blamed nationals from other African countries, or from abroad, as the source of the virus:

Pemeido: Yes, they always, always blame the foreigners. Our brothers! They always blame our brothers! They don't want to say, no, maybe it came from Canada, no, no, no, it came from Nigeria, the Nigerians! It came from, what, the Congo guys, you know? They always say that.

Lina: But most of them, they didn't want to understand any more because some they say, it comes from the foreigners.

Nonqaba: Yes, there also people who say that it came with white people, because many people who are HIV positive are people who are black.

One peer educator, when asked if she heard people attribute the origins of HIV to foreigners, said “No, my brother I don’t even want to lie to you – I have not encountered a person who says that to me”, before continuing: “And some people will just say “No, I heard that it came from oranges – they injected oranges with HIV and so forth” (Pretty).

This reference to oranges has been noted in several studies of alternative beliefs in South Africa. The origin of this suspicion is uncertain but seems to invoke some sort of geopolitical conspiracy. Natrass points to press reports of Wouter Basson’s murder trial that listed a variety of poisoned household items including orange juice (2012a, 17). Niehaus and Jonsson’s ethnography of alternative beliefs highlight fears that in the mid 1990’s, white farmers were dumping oranges that had been doctored with blood containing HIV at shopping centers and schools (2005, 196). Steinberg reports a discussion with the MSF doctor Hermann Reuter, in which Reuter talks about the belief that oranges have been infected with HIV. He attributes it to an episode from history: During the anti-apartheid boycotts in the 1980’s, activists used to pour blood on South African oranges so that they would not be bought. “I’m sure that there’s a connection between the two stories”. He continues, stating that “Back in the 80’s, those oranges were seen as the epitome of apartheid: you had to fight the oranges to fight the regime. And now, a decade later, the story had turned around: these oranges were being used by white people to fight back” (Steinberg 2008a, 155).

Another peer educator had been questioned more deliberately by a client about the role of the apartheid regime:

Neliswa: These guys were asking ‘where does this HIV come from?’, and I tried to explain and then they said ‘no, ma, you are bitten by the Boers, there is no such thing, HIV was done by them!’.

Similarly, when asked where they thought these kinds of attributions came from, several peer educators connected it to the history of apartheid in South Africa:

Poppy: Some they just say 'whizt, this is a disease from white people from apartheid, you know?'

Lloyd: Ah, I think, if you are not well informed, it's easy to take a myth and make it as the reality. Because you're not informed, you have small information. So those people, they have associated that myth with apartheid regime.

Although peer educators had heard people attribute HIV to a deliberate plot to harm Africans, for most focus group respondents, the question of the virus' true origins remained unclear and obscure. Some made sense of the origins of HIV in relation to their observations about past and present sexual behaviours:

N2: I think it came from the people that are dating three or four people at the same time.

N3: But originally where did it 'come' from? Because remember that originally in the old days people used to have three wives, four wives and there was no HIV and they were sleeping with the three wives and the same time. But there was nothing (Female Mixed 21/08/2010).

Other focus group respondents attributed the virus to contact between humans and animals. While this drew on the notion that HIV originated as SIV in animals, the exact mode of transmission was often not comprehensively understood. One non-endorser respondent offered, "But some say it came with the monkeys. I really don't understand and I don't know where it came from" (N3 Female Mixed 21/08/2010). Another stated, "HIV comes from an animal – like these Swine Flus. Swine Flu comes from pigs, right? So it too must have come from animals and was transferred to a human" (N2 Female Non-Endorser 12/08/2010). Some respondents believed that an animal virus had infected white people or foreigners first, before being transmitted to black South Africans. An exchange between a male non-endorser and the facilitator illustrates this notion:

N4: It came from an animal and then it went to a white person and then it came to black people.

Facilitator: I hear you number 4. So when you think – it came from an animal to a person – so how did the animal infect a person? Because we here talking of ways in which HIV is transferred in.

N4: Quite obviously – the person had sex with an animal. White people have long done strange things (Male Non-Endorser 13/08/2010).

Explanations centering on scientific experimentation in laboratories were raised in several different groups and reiterated by peer educators. Echoing the survey questions “HIV was deliberate created by humans” and “HIV was created by scientists in America”, some respondents believed that scientists had created a new virus in a lab that had then spread to people in Africa. In these explanations, scientists were seen as all-powerful individuals, capable of interfering with nature with both positive and negative results. One male endorser drew on his awareness about the pervasiveness and power of technological innovation to explain:

I think it [HIV] is something that came from scientists – I mean this thing came from them. Because each and every thing that happens – it’s them. I mean the food we eat, everything that’s done – planting and so forth – it comes from? It comes from them. They are the ones who fertilize all that. So I would say it is something that came from scientists, but in a way we never took note of. (N4 Male Endorser 11/08/2010).

A female respondent spoke of a theory about blood samples becoming mixed in a laboratory:

In the rumours that we hear, they say, I’d heard that AIDS or HIV comes from baboons. And then I don’t understand if it was a person who met that baboon somewhere and then – I don’t know what to say, but what I’ve also heard is that blood samples were mixed up in a lab and then whatever ‘friction’/combination happened and then this virus came into being... [Laughing]... but, I’m not saying that’s the case, but according to what I’ve heard they say blood samples were mixed/combined in a lab and then I don’t know if it was the baboon’s blood or what. (N3 Female Mixed 8/07/2010).

In the detailed account of why they found these beliefs plausible, respondents frequently touched on themes related to poverty and inequality. For instance, one man explained that while he believed scientists in the West had created HIV, it came to be in Africa through the same processes as genetically modified foods. According to his observations, scientists were forever modifying and creating new organisms, and these new inventions were not always properly tested before they found their

way into the market place. Those who were most susceptible to buying these 'experiments' were the people most lacking in choice due to poverty.

[The mealie] was produced in the lab... And people who buy big and cheap food, you see this big cob of mealie and it's cheap, it's the black person who'll buy that because they are struggling. That's why it comes to black people. That's why I shift this to scientists. And scientists are still conducting research. They haven't stopped, they are still searching for a cure [for HIV]. (N3 Male Endorser 11/08/2010).

In this account, scientific experimentation and innovation disproportionately affects those too poor to have meaningful choices in what they consume. These observations highlight persistent injustices and inequalities in South Africa as well as the legacy of mistrust between the South African public and their public health institutions. The legacy of state-sponsored racism and historical abuse that was discussed in Chapter 2 has meant that there are myriad examples in South Africa that reinforce respondents' anxieties. These are reflected in the increasing gap between rich and poor in South Africa, evident in the first-world medicine available in the private health sector as compared to the low-resource care available in public clinics. Though South Africans now live in a post-apartheid democratic country, many still experience and observe gross inequalities and injustices that can fuel speculations and suspicions about disparities in health care.

Respondents also reflected on the ambivalent South African experience of globalization through their discussions of the origins of the virus. In citing fears of untested scientific developments being passed along to the most economically vulnerable populations, or of the tremendous yet opaque power of scientific research, respondents are venturing explanations about the forces that buffet them about but remain invisible (Sanders and West 2003; Niehaus and Jonsson 2005; Steinberg 2008a). As Kaler observes, "even the most superficially bizarre rumours can be credible if they can explain conjunctions between day-to-day experiences and larger historical processes in which the people who disseminate the rumours are involved" (2009, 1714).

The post-apartheid context in South Africa was “one in which the power of science was being felt in more intimate ways” (Nattrass 2012a, 20). The exact mechanism for transmission of disease is not specified in these discussions; rather, it is the very uncertainty of scientific development that inspires such awe and fear. Ellis and Haar note that there is “a profound ambiguity in the ideas people have about the true nature of the power that emanates from the West” (2004, 46). On the one hand, respondents view scientists as the architects of the HIV virus in a laboratory experiment, while at the same time, as will be discussed below, they are seen as being capable of, and committed to, developing a cure. While this suggests that the motives of scientists are sometimes suspect – potentially driven by financial self-interest rather than benevolence – the potential for science to innovate and invent is a widely endorsed perspective.

In short, alternative explanations about HIV/AIDS among this population reflect accumulated observations from both past and present experiences. In this context, respondents see Africans as often vulnerable to the spread of disease through scientific experimentation, and view unequal access to treatment and care as partially explained by privilege and prosperity.

Blame

Given the historical weight of these observations, it is notable that a majority of respondents were unwilling to concede that scientists would have created the virus on purpose. Despite widespread discussions about the role of scientists in creating the virus, most were far more disposed to view the virus as an accidental byproduct of scientific experimentation rather than a deliberate plot. It is interesting to note that only one survey question out of the four implied a specific intention to harm others, that “AIDS was invented to kill black people”. Some respondents actively disputed the maliciousness of this invention. As one non-endorser respondent stated:

I want to say their reasons were not to kill people, or maybe they were trying to cure, but they created this disease – HIV came about – not that they had

intentions to kill people - As the people who are of help to people, so maybe, I would say they were trying to help at that time. (N1 Male Mixed 15/08/2010).

Others reinforced the view that AIDS was accidentally created. Two female respondents, the first a non-endorser and the second an endorser from a mixed group argued that doctors would not have created a disease on purpose.

N4: I mean I don't think doctors would let you, if they know this thing can be spread, they'd let you to be free for other people even though they know it can be spread.

N5: I don't think they knew it was a disease. That's what I think. They were experimenting on whatever they were experimenting on. So I think so. (Female Mixed 21/08/2010).

These comments suggest that the existence of abuse and discrimination in some places and at certain times in South Africa has not created an *a priori* expectation of duplicity and conspiracy among respondents. Rather, they were evaluating the likelihood of malicious scientific conspiracy against their own experiences and observations and ended up defending scientists' intentions if not their actions.

Even after acknowledging that HIV affected certain groups disproportionately, many respondents still resisted blaming scientists or doctors for the spread of the disease. Rather, many respondents blamed others in their communities for the high rates of infection, as part of a strong-worded self-indictment that pointed to widespread sexual behavior and carelessness in their communities.

At first glance, this would seem to contradict previous studies suggesting alternative beliefs about HIV/AIDS often spring from a desire to attribute blame to an external source, either because of the psychological comfort this brings (Crocker, Broadnax, and Blaine 1999) or as a retaliatory reaction against stigmatizing discourses (Farmer 1992; Briggs 2004; Nations and Monte 1996; Sabatier 1988). Rather than accuse others, several endorser respondents conclusively placed the blame on their own population group:

If you notice, most of the time, this thing, most things happen to us black people – like diseases, TB and so on. All these existing diseases and new ones – the new ones start with us. So that is why I can't change this view that this

HIV thing is made for us black people. Most of the people who have it are black people, more than other races. So that is why I say this thing is prevalent with us black people. And how did it become prevalent with us? Through our carelessness, us black people, by not using these things that protect us from what we must protect ourselves from. (N2 Male Endorser 11/08/2010).

Though this respondent began speaking about HIV as if it was “made for us black people”, suggesting a possible plot by others, by the end of his comment, it became clear that he believed HIV arose because of a lack of precaution. This sentiment was echoed by another endorser respondent:

[HIV] wasn't made for black people. It didn't happen to black people only. But it's just a manner of how people take care of themselves. How we black people take care of ourselves, because HIV has no colour, no nothing – it does not discriminate – whether you are rich or poor, if it comes to you, it has come (N1 Male Endorser 11/08/2010).

One could anticipate that focus group respondents might have attributed the high HIV prevalence rates in South Africa to the malevolence of outside forces. Yet, in these discussions, the disproportionate infection rates in southern Africa were seen less as an indication of targeted extermination campaigns, and more as the consequence of ‘carelessness’ about one’s health in the context of poverty and joblessness.

Self-blame was also reflected in respondents’ views about disparities in care after someone was infected. While recognizing that all people were susceptible to infection, a non-endorser respondent discussed how if infected, other population groups would react differently.

Okay, yes, they [white people] have it too. But they are not like us, if you take note we – once they said, “You are positive” - we do not take care of ourselves. They take care of themselves. Like she has said they take boosters and so and so on. With us you'll find that a person is positive and you will get a grant as well, and with that grant money on their payday they will get so drunk with it. But a person knows that they are sick – they'll get drunk. Another one will get pregnant. So I mean for us we don't take care of ourselves and we just tell ourselves, “My life is over anyway!” (N3 Female Mixed 21/08/2010).

Though respondents were willing to attribute blame for infection rates to carelessness and promiscuity, these comments were all directed towards others in their population group rather than themselves personally. This suggests that there is an important distinction between recognizing irresponsible behavior among one's own community or population group and seeing it within oneself. As Steinberg notes, people were quick to accuse others of promiscuity but when asked why contracting AIDS themselves would be shameful, his respondents cited witchcraft: "One would be weakened in the face of those who wished one ill" (2008b, 10). Thus, this willingness to blame one's own population group or community does not indicate that accusation and blame are absent. Rather, it highlights how respondents seemed to apportion blame for the HIV epidemic in precise ways, differentiating between those responsible for creating the virus (scientists) and those responsible for the virus' spread (members of their community).

Witchcraft

These findings raised the important role of witchcraft as potentially responsible for the spread of HIV. There was no consensus among respondents as to whether witchcraft could cause HIV. While one non-endorser respondent felt that "It does have a bit of witchcraft in it" (N2 Female Mixed 18/08/2010), an endorser in the same group stated, "I say AIDS goes alone – it is not together with witchcraft" (N3 Female Mixed 18/08/2010). This last respondent elaborated on why witchcraft remained a salient explanation for some:

For me this whole thing of witchcraft and HIV – firstly we black people were raised how? We were raised believing in traditional medicines. Let's say there are three of us, children, here in the house growing up – as we grow we go to school and once you fail a grade at school they will say "It's that woman next door! Because she does not want you to succeed!" So for us this thing is embedded into our brains – whenever something bad happens, "You have been bewitched!" So even when a person finds out that they are positive, black people, most of us black people will just think that there is nothing else "I've been bewitched", you see?

She concluded by reflecting on her own beliefs:

I do not believe it can come through witchcraft and at the same time I do not want to say witches do not exist – witches exist. But now I would wish that we look at this in another way and not, when you are positive, say “No, witches brought it upon me!”

This respondent highlighted how prevalent it is to attribute the specific cause of an affliction to the envy of a neighbour or friend. Yet in her own doubts about the role of witchcraft, she illustrated a different trend. Another non-endorser respondent also believed that people were less likely to attribute HIV to witchcraft now than ever before:

But now people’s minds are changing now, they are becoming converted from that, that means that on this matter of where HIV comes from – people’s minds are changing and they’re seeing that “No man, HIV was not brought by witches”, “HIV was not brought by certain things” you understand? They are getting knowledge on all those things (N2 Male Mixed 15/08/2010).

Discernible in these accounts is a degree of uncertainty and doubt about the range of explanations for the origins of the virus, from man-made to witchcraft to sexual promiscuity. Some explanations may even overlap in logically consistent ways with each other; as Steinberg notes, “The notion that Aids was invented in a laboratory does not preclude local witches from using it to kill those they envy” (2008b, 50). In other cases, these accounts may function as competing explanations. A peer educator reported hearing a range of explanations for HIV among her clients:

Bonelwa: Well some of them have this idea that HIV gets injected into people by white people. White people inject it into people and then others say it comes from witches and there are powders that are sprayed on people and so on – stories like that.

Similarly, some respondents seemed unsure whether HIV was deliberately created or not. A non-endorser reflected on this uncertainty:

So it came to people in the way in which N4, N3 say – because people use the same needles that are used on animals. So that is where it all happened. So I don’t know if it happened as a mistake or it happened because it was intentional. That is where I am not sure (N5 Male Mixed 28/08/2010).

Even in groups composed solely of those characterized as ‘endorsers’ in the survey, individuals expressed open-mindedness about the origins of HIV. Echoing Evans-

Pritchard's well-known explanation for the causal logic of the Azande³⁰, one male endorser expressed a desire to explain how and why the virus affected some people and not others.

And then what happens when a problem arises, as we are seated here and say something happens to this building and it happens to all of us and I get injured alone – or something happens to me – I will ask, “Why me alone?” I’ll have to establish why I was the only one injured – how was I seated? And investigate and see that ‘okay I was seated under the light and it struck me’. You see? So what is happening is that, since this affects black people a lot, this HIV, why doesn’t it affect them [white people] a lot? That’s why – it’s natural to look for a source or whomever did something when something happens. So that is why it’s easy for us to search – we’re not saying we’re scientists, we’re not saying it’s for whites or it’s for blacks, but it’s just the way I’m stating it. We are debating it until the answer comes up and we address it (N3 Male Endorser 11/08/2010).

The persistence of respondents’ interest in, and confusion about, the question of the virus’ origins could be seen as foundational to subsequent acceptance of other aspects of HIV science. Steinberg observes that as much as his protagonist’s views about other aspects of HIV science had shifted over the course of their acquaintance, he still remained convinced that HIV had originated in foreign laboratories. When asked to account for this belief, Steinberg’s protagonist Sizwe remarked: “When you see smoke in the sky, it means some people have been lighting a fire. It is not just there in the sky. There are people at the bottom” (2007a). For him, then, everything has a cause and in the absence of a plausible account of the origins of HIV, the belief in a foreign laboratory experiment gone wrong can persist. For respondents, the

³⁰ Evans-Pritchard’s 1937 study of the Azande people of Sudan highlights the distinction between a proximal and a distal cause of an event using the Azande’s explanation for a granary that collapses, resulting in the injury of those sitting beneath it: “The Zande knows that the supports were undermined by termites and that people were sitting beneath the granary in order to escape the heat and glare of the sun. But he knows besides why these two events occurred at a precisely similar moment in time and space. It was due to the actions of witchcraft. If there had been no witchcraft people would have been sitting under the granary and it would not have fallen on them, or it would have collapsed but the people would not have been sheltering under it at the time. Witchcraft explains the coincidence of these two happenings” (Evans-Pritchard 1937, 23). Similarly, this respondent accepts that HIV is a virus yet wants to understand the underlying reason to explain why it is more prevalent among some people than others.

lack of a satisfactory or conclusive explanation for the source of the disease constitutes a significant disjuncture in information about HIV. Such disjunctures, left unaddressed, may fuel further doubts about the trustworthiness of HIV scientific claims. Discussion will now turn to the second dominant theme raised among both respondents and peer educators – whether or not a cure exists.

Section 4: Existence of a cure

There was considerable discussion among focus group participants about the existence of a cure. Peer educators noted similar concerns arose in discussions with clients. The survey question, “There is a cure for AIDS but it is being kept a secret from some people” was often rearticulated in focus group discussions as a source of some confusion. Some respondents saw it as incomprehensible that a cure would not have been discovered yet, largely because of the perception that if ARVs could ‘slow the disease down’, it was only a matter of dosage to stop it altogether. Other studies have reported similar disjunctures. A respondent from Connor’s study with injection drug users questioned, “If they give you bleach to clean and all that why can't they give you bleach [inside your body] to kill the germ, is that crazy?” (1995, 428). Steinberg’s protagonist insists, “And as for AIDS, the *umlungus* definitely have a cure. I know absolutely for sure that they do. And they are holding it back. The *umlungus* are so clever. It is not possible that they don’t have a cure” (2008a, 307). One peer educator explained this confusion among his clients. “They are asking about that cure. When, why there is a treatment but there is no cure?” (Lloyd).

Respondents generally endorsed one of several possibilities to explain a cure’s lack of availability in the South African market. Some respondents thought that a cure existed, and was being kept exclusively for people who could afford it. People observed that scientists have been working on a cure for so many years that their failure seemed implausible. One respondent expressed disbelief that western countries would not have been able to manufacture a cure after three decades:

I would want to agree with this statement, because – and I will talk about people from Europe – the way in which they are advanced in the sciences and

yet they have still not found a cure for something that is killing people like this – is unbelievable. Because they are very advanced and a cure must have been created a long time ago. Because HIV has been in existence for around 30 years – from 1970 – for the first patients – so for them to not have developed a cure by now is unbelievable. So agree with this statement (N5 Male Uncertain 27/08/2010).

This was echoed by a peer educator, who observed her clients were impatient for a new discovery.

Nonqaba: Yho! [exclaims] They are always asking about it – saying, “It’s been a long time! We’ve been treating for so long and we get different regiments and these types of pills, new pills and another pill! Can’t they develop something new – even something like an injection?”

As with discussions about the origins of the virus, scientists were held in high esteem and viewed as competent individuals who would not fail at developing a cure if they had tried. While some peer educators’ clients merely wondered why a cure had not yet been discovered, others believed that it already existed but was being withheld.

Pemeido: A lot. I think people everyone is like -- everyone, everyday, everyday, there will be at least one person who will ask you about the cure and some will come up with a story like ‘I think that they’ve made a cure, it’s in Europe, there’s a cure in Europe’.

A female non-endorser also thought that wealth was key to accessing a cure:

So I believe somewhere, somehow it [cure] exists, but you just have to be rich in order to get access to that medicine. I believe it to be like that. You can’t go to the clinic – the day hospital and get it there – when you’re getting your medication they give it to you too – never. I believe it exists (N3 Female Non-Endorser 12/08/2010).

Other focus groups respondents thought that a cure did not yet exist because scientists from western countries did not have a sufficient incentive to make one for such relatively small numbers of infected people in the global north. One respondent insisted, “Only 5 or 10% of Europeans were infected” (N5 Male Uncertain 27/08/2010), arguing that this was too small a prevalence rate for scientists to feel urgency about generating a cure. A male endorser offered the further explanation

that a cure does not exist because it is far more lucrative to treat people forever than to eliminate demand for ARVs.

AIDS was invented for business, because if you look now there are so many brilliant people in the world who can actually come up with that cure. Maybe some have already come with it. And you look at this ARVs thing – they say it slows it down so that it doesn't have strength, but then if you look closely they can make something that can end it. And then you think that, if they have made that medicine and AIDS is eradicated – and then the one who came up with the idea – I mean people will go once per time to him and you will be cured and you will then not have to go back and buy again and then business goes down in that way (N2 Male Mixed 28/08/2010).

A peer educator reported a similar conclusion among his clients:

Snax: Yeah, some people, they say, there is a cure, but they're just threatening the cure, they're holding the cure, because they're thinking about, for example, the economy, most people will lose their job, or HIV will no longer, like, bring in money to other people, something like that.

A variation on this explanation was that a cure had already been made available to 'high priority groups' – in other words, babies and women. One male non-endorser explained how scientists were 'saving' children and women from infection, while maintaining a profit by exploiting the rest of the population:

Which means that they [scientists] have sympathy for the baby – and that baby's future is still bright. And you are grown up – so you die. I mean really they can make it – to ensure that the baby doesn't get it. And yes, we understand it is Nevirapine, but I mean they can, I mean look for example now – there is this new one for ladies which they have to apply 12 hours before and it has a percentage which will prevent them from getting HIV and AIDS and they won't get infected. And I mean if they can create things like that – you see now they are coming out with these things slowly – they start with children and then they come to the ladies. Which means that if they could combine all these ideas we could have a cure. But as he's said – it's business (N5 Male Mixed 28/08/2010).

In discussing the financial incentives associated with a cure, respondents were consistently pragmatic about scientists' motives:

N4: And I don't think that a person – who would know that they have a cure for HIV – that they would just sit down with it. Even though they know that a person who makes ARVs gets paid a lot. Would that person just sit there with that medicine and starve – knowing that it will help?

N3: And that person can be a millionaire. (Female Mixed 21/08/2010).

At most, respondents acknowledged that scientists and pharmaceutical companies demonstrated a cold calculation by being influenced by financial incentives to treat HIV while withholding a cure. As with discussions about the origins of HIV, very few respondents endorsed the idea of outright maliciousness when it came to the presence or absence of a cure. Rather, their suspicions and distrust arose from disjunctures between their own observations and official scientific claims.

The ability to prevent mother-to-child transmission was also seen as an indication of scientists' benevolent intentions, in that scientists would 'surely not let such innocents die'. However, Prevention of Mother to Child Transmission (PMTCT) was also a source of significant confusion. Some respondents viewed PMTCT as either impossible or a sort of 'cure in disguise', reasoning that it could only be a matter of ARV dosage to treat adults. One female endorser conveyed confusion about this issue:

I am sick and my boyfriend is sick and then we make a child – you realize that those sperms are infected too and they make this baby – so how did that baby survive that? That's what drives me crazy, I won't lie. How did that baby survive yet we are both sick? And that baby was surrounded by that infected person's blood (N4 Female Mixed 18/08/2010).

Another respondent, a non-endorser, also believed that scientists' ability to treat an unborn baby constituted a 'cure':

No you are right on the side where you say 'Really they can make it and it can cure a person'. Because look, a person with AIDS can sleep with another person with AIDS and then the child that they give birth to will be born without it [AIDS] – and that is why I am saying that they are still fooling us in that way. Because how can two people with AIDS have sex and make a baby that doesn't have it? (N4 Male Mixed 28/08/2010).

Peer educators recall how they too encounter confusion among clients about whether PMTCT could be considered 'a cure'.

Snax: Because how can they prevent a baby inside with the same treatment that you are eating, because a pregnant woman within 14 weeks is given AZT and nevirapine, yeah, why is she going to be in labour, they get Nevirapine. So they say, how can this person be treated, the child can be protected, or make sure that the child is not getting HIV, with the same ARVs that I'm eating? So people, they're confused.

Isaac: A few months ago, people are saying to me, Isaac, you are saying ARVs would prolong the virus, not to multiply itself in your body, and Nevirapine will protect a child, not to be born with HIV, so why don't you take Nevirapine and add ARVs and mix it together and stop that virus at all!! Because it's, at some point, when you go to a doctor, and take your CD4 count or check your viral load, a doctor will say it's undetectable. So it's undetectable, it doesn't mean, its gone. But they can't see it, but you still have the virus in your body. Because the ARVs are working. So it's undetectable. You are not defaulting, you are taking ARVs according to instruction. But you'll find out when you are doing that explanation, the person will ask you, 'why don't you...so there *is* a cure for HIV but it's somewhere, it lies there, between those ARVs. Why they don't mix it and make it to be gone? Because the ARVs can make your HIV to be undetectable, but it doesn't mean it is gone'. But they ask the same question, like 'why it can't be mixed together'?

As indicated by Isaac, the revelation that patients could exhibit undetectable viral loads sometimes became intertwined and conflated with questions about a cure.

Nomandithini: Yes, we get problems that we encounter, because mostly, people use ARVs and then their virus become undetectable and then I go and get tested and then maybe I go to a certain church and my pastor says he has prayed for me and my virus is gone. And I also get into that mindset that "It's not the ARVs, it's the pastor's prayer!" and so that's one of the big challenges that we get.

Poppy: Oh, it's a big challenge. It's a big issue, especially those who believe in God, shame. Because when they go to these churches, they are told that the HIV is gone. So you have to explain that this will never go, my dear, unless you go.

In some cases, peer educators reported that clients were starting to call themselves 'HIV-free' or 'HIV-negative' after being told that their virus was undetectable.

Isaac: They are saying 'I'm HIV free'. Then you ask 'why are you saying so, because I know that you're taking ARVs'. And they say, 'yes, the doctor said to me that the HIV is undetectable'. And so, there was not enough explanation.

Poppy: Yes, and when you are tested and your HIV is undetectable, some doctors will say 'It doesn't show'. So they will assume that doctors are saying I'm negative now. So they're confusing that.

Pemeido: Yeah! I think when they are told 'Your viral load is undetectable', maybe the nurse don't really explain it to them, what does it mean, because more people will come up and say 'The nurse told me that I don't have the virus anymore', you know?

A further issue that commonly arose in discussions with focus group respondents about a cure was the controversy surrounding President Jacob Zuma's HIV status. Respondents observed that there is ample evidence that he has had unprotected sex, citing well-publicized out-of-wedlock affairs and pregnancies. A further source of respondent's observations arose in relation to Zuma's rape case, where he notoriously said that rather than use a condom, he had showered after having sex with an HIV-positive woman in order to prevent infection. Respondents highlighted that Zuma had recently announced the results of his public HIV test as negative. The following exchange between several female non-endorsers highlights the confusion surrounding Zuma's HIV-status and the issue of 'his shower':

Facilitator: Alright and then father Zuma – how do you trust him? About him giving you information about HIV?

N5: I don't trust him.

Facilitator: You don't trust him why?

N5: Because I'm sure he doesn't use a condom, because he has lots of children – Zuma impregnates.

N2: This thing of brother JZ [Jacob Zuma] confuses me, because he is also the same one who said he showered. And thereafter he didn't contract HIV! No, I don't believe him. Information that comes from him [LAUGH] – I don't believe him. Clean (Female Non-Endorser 12/08/2010).

Peer educators also stated that they faced numerous questions about 'the shower' incident:

Interviewer: Yes, about uZuma and the shower?

Poppy: Alright. He confused so many people about that statement he made about it. Yes he did.

Snax: Yeah, because people, they say, after that shower thing, it was another challenge for peer educators.

Interviewer: Do people ask you questions about Zuma, the shower... other things?

Pemeido: They do, a lot. The other guys just say to me, 'Every time I have sex with my girlfriend, I go and take a shower, after sex, I go and take a shower, just like what Zuma did'.

Several respondents raised the question of whether Zuma was hiding his 'true' positive status.

And then now when Zuma says we must not do this and yet he wants to do it – maybe Zuma already knows he is positive and he just wants to die. Maybe he is in that group of people already (N1 Female Non-Endorser 12/08/2010).

One peer educator thought that people were evenly divided in their interpretation of Zuma's public test result.

Isaac: I think it's 50/50. People think that he did the test and lied about the results, people are thinking that he did not do the test at all. Because why did he not allow the cameras to be inside, to be seen when he was pricked, he was done with the pre-counseling and post-counseling, everything, and then the prick, and then the results on the blood is there.

Some focus group respondents wondered whether Zuma's controversial 'shower' was in fact effective in preventing infection, with some respondents questioning whether a shower after risky sex could prevent them from infection. As one male endorser advised,

They should have explained that clearly as to what Zuma did to actually not get HIV from that girl. Or maybe they could have explained that thing we spoke about – on the difference between a boy and a man³¹ and the difference, or even when you go shower – because that leaves us with a question mark. It's not clear even now (N3 Male Endorser 11/08/2010).

In short, focus group respondents demonstrated how they gauged the truthfulness of the 'official story' about HIV alongside myriad other sources of information, one of the most important of which was their own observations and experiences. Numerous questions and confusion about HIV are unresolved, reflected in high levels of endorsement for the survey question "A lot of important information about AIDS is being kept from the public". As the focus group discussions illustrated, the official version of HIV science does not always align with observable evidence. Thus, the claim that HIV can infect anyone is challenged by the far higher rates of infection among the Black South African population, and the claim that HIV originated in Africa is contradicted by the fact that the first reports of HIV came from overseas.

³¹ This comment is alluding to an earlier part of the discussion about the potential protective benefits of male circumcision.

Similarly, the claim that no cure exists is refuted by respondents' overly optimistic confidence about scientists' capacity to develop treatments for disease. Rather than interpret the absence of a cure as an indication of science's failure to date, respondents read this as evidence of a hidden cure. Likewise, respondents questioned the existence of a 'pseudo-cure' because of confusion about how exactly PMTCT worked, and in response to the announcement of undetectable viral loads among some patients. Lastly, Jacob Zuma's claim to be HIV negative was called into question by his admission of personal behavior. Peer educators reinforced the salience of these 'disjunctures in information' among clients.

As with the origins of HIV, respondents' unresolved questions about a cure might preclude their trust in HIV science. The Treatment Action Campaign has noted the difficulty of addressing some of these issues. In particular, TAC highlights the challenges of explaining PMTCT to the public, stating: "This can be one of the hardest things to explain when we do our training workshops" (TAC 2010, 11). They conclude by exhorting the public to focus on pragmatic issues: "The most important thing to know about PMTCT is not how it happens, but how we can prevent it from happening. We can do this with ARVs. Fortunately we know a lot more about that!" (2010, 14).

In the absence, however, of a satisfactory response from official sources such as doctors and scientists, respondents may be more easily swayed by alternative explanations offered by those in positions of power. These dynamics are explored further below.

Leadership

The possibility of a cure was obscured and complicated by contradictory claims from traditional healers, churches and culturopreneurs selling alternative HIV treatments (Nattrass 2012a), such as Matthias Rath. One peer educator reported how clients would question them about ARVs in light of alternative treatments:

Isaac: Yes. There was a confusion, wasn't there? There was this doctor called Matthias Rath who was saying he could cure HIV, that was like multivitamins, of 30 per day, so big. So at that time, we were struggling. Because people were asking 'Why are you saying ARVs?'

A male non-endorser doubted whether traditional healers could, in fact, cure HIV:

You see witchdoctors, we cannot be certain about whether or not they can cure it or whether or not they can't cure it – we do not know (N6 Male Mixed 28/08/2010).

According to a peer educator, some churches were adding to the confusion by claiming to cure those who are faithful:

Khanyisa: Yah, I did talk with a lady that was, she said, she is saved, you know. Their pastor healed the HIV, when you go to the hillside, you'll be healed from being HIV positive. I was trying my best, because she was staying with the crowd people, so I was trying my best to understand. I was giving an example that we do understand that HIV is not cured. It's suppressed by ARVs. So I was trying my best to convince others that say, eh, you can take the horse to the river but you can't force to drink.

A male endorser respondent observed that churches would claim the ability to cure HIV.

These churches like Universal, in churches where they say that they healed HIV in that church and a person will proudly claim they were cured (N3 Male Endorser 11/08/2010).

Similarly, a non-endorser felt that churches and traditional healers were manipulating people with their false claims:

Okay, for me, there are people who say they went to get prayed for and when they went to go and get tested the next day, they found that it was gone. But then, how long does that last – that thing of getting prayed – does it mean that when they go test the next month and they no longer go to that church they will find themselves to be still negative? So I am of the view that people's minds can get played around with – they play with people's minds. By other churches and other religions. Let me not say churches only, there are traditional healers who claim they can cure it too. "We can cure it!" and people believe in what they say. You understand? (N2 Male Mixed 15/08/2010).

A non-endorser from the same group admitted to being susceptible to these claims of a cure from churches.

N1: I have something that keeps changing my mind....because there are people who say “I have AIDS” and then they go and get tested and discover that they indeed have it. And then again, they go to church and they pray for him/her – and they have taken pills or anything – and they say they will get prayed for. And then when they go and get tested again, they find that they are negative.

Facilitator: So, you believe?

N1: I have this little thing that changes me a bit.

Facilitator: So according to your views do you believe in this? That if a person is HIV positive, they can through prayer, become negative?

N1: I believe it a bit (Male Mixed 15/08/2010).

Clearly, the disjunctures in information discussed above can be exploited and exacerbated by disingenuous people within the community and the state. This suggests that political leadership - both within the community and in the government – can play an important role in appeasing or exacerbating public doubt about HIV science. This focus on local, provincial and national level leadership within civil society and government is important, Natrass argues, because as much as the wider socio-historical setting can give rise to people’s sense of uncertainty or distrust, alternative beliefs about HIV/AIDS “do not simply arise out of the social context” (Natrass 2013, 114).

Respondents and peer educators testified to the impact of poor community leadership on HIV/AIDS. Several respondents questioned whether a cure existed as a result of hearing claims of a cure by religious leaders or *sangomas*. While active promotion of alternative cures, such as those advertised by Matthias Rath, has been successfully contested by activists, policy makers, and academics associated with the Treatment Action Campaign (Geffen 2010; Natrass 2012a), less prominent and well-funded individuals and groups at the community level can continue to undermine public confidence in HIV science. Natrass has persuasively argued that alongside a socio-historical analysis of alternative beliefs about HIV/AIDS, “analytical space needs to be created to critique the political leaders who promoted AIDS conspiracy beliefs” (2013, 113). These include those at the local as well as national level.

A distinction should be drawn between leaders who actively – in their words or deeds - attempt to undermine the scientific consensus around HIV/AIDS, and those who undermine this consensus with contradictory messages or actions. Jacob Zuma is one such public figure who has actively promoted HIV science in his policies and public rhetoric, and yet simultaneously damaged the public's confidence. Many respondents expressed suspicions about HIV science, particularly whether there is a cure because they see people such as Zuma, have multiple sexual partners yet avoid infection (PlusNews 2010). These disjunctures between the public's observations about a political leader's behavior and scientific facts about HIV are also significant influences on alternative beliefs about HIV/AIDS, and will be explored in more detail in Chapter 5, which looks at trusted sources of information.

Section 5: Contradictions between qualitative and quantitative data

Though there are myriad examples of congruence between different forms of data in this study, several key divergences emerged, posing challenges in interpreting these data during analysis. While one might have expected respondents who endorsed alternative beliefs about HIV on the survey to blame evil scientists or malicious government plots for the spread of HIV, during focus group discussions, this was not generally the case. Deliberate and malevolent conspiracy beliefs about the creation of HIV/AIDS were raised far less often by endorser respondents than stories about HIV originating in some kind of imperfect scientific exploration by curious, albeit self-interested, scientists. As Natrass observed, "Participants were more concerned with the gaps in our scientific knowledge, the potential for experiments to go awry, and the confusing aspects of HIV's pathogenesis than they were about AIDS origin conspiracy theories" (2012a, 22). That respondents who seemed strongly conspiratorial on the survey would express more ambivalence and agnosticism in the focus groups merits further examination.

Rather than interpret divergences between qualitative and quantitative data as indicative of a fundamentally inconsistent contradiction, discrepancies can be viewed as an opportunity to explore potential complementarity of the data sets. As

Teddle and Tashakkori note, divergences provide “information that might otherwise be lost, including possibly new theoretical perspectives on the phenomena under investigation” (2008). Several explanations exist for these divergences. The first is that endorsements of survey questions about malicious conspiracy beliefs – such as HIV being manufactured by humans generally or scientists specifically – may in fact be endorsers’ observation that science has the power to kill and to cure, to create (accidentally or not) a virus capable of killing millions of people, but also to invent ARVs to prolong people’s lives and prevent infection of newborns. It should be noted that there is nothing inherently inconsistent with believing that scientists created the virus while also rejecting the notion that they did so on purpose or with the intent to do harm to a particular group. Steinberg notes his protagonist’s uncertainty about whether the virus was intentionally created or not: “Somebody must have made AIDS. Maybe it went out of control. Maybe this is not what they wanted. But somebody made it” (2008a, 230). This distinction should be kept in mind when designing future surveys so as to capture the nuances of alternative beliefs and avoid attributing perceptions of malevolent intent where it does not exist.

These findings are consistent with previous quantitative research in both South Africa (Tun et al. 2012; Bogart, Kalichman, and Simbayi 2008) and the US (Bogart and Thorburn 2005; Bogart et al. 2010), wherein respondents were far more likely to endorse the idea that HIV was a man-made virus rather than one that had been deliberately created to hurt or kill black people specifically.

This divergence may also be a reflection of selection bias within the qualitative sample. As noted in Chapter 3, the composition of focus groups may have been skewed towards less conspiratorial people, as those who distrusted scientific institutions more might also be less likely to participate in a university-sponsored study.

A further explanation is that the different data collection methods had different effects on the population sample. For instance, the closed nature of the survey questions may have led people to answer in direct, strongly worded ways, concealing the nuances of blame and attribution contained within these views. That peer educators operate in their day-to-day lives outside of the artificial constraints and biases of research may mean that they encounter a more accurate spectrum of beliefs than that recorded in closed focus group discussions. It is also possible that focus group respondents themselves, having participated first in the CAPS survey and then in the follow-up qualitative study, shifted their views or chose to represent themselves differently to researchers.

This would not be the first time that different methods in studies on alternative beliefs have yielded different results. Rodlach's research in Zimbabwe found that respondents were more likely to strongly endorse beliefs about witchcraft, sorcery and government plots in interviews rather than surveys. He hypothesized this was because the surveys reinforced certain hierarchies of knowledge, making respondents uncomfortable about endorsing non-orthodox science, whereas one-on-one interviews created a comfortable atmosphere where respondents felt able to discuss their less-conventional views (Rodlach 2006). The reverse may also be true when it comes to focus groups. During the focus groups in this study, people may have felt more reluctant to endorse malevolent beliefs than they had in the survey. The process of answering a survey question is a relatively private process, whereas a focus group discussion may prompt public, reflexive deliberation, which in turn may have had a moderating effect on responses.

However, previous research suggests that group polarization effects can frequently result in a group expressing *more* extreme positions than before deliberation began (Brown 2003). If these effects had been at play in the focus group discussions, we would expect to hear *more* conspiratorial articulations rather than less, particularly in the focus group composed entirely of endorser respondents. Instead, respondents in both the endorser focus groups and mixed groups seemed to go to great lengths

to describe why the non-malevolence of scientists was plausible. These accounts bear the impression of verisimilitude rather than evasion, and suggest that there is an underlying rationale and sincerity to the non-malevolence of conspiracy beliefs in this community, rather than simply a moderating effect of using group methodology. That alternative beliefs transcended the 'endorser' category, and were raised by non-endorsers on occasion, also reinforced the idea that these doubts or suspicions may be more fluid than indicated on the survey.

A final explanation for the divergence between the survey and focus groups is that, as Steinberg (2008) has suggested, people change their minds about the plausibility of conspiracies over time, in ways that neither surveys nor one-off focus group discussions adequately capture. This points to the value of longitudinal studies to measure this phenomenon, either in the form of several waves of survey data collection (Bogart et al. 2010) or ethnography (Kaler 2009; Steinberg 2008a; Wilson 2008; Rodlach 2006). Steinberg highlights how long it can take to uncover a respondent's sincere beliefs when they feel cautious about revealing themselves. He writes, "For all our talk on the causes of AIDS, it had taken this trip to Nomvalo to out his strongest suspicion about the origin of the epidemic. It was brewed, not by witches and their demons, but in the vividly imagined laboratories of Western science" (2008a, 146). The inclusion of the interviews with peer educators was intended as a check on the cross-sectional nature of this study, by hearing about clients' concerns, doubts and areas of confusion with the "antennae" of Khayelitsha. Though this was never intended to stand-in as a longitudinal component, these interviews give insight into the range of alternative beliefs within this community, as well as questions and doubts that persist.

These areas of discrepancy and divergence between the survey, focus group discussions, and interviews are a reminder that methodological issues should be carefully considered when designing future studies to measure the prevalence and nature of alternative and conspiratorial beliefs.

These findings also highlight certain theoretical implications of examining alternative beliefs through a Public Understandings of Science framework. These discussions highlight the essentially non-malevolent nature of the majority of these beliefs, and the fact that such beliefs are more fluid than previously thought. Had these results been viewed through the narrower lens of conspiracy theories, many of the views espoused by respondents and reported by peer educators might have been excluded for being insufficiently 'conspiratorial'. Recent research by Ford and colleagues reinforces the benefits of focusing on mistrust as well as conspiratorial beliefs. The study measured both AIDS-related conspiracy theories and mistrust in the government; not only were levels of mistrust far higher than conspiracy theories, but mistrust was also significantly associated with lower likelihood of HIV testing (2013). This suggests that measuring mistrust as well as more conspiratorial beliefs is essential in order to gather a fuller picture of a population's beliefs about the trustworthiness of information about HIV.

A further advantage of the PUS framework over conspiracy theories is its treatment of uncertainty. Ambivalence or uncertainty in conspiracy theory studies might have been recoded as simply 'undecided' or excluded from the analysis altogether, as has occurred in previous studies. For instance, in Russell and colleagues' study measuring conspiracy beliefs among different population groups in the US, they found an increase in the proportion of respondents who answered "don't know or not sure" in the 2003 sample as compared with the 1999 sample. Rather than regard this as a potential increase in respondents' uncertainty about HIV science, the authors exclude this group from further analysis because they hypothesized they "were not committed to either side" (2011, 41). Elsewhere, they discuss the exclusion of the uncertain group because they "considered them to be neither true believers nor true non-believers" (2011, 39). Similarly, Ross and colleagues' recorded high percentages of African American respondents answering "don't know" to HIV conspiracy belief questions (16.6% and 18.6% for men and women respectively), yet performed no further analysis on this category (Ross, Essien, and Torres 2006). Thomas and Quinn note high percentages of respondents answering

“unsure” to key questions about trust in HIV science, summarizing, “Many Black Americans are unsure about the degree to which they trust the government reports on AIDS. Many are unsure about the origins of HIV” (1993, 331). Again, no further analysis occurs about the meaning of such high levels of uncertainty. If, however, ambivalence is a key aspect of distrust in HIV science, this category should be regarded as meaningful for further analysis. The PUS framework highlights the importance of viewing alternative beliefs along a spectrum, ranging from highly conspiratorial to simply doubtful or questioning.

Conclusion

Alternative beliefs about HIV/AIDS express an eroded public trust in HIV science and pose a potential threat to the achievements of HIV prevention and treatment programmes. This chapter highlights how alternative accounts about the origins of the virus and the existence of a cure are discussed by young African men and women living in Khayelitsha. Respondents reflected on how past experiences and current observations informed the manner in which they evaluated the trustworthiness of certain scientific claims about HIV. These observations and experiences drawn from past and present inequities and abuses, combined with awareness of certain aspects of HIV science that did not ‘add up’, fuelled respondents’ beliefs in alternative beliefs about HIV/AIDS. They pointed to certain crucial areas of ongoing confusion and uncertainty – the origins of the virus and the existence of a cure – which remain inadequately addressed by official sources. These types of questions or uncertainties stemmed less from people’s rejection or estrangement from science than from their skeptical engagement with biomedical assertions (Connors 1995; Larson and Heymann 2010; Leach 2007). That such questions persist suggests that clarifying the origins of HIV and the existence of a cure is still a significant and fundamental point of interest for much of the South African public, and not merely a symbol of broader anxieties. Though few studies have measured respondents’ knowledge about the question of origins, those that exist suggest high levels of uncertainty. For instance, Makongoza and colleagues’

studied South African adolescents' knowledge about the origins of HIV and found that only 21% could answer correctly, while 47.6% were unsure (2012).

The fact that respondents in this study indicate some flexibility and open-mindedness to new information about HIV implies a possible opportunity for trusted individuals to disseminate different viewpoints (Dickinson 2010b; Dickinson 2009; Bogart et al. 2010). To this end, the following chapter examines the extent to which various sources of information about HIV – including politicians, community leaders, doctors, and traditional healers – are trusted by respondents. It examines how the dynamics of relational trust between respondents and sources of authority are generated and sustained, and what aspects of a person or organization's 'reputation' are salient.

Chapter 5: Trusted Sources of Information about HIV/AIDS

“The effectiveness of a message depends, in part, on the credibility that recipients attach to its source” (Herek and Capitanio 1994).

Introduction

This chapter examines the evidence from the CAPS survey and focus group discussions relating to whom people trust as sources of information about HIV/AIDS. Studies have suggested that identifying trusted sources of information about HIV/AIDS is essential in order to combat alternative beliefs about HIV/AIDS and increase trust in scientific authorities. The chapter argues that people judge trustworthiness through their own personal observations, impressions, and experiences with various sources of information including doctors, traditional healers, politicians, and activists. In some cases, well-known figures are judged more for their personal life decisions than for their policy choices, highlighting the complex, and at times contradictory, meanings of these figures to key populations.

This chapter is divided into 4 sections. Section 1 briefly examines the rationale for examining trusted sources of information, and reviews some of the relevant literature from Chapter 3. Section 2 details the results from the CAPS survey and focus group discussions about trustworthy groups and individuals, highlighting the rationale provided by respondents for their perceptions and reflecting on the importance of empirical observations in shaping trust. Section 3 examines trust in political figures, drawing on Fine’s (2001) theorization of “difficult reputations” to highlight the nuanced views of political figures among focus group respondents. Section 4 highlights key divergences between the qualitative and quantitative data and posits various explanations for these differences. The chapter concludes by outlining how these results were explored in more detail with a case study of the Treatment Action Campaign in Chapter 6.

Section 1: Rationale for focus on trusted sources of information

Given the persistence of doubt, uncertainty and mistrust of scientific information about HIV/AIDS discussed in Chapter 4, focus group respondents relied on everyday observations to test the plausibility of scientific claims. These observations encompassed the behaviors and rhetoric of public and political figures. This raised the question of who is considered a trusted source of information about HIV/AIDS and why. Several studies have suggested that identifying trusted sources of information about HIV/AIDS is essential in order to combat alternative beliefs about HIV/AIDS and restore trust in scientific authorities. For example, Hutchinson and colleagues' study of a sample of men who have sex with men (MSM) in the US identified primary care physicians as the most trusted sources of HIV information and the US government as the least-trusted (2007). Exploring whom people trust can indicate those people who perpetuate alternative or conspiratorial ideas (Grebe and Natrass 2012; Natrass 2012a), as well as reveal appropriate people to be involved in credibly countering these beliefs (Bogart et al. 2010; Bogart and Thorburn 2005; Hutchinson et al. 2007; Larson and Heymann 2010).

As discussed in Chapter 2, in the Public Understandings of Science framework, trust is theorized as an evolving, relational, and multi-dimensional concept, developed as a function of the social identities and relationships in a particular society. This conceptualization suggests that an individual can have differing levels of trust in a specific health care provider, the general health care system or political figures in the government. In practice, then, an individual could mistrust certain biomedical claims about HIV while still maintaining high levels of trust for biomedical practitioners, such as doctors and nurses. This contradicts a common intuition that people who endorse alternative beliefs about HIV have turned away from biomedical sources of information towards some other less-biomedically orthodox source, such as South Africa's recent political leadership, or traditional healers.

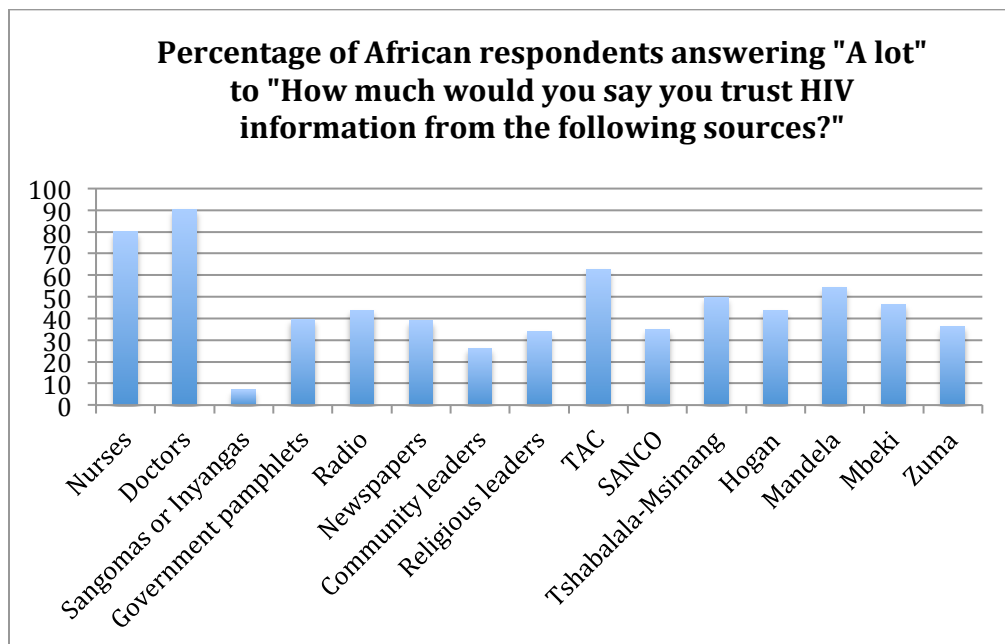
CAPS survey data and the focus group discussions presented in this chapter highlight this seeming contradiction. In these data, respondents from both

'endorser' and 'non-endorser' groups report high levels of trust in doctors and nurses, and low levels of trust in traditional healers, *sangomas* and *inyangas*. These perceptions of trustworthiness were generated through what Hardin calls "a street level epistemology of trust" (1992), whereby respondents come to know or believe something through personal observations and empirical experiences. Conditions of uncertainty and doubt, such as those discussed in Chapter 4, prompt people to "turn to their social experiences to fill the gaps" (Fischer 2005, 60).

Section 2: Trust in sources of information

Table 3 shows the results from African respondents for the 2009 CAPS survey question G.43, which asked respondents "How much would you say you trust HIV information from the following sources?" Respondents were prompted to answer with reference to a five point Likert Scale, with the possible answer of 'A lot', 'Somewhat', 'Not really', 'Not at all' or 'Don't know'.

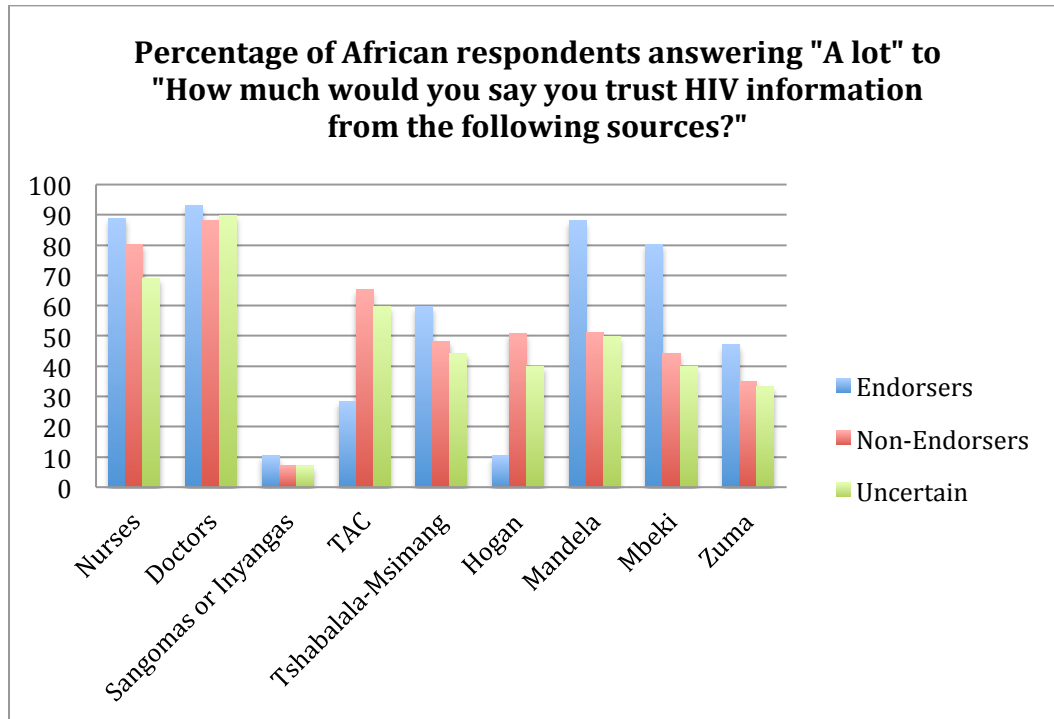
Figure 3: Trust in sources of HIV information



While general tendencies of trust towards certain groups and individuals and away from others can be observed, Figure 4 shows these same sources of information,

disaggregated by African respondents' answers to questions about alternative beliefs about HIV/AIDS. As these were the basis for organizing and grouping focus group discussions, results will be discussed in relation to these categories.

Figure 4: Trust in sources of HIV information by category



Doctors and nurses

A majority of all African respondents on the survey indicated very high levels of trust for doctors and nurses. There was little uncertainty expressed about their trustworthiness. Figure 5 and Figure 6 show respondents' assessments of the trustworthiness of their information about HIV/AIDS.

Figure 5: Trust in HIV Information from doctor

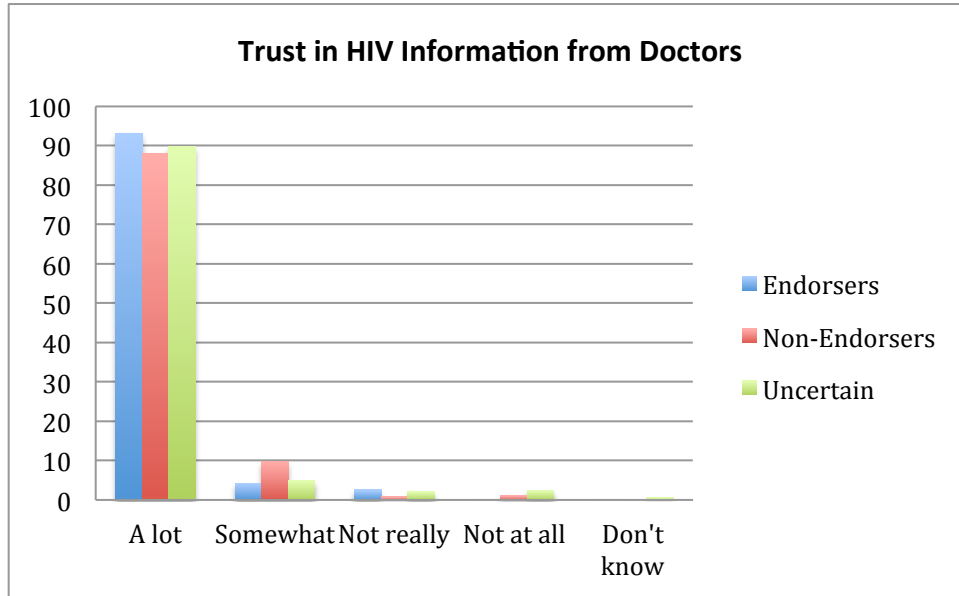
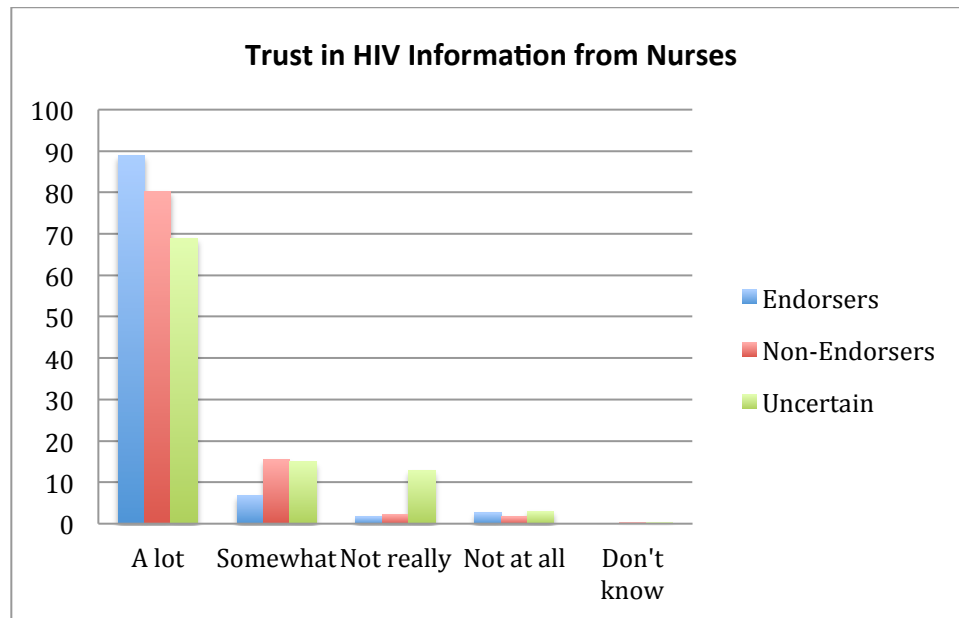


Figure 6: Trust in HIV Information from nurses



As with respondents' beliefs about the origins of HIV and the existence of a cure (Chapter 4), for focus group respondents to trust certain sources of information, personal observations and experiences mattered as much as or more than professional claims or qualifications. Doctors and nurses' credibility was attributed to their lack of ulterior motives, and their extensive and specialized education in

managing health and disease. Their claims were tested by observations of people going on treatment and becoming well. They were able to explain the underlying rationale for their judgment. One female non-endorser agreed with other respondents in her group about the trustworthiness of doctors, stating:

I also say so, because they are the ones who have been taught about it. Because we have not been taught in-depth about it, about our bodies and infections and diseases. They are the ones who came up with “There is HIV” from the start. We wouldn’t know that we have HIV – we would just say “I am sick” only. You see? So we can’t say they are lying (N1 Female Non-Endorser 25/08/2010).

It was not only non-endorsers who expressed trust in doctors and nurses. Both female and male endorsers saw doctors as trustworthy sources of information about HIV. One female endorser stated, “No, I trust it shame, because they have studied for it. And I am still new to this ‘industry’ so I will listen to what they tell me. If they say I must do this, I will do this....” (N4 Female Mixed 18/08/2010). Similarly, a male endorser believed in doctors’ information because they had evidence to support their claims:

So we believe in them, because they are talking about things that we are seeing and things that are happening. They are not just talking about things we do not know or haven’t seen. They come with advice that “in order to be protected from this you must do this and that, to not get this virus” (N2 Male Endorser 11/08/2010).

At times, respondents suggested that they trusted information about HIV from health care providers because they had no choice. This was not because they felt coerced by doctors and nurses but rather because these professions had demonstrated expertise about HIV. One male non-endorser explained, “It is a must that we believe them, because really they are the ones who can really ‘predict’ that ‘you are sick and you are suffering from this and in order for you to become alright do this’ – they go to school for this. They have studied for it. They are not like us. They are more advanced, than us”. He concluded, “So we have no choice but to believe them” (N3 Male Mixed 15/08/2010). An endorser shared this sense of passivity stating, “I also agree that we can trust them – sometimes we trust them with no other choice – because when you are sick and you want help you don’t have

any other option and you want to get well” (N2 Male Mixed 28/08/2010). Another non-endorser echoed this, arguing, “Yes, I think we don’t have much choice in that question. Because they are the most knowledgeable people on health. Doctors and nurses – they are the ones who know a person’s health most” (N2 Male Mixed 15/08/2010).

Trust in doctors and nurses, however, was not universal, with some respondents criticized these health care workers. When respondents talked about their untrustworthiness, it was sometimes due to the perception that they rushed patients through treatment, not taking sufficient time to counsel or understand a problem. One female non-endorser argued, “Their counseling is not enough. Someone else who comes out there HIV positive might dismiss what they say there and do as they please instead. It’s not solid. It’s not adequate. The information they give us in those counseling sessions is not enough” (N2 Female Non-Endorser 12/08/2010). Another female non-endorser thought the nurses who operated in the townships were unprofessional and impolite, stating,

For me, the township nurses are tiring – they have no respect – they swear and so forth. So I wouldn’t go to the ones in the townships – I would choose to go here towards the city center, because they sit down and listen to what you want to say whether you are wrong or right” (N1 Female Mixed 18/08/2010).

An endorser in the same group echoed this sentiment: “Yes, I also agree with her. Townships, I won’t lie, nurses lack manners. Because you could end up not going to the clinic because of nurses” (N4 Female Mixed 18/08/2010).

Others felt that doctors were driven by the profit motive, trying to see as many patients as possible. One female non-endorser said,

Doctors are after money – how many other people are in the queue behind me? They have no time to say, “Okay, let me give her some counseling” or “Let me take her to that other room”. He/she is just after money only! (N3 Female Mixed 21/08/2010).

Other respondents held doctors primarily responsible for inconclusive or contradictory test results. One male endorser respondent explained:

I'd also say I am in-between on this one and agree with this man here. I am in-between. Because what happens is that you can go to the clinic and get tested for AIDS and then the results come out saying you're positive. And then they will give you another date to come and test again. And then these results come out saying you're negative. You see that doesn't make sense? And then again, you test again and it says you're negative – yet at first they had said you were positive. You see? Which means that you can trust it or you can't trust it. Which means you are on two minds and you wonder why at first they said you're positive? Why are they now saying I'm negative? (N4 Male Endorser 11/08/2010).

Another respondent in the same group had a similar experience, but the manner in which the doctors handled the inconsistent result led him to trust them.

Okay. What happened is that I once experienced something like that. But what happened – what I realized is that those people there are able to answer your questions there. They have the information and it's sufficient... (N3 Male Endorser 11/08/2010).

Only one respondent voiced the belief that doctors were somehow involved in spreading HIV. A male endorser felt that the needles used in clinics could be accidentally contaminated with HIV.

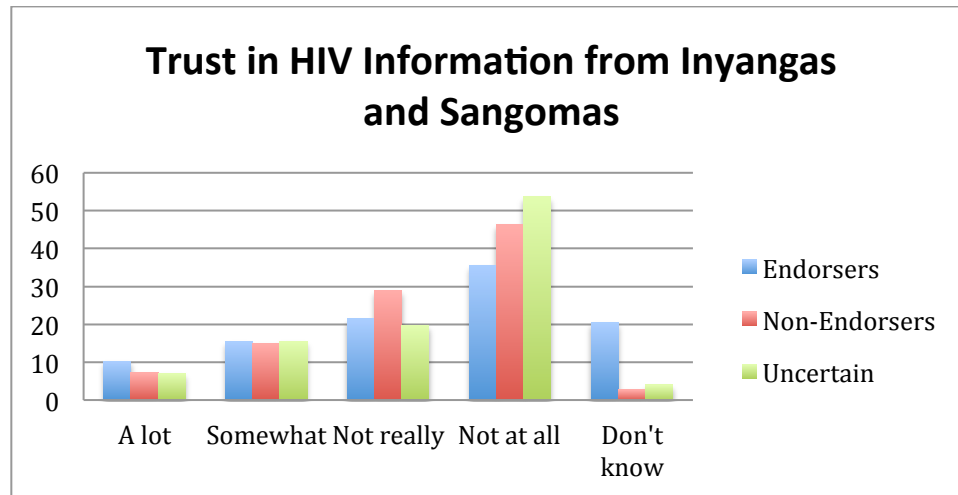
It is hard, sometimes, even these doctors too are liars – I just want to show something else – you can, whilst knowing that you are HIV negative and have one partner – you can go and get tested and then that doctor inserts the wrong needle into you or they draw your blood or they put someone else's syringe into you and as such you can get AIDS like that. Mistakes like that happen at hospitals. So we must also look at that (N2 Male Endorser 11/08/2010).

In general, doctors and nurses were sometimes held responsible for bad outcomes or rushed care, but were also seen as one of the most trustworthy sources of information on HIV because of their training and expertise. Their preparation for dealing with HIV was often contrasted with that of traditional healers, as illustrated in the next section.

Trust in traditional healers: *sangomas* and *inyangas*³²

CAPS respondents failed to endorse *sangomas* and *inyangas* as trustworthy sources of information about HIV, with results remaining consistent between endorser, non-endorser and uncertain respondents (Figure 7).

Figure 7: Trust in HIV Information from traditional healers



There was a degree of uncertainty or ambivalence from endorser respondents, with 20% of them answering “Don’t know” to the question of trustworthiness of HIV information from this source. In general, traditional healers (sometimes called “witchdoctors” by respondents) were nearly universally perceived as unreliable sources of information about HIV/AIDS. Focus group respondents suggested that while *sangomas* and *inyangas* could be relied on for information and treatment for many other ailments, AIDS was not a disease they could treat or prevent. The message that HIV and AIDS are somehow different from other diseases – and

³² *Sangomas* and *inyangas* represent the two main types of traditional healers in South Africa. Generally, *sangomas* are diviners while *inyangas* are herbalists, though Ashforth has argued that this distinction is “deeply problematic” because this depiction of healing categories is “thoroughly Western and modernist in conception” (2005, 228–9). In using these descriptions on the survey and in focus groups, this study acknowledges the imprecise or conflated representation of different aspects of traditional medicine.

consequently, beyond the range of treatable conditions by traditional healers - was clearly reflected in respondents' comments.

N3: No, I do not trust those people. I only trust those people in the procedures of cleaning your blood. But on HIV? No, I do not trust them at all. I could trust them if you have a 'drop' [a sexually-transmitted infection] and they make you whatever, but I never drank their medicine. I trust sangomas for many other things but not for HIV" (Male Uncertain 27/08/2010)

A female non-endorser agreed: "I want to say that. Witchdoctors are alright in certain things – but on the side of AIDS – I do not see it clearly" (N1 Female Mixed 21/08/2010). A male non-endorser concurred, stating, "Witchdoctors have got nothing to do with AIDS – they don't know nothing about AIDS, because it is only about – it is something that we also read in books. It is something that came through research" (N1 Male Mixed 28/08/2010).

Along with this perspective, some respondents suggested that traditional healers would be more trustworthy if they subjected their treatments to the same standards as biomedical ones. In another study, trust in western versus traditional medicine is distinguished by perceptions of transparency. As Geffen reports on a conversation he had with a TAC activist: "I asked Andile what he understood by science and why it is different from traditional medicine. "Science to me means you can trust the medicine because they will tell you the side effects and what is in the medicine. There is an expiry date on the medicine. Traditional healers will not tell you this" (Geffen 2010, 83). One respondent disagreed with another respondent in the focus group for similar reasons:

I am not disputing what you are saying, right? They – if their things could be proven like those of doctors – they get taken to labs and get tested and so on – we would drink them. But their things – you find a person just digs there and they don't even know what tree that is and they just cook it and then lie to you and say, "this is HIV medicine" (N3 Female Mixed 21/08/2010).

This perspective was shared by non-endorsers and endorsers alike. One male endorser contrasted treatments from traditional healers and doctors, arguing:

Well, in my thoughts, things that have to do with witchdoctors and sangomas on matters pertaining to HIV – no, it's not easy to believe them. Because they

firstly profit from you. There is nothing else. So they don't examine you, draw your blood, so they just tell you 'you have this and that'. So it's not easy to believe someone like that. So we can believe in doctors because you can see what they are doing, it happens physically – they draw your blood and they test it. That's where HIV resides anyway (N4 Male Endorser 11/08/2010).

The empirical basis of knowledge among doctors and nurses was contrasted with traditional healers and sangomas, who were seen to prescribe treatments without proper testing. Respondents noted that claims made by traditional healers were often unsubstantiated by tangible evidence, and accused them of deriving treatments from “dreams” or visions instead of scientific exploration. A female non-endorser remarked,

Witchdoctors, firstly, the reason the doctors and nurses do not want their medicines is because – medicine is made and tested in the lab to see if it will be suitable for a human. And those ones – where do they get tested? They get dug up from the forest and a person will just cook it and say, “Take it!” where was it tested? (N4 Female Mixed 21/08/2010).

Traditional healers were held as having self-interested intentions in their treatment of HIV and AIDS. Respondents criticized the profit motive of traditional healers, suggesting that this led them to prescribe treatments without adequate information and training. A male endorser claimed, “No, just one thing – a *sangoma's* main thing is business – they want your money. Even if you can go there and say “I've got AIDS!” they'll say no I'll try something with my medicine although they're lying, they know that, they just want your money, they wont let you leave with your money” (N6 Male Endorse 11/08/2010). A male non-endorser agreed, stating:

I don't believe in it [traditional healers' information about HIV] at all. There are people who just want to take advantage of people by stating that “No, I can cure this!” And then after five days you'll find that person changing their tune. And then another one will come saying “I cured so and so!” although we never knew how true that is and whether that person they cured actually had it (N2 Male Non-Endorser 13/08/2010).

People also felt suspicious of their qualifications and the source of their knowledge. One male non-endorser stated it plainly, “These [people] are dreamers” (N5 Male Mixed 28/08/2010). Another group of men from the 'uncertain' group concurred:

N5: The witchdoctors. I do not trust them at all.

N3: *Sangomas*. *Sangomas* cannot be trusted.

N4: Me too – I mean I can't see where they would say they got the information from. Would they say they dreamt it up or what? No. Those people cannot be trusted (Male Uncertain 27/08/2010).

Some respondents took a more nuanced view, acknowledging that just as there could be good doctors and bad doctors, the trustworthiness of traditional healers depended on the specific person. One female endorser explained that “There are witchdoctors that are sincere and there are witchdoctors that are liars and you can see that he is lying” (N5 Female Mixed 21/08/2010), while a male endorser felt that “Sometimes others are right, sometimes others are not. They're just like doctors too – some are honest, some lie. You see?” (N2 Male Endorser 11/08/2010). Integral to some respondents was the notion that one had to believe in the power of traditional healers for them to be effective. As one respondent noted, “What I think about that is that a person – a person gets healed by what they believe in. if you believe in prayer, pray a lot. If you believe in medicine, use them a lot and they will help you” (N2 Male Mixed 13/08/2010).

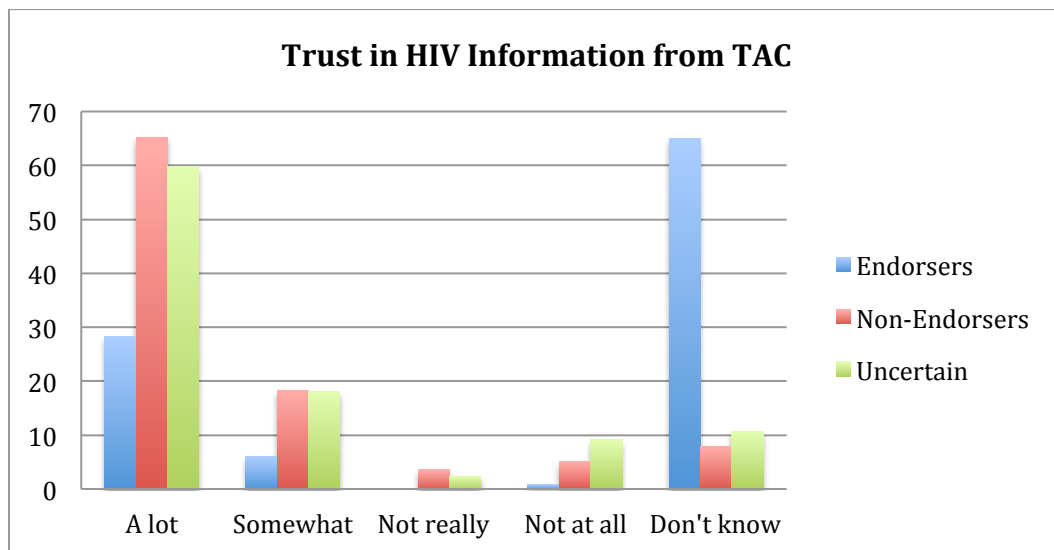
Overall, traditional healers were trusted for non-HIV related concerns but not viewed as trusted sources of information about HIV. The separation between those who are seen as knowledgeable about treating HIV and those who are not is, of course, connected with whether HIV is viewed as caused by witchcraft or by a virus. The claim that witchcraft does not cause HIV has been called “the fence around AIDS” (Steinberg 2008a, 119), serving to protect people from the notion that “neighbours and family are murdering one another in droves” (Steinberg 2008a, 132). As discussed in Chapter 4, respondents were not entirely decided on whether witchcraft played a role in the origins of HIV or not. The ‘fence around AIDS’ may mean that one can still believe in witchcraft but think that traditional healers are ill-equipped to manage the virus. As Steinberg highlights, people have lost some faith in traditional healers in the face of widespread and dramatic societal change. His protagonist remarks, “Today, the *sangomas* still tell you to do this and this, but the ancestors have not spoken to them” (2008a, 158).

While some respondents thought that certain traditional healers could be trusted while others were disreputable, others felt that all were equally untrustworthy and driven largely by profit. HIV was seen as a ‘western’ or ‘medical’ disease and thus one that required formal education or research to understand. Thus it was outside of the remit of traditional medicine. This notion, that HIV can only be understood through proper research and study, was pervasive in focus group discussions and was maintained in subsequent discussions about trust in the Treatment Action Campaign and *Medicins Sans Frontieres* (MSF).

Trust in TAC and MSF

When asked about the trustworthiness of organizations such as TAC and MSF, non-endorser and uncertain respondents widely endorsed their credibility (Figure 8).

Figure 8: Trust in HIV Information from TAC and MSF



However, endorser respondents expressed much lower levels of trust in TAC. This was one of the few instances where endorser respondents expressed *less* trust than other CAPS respondents. This may reflect non-endorser and uncertain respondents' greater familiarity with the organization. In Grebe and Natrass's (2012) study of the CAPS population, having ever heard of the Treatment Action Campaign was

negatively associated with endorsement of AIDS conspiracy beliefs, suggesting that “the scientific approach to AIDS adopted by the TAC may have undermined the credibility of rival conspiracy accounts” (Nattrass 2012a, 54). Approximately 65% of endorser respondents were uncertain about their trust of HIV information from TAC, suggesting that they may not be familiar with the organization. Alternatively, endorser respondents could be less trusting or less certain of TAC because of the organization’s active contestation and critique of Thabo Mbeki and Manto Tshabalala-Msimang, both of whom reinforced certain alternative beliefs about HIV/AIDS. They also represented TAC as “‘anti-patriotic’, ‘anti-African’ and salespersons for the international pharmaceutical company” (Robins 2005, 126). In this case, endorser respondents may have felt as though TAC did not adequately take into account their sources of distrust of HIV science.

Though these criticisms may exist, respondents from all focus groups generally viewed TAC as a good source of HIV information, due to the perception that TAC workers were visible at the local level and effective at the policy level. This trust was conferred as a result of respondents’ tangible, evidence-based observations of this group’s professionalism, training and respect for key populations. Many respondents reported having actually seen or spoken directly to a member of the organization, and having seen the concrete evidence of their achievements in the form of the availability of ARVs. As a male, uncertain respondent states:

I can also say that I trust that [organization] fully. Because now we even have ARVs through their efforts. I mean they are the people that seem to understand this situation most and they are following it up well. So you can trust them fully (N4 Male Uncertain 27/08/2010).

A female from a mixed focus group agrees:

TAC fights a lot on our behalf – more especially on the ARVs. Because if TAC was not around we wouldn’t have ARVs or if there were ARVs we’d still be in line 1. We wouldn’t have line 2 (N4 Female Mixed 21/08/2010).

Another male non-endorser felt TAC was trustworthy “because it isn’t just something someone has just thought up. They go and do particular research and

establish that. On the thing I didn't know, I discovered, this and that today" – to then enable him/her to be able to reiterate this upon us" (N1 Male Non-Endorse 13/08/2010). The following exchange between a female non-endorser and the facilitator illustrates the tangible nature of TAC's contribution to knowledge in the community.

Facilitator: Like what kind of information do they spread to people?

N1: Like ARVs and these pills – AZT and Neverapine and all those things. I first heard about those things from TAC. And even these ones for pregnant people as well – are they also ARVs?

Interviewer: Yes, ARVs.

N1: That a pregnant person must use them in order to protect that child. I first heard about them at TAC. So that is when I started believing because really when a child is born by an HIV positive person – that child comes out negative even though the mother is positive. So that is why I would believe it (Female Non-Endorser 25/08/2010).

A key aspect of TAC's credibility, therefore, is derived from people's observations that the biomedical interventions they espouse have real results. It is notable that this respondent began trusting TAC's information when she learned that prevention of mother to child transmission was possible. Although, as discussed in Chapter 4, PMTCT struck so many respondents as incredible bordering on unbelievable, this respondent was clearly awed and impressed by this capacity. MSF was trusted for similar reasons. One male non-endorser observed that MSF had worked in solidarity with HIV positive people in the community, and again, had achieved tangible results:

Information from MSF is very trustworthy, because they are some of the people that – MSF is one of the people who are involved a lot or who befriend themselves with people who have this virus in the area. So for me, their thing [information] is very trustworthy, because now we can see that people are becoming better, I mean they are able to get health through the information they get through, through the medicine they get there, so MSF's information I trust it a lot (N2 Male Mixed 15/08/2010).

Interestingly, TAC and MSF were seen as trusted by both endorser and non-endorser focus group respondents. One female endorser saw TAC as a source to clarify confusing information, stating, "So if you are doubtful about something you can just go there to TAC and you will get information from TAC" (N5 Female Mixed 21/08/2010). A male endorser shared this view, affirming, "I believe it all – because

like I said, they answer my questions clearly when I ask. They have proof of what they talk to me about. Which satisfies me. I believe them” (N3 Male Endorser 11/08/2010). Another endorser respondent from the same group raised the importance of visible, observable proof. He stated, “I also trust them – the doctors and TAC – because they do things physically and we see them with our own eyes (N4 Male Endorser 11/08/2010).

One non-endorser man felt that the public was somewhat constrained in their trust of TAC, stating, “In terms of trusting the information – I think we don’t have a choice – we are forced to trust the information they give out, because I believe they are trained to give us information and educate us and all that” (N3 Male Mixed 15/08/2010). This echoed sentiments expressed by respondents about trust in doctors and nurses, suggesting that when people were educated and trained to disseminate HIV information, the public had no option but to trust them.

In some cases, respondents who were skeptical about TAC’s trustworthiness had actually had little knowledge about the organization. One male endorser said, “Its presence I also do not see, because I do not have that much knowledge about them. If I had more knowledge on them, it would be clearer” (N4 Male Mixed 15/08/2010). Others had encountered them in confrontational situations with politicians. One non-endorser man stated, “They’re always arguing and shouting at politicians on TV and on radio. There is no information that I’ve gotten from the TAC” (N3 Male Mixed 15/08/2010).

In general, people trusted individuals who seemed informed and responsible, and who took the time to answer questions. This criterion for trustworthiness was shared by endorsers and non-endorsers alike. One male endorser explained how he determined the trustworthiness of a particular source:

If ever I am given a chance to ask questions and it gets explained to me in the way that I best understand it, then I trust that information. If I am satisfied with the responses I get. And that person knows what they are talking about

and not come with half-information. I'll trust that person if they answer my questions fully (N3 Male Endorser 11/08/2010).

Other respondents were reluctant to say whether a source was trustworthy or not when they did not feel they had adequate information. The following exchange between a female non-endorser and the interview is indicative of this reticence.

N3: But I won't trust information from places I do not know. I stand by TAC only.

Facilitator: So MSF? You don't trust it at all?

N3: I do not know them – I don't know them at all (Female Mixed 21/08/2010).

By refusing to pronounce on a source with which they are not familiar, respondents indicated the extent to which they valued forming an opinion based on observations and tangible evidence. This tendency was even more apparent when respondents were asked about the trustworthiness of political figures.

Section 3: Trust in Political Figures

Trusted political leadership is rightly considered an important factor in the dissemination of accurate information on the prevention of HIV/AIDS (Nattrass 2012a), but the credibility of public figures and the meanings attributed to their statements and actions is complex and under-studied. On the CAPS survey, respondents endorsed the trustworthiness of certain political figures while disparaging others, with some striking differences between endorser and non-endorser/uncertain respondents.

Uncertain respondents had similar levels of trust to non-endorsers. With the exception of Barbara Hogan, endorser respondents tended to be more trusting of political figures in general. This may be because, as Nattrass has suggested, endorsers may feel they have no choice but to trust political leaders (2012a, 22). Several endorsers in the focus group discussions allude to this sentiment, suggesting that given the high stakes associated with HIV, they had to trust what they were told by those in power. It may also be due to the perception, shared by some focus group

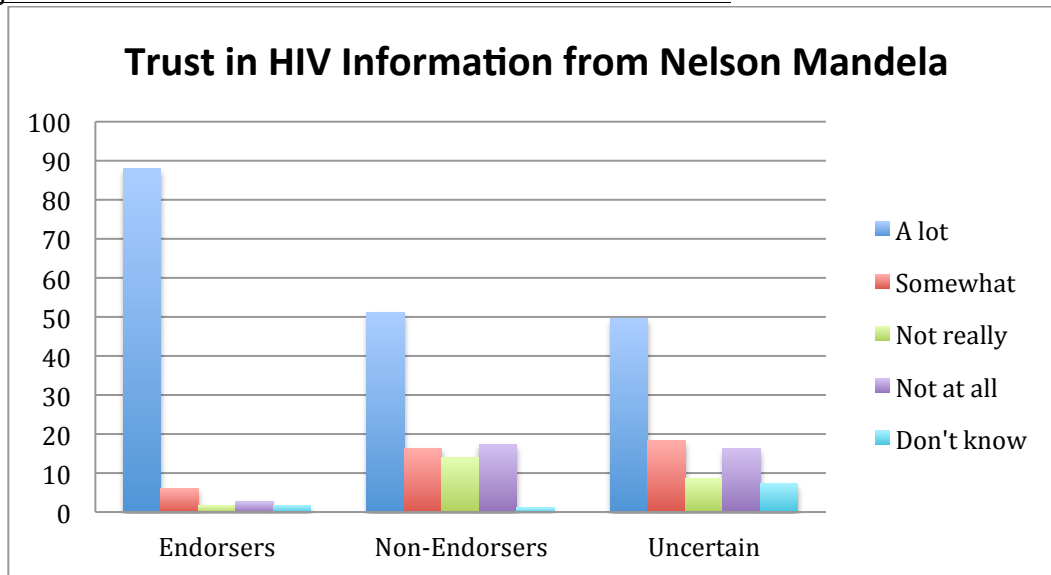
respondents, that politicians are merely acting as conduits of information from those with biomedical expertise, such as doctors and scientists.

Despite these general observations about politicians, trust in specific politicians was still explained with regards to explicit characteristics or behavior, rather than an overall deference to power. By drawing on these local perceptions and experiences, respondents discerned the trustworthiness of political figures that reflected their own values and priorities. At times, these perceptions diverged from how these political figures have been represented in international, academic and activist circles. Gary Fine's (2001) work on 'difficult reputations' and his typology of some reputations as 'contested' – namely that they are openly debated between different groups or populations – is useful to assess how political figures are viewed and assessed in this sample. By examining politicians' reputations among focus group respondents, these discussions enable greater understanding of what exactly is 'trusted' or 'not trusted' about a particular political figure.

Nelson Mandela

Former President Nelson Mandela was seen as trustworthy by approximately half of non-endorsers and uncertain respondents, and highly trustworthy by endorsers (Figure 9). Despite the fact that some respondents could not always recall specific details about his HIV policies, all groups displayed low levels of uncertainty or ambivalence about his trustworthiness. Rather, respondents expressed complete faith in Mandela's motives and intentions, derived from his years of struggle on behalf of the South African public.

Figure 9: Trust in HIV Information from Nelson Mandela



In the focus group discussions, some respondents abstained from the conversation of Mandela’s trustworthiness. They did not feel that HIV had been in the public sphere during Mandela’s administration, making it difficult to say if he was a trustworthy source of information on this topic.

You see my brother, during Mandela’s era – this thing of AIDS hadn’t fully emerged. Yes, it was there, but it wasn’t fully out there that this thing of AIDS exists. So I don’t want to enter deeply into the subject of Nelson Mandela’s time (N2 Male Endorser 11/08/2010).

Another respondent agreed:

No, I would say that in Nelson Mandela’s time it was not so prevalent. We had not gotten any information (N1 Male Mixed 15/08/2010).

However, even when they lacked full information about Mandela’s particular stance on HIV, respondents frequently regarded Mandela as trustworthy because of his overarching commitment and public service for South Africa. As one male respondent stated:

I mean Mandela would never kill his nation – I supported what he gave us – even though at that time I was still young. In the sense that I studied him as I grew up, I do not believe he would kill us. So I supported it and still support it today (N4 Male Non-Endorser 13/08/2010).

A female endorser also felt that Mandela was unquestionably trusted by everyone:

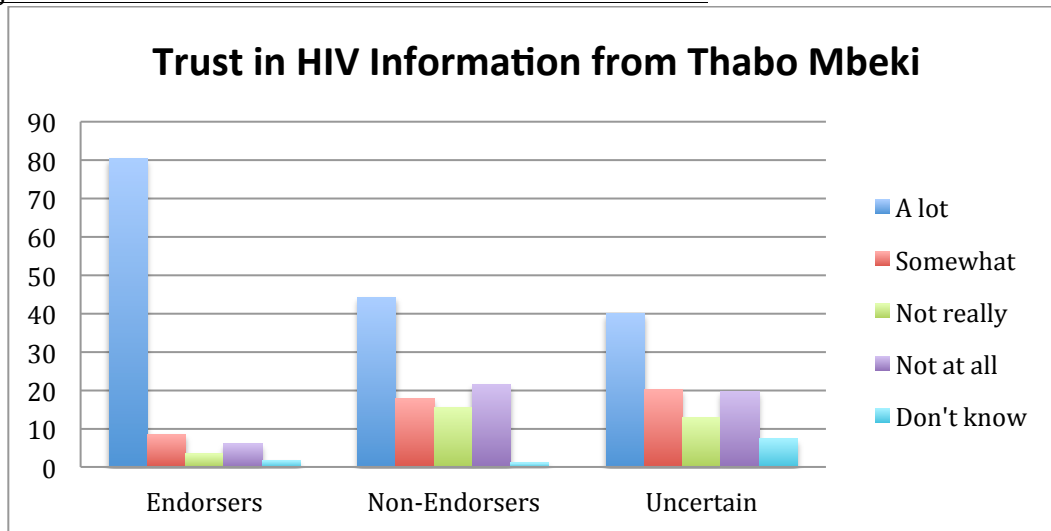
Well, Mandela – anything that comes out of his mouth everyone believes it. Even if Mandela can come up with something to destroy us, we will all go to him, because he is Mandela. Because we have told ourselves that this is Mandela. Even if you didn't hear what Mandela said people will say "Mandela spoke and he was right!" even though you didn't hear what he said and you'll believe (N4 Female Mixed 18/08/2010).

Respondents unanimously endorsed former President Mandela as a credible source of information about HIV despite the fact that respondents were not always clear about specific aspects of his policies or public statements about HIV. For instance, several respondents asked for clarification on what Mandela's stance on HIV had been. When asked if she trusted Mandela as a source of information about HIV, one female non-endorser participant responded by asking: "I'd like to ask what was the information?" (N3 Female Non-Endorser 25/08/2010). After being given a vague summary of Mandela's main stance on HIV by the facilitator ("he supported people who are HIV positive"), the same respondent declared, "I would trust it. 100%" (N3 Female Non-Endorser 25/08/2010).

Thabo Mbeki

Survey responses about Mbeki's trustworthiness closely mirrored those about Mandela's. The same pattern was visible, whereby a much higher percentage of endorsers felt Mbeki was trustworthy on the subject of HIV (Figure 10).

Figure 10: Trust in HIV Information from Thabo Mbeki



As with Mandela, there were also low levels of uncertainty reported by all groups. On the whole, however, focus group respondents' comments about the trustworthiness of HIV information from Mbeki were more critical. One female endorser respondent demonstrated a differentiated view of politicians:

N4: But I won't lie, because we all know that Mandela is trying his best to make our world alright.
 Facilitator: What about our former President? Mister Mbeki?
 N4: I don't even want to lie – I never had any time for Mbeki.
 (N4 Female Mixed 18/08/2010).

Some respondents judged Thabo Mbeki's trustworthiness about HIV in relation to his past history with the anti-apartheid struggle. He was viewed as having been appointed to his position rather than earning it through hard-work or personal sacrifice (in contrast with Mandela). His perceived lack of 'true' struggle credentials were translated by some into disengagement with South Africans' concerns, as indicated by one female non-endorser:

Mbeki was never in the MK³³ and all these things of the struggle, so he knows nothing. He just came in because his father had reserved him a seat there. And he never studied here in South Africa [sic] and he only came back after

³³ This is inaccurate as Mbeki joined MK (*Umkhonto we Sizwe*), the armed wing of the ANC, prior to being sent abroad to continue his education in exile. The BBC described him as having an "impeccable pedigree in the political struggle against apartheid" in 1997, when he assumed the ANC leadership (BBC News 1997).

the struggle. So he doesn't know anything about South Africans – what we want and need? And so on – even when he was president, the only thing he would do was just be overseas all the time (N1 Female Mixed 18/08/2010).

A female endorser respondent contrasted Mandela's struggle on behalf of the South African public with other politicians' self-interest:

Those people endured no pain whatsoever and they became presidents – Mandela sat on that presidential chair knowing that “This is what I wanted in life – to sit in this chair and help the people”. These other ones [after him] are just busy and they just want to see their ‘thick’ wages (N4 Female Mixed 18/08/2010).

Several respondents echoed the claim that Mbeki spent much of his administration focused on overseas concerns.

Well when I look at Mbeki – he wasn't too concerned on things related to South Africa – he was more concerned on peace in Africa and directing things to African nations (N2 Male Non-Endorser 13/08/2010).

Another respondent agreed:

When it comes to Mbeki I will agree with the brother that ‘Okay, well he was focused a lot on the outside and was not involved here’ but economically he boosted us here in South Africa (N4 Male Non-Endorser 13/08/2010).

Although some respondents clearly assessed Mbeki's trustworthiness based on facts that were not directly connected to his stance on HIV/AIDS, others included Mbeki with the general messaging around HIV at that time. One non-endorser explained, “Yes, we trusted it as others – the information that we got from Mbeki, because they were always preaching, ‘Let's be safe’, ‘Do this, don't do that’” (N1 Male Mixed 28/08/2010). An endorser in the same group concurred, “Me too, I agree with what number 1 said – in the sense that we all believed that Mbeki could bring some better change and that we would have better health than before so we believed the information he gave us” (N2 Male Mixed 28/08/2010). A man from the uncertain group agreed:

Yes, I mean during the time in which he was president, which was quite recent – I would say that he worked hard, because that was the time in which we started to get a lot of information as compared to Mandela's days. So I could say that I do not remember him talking about it, but where we got the most information was during his time (N1 Male Uncertain 27/08/2010).

A fellow respondent echoed this sentiment, perceiving a shift in focus towards HIV/AIDS that he attributed in part to the Mbeki administration:

During the time of Mbeki and Manto at least there was some movement for this HIV and AIDS thing – and for even this medicine that slows it down came during his time. So I would give him some credit (N2 Male Uncertain 27/08/2010).

A minority of respondents thought Mbeki had been actively working to address the HIV epidemic. One non-endorser stated, “So I was going to say we believed Mbeki and we would hear that he was overseas and he is trying to find a cure for HIV and he was meeting with scientists and whatnot and what” (N5 Male Mixed 28/08/2010).

Despite the perception among some respondents that Mbeki was a less-than-trustworthy source of information about HIV, it is striking how infrequently Mbeki’s controversial stance towards HIV science was raised in discussions. The fact that Thabo Mbeki was, and remains, publicly associated with AIDS denialism was a less salient factor in respondents’ perceptions of him than his personal behavior and history. Though it may be true that “the HIV/AIDS controversy has become a sine qua non of Mbeki’s presidency in international, national, and local debates” (Posel 2005, 140), and that Thabo Mbeki “will be most remembered throughout the world for his ‘AIDS denialism’ (Decoteau 2008, 166), this was not the dominant image presented by respondents from Khayelitsha. As a male non-endorser respondent stated, “Well, Thabo Mbeki, I don’t recall there being a scandal of his around things on HIV” (N4 Male Non-Endorse 13/08/2010).

One of the few mentions of Mbeki’s denialism around HIV and AIDS came from a male non-endorser:

Well, Mbeki had information – I won’t lie. But there was a time whereby in which – and I think this was shown on TV – when he said people can cure AIDS by eating healthy foods like vegetables and so on, you understand? So that eventually became an issue and it even went to courts. So I say that Mbeki had information, but which we could not trust in its entirety... So a

person can distinguish between right and wrong for themselves (N2 Male Mixed 15/08/2010).

Another discussion about Mbeki's intransigence about HIV/AIDS occurred in the 'uncertain' focus group of men. One respondent highlighted the controversy about the former president's position:

But Thabo Mbeki – he once said a statement that “HIV does not cause AIDS” - he once said that and that caused people to be confused. But then he changed it towards the end of his reign and said that “HIV does cause AIDS” but, so I would say that I give Thabo Mbeki 40 out of 100 (N5 Male Uncertain 27/08/2010).

Yet even when this was plainly brought forward, another respondent in the same group argued to give Mbeki the benefit of the doubt.

I mean, on that statement that the brother raises – that he [Mbeki] said, “HIV does not cause AIDS” and so on – I mean it was his opinion based on the information he received at that time. For example I hear and I have heard some things I have never heard of from this brother, there are some things this brother said and so now when a person asks me I will say, “According to what I have heard” and then I can put a statement that people can discuss. But when Mbeki was in charge that is the time in which where I got a lot more information (N1 Male Uncertain 27/08/2010).

This prompted a retort from the original respondent, N5.

Okay, I hear you, but for him as the president – I mean as a president mustn't I first do my research before saying something like that? Because that's confusing and there is no excuse for him to say a statement like that. He must first do his research and if he is going to say such a statement then he must keep his opinion to himself (N5 Male Uncertain 27/08/2010).

Though overt discussions or endorsements of Mbeki's denialism were rare, one exchange within the male endorser focus group bears further discussion. When questioned as to whether they believe HIV causes AIDS, one respondent replied:

HIV is, we have to establish 'what is HIV?' and what is AIDS? Because I believe the two are not the same – HIV and AIDS are not the same. HIV according to my knowledge, I think is a virus. And then AIDS is a disease. That is according to my knowledge. So I'd like to ask – this HIV is a virus and AIDS is a disease, so can't HIV turn into AIDS? (N4 Male Endorser 11/08/2010).

Following this comment, a long discussion ensued between respondents about this issue. After several minutes, the same respondent concluded:

So AIDS includes all those diseases – they all result in AIDS – so that is all one and the same thing, just with different names. That’s where it gets complicated for us (N4 Male Endorser 11/08/2010).

Though this seemingly resolves the issue, the style of questioning by the respondent is strongly reminiscent of Mbeki’s skepticism. In a parliamentary debate in 2000, Mbeki asked, “Does HIV cause AIDS? Can a virus cause a syndrome?” (Harvey 2000). That the respondent raised the issue in this manner may suggest that he tacitly supports Mbeki’s line of questioning.

These findings are most important to consider when comparing ‘endorser’ and ‘non-endorser’ respondents. The persistence of alternative beliefs about HIV/AIDS in South Africa has often been attributed to the intransigence of Thabo Mbeki and certain members of his administration while in power. Speculating about the ‘long shadow’ cast over AIDS science by the Mbeki administration’s stance, Tun and colleagues suggest that, “although these denialist positions have been retracted, the messages have already spread and continue to spread” (2012, 1). Until Mbeki and members of his administration admit their errors around HIV/AIDS science, argues Kenyon, “their views will continue to warp the thinking and practice of millions of South Africans” (Kenyon 2006, 16). If Mbeki’s legacy is truly to have spread AIDS denialism among members of the South African public, we would be most likely to see this manifested in strong endorsements for him and his administration among endorser respondents, and strong condemnation of him among non-endorser respondents.

Comments by both groups, however, challenge such assumptions. One of the endorsers from a mixed focus group (Female Mixed 18/08/2010) spoke about how she “never had any time for Mbeki”. Conversely, several non-endorsers felt that Mbeki had presided over improvements in the government’s response to HIV/AIDS during his tenure. Only a small minority of non-endorser and uncertain respondents

singled out Mbeki's stance as a specific - and problematic - policy choice. Absent were the sorts of attributions of influence documented elsewhere, as when Zambian AIDS activist Winstone Zulu described how Mbeki's denialism affected his own: "Here was Thabo Mbeki, my hero - when Thabo Mbeki questioned it, I was sold" (Nolan 2007, 232).

The absence of widespread discussion of Mbeki's intransigence can be explained in three ways. The first is methodological: Those respondents who strongly supported Mbeki's AIDS denialist stance felt uncomfortable endorsing these beliefs openly in focus group discussions, and instead offered opaque support for his leadership in general. The second is that respondents were not highly familiar with the specifics of Thabo Mbeki's AIDS policies. The third is that Mbeki's denialism sufficiently permeated the public 'airspace' in South Africa to the extent that respondents could be affected by it without attributing it directly to their former President.

The first explanation hinges on a homogenizing effect of the focus group methodology. Is it possible that respondents, in effect, concealed their deeper familiarity with Thabo Mbeki's policies, alluding instead to his overall achievements while in office? If homogenizing effects were in play, one would expect to hear much more strongly voiced trust of Mbeki in the male endorser group, where no representatives from the non-endorser community were exerting an influence. Indeed, the comments from one respondent in the endorser group are reminiscent of Mbeki's style of expressing skepticism about HIV science. That this respondent later acknowledged the consensus that HIV causes AIDS may have been the result of pressure from his peers. However, that pressure to conform to orthodox HIV science existed among a group of 'endorsers', and that no other members of the group joined in on this open questioning of the link between HIV and AIDS, suggests the other explanations as plausible alternatives.

The second explanation, that respondents simply may not have had strong familiarity with Mbeki's AIDS denialist stance, is difficult to comprehend in the

context of Mbeki's 'global' and 'activist' reputation, as a villain who deserved to be tried for genocide (Mouton 2009)³⁴, or culpable homicide against his own people (Geffen 2009; 2010). In international and activist circles, Mbeki's denialism is the lasting legacy of his administration and his questioning of HIV science is the central debate on which memories of him hinge (Hlongwane 2010; Geffen 2010), yet, for some South Africans, it may not have significantly shaped or defined his reputation.

This links into the third explanation: Respondents need not express familiarity with Mbeki's specific brand of denialism to have been affected by the climate of confusion surrounding HIV science in South Africa. As Bogart and colleagues put it, official government denialism may make it difficult for individuals to distinguish "between accurate HIV/AIDS information and the misconceptions about HIV present in communities" (Bogart, Skinner, et al. 2011, 182). To expect that Mbeki's policies would be explicitly endorsed by respondents may be assuming too direct a connection between national politics and local realities. Steinberg wonders about the extent to which Mbeki's pronouncements have been accepted and endorsed by the public, and differentiates between the political awareness of a local government official in Lusikisiki and that of the rural villagers under his jurisdiction: "The councillor who fed me barbecued mealies was literate, middle class, and immersed in the politics of the provincial elite", he writes. In contrast, "Ithanga is only obliquely connected to this world. Without television or newspapers, the village receives its politics third or fourth hand, through this individual and that public service announcement. By the time national debates arrive in such places, they have been translated into a thoroughly local register" (2008a, 153). The respondents in this study may not necessarily be willing or able to trace these views to a more explicitly political source; the local expression of this national debate may be reflected in the disjunctures and distrust discussed in Chapter 4.

³⁴ Young Communist League national secretary Buti Manamela said Mbeki and former health minister Manto Tshabalala-Msimang should be charged with genocide as a result of their actions to deny the public access to antiretroviral drugs (Mouton 2009).

These doubts and areas of disjuncture, therefore, may have been exacerbated by a lack of strong leadership and confusing public statements about HIV/AIDS during Mbeki's tenure in office. The Mbeki-style questioning within the male endorser group, and the general confusion and doubts expressed throughout the focus groups, suggest that public distrust of HIV science persists. Indeed, Geffen observes that, "the confusion generated from the era of state-supported AIDS denialism will be with us for a long time" (Geffen 2010, 197)³⁵.

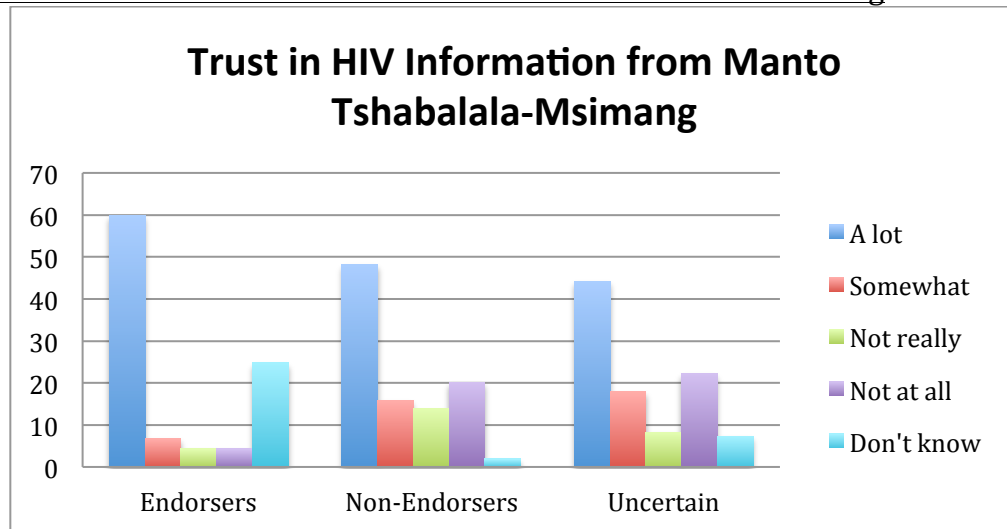
This tendency to overlook a politician's AIDS denialism is also apparent in focus group discussions about Mbeki's health minister, Manto Tshabalala-Msimang.

Manto Tshabalala-Msimang

Responses on the CAPS survey suggest approximately one half of respondents view former Minister of Health Tshabalala-Msimang as trustworthy about HIV information. Once again, endorsers were more likely to find her trustworthy than non-endorsers and uncertain respondents, though the gap between these groups was smaller than in regards to Mandela and Mbeki (Figure 11).

³⁵ That Mbeki's denialism may be a less explicit aspect of his reputation among respondents than one would expect from scholarly and activist accounts should not, of course, be interpreted as an apology or vindication for Mbeki's conduct while in office. The primary impacts of his stance, namely that more than 300,000 people died unnecessarily due to delays and obstructions in the roll-out of treatment and prevention (Nattrass 2008; Chigwedere et al. 2008), as well as the secondary impacts of mistrust and confusion (Geffen 2010), are reason enough to condemn his policies.

Figure 11: Trust in HIV Information from Manto Tshabalala-Msimang



Approximately one quarter of endorsers felt uncertain or ambivalent about her trustworthiness. In contrast, few non-endorser and uncertain respondents seemed unsure about her credibility. This may be because of certain contradictions evident in Tshabalala-Msimang’s professional and personal life. When respondents were critical of her in focus group discussions, it was often due to the perception that she was unfit to be Health Minister, as she herself had died of ‘health complications’ and was therefore seen as a bad example in her personal life.

She didn’t live according to what she said in her position. Even the things she was doing were not in-sync with health and how people should live (N3 Male Endorser 11/08/2010).

Another respondent confirms:

She just kind of confused me a bit in the sense that she died from health complications even though she was the Minister of Health (N1 Female Non-Endorser 12/08/2010).

Both endorser and non-endorser respondents agreed that Tshabalala-Msimang did not lead an exemplary life, which led some to feel that she was untrustworthy as a source of information about HIV. A female endorser explained:

You see me, I trusted it a lot on the subject of vegetables. But my heart was very sore when it was found that she died from her own liver complications. So quite clearly she was making us eat vegetables yet she wasn’t eating them herself (N5 Female Mixed 21/08/2010).

A male non-endorser from a mixed group concurred:

You know, that woman, she was an alright woman, but not for that department. Not for that department. You could see it on her face that “No, this is a drunkard!”, “This woman really drinks” and she is not taking care of herself. Maybe in another department she would have been alright. You know in a department that involves health, with things that will help people, you need someone who is an example (N3 Male Mixed 15/08/2010).

A fellow non-endorser from the same group expressed support for Tshabalala-Msimang’s time in office, associating her presence in the Ministry of Health with general progress on HIV/AIDS in South Africa. But he too felt that she was misplaced in the role of Minister of Health.

Manto is one of the people – if we look carefully during her reign – a lot of things on HIV emerged, for instance things like how to not get to the stage of AIDS and how to prevent that, that is where we heard all of this. Information came out during Manto’s time mostly, if we look carefully. I would say she had the information and it became trustworthy and I also learnt to trust it. But she, as the previous brother said, the way she was, she was not deserving to be in that health position, but still there was information during her time (N2 Male Mixed 15/08/2010).

As was the case with Mbeki, respondents sometimes lacked immediate recall about Tshabalala-Msimang’s policies. This is surprising in light of the moderate endorsements of trustworthiness reported in the survey. In one instance, the facilitator for one group of mixed respondents asked, “So do you trust information that we used to get from our former Health Minister Manto Tshabalala-Msimang who is no longer alive – the information that Manto gave to people?” After being greeted by silence, she queried, “Or we no longer remember what she was saying?” To this, all the respondents replied, “We don’t” (Female Mixed 18/08/2010). In another discussion, the facilitator asked, “So did you trust the information she gave about HIV?”, to which the respondents replied, “What was she saying? Refer us a bit to what she said?” (Female Non-Endorser 12/08/2010).

Tshabalala-Msimang’s reputation among respondents is more complex than that of her former boss. Though Tshabalala-Msimang may have become “the public face of

denialism - at Mbeki's bidding" (Decoteau 2008, 184) - once again most respondents did not characterize her primarily in those terms. Contrary to perceptions in scientific and AIDS activist circles that Tshabalala-Msimang played a destructive – and conceivably criminal³⁶ - role in the country's fight against HIV and AIDS, many respondents overlooked or downplayed these actions. Others overlooked or downplayed any controversy around her stance on HIV/AIDS. One non-endorser stated this plainly, "Well I mean her information was the same as other people's information, that I have heard" (N4 Male Non-Endorser 13/08/2010). However, this comment seemed slightly disingenuous, as this same respondent later argued that the debate about HIV science had been misrepresented or exaggerated by the media:

Well like this thing of Manto Tshabalala-Msimang's ministry – a lot of people, like the media sometimes likes to show things in manner that is incorrect... But according to my view – I think they criticized her too much. Like the way she was saying things, like people must eat beetroot and so on, like here in society we just turned that around and interpreted it as "She says we must eat beetroot and we will get cured." And she wasn't stating it like that – she was saying people must eat healthily, eat vegetables and so on – that will make them stronger, whilst using these treatments they're talking about. But, our media, sometimes tends to criticize – I believe it oppressed her or it wanted to get her out of her position or whatever (N3 Male Non Endorser 13/08/2010).

Repeatedly, respondents discussed her emphasis on nutrition as a sensible response to the epidemic, viewed as consistent with current advice from doctors and nurses about eating well to maintain health when infected, as the following two respondents claim:

I support the information she gave us. I think where she placed emphasis was on the fact that people must eat healthily and not go drink beer whilst taking your treatment – you must take your treatment and also eat healthily so that you can lead a proper life (N2 Male Non-Endorser 13/08/2010).

I trusted it. Because even now – when you go to the clinic you get told what to do, eat this and do this and this. So she was not misleading us. She wasn't saying, "Go to witchdoctors" (N3 Female Mixed 21/08/2010).

³⁶ In 2003, the Treatment Action Campaign laid a charge of culpable homicide against Manto Tshabalala-Msimang (Geffen 2009; 2010).

In one exchange between an endorser participant and the facilitator, the respondent refuses to acknowledge Tshabalala-Msimang's intransigence even when informed about it by the facilitator³⁷.

Facilitator: Okay. What was happening is that she wouldn't allow for ARVs to be distributed because she was saying they were toxic and she was saying people must just eat those vegetables and all of those things.

N5: And that is why I said I trusted her on the vegetables (Female Mixed 21/08/2010).

Some respondents expressed more ambivalence about her trustworthiness. Many were torn over whether her stance on nutrition was actually controversial. One female non-endorser explained, "What I know is that an HIV person must eat healthy. So maybe in her speech she was being honest or not being honest. But I don't know" (N1 Female Non-Endorser 25/08/2010).

Though the non-endorser respondents might have been expected to condemn Tshabalala-Msimang's policies in vehement terms, it was the respondents in the uncertain group that were most explicit in their criticism of Tshabalala-Msimang's policies.

No, she was not trustworthy that woman. Because her statement that you must eat beetroot – eat healthily and not mind ARVs too much – because that is what she was saying. Her statements could not be trusted. I could not trust them personally (N5 Male Uncertain 27/08/2010).

In general, respondents viewed Manto Tshabalala-Msimang as either an inept politician with personal failings, or as an advocate for a common-sense approach to nutrition. Where she was faulted most explicitly was in her personal qualities; respondents viewed her as a bad example, and as a politician who gained power

³⁷ Though the facilitators were trained to neutrally elicit perspectives from respondents about these political figures, at times respondents asked for more information about politicians' specific stance on HIV/AIDS (as seen above). When this occurred, facilitators would provide a brief summary. This was not intended to influence respondents, although given the political nature of the debate around nutrition and ARVs, it was difficult for facilitators to avoid indicating their own bias in their language.

through connections rather than expertise. As more than one respondent asked: What kind of a Health Minister dies of health complications? Her controversial stance on ARVs and her obstruction of treatment roll-out were rarely raised in an explicit manner.

Several years have elapsed since the height of the controversies between her and the Treatment Action Campaign over the provision of ART. This may have affected the ability for respondents to recall exactly what she stood for during her tenure in power. Alternatively, respondents may have failed to register the oppositional nature of her ‘and/or’ debate around nutrition and simply viewed her emphasis on nutrition as reasonable. More worryingly, however, respondents’ tendency to overlook or downplay the debate surrounding her policies may be the result of Tshabalala-Msimang’s concerted effort to blur the line between nutrition as a complementary treatment for HIV, and nutrition as *the* alternative treatment for HIV. While in power, she employed a rhetoric of ‘choice’ around HIV treatment³⁸, as in this instance at a press briefing in 2005 when she remarked:

There is no single clear intervention that can solely solve the challenges of people living with HIV and Aids....I know I get attacked if I say it’s nutrition *or* micro-nutrients *or* antiretrovirals and people want me to say, “and”, and “and”, and “and”. I think we need to give South Africans options” (Geffen 2010, 118).

During a public meeting in Khayelitsha in 2005, Tshabalala-Msimang was called upon to publically condemn Matthias Rath’s activities in the township. Again, she relied on the rhetoric of choice in her defense, arguing that people could “choose between TAC and Rath” (Geffen 2010, 144). At the same time, of course, she pursued policies that singularly favored traditional treatments for HIV. Her infamous display at the Toronto International AIDS Conference in 2006, which featured lemons, beetroot and garlic but not ARVs, is indicative of this wider tendency. Throughout

³⁸ Geffen usefully deconstructs how this rhetoric of choice was employed inappropriately by both Manto Tshabalala-Msimang and the “cultropreneur” Tine van der Maas (2010, 116–118). “Cultropreneur” is a term used by Natrass to describe a person who opposes the scientific consensus on HIV/AIDS in order to make a profit marketing alternative remedies and false cures (Natrass 2012a).

her tenure, she downplayed the controversial nature of her stance, seeking to represent her views as entirely sensible reactions to a public health problem in a developing country. Comments from focus group respondents may, therefore, reflect the success of this long-fought campaign to represent her oppositional stance as ‘choice’³⁹. In Grebe and Natrass’ (2012) study using CAPS survey data, trusting Tshabalala-Msimang more than her successor Barbara Hogan was associated with higher endorsement of conspiracy beliefs. As with Mbeki’s reputation among respondents, the dearth of explicit attributions of denialism to Tshabalala-Msimang does not mean that her equivocations did not contribute to confusion and doubt.

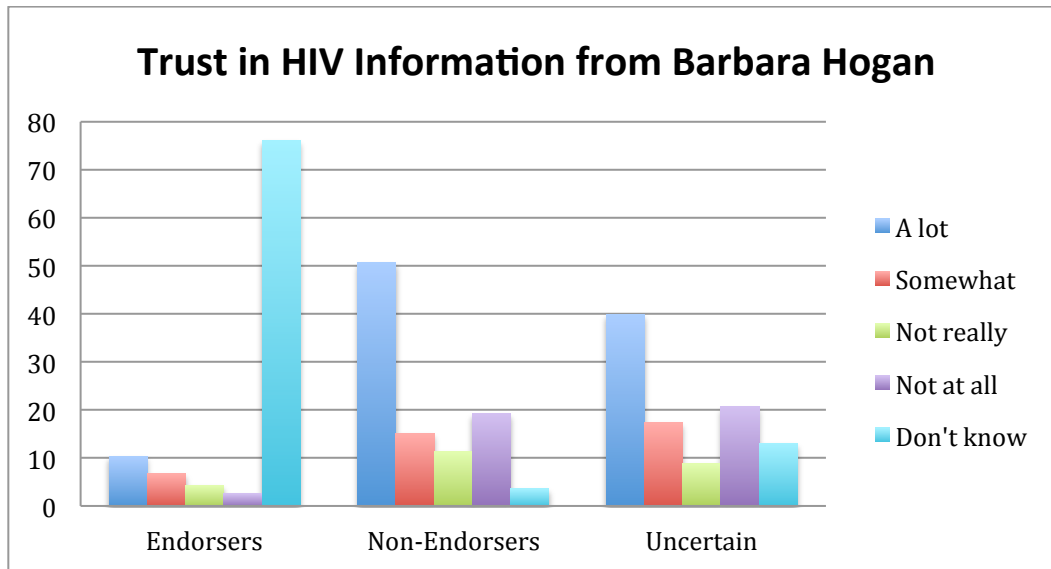
Barbara Hogan

Barbara Hogan was interim Minister of Health after Manto Tshabalala-Msimang was removed from the post and as such, was in the position only for a brief period of time. Given her public statement upon entering the post, that “the era of denial is over in South Africa” (Dugger 2008), she was included on the CAPS survey to probe respondents’ perceptions of ‘a sea change’ after Tshabalala-Msimang’s time in office. In the survey results, Hogan is viewed as trustworthy by approximately half of non-endorser and uncertain respondents, but by very few endorser respondents (Figure 12). Strikingly, endorsers in particular seemed uncertain or hesitant about her trustworthiness; this is the second and last instance on the CAPS survey when endorsers trusted the source *less* than non-endorsers. While this could be because she was unfamiliar to these respondents, it may also be that she actively promoted a view about HIV/AIDS science contrary to that of her (as they believed) more trustworthy predecessor. If this was the case, it might mean that endorser

³⁹ This picks up on the general tendency in positive post-mortems of Mbeki’s time in office to suggest they were never actually AIDS denialists – they were just ‘questioning’ and people wrongly mislabeled them with a more extreme name (R. S. Roberts 2008). Fine calls such people “reputational entrepreneurs” for the work they undertake to “persuade others that their interpretation deserves to be accepted” (2001, 13).

respondents subtly signaled their disapproval of her through a more ambiguous answer.

Figure 12: Trust in HIV Information from Barbara Hogan



Evidence for the former suggestion is that focus group respondents rarely exhibited detailed awareness of her specific stance. In fact, several recused themselves from further discussions about her trustworthiness because they did not feel sufficiently knowledgeable about her policies. The following discussion in a mixed male group illustrates this tendency:

Facilitator: Tell me, did we trust the information we got from Barbara Hogan?

N1: I would say we trusted it, because she was able to talk about it, but she never spoke about it in detail because her time was short – she was quickly got off.

Facilitator: So our brother says Barbara Hogan was not given enough time. Number 3?

N3: Yes, she never had enough time, so I don't, in fact I don't know her I just know her name. I can't picture who she is and wouldn't be able to point her out. She had little time in office and as such I wouldn't be able to even say I know her information. I can't say (Male Mixed 15/08/2010).

In this exchange, Hogan is viewed as generally competent but not sufficiently differentiated from her predecessor to have made a specific impression. An endorser from the same group commented, “Yes, I agree with them – the time she

was allocated was little and she didn't even bring any shocking or new news – she just expanded on what was already known (N6 Male Mixed 15/08/2010).

Another respondent echoed this sentiment, suggesting that Hogan was generally trustworthy because she was transmitting known scientific facts from doctors and scientists. He concluded:

I mean she herself was saying things I already knew and even her, not that the information she gave was wrong or what, it's the same as what other people say that "HIV kills and that's it" because there is no person who can give people the wrong information whilst knowing that it kills. So the information that she gave us, I maintain, was enough. I still follow it to this day. It hasn't changed (N4 Male Non-Endorser 13/08/2010).

Only one respondent - from the 'uncertain' group of men - was deeply familiar with Hogan and the break from the past she represented:

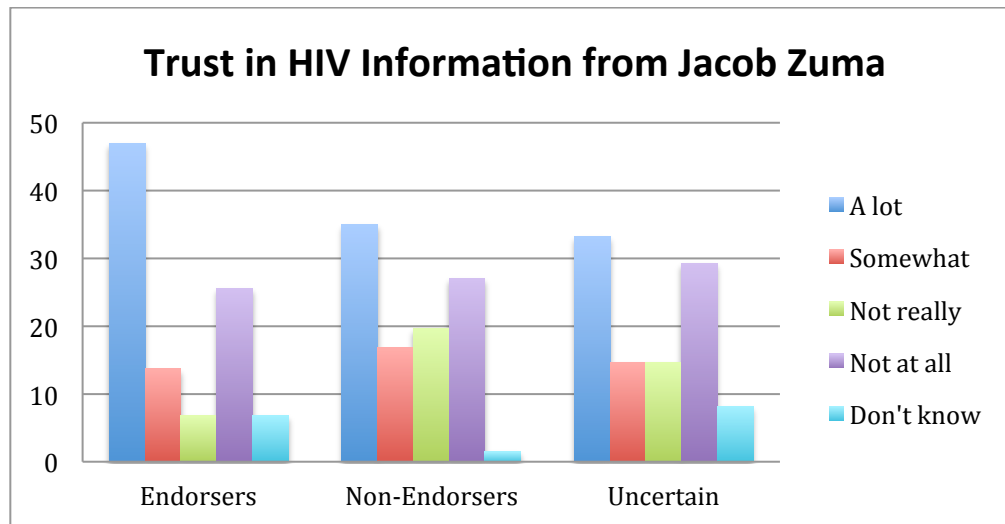
Well, she just changed things immediately once she came in. It seems like she changed all the statements that were made by Mrs Manto Tshabalala-Msimang. So she was in charge for a year or six months but in that period she was in charge the Health Department regained its credibility (N5 Male Uncertain 27/08/2010).

In general, Hogan's reputation with respondents was as a competent conduit of scientific information about HIV/AIDS. She was not, however, generally viewed to have represented a strong policy stance during her time in office.

Jacob Zuma

In contrast to the relatively charitable representation of previous political leaders, President Jacob Zuma received relatively low assessments of trustworthiness by all groups (Figure 13). This perspective may reflect the location of fieldwork and the identities of respondents. All the focus groups were composed of residents from Khayelitsha, most of whom are Xhosa and originally from the Eastern Cape. There might have been a very different perspective if the focus groups had been held in a strongly pro-Zuma area such as KwaZulu-Natal province. More than a quarter of all respondents suggested that he was "not at all" trustworthy and few seemed undecided or torn about assessing his trustworthiness.

Figure 13: Trust in HIV Information from Jacob Zuma



One respondent summarized the progression in the discussion about various political leaders, saying, “We called Mandela respectfully, then we said ‘Mr. Mbeki’, but this one we call by name – okay, so we come to Zuma” (N5 Male Mixed 28/08/2010). Respondents consistently cited his personal behavior – specifically, his polygamy and other public relationships outside of marriage - as the main reason not to trust him as a credible source of information about HIV/AIDS. One non-endorser stated it plainly:

And then I will go back to Zuma – Zuma is not exemplary. I mean he is an elderly, a president, but he is not an example not even to us as the youth. When I look closely he says, “Let’s have one partner” but if you check – how many partners does he have? He has more partners than the fingers on my hand. He has many partners and without a doubt we know he can sleep without a condom, because we heard that – it was all over the media – so we are sure about that (N2 Male Mixed 28/08/2010).

Another non-endorser in the same group concurred, saying, “How can you have so many partners and six wives – so you want to tell me that you use a condom on all six wives?” (N4 Male Mixed 28/08/2010).

The issue of his polygamy was particularly salient in conversations among women, as the following respondents attest:

I don't trust him my sister. Not at all! I don't trust. It's only Jacob Zuma, but all of the people who are polygamists, people who marry three wives or four. I don't trust people like that (N3 Female Mixed 8/07/2010).

We cannot trust what comes from him, because you cannot be as one man – have so many wives. What is being stopped – that people mustn't have many partners – he is busy doing it. You see? (N2 Female Mixed 21/08/2010).

No, Zuma – there is also nothing I could say he is a leader in (N3 Female Mixed 18/08/2010).

Women from the endorser group were also explicit in their condemnation of Zuma's personal life:

Zuma is not an example to us – there is nothing I could learn from Zuma – so that is why I ignore him and don't care about him at all, because he does not concern me (N4 Female Mixed 18/08/2010).

Among men, the discussions frequently revolved around Zuma's rape trial and its aftermath. Respondents felt that he had directly undermined messages advocating condoms by claiming to have had a shower after having unprotected sex with an HIV positive woman to prevent HIV infection. One man from the uncertain group exclaimed:

And he is killing us on the other hand and he is going to lead us not to use condoms. You have sex and then you will have water in a washing bowl and then wash your penis in it afterwards. And then you have sex again. And that is just a way of killing us. He is killing us in that way! (N3 Male Uncertain 27/08/2010).

This sentiment was expressed by both endorser and non-endorser respondents.

We can't say Zuma is right, Zuma is not right. Because, I mean, he is destructive – because you will want to sleep with a girl you get from the *shebeen* without a condom and thereafter you get AIDS. He's leading us into destruction" (N4 Male Endorser 11/08/2010).

No, on my side, our president is not an example of a person who can tell people about HIV. Because the 'status' he puts out there is not encouraging – that when you sleep with someone with AIDS you can go and shower. I don't see that as something sane (N6 Male Mixed 15/08/2010).

This Mr. Zuma, no. It's not that he is uneducated, but it's the things that he does. He talks about AIDS and then he goes against what he was preaching

and he does as he likes. Because you can't tell me to use a condom whilst you on the other hand aren't using it and you go flesh-to-flesh and then you come to me and say "Use a condom! To prevent AIDS!" (N6 Male Mixed 28/08/2010).

Evident in these quotations is the sentiment that respondents' distrust of Zuma had little to do with his official policies on HIV, focusing instead on his personal behavior and public statements. It is notable that no respondents compared him favorably to his predecessor, Mbeki, despite the fact that his official policies for HIV/AIDS prevention and treatment are arguably an improvement on the Mbeki administration's stance.

In the context of interrogating South African politicians' HIV responses, Zuma is generally cast as a progressive albeit flawed politician by activists and academics, particularly in comparison with his predecessors (TAC 2009a; Dugger 2009; 2010). Though his personal behaviour is often judged critically, his HIV policies upon taking up the Presidency have somewhat redeemed him. His public HIV test and the subsequent disclosure of his test results were rightly hailed as a progressive step for HIV prevention by AIDS activists (Dugger 2010). Geffen gives the following assessment of his reputation when he first assumed the presidency:

Jacob Zuma took over the presidency with his integrity in doubt and his commitment to the Constitution and women's rights especially in question. As Deputy President he headed the South African National Aids Council and failed to run it properly. Although he was acquitted of rape, his claim during the trial that he showered after unprotected sex with his accuser, an HIV-positive woman, to reduce the risk of contracting HIV was met with ridicule – and rightly so. The behaviour of his supporters in the rape trial towards his accuser was frightening.

After chronicling Zuma's numerous failings, Geffen concludes,

But there are things to be said in his favour. He apologised for his shower comment and it was he who negotiated with TAC during our civil disobedience campaign. He came through on his promise that the government would deliver a treatment plan. And as President he has banished Aids denialism" (2010, 200).

This balanced assessment of him is not reflected in respondents' views of him as a

trustworthy source of information about HIV. Most respondents from all groups doubted Zuma's claims about HIV because his public pronouncements did not line up with his actions. Beyond his perceived hypocrisy, they claimed he did not behave in an 'exemplary' manner⁴⁰ as befitting of a public figure, by marrying multiple spouses, and fathering children with several other women.

Others expressed suspicions about Zuma's pronouncements on HIV science because they deduced – from his child resulting from relationships with multiple women – that he was not using condoms, and yet he was not HIV positive. His claims to have used a shower to protect himself after unprotected sex with an HIV positive woman struck respondents as confusing and problematic. His subsequent HIV test failed to boost his trustworthiness, as several respondents questioned whether he had actually taken the test, or whether his results had been falsified. In short, Zuma's reputation among respondents does not reflect his administration's progressive HIV policy, nor does it represent his public HIV test as a brave act of leadership. Rather, his professional policies and rhetoric are undermined by what respondents see as hypocritical and contradictory personal decisions.

Politicians in general

Respondents commented on what it meant to generally trust political figures on matters pertaining to health. Some viewed politicians as conduits of information from doctors and scientists to the public, rather than experts in their own right. Others viewed all post-Mandela politicians as essentially operating without expertise, performing their role as a political exercise rather than out of a deep commitment to or knowledge about a particular portfolio. One non-endorser explained, "The information that comes from a minister – I mean a minister is like, is like me, because a minister conducts no research – they hear it from doctors and scientists" (N4 Male Non-Endorser 13/08/2010).

⁴⁰ Although as Robins (2008) and others have noted, Zuma's conduct may have been judged as exemplary of a traditional Zulu masculinity.

The absence of politicians' expertise led some respondents to express doubts about their trustworthiness. An 'uncertain' respondent argued that politicians lacked any specific skills for their portfolio.

Yes, I want to agree with him. I mean those people in government – a person does not stay in one thing all the time. When another president comes in they just say “I see you and I am just going to put you there and you there” and you find that they place people in positions in which they lack information on, but just because they are already in senior positions they take them in there. You see? (N1 Male Uncertain 27/08/2010).

To this, another respondent replied, “It also depends on who you knew during the struggle days. Plus politics are based on your seniority” (N5 Male Uncertain 27/08/2010).

Coupled with the sense that politicians are appointed based on seniority and personal contacts rather than expertise for a specific portfolio was the perception that political figures lacked accountability because of their separation from the public. Respondents discussed feeling powerless in relation to political figures; this powerlessness had two distinct effects. Some respondents felt they lacked choice about whether to trust political leaders because they remained distant and untouchable. As one male endorser explained:

I'm just trying to establish – the minister and things relating to parliament, there are some things that get hidden there so that that information never reaches us and you won't even have another choice, because you want to get better, you have the virus and so you are forced to trust them. And if you don't trust them – I mean you can see there are others dying and others living – so you have to trust it (N3 Male Endorser 11/08/2010).

Another respondent felt that people had to passively believe what they were told because they lacked information.

We can't say much on trusting because we knew nothing – we didn't know whether it was right or it was wrong – so we just trusted and listened to what we were told. Because we didn't know anything about AIDS and HIV, so the information we were getting we took it and welcomed it. Because we do not know whether it is right or it is wrong (N2 Male Mixed 28/08/2010).

Other respondents explained how the distance between themselves and their politicians led them to distrust political figures as a source of information. As one man stated, “Yes, we can trust presidents but there is nothing we can do if they are lying”. He continued,

What is most important is that you have someone in front of you who is going to tell you “This is what is happening” so that even when you have a question, you ask them and it becomes clearer for you. So the most trustworthy people are the ones we see, who are visible and we can talk to” (N2 Male Mixed 15/08/2010).

Another respondent agreed, “Because the presidents and so forth are too far from us. They are far from us. They say those things on TV and on radio” (N3 Male Mixed 15/08/2010). A male endorser went on at length to describe why he did not trust Manto Tshabalala-Msimang. As opposed to the specific arguments against her character, discussed in detail above, he argued that she was untrustworthy because “she is speaking far away from us”. He went on to describe the consequences of following a politician’s advice:

If she was speaking and acting and we were seeing her actions – then we would understand it better... She’ll say “Go to the clinic if you have this and that and you’ll get this and that there!” and then when you get to the clinic they won’t even pay you attention and they don’t even have what she said is there. Who do you open a case against? (N2 Male Endorser 11/08/2010).

Overall, respondents were pessimistic about the trustworthiness of post-Mandela political figures in South Africa. One woman commented on Zuma’s leadership: “He is just leading us because we need people to lead, really” (N3 Female Mixed 18/08/2010). A female endorser from the same group was dismissive of debates about the trustworthiness of contemporary South African politicians: “Let’s forget about the president now. We will never have an alright president ever again (N4 Female Mixed 18/08/2010).

This pessimism, however, did not always lead to passivity. Respondents urged each other to take responsibility for their own knowledge about HIV/AIDS. One respondent advocated for people to “Be careful of your information sources – make sure you get it from the right places”. He urged other respondents to make up their

own minds about the trustworthiness of a particular source of information and not to be swayed by a person's position in power:

Take the right information from what that person says and not only look to that person as the source, because they are the president or whatever. You, yourself must also go look for yourself and then you can compare that indeed your information is similar (N4 Male Non-Endorser 13/08/2010).

A female endorser respondent counseled against complacency among the public:

If you don't do things for yourself and change your life for the better yourself, forget it, you will be waiting for the your president to come and build you a house and whatnot. If you don't do things yourself. Because you are just a number. If you are not present there on the tables in parliament – forget it (N4 Female Mixed 18/08/2010).

Commenting on Zuma's trustworthiness, a female non-endorser respondent from the same group advocated for people to do their own investigation.

You have to know that after he has said that you also go and do your own research to establish that what he said is indeed right. And then you will believe. Or not believe (N1 Female Mixed 18/08/2010).

One man simply concluded, "So a person can distinguish between right and wrong for themselves" (N2 Male Mixed 15/08/2010).

In short, respondents held certain general pessimistic feelings towards post-Mandela politicians, while at the same time viewing them as differentially trustworthy. They consistently cited experiential and observational reasons why they trusted some authority figures and not others. They criticized claims that they could not witness for themselves, or claims that were not supported by the body of evidence to which they had access.

That respondents generated these street-level epistemologies of trust based on personal observations and experiences rather than professional qualifications is echoed by studies from other countries. Brownlie and Howson (2005) highlight the experiences of parents in Scotland for whom knowledge alone is not sufficient for them to trust childhood vaccination for measles, mumps and rubella (MMR); many

talk about the “leap of faith” they took in trusting the science of vaccination, justified through familiarity with their health-care providers. When parents had doubts about the trustworthiness of vaccination, they sometimes asked doctors and nurses about their personal vaccination practices with their own children; if doctors vaccinated their own children, this was seen as sufficiently persuasive evidence that MMR was safe.

British parents were also eager to uncover whether Tony Blair had vaccinated his own son Leo with the MMR vaccine at the height of public fears of the links between the MMR vaccine and autism (Burgess, Burgess, and Leask 2006). His delay in disclosing this information encouraged fears that the Prime Minister was aware of information about the health risks of the vaccine that were not available to the public (Burgess, Burgess, and Leask 2006; Nattrass 2012a; Larson et al. 2011). Of all the media coverage that occurred the year of the MMR vaccine controversy, 32% mentioned whether Leo Blair had had the vaccine (Goldacre 2010). As Ben Goldacre argues, “the public, quite understandably, was taking Leo Blair’s treatment as a yardstick of the prime minister’s confidence in the vaccine” (2010, 226). In the UK, as in South Africa, individuals judged politicians based on what they do rather than what they prescribe as best for others.

Section 4: Divergence between qualitative and quantitative data

As in Chapter 4, certain divergences between quantitative and qualitative data become apparent in this chapter, and were most apparent when considering data about trust in three different entities: Mbeki, Tshabalala-Msimang, and TAC. In brief, the seeming contradictions were as follows:

1. Though survey responses about trust in Mbeki closely mirrored those regarding trust in Mandela, focus group respondents were more critical of Mbeki;
2. Survey respondents expressed moderate amounts of trust in the survey but sometimes lacked immediate recall about Tshabalala-Msimang’s policies in the focus group discussions;

3. Apparent in CAPS data, endorsers recorded comparatively low levels of trust in TAC, but seemed generally to trust information from TAC in the focus groups.

Drawing on Slonim-Nevo and colleagues, these discrepancies can reveal “different aspects of the phenomena under investigation” and be partially explained by methods of data collection (2009, 124). Whereas respondents answered questions on the survey in a one-on-one environment where input and debate were minimal, focus group discussions were often lively affairs, with respondents challenging each other about the trustworthiness of different sources. Thus, focus groups may represent trust in certain sources as it has been reflected upon and negotiated with input from others. Respondents’ main criticisms of Mbeki were that he lacked proper struggle credentials and had remained aloof from the public during his tenure in office. These complaints could have been exacerbated and intensified during focus group discussions, particularly among mixed groups. This same homogenizing effect may have played a role in endorsers’ comments about TAC in the focus groups. Though they may harbor a certain amount of distrust of the organization because of the challenges it wielded against the government, in focus groups, these objections may have been overruled by general levels of support and trust.

Additionally, there may have been a time-lag effect between the quantitative and qualitative data collection periods. When the survey was completed in 2009, Mbeki had left office only one year before. Tshabalala-Msimang had been removed from the Ministry of Health at the same time as Mbeki’s departure from office, and had been the Minister of the President until mid-2009. Thus, both had recently been in the public eye and would have been more easily recalled by survey respondents. By the time the focus group discussions were conducted in mid-2010, a significant period of time had elapsed since Mbeki’s presidency. His time in office was being reviewed in retrospect and his conduct as President was being compared with that of his replacements, Kgalema Motlanthe and Jacob Zuma. Tshabalala-Msimang had passed away at the end of 2009 and by mid-2010, most retrospective assessments of

her time in office had been completed. It is possible that Tshabalala-Msimang was less familiar to some focus group respondents because of these changes over time.

These findings draw attention to certain advantages of the Public Understandings of Science framework. By conceptualizing trust as relational, the PUS framework highlights the contingency of trust, how it can be expanded or withdrawn depending upon new information and experiences. It also directs attention to why certain sources of information are trusted rather than just the presence or absence of trust.

Conclusion

Individuals who are trusted sources of information about HIV can help to address persistent questions and resolve enduring doubts about HIV science (Saha et al. 2010; Racey et al. 2010; Hutchinson et al. 2007). Respondents appeared to trust a variety of sources of information about HIV, including doctors, nurses, scientists, and employees of the Treatment Action Campaign. Using empirical observations and experiences provided respondents with a means of ascertaining trustworthiness in conditions of uncertainty.

At times, these empirical observations led to characterizations of political figures that diverged from these figures 'reputations' in international, academic and activist circles. This, by itself, should not be surprising. As Robin's argues, "It has become apparent that people's interpretations of the AIDS pandemic are far more complex and differentiated than either government or TAC originally anticipated" (2005, 129). Rather, that political figures are interpreted in diverse ways by members of the public raises the question of what truly underlies public distrust in HIV scientific claims.

Observers of the history of South African HIV controversies over the past decade have often attributed public distrust to Mbeki and his administration's obfuscation and denial of HIV science. These results suggest that relationship between respondents' perceptions of Mbeki and Tshabalala-Msimang and their doubts and

confusion about HIV science is complex. Most focus group respondents indicate that Mbeki and Tshabalala-Msimang's involvement in past HIV controversies does not necessarily define their time in power. This indicates that the question of whether HIV causes AIDS may now exist independently of Mbeki's obfuscation. To the extent that Tshabalala-Msimang's reputation is bound up with her emphasis on nutrition, respondents largely did not problematize this stance as 'anti-ARVs'. This representation may be indicative of Tshabalala-Msimang's triumph in successfully blurring the lines between complementary and alternative medicine in the eyes of the public; in essence, making support for nutrition an uncontroversial matter of 'choice'.

In short, Mbeki and Tshabalala-Msimang's lack of leadership and equivocating public statements may have had a devastating secondary legacy, of aggravated public doubts and confusion. That they themselves may not be cited by respondents as the source of this confusion is indicative of how successfully they permeated the public sphere.

In contrast, Jacob Zuma is interpreted largely with reference to the confusion his personal behavior has created, rather than his policies. That he is arguably the most progressive politician of the three in his HIV policies is ignored by the weight placed on personal credibility over professional rhetoric or policies. Interventions that harness the influential clout of politicians in HIV campaigns – such as the high-profile HIV test of President Zuma – should be mindful of the complex, and at times contested, meanings of these figures to key populations (Fine 2001).

These reputations may be partly a function of media coverage. That respondents largely overlooked the HIV-related controversies of Mbeki's tenure in office, and instead assessed his trustworthiness based on other aspects of his leadership could be attributed to declining media coverage of HIV/AIDS in general, and the Mbeki administration in particular (Finlay 2004). Tshabalala-Msimang's death in December 2009 launched vehement debates about her permanent legacy

(Anonymous 2009), but may also have curtailed further long-term coverage, debate, and discussion of her policies. In contrast, President Zuma remains in the public eye, where consideration of his policies remains ever-present. The political cartoonist Zapiro's depictions of Zuma with a shower head coming out of the top of his head constantly remind the South African public of his follies in relation to HIV/AIDS⁴¹. The issue of media coverage raises a key question: If the public is not exposed to regular reminders of a key political controversy, how long will they recall it as a significant episode?

That there are numerous trusted sources of information about HIV in Khayelitsha is promising. Harnessing these trusted sources to disseminate accurate information about HIV in order to clarify areas of confusion about HIV science and research is essential. Little is known about the dynamics of these interactions, particularly on how doctors, nurses, community leaders, and peer educators seek to dispel alternative beliefs about HIV science in their communication with others, and what challenges they face in this endeavor. The next chapter will explore one case where peer educators respond to the public's doubts, distrust and confusion about HIV/AIDS.

⁴¹ It should be noted that Jonathan Shapiro - aka the cartoonist Zapiro - 'took a break' from this depiction, representing the shower head as floating above Zuma's head rather than attached to it in 2009, because "I thought, I will take stock of where we are and give the presidency a chance to get going" (BBC news 2009).

Chapter 6: Peer educators' responses to mistrust about HIV/AIDS science

Introduction

If, as appears from the evidence set out in Chapter 5, the Treatment Action Campaign is a trusted source of reliable information about HIV/AIDS, this suggests that TAC peer educators may be well-placed to act as ambassadors for HIV science to the South African public. This chapter focuses on interviews with TAC peer educators, highlighting their perceptions of their treatment literacy activities and the challenges faced in these encounters. In order to maintain clients' trust in themselves and their information about HIV, they employ various "rhetorics of persuasion", including accurate mobilization of biomedical facts, personal testimonies, and figurative language such as parables and metaphors. These tactics build on community members' everyday observations and experiences and draw from peer educators' own credibility and trustworthiness as TAC members, and as members of the community. This chapter draws attention to the ways in which peer educators' personal agency and judgment are brought to the task of peer education, as well as the implications for future interventions of this nature.

The chapter is divided into 5 sections. Section 1 outlines the rationale for studying TAC peer educators as key interlocutors with the South African public's understanding of, and trust, in HIV science. Section 2 examines the strategic communication tactics employed by peer educators in communicating complex science to TAC's clients. Section 3 outlines how peer educators employ their own judgment in determining how to represent certain scientific findings to clients, while section 4 explores the uses of metaphors and parables to communicate complex concepts in a familiar manner. Finally, section 5 highlights how peer educators experienced their role less as a neutral bridge between science and the target population, and more as a mediator or broker, forced to make their own judgments about how to explain certain topics and whether clients could handle the truth about scientific developments in all their complexity.

Section 1: Rationale for the case study of peer educators

In response to the doubts, uncertainties or conspiratorial beliefs about the origins of the virus and existence of a cure discussed in Chapter 4, some scholars have recommended enlisting “trusted sources of information”, including community leaders (Bogart et al. 2010; Larson and Heymann 2010) and peer educators (Bogart et al. 2010; Bogart, Skinner, et al. 2011; Bogart and Thorburn 2005) to work with target populations. Evidence from Chapter 5 suggests that the Treatment Action Campaign (TAC) generally enjoys a trusted reputation as a reliable source of information about HIV/AIDS. As a result, TAC peer educators may be influential in shaping individuals’ understanding of, and trust in, HIV science, and can be viewed as ambassadors for HIV science to the South African public. Before exploring the specific techniques used by peer educators to build trust in HIV science, it is important to outline exactly how TAC’s peer education programme is conceptualized in relation to alternative beliefs about HIV.

Starting in 2002, the Treatment Action Campaign’s Treatment Literacy Programme (TLP) deliberately mobilized against the state’s AIDS denialism by teaching HIV science to the public. Conducting widespread instruction on how HIV works as well and how ARVs operate enabled the TLP to demystify HIV science to people with limited formal education (Steinberg 2008a; McNeill 2009). TAC has described the importance of understanding all aspects of HIV treatment:

We must know our medicines by name, how they were found to be effective, how and where in the body they work. We must know their side effects and how they can be managed, how to monitor the safety of these medicines, and what foods you should eat and not eat with them. We must also follow new scientific research that throws light on how best to use the drugs we take. All these things are part of what we call ‘treatment literacy’. This knowledge lets us have more control over our health and participate effectively in health policy formulation processes (Treatment Action Campaign 2006, 3).

In teaching people about HIV, the TLP “tries to change the idea that understanding scientific and medical information is only the business of healthcare workers, scientific researchers or trained traditional healers” (Treatment Action Campaign 2006, 3–4). The success of earlier experiences of Treatment Literacy activities

worldwide were important to TAC's approach in that these activities show "that 'ordinary' people have made it possible for poor people to access these medicines and information about them in a way that governments would never have done" (Treatment Action Campaign 2006, 4). This treatment literacy model was based on the activities of US activist organizations such as Gay Men's Health Crisis (GMHC) and ACT-UP, who came to South Africa in 1999 to train local HIV activists in their techniques (Heywood 2009, 17).

Two types of peer educators operate within TAC's organization. Treatment Literacy Practitioners (TLP) are TAC volunteers who have been trained and passed an examination in techniques for disseminating HIV information (Heywood 2009). Community Health Advocates (CHA) organize public health education and advocacy campaigns (TAC 2009b). In the Khayelitsha office, the key distinction between these two types of TAC employees was that TLPs educate the public in health clinics and CHAs conduct door-to-door educational activities.

Peer Education

Scholars of peer education suggest that peer educators act as "antennae" (Dickinson 2011) within their communities for alternative beliefs about HIV/AIDS. Once such beliefs have been identified, peer educators can act as "brokers" on behalf of biomedical science, by employing certain "rhetorics of persuasion" to disseminate scientific information, reiterate the trustworthiness of key sources of scientific authority, and clarify uncertainties (Robins 2009b).

There are good reasons to believe that peer educators could be helpful allies in efforts to spread biomedically sound, culturally appropriate information about HIV and AIDS. On the principle that "learning occurs most efficiently when individuals are trained by their 'near peers'" (Rice 1993), peer educators are recruited from the same communities they are expected to serve in order that their services may be more convenient and socio-culturally resonant (Bastien 1990; Standing and Chowdhury 2008; Vale 2012). Viewed from the perspective of Public

Understandings of Science studies, peer educators build on their existing relational trust and credibility with the target population, with whom their familiarity is assumed to foster greater trust (Dutcher et al. 2011; Mitchell, Peterson, and Latkin 2006). The use of peer education in HIV prevention interventions is common, with one study estimating that 60% of major HIV prevention NGOs carry out peer education (Kelly et al. 2006). Some peer-based programmes have had measurable impact on knowledge about HIV (McKirnan, Tolou-Shams, and Courtenay-Quirk 2010), and a meta-analysis conducted on peer education in HIV prevention and treatment programmes in developing countries showed a significant effect on improving HIV knowledge and condom use (Medley et al. 2009).

However, other studies complicate the notion that peer educators will be willing or able to act consistently as sources of orthodox scientific facts to their family, friends, colleagues, and neighbours (Standing and Chowdhury 2008; Cornish and Campbell 2009). Though peer education projects are often designed as 'vertical' communication programs, where peer educators act as conduits of information from experts, in practice they often end up being more 'horizontal' in nature, with peer educators actively engaging in mediation and contestation with their peers (Dickinson 2010a). In these horizontal discussions, communication between peer educators and their target audience is stressful (Dickinson and Kgatea 2008) and "messy", with peer educators regularly encountering "small acts of resistance" (Robins 2009b, 104) from those who refuse to accept their information unquestioningly as valid. Robins suggests that people should not be surprised when these "biomedical foot soldiers" encounter "friction" in their interactions with the targets of these interventions (Robins 2009b).

Whereas in some cases resistance may arise because their message is deemed unreliable or untrustworthy, in other cases peer educators themselves may be deemed illegitimate or untrustworthy. In such circumstances, peer educators' familiarity and informal status within the community, visible through their lack of "symbolic markers of authority", such as uniforms and technical instruments, may

make their authority suspect to both clinical professionals and patients (Vale 2012). If peer educators are viewed as less knowledgeable than formal health workers, they may struggle to achieve authority and maintain credibility about scientific facts in the eyes of the very people they strive to influence (Standing and Chowdhury 2008). Other factors affecting their trustworthiness include whether they are seen as exemplary or hypocritical; for instance, peer educators who counsel others on drug abuse yet continue to use drugs themselves may be deemed less credible (Mitchell, Peterson, and Latkin 2006).

A further challenge to peer educators' ability to advocate on behalf of HIV science is their relative status in their communities. Both Steinberg and McNeill have observed that biomedical facts about HIV are filtered through the reputations and meanings of the messengers of such facts (Steinberg 2008a; McNeill 2009). Due to their gender, age, or educational level, peer educators may find their information about HIV to be tainted by their relatively lower status in society. Steinberg notes this effect in relation to young women in rural South Africa:

The category of people who are traditionally considered to be people with very little social power, single young women, in this instance, were the first to embrace treatment, did it with the most enthusiasm. And with the most voice. And thus came to play a very profound role in shaping the meaning of treatment (Steinberg 2011).

Thus, these women's comparably lower status became inseparable from their information about HIV, which then took on a similarly compromised meaning. In extreme cases, peer educators' knowledge about HIV may be so conspicuous and compromised as to result in their being "implicated in harbouring and distributing a source of unnatural death" (McNeill 2009, 367).

In addition to these outward challenges to their credibility, peer educators may also experience internal conflicts in their role as ambassadors for HIV science. They may, for instance, continue to hold a range of alternative explanations for HIV/AIDS alongside the biomedical explanations that they have been taught. Dickinson writes that the separation between biomedical and alternative explanations is "not always

stable and [peer educators'] commitment to messages taught to them in their training could be undermined by arguments drawn from other paradigms of health belief" (Dickinson 2010b, 7). He cautions that this should not be surprising, as "if peer educators are peers, we should expect them to represent the full range of social beliefs" (Dickinson 2009, 137).

Given the central role peer educators are expected to play in promoting public understandings of HIV science, it is important to consider how they approach this task and navigate these various challenges. The remainder of this chapter explores TAC peer educators' experiences in responding to alternative beliefs and disseminating scientific literacy about HIV in Khayelitsha, South Africa.

Section 2: Strategic Communication

As discussed in Chapter 4, scientific information about HIV/AIDS in South Africa is at times greeted by doubts, confusion and skepticism. Given this context, peer educators are keenly aware of the need for clarity and consistency. To borrow Robins' term, peer educators employ various "rhetorics of persuasion" (Robins 2009b) in their attempts to build public understanding of, and trust in, HIV science. These include providing straightforward scientific explanations, using stories and metaphors to clarify uncertainty and confusion, and drawing examples from their personal experience while always taking into consideration the experiences and observations of clients.

One of the simplest strategies was to calibrate their message to suit specific audiences. Some descriptions from several TAC peer educators of some techniques that they use are below:

Pemeido: So the big words, the scientific big words, the bombastic⁴² words, sometimes people get confused, so you have to clarify each and every, define

⁴² This word was sometimes used by TAC peer educators to describe scientific terminology. This raises the question of the extent to which this word represents scientific terminology as pompous, overbearing or exaggerated. This is not the only time scientific vocabulary has been so termed; in a critical analysis of Beckett's

each and every word and try to make people understand what you're talking about, and try to differentiate the virus and the bacteria. So people can understand what exactly you're talking about.

Chunyiswa: Select your group, then you select your words.

Pretty: Well, you see my brother – an example, HIV and ARVs – we try to show them, but the problem is that at our clinic we have educated people, we have uneducated people, we have elderly people who take long to speak or understand – so when we illustrate these things to them; like for example when HIV enters the body – what happens? We have to try and make it simple so that the elderly can understand it too.

Snax: So you ask about my techniques, when I'm at home, I always study those manuals, I'm always looking if there is an example in this community that can fit. So if this name will always be a bombastic word, but the example will never be a bombastic word. That's what I believe in. Because if you say that this word, okay it's a bombastic word, but the example, try to make an example about it that they are actually living. So we are 100% accurate.

Khanyisa: Because you have firstly the – it's so flexible and active, most especially to the child. So you have to understand the language of the young to be on the same level. So you can't hide anything but try your best to put it the right way.

In trying to clarify clients' persistent questions – about a cure, the origins of the virus, or PMTCT (as discussed in Chapter 4) - peer educators describe the explanations they provided, drawing on the training they received from their supervisors and the staff at MSF, as well as their own research.

Pretty: For example we heard that it came from monkeys and so forth and we have to elaborate on all of that. You see? It depends on the type of audience you're addressing on that day.

Snax: There was Dr. Dave, we were having a training at UCT, and we asked about 'where does HIV come from, please won't you tell us', and Dr. Dave tells

Waiting for Godot, Velissariou states, "Didi and Gogo play incessantly with words; they treat the same word as its opposite, they find synonyms, they use scientific terms because they sound bombastic, they rhyme". In doing so, they dismantle and parody "the pretentious rhetoric and logic of conventional philosophical thinking" (Velissariou 1982). Rather than this wholly derogatory connotation, however, a former TAC employee thought that this usage among peer educators signaled "the terms are difficult and exclusive, not accessible" (Personal communication).

us that HIV is from the chimpanzee. Because, I say “okay, how did we get it from the chimpanzee”, animals?

Bonelwa: I say, according to my readings in the books they say it came from animals – since there were hunters in earlier years and then there one of those animals, a chimpanzee, had this HIV and then when that person was fighting with that chimpanzee – a chimpanzee also fights because it is also hunting. So during that fight blood from the chimpanzee spilt onto the person. And then the person then brought it to his wife. And then it started spreading like that amongst humans. And then as it changed, I mean it was SIV in the animals, so it got to the people and because a person is human it became Human Immune-Deficiency Virus.

Chunyiswa: For my side, I try to engage and ask them what they know. Because in them, they do have some information but we’ve got to clarify, now and then. So I do ask them their knowledge, like what do they know about the virus. So there are people who know where it actually came from. The next question that we have, we get some other people who begin to know, they just need some clarification.

Some peer educators felt that providing these explanations in as much detail as possible was essential to clearing up misinformation and myths about the virus. Likewise, when dealing with a different persisting question, the issue of a cure, peer educators sought to be honest and direct.

Snax: If there’s a cure it’s coming, let us work for a cure, but while we’re waiting for a cure, let us preach what is good for people. Adherence, that is good for people.

Pemeido: But the answer is like, ‘when there is a cure, I’ll be the first one to tell you, there’s no cure, right now you only have ARVs’. Which suppress the virus, you know, that’s the only answer I’ll give them.

When addressing mistrust and doubts around Jacob Zuma’s shower or certain churches’ claims to heal HIV, the response was equally direct and unequivocal.

Nomandithini: When you have sex, HIV stays in the blood and in your bodily fluids – we know this. It wont just go away by washing. We have washed for years and people have taken showers for years. If that were the case then I would simply have to take a shower after having sex. So which means we wouldn’t have as much HIV then. You see?

Chunyiswa: It lives in the blood and if you go to church, you heal your spirit not the blood.

Lloyd: We cannot worship so that the illnesses go away. But spiritually, we can go to the church and worship so that you can be cured spiritually. Not physically.

Whenever possible, peer educators spoke to respondents' "street-level epistemologies of trust", drawing on experiential aspects of everyday life in Khayelitsha in order to lend practical plausibility to their claims. As Robins observed in his study of HIV advocacy in rural South Africa: "There appears to be an agnostic and experimental attitude towards both modern medicine's 'magical drugs' and the claims of traditional healers and diviners", necessitating "concrete, observable evidence" of the truthfulness of any claims (Robins 2009b, 102). In order to buttress their assertions, peer educators constantly referenced their own experiences as people living with HIV, pointed out illogical aspects of myths and misinformation, and used easily observable data to prove their argument.

Nomandithini: Another thing that helps us a lot, is that we make examples with people – we use ourselves as examples – we can also make examples about other people. Like other activists from back then – we can use them as examples too. We are not just saying "ARVs help!" and then we sit down and say that's where it ends. We say "you see so and so and so – they were sick – and also us, this and that happened with us!" so we give them information and that is why they trust us. We give them detailed information. We don't just give and leave them.

Interviewer: But do they trust the information that you gave them?

Chunyiswa: Yeah, they do. Because we are telling them about the practical things that they see. So they do. They do.

Nonqaba: Yes, there also people who say that it came with white people, because many people who are HIV positive are people who are black and I tell them that – even if you go to a white community you will get there and find people sitting on benches waiting for ARVs. It's just that we are in are Khayelitsha and hence we can only see Khayelitsha! If we could relocate to another place we'll get there and see that they also get it there as well.

Bonelwa: And then some still believe that condoms have lice, but then I do exercises – because they once asked us – me and Andile – on the radio: "These condoms they say these condoms are rotten and have lice!" and then I came back and did an exercise there at the clinic. I took out a condom and then I opened it and unraveled it and said "Now let's look at this condom and see where these lice are" and they saw no lice – the ones I had met with.

Though they sought to clarify key concepts whenever possible, at times, peer educators seemed uncertain about the correct answer. This was particularly the case when it came to discussions about the origins of HIV. In such situations, peer educators fell back on their scientific training and their own personal experience. A peer educator expressed her own feelings of insecurity when asked to reply to this scientific question but described how she relayed her training.

Pemeido: People will say, "Where did this virus come from?" Then you have to tell the story that we read because it's what we read, we don't really know, it's what we read in the book. 'Where HIV came from', chimpanzees in West Africa, yah, they think that people who got it were the people who contracted it from the animals, yah, from the chimpanzees, the hunters. Yah, we tell that story.

Several peer educators discussed circumstances when they had doubts about their ability to explain something clearly and accurately.

Neliswa: Because even us, sometimes to be quite honest, you can't even answer your questions yourself. How can I contract HIV, and then where does this HIV come from, what was going on at that time? You see, there were those questions, and you can't even answer them.

Snax: Even for me, I don't quite understand.

That peer educators were themselves unclear about the origins of HIV is significant given the evidence from Chapter 4 that this question remains a deeply perplexing and important issue for respondents. Indeed, several peer educators were not certain about the origin of the virus, or how to talk about this issue with clients:

Isaac: It's simple, the research is been still going on, they can't say at the moment that HIV is coming from where.

Bonelwa: But then we answer then and say that no one knows quite exactly where HIV comes from – there are various stories – what we are still getting are just stories, that it came from animals, so some people have differing information and some people say it came from white people and some say it came from this and that place – so there isn't yet a tangible response to where HIV came from.

Lloyd: Ah, HIV, the first case of HIV was found in Egyptian mummy⁴³.

Nthabiseng: I also heard a story that there were hunters up in Africa, whereby the hunters used to go and take months away from home, and then a hunter met a chimpanzee and sort of had sex with a chimpanzee, not knowing that the chimpanzee had this virus on it. And then it's whereby a human had this virus from a -- I sort of told them they got it from a chimpanzee. It's whereby, because the person came back home, and he slept with his wife, and then it's whereby it's starting to spread.

When examining peer educators' various responses to the question of origins, it is apparent that while many of them allude to zoonotic transmission between an animal and a human, few specify the exact nature of this contact (through cuts and grazes while butchering bush meat). One wonders whether their hesitancy to point to bush meat is a deliberate tactic or one born of confusion or uncertainty. It may be that this link is seen as taboo⁴⁴ by some peer educators, who then strive to explain the transmission between animals and humans in some other way. However, the absence of an explicitly stated transmission route opens up the discussion to alternatives, such as humans having sex with animals or white people bringing the virus to Africa's shores.

When asked how they accounted for clients' preoccupation with the question of origins, peer educators provided different explanations. One thought that it was due to a lack of information about HIV's origins from the outset of the epidemic:

Poppy: I mean it's ten years, people are more educated about HIV than anything else, but it's still there. Sure, I think it was the way it was introduced. [Pause] It was never mentioned in the community that it was coming from the chimpanzee.

Yet another felt that the issue of origins served as a distraction from other more important concerns:

⁴³ This reference to an Egyptian mummy is most likely confusion with TB. Evidence revealing signs of tuberculosis infection in an Egyptian mummy has been documented (Nerlich et al. 1997).

⁴⁴ Taboos about butchering certain kinds of simians for consumption, particularly those that most closely resemble humans such as chimpanzees and lemurs, exist in various sub-Saharan African countries (Kormos et al. 2003; Jenkins et al. 2011).

Nonqaba: But I always tell them: “That [the origins of HIV] is not very important to know, because you will end up hating it or you will end up pointing fingers to the wrong people, wrong things! So the best thing is to just accept that you are HIV positive – you deal with your status or you treat your HIV and not to dig where does it come from!”. But they are very difficult clients – the ones that will ask you “where exactly does it come from!?”

Later on in this interview, the peer educator was asked why she thought people kept on asking about origins. She replied that those “that are asking that question are the people that are in denial”. Another peer educator felt that the global origin of the virus was intertwined with personal preoccupation with who was the source of infection in a sexual relationship. She too urged people to move beyond these concerns:

Pemeido: For me, it’s very important to tell them ‘know that you don’t really have to blame anyone, all you can do now is like look for what to live your life’, encourage them, like living positively, eating right with a nutritious balanced diet. Don’t go back and dig the past, you know?

Yet viewing questions about the origins of HIV as a distraction or a manifestation of denial rather than as a central component of understanding HIV science may affect peer educators’ inclinations to take these concerns seriously⁴⁵. Consistent and clear information may help to alleviate some people’s concerns about the question of origins. At the very least, this issue should not be regarded as past and dismissed from current discussions. Indeed, viewed as a key disjuncture in information, the question of the virus’ origins could be seen as foundational to subsequent acceptance of and trust in other aspects of HIV science. Steinberg’s account of his protagonist’s view that “when you see smoke in the sky, it means some people have been lighting a fire” serves as a reminder that *rerum cognoscere causas* - ‘to

⁴⁵ In his book, *The Origins of AIDS*, Jacques Pepin recognizes a similar reluctance to focus attention on the question of origins: “Some may say that understanding the past is irrelevant, what really matters is the future” (2011, 4). Yet he believes that there are two compelling reasons why this question should matter. First, “we have a moral obligation to the millions of human beings who have died, or will die, from this infection. Second, this tragedy was facilitated (or even caused) by human interventions: colonization, urbanization and probably well-intentioned public health campaigns. Hopefully, we can gain collective wisdom and humility that might help avoid provoking another such disaster in the coming decades”(2011, 4–5).

understand the causes of things' - is a natural, human instinct. In the absence of a plausible account of the natural origins of the virus, alternative explanations may flourish.

Despite their own doubts and uncertainties, peer educators claimed never to hesitate from seeking help when they felt they did not know the answer to a client's question. Every peer educator interviewed spoke openly about searching for new evidence, exploring better ways of explaining things, and seeking clarity on difficult topics from fellow educators, trainers, doctors or the internet.

Abongile: If you, for example a person asks you a question and you are thinking – this question, I didn't research it properly, that person will tell you 'My brother, I will give myself some time and come back to you, but I just have to first go and research this further so that I can come back to you with something I am certain will not harm you or mislead you!'

Pretty: I tell them that I am going to go do some research on it. No, I am very open with them and I tell them that "I do not know the answer to this one – give me a chance – tomorrow I will come back with the answer, or if you are not here tomorrow, the next time you come back for your appointment, just call me and I will respond to you!"

Bonelwa: I will answer the ones I can answer and the ones I do not know I won't answer and questions that concern the doctor I will go ask the doctor for them or I will go get the information myself from the doctor. Do my own research and bring back the information.

Nomandithini: And with information – yes, we have it, but there are some things which we find we don't know and we can't say to the people when they ask us questions – we can't lie. We can't lie because that lie might backfire on some other day.

Nonqaba: Most of the information I have I get from TAC – at MSF, at those workshops and then at the trainings.

Chunyiswa: Yeah, Google and the internet. I use Google.

This willingness to seek out additional help contrasts sharply with Dickinson's study of peer educators in South Africa. In his interviews with peer educators, they discussed enlisting outside expertise to answer queries, and characterized this strategy as 'calling an expert'. The peer educators in Dickinson's study viewed this

approach as a passive transfer of information from an expert to the target audience - an approach that is ultimately “likely to undermine the peer educators’ credibility if an audience is already skeptical of their messages” (Dickinson 2010b, 12). Here, Dickinson suggests that the peer educators felt they were merely performing an intermediary role between the two groups (Dickinson 2010b, 9).

In contrast, in this research, peer educators in Khayelitsha felt that asking for help boosted their credibility with their clients, by showing that they would not pass along information of which they were unsure. By and large, peer educators felt that the internet was a help rather than a hindrance, serving to clarify information for themselves and their clients. Though peer educators in this study were not always 100% accurate or completely certain about their information, most of their errors were minor in nature. This is consistent with other studies of peer education showing that gaps in knowledge about HIV exist, even among experienced educators (Tobias et al. 2010). The exception was their responses to the origins of HIV. Though peer educators’ uncertainty about this topic may simply reflect the newness of scientific discoveries (Pepin 2011; Timberg and Halperin 2012), or the complex detail of the scientific account, it remains a key topic of concern to respondents and should be addressed with clarity and consistency.

Having explored instances where peer educators were uncertain about how to convey scientific information, discussion will now turn to certain occasions when peer educators engaged in more deliberate shaping of their messages around HIV.

Section 3: Exercising judgment and maintaining trust

As first responders for HIV scientific orthodoxy, peer educators are often tasked with bridging the gap between public understandings of HIV and scientific fact. However, they do not act as passive conduits of this information. Rather, they employ their own judgment in determining how to represent certain scientific facts. Peer educators were torn over whether to reveal certain types of health information to their clients when they worried it would have unintended consequences. They

were also mindful of the need to remain trustworthy to their clients, and sought to manage the dissemination of information in ways that would not undermine this trust. According to them, the recurring examples of difficult issues were undetectable viral loads and alcohol use among HIV positive patients.

In deciding whether to inform patients that it was now possible to achieve an undetectable viral load if they adhered properly, some peer educators felt they had to exercise some form of self-censorship. Some questioned whether some clients would engage in risky behavior upon learning that they were minimally infectious, and reflected that this information would be 'too dangerous' if communicated to the public, resulting in less condom use.

Abongile: I think that for us, the people who are getting trained on this information – there are certain types of information we cannot just break down to people. Because once we start doing that we will be spoiling the people and they will stop using condoms, thinking that because their viral load is undetectable so that means "I can't infect another person! So I can do as I please – sleep with other people!" and forget that there are many other diseases that they can pick up or get.

Neliswa: Yeah, for me, I think we have to stop giving people that information.

Lloyd: Because we are not passing that information. If you are adhering to your treatment, there are less chances that you can transmit that virus to your partner. But in the public, we do not pass that information because people will be reluctant to use condoms consistently.

Pretty: We do not pass it on to them! Yes, we went – and here I am talking about myself only – we were trained on this by the doctor there at MSF and we were told that if you are taking ARVs your viral load is undetected, it can't be seen – even if you have sex without a condom you won't infect another person. But when I go to the clinic I will not make mention of that.

However, peer educators were also aware that clients might encounter information about 'undetectable viral loads' from other sources, which might serve to undermine their credibility.

Nomandithini: But that information – we rarely release it to people. Because it is dangerous. But the doctors say that we mustn't hide information, because there are people who have this information.

Nonqaba: No, we don't mention that one. But when we talk about – you know there are those posters of early initiation of 350 – treatment as prevention, so they will ask: “When you say ‘Treatment as Prevention’ what do you mean? Prevent who? From what?”

One educator reflected on a recent training between TAC and MSF where peer educators were encouraged to tell their clients about undetectable viral loads.

Pemeido: Yeah, we were keeping the information before, until recently, when we went to a training and the doctors told us that it's very much important for us to tell the people, you know, because we need to be transparent, we need to tell them everything. Even though we didn't tell them, but they knew because they were reading it on newspapers and in books and stuff, and even Equal Treatment, that we distribute in our clinics, it had the same information. So now we tell them.

Others believed that it is both their duty and in their best interests to be transparent and tell clients about this information, so long as they included important caveats about the necessity of still using other forms of protection. They told clients that undetectable viral loads were a possibility and reiterated the importance of adhering to ARVs.

Snax: Nah, I release it into the community. I say that, if the doctor says that your viral load is undetectable, meaning that there is no virus, so meaning your CD4 count is 100% good, that doesn't mean you must stop your ARVs.

Bonelwa: We tell them. Because these news comes out even on the TVs and radios – or it just written about in the newspapers. We tell them.

Poppy: No, I do tell them, because I want to encourage them to take their treatment. So that their virus can be undetectable. And I tell them, if your virus is undetectable, it doesn't mean that you are cured. It means that it has been suppressed by the ARVs. That's the evidence of the ARVs.

These peer educators were acutely aware that information about undetectable viral loads was unlikely to remain private for long; it would only undermine their credibility and trustworthiness if they failed to disclose this information to their clients.

As with undetectable viral loads, peer educators faced challenges while advising clients about mixing alcohol with antiretroviral medication. Alcohol use was cited as

an impediment to proper adherence and defaulting. All peer educators felt that mixing the two substances created the possibility for a drug interaction with potentially harmful consequences⁴⁶. However, they also recognized that clients would frequently default from their treatment if they were drinking. Peer educators spoke about the difficulty of banning all alcohol consumption. Many preferred to engage with the practical realities of daily life in Khayelitsha, advising clients to enlist the help of a friend to ensure they continued to take ARVs even if intoxicated.

Several had been urged by doctors and nurses to embrace a position of compromise, whereby clients would be told to drink in moderation while remembering to take their ARVs. This seemed to reflect a change of policy, from one of warning of the dangers of mixing alcohol and ARVs to recognizing the inevitability of alcohol intake. Again, peer educators were in the center of this debate, and were involved in communicating this change of policy to clients and community members. This sometimes placed peer educators in awkward positions vis-à-vis their clients.

Pretty: So some will ask – “Can we drink alcohol?” and we tell them “Don’t drink whilst you’re on ARVs!” and the sister in charge, Sister Mpumi from Ubuntu [clinic] came out and told them outright that “Dear people we know it’s holidays and you will be heading home – you are going to get drunk. Get drunk! But make sure you take your ARVs!” and I could see that they were all interested in what Sister Mpumi was saying. And they were all saying “Really? Really?” and yes, fine, we’d heard about this thing that “if you drink alcohol you can still take your ARVs”, but we never put it out there. So now, we had no choice – because Sister Mpumi had let it out and we were forced to speak about it, “No, she is right – if you’re going to drink alcohol make sure you take your ARVs though!” So now we are promoting that people continue drinking! You see?

⁴⁶ There is no scientific evidence to support a total ban on alcohol use by people using ARVs. Rather, as Steinberg highlights, peer educators and other community members have sometimes used their authority to prohibit alcohol use among HIV-positive people. Eric Goemaere, head of MSF in South Africa, reported to Steinberg that the prohibition on alcohol use was created by activists and lay counsellors: “If you want to create a club, you must create rules. Because otherwise everyone is in, which means nobody is in. It is amazing: they set up artificially a number of rules; it was never pushed by us. And they give challenges to each other” (Steinberg 2008a, 181).

Bonelwa: Well, I haven't spoken about the issue of ARV and alcohol. Because it confuses people. Because we just told the people recently – that alcohol and ARVs don't mix. And so I haven't spoken about this issue of alcohol and ARVs. I still stop them from indulging in alcohol. Because if we release it, they are going to see that alcohol does nothing when I mix it with ARVs.

Nomandithini: What happens is that we advise them and we show them the danger of drinking and at the same time we advise them to take their pills even if they have drunk alcohol. But at least they must have limits.

As with the issue of the cure, peer educators were keenly aware that clients gathered information from their own experiences and used it to challenge inconsistent claims.

Nonqaba: Ja, the challenges are adherence, alcohol and ARVs – there, there is also a conflict that exists. Because there is a side of people who say they've been using alcohol since they started ARVs and they have no problems. So they are sharing stories – that you are trying to give information to new clients, so they come with their old stories that "I have been taking these ARVs and drinking alcohol and I am still alive! So this thing you're saying – I won't understand! And I do test my blood and it's undetectable! So you are talking nonsense!" So it becomes challenging in that sense.

Section 4: The use of parable and metaphor

In this environment, where complex scientific information needs to be conveyed so that it can be easily understood, some peer educators report using creative strategies to explain difficult concepts or to make an emphatic point. Many said that they employed figurative language such as parables or metaphors to clarify a concept that was not easily accessible on a purely scientific level. In doing so, they attempted to build public trust in HIV science by rendering its concepts more accessible to people with limited science education.

Metaphor is described by Aristotle as "giving the thing a name that belongs to something else" (Aristotle 2004, 32). This study follows the distinction made by Lakoff and Johnson between two different types of metaphor (1980). While 'conventionalized' metaphors refer to those expressions that have become so commonplace as to enter into everyday usage without deliberate thought (e.g. the

leg of the table; the eye of the storm), the more noteworthy category of 'conceptual' or 'novel' metaphors is seen as a device to expand language "to create new ways of understanding" (Kirklin 2007, 12). Thus, while the former type of metaphor is a figure of speech, the latter creates new meaning "to fill a semantic lacuna" (Kirklin 2007, 12). Parables are extended metaphors, used allegorically, in which one thing is described as another in a short story (Dickinson 2011).

In this study, peer educators used metaphors and parables to clarify crucial facts. One of the recurring challenges for the peer educators were defaulters, people who would begin ARVs when they were ill yet once their health was restored, would stop treatment. In communicating with and about such patients, several peer educators used a snake metaphor to reiterate how important it was to continue treatment once it had been started:

Bonelwa: Ja, well I do have my own example for the pills. I usually say take a snake, place a rock on the snake and when you remove that rock off the snake – the snake moves fast you know – so it will have energy and anger to the extent that it will want to bite you now. And then now if that rock on top of that snake stays there – that snake doesn't have the energy to bite you. So it's also like that with HIV – if you take your pills you are suppressing HIV so that it won't rise or duplicate itself with you.

Nomandithini: For example, like in Xhosa I usually make an example – particularly for those who default. A person just says, "No, I am tired of these pills I won't take them! I see no difference whether I take them or not!" and then I make an example of a snake – if you place a rock on top of a snake and it doesn't die and wakes up, once that snake wakes up, it'll wake up stronger and even if I the person who place the rock on it ran away – you the person who was just walking along the road innocently, it'll just come to you with the anger I caused it. You see? And it'll just destroy everything much much more than it did before the rock was placed on it. Maybe it hadn't done anything before you put the rock on it, but after the rock it wakes up much more angry. And it wakes up much stronger. So I give them that example in the side of defaulters.

Nonqaba: The snake is your threat. So if you want to protect or fight safely with that snake you must get a stone and put it on top of it – because you won't be able to kill it if you don't have the strength to kill it. so for you to be safe, just at least take a rock and press it down there.

Chunyiswa: I use a good example of a snake, that if you find a snake, then you take a – sorry, my English is bad – you take a stone, and you put it on a snake. Then that’s how ARVs work. But if you stop them, then you are lifting up the stone and then the snake will be dangerous and come and bite.

Individual peer educators would vary the snake story in small ways, but all who used it had the same underlying point: stopping antiretrovirals after you have started them carries great risks. Similarly, when trying to explain how HIV enters the body and operates with impunity against the body’s immune system, peer educators repeatedly told a story about an outsider, sometimes a ‘thug’ or criminal, trying to gain entry to a school. Recognizing that entry would only be granted to those wearing identical uniforms, the thug steals or otherwise obtains a uniform, enters the school in disguise, disables the school principal, and is therefore able to enact his terrible plan.

Pretty: Like for example, I like to use – like when I am trying to show them how HIV enters the body – like for example I usually make an example with school, the Masiyile School, when you are at that school you wear a brown school uniform and then once someone from Matthew Goniwe [a nearby school] wearing a grey uniform and enters this school – if he wants to cause trouble and make the school corrupt he will get a brown uniform too, so as to blend in as well, and others won’t know he’s not from Masiyile. Because if he comes in wearing the Matthew Goniwe uniform they will see that he is not from here. So he’ll wear a brown uniform and then start influencing all the other children inside to do as he does. And then all the children become rebels. So it’s like HIV when it enters the body – it comes in and camouflages itself and looks like your body’s soldiers and once it looks like them it starts eating those soldiers in your body. And then it becomes clearer for the people then. Whereas if you are going to talk about DNA and this and that about the condom and so on – you have already lost them.

Nomandithini: You have to first have to get a school uniform that is going to look like that of the other children, and then you can come in and see all the things that are inside. Like HIV enters it comes in and checks out the security of the body or you just kill the security guard and wear its uniform.

Lloyd: And when you are inside, you can change the whole school, to do your focus, because you are not having the same focus as the people at this school. But you came as an opportunist. That’s how HIV attacks our CD4 cells. So I make those stories, I create those stories so that people can have a broader picture of what we are trying to educate them.

Neliswa: We are at school, and then there is this guy who wants to come, maybe a gangster who wants to come and kill somebody in the school. But because of that particular gangster is not wearing our same uniform, he can't be allowed to get inside to do whatever he wants to do inside.

As with the snake parable, though the level of elaboration and certain details changed with each peer educator's unique telling, the overall message of the story was the same. It is similar to a metaphor used in a TAC pamphlet to describe how HIV interacts with the immune system. Entitled, "HIV, the thief", it states:

HIV is a thief that comes to a house (CD4 cell) and has a master key to open the door lock. The thief will come and open the door and see what is inside the house that s/he wants. The thief will look around the drawers, everywhere, sit on the chairs and make him or herself feel at home. Then, s/he will take all the things s/he wants and destroy the house. When the thief leaves the house, s/he goes to find another house that has not been robbed. The thief breaks into this house, takes what s/he wants and destroys the home. All the homes in the neighbourhood are soon robbed by the thief and his or her friends. So they go to other neighbourhoods and rob those homes. Eventually, all the homes are destroyed by the thieves. Similarly, this is what happens when we have been infected with HIV. Our immune system makes many CD4 cells – the home in our example – because we are trying to kill off the virus (Treatment Action Campaign 2006, 18)

In his work documenting stories and parables used by peer educators, Dickinson points out that "a noticeable feature of the stories is the relevance of the plots and contexts to the target audience" (Dickinson 2011, 338). Others have suggested that a high level of congruence and cultural understanding between patient and provider metaphors is needed if this is to be an effective communication strategy for medicine (Fuks 2009; Fuks et al. 2011). A meta-analysis of the influential effects of metaphor found that "the persuasive impact of metaphor is maximized when the audience is familiar with the metaphor target", suggesting the need for shared social and cultural experience (Sopory and Price Dillard 2002, 413). Thus, it is not surprising that the metaphors and parables contain some familiar objects, events and experiences from everyday life, such as schools, snakes, crime, and, as discussed below, football.

When asked where they had received the idea to use these stories as part of their explanations, some peer educators credited their mentors or supervisors in the Treatment Literacy Programme for this technique. Some of TAC's written educational materials use similar strategies. In a 2006 pamphlet for treatment advocates, TAC highlights how a metaphoric explanation could be used to explain how the immune system works. Under the heading "Immune system is like the Bafana Bafana team", it states:

In a football team, there is a coach, the CD4 cell (T helper cell), who works out ways in which the team can be successful and win its matches. It also co-ordinates and keeps watch that each person is playing their role and understands best what is each player's weakness and strength. Then there are the player categories: the midfield or defenders who make it hard for the other team, HIV, to come close to a place where they are likely to score a goal, there are the strikers who try to score goals for their team and run fastest, there is the goalie who makes sure that even if the other team has managed to go past the defender and come into the territory of his team to score a goal he tried to prevent them from doing so. So, you can see that each person has their role and sticks to it and that everyone works together as a team to achieve the one goal – to win the match! A similar process happens with the immune system (Treatment Action Campaign 2006, 13).

TAC's official sanction and oversight of metaphoric tactics suggests an opportunity for improved use in the future. Other peer educators, however, claimed to have developed the idea of stories on their own initiative. Those initiating these stories on their own may be highly motivated, innovative individuals. There is a clear instinctual skill in telling stories, as Aristotle observed: "The greatest thing by far is to be a master of metaphor. It is the one thing that cannot be learnt from others; and it is also a sign of genius, since a good metaphor implies an intuitive perception of the similarity in dissimilars" (2004, 35).

Beyond natural aptitude, the use of metaphors and parables in these situations could also be improved by careful training. Peer educators have to deploy a sufficiently complex story to accurately represent the science without creating additional confusion. Again, as Aristotle observes, "Metaphors must not be far-fetched, or they will be difficult to grasp, not obvious, or they will have no effect"

(Barnes 1995, 265; Aristotle 350AD). The potential for confusion was possible even in the case of the simplest metaphor, as in the case of describing the immune system as the ‘body’s soldiers’⁴⁷. This metaphor was used by TAC (referring to ‘*amajoni omzimba*’ as “soldiers of the body”) in official pamphlets in order to explain how white blood cells function (Treatment Action Campaign 2006, 11). One peer educator recounted how she used this figurative construction⁴⁸ to explain how HIV deactivates the ‘command center’ in the body:

Pemeido: You know we have a soldier in our bodies, the big one, the CD4 cells issues commandments in our body, so what does HIV do, it attacks the commander, the CD4 cell. You know? So when it attacks the commander, you know the commander gives the instructions to the other soldiers, so who is going to give instructions to other soldiers if the commander is dead, you know?

However, she also explained that sometimes this metaphor was taken too literally by some of her clients, causing additional confusion:

Pemeido: You just have to make it that way, to make it a little bit simple, because sometimes the clients will ask you ‘where are the soldiers in my body?’, and you’ll be like ‘woah’...-- [laughs]
Interviewer: [laughs] ‘Are there actually little soldiers...?’

⁴⁷ The origin of the depiction of the human immune system as ‘soldiers’ has been debated. Ashforth and Natrass discuss the claim that this is an ancient Zulu notion but conclude that, “It is, most likely, a Zulu translation of the concept of immunity. “*Amasojha*’ is, after all, a phonetic rendering in Zulu of the English word ‘soldiers” (2005, 286). An adherence counselor in Steinberg’s ethnography in Lusikisiki uses the term “*bala amajoni*” to instruct patients about CD4 count. Literally, to “count your body’s soldiers” (Steinberg 2008a, 188).

⁴⁸ There is a significant body of literature critiquing military metaphor usage in relation to disease and, in particular, cancer and HIV/AIDS. Sontag (2001) argues that, “the effect of the military imagery on thinking about sickness and health is far from inconsequential. It over mobilizes, it over describes, and it powerfully contributes to the excommunicating and stigmatizing of the ill” (Sontag 2001, 182). Similarly, Fuks contends that “the military metaphors that pervade medicine undermine the ability of physicians and society to deal with the burgeoning burden of chronic illness” (Fuks 2009, 1). In their instructional pamphlet, TAC notes that “TAC and the activists who wrote this handbook do not endorse or believe in violence or wars and therefore do not like this example. We use the example because it is the one most people will be familiar with, but we prefer the one of a football team explained above” (Treatment Action Campaign 2006, 13).

Pemeido: Yeah, you have to explain that, you have to say 'no, I'm talking about the cells'.

At times, the use of metaphor became too cumbersome for some, losing its effect by being unclear or confusing.

Isaac: Why are you wearing your jeans sitting on the chair? There's something that you're preventing. What is it? Can you explain it? Then the answer that you'll get is that 'I'm wearing the jeans because I'm preventing something'. So that is why I'm saying to you, if you're preventing this HIV from this chair, or from this jean that you are wearing, it's not going to follow you. Because you're preventing it.

Although there were occasional failed or inappropriate uses of metaphor, on the whole peer educators felt that this technique rendered scientific information more accessible to their clients. One of the TAC trainers explained it as a strategy to represent science in familiar terms:

Lloyd: I communicate that training that I do with TAC, that scientific training, in the Xhosa language, so that those who are not educated, they can understand. And we relate HIV scientific training with things that are happening. We transform HIV as soldiers that attack the human immune system. So if we are creating that story, one can have the picture of how the soldiers attacked, so if they can make that picture in their minds, they can be aware of what we are trying to educate about HIV. So that's how I handle the difference between the scientific education, the scientific training with the public who is not well educated.

In sum, peer educators used stories, metaphors, and parables as a creative way of introducing complex information that might otherwise be difficult to convey. They served similar purposes to the parables and metaphors recorded by Dickinson (2009; 2010b; 2011) in his work with peer educators at a South African mining company. Though few studies have discussed this method of communication among peer educators, numerous studies have demonstrated the widespread use of metaphors in business, politics, education and medicine to assist in communicating new information in familiar terms and challenging existing mindsets (Arroliga et al. 2002; Krieger, Parrott, and Nussbaum 2011; Periyakoil 2008; Fuks et al. 2011; Reisfield and Wilson 2004; Wortmann 2008; Hutchings 1998). Common medical metaphors include the pumps and pipes of the circulatory system, the circuits and

wires of the nervous system (Periyakoil 2008; Arroliga et al. 2002; Fuks et al. 2011), the fog and immobilizing experience of mental illness (Rhodes 1984), and military metaphors of battle, survival, fighting, and defense (Fuks 2009).

The use of metaphors and parables, however, is not without the potential for misunderstandings or misappropriation (Bedell et al. 2004; Rhodes 1984; Periyakoil 2008). Perhaps the most vehement critic of metaphorical use in medicine is Susan Sontag. In *Illness as Metaphor* and *AIDS as Metaphor*, Sontag argued that “illness is *not* a metaphor” and that disease should be spoken about purified of “metaphoric thinking” (Sontag 2001, 3). To think of disease as a metaphor too often turns into blame for the affliction based on the personal characteristics of the afflicted; thus, the tubercular patient of the 19th century is viewed as passionate, melancholy, creative, and romantic, whereas the cancer patient of the 20th century is perceived as repressed, angry, and emotionally inhibited. Such negative characterizations, she argued, “deformed” the patients’ experiences of their affliction, convinced them that they were disgusting and their situation hopeless, and ultimately, discouraged them from seeking appropriate care. Thus, she argues, “metaphors and myths, I was convinced, kill” (Sontag 2001, 102).

Using figurative techniques to build public understandings of science also carries less dramatic dangers: the risk that the scientific meaning will become less accurate as the metaphor evolves. In the example discussed above, it is possible that the snake used in peer educators’ discussions may shift into a positive symbol rather than dangerous or undesirable object. How would that affect people’s understanding of the value of ARVs in halting the progression of the virus? Ashforth and Natrass observe that snakes take on different meanings depending on varying cultural traditions in southern Africa. While Green (1996) observes that snakes can symbolize “bodily power and purity” in southern Africa, they can also be seen, according to Ashforth (2005), as the “familiar dispatched by a witch in order to cause harm and misfortune” (Ashforth and Natrass 2005, 289).

This potential for a medical metaphor to obscure rather than clarify scientific concepts is further highlighted in Ashforth and Natrass' (2005) analysis of a video designed by a Yale University medical student and used by the South African Department of Health (Wong 2004; Wong et al. 2006)⁴⁹. In it, the metaphor of a snake is employed to represent HIV, while the idiom of 'poison' is used to refer to the power of antiretrovirals. An excerpt from the script reads as follows:

Your body's immune system – or *amaso tsha amzimba* (sic) is an army of soldier cells that guard your body from sicknesses like HIV. But HIV is a particularly bad sickness because it not only fights your body, it fights CD4 soldier cells. HIV is like a poisonous snake, sneaking up to the CD4 soldiers while they are sleeping and killing them.

The video then expands on the metaphor to explain how ARVs work:

This is where ARVs come in. ARVs can prevent the multiplication of the HIV virus. It is as if the body's soldiers could find the HIV snake nests, and pour poison⁵⁰ on the snake eggs to keep the eggs from hatching. However, ARVs are a kind (sic) poison that only works for a limited amount of time. They must be taken every day, in the morning and evening, otherwise the HIV virus has a chance to reproduce itself (Wong 2004, 59).

Ashforth and Natrass note that 'poison' is a common translation for *idliso*, a form of witchcraft. Thus, "a video embracing both the image of the snake and the idiom of poisoning", the authors argue, "is entering a cultural zone where interpretations of meaning cannot easily be predicted" (2005, 289). This is particularly problematic in South Africa, where the former Health Minister depicted ARVs as 'poisonous' and toxic on numerous occasions (Geffen 2010). The deployment of the snake and poison metaphor in this video risks reinforcing denialist representations of ARVs as toxic for humans⁵¹.

⁴⁹ The video can be viewed at: <http://cushing.med.yale.edu/greenstone/cgi-bin/library.cgi?a=d&c=ymtdl&d=etd-08202004-175255html> (Accessed May 15 2013).

⁵⁰ In the final version of the video, currently available online, the word 'poison' is replaced with 'drug'. The author does not comment on which version was circulated by the Ministry of Health in South Africa, nor on why this substitution occurred.

⁵¹ These objections may seem petty given the recorded improvement in ARV access and adherence knowledge among participants in Wong and colleagues' study. However, it bears noting that, given the pre/post study design, the study did not

A further challenge in using metaphors to communicate science is that some metaphors can “freeze”, becoming “part of the language system to which the terms making up the metaphor belong” (Fricke 1998, 3). For instance, when a war metaphor is used to describe cancer, there is a risk that “all the facts and knowledge related to warfare are thought to apply *entirely* to cancer therapy as well thereby resulting in errors in inference and the resultant desire to ‘fight to the bitter end’” (Periyakoil 2008, 843). While this limits the creative use of metaphor, the opposite tendency – that a metaphor will fail to adapt to changing circumstances – is also present. Though the image of the thug using a disguise to enter the school is dramatic, one wonders how this parable will evolve to incorporate and articulate new scientific information about HIV, such as the discovery that ARV treatment, administered rapidly after birth, may be able to prevent HIV infection in newborn babies (Guardian Reporter 2013).

In short, metaphors and parables can evolve in an unpredictable and inaccurate manner, freeze in meaning or fail to adapt to changing circumstances as needed. When this occurs, they can increase rather than diminish ambiguity and uncertainty. This does not mean, however, that metaphors and parables cannot be a useful complementary tool in explaining scientific concepts. If deployed appropriately and sensitively, they can augment understanding and clarify concepts that might otherwise be difficult to understand (Bedell et al. 2004; Arroliga et al. 2002; Reisfield and Wilson 2004; Krieger, Parrott, and Nussbaum 2011). In a meta-analysis of the benefits of metaphors as compared to literal language, metaphors

compare exposure between a health literacy approach and the ‘culturally-sensitive’ video designed by Wong. Rather, the study measured whether there was improvement in knowledge *before* the video was screened compared to *after*; it established that the video did not measurably *decrease* ARV-related knowledge. Failure to use the ‘best available standard of care’ as a comparison (such as the *Beat it!* materials noted in the introduction), as would be the case in a randomized control trial, leaves open the question of whether this video is actually an improvement over existing materials.

were found to enhance persuasion, producing greater attitude change (Sopory and Price Dillard 2002).

This discussion suggests neither that metaphors and storytelling are a uniquely African phenomenon nor that those with limited formal education require such figurative techniques as an alternative to scientific explanations. Nathan Geffen, from TAC's Research Office, rightly argued that an exclusive emphasis on metaphors is inappropriate. In his words, it is "a patronizing, racist, Verwoedian attitude to presume black people can't learn science" (Ashforth and Natrass 2005, 297). The exclusive use of metaphor and storytelling to communicate science, however, should not be conflated with the *complementary* use of such techniques. Though TAC itself promotes metaphorical explanations for scientific processes⁵² (Treatment Action Campaign 2006), the relationship between metaphors and scientific explanations is sometimes represented as oppositional and hierarchical, with educators forced to make a choice between competing approaches, and with health literacy positioned as the preferred method (Krieger, Parrott, and Nussbaum 2011). Framed in this way, TAC's biomedical approach is represented as "education and profound cultural transformation in favour of biomedical understandings of HIV and HAART", *rather than* "trying to manipulate local understandings" (Ashforth and Natrass 2005, 296). Similarly, Geffen derides the uses of metaphor to explain HIV science, pointing to the sophisticated scientific literacy of many TAC members: "Try doing that with snakes and soldiers!" (Ashforth and Natrass 2005, 297). He continues, "If teaching HIV using the language of science couldn't work or wasn't working, then by all means

⁵² In addition to the metaphors and parables outlined above, TAC also explained as the reason for some people calling AIDS 'slimming disease' the fact that "your body gets smaller and smaller like a piece of wood that is being chopped into small pieces" (Treatment Action Campaign 2006, 27), described the role of ARVs as a friend who can help you when you are exhausted during a long journey (2006, 36), clarified the function of ARVs using the example of bread dough (2006, 39), and cautioned that missing a dose of ARVs is like "leaving a gate open. The HIV gets a chance and before you know it, a whole herd of HIVs is inside your field grazing happily and destroying your maize" (2006, 39).

use snakes and soldiers if it saves lives. But we, ARK, MSF and others have all demonstrated that it does work” (Ashforth and Nattrass 2005, 297).

Rather than viewing metaphors and parables as oppositional to biomedical scientific explanations, these techniques can be seen as a complementary strategy to communicate science (Kirklin 2007). TAC peer educators have been well trained in biomedical explanations about HIV; these interviews suggest that they have found figurative language to be a useful and perhaps even necessary adjunct strategy. By using both orthodox scientific educational techniques – where a CD4 cell is identified as such – as well as more creative, story-based descriptions, TAC peer educators feel themselves better able to communicate with their clients. That this has been noted in other studies of peer educators suggests that it may be a common strategy for communicating biomedical information to the public (Dickinson 2007; Dickinson 2011). Peer educators’ ability to alternate between these techniques in communicating with clients is testament to their expertise and training, as well as their commitment to their work.

The results from this study suggest that all metaphors and parables should not be assessed under the same rubric. Though metaphor usage may be universal and ubiquitous (Lakoff and Johnson 1980; Geary 2011), certain stories work better than others. As Robinson argued in response to Sontag’s *AIDS and Its Metaphors*, “The correct question to ask regarding the way we think about AIDS is whether its metaphors are well or ill chosen” (Robinson 1989). Dickinson found that while some stories succinctly and dramatically conveyed the importance of certain behaviours, others served to reinforce a misconception about HIV rather than challenge it (Dickinson 2011). The straightforwardness and stickiness (Gladwell 2000; Wortmann 2008) of the ‘snake and the rock’ parable stands in contrast to the complex and contradictory meaning contained in the ‘snake and poison’ story used by Wong (2004; 2006). Rather than viewing these figurative techniques as less important than biomedical facts, more attention should be devoted to training peer educators to show discretion in the appropriate use of metaphors and parables

(Dickinson 2011). Moreover, it is crucial to continue evaluating the meanings of metaphors and parables in the community at large in order to ensure these stories do not take on a different, inaccurate meaning from what was originally intended (Bedell et al. 2004).

It is also noteworthy that although various metaphors have been found useful, none addresses the key sources of confusion or doubt that were raised in Chapter 4. These include: the existence of a cure, the logic of PMTCT, the trustworthiness of Jacob Zuma’s HIV test result, and the origin of the virus. This may be because these topics are complex and difficult to capture succinctly in a story or metaphor. A TAC publication called “Pregnancy in our Lives” used a visual metaphor to portray the value of PMTCT. It depicts a strand of ARVs encircling a baby *in utero*, preventing the HIV virus from penetrating within:

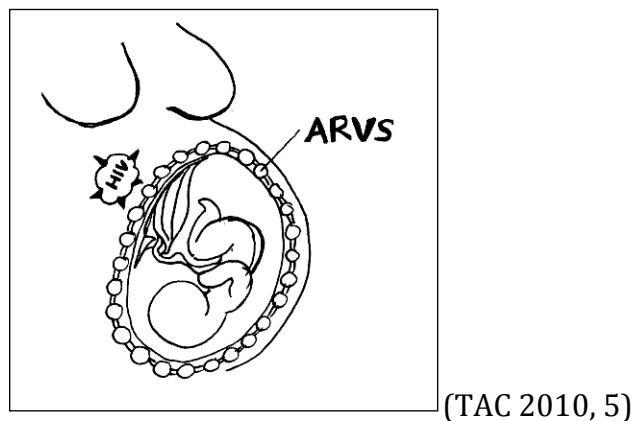


Image 3: TAC Pamphlet depicting PMTCT

Although this visual depiction indicates that ARVs represent a protective force around the unborn baby, it does not clarify how PMTCT actually works. This may be because there has yet to be a clear scientific explanation. The pamphlet notes, “Despite remarkable achievements in reducing mother-to-child transmission, we do not understand fully how it happens. This can be one of the hardest things to explain when we do our training workshops” (TAC 2010, 11). Similarly, it may be difficult to pithily and concisely explain the origins of HIV, why Post-Exposure Prophylaxis

(PEP) and Pre-Exposure Prophylaxis (PreP) are preventive measures not cures, or why it is possible that Jacob Zuma is HIV negative even after having unprotected sex with an HIV positive woman. The difficulty in conveying these concepts, however, should not dissuade peer educators from trying to find explanations that satisfy clients' curiosity and confusion. If these key disjunctures in information remain inadequately addressed, they may continue to undermine clients' trust in HIV science.

Section 5: Power and Persuasion

In his study of HIV activism by the Treatment Action Campaign, Robins concludes: "It also remains to be seen what role TAC/MSF will play in mediating these universalist biomedical understandings of 'disease' and 'illness' in South African communities where there are competing explanations for misfortune and ill-health" (Robins 2004, 671). This chapter provides some insight into these dynamics in an urban context in South Africa.

Peer educators' status as trusted sources of information about HIV meant that they could engage with clients' questions and suspicions about HIV information (Chapter 4). In response, peers educators report using various rhetorics of persuasion to boost understanding of, and trust in, HIV science. These ranged from relating and reiterating biomedical facts about HIV to employing creative story-telling techniques to illustrate key scientific concepts. They also drew upon different sources of credibility in the face of doubts and mistrust. One technique was to highlight evidence that was apparent to clients in everyday life. This was deemed appropriate in situations where clients' questioned something in the public sphere, such as the potential existence of a cure, or the 'shower' claims of Jacob Zuma. Peer educators reiterated that a cure would be plainly evident if it existed, and that people had been showering for years with no discernable effect on rates of HIV infection. Another technique was for peer educators to draw on their own history and experience as HIV positive people. As someone who had experienced testing,

counseling, diagnosis and treatment just like their clients, peer educators could claim to have ‘walked the walk’ and possess the authority to advise others.

The results of this study echo previous studies showing that peer educators “encountered numerous obstacles and challenges during their daily attempts to implant these [scientific] ‘facts’ in the hearts and minds” (Robins 2009c, 29). In responding to key areas of controversy, doubt and confusion, peer educators experienced their role less as a neutral bridge between science and the target population. Rather, they acted more as a mediator or broker, compelled to make their own judgments about how to explain certain topics and whether clients could handle the truth about scientific developments in all their complexity. This suggests that peer educators are rarely operating in purely didactic environments, and more frequently must actively engage with the questions and debates of the target audience.

This study challenges the conceptualization of peer educators as people engaged in vertical communication with passive recipients of a focused, stable, scientific message. Rather, peer education in this context involves much more horizontal communication with active, engaged receivers of complex, changing facts and understandings. As described in other studies of this more engaged, horizontal form of peer education (Robins 2009c, 29) equipping such peer educators to work in the field will require more than just training in good scientific literacy. It will necessitate instruction in how to manage contentious communication with peers, how to steer a discussion towards a productive end, and how to employ creative tactics to best effect.

This conceptualization of peer education as a complex activity involving mediation, agency and judgment also highlights the unequal dynamics of power that are present in all peer education relationships. Though the premise of peer education is that “similarity between message source and recipient is vital to the ultimate impact of the message” (Wolf and Bond 2002, 362) so that they can impart credible socio-

culturally resonant information, in reality, peer educators will differ from their peers in important dimensions. As James observes, the model of peer education posits two seemingly contradictory sets of qualities: the “egalitarian and non-authoritarian character of a relationship between equals with a more hierarchical relationship in which knowledge...can be passed on from the informed to the ignorant (James 2002). The comment of one of the peer educators, “Select your group, then you select your words” (Section 2), illustrates how conscious she is in determining appropriate language for her target group, which may or may not be identical to her own.

By virtue of their education, status, and training, peer educators are set apart from others in their communities and positioned to impart the “correct” basis for decision-making around HIV care. This creates tension between peer educators vis-à-vis their clients, particularly when peer educators believe that certain information should not be openly discussed, and raises the question: How much discretion are peer educators expected to exercise in their decisions about education and advocacy? These interviews suggest that TAC peer educators perceive themselves to be differentiated in significant ways from their peers, by virtue of their training and education. While some believe in complete transparency around all scientific issues, all were cognizant of the challenges bound within the process of imparting complex scientific information to an audience that lacked general scientific education. In practice, peer educators must balance the inclination to withhold information with the danger that clients will discover their dishonesty. If clients believe that there are inconsistencies between the information they receive from TAC and what they hear and see in their communities and the media, peer educators risk losing their trusted status in the community.

Conclusion

This chapter suggests that in response to alternative beliefs about HIV/AIDS, peer educators employ various rhetorics of persuasion to augment clients’ understanding of, and trust in, HIV science. They make use of their scientific training from TAC,

recognizing the importance of harnessing concrete observable data from everyday life and using the easily grasped nature of stories and metaphors to communicate intricate concepts. The success of these tactics can be enhanced with even more training and guidance on the appropriate ways of mobilizing creative communication for the challenging task at hand. Further discussion of practical interventions will be discussed in the following chapter.

Chapter 7: Conclusions and Implications for Future Interventions

Introduction

This chapter will summarize key research findings before outlining the implications of these findings for policy and practice. Certain conceptualizations of alternative beliefs foreclose much meaningful engagement with those who hold them; if individuals are seen to have developed an unmitigated suspicion of scientific principles, there are few opportunities to reestablish a basis for trust. However, the results from this study suggest that many of those who hold alternative beliefs are more flexible, nuanced and open-minded than is sometimes believed. A range of possible interventions is therefore appropriate for some people; these are outlined below. The final section of this chapter focuses on future research, outlining several potential lines of enquiry related to the current study.

Summary of Key Research Findings

This study sought to understand alternative beliefs about HIV/AIDS in South Africa in the post-Apartheid, post-Mbeki period. Guided by the Public Understandings of Science framework, it comes to three main conclusions about the nature and extent of alternative beliefs about HIV/AIDS in South Africa. First, the sorts of alternative belief encountered in this study are often less ‘conspiratorial’ in nature than originally anticipated. Though some respondents clearly viewed HIV as part of a western or government plot, far more of them believed it originated in a natural or accidental process. These beliefs can be understood far less as a “conspiratorial move” and more as a mixture of distrust and suspicions born of historical and political observations, and disjunctures in information between what is claimed at the biomedical level and what is apparent or visible in people’s experiences. Respondents employed various “street level epistemologies of trust” to determine what was plausible and trustworthy about HIV science, and what appeared to be contradictory or confusing. Thus, respondents’ distrust of HIV science should be seen less as a rejection of scientific principles and more as a form of agnostic engagement with certain aspects of these scientific claims. Respondents’

preoccupation with certain topics – the origins of the virus and the existence of a cure - could be read as evidence of wider anxieties and distrust of expert systems, but should also be considered as real, articulated areas of ongoing inquiry and curiosity.

Second, identifying trusted sources of information about HIV in South Africa is not always straightforward. Those who are trusted include doctors, nurses and activists, the people most closely identified with the epidemic, its effects, and its treatment. Those who are distrusted are those who are seen to have something to gain from the epidemic – traditional healers, sangomas, and politicians. Yet this dichotomy between public service and self-interest is blurred with reference to politicians. Politicians are seen as people distanced from the science of HIV, focusing instead on their own political agendas. Yet people did not view all politicians alike. Some – most notably Mandela - were seen as more credible than others. Other politicians, particularly Mbeki, Tshabalala-Msimang, and Zuma, were judged in ways that diverged significantly from the judgments of activist and academic communities. The varying opinions of politicians that emerged in this study serve as a reminder that reputations for trustworthiness can vary significantly between groups, even from within the same country, and highlights the notion that one cannot demand to be trusted, one can only be deemed trustworthy or not by others. As Wynne observes,

It is a contradiction in terms to instrumentalize a relationship which is supposed to be based on trust. It is simply not possible to expect the other in a relationship to trust oneself, if one's assumed objective is to manage and control the other's response. The only thing which one can expect to control, and to take responsibility for, is one's own trustworthiness (2006, 219–220).

Interventions using trusted sources of information to address alternative beliefs about HIV/AIDS should be mindful of the fluctuating, dynamic, and relational nature of trust. In particular, individual politicians' 'trustworthiness' may evolve in ways not always apparent to those seen as outside a certain community.

Third, in their efforts to address these concerns and alleviate doubts, TAC peer educators are among the most trusted and skilled interlocutors with the respondents from this study. Despite the trust invested in peer educators, they routinely find themselves challenged by clients about the biomedical information they disseminate. In order to overcome these doubts and challenges, peer educators report employing various rhetorical techniques including drawing on their own experiences, referencing commonly observable evidence and using figurative language such as metaphors and parables to communicate complex scientific ideas. Some of these techniques may have helped to clarify certain topics among clients. However, it is notable that none of the peer educators reported using figurative techniques to address the two key areas of confusion surrounding the origins and the cure.

Implications for Policy and Practice

The extent to which certain types of future interventions are possible depends upon one's conceptualization of alternative beliefs and those who hold them. Reaching those who endorse alternative beliefs has been identified as one of the greatest challenges for policy-makers and scholars (Keeley 1999; Lewandowsky et al. 2013). Sunstein and Vermeule claim there is a "self-sealing" quality to alternative and conspiratorial belief that makes adherents unlikely to listen to the viewpoints of others (2009). Indeed, many suggest that some individuals will never change their minds regarding their alternative beliefs; whether about HIV/AIDS, vaccines, or 9/11, some people seem to be permanently fixed in these positions and will "broaden the scope of presumed malfeasance" when challenged rather than admit they are wrong (Lewandowsky et al. 2012; Lewandowsky et al. 2013, 12). For those who have made the "conspiratorial move", Natrass argues, "science and reason cannot penetrate this armour of arrogant dismissal" (2012b, 332). Some suggest that engaging with such individuals is not only frustrating, but that in participating in a discussion about alternative beliefs, scholars may inadvertently lend credence to the notion that a legitimate debate exists (Goldacre 2010).

Conceptualized in this manner, those who endorse alternative beliefs are seen as almost beyond reach. This perspective, though it may be accurate for some individuals, bars interventions to reach other, more open-minded people, as one anti-conspiracy blogger argued:

Such fatalism, such rejection of any attempt to directly challenge conspiracy theories of all stripes in public debate, seems to foreclose any meaningful opportunity for mutual understanding, and seems to acquiesce to the view that those who have fringe and unsupportable views will never be able to change their minds (Grothe 2013).

Fortunately, those who cannot be shifted from their dissident positions may be “the exception rather than the rule” (Nattrass 2012a, 161). The fact that respondents in this study could endorse alternative and conspiratorial beliefs strongly in the survey but indicate greater flexibility and doubts in the focus group discussions implies a possible opportunity for interventions attempting to influence distrustful or skeptical individuals with public health messages. If some individuals in the ‘endorser’ community are more receptive to alternative perspectives, or if individuals move fluidly between these categories, they have made less of a “conspiratorial move” than indicated their openness to a range of explanations. A letter sent to Justin Terry-Smith’s pro-science blog in 2013 highlights this attitude:

I'm somewhat of an "AIDS denialist." For all that I have researched, read, studied and learned, I have a hard time accepting what I've "unlearned." At the same time, the passing of a close cousin and Christine Maggiore⁵³ has forced me to ask myself, "If I were HIV-positive, would I have the strength of my convictions to live the life I advocate, like Christine, or would I take the path that most people take?" My mind rejects conventional wisdom on HIV and the use of HIV medications, but I don't think I would take the "holistic" route, either. I just don't understand why there can't be an alternative clinical option. Let me know what your thoughts are. Thanks!
-- dnahotep (Terry-Smith 2012).

This letter writer is clearly seeking additional information more than foreclosing further discussion. This opens up the possibility for a number of responses, focusing

⁵³ Christine Maggiore, founder of the dissident website *Alive and Well*, was a prominent AIDS denialist until her death from AIDS-related illnesses in 2008.

on both the sources of information and the nature of communication around alternative beliefs.

Sources of information

First, trusted individuals may be able to engage with alternative beliefs in a culturally sensitive manner while disseminating different viewpoints. Some have suggested that peer educators are ideal interlocutors for this task, as they are able to engage in horizontal communication in informal settings (Dickinson 2009; Bogart et al. 2010). Others have suggested using trusted authority figures such as pastors or community leaders to reach those endorsing alternative beliefs (Bogart et al. 2010). To help them in this task, motivational interviewing techniques, which focus on helping individuals to explore and resolve ambivalence and uncertainty, may be well suited to discussions about distrust of HIV science and alternative beliefs (Bogart, Elliott, et al. 2011; Gillman et al. 2013; Miller and Rollnick 2002; Parsons et al. 2005; Golin et al. 2012). Motivational interviewing also encourages counselors to “roll with resistance” from clients; this technique emphasizes using “the client’s ‘momentum’ to further explore client’s views” (Miller et al. 1992).

Attention to trusted individuals raises the question of political responses to alternative beliefs. Mbeki and Tshabalala-Msimang unquestionably exemplify poor leadership on the subject (Nattrass 2012a; Geffen 2010), and were rightfully challenged by those in the academic and activist community. In making this challenge, it was crucial to distinguish between Mbeki’s stance as a head of state as compared to his stance “as emblematic of some broader understandable subaltern counter-narrative to western expert opinion” (Nattrass 2013, 125), speaking for those who could not speak for themselves. During Mbeki’s administration, Steinberg observes, some scholars represented Mbeki as “giving voice to an aggrieved and quintessentially African experience, one shared by millions” (Steinberg 2007b). For example, Fassin writes:

The series of controversies raised by President Mbeki’s statements on AIDS, which received much more favourable echo in the Black population than is

usually said, obviously belong to the collective experience of the epidemic (2002, 66).

However, such an approach misses the key point, Natrass writes, that “the cultural and political terrain is more complex than a putative binary between the poor/oppressed people and the power/western/scientific experts” (Natrass 2013, 125). Given that those who opposed Mbeki had strong working-class support (Geffen 2010), whereas Mbeki is a powerful national politician, it seems incongruous to ignore how Mbeki’s position was fundamentally privileged, and that he is not, in short, “a spokesman of the vanquished” (Natrass 2012a; Steinberg 2007b).

Instead of engaging in “generous anthropologies of African mistakes” (Steinberg 2007b), Natrass argues that more attention should focus on precisely this parsing of relative power between political leaders and the public. To assist in this task, she argues for distinguishing between ‘primary marginalization’ – understood as the socioeconomic and institutional disadvantages faced by members of the public - and ‘secondary marginalization’ - resulting from cynical exercises of power by privileged leaders (Natrass 2013; Cohen 1999).

Natrass’ use of secondary marginalization creates analytical space for acknowledging “the legacy of apartheid and the scale of the challenge posed by HIV while simultaneously holding [Mbeki] and his health minister to account for furthering AIDS conspiracy theories and undermining public health” (2013, 125). It also directs attention towards the agency embedded in Mbeki’s choices, rather than viewing his policies as dictated by history. “We are not simply victims of the past”, Shula Marks asserted in 2002, “human agency is important” (2002, 22). In Steinberg’s words, Mbeki “followed rather than led” – reflecting the anxieties of the time rather than rising above them (2007b).

Such a focus on personal agency draws attention, for example, to the fact that the sort of racist discourse that Mbeki reacted against had, by the time he became

President, “been massively surpassed in the ‘AIDS world’ by rights-based, anti-discrimination discourse and a shift to a medical, technical, non-‘moralistic’/stigmatizing approach” (Mbali 2004, 116). Thus, while recognizing government denialism as partly a reaction to racist understandings of African sexuality and apartheid-era discriminatory public health policy, Mbali stops short of granting Mbeki full historical justification for his stance (2004, 110).

Instead, she suggests that the “key historical shift in the late 1980’s and early 1990’s in discourse around AIDS policy towards rights-based discourse” in both South Africa and international circles has rendered “denialism historically obsolete” (2004, 113–114) and “out of date” (2004, 111). She indicts Mbeki as “fundamentally constrained in his thinking by the ghosts of apartheid and colonial discourse around Africans, medicine and disease” (2002, 8) and challenges the South African leadership to “get out of the constraints of discourse defined by the boundaries of nationalism and colonialism” (2004, 116). After all, as Natrass observes, Jacob Zuma, Mbeki’s successor as President, endorsed pro-science AIDS policies “although he had participated in the same struggle against apartheid and confronted the same HIV epidemic” (2013, 125).

In light of the poor leadership on how to manage alternative beliefs in South Africa, it is important to explore how current and future leaders around the world can better address people’s concerns. Responses to alternative beliefs should acknowledge the current and historical context in which distrust is “thinkable” (Natrass 2012a) while also encouraging people to invest trust in public health institutions. An example of a more desirable approach was visible during the 2008 US Presidential election, when then President-elect Obama learned that his former pastor Reverend Jeremiah Wright had preached a sermon that included AIDS conspiracy beliefs about the man-made creation of HIV targeting the African-American community stating: “The government lied about inventing the HIV virus as a means of genocide against people of color” (Wright 2003).

President-elect Obama found himself in the midst of the Wright controversy in the challenging position of having to speak to the validity of a conspiracy belief simultaneously to two different communities. Had Obama unequivocally condemned Wright's claims in the strongest language, he risked alienating his African-American base, whose past experiences of racism and discrimination make the claims of man-made HIV both rational and plausible (Nattrass 2012a). Had he placated that base with apologist rhetoric for Wright, Obama risked being branded as a conspiracy theorist himself, a profoundly effective label to destroy the mainstream appeal of the first African-American candidate for U.S. President. This is a common tension for those attempting to address conspiracy beliefs from within a particular community (see Nattrass 2012a for a discussion of David Gilbert's work in US prison populations).

In his now-famous address on race in America in 2008, Obama effectively balanced these competing claims (Marable 2009). Kaler has argued that interventions need to address the *credibility* of alternative beliefs at the same time as commenting on their *truth* (2009, 1717). Obama did precisely this. He reminded all Americans that "many of the disparities that exist in the African-American community today can be directly traced to inequalities passed on from an earlier generation that suffered under the brutal legacy of slavery and Jim Crow" (Obama 2008). At the same time, he urged his African-American followers to embrace "the burdens of our past without becoming victims of our past" (Obama 2008). This example serves as a model for how to "work within" the worldview of target populations while also advocating for certain health beliefs and behaviours (Kaler 2009, 1718).

Addressing alternative beliefs: disjunctures and context

A second type of response to alternative beliefs would focus on the content and nature of communication about such beliefs. Future interventions should address the key disjunctures in information about HIV identified by respondents. HIV prevention campaigns should recognize the potential for doubts about science to indicate a form of skeptical engagement rather than of rejection and alienation, and

attempt to address issues that feed doubts about HIV science. These points of leverage include: the origins of the virus, the efficacy of PMTCT, and the existence of a cure. Respondents' enquiries and doubts about the logic of PMTCT or the existence of a cure should serve as a reminder that science is constantly being reviewed and reinterpreted with available evidence. Communication about HIV science to people with alternative beliefs needs to strike the correct balance between providing clear, easily understood explanations and acknowledging the provisional and evolving nature of scientific knowledge.

Simple and clear explanations for seeming disjunctures may be part of what is required to address initial distrust. A newer, correct explanation for a certain phenomenon may be more likely accepted if it includes an explanation for why "the initial incorrect information was offered" (Lewandowsky et al. 2012, 117). For instance, Rochon and colleagues documented barriers to adherence among HIV positive patients. One barrier was mistrust of the US public health system. A patient discussed his observations in the early years of the epidemic that people were dying after taking AZT [an antiretroviral]: "I seen all my friends die because they were taking AZT. To me, I didn't think AZT was for black people. They were dying like flies. They wanted to give me AZT and I wouldn't let them". In response, the authors recommend a clear, concise response: "Because AZT was first given in very high doses to AIDS patients but was ineffective as a monotherapy, many patients suffered serious adverse events and most died of AIDS anyway. Patients taking the currently recommended, lower dose formulation in combination with other drugs no longer have the same adverse events and can go on to live long and healthy lives with HIV infection" (2011, 464–465).

This response reflects Lewandowsky and colleagues' observation that it is important to provide an alternative explanation when seeking to debunk a false one. Failure to fill this gap may "motivate reliance on misinformation in spite of a retraction" or rebuttal (Lewandowsky et al. 2012, 117). However, this response also addresses only the truth of the belief, not the plausibility of it. To truly undermine

this patient's doubts, the health care provider would have to address the wider contextual issues that make such a belief plausible.

Indeed, Kaler argues that providing accurate information and correcting misconceptions “engages only with the question of whether rumours are true...This truth-based approach, however, does not engage the question of whether the rumours are credible”⁵⁴. This perspective posits that interventions to address sources of confusion may rely on simplistic reeducation campaigns and as a result, may fail to address underlying contextual sources of distrust such as colonialism and apartheid.

Interventions should attempt to address and acknowledge both the historical and the contemporary forces that lend plausibility to alternative and conspiratorial beliefs (Larson et al. 2011; Larson and Heymann 2010; Larson and Ghinai 2011; Bogart et al. 2010; Thomas and Crouse Quinn 1993). Drawing on their research on vaccine refusal and distrust, Larson and colleagues advise, “To build public confidence, it is key to understand what drives public trust in each community” (2011, 8). An appreciation of this type of approach was central to Delany-Woretiwe and colleagues' communication with study participants in South Africa. Recognizing that the cultural context was an important factor in translating evidence into policy, they wrote,

Researchers stepped outside of their traditional role and actively engaged in the communication process. In so doing, they were required to respond to the legacies of apartheid, that is the lack of knowledge, the lack of skill, and the lack of trust in science (2011, 2).

⁵⁴ This latter task is made difficult, Kaler argues, because the plausibility of certain alternative beliefs “is almost over-determined by the convergence of social and political forces far outside the control of any health programme” (2009, 1717–1718). Since these are historical realities and cannot be undone, this frames the issue of distrust as an over-determined, inevitable problem, virtually unsolvable for many generations. Kaler concludes, “short of rewriting the last two centuries of global history and redistributing global and national wealth (not a likely prospect), I do not believe there are any foolproof solutions” (2009, 1717–1718).

By acknowledging some of the reasons why alternative beliefs are thinkable, researchers and scientists can build public trust. Natrass has argued that “recognizing and exposing the limitations of science not only builds credibility by acknowledging reasonable concerns, but assists the broader project of promoting good science” (2012a, 163). Yet there is also a tension between analyzing the history of science with reference to abuses and mistakes, and maintaining sufficient clarity of purpose to be able to act in the field of public health. In an editorial in *Equal Treatment*, Siphso Mthathi, TAC’s General Secretary in 2006, writes about the importance of recognizing “justified mistrust of the scientific community” due to past abuses, yet also urges readers not to “discard science and its benefits that are rightfully ours because of our mistrust” (2006, 1). She concludes:

Science must be held to account for its inadequacies. But we must not allow our own government to misuse legitimate questions about science to refuse us our rights. TAC’s treatment literacy programme works to demystify science. Join our community of activists in discovering the common sense of science (Mthathi 2006, 1).

Mthathi’s observation raises the issue of balance, between the need to clarify misconceptions about HIV and the importance of addressing underlying causes of distrust and suspicion. This study echoes her contention that working to elucidate key aspects of HIV science is a no less important endeavor as acknowledging past legacies. At times, however, the goal of clarifying misconceptions has been characterized in two less positive ways. The first represents activities designed to address confusion and disjunctures in information as “practices of refutation” (Kaler 2009, 1717), conceptualized as a somewhat naïve or condescending correction of misunderstandings. The second suggests that distrust and disjunctures in information be principally regarded as symbols of deeper anxieties, metaphors for an uncertain age. Some scholars suggest that alternative beliefs are “a narrative articulation of social inequalities” (Mackenzie 2011, 500) and that such beliefs seek “to penetrate the impenetrable, to unscrew the inscrutable, to recapture the forces suspected of redirecting the flow of power in the world” (Comaroff and Comaroff

1993, xxx). While this may be the case in certain instances, respondents in this study sincerely and consistently requested further clarity on key aspects of HIV science that remain perplexing or incongruous to them. To treat these disjunctures in information as purely symbolic concerns, then, would be doing a disservice to this population⁵⁵; they truly want to know whether Jacob Zuma is HIV positive; why there is no cure; how PMTCT works; and where HIV came from originally. Such persistent areas of confusion should be seen as important and responded to with clarity and candor.

While it is important to clarify these questions, individuals advocating on behalf of HIV science should be careful not to overstate or oversimplify research findings; as Smith and Novella argue, oversimplification could backfire as more complex or provisional aspects of HIV science come to light (2007). In a situation where uncertainty is uncomfortable, researchers or activists may be tempted to eliminate complexity in their communication with the public. Previous studies, however, have suggested that over-confidence or overzealous advocacy can lead the public to distrust scientific claims to an even greater extent (Lewandowsky et al. 2012; Wynne 1992; Leask and McIntyre 2003). Betsch and Sachse report that strong risk negations (i.e. claiming that there is “no risk”) can paradoxically lead to a higher perceived risk (2013).

Several studies have identified a so-called “inoculation effect” for alternative beliefs, whereby individuals who are primed to expect certain information to be false or misleading information are less likely to believe it after exposure (Papageorgis and

⁵⁵ Scheper-Hughes relates her own experience of studying alternative beliefs about medical abuses in organ harvesting. Notably, once she “abandoned more symbolic analyses for practical and material explanations” – namely, that organ stealing rumours found “some basis in contemporary transplant practices”, she found her colleagues and medical professionals were less receptive to her findings. Some even “suggested that [she] had fallen into the assumptive world of [her] uneducated informants” (Scheper-Hughes 2000, 203). It is worth considering how symbolic analyses are sometimes privileged and preferred over practical ones, and how this may disfavor informants’ true perspectives and priorities.

McGuire 1961; Banas and Miller 2013). In Banas and Miller's study, students who were preemptively inoculated with correct facts were significantly less likely to believe the conspiratorial messaging in *Loose Change*, the 9/11 conspiracy film. They speculate that "preemption may be so crucial because it creates frames or schema for perceiving subsequent messages" (2013, 201). Similarly, other studies suggest that individuals are less likely to cling to misinformation even after a retraction if they have been alerted beforehand that the information they will hear may be suspect (Chambers and Zaragoza 2001; Ecker, Lewandowsky, and Tang 2010; Lewandowsky et al. 2012).

Though real-world inoculation strategies may be harder to implement, it is worth considering how trusted sources of information – such as peer educators or health care workers – could preemptively address alternative beliefs about HIV/AIDS. Steinberg notes the importance of responding to possible disjunctures and uncertainty among the newly diagnosed: "They had to be scooped up very quickly into a forum of their peers, one where they would feel the presence of collective sympathy and the absence of ill-feeling; where they would hear a confident and simple account of what to expect and what to do over the coming weeks, months, and years" (2008a, 186). These discussions could provide an opportunity to address alternative beliefs proactively. By broaching the topic along the lines of "You may have heard some people say that HIV is a man-made virus...", peer educators or health providers may be able to steer peers, clients or patients towards greater trust in HIV science.

Though these interactions may not be the first time such beliefs are encountered, Ford and colleagues point out that, "Persons who mistrust the government are unlikely to disclose this to their providers. Therefore, providers and health educators must use strategies that account for potential mistrust even if patients do not mention it as a concern" (2013, 9). This preemptive approach was operationalized in a recent intervention to improve participation of African-Americans in clinical trials through the use of a culturally targeted video. In

recognition of distrust and concerns about ethical misconduct among the target population, the content of the video included preemptive discussion of the Tuskegee Syphilis Study “in an attempt to break down the related barriers of misinformation and myth surrounding the events at Tuskegee” (Banda et al. 2012, 709).

Building trust in new science

Future research about HIV/AIDS needs to be communicated with sufficient precision and clarity to avoid giving rise to additional confusion. The notion that a cure already exists or is close to being discovered is at odds with the current reality of research and should be addressed so as not to encourage conspiracy beliefs in the future if a cure fails to materialize. Similarly, the success of recent scientific trials on the preventative value of Pre-exposure Prophylaxis as well as the announcement that certain patients exhibit ‘undetectable viral loads’ should be clearly explained so as not to give false hope about the existence of a cure. The media coverage of Timothy Brown, the so-called “Berlin Patient”, who stopped exhibiting HIV in his blood after undergoing a bone-marrow transplant for cancer (Banda et al. 2012, 709), and the ‘functional cure’ of a previously HIV-infected infant in the US (Mail and Guardian 2013), may also cause confusion if the exceptional nature of these cases is not elucidated. Recognizing this possibility in the latter case, TAC issued a report on their district blog clarifying the unique circumstances of the situation and providing further information (Treatment Action Campaign 2013).

Building public understanding and trust in science in the context of uncertain scientific results is difficult, and scientists and policy makers must frequently balance the need to keep the public abreast of any new developments with the desire to avoid causing alarm. The media can exacerbate public distrust by reporting scientific data in the most sensational manner possible, for instance, by communicating increases in risk by using the relative risk increase rather than

natural frequencies⁵⁶ (Goldacre 2010). When scientific policies influence politics, policy makers should be prepared to account for changes in the underlying science. Too many changes in official policy, occurring too frequently, and people begin to doubt the empirical basis of science (Campbell 2011, 4892). While in one context, Wynne (1992) demonstrates how officials' exaggerated claims undermined public trust in their authority, Kalichman and colleagues have shown that those who perceive there to be a debate among scientists about whether HIV causes AIDS are more likely to refuse HIV treatments (2010). Scientists are challenged to make the scientific consensus known while also acknowledging the uncertainty and provisionality inherent in the scientific method.

Recent controversy about the WHO breastfeeding policy illustrates the tension between adapting policies to reflect current research and maintaining reliably consistent guidelines⁵⁷. Breastfeeding policy has also recently changed in South Africa, with the government no longer providing formula to HIV positive mothers (Makhubu 2010). The message the government is now sending is that it is less risky for HIV-positive mothers to breastfeed their children, a statement that flies in the face of previous public health messages (IRIN News 2011). The evidence from this study - that PMTCT remains a confusing aspect of HIV prevention and treatment - serves as a reminder that this seemingly contradictory decision needs to be addressed with a direct and honest approach.

⁵⁶ Goldacre outlines how communicating changes in risk using the relative risk increase can make small increases in risk seem dramatic. If out of 100 men with normal cholesterol, 4 are expected to have heart attacks, whereas out of 100 men with high cholesterol, 6 are expected to have heart attacks, this can be expressed either as "a 50% increase in risk" (relative risk increase) or "an extra two heart attacks per 100 men" (natural frequency). These methods of reporting will have important implications for how the public understands risk (Goldacre 2010, 187).

⁵⁷ In 2001, the WHO announced that exclusive breastfeeding for the first six months was best for infant health. However, in January 2011, the *British Medical Journal* published a study suggesting that failure to provide additional solid food before six months might be harmful (Fewtrell et al. 2011). In response, parent advocacy groups accused scientists of being paid off by the formula milk companies to lower their previous estimates (Boseley 2011).

TAC has endeavored to do so in their popular literature about HIV prevention and treatment. Whereas in 2007, TAC's pamphlet *HIV in our Lives* stated, "For women who are HIV positive, it is best to formula feed their babies" (Treatment Action Campaign 2007, 43), and the 2009 pamphlet framed breastfeeding versus formula feeding as the mother's "choice" (Treatment Action Campaign 2009), by 2012, TAC devoted an issue of *Equal Treatment* to babies and used this opportunity to address the government's change in policy head-on:

There is a risk that HIV-positive mothers can transmit HIV to their babies during breastfeeding. This is because the HI-virus can be passed on through breast milk. Therefore, for a number of years, mothers living with HIV were advised not to breastfeed their infants. Instead, they were provided with formula milk through public health clinics and hospitals. This has now changed. Health workers no longer advise HIV positive mothers to exclusively formula feed and have stopped providing mothers with free formula. This sudden withdrawal of formula has caused much fear and anxiety amongst mothers with HIV. However, there are well-intentioned reasons for the withdrawal of formula (Treatment Action Campaign 2012, 4).

Using clear, precise language that addressed the discomfort caused by changes in formula subsidies, TAC attempts to maintain trust in HIV science and the government's corresponding policy.

Given the existence of those who seek to undermine the scientific consensus around HIV, scholars must also be mindful of how scientific publications can be misconstrued or taken out of context, and ultimately raise doubts about HIV science. Two books published in recent years about the origins of the virus offer support for the human role in *amplifying* though not *creating* the HIV virus. In both Jacques Pepin's *The Origins of AIDS*, and Craig Timberg and Daniel Halperin's *Tinderbox: How the West Sparked the AIDS Epidemic and How the World Can Finally Overcome it*, the authors discuss how the initial HIV infection of a small number of individuals was augmented by human activities. Pepin emphasizes the culpability of colonial-era mass vaccination campaigns using unsterile needles in spreading HIV infection from remote villages to cities and back again (Pepin 2011). Timberg and Halperin point to

the mass movement of workers to urban centres during the scramble for Africa at the turn of the century (Timberg and Halperin 2012).

Though such findings have been published before (Ilfie 2006), selected excerpts from both books could be misinterpreted as lending credence to the belief that humans deliberately created or spread the virus. As Hermann Reuter remarks in *Three Letter Plague*, “There is a half-truth. It is always when stories mix that they become much more credible” (Steinberg 2008a, 155). Simply just because these findings have been disseminated in scholarly publications does not mean they will remain immune to reinterpretation by members of the non-academic public. Indeed, a recent review of Timberg and Halperin’s book appeared on a South African website with the title, *HIV: Colonialism’s Gift to the World* - a heading that will undoubtedly stick in people’s minds long after the details of the publication have been forgotten (Terblanche 2012). Scientists, politicians, and especially front-line health-care workers and peer educators will have to be prepared to face difficult questions and address these results with respect and candor, ever mindful of how best to interpret and incorporate new and challenging research findings when communicating with at-risk populations.

Using the internet

A final response to alternative beliefs is through the internet. This medium is a primary source of information about health issues, although physicians still remain the most trusted “arbiter of information quality” (Hesse et al. 2005, 2623). This medium, however, is the subject of significant concern, with one scholar calling it a “Pandora’s Box” (Kata 2010). Some scholars have rightly pointed out the potential for the internet to provide an additional venue for the dissemination of alternative beliefs (Betsch et al. 2012; Witteman and Zikmund-Fisher 2012; Betsch and Sachse 2012). Precisely because the peer review process operates to exclude material that is insufficiently based on evidence, alternative beliefs have flourished online. These sites enable “communities of denialists to grow by feeding each other’s feelings of persecution by a corrupt elite” (McKee and Diethelm 2010, 1310–1311). The

consequences of this sense of community can be seen in South Africa, where President Mbeki infamously went online to learn about alternative beliefs about HIV/AIDS. As Natrass outlines, “When Mbeki surfed the internet about AIDS, he came across more than just a set of bad ideas; he encountered a community in which conspiracy theory fostered new forms of identity (bold truth-seeker) and social solidarity (we, the oppressed) (2012b, 332).

Morozov suggests that online search engines such as Google should exercise more “curatorial control” over the websites they display for controversial searches such as “vaccination” or “global warming”. Search engines and social networks that have begun displaying the searches of one’s contacts and peers may inadvertently reinforce clusters of alternative beliefs or “cyber-ghettos” (Johnson, Bichard, and Zhang 2009). This would make encountering information that contradicts one’s own views more unlikely (Morozov 2012). One option would be to display a red banner in response to certain searches such as “HIV man-made”, cautioning online users to exercise restraint and seek other opinions (Morozov 2012). Such a practice might be similar to Wikipedia’s current practice of indicating when content exhibits a particular bias or is insufficiently supported by evidence. However, this type of intervention might also alienate those who seek self-directed, autonomous access to information; public trust in certain online sites might drop if people felt that their search results were subject to oversight. Commenting on Morozov’s suggestion, one journalist pointed out that “one person’s ‘heavier curatorial control’ is another’s censorship” (Thierer 2012). According to Witteman and Zikmund-Fischer, a preferable response is “not about controlling what is available but rather, it is about responding and participating in an interactive, user-responsive environment” (2012, 3738).

In this light, others observe that the internet can provide a forum to engage alternative beliefs in a new manner. Precisely because they are in the public sphere, messages advocating as well as criticizing orthodox HIV science can be easily encountered. Websites such as virusmyth.org, which challenges HIV science and

argues that ARVs are toxic are as easily accessed as AIDStruth.org, which advocates for the scientific consensus about HIV/AIDS. As Natrass highlights,

These days, a “google search,” the modern-day equivalent of practical seekership, catapults one from AIDS denialist to pro-science activist websites, and exposes a person to news (like Maggiore’s death) which sites like Alive and Well prefer to downplay, if not hide” (2012a, 162).

This makes the internet “both a source of opportunity for culturoproneurs – and a site of danger for them as converts can easily be lost” (Natrass 2012a, 157).

Websites can also be used to reinforce the notion that there is no productive or active debate around basic HIV scientific principles. Those managing the website aidstruth.org debunk a series of denialist beliefs about HIV/AIDS including the idea that HIV does not cause AIDS, that HIV in hemophiliacs is caused by Factor VIII, and that AZT causes AIDS (AIDStruth.org). By zeroing in on specific claims by denialist groups, the website seeks to boost its credibility among viewers.

Future Research

The current research could be expanded and extended in several productive directions. First, in relation to the quantitative data contained in the CAPS survey, one could conduct further analysis on predictors of ambivalence about certain alternative beliefs about HIV/AIDS. Those answering “neither agree nor disagree” amount to approximately 10% of the African sample. Given the evidence that uncertainty can be a meaningful category of analysis in its own right, further investigation of this subsample of the CAPS population may yield important insights.

Second, one could conduct further quantitative research on the association between the historical experiences of apartheid, reflected in racism, abuse and discrimination and current interpretations of biomedical claims. The evidence from this study suggests that respondents reflect on past experiences and observations when making judgments about the plausibility of scientific claims. Testing this association using regression analysis would provide new insights and evidence for claims about

the “embodied” nature of apartheid and its interaction with the South African experience of biomedicine.

Third, in relation to further qualitative investigation of alternative beliefs about HIV/AIDS, one could explore the evolution of alternative ideas about HIV in a particular time, space and context and develop a theory of such evolution. This kind of study would focus on establishing what kind of specific circumstances in a community facilitate the growth of alternative beliefs about HIV/AIDS.

Fourth, in relation to further study of peer educators as “antennae” within communities, one could systematically record what kinds of alternative beliefs are encountered by peer educators on a regular basis as well as how they respond. The use of ‘topic’ or ‘conversation’ journals (Watkins and Kaler 2009; Watkins and Swidler 2009) might enable more accurate and detailed reporting than the cross-sectional design used in this study. This could provide an assessment of how prevalent alternative beliefs are in certain contexts and which beliefs in particular are salient at a given time.

Fifth, one could systematically document the complementary communication strategies used by peer educators and health care providers in order to compare the use and benefits of health literacy and figurative language. By interviewing clients as well as peer educators in such a study, researchers could explore whether the communication strategies being used are having the desired effect of improving retention of the scientific material. This would be useful to identify instances where a communication strategy is having an unintended effect – either by boosting comprehension and trust in unexpected ways or by increasing confusion and distrust.

Sixth, and related to the fourth possible topic for future research, one could explore the characteristics of effective peer educators in light of the evidence from this study that they are expected to regularly engage in skillful horizontal communication with

clients. Previous studies have examined qualities of 'good' peer educators in terms of the accuracy of the information they provide and their empathetic qualities, but to date, none have included a measure of the quality of horizontal communication skills such as effectively managing resistance from clients, explaining difficult concepts in a creative manner, or preemptively addressing common sources of confusion. As noted previously, the skills required to communicate in this manner are not insignificant and should be factored into a peer educator's selection for the position as well as subsequent salary.

Summary

This thesis was conceptualized and designed over four years ago, when Mbeki had just resigned as President of South Africa and discussions of his legacy - as a leader in general and specifically in relation to HIV/AIDS - were widespread. I had wondered how the discussion about the South African public's response to HIV/AIDS would change over time. There remains, however, a strong consensus among academics that the abuses of apartheid and the confusion sown by Mbeki provide comprehensive explanations for persisting distrust of HIV science. There is also still a tendency to view distrust of the scientific consensus as conspiratorial beliefs. As this thesis has argued, this conceptualization has implications for how such beliefs are addressed by future research and interventions. Ultimately, this thesis highlighted the relational, evolving basis of distrust among the study population and drew attention to key disjunctures in information that remain disconcerting. Using the Public Understandings of Science framework to study alternative beliefs, this thesis was able to suggest new ways of viewing distrust of HIV science, as a form of skeptical engagement with science's rationale rather than an act of outright rejection.

References

- AIDSTruth.org. "AIDSTruth.org: The Scientific Evidence for HIV/AIDS."
<http://www.aidstruth.org/denialism/myths>.
- Albrecht, TL, GM Johnson, and JB Walther. 1993. "Understanding Communication Processes in Focus Groups." In *Successful Focus Groups: Advancing the State of the Art*, 51–64. Newbury Park, CA: Sage.
- Anonymous. 2009. "Manto Tshabalala-Msimang Dies." *The Mail and Guardian*, 16 December 2009 edition. <http://mg.co.za/article/2009-12-16-manto-tshabalalamsimang-dies>.
- Aristotle. 350AD. *Rhetoric*. Translated by W. Rhys Roberts. Vol. Book III, Chapter 10. <http://classics.mit.edu/Aristotle/rhetoric.3.iii.html>.
- . 2004. *Poetics*. Translated by Ingram Bywater. Kessinger Publishing.
- Arroliga, Alejandro C, Sara Newman, David L Longworth, and James K Stoller. 2002. "Metaphorical Medicine: Using Metaphors to Enhance Communication with Patients Who Have Pulmonary Disease." *Annals of Internal Medicine* 137 (5): E-376–E-380.
- Ashforth, Adam. 2005. "Muthi, Medicine and Witchcraft: Regulating 'African Science' in Post-Apartheid South Africa?" *Social Dynamics* 31 (2): 211–242.
- Ashforth, Adam, and Nicoli Natrass. 2005. "Ambiguities of 'Culture' and the Antiretroviral Rollout in South Africa." *Social Dynamics* 31 (2): 285–303.
- Banaji, Mahzarin R, and Anthony G Greenwald. 2013. *Blindspot: Hidden Biases of Good People*. New York: Delacorte Press.
- Banas, John A, and Gregory Miller. 2013. "Inducing Resistance to Conspiracy Theory Propaganda: Testing Inoculation and Metainoculation Strategies." *Human Communication Research* 39 (2): 184–207.
- Banda, Deliya R, Alexander V Libin, Hong Wang, and Sandra M Swain. 2012. "A Pilot Study of a Culturally Targeted Video Intervention to Increase Participation of African American Patients in Cancer Clinical Trials." *The Oncologist* 17: 708–714.
- Barnes, Jonathan. 1995. *The Cambridge Companion to Aristotle*. Cambridge University Press.
- Barrell, Howard. 2000. "Mbeki Fingers the CIA in AIDS Conspiracy." *Mail and Guardian*, 6 October 2000 edition.
- Bastien, J.W. 1990. "Community Health Workers in Bolivia: Adapting to Traditional Roles in the Andean Community." *Social Science and Medicine* 30 (3): 281–287.
- BBC news. 2009. "Cartoonist 'Removes' Zuma Shower." *BBC*, 13 May 2009 edition. <http://news.bbc.co.uk/1/hi/world/africa/8047418.stm>.
- BBC News. 1997. "Thabo Mbeki: the New President of the ANC." <http://news.bbc.co.uk/1/hi/39789.stm>.
- Beck, Ulrich. 1992. *Risk Society: Towards a New Modernity*. London: Sage Publications.
- Bedell, Susanna E, Thomas B Graboys, Elizabeth Bedell, and Bernard Lown. 2004. "Words That Harm, Words That Heal." *Archives of Internal Medicine* 164 (12 July): 1365–1368.

- Berry, Dianne C, D K Raynor, Peter Knapp, and Elisabetta Bersellini. 2003. "Patients' Understanding of Risk Associated with Medication Use." *Drug Safety* 26 (1): 1–11.
- Betsch, Cornelia, Noel T Brewer, Pauline Brocard, Patrick Davies, Wolfgang Gaissmaier, Niels Haase, Julie Leask, et al. 2012. "Opportunities and Challenges of Web 2.0 for Vaccination Decisions." *Vaccine* 30: 3727–3733.
- Betsch, Cornelia, and Katharina Sachse. 2012. "Dr. Jekyll or Mr. Hyde? (How) the Internet Influences Vaccination Decisions: Recent Evidence and Tentative Guidelines for Online Vaccination Communication." *Vaccine* 30: 3723–3726.
- . 2013. "Debunking Vaccination Myths: Strong Risk Negations Can Increase Perceived Vaccination Risks." *Health Psychology* 32 (2): 146–155.
- Bhaduri, Saradindu, and Aviram Sharma. 2012. "Public Understanding of Participation in Regulatory Decision-making: The Case of Bottled Water Quality Standards in India." *Public Understanding of Science* Published online before print July 24 2012 (doi: 10.1177/0963662512452231).
- Bird, ST, and LM Bogart. 2003. "Birth Control Conspiracy Beliefs, Perceived Discrimination, and Contraceptive Attitudes and Behavior Among African Americans: An Exploratory Study." *Journal of Health Psychology* 8: 263–276.
- Bogart, LM, Marc N Elliott, Kimberly Uyeda, Jennifer Hawes-Dawson, David J Klein, and Mark A Schuster. 2011. "Preliminary Health Eating Outcomes of SNaX, a Pilot Community-Based Intervention for Adolescents." *Journal of Adolescent Health* 48 (2): 196–202.
- Bogart, LM, Seth Kalichman, and Leikness Simbayi. 2008. "Endorsement of a Genocidal HIV Conspiracy as a Barrier to HIV Testing in South Africa." *Journal of Acquired Immune Deficiency Syndromes* 49: 115–116.
- Bogart, LM, Donald Skinner, Lance S Weinhardt, Laura Glasman, Cheryl Sitzler, Yoesrie Toefy, and Seth Kalichman. 2011. "HIV/AIDS Misconceptions May Be Associated with Condom Use Among Black South Africans: An Exploratory Analysis." *African Journal of AIDS Research* 10 (2): 181–187.
- Bogart, LM, and Sheryl Thorburn. 2005. "Are HIV/AIDS Conspiracy Beliefs a Barrier to HIV Prevention Among African-Americans?" *Journal of Acquired Immune Deficiency Syndromes* 38 (2): 213–218.
- Bogart, LM, Glenn Wagner, Frank Galvan, and Denedria Banks. 2010. "Conspiracy Beliefs About HIV Are Related to Antiretroviral Treatment Non-adherence Among African American Men With HIV." *Journal of Acquired Immune Deficiency Syndromes* 53: 648–655.
- Boseley, Sarah. 2011. "Six Months of Breastmilk Alone Is Too Long and Could Harm Babies, Scientists Now Say." *The Guardian*, January 14. <http://www.guardian.co.uk/lifeandstyle/2011/jan/14/six-months-breastfeeding-babies-scientists>.
- Brandon, Dwayne T, Lydia A Isaac, and Thomas A LaVeist. 2005. "The Legacy of Tuskegee and Trust in Medical Care: Is Tuskegee Responsible for Race Differences in Mistrust of Medical Care?" *Journal of the National Medical Association* 97 (7): 951–956.

- Briggs, Charles L. 2004. "Theorizing Modernity Conspiratorially: Science, Scale, and the Political Economy of Public Discourse in Explanations of a Cholera Epidemic." *American Ethnologist* 31 (2): 164–187.
- Broom, G M, and D M Dozier. 1990. *Using Research in Public Relations: Application to Program Management*. Englewood Cliffs, NJ: Prentice-Hall.
- Brown, Roger. 2003. *Social Psychology*. 2nd ed. New York: Free Press.
- Brownlie, Julie, and Alexandra Howson. 2005. "'Leaps of Faith' and MMR: An Empirical Study of Trust." *Sociology* 39 (2): 221–239.
- Burgess, David C, Margaret A Burgess, and Julie Leask. 2006. "The MMR Vaccination and Autism Controversy in United Kingdom 1998-2005: Inevitable Community Outrage or a Failure of Risk Communication?" *Vaccine* 24: 3921–3928.
- Butler, Anthony. 2005. "South Africa's HIV/AIDS Policy, 1994-2004: How Can It Be Explained?" *African Affairs* 104 (417): 591–614.
- Calnan, Michael, and Rosemary Rowe. 2004. "Trust in Health Care: An Agenda for Future Research". Nuffield Trust Seminar 17th November 2004.
- Calnan, MW, and E Sanford. 2004. "Public Trust in Health Care: The System or the Doctor?" *Quality and Safety in Health Care* 13: 92–97.
- Cameron, Edwin. 2005. *Witness to Aids*. South Africa: Tafelberg.
- Campbell, Cathy. 2003. *"Letting Them Die": Why HIV/AIDS Prevention Programmes Fail*. Indiana University Press.
- Campbell, Philip. 2011. "Understanding the Receivers and the Reception of Science's Uncertain Messages." *Philosophical Transactions of the Royal Society A* 369: 4891–4912.
- Cape Area Panel Study. 2006. "About the Cape Area Panel Study." <http://www.caps.uct.ac.za/>.
- Carey, Martha Ann. 1995. "Concerns in the Analysis of Focus Group Data." *Qualitative Health Research* 5 (4): 487–495.
- Cassidy, Rebecca, and Melissa Leach. 2009. "Science, Politics, and the Presidential AIDS 'Cure'." *African Affairs* 108 (433): 559–580.
- Chambers, K L, and M S Zaragoza. 2001. "Intended and Unintended Effects of Explicit Warnings on Eyewitness Susceptibility: Evidence from Source Identification Tests." *Memory and Cognition* 29: 1120–1129.
- Chigwedere, P, GR Seage, S Gruskin, and TH Lee. 2008. "Estimating the Lost Benefits of Antiretroviral Drug Use in South Africa." *Journal of Acquired Immune Deficiency Syndrome* 49: 410–415.
- Clark, April, Jennifer K. Mayben, Christine Hartman, Michael A. Kallen, and Thomas P. Giordano. 2008. "Conspiracy Beliefs About HIV Infection Are Common but Not Associated with Delayed Diagnosis or Care." *AIDS Patient Care & STDs* 22: 753–759.
- Cohen, C. 1999. *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*. Chicago: University of Chicago Press.
- Cohen, Jon. 2000. "South Africa's New Enemy." *Science* 288 (23 June 2000): 2168–2170.

- Comaroff, Jean, and John Comaroff. 1993. "Introduction." In *Modernity and Its Malcontents: Ritual and Power in Postcolonial Africa*, 233. Chicago: University of Chicago Press.
- Connors, Margaret M. 1995. "The Politics of Marginalization: The Appropriation of AIDS Prevention Messages Among Injection Drug Users." *Culture, Medicine and Psychiatry* 19: 425–452.
- Cooper, P, I Diamond, and S High. 1993. "Choosing and Using Contraceptives: Integrating Qualitative and Quantitative Methods in Family Planning." *Journal of the Market Research Society* 35: 325–339.
- Corbie-Smith, Giselle, Stephen B Thomas, and Diane Marie M St. George. 2002. "Distrust, Race, and Research." *Archives of Internal Medicine* 162: 2458–2463.
- Cornell, Morna, Anna Grimsrud, Andrew Boulle, and Landon Myer. 2011. "Retention Among Adults Initiating Antiretroviral Therapy in South Africa: 2002-2007." *Journal of Acquired Immune Deficiency Syndromes* 56 (3): e102.
- Cornish, F., and C. Campbell. 2009. "The Social Conditions for Successful Peer Education: a Comparison of Two HIV Prevention Programs Run by Sex Workers in India and South Africa." *American Journal of Community Psychology* 44 (1-2): 123–135.
- Creswell, John W, and D L Miller. 2000. "Determining Validity in Qualitative Inquiry." *Theory into Practice* 39 (3): 124–131.
- Crocker, Jennifer, Stephanie Broadnax, and Bruce Evan Blaine. 1999. "Belief in U.S. Government Conspiracies Against Blacks Among Black and White College Students: Powerlessness or System Blame?" *Personality and Social Psychology Bulletin* 25: 941–953.
- Cullinan, Kerry, and Anso Thom. 2009. *The Virus, Vitamins and Vegetables: The South African HIV/AIDS Mystery*. Johannesburg: Jacana.
- Deber, Raisa B, Nancy Kraetschmer, Sara Urowitz, and Natasha Sharpe. 2005. "Patient, Consumer, Client, or Customer: What Do People Want to Be Called?" *Health Expectations* 8 (4): 345–351.
- Decoteau, Claire Laurier. 2008. "The Bio-Politics of HIV/AIDS in Post-Apartheid South Africa". PhD Thesis, Sociology, Michigan: University of Michigan.
- Delany-Moretlwe, Sinead, Jonathan Stadler, Phillippe Mayaud, and Helen Rees. 2011. "Investing in the Future: Lessons Learnt from Communicating the Results of HSV/HIV Intervention Trials in South Africa." *Health Research Policy and Systems* 9 (S8): 1–9.
- Denzin, NK, and YS Lincoln, ed. 1998. *Collecting and Interpreting Qualitative Materials*. Thousand Oaks, CA: Sage Publication.
- Dickinson, David. 2007. "Talking About AIDS: A Study of Informal Activities Undertaken by Workplace HIV/AIDS Peer Educators in a South African Company". Johannesburg: University of Witwatersrand, Wits Business School.
- . 2009. *Changing the Course of AIDS: Peer Education in South Africa and Its Lessons for the Global Crisis*. Ithaca: Cornell University Press.
- . 2010a. "Changing the Course of AIDS? Peer Educators and the Challenges of Sexual Norms, Folks Theories, and Social Shame". Inaugural Lecture October 21, University of the Witwatersrand.

- . 2010b. “Whatever I Was Saying, He Came up with His Opinions as Well. Interaction Between HIV/AIDS Peer Educators and Peers: A Grounded Perspective on Horizontal and Vertical Health Communication.” In *Health Communication for International Sexual Health*.
- . 2011. “Myths, Science and Stories: Working with Peer Educators to Counter HIV/AIDS Myths.” *African Journal of AIDS Research* 10 (supplement): 335–344.
- Dickinson, David, and Kabelo Duncan Kgatea. 2008. “They Don’t Want to Listen, You Don’t Want to Pay: Peer Educators and Stress.” *African Journal of AIDS Research* 7 (3): 293–303.
- Dugger, Celia W. 2008. “Study Cites Toll of AIDS Policy in South Africa.” *New York Times*, November 26, 2008 edition. http://www.nytimes.com/2008/11/26/world/africa/26aids.html?_r=2&hp.
- . 2009. “Breaking With Past, South Africa Issues Broad AIDS Policy.” *New York Times*, December 2, 2009 edition. <http://www.tac.org.za/community>.
- . 2010. “In South Africa, an Unlikely Leader on AIDS.” *New York Times*, May 14, 2010 edition. http://www.nytimes.com/2010/05/15/world/africa/15zuma.html?_r=0.
- Duggleby, Wendy. 2005. “What About Focus Group Interaction Data?” *Qualitative Health Research* 15 (6): 832–840.
- Durant, John. 1999. “Participatory Technology Assessment and the Democratic Model of the Public Understanding of Science.” *Science and Public Policy* 26 (5): 313–319.
- Dutcher, Marcia Veronika, Sheila Noely Phicil, Sarah B Goldenkranz, Serena Rajabiun, Julie Franks, Brenda S Loscher, and Natabhona Marianne Mabachi. 2011. “‘Positive Examples’: A Bottom-Up Approach to Identifying Best Practices in HIV Care and Treatment Based on the Experiences of Peer Educators.” *AIDS Patient Care and STDs* 25 (7): 403–411.
- Ecker, U K H, S Lewandowsky, and D T W Tang. 2010. “Explicit Warnings Reduce but Do Not Eliminate the Continued Influence of Misinformation.” *Psychonomic Bulletin and Review* 38: 1087–1100.
- Ellis, Stephen, and Gerrie Ter Haar. 2004. *Worlds of Power: Religious Thought and Political Practice in Africa*. Series in Contemporary History and World Affairs. New York: Oxford University Press.
- Epstein, Steven. 1997. “AIDS Activism and the Retreat from the ‘Genocide’ Frame.” *Social Identities* 3 (3): 415–438.
- Evans-Pritchard, E.E. 1937. *Witchcraft, Oracles and Magic Among the Azande*. Edited by Eva Gillies. Abridged edition 1976. USA: Oxford University Press.
- Fairhead, James, Melissa Leach, and Mary Small. 2006. “Where Techno-science Meets Poverty: Medical Research and the Economy of Blood in The Gambia, West Africa.” *Social Science and Medicine* 63: 1109–1120.
- Farmer, Paul. 1992. *AIDS and Accusation: Haiti and the Geography of Blame*. Berkeley: University of California Press.
- Fassin, Didier. 2002. “Embodied History: Uniqueness and Exemplarity of South African AIDS.” *African Journal of AIDS Research* 1: 63–68.

- . 2007. *When Bodies Remember: Experiences and Politics of AIDS in South Africa*. Berkeley: University of California Press.
- Fassin, Didier, and Helen Schneider. 2003. "The Politics of AIDS in South Africa: Beyond the Controversies." *British Medical Journal* 326: 495–497.
- Fenster, Mark. 1999. *Conspiracy Theories: Secrecy and Power in American Culture*. University of Minnesota Press.
- Fewtrell, Mary, David Wilson, Ian Booth, and Alan Lucas. 2011. "Six Months of Exclusive Breastfeeding: How Good Is the Evidence?" *British Medical Journal* 342 (5955).
- Fine, Gary Alan. 1992. "Rumors of Apartheid: The Ecotypification of Contemporary Legends in the New South Africa." *Journal of Folklore Research* 29: 53–71.
- . 2001. *Difficult Reputations: Collective Memories of the Evil, Inept, and Controversial*. Chicago: University of Chicago Press.
- . 2007. "Rumor, Trust and Civil Society: Collective Memory and Cultures of Judgment." *Diogenes* 213: 5–18.
- Fine, Gary Alan, and KL Sandstrom. 1988. *Knowing Children: Participant Observation with Minors*. Newbury Park, CA: Sage.
- Finlay, A. 2004. "Exposing AIDS: Media's Impact in South Africa." *Communicare* 23 (2).
- Fischer, Frank. 2005. "Are Scientists Irrational? Risk Assessment in Practical Reason." In *Science and Citizens: Globalization and the Challenge of Engagement*, 54–65. Claiming Citizenship: Rights, Participation and Accountability. London: Zed Books.
- Ford, Chandra L, Steven P Wallace, Peter A Newman, and W E Cunningham. 2013. "Belief in AIDS-Related Conspiracy Theories and Mistrust in the Government: Relationship with HIV Testing Among At-Risk Older Adults." *The Gerontologist* Epub ahead of Print (January 28 2013): 1–12.
- Fourie, Pieter. 2006. *The Political Management of HIV and AIDS in South Africa: One Burden Too Many?* Basingstoke, UK: Palgrave Macmillan.
- Freimuth, Vicki S., Sandra Crouse Quinn, Stephen B. Thomas, Galen Cole, Eric Zook, and Ted Duncan. 2001. "African Americans' Views on Research and the Tuskegee Syphilis Study." *Social Science and Medicine* 52: 797–808.
- Fricke, Christel. 1998. "Falsity, Ambiguity, and Metaphors." *Canadian Aesthetics Journal* 2 (Winter): 1–18.
- Fuks, Abraham. 2009. "The Military Metaphors of Modern Medicine" presented at the Conference on Health, Illness and Disease, Oxford, United Kingdom. http://www.inter-disciplinary.net/wp-content/uploads/2009/06/hid_fuks.pdf.
- Fuks, Abraham, Martin Kreiswirth, Donald Boudreau, and Tabitha Sparks. 2011. "Narratives, Metaphors, and the Clinical Relationship." *Genre* 44 (3): 301–313.
- Geary, James. 2011. *I Is an Other: The Secret Life of Metaphor and How It Shapes the Way We See the World*. New York: HarperCollins Publishers.
- Geffen, Nathan. 2005. "Echoes of Lysenko: State-Sponsored Pseudo-Science in South Africa." *Social Dynamics* 31 (2): 183–210.

- . 2009. "Justice After AIDS Denialism: Should There Be Prosecutions and Compensation?" *Journal of Acquired Immune Deficiency Syndrome* 51 (4): 454–455.
- . 2010. *Debunking Delusions: The Inside Story of the Treatment Action Campaign*. Cape Town: Jacana Media.
- Geissler, P Wenzel. 2005. "Kachinja Are Coming! Encounters Around Medical Research Work in a Kenyan Village." *Africa: Journal of the International African Institute* 75 (2): 173–202.
- Geissler, P Wenzel, and R Pool. 2006. "Popular Concerns About Medical Research Projects in sub-Saharan Africa - a Critical Voice in Debates About Medical Research Ethics." *Tropical Medicine and International Health* 11 (7): 975–982.
- Gevisser, Mark. 2007. *Thabo Mbeki: The Dream Deferred*. South Africa: Jonathan Ball Publishers.
- Giddens, Anthony. 1990. *The Consequences of Modernity*. Stanford University Press.
- . 1991. *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Cambridge: Polity Press.
- Gillman, Jason, Jessica Davila, Shubhada Sansgiry, Diana Parkinson-Windross, Nancy Miertschin, Beau Mitts, Charles Henley, and Thomas P Giordano. 2013. "The Effect of Conspiracy Beliefs and Trust on HIV Diagnosis, Linkage, and Retention in Young MSM with HIV." *Journal of Health Care for the Poor and Underserved* 24: 36–45.
- Gilson, Lucy. 2003. "Trust and the Development of Health Care as a Social Institution." *Social Science and Medicine* 56: 1453–1468.
- Gladwell, Malcolm. 2000. *The Tipping Point: How Little Things Can Make a Big Difference*. Little Brown.
- Glaser, Barney G. 2002. "Conceptualization: On Theory and Theorizing Using Grounded Theory." *International Journal of Qualitative Methods* 1: 23–38.
- Golafshani, Nahid. 2003. "Understanding Reliability and Validity in Qualitative Research." *The Qualitative Report* 8 (4): 597–607.
- Goldacre, Ben. 2010. *Bad Science: Quacks, Hacks, and Big Pharma Flacks*. New York: Faber and Faber Inc.
- Goldstein, Diane E. 2004. *Once Upon a Virus: AIDS Legends and Vernacular Risk Perception*. Utah: Utah State University Press.
- Golin, Carol E, Jo Anne Earp, Catherine A Grodensky, Shilpa N Patel, Chirayath Suchindran, Megha Parikh, Seth Kalichman, et al. 2012. "Longitudinal Effects of Safe Talk, a Motivational Interviewing-Based Program to Improve Safer Sex Practices Among People Living with HIV/AIDS." *AIDS and Behavior* 16: 1182–1191.
- Google Maps. 2013. "Khayelitsha, Western Cape."
- Goritz, Anja S. 2008. "The Long-Term Effects of Material Incentives on Participation in Online Panels." *Field Methods* 20 (3): 211–225.
- Gould, Chandre. 2005. "South Africa's Chemical and Biological Warfare Programme 1981-1995". Doctoral Thesis, South Africa: Rhodes University.

- Gould, Chandre, and Peter I Folb. 2002. *Project Coast: Apartheid's Chemical and Biological Warfare Programme*. Edited by Robert Berold. Geneva: United Nations Publications UNIDIR.
- Gray, Matthew. 2008. "Explaining Conspiracy Theories in Modern Arab Middle Eastern Political Discourse: Some Problems and Limitations of the Literature." *Critique: Critical Middle Eastern Studies* 17 (2): 155–174.
- Grebe, Eduard. 2011. "The Treatment Action Campaign's Struggle for AIDS Treatment in South Africa: Coalition-building Through Networks." *Journal of Southern African Studies* 37 (4): 849–868.
- Grebe, Eduard, and Nicoli Nattrass. 2012. "AIDS Conspiracy Beliefs and Unsafe Sex in Cape Town." *AIDS and Behavior* 16: 761–773.
- Green, E C. 1996. "Purity, Pollution and the Invisible Snake in Southern Africa." *Medical Anthropology* 17 (1): 83–100.
- Grothe, D J. 2013. "Let the Best Ideas Win: Should Skeptics Engage Conspiracy Theorists Directly?" *Conspiracy Check*.
<http://conspiracycheck.net/2013/02/26/let-the-best-ideas-win-sh>.
- Guardian Reporter. 2013. "Child Born with HIV Seemingly Cured by US Doctors." *Mail and Guardian*, March 4. <http://mg.co.za/article/2013-03-04-child-born-with-hiv-seemingly-cured-by-us-doctors>.
- Gumede, William Mervin. 2005. *Thabo Mbeki and the Battle for the Soul of the ANC*. Cape Town, South Africa: Zebra Press.
- Hardin, Russell. 1992. "The Street-Level Epistemology of Trust." *Analyse and Kritik* 14: 152–176.
- Harvey, Marjolein. 2000. "How Can a Virus Cause a Syndrome? Asks Mbeki." *AIDS Education Global Information System (AEGIS)*.
<http://www.aegis.org/DisplayContent/?SectionID=370502>.
- Health Council of Canada. 2012. "Empathy, Dignity, and Respect: Creating Cultural Safety for Aboriginal People in Urban Health Care". Toronto: Health Council of Canada.
- Herek, Gregory M, and John P Capitanio. 1994. "Conspiracies, Contagion, and Compassion: Trust and Public Reactions to AIDS." *AIDS Education and Prevention* 6 (4): 365–375.
- Hesse, B.W., D.D. Nelson, G.L. Kreps, R.T. Croyle, N.K. Arora, and K.Viswanath. 2005. "Trust and Sources of Health Information: The Impact of the Internet and Its Implications for Health Care Providers: Findings from the First Health Information National Trends Survey." *Archives of Internal Medicine* 165: 2618–2624.
- Heywood, Mark. 2009. "South Africa's Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health." *Journal of Human Rights Practice* 1 (1): 14–36.
- Hitchens, Christopher. 1991. "On the Imagining of Conspiracy." *London Review of Books*.
- Hlongwane, Siphon. 2010. "Mbeki's Mistakes Will Be His Lasting Legacy." *Daily Maverick*, 18 October 2010 edition.
<http://www.dailymaverick.co.za/opinionista/2010-10-18-mbekis-mistakes-will-be-his-lasting-legacy/#.UXevYUT74b0>.

- Hofstadter, Richard. 1965. *The Paranoid Style in American Politics and Other Essays*. New York: Knopf.
- Hoyt, Michael A., Carol J. Nemeroff, David M. Huebner, Lisa R. Rubin, Joyce Lee, and Rae Jean Proeschold-Bell. 2011. "HIV/AIDS-Related Institutional Mistrust Among Multiethnic Men Who Have Sex With Men: Effects on HIV Testing and Risk Behaviors." *Health Psychology*.
- Hutchings, Deanna. 1998. "Communicating with Metaphor: A Dance with Many Veils." *American Journal of Hospice and Palliative Medicine* 15 (5): 282–284.
- Hutchinson, Angela B., Elin B Begley, Patrick DVM Sullivan, Hollie A. Clark, Brian C Boyett, and Scott E Kellerman. 2007. "Conspiracy Beliefs and Trust in Information About HIV/AIDS Among Minority Men Who Have Sex with Men." *Journal of Acquired Immune Deficiency Syndrome* 45: 603–605. doi:Letter to the Editor.
- IBM Corp. 2010. *SPSS Statistics for Mac*. Armonk NY: IBM Corporation.
- Illife, John. 2006. *The African AIDS Epidemic: A History*. Cape Town, South Africa: James Currey and Double Storey.
- IRIN News. 2011. "HIV-positive Women Still Confused About Infant-feeding Choices." <http://www.plusnews.org/report.aspx?ReportID=94432>.
- Irwin, Alan, and Brian Wynne. 1996. *Misunderstanding Science? The Public Reconstruction of Science and Technology*. Cambridge: Cambridge University Press.
- Ivankova, Nataliya V, John W Creswell, and Sheldon L Stick. 2006. "Using Mixed-Methods Sequential Explanatory Design: From Theory to Practice." *Field Methods* 18 (1): 3–20.
- James, Deborah. 2002. "'To Take the Information down to the People': Life Skills and HIV/AIDS Peer Educators in the Durban Area." *African Studies* 61 (1): 169–191.
- Jenkins, R K B, A Keane, A R Rakotoarivelo, V Rakotomboavonjy, F H Randrianadrianina, H Julie Razafimanahaka, S R Ralalarimalala, and Julia P G Jones. 2011. "Analysis of Patterns of Bushmeat Consumption Reveals Extensive Exploitation of Protected Species in Eastern Madagascar." *PLoS ONE* 6 (12): e27570.
- Johnson, Krista. 2004. "The Politics of AIDS Policy Development and Implementation in Postapartheid South Africa." *Africa Today* 51 (2): 107–128.
- Johnson, T J, S Bichard, and W Zhang. 2009. "Communication Communities or 'Cyberghettos?': A Path Analysis Model Examining Factors That Explain Selective Exposure to Blogs." *Journal of Computer-Mediated Communication* 15: 60–82.
- Jones, J. 1981. *Bad Blood: The Tuskegee Syphilis Experiment - A Tragedy of Race and Medicine*. New York: The Free Press.
- Jones, P. 2005. "'A Test of Governance': Rights-based Struggles and the Politics of HIV/AIDS Policy in South Africa." *Political Geography* 24: 419–447.
- Kaler, Amy. 2004. "The Moral Lens of Population Control: Condoms and Controversies in Southern Malawi." *Studies in Family Planning* 35: 105–115. doi:Qualitative Anthropological Study.

- . 2009. "Health Interventions and the Persistence of Rumour: The Circulation of Sterility Stories in African Public Health Campaigns." *Social Science and Medicine* 68: 1711–9.
- Kalichman, Seth C, Lisa Eaton, and Chauncey Cherry. 2010. "'There Is No Proof That HIV Causes AIDS': AIDS Denialism Beliefs Among People Living with HIV/AIDS." *Journal of Behavioral Medicine* 33: 432–440.
- Kata, Anna. 2010. "A Postmodern Pandora's Box: Anti-vaccination Misinformation on the Internet." *Vaccine* 28: 1709–1716.
- Keeley, Brian L. 1999. "Of Conspiracy Theories." *The Journal of Philosophy* 96 (3): 109–126.
- Kelly, J.A., A.M. Somlai, E.G. Benotsch, Y.A. Amirhanian, M.I. Fernandez, L.Y. Stevenson, C.A. Sitzler, T.L. McAuliffe, K.D. Brown, and K.M. Opgenorth. 2006. "Programmes, Resources, and Needs of HIV-prevention Non-governmental Organizations (NGOs) in Africa, Central/Eastern Europe and Central Asia, Latin America and the Caribbean." *AIDS Care* 18 (1): 12–21.
- Kenyon, Chris. 2006. "The Origins, Evolution and Outsourcing of Denialism." *The Southern African Journal of HIV Medicine* 7 (4): 15–16.
- . 2008. "Cognitive Dissonance as an Explanation of the Genesis, Evolution and Persistence of Thabo Mbeki's HIV Denialism." *African Journal of AIDS Research* 7 (1): 29–35.
- Kirklín, D. 2007. "Truth Telling, Autonomy and the Role of Metaphor." *Journal of Medical Ethics* 33: 11–14.
- Kitzinger, Jenny. 1994. "The Methodology of Focus Groups: The Importance of Interaction Between Research Participants." *Sociology of Health and Illness* 16 (1): 103–121.
- Knight, Peter. 2002. "Introduction: A Nation of Conspiracy Theorists." In *Conspiracy Nation: The Politics of Paranoia in Post-war America*, edited by Peter Knight. New York: New York University Press.
- Knox, Hannah. 2005. "Imitative Participation and the Politics of 'Joining in': Paid Work as a Methodological Issue." *Anthropology Matters* 7 (1): 1–9.
- Kormos, Rebecca, Christophe Boesch, Mohamed I Bakarr, and Thomas M Butynski. 2003. "Status Survey and Conservation Action Plan: West African Chimpanzees". IUCN/SSC Primate Specialist Group: The World Conservation Union (IUCN).
- Kramer, Larry. 2011. "Please Know". The Normal Heart on Broadway. New York, NY.
- Kramer, Roderick M. 1999. "Trust and Distrust in Organizations: Emerging Perspectives, Enduring Questions." *Annual Review of Psychology* 50: 569–598.
- Krieger, Janice L, Roxanne L Parrott, and Jon F Nussbaum. 2011. "Metaphor Use and Health Literacy: A Pilot Study of Strategies to Explain Randomization in Cancer Clinical Trials." *Journal of Health Communication* 16: 3–16.
- Kroeger, Karen. 2003. "AIDS Rumors, Imaginary Enemies, and the Body Politic in Indonesia." *American Ethnologist* 30: 243–257.
- Lain, M A, M Valverde, and L M Frehill. 2007. "Late Entry into HIV/AIDS Medical Care: The Importance of Past Relationships with Medical Providers." *AIDS Care* 19 (2): 190–194.

- Lakoff, George, and Mark Johnson. 1980. *Metaphors We Live By*. Chicago: University of Chicago Press.
- Larson, Heidi, Louis Z. Cooper, Juhani Eskola, Samuel L. Katz, and Scott Ratzan. 2011. "Addressing the Vaccine Confidence Gap." *The Lancet* 6736 (11): 60678–8.
- Larson, Heidi, and Isaac Ghinai. 2011. "Lessons from Polio Eradication." *Nature* 473 (26 May 2011): 446–447.
- Larson, Heidi, and David L Heymann. 2010. "Public Health Response to Influenza A (H1N1) as an Opportunity to Build Public Trust." *Journal of the American Medical Association* 303 (3): 271–272.
- Larson, Heidi, Pauline Brocard Paterson, and Ngozi Erondu. 2012. "The Globalization of Risk and Risk Perception." *Drug Safety* 35 (11): 1053–1059.
- Leach, Melissa. 2007. "Accommodating Dissent." *Nature* 450 (22 November 2007): 483.
- Leask, Julie, and Peter McIntyre. 2003. "Public Opponents of Vaccination: a Case Study." *Vaccine* 21: 4700–4703.
- Lennon, C, and S Kalichman. 2012. "The Relationship Between Endorsement of HIV/AIDS Conspiracy Beliefs, HIV Stigma and HIV Prevention in South Africa." In *19th International AIDS Conference*. Washington, DC: THPE432 - Poster Exhibition.
- Lewandowsky, Stephan, John Cook, Klaus Oberauer, and Michael Marriott. 2013. "Recursive Fury: Conspiracist Ideation in the Blogosphere in Response to Research on Conspiracist Ideation." *Frontiers in Psychology* 4 (73): 1–15.
- Lewandowsky, Stephan, Ullrich K H Ecker, Colleen M Seifert, Norbert Schwarz, and John Cook. 2012. "Misinformation and Its Correction: Continued Influence and Successful Debiasing." *Psychological Science in the Public Interest* 13 (3): 106–131.
- Lipkus, I M, and E Peters. 2009. "Framework and Practical Insights Understanding the Role of Numeracy in Health: Proposed Theoretical Insights." *Health Education and Behavior* 36: 1065–1081.
- Luhmann, N. 2000. "Familiarity, Confidence and Trust Problems and Alternatives." In *Trust: Making and Breaking Cooperative Relations*, edited by D Gambetta, 94–107. Oxford: University of Oxford.
- Lyotard, J. 1984. *The Postmodern Condition: A Report on Knowledge*. Minneapolis: University of Minneapolis Press.
- Macdonald, Mary Ellen, Nicole Rigillo, and Paul Brassard. 2010. "Urban Aboriginal Understandings and Experiences of Tuberculosis in Montreal, Quebec, Canada." *Qualitative Health Research* 20 (4): 506–523.
- Mackenzie, Sonja. 2011. "Dissecting the Social Body: Social Inequality through AIDS Counter-narratives." *Public Understandings of Science* 20 (4): 491–505.
- Mail and Guardian. 2013. "Child Born with HIV Seemingly Cured by US Doctors." *Mail and Guardian*, 4 March 2013 edition. <http://mg.co.za/article/2013-03-04-child-born-with-hiv-seemingly-cured-by-us-doctors>.
- Makhubu, Ntando. 2010. "Babies at Risk If Milk Formula Cut." *Times Live*, December 6. <http://www.timeslive.co.za/local/article801523.ece/Babies-at-risk-if-milk-formula-cut>.

- Makongoza, M, J Dietrich, B Nkala, S Kanters, C Tshabalala, R Hogg, A Kaida, G Gray, and C Miller. 2012. "Determinants and Knowledge of the Origin of AIDS Among Adolescents in South Africa." In *19th International AIDS Conference*. Washington, DC: THPE357 - Poster Exhibition.
- Malan, Mia. 2013. "Household Survey: HIV Prevalence Increases." *Mail and Guardian*, 20 June 2013 edition. <http://mg.co.za/article/2013-06-20-household-survey-hiv-prevalence-increases>.
- Marable, Manning. 2009. "Racializing Obama: The Enigma of Post-Black Politics and Leadership." *Souls* 11 (1): 1–15.
- Marcus, George E. 1999. "Introduction to the Volume: The Paranoid Style Now." In *Paranoia Within Reason: a Casebook on Conspiracy as Explanation*, edited by George E. Marcus. Chicago: University of Chicago Press.
- Marks, Shula. 2002. "An Epidemic Waiting to Happen? The Spread of HIV/AIDS in South Africa in Social and Historical Perspective." *African Studies* 61 (1): 13–26.
- Maynard, M, and J Purvis. 1994. "Introduction: Doing Feminist Research." In *Research Women's Lives from a Feminist Perspective*, edited by M Maynard and J Purvis, 1–9. London: Taylor and Francis.
- Mayosi, Bongani M, Joy E Lawn, Ashley van Niekerk, Debbie Bradshaw, Salim S Abdool Karim, Hoosen M Coovadia, and The Lancet South Africa team. 2012. "Health in South Africa: Changes and Challenges Since 2009." *The Lancet* 380 (November 30, 2012): 2029–2043.
- Mbali, Mandisa. 2002. "Mbeki's Denialism and The Ghosts of Apartheid and Colonialism for Post-apartheid AIDS Policy-making." In *Public Health Journal Club Seminar Paper*. Vol. May 3, 2002. University of Natal, Durban.
- . 2004. "AIDS Discourses and the South African State: Government Denialism and Post-apartheid AIDS Policy-making." *Transformation: Critical Perspectives on Southern Africa* 54: 104–122.
- McCallum, Jan M, Dhananjaya M Arekere, B Lee Green, Ralph V Katz, and Brian M Rivers. 2006. "Awareness and Knowledge of the U.S. Public Health Service Syphilis Study at Tuskegee: Implication for Biomedical Research." *Journal of Health Care for the Poor and Underserved* 17: 716–733.
- Mcetywa, Mfundo. 2006. "Bhengu Funeral Turns into Aids Slanging Match." *IOL News*, May 28 2006 edition. <http://www.iol.co.za/news/south-africa/bhengu-funeral-turns-into-aids-slanging-match-1.279382>.
- McKee, Martin, and Pascal Diethelm. 2010. "How the Growth of Denialism Undermines Public Health." *British Medical Journal* 341 (18-25 December 2010): 1309–1311.
- McKirnan, David J., Marina Tolou-Shams, and Cari Courtenay-Quirk. 2010. "The Treatment Advocacy Program: A Randomized Controlled Trial of a Peer-Led Safer Sex Intervention for HIV-Infected Men Who Have Sex With Men." *Journal of Consulting and Clinical Psychology* 78 (6): 952–063.
- McNeill, Fraser G. 2009. "'Condoms Cause AIDS': Poison, Prevention and Denial in Venda, South Africa." *African Affairs* 108 (432): 353–370.
- Medley, Amy, Caitlin Kennedy, Kevin O'Reilly, and Michael Sweat. 2009. "Effectiveness of Peer Education Interventions for HIV Prevention in

- Developing Countries: a Systematic Review and Meta-analysis." *AIDS Education and Prevention* 21 (3): 181–206.
- Michael, Mike. 2002. "Comprehension, Apprehension, Prehension: Heterogeneity and the Public Understanding of Science." *Science, Technology and Human Values* 27 (3): 357–378.
- Miller, Steve. 2001. "Public Understanding of Science at the Crossroads." *Public Understanding of Science* 10: 115–120.
- Miller, W R, and S Rollnick. 2002. *Motivational Interviewing: Preparing People for Change*. 2nd ed. Guilford Press.
- Miller, W R, A Zweben, C C DiClemente, and R G Rychtarik. 1992. *Motivational Enhancement Therapy Manual: A Clinical Research Guide for Therapists Treating Individuals with Alcohol Abuse and Dependence*. Rockville, MD: National Institute on Alcohol Abuse and Alcoholism.
- Misztal, B A. 1996. *Trust in Modern Societies: The Search for the Bases of Moral Order*. Cambridge: Polity Press.
- Mitchell, Shannon Gwin, James A Peterson, and Carl A Latkin. 2006. "The Impact of Drug Use on Perceptions of Credibility in Indigenous Outreach Workers." *Qualitative Health Research* 16 (8): 1108–1119.
- Mollering, G. 2001. "The Nature of Trust: From Georg Simmel to a Theory of Expectation, Interpretation and Suspension." *Sociology* 35 (2): 403–420.
- Morgan, David L. 2007. "Paradigms Lost and Pragmatism Regained: Methodological Implications of Combining Qualitative and Quantitative Methods." *Journal of Mixed Methods Research* 1: 48–76.
- Morozov, Evgeny. 2012. "Anti-vaccine Activists, 9/11 Deniers, and Google's Social Search." *Slate Magazine*.
http://www.slate.com/articles/technology/future_tense/2012/01/anti_vaccine_activists_9_11_deniers_and_google_s_social_search.html.
- Mouton, Schalk. 2009. "Malema Springs to Mbeki's Defence." *The Mail and Guardian*, 17 November 2009 edition. <http://mg.co.za/article/2009-11-17-malema-springs-to-mbekis-defence>.
- Mthathi, Siphon. 2006. "Science and Human Rights." *Equal Treatment*.
- Nations, Marilyn K., and Cristina M.G. Monte. 1996. "'I'm Not Dog, No!': Cries of Resistance Against Cholera Control Campaigns." *Social Science and Medicine* 43 (6): 1007–1024.
- Nattrass, Nicoli. 2007. *Mortal Combat: AIDS Denialism and the Struggle for Antiretrovirals in South Africa*. South Africa: University of KwaZulu Natal Press.
- . 2008. "AIDS and the Scientific Governance of Medicine in Post-Apartheid South Africa." *African Affairs* 107 (427): 157–176.
- . 2012a. *The AIDS Conspiracy: Science Fights Back*. New York: Columbia University Press.
- . 2012b. "How Bad Ideas Gain Social Traction." *The Lancet* 380 (July 28, 2012): 332–333.
- . 2013. "Understanding the Origins and Prevalence of AIDS Conspiracy Beliefs in the United States and South Africa." *Sociology of Health and Illness* 35 (1): 113–129.

- Nelson, Jessica T, Glenn Adams, Nyla R Branscombe, and Michael T Schmitt. 2010. "The Role of Historical Knowledge in Perception of Race-Based Conspiracies." *Race and Social Problems* 2: 69–80.
- Nerlich, Andreas G, Christian J Haas, Albert Zink, Ulrike Szeimies, and Hjalmar G Hagedorn. 1997. "Molecular Evidence for Tuberculosis in an Ancient Egyptian Mummy." *The Lancet* 350 (9088): 1404.
- Nichter, Mark. 2008. *Global Health: Why Cultural Perceptions, Social Representations, and Biopolitics Matter*. University of Arizona Press.
- Niehaus, Isak, and Gunvor Jonsson. 2005. "Dr. Wouter Basson, Americans and Wild Beasts: Men's Conspiracy Theories of HIV/AIDS in the South African Lowveld." *Medical Anthropology* 24: 177–206.
- Nolan, Stephanie. 2007. *28: Stories of AIDS in Africa*. London: Portobello Books.
- Obama, Barack. 2008. "A More Perfect Union" March 18, Philadelphia, Pennsylvania.
- Papageorgis, D, and W J McGuire. 1961. "The Generality of Immunity to Persuasion Produced by Pre-exposure to Weakened Counterarguments." *Journal of Abnormal and Social Psychology* 62: 475–481.
- Parker, Melissa, and Tim Allen. 2011. "Does Mass Drug Administration for the Integrated Treatment of Neglected Tropical Diseases Really Work? Assessing Evidence for the Control of Schistosomiasis and Soil-transmitted Helminths in Uganda." *Health Research Policy and Systems* 9 (3): 1–20.
- Parsons, Jeffrey, Elena Rosof, Joseph Punzalan, and Lauren Di Maria. 2005. "Integration of Motivational Interviewing and Cognitive Behavioral Therapy to Improve HIV Medication Adherence and Reduce Substance Use Among HIV-Positive Men and Women: Results of a Pilot Project." *AIDS Patient Care and STDs* 19 (1): 31–39.
- Parsons, Sharon, William Simmons, Frankie Shinhoster, and John Kilburn. 1999. "A Test of the Grapevine: An Empirical Examination of Conspiracy Theories Among African Americans." *Sociological Spectrum* 19: 201–222.
- Pepin, Jacques. 2011. *The Origins of AIDS*. Cambridge: Cambridge University Press.
- Periyakoil, Vyjeyanthi S. 2008. "Using Metaphors in Medicine." *Journal of Palliative Medicine* 11 (6): 842–844.
- PlusNews. 2010. "Africa: Leaders Go Public with the Test." *PlusNews: Global HIV/AIDS News and Analysis*.
<http://www.plusnews.org/Report.aspx?ReportId=89005>.
- Porter, SR, and ME Whitcomb. 2003. "The Impact of Lottery Incentives on Student Survey Response Rates." *Research in Higher Education* 44 (4): 389–407.
- Posel, Deborah. 2005. "Sex, Death and the Fate of the Nation: Reflections on the Politicization of Sexuality in Post-Apartheid South Africa." *Africa: Journal of the International African Institute* 75 (2): 125–153.
- Posel, Deborah, Kathleen Kahn, and Liz Walker. 2007. "Living with Death in a Time of AIDS: A Rural South African Case Study." *Scandinavian Journal of Public Health* 35 (Suppl 69): 138–146.
- Power, S. 2003. "The AIDS Rebel: Letter from South Africa." *The New Yorker*.
- Racey, C Sarai, Wendy Zhang, Eirikka K Brandson, Kimberly A Fernandes, Despina Tsemis, P Richard Harrigan, Julio S Montaner, Rolando Barrios, and Robert S

- Hogg, 2010. "HIV Antiviral Drug Resistance: Patient Comprehension." *AIDS Care* 22 (7): 816–926.
- Reisfield, Gary M, and George R Wilson. 2004. "Use of Metaphor in the Discourse on Cancer." *Journal of Clinical Oncology* 22 (19): 4024–4027.
- Republic of South Africa. *Debates of Parliament 1990*. Cape Town: Government Printer.
- Rhodes, Lorna Amarasingham. 1984. "'This Will Clear Your Mind': The Use of Metaphors for Medication in Psychiatric Settings." *Culture, Medicine and Psychiatry* 8: 49–70.
- Rice, Ronald E. 1993. "Using Network Concepts to Clarify Sources and Mechanisms of Social Influence." In *Progress in Communication Science*, W.D. Richards and G.A. Barnett. Vol. 12. Norwood, NJ: Ablex.
- Richey, Lisa Ann. 2008. "Science, Denial and Politics: 'Boundary Work' in the Provision of AIDS Treatment in South Africa." *New Political Science* 30: 1–21.
- Roberts, Kathleen Johnston, Peter A Newman, Naihua Duan, and Ellen T Rudy. 2005. "HIV Vaccine Knowledge and Beliefs Among Communities at Elevated Risk: Conspiracies, Questions and Confusion." *Journal of the National Medical Association* 97 (12): 1662–1671.
- Roberts, Ronald Suresh. 2008. *Fit to Govern: The Native Intelligence of Thabo Mbeki*. Real African Publishers.
- Robins, Steven. 2004. "'Long Live Zackie, Long Live': AIDS Activism, Science and Citizenship after Apartheid." *Journal of Southern African Studies* 30 (3): 651–672.
- . 2005. "AIDS, Science and Citizenship after Apartheid." In *Science and Citizens: Globalization and the Challenge of Engagement*, 113–129. Claiming Citizenship: Rights, Participation and Accountability. London: Zed Books.
- . 2008. "Sexual Politics and the Zuma Rape Trial." *Journal of Southern African Studies* 34 (2): 411–427.
- . 2009a. "End of Aids Denial Era a Chance to Move Forward." *The Cape Times*, 24 December 2009 edition.
- . 2009b. "Foot Soldiers of Global Health: Teaching and Preaching AIDS Science and Modern Medicine on the Frontline." *Medical Anthropology* 28 (1): 81–107.
- . 2009c. "Mobilising and Mediating Global Medicine and Health Citizenship: The Politics of AIDS Knowledge Production in Rural South Africa". Working Paper Number 324. Sussex: Institute of Development Studies.
- Robinson, Paul. 1989. "'AIDS and Its Metaphors'." *The New York Times*, January 22.
- Rochon, Donna, Michael W Ross, Carol Looney, Vishnu P Nepal, Andrea J Price, and Thomas P Giordano. 2011. "Communication Strategies to Improve HIV Treatment Adherence." *Health Communication* 26: 461–467.
- Rodlach, Alexander. 2006. *Witches, Westerners, and HIV: AIDS and Cultures of Blame in Africa*. Walnut Creek California: Left Coast Press.
- Ross, Michael W., E. James Essien, and I Torres. 2006. "Conspiracy Beliefs About the Origin of HIV/AIDS in Four Racial/Ethnic Groups." *Journal of Acquired Immune Deficiency Syndrome* 41: 342–344.

- Rothman, David J. 2000. "The Shame of Medical Research." *The New York Review of Books*, November 30.
- Rubincam, Clara. 2008. "Managing Conspiracy Theories in Public Health: Ensuring That Voice Does Not Lead to Exit". Working Paper No. 88. London School of Economics.
- Russell, Stefanie L, Ralph V Katz, Min Qi Wang, Ryan Lee, B Lee Green, Nancy R Kressin, and Cristina Claudio. 2011. "Belief in AIDS Origin Conspiracy Theory and Willingness to Participate in Biomedical Research Studies: Findings in Whites, Blacks, and Hispanics in Seven Cities Across Two Surveys." *HIV Clinical Trials* 12 (1): 37–47.
- Sabatier, Renee. 1988. *Blaming Others: Prejudice, Race and Worldwide AIDS*. Washington: The Panos Institute.
- Saethre, Eirik, and Jonathan Stadler. 2013. "Malicious Whites, Greedy Women, and Virtuous Volunteers." *Medical Anthropology Quarterly* 27 (1): 103–120.
- Saha, Somnath, Elizabeth A. Jacobs, Richard D. Moore, and Mary Catherine Beach. 2010. "Trust in Physicians and Racial Disparities in HIV Care." *AIDS Patient* 24 (7).
- Sanders, Todd. 2003. "Imagining the Dark Continent: The Met, The Media, and the Thames Torso." *Cambridge Anthropology* 23: 53–66.
- Sanders, Todd, and Harry West. 2003. "Power Revealed and Concealed in the New World Order." In *Transparency and Conspiracy: Ethnographies of Suspicion in the New World Order*, edited by Todd Sanders and Harry West, 1–37. Durham: Duke University Press.
- Sasson, Theodore. 1995. "African American Conspiracy Theories and the Social Construction of Crime." *Sociological Inquiry* 65 (3/4): 265–285.
- Scheper-Hughes, Nancy. 1996. "Theft of Life: The Globalization of Organ Stealing Rumours." *Anthropology Today* 12 (3): 3–11.
- . 2000. "The Global Traffic in Human Organs." *Current Anthropology* 41 (2): 191–224.
- Scheyvens, Regina, and Donovan Storey, ed. 2003. *Development Fieldwork: A Practical Guide*. London: Sage Publications.
- Schoofs, Mark. 2000. "Flirting with Pseudoscience." *Village Voice*, March 21, 2000 edition, sec. 56.
- Seekings, Jeremy. 2007. "Race, Discrimination and Diversity in South Africa". CSSR Working Paper No. 194. Cape Town.
- Shisana, O, T Rehle, L C Simba, S Jooste, V Pillay-Van Wyk, N Mbelle, J Van Zyl, et al. 2009. "South African National Prevalence, Incidence, Behaviour and Communication Survey 2008: A Turning Tide Among Teenagers?" Cape Town: HSRC Press.
- Simmons, William, and Sharon Parsons. 2005. "Beliefs in Conspiracy Theories Among African Americans: A Comparison of Elites and Masses." *Social Science Quarterly* 86 (3): 582–598.
- Skinner, D, S C Kalichman, K J Sikkema, M H Watt, L Bogart, and D Pieterse. 2012. "HIV-related Conspiracy Theories Need to Be a Focus of HIV Interventions: Evidence from Cape Town, South Africa." In *19th International AIDS Conference*. Washington, DC: THPE508 - Poster Exhibition.

- Slonim-Nevo, Vered, and Isaac Nevo. 2009. "Conflicting Findings in Mixed Methods Research: An Illustration from an Israeli Study on Immigration." *Journal of Mixed Methods Research* 3: 109–128.
- Smith, Tara C, and Steven P Novella. 2007. "HIV Denial in the Internet Era." *PLoS Medicine* 4 (8): 1312–1316.
- Sontag, Susan. 2001. *Illness as Metaphor and AIDS and Its Metaphors*. New York: Picador USA.
- Sopory, Pradeep, and James Price Dillard. 2002. "The Persuasive Effects of Metaphor: A Meta-Analysis." *Human Communication Research* 28 (3): 382–419.
- South Africa Municipal Demarcation Board. 2013. "Khayelitsha Within South Africa". Wikipedia. <http://en.wikipedia.org/wiki/Khayelitsha>.
- South African MRC. 2007. "What Is the Impact of HIV/AIDS in South Africa?" *Medical Research Council*. <http://www.mrc.ac.za/bod/faq aids.htm>.
- Sparks, Allister. 2003. *Beyond the Miracle: Inside the New South Africa*. South Africa: Jonathan Ball Publishers.
- Standing, H., and A. Mushtaque R. Chowdhury. 2008. "Producing Effective Knowledge Agents in a Pluralistic Environment: What Future for Community Health Workers?" *Social Science and Medicine* 66: 2096–2107.
- Statistics South Africa. 2012. "Census 2011: Census in Brief". Pretoria: Statistics South Africa.
- Steinberg, Jonny. 2007a. "When Aids Treatment Is Viewed as Collective Racial Humiliation." *Business Day*, 2 July 2007 edition.
- . 2007b. "Anthropology of Low Expectations." *Business Day*, 5 June 2007 edition.
- . 2008a. *Three Letter Plague*. South Africa: Jonathan Ball.
- . 2008b. "Aids and Aids Treatment in a Rural South African Setting". Monograph 149. Institute for Security Studies.
- . 2011. "HIV/AIDS in Africa and Beyond: The Story the Media Missed" Northwestern University, Evanston, Illinois. <http://www.youtube.com/watch?v=6m9GtMushn8>.
- . 2013. "Apartheid Past Still Resonates with 'Born Frees'." *Business Day*, April 18. <http://www.bdlive.co.za/opinion/2013/04/18/apartheid-past-still-resonates-with-born-frees>.
- Stewart, Kathleen. 1999. "Conspiracy Theory's Worlds". University of Chicago Press.
- Strauss, A, and J Corbin. 1990. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Newbury Park, CA: Sage.
- Suite, Derek H, Robert La Bril, Anelle Primm, and Phyllis Harrison-Ross. 2007. "Beyond Misdiagnosis, Misunderstanding and Mistrust: Relevance of the Historical Perspective in the Medical and Mental Health Treatment of People of Color." *Journal of the National Medical Association* 99 (8): 879–885.
- Sunstein, Cass R., and Adrian Vermeule. 2009. "Conspiracy Theories: Causes and Cures." *The Journal of Political Philosophy* 17 (2): 202–227.
- Swami, Viren, Tomas Chamorro-Premuzic, and Adrian Furnham. 2010. "Unanswered Questions: A Preliminary Investigation of Personality and Individual

- Difference Predictors of 9/11 Conspiracist Beliefs." *Applied Cognitive Psychology* 24: 749–761.
- Swami, Viren, Rebecca Coles, Stefan Stieger, Jakob Pietschnig, Adrian Furnham, Sherry Rehim, and Martin Voracek. 2011. "Conspiracist Ideation in Britain and Austria: Evidence of a Monological Belief System and Associations Between Individual Psychological Differences and Real-world and Fictitious Conspiracy Theories." *British Journal of Psychology* 102: 443–463.
- TAC. 2009a. "Landmark Speech by President Zuma." *TAC Community Blog*. <http://www.tac.org.za/community>.
- . 2009b. "About TAC's Community Health Advocacy Programme." *Treatment Action Campaign*. <http://www.tac.org.za/community/about/cha>.
- . 2010. "Pregnancy in Our Lives."
- Tashakkori, Abbas, and John W Creswell. 2007. "Exploring the Nature of Research Questions in Mixed Methods Research." *Journal of Mixed Methods* 1 (3): 207–211.
- Teddlie, C, and A Tashakkori. 2008. *Foundations of Mixed Methods Research: Integrating Quantitative and Qualitative Techniques in the Social and Behavioral Sciences*. Thousand Oaks, CA: Sage Publications.
- Terblanche, Stef. 2012. "Out of Africa: HIV, Colonialism's Gift to the World." *Out of Africa*, March 19. <http://www.leadershiponline.co.za/articles/other/1861-out-of-africa>.
- Terry-Smith, Justin B. 2012. "Just*In Time: July 2012." *A&U America's AIDS Magazine*. <http://aumag.org/wordpress/2012/07/20/justin-time-july-2012/>.
- The Economist. 2004. "Kenya's Nobel Laureate: The Woman Who Planted Trees." *The Economist*, October 14, 2004 edition.
- Thierer, Adam. 2012. "Do We Need a Ministry of Truth for the Internet?" *Forbes*. <http://www.forbes.com/sites/adamthierer/2012/01/29/do-we-need-a-ministry-of-truth-for-the-internet/>.
- Thomas, Stephen B, and Sandra Crouse Quinn. 1993. "The Burdens of Race and History on Black Americans' Attitudes Toward Needle Exchange Policy to Prevent HIV Disease." *Journal of Public Health Policy* 14 (3): 320–347.
- Thomas, Stephen B, and James W Curran. 1999. "Tuskegee: From Science to Conspiracy to Metaphor." *The American Journal of the Medical Sciences* 317 (1): 1–4.
- Thomas, Stephen B., and Sandra C. Quinn. 1991. "Public Health Then and Now: The Tuskegee Syphilis Study, 1932-1972: Implications for HIV Education and AIDS Risk Education Programs in the Black Community." *American Journal of Public Health* 81: 1498–1505.
- Thompson, Damien. 2008. *Counterknowledge: How We Surrendered to Conspiracy Theories, Quack Medicine, Bogus Science, and Fake History*. London: Atlantic Books.
- Thrasher, Angela D., Jo Anne L. Earp, and Carol E. Golin. 2008. "Discrimination, Distrust and Racial/Ethnic Disparities in Antiretroviral Therapy Adherence Among a National Sample of HIV-Infected Patients." *Journal of Acquired Immune Deficiency Syndrome* 49: 84–93.

- Timberg, Craig, and Daniel Halperin. 2012. *Tinderbox: How the West Sparked the AIDS Epidemic and How the World Can Finally Overcome It*. The Penguin Press.
- Tobias, Carol R, Serena Rajabiun, Julie Franks, Sarah B Goldenkranz, David N Fine, Brenda S Loscher-Hudson, Paul W Colson, and Sharon M Coleman. 2010. "Peer Knowledge and Roles in Supporting Access to Care and Treatment." *Journal of Community Health* 35: 609–617.
- Tong, Allison, Peter Sainsbury, and Jonathan Craig. 2007. "Consolidated Criteria for Reporting Qualitative Research (COREQ): a 32-item Checklist for Interviews and Focus Groups." *International Journal for Quality in Health Care* 19 (4): 349–357.
- Treatment Action Campaign. 2006. "ARVs in Our Lives: A Handbook for People Living with HIV and Treatment Advocates in Support Groups, Clinics and Communities". TAC.
- . 2007. "HIV in Our Lives: A Book of Information Sheets for People Living with HIV, Support Groups and Clinics". TAC.
- . 2009. "HIV, Pregnancy and Your Choices!" TAC.
- . 2012. "HIV and Babies." *Equal Treatment*.
- . 2013. "Functional Cure of HIV-Positive Infant." *Treatment Action Campaign*. <http://www.tac.org.za/news/functional-cure-hiv-positive-infant>.
- . 2012. "Improving Health: TAC at Work - 10 Years of ARVs, 'Those Who Are Sick Come to TAC for Help'." *Treatment Action Campaign*. Accessed November 12. <http://www.tac.org.za/community/node/3079>.
- Treichler, Paula. 1999. *How to Have Theory in an Epidemic: Cultural Chronicles on AIDS*. Durham: Duke University Press.
- Truth and Reconciliation Commission. 1998. *Chemical and Biological Warfare Hearings*. Cape Town, South Africa. <http://www.justice.gov.za/trc/special/cbw/cbw9.htm>.
- Tun, Waimar, Scott Kellerman, Senkhu Maimane, Zukiswa Fipaza, Meredith Sheehy, Lung Vu, and Dawie Nel. 2012. "HIV-related Conspiracy Beliefs and Its Relationships with HIV Testing and Unprotected Sex Among Men Who Have Sex with Men in Tshwane (Pretoria), South Africa." *AIDS Care* 24 (4): 459–467.
- Turner, Patricia A. 1993. *I Heard It Through the Grapevine: Rumor in African-American Culture*. Berkeley: University of California Press.
- UNGASS. 2012. "Global AIDS Response Progress Report 2012". South Africa.
- University of Cape Town. 2010. "Traditional Healing Versus Scientific Medicine in the Fight Against TB and HIV." In University of Cape Town.
- Vale, Beth. 2012. "'I Know This Person. Why Must I Go to Him?' Techniques of Authority Among Community Health Workers in Cape Town". Working Paper. University of Cape Town, South Africa.
- Van den Brakel, Jan A, Rachel Vis-Visschers, and J J G Schmetts. 2006. "An Experiment with Data Collection Modes and Incentives in the Dutch Family and Fertility Survey for Young Moroccans and Turks." *Field Methods* 18 (3): 321–334.

- Van Prooijen, Jan-Willem, and Nils B Jostmann. 2013. "Belief in Conspiracy Theories: The Influence of Uncertainty and Perceived Morality." *European Journal of Social Psychology* 43: 109–115.
- Velissariou, Aspasia. 1982. "Language in 'Waiting for Godot'." *Journal of Beckett Studies* 8. <http://www.english.fsu.edu/jobs/num08/Num8Velissariou.htm>.
- Ward, Paul, and Anna Coates. 2006. "'We Shed Tears, but There Is No One There to Wipe Them up for Us': Narratives of (mis)trust in a Materially Deprived Community." *Health (London)* 10 (3): 283–301.
- Waters, A.M. 1997. "Conspiracy Theories as Ethnosociologies: Explanation and Intention in African-American Political Culture." *Journal of Black Studies* 28: 112–125.
- Watkins, Susan Cotts, and Amy Kaler. 2009. "Field Journals: An Introduction." *Malawi Diffusion Ideational Change Project*.
- Watkins, Susan Cotts, and Ann Swidler. 2009. "Hearsay Ethnography: Conversational Journals as a Method for Studying Culture in Action." *Poetics* 37: 162–184.
- Weinreb, Alex A, Sangeetha Madhavan, and Patricia Stern. 1998. "'The Gift Received as to Be Repaid': Respondents, Researchers and Gifting." In *Annual Meeting of the Eastern Sociological Society*. Philadelphia, PA.
- White, Luise. 2000. *Speaking with Vampires: Rumour and History of Colonial Africa*. Berkeley: University of California Press.
- Wilkinson, Sue. 1999. "Focus Groups: A Feminist Method." *Psychology of Women Quarterly* 23: 221–244.
- Willan, Samantha. 2004. "Briefing: Recent Changes in the South African Government's HIV/AIDS Policy and Its Implementation." *African Affairs* 103: 109–117.
- Wilson, Anika. 2008. "'There Is No Secret Under the Sun': Rumors, AIDS Beliefs, and Prevention Strategies of Wives in Rural Malawi". PhD Thesis, University of Pennsylvania.
- Witteman, Holly O, and Brian J Zikmund-Fisher. 2012. "The Defining Characteristics of Web 2.0 and Their Potential Influence in the Online Vaccination Debate." *Vaccine* 30: 3734–3740.
- Wolf, R Cameron, and K C Bond. 2002. "Exploring Similarity Between Peer Educators and Their Contacts and AIDS-protective Behaviours in Reproductive Health Programmes for Adolescents and Young Adults in Ghana." *AIDS Care* 14 (3): 361–373.
- Wong, Irene Y. 2004. "Development and Assessment of an Innovative Video to Introduce Concepts of Adherence in Soweto, South Africa". MD Thesis, New Haven, CT: Yale University. <http://cushing.med.yale.edu/greenstone/cgi-bin/library.cgi?a=d&c=ymtdl&d=etd-08202004-175255html>.
- Wong, Irene Y, Nicholas V Lawrence, Helen Struthers, James McIntyre, and Gerald H Friedland. 2006. "Development and Assessment of an Innovative Culturally Sensitive Educational Videotape to Improve Adherence to Highly Active Antiretroviral Therapy in Soweto, South Africa." *Journal of Acquired Immune Deficiency Syndrome* 43 (1): S142–S148.

- Wortmann, Craig. 2008. "Can Stories Change a Culture?" *Industrial and Commercial Training* 40 (3): 134–141.
- Wright, Jeremiah. 2003. *Confusing God and Government*. Sermon. Trinity United Church of Christ: Chicago. <http://www.youtube.com/watch?v=TYqrXVNFYUI>.
- Wynne, Brian. 1992. "Misunderstood Misunderstanding: Social Identities and Public Uptake of Science." *Public Understanding of Science* 1: 281–304.
- . 2006. "Public Engagement as a Means of Restoring Public Trust in Science - Hitting the Notes, but Missing the Music?" *Community Genetics* 9: 211–220.
- Yancey, WL, and L Rainwater. 1970. "Problems in the Ethnography of the Urban Underclass." In *Pathways to Data*, edited by RW Habenstein, 78–97. Chicago: Aldine.
- Youde, Jeremy. 2005. "The Development of a Counter-Epistemic Community: AIDS, South Africa, and International Regimes." *International Relations* 19 (4): 421–439.
- Zapiro. 2003. "Manto's ARV Roll-out Plan Is Approved after How Many Avoidable Deaths?" *The Sowetan*, 21 November 2003 edition. <http://www.zapiro.com/cartoon/123642-031121so#.Uc21hhzGo94>.
- . 2004. "All These Vegetables Prevent the Roll-out of Antiretrovirals - True or False?" *Sunday Times*, 15 February 2004 edition. <http://www.zapiro.com/cartoon/123054-040215st#.Uc203BzGo94>.

Appendix A: Focus Group Facilitation Guide

Focus Group Interview Guide for CAPS Follow-up Study **July/August 2010**

Introduction to Study:

Throughout this conversation, please adapt this guide in response to participants' comments. If the group seems very comfortable speaking personally about their beliefs, ask them more direct questions. If the group is distancing themselves from certain beliefs, be more general in the tone of questions. Above all, ask "why?" as much as possible – it helps us understand the reasons for certain opinions and behaviours.

Guidance Notes for Facilitator:

Introduction:

We are here today to talk about your perspectives on HIV/AIDS. We are not here to share information, or to give you our opinions. Your perceptions are what matter. There are no right or wrong or desirable or undesirable answers. We encourage you to disagree with each other, to express your opinion, and to change your mind throughout the discussion if you feel differently. We would like you to feel comfortable saying what you really think and how you really feel.

Discuss procedure:

We will be taking notes and tape recording the discussion so that we do not miss anything you have to say. I explained these procedures to you when we set up this meeting. As you know everything is confidential. No one will know who said what. We want this to be a group discussion, so feel free to respond to me and to other members in the group without waiting to be called on. However, we would appreciate it if only one person did talk at a time. Before you speak, please identify yourself by your number that we have provided. The discussion will last approximately one hour.

Discussion Topic #1:

How do you think HIV/AIDS originally came into the world – what was the source of the disease? (Probe not 'where it first came into the body' but how it was created or invented).

Probes: *What have you heard other people say about this?*

Has your opinion changed over time? Why?

How did you come to this perspective?

Do you think your friends and family agree with you? Why?

Does anyone in the group disagree with this? Why?

Some people say that HIV was created by humans, or by scientists in America. What do you think about these ideas? Do you agree or disagree? Why?

Some people say that HIV was deliberately created to kill black people, in Africa and in other countries. What do you think about this? Do you agree or disagree? Why? Some people say that there is a cure for AIDS but that it is not being given to some people. What do you think about this? Do you agree or disagree? Why?

Some people say that HIV does not cause AIDS or that AIDS does not exist. Do you agree with this? Why or why not?

Discussion Topic #2:

(Probe the next series of questions based on the answers given in the first section – have people openly identified themselves or people close to them as having any of these beliefs? Or distanced themselves from these ideas?)

Based on what you've just said, are there certain groups of people or individuals whom you trust everything they say about HIV?

Are there certain sources that have persuaded or reinforced the ideas shared above? (Probe for specific names or identities of organizations and probe why or why not? Ask for specific reasons why certain sources are trusted and others are not).

Probe: (For example) *Do you trust all HIV information from doctors? Nurses? Sangomas or Inyangas?*

Do you trust all HIV information from our former health minister Manto Tshabalala-Msimang? Our former health minister Barbara Hogan? Our current health minister Aaron Motsaoleli?

Do you trust all HIV information from our former President Mandela? Our former President Mbeki? Our current President Zuma? US President Obama? Julius Malema?

What is it about _____'s public statements about HIV that makes you trust them?

Do you trust information about HIV from people from the Treatment Action Campaign? Why?

Do you trust information about HIV from MSF?

*Who do you trust THE MOST for information about HIV?
From whom do you NOT trust information about HIV?*

Has anyone changed your mind about your beliefs about HIV? Who? Why were they influential in changing your views? Has anyone tried to change your views but not succeeded? Why or why not?

Discussion Topic #3:

(Probe the next series of questions based on the answers given in the first and second section – have people openly identified themselves as believing in conspiracy beliefs or people close to them as having any of these beliefs? Or distanced themselves from these ideas?)

Based on the ideas and opinions expressed earlier in our conversation about the origins of HIV/AIDS, do you think it's possible to protect yourself from HIV? How can a person do this?

Probes: *What methods would do people use to protect themselves?*

What is the best way to protect yourself?

What does not work? Why?

What other methods do you hear people talking about?

You haven't mentioned _____ (condoms, abstinence, traditional medicine, prayer, etc.) – is that because you don't think it is a good way to protect yourself from HIV?

What about getting an HIV test? Do you think everybody wants to know their HIV status?

(Probe specific ideas that have been shared throughout the focus group. If someone has said that HIV was deliberately created to cause harm, ask them if they are less likely to try to protect themselves from HIV? Or ask broadly “Are people who believe this less likely to use a condom when they have sex?”).

Closure:

Though there were many different opinions about this topic, it appears unanimous that _____. Does anyone see it differently? It seems most of you agree _____, but some think that _____. Does anyone want to add or clarify an opinion on this? Is there any other information regarding your perspective that you think would be useful for me to know? Do you have any further questions?

Thank you very much for coming this afternoon. Your time is very much appreciated and your comments have been very helpful.

Appendix B: Ethics Document

I. Project Details

Project Title: Assessing the Origins and Impacts of Alternative and Conspiratorial Beliefs on HIV Prevention and Treatment Behaviour in Cape Town, South Africa

II. Applicant Details

Name:	Clara Rubincam
Status (delete as applicable)	PhD
Email address:	c.c.rubincam@lse.ac.uk
Room number/contact address:	

III. Research Aims

Please provide *brief* details of the research aims and the scientific background of the research. A full copy of the proposal should be attached to this document.

<p>The prevention and treatment of HIV infections is of paramount importance to high prevalence countries in Southern Africa. In some populations alternative and conspiracy beliefs impede the promotion of condoms (Bogart and Thorburn 2005) and deter target populations from getting an HIV test (Simbayi, Kalichman and Bogart 2008) or adhering to antiretroviral treatment programmes (Steinberg 2008). This study examines the origins and impacts of alternative and conspiracy beliefs in Cape Town, South Africa.</p> <p>Existing studies on alternative and conspiracy beliefs and HIV/AIDS focus almost exclusively on marginalized populations in the United States. To date, only one, purely quantitative study has examined the prevalence and impact of conspiracy beliefs in South Africa. There are no known studies that employ mixed-method analysis. This study is focused on exploring the origins of alternative beliefs, and on uncovering the extent to which 'conspiracy theories' and 'denialism' are an</p>
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integrated part of the worldview of young adults in Cape Town.

Guiding research questions include:

1. To what extent do South Africans endorse alternative beliefs relating to HIV/AIDS origins, treatment and testing?
2. What are the underlying reasons why these beliefs still hold currency in the post-apartheid era?
3. What are the implications of these beliefs for HIV prevention and treatment interventions, and trust of health information from certain sources?
4. How can interventions address these beliefs in a culturally-sensitive and effective manner?

ONLY COMPLETE THE RELEVANT PARTS OF THIS DOCUMENT. THESE WILL HAVE BEEN IDENTIFIED AFTER COMPLETION OF THE RESEARCH ETHICS CHECKLIST.

1. Informed consent.

1.1 Will potential participants be asked to give informed consent in writing and will they be asked to confirm that they have received and read the information about the study? If not, why not?

Yes, all participants will be asked to give informed consent after a) having a discussion with the facilitator over the phone before arranging to participate, b) having access to an information sheet about the project and its implications and c) having the project aims and objectives verbally explained prior to the commencement of the focus group discussion/interview.

1.2. How has the study been discussed or are there plans to discuss the study with those likely to be involved, including potential participants or those who may represent their views?

Topics in this study have been discussed with the facilitator for the focus group discussions, who is a trained HIV counselor and qualitative researcher. The study will also be discussed with participants prior to beginning the study.

1.3. Has information (written and oral) about the study been prepared in an appropriate form and language for potential participants? (see Informed Consent guidance which lists questions to be considered). At what point in the study will this information be offered?

Information about the study will be offered to participants at the first point of contact. Participants will have an opportunity to look over the document and ask questions of the PI and facilitator before agreeing to participate in this study.

1.4 How will potential participants be informed of whether there will be adverse consequences of a decision not to participate? Or of a decision to withdraw during the course of the study?

Part of the information sheet about the study (given to participants in the first meeting) will include reassurance that there will be no adverse consequences for the participant if they decide not to participate in the study initially, or if they decide to withdraw at some point during the course of the study.

1.5 What provision has been made to respond to queries and problems raised by participants during the course of the study?

The content of the interviews is not intended to be disturbing or overly personal. Participants are being asked about their views about particular issues in order to see if certain topics emerge organically. Thus, participants will not be forced to discuss anything they are not comfortable volunteering on their own. Should these discussions prove unsettling for any participants, the focus group discussion facilitator is also a trained HIV counsellor and has experience providing counselling and advice to similar groups.

Participants will be encouraged to ask general questions or concerns about the study to the PI or any of the trained research assistants. Participants will also be provided with a contact list of phone numbers of the PI, other researchers from the Centre for Social Science Research (CSSR) at the University of Cape Town and research assistants in case concerns or questions arise after the end of the study.

2. Research methodology.

2.1. How does the research methodology justify the use of deception?

N/A

2.2. If the proposed research involves the deception of persons in vulnerable groups, can the information sought be obtained by other means?

N/A

2.3. How will data be collected during the project? Please provide details of data analysis.

Qualitative data will be collected in a series of focus group discussions (FGDs) and follow-up interviews with select respondents from a quantitative survey (Cape Area Panel Study) conducted in 2009. Data analysis will be done on both the survey and the FGDs in order to provide quantitative and qualitative data on the same topic.

Participants will have been invited to participate in a discussion about HIV and given full information about the study prior to agreeing to be involved. Focus group discussions will be held in a relaxed environment at the University of Cape Town over the course of a few hours. Transportation and lunch will be provided and a voucher will be given at the end of the discussion. Respondents' consent will be sought to tape record the discussion, and they will be asked if they would mind being contacted for a follow-up interview.

All survey respondents' identities are protected by the assignment of an identification number, which is used throughout all quantitative data analysis. FGD respondents and interviewees will also be assigned a number and no personal information will be collected. There is no attempt to connect the responses during FGDs with the same respondent's answers on the survey.

Quantitative analysis will be performed with SPSS and qualitative analysis will be performed using NVivo.

2.4. How have ethical concerns arising from data collection been addressed?

The main ethical concerns arising from the qualitative data collection is that respondents feel appropriately informed about the nature of the research and the fact that their participation is fully voluntary and confidential, and that they can halt their participation at any time. This information will be conveyed in writing (on the informed consent form) and orally from the PI and the facilitator. Ethical approval for this study has also been submitted to and approved by the Centre for Social Science Research at the University of Cape Town.

3. Research design.

3.1 What concerns have been taken into account with regard to the design of the research project? If agencies, communities or individuals are directly affected by the research (e.g. participants, service users, vulnerable communities or relations), what means have you devised to ensure that any harm or distress is minimized and/or that the research is sensitive to the particular needs and perspectives of those so affected?

The research project design has considered the possibility that participants may feel

distressed by discussing the reasons why certain conspiracy beliefs are plausible to them, particularly if these are derived from experiences during the apartheid regime or during the Mbeki government's era of AIDS denialism. The focus group facilitator is a trained HIV counselor and has experience conducting discussions around these topics.

A further area of potential distress is the fact that those endorsing conspiracy beliefs (sometimes called 'conspiracy theorists') are frequently derided in popular media as delusional and paranoid members of society. Though this study is concerned with documenting the prevalence of these beliefs in South African society, it is also the explicit intention *not* to stigmatize individuals holding these beliefs. Nor is it the intention to put people on the spot during focus group discussions about their beliefs about conspiracy theories or AIDS denialism. Rather, the aim is to understand the ways that these beliefs fit into their overall worldview, and to determine how integrated these beliefs are in individual's worldview. Results of the study will be communicated in a respectful way, and any discussion of conspiracy beliefs or those who hold them will be with an aim of understanding, not judging such beliefs or people.

3.2. How has the methodology addressed how sensitive information, data or sources will be handled?

The methodology has addressed potentially sensitive issues of data collection, analysis and storage by ensuring that participation is fully informed and voluntary, that no personal information is captured during the qualitative interviews that could tie individuals to their responses on the quantitative survey, and that pseudonyms or identification numbers will be used in lieu of names of participants. All transcripts of interviews will be stored in a secure facility at the University of Cape Town.

3.3. Have you been able to devise a timetable of research?

The qualitative data collection is set to begin in June 2010. It is scheduled to last for approximately 4 months, although allowance is made for this timing to be extended if deemed necessary by the principal investigator (Clara Rubincam) and her advisor (Tony Barnett). Analysis of the qualitative transcripts will be conducted from October 2010 until June 2011, at which point write-up of results will commence.

4. Ethical questions arising from financial support/the provision of incentives

4.1 Are there any real or perceived conflicts of interest which could compromise the integrity and/or independence of the research due to the nature of the funding body?

N/A

4.2 Have any incentives to the investigator been declared?

N/A

4.3 Are there any restrictions on the freedom of the investigator(s) to publish the results of the research?

N/A

4.4 Are any incentives being offered to participants?

Participants in the FGD will be offered reimbursement for the cost of their transportation and a 75 Rand voucher to Checkers, a local grocery store. Participants will also be provided with lunch. It is seen that these incentives will adequately compensate participants for their time while not creating excessive inducement to participate in the research.

5. Research Subjects

5.1 Who do you identify as the participants in the project? Are other people who are not participants likely to be directly impacted by the project?

Participants in the project are those individuals who agree to participate in the focus group discussions. Other potential participants are key informants from the health sector (government and civil society) who agree to be interviewed about their experiences.

5.2 What arrangements have been made to preserve confidentiality for the participants or those potentially affected?

All participants will be assigned an identification number (Focus group participant #2, for example) and no personal information will be collected either before or after data collection. Key informants will be offered the option of a pseudonym if preferred.

5.3. What are the specific risks to research participants or third parties?

There are no specific physical risks to participants who participate in this research. As mentioned elsewhere in this application, there is the possibility that participants will find it disturbing to discuss experiences with the health sector and/or government agencies that have led them to believe certain conspiracy beliefs.

5.4. If the research involves pain, stress, physical or emotional risk, please detail the steps taken to minimize such effects? Explain why this is reasonable within the context of the project?

N/A

6. Risk to researchers.

6.1 Are there any risks to the researcher(s)? Please provide details if risk identified.

N/A

7. Confidentiality

7.1 Explain the mechanisms in place to ensure confidentiality, privacy and data protection.




All participants will be assigned an identification number that will be used throughout the study so as to avoid the use of names or any other personal details. During the course of the focus groups, participants will be referred to only by their identification numbers. Data analysis on the content of focus groups will use only the identification numbers as reference points. The transcripts of all focus groups will be made available only to a small number of individuals in the CSSR office and no identifying information will connect FGD participants with their CAPS survey details.

8. Dissemination

8.1 Will the results of the study be offered to those participants or other affected parties who wish to receive them? If so, what steps have been taken to minimize any discomfort or misrepresentation that may result at the dissemination level.

The results of this study will be disseminated at academic, policy and community levels. In academic publications, the PI will endeavor to represent the full scope of what was said during FGDs and interviews, by including larger quotations instead of small sound bites. It is also a key part of the study to investigate structural reasons for individuals' beliefs, so all quotations and statements will be placed in historical and political context. When disseminating results at the policy level, the PI will again endeavor to provide contextual background for the content of the FGDs, interviews and the CAPS survey results. At the community level, the PI will aim to engage interested parties in a discussion of the significance of the findings, and particularly, to place the findings from South Africa into a global context.

Appendix C: Informed Consent Form

 <p>University of Cape Town</p>  <p>University of Michigan</p>  <p>Health Economics & HIV/AIDS Research Division University of KwaZulu- Natal</p>	<h1>Cape Area Panel Study</h1> <p><i>A study of the changing lives of young people in Cape Town</i></p> <h2>Wave 5 Qualitative Follow-up (Cape Area Study 2009)</h2>
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In 2002 you kindly agreed to be a part of the Cape Area Panel Study. The Cape Area Panel Study is a study of the health and well-being of young people in Cape Town. We may have asked you questions a few times between 2003 and 2007. Most recently, we interviewed you again for our 2009 survey. We would like to interview you in a group as a follow up to your responses on the 2009 survey. We will be asking you general questions about your opinions and attitudes about health, HIV/AIDS, and South African politics.

We want to make sure that you understand the following information about the study.

- Whether you take part in the study is entirely up to you.
- You may refuse to take part in the focus group discussion, and may stop at any time if you feel uncomfortable and do not want to continue. You may also avoid answering particular questions if you do not wish to answer them.
- We expect that the focus group interview will take approximately 1.5 hours; it will often take less than 1 hour.
- All information collected for this study will be kept strictly confidential. Individual responses to our questions will never be made public, and no information which could identify you or your household will ever be released.
- You have the right to ask questions at any point before the focus group interview, during the focus group interview, or after the interview is completed.
- We may want to ask questions to you again in the future. But we will ask for permission again at that time.

By signing below, you signify that you agree to be a participant in the Cape Area Panel Study qualitative follow-up.

SIGNATURE

DATE

If you have questions about this interview or the CAPS project contact Keith Christmas (tel: 021-6505908 or email: caps.uct@gmail.com). More information about CAPS is available on <http://www.caps.uct.ac.za/>. This study has been reviewed and approved by the ethical review committees of The University of Cape Town (contact: Sandra Naidoo, the administrative officer of the Humanities Faculty Ethics in Research Committee at UCT: telephone 021-650-2456 or email Sandra.naidoo@uct.ac.za) and the University of Michigan (Contact: Kate M. Keever; email: irbhsbs@umich.edu).