



UNIVERSITY OF CAPE TOWN

CENTRE FOR
SOCIAL SCIENCE RESEARCH

**Alternative explanations about HIV and
AIDS: re-examining distrust among
young adults in Cape Town, South
Africa**

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CSSR Working Paper No. 342
July 2014



Published by the Centre for Social Science Research
University of Cape Town
2014

<http://www.cssr.uct.ac.za>

This Working Paper can be downloaded from:

<http://cssr.uct.ac.za/pub/wp/342/>

ISBN 978-1-77011-329-9

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Acknowledgments:

The author would like to acknowledge the support of Professor Nicoli Nattrass, who provided guidance throughout this study and insightful feedback on earlier drafts of this paper, and Eduard Grebe, who assisted in the recruitment and design of the focus group discussions. This study was supported by a doctoral research award from the Canadian Institutes for Health Research, a PhD studentship award from the London School of Economics, the University of London's Central Research Fund, and in-kind contributions from the Centre for Social Science Research at the University of Cape Town and the Health Economics and HIV/AIDS Research Division at the University of KwaZulu-Natal. The material contained in this paper has been presented, in modified form, at the following conferences and gatherings: John Ruedy Immunodeficiency Clinic at St. Pauls Hospital. University of British Columbia, Vancouver, Canada. September 7, 2012; Plenary Address. CANAC/ACIIS 20th Annual Conference. Canadian Association for Nurses in AIDS Care. May 13-16 2012; Saw Swee Hock School of Public Health. National University of Singapore (NUS), Singapore. April 19, 2012; 1st International HIV Social Science and Humanities Conference. Durban, South Africa. 11 June 2011.

Alternative explanations about HIV and AIDS: re-examining distrust among young adults in Cape Town, South Africa

Abstract

Alternative beliefs about HIV – such as the man-made origins of the virus or the existence of a cure – can undermine trust in and engagement with HIV prevention and treatment initiatives. It is therefore crucial to study the reasons why these beliefs are plausible to some individuals, and how we might better address them in future prevention and treatment campaigns. This study contributes to understanding these beliefs by examining the explanations provided by African respondents in Khayelitsha Township for the plausibility of alternative beliefs about HIV and AIDS. Drawn from a sub-selection of over 2900 respondents to the Cape Area Panel Study, ten focus group discussions (n=47) were held with African men and women from the township of Khayelitsha. Previous studies maintain that the experience of apartheid, of former President Mbeki’s AIDS denialism, and of the unsettling transformations of globalisation have negatively influenced the South African public’s trust in biomedical claims. This paper argues 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”, an informal manner of empirically engaging with science’s rationale. HIV prevention campaigns should draw on experiential aspects of HIV and AIDS to lend credibility to scientific claims and recognize that some doubts about science are a form of skeptical engagement rather than an outright rejection.

Introduction

According to a recent *Lancet* article, “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). This assessment is supported by other studies showing that misperceptions about the origin of HIV are associated with lower likelihood of condom use (Bogart *et al.*, 2011; Grebe and Nattrass 2012; Tun *et al.*, 2012), lower likelihood of HIV testing (Bogart *et al.*, 2008; Tun *et al.* 2012; Skinner *et al.*, 2012), and lower rates of uptake of antiretroviral medication (Lennon and Kalichman, 2012). This paper focuses on understanding the reasons why certain alternative beliefs about HIV and AIDS are plausible to some South Africans and posits new interpretations in the context of contemporary South Africa.

Explanations for alternative beliefs

Previous studies maintain that the experience of apartheid rule, the influence of former President Mbeki’s AIDS denialism, the transition to democracy, and controversies in the early years of the new democratically-elected government have had permanent implications for the South African 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, essentialising language of the early HIV years¹, various HIV-related funding scandals within

¹ In the 1980’s and early 1990’s, some scholars pointed to a “hypersexualised pan-African culture” as the key driver of the HIV epidemic in sub-Saharan Africa. Stillwaggon observes how “discredited racial science reared its ugly head in the form of a metaphor with formidable generative powers, carried along by deeply imbedded Western racial views that presume exceptional sexual behavior by Africans” (2003, 830). This metaphor was of African culture as distinct, “pan-African, ahistorical, and exotic” (Stillwaggon, 2003: 814) as compared with western cultures. Studies, such as those by the Caldwell’s (1987; 1989), were cited repeatedly to lend credence to the notion that bizarre rituals and rampant promiscuity were inherent characteristics of this “African culture”. These stereotypes significantly influenced research and policy, drawing attention away from developmental interventions such as treatment of parasitic infection and focusing attention almost exclusively on behavioural interventions (Stillwaggon, 2003; Stillwaggon and Sawers, 2012). They also provided fodder for those arguing that western science was irredeemably corrupted by racism (Chirimuuta and Chirimuuta, 1989).

South Africa's newly elected government², and routine acts of discrimination and marginalisation (Mbali, 2002; Fassin and Schneider, 2003; Stillwaggon 2003; Mbali, 2004; Fassin, 2007). "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). 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 assertions³. 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 nature need to more specifically identify the mechanism by which these experiences become manifest. As Natrass argues, studies of alternative beliefs need to go beyond the simple, "there are good historical reasons for these beliefs" analysis that has characterised some past scholarship (2012, 11).

Beyond perceptions of historical abuse and exploitation, scholars assert that the South African public has been exposed to an additional influence on public skepticism and conspiratorial beliefs about HIV and AIDS in the form of state-sponsored HIV and AIDS denialism during former President Thabo Mbeki's administration. Beginning in 1997, former President Mbeki and then-Minister of Health Dr. Mantombazana Tshabalala-Msimang began publically endorsing pseudo-scientific theories about HIV and AIDS. They also supported unethical

² For example, government's support for Sarafina II, a "badly conceived and inappropriately funded" AIDS awareness play, and for 'Virodene', an industrial solvent portrayed as an AIDS cure (Natrass, 2008).

³ A similar instinct exists in US scholarship on medical mistrust within the African-American community. Studies attributing African-American mistrust to the legacy of the Tuskegee Syphilis Study are ubiquitous (Roberts *et al.*, 2005; Suite *et al.*, 2007; Bogart, Wagner, Galvan, and Banks, 2010; Mackenzie, 2011), though empirical investigations have at times indicated a more nuanced connection between past experience and present mistrust (Brandon *et al.* 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).

research on an industrial solvent to treat HIV (Geffen, 2010; Natrass, 2012) and convened a Presidential AIDS Advisory Panel in 2000 with equal numbers of AIDS denialists and orthodox scientists (Geffen, 2005; Natrass, 2007). Mbeki's views were aired on the world stage when he delivered a controversial speech at the opening ceremony of the 12th International AIDS Conference in Durban 2000, stating 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; 2010), suggestions that have been widely criticized and lampooned in South Africa and abroad⁴.

In light of Mbeki's behaviour, 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). 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). Few scholars, however, have empirically investigated the influence of the former president and his health minister in influencing the South African public's trust in HIV science in the present day⁵. McNeill (2009) problematizes the notion that the president's denialism is a major influence on public discourse about HIV and AIDS. He suggests that a key distinction should be drawn between the "state denialism" of the President and members of his

⁴ 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 examples, see Zapiro (2003; 2004).

⁵ One of the few exceptions is Grebe and Natrass's paper (2012), which compared trust in Manto Tshabalala-Msimang with trust for her successor, Barbara Hogan, finding that those who trusted the former more than the latter were more likely to endorse alternative and conspiratorial statements. They conclude that political leadership may be an important dimension of such beliefs.

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). 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, updated⁶.

A final explanation for alternative beliefs about HIV and AIDS centres on the particular anxieties and insecurities that are born of economic and social globalisation (Sanders and West, 2003; Niehaus and Jonsson, 2005; Steinberg, 2008a). As South Africa faces increasing economic inequality from integration into the world economy (Natrass and Seekings, 2001) and growing doubts about the proclaimed transparency of political power in the post-apartheid era (Knaup, 2008; *The Economist*, 2010; Gordimer, 2012), alternative beliefs may provide explanations for forces that exert influence over people’s lives without any accompanying sense of accountability. Steinberg observes that for many rural South Africans, “...life has always been shaped by invisible powers exercised by people far away – like the powers that wooed all adult men to work in the goldmines at the beginning of the 20th century, then retrenched all their great-grandsons 90 years later” (Steinberg, 2011). Alternative beliefs may serve as ‘weapons of the weak’ (Scott, 1985) for those affected by HIV and AIDS by acting as a powerful symbolic protest against the uncertainty of these everyday realities (Connors, 1995). However, as with the explanations focused on apartheid and Mbeki, these accounts lack specificity and tend towards explanation by association rather than evidence (Leach and Fairhead, 2007: 33). When alternative beliefs are viewed as “responses to a nascent modernity, it is difficult to discern among the different things that might be resisted, or commented upon” (Leach and Fairhead, 2007: 34). Focusing on the symbolic, metaphoric meaning of distrust or alternative beliefs may also take analytic focus away from more substantive concerns (2007: 33).

This study echoes the position taken by McNeill (2009), that the question of the influence of historical experience and Mbeki’s ‘long shadow’ should be subject

⁶ 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).

to continual reevaluation. As Robins argues, “it has become apparent that people’s interpretations of the AIDS pandemic are far more complex and differentiated” (2005: 129) than originally anticipated by activists or the South African government, 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 paper 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. 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 and 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?

This study situates this inquiry in the Public Understandings of Science and Technology (PUSAT) literature rather than the more narrowly defined study of conspiracy theories. Previous studies have conceptualized certain forms of distrust about HIV science as “conspiracy belief” (Ross *et al.*, 2006; Hutchinson *et al.*, 2007; Clark *et al.*, 2008; Russell *et al.*, 2011; Lennon and Kalichman, 2012; Tun *et al.*, 2012; Grebe and Nattrass, 2012; Nattrass, 2012). The PUSAT framework views alternative beliefs in the context of everyday experiences and observations, examines how trust and distrust is formed through relationships between people and institutions, and explores the underlying meanings of uncertainty. The distinction between these frameworks lies in PUSAT studies’ broader investigation of alternative explanations, including but not limited to, conspiracy beliefs, rather than the exclusive focus on conspiratorial explanations. This paper argues that by focusing on expressions of distrust as “conspiracy beliefs”, previous studies have unintentionally obscured the extent to which most individuals express doubts about HIV science as agnostics rather than as committed 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.

After outlining the methods used to collect and analyse data for this study, this paper examines the prevalence of endorsement for certain alternative and conspiratorial beliefs among the CAPS (Cape Area Panel Study) sample. The remaining results are derived from data from the focus group discussions, centering on explanations for the origins of HIV and the existence of a cure for the virus. The reasons for certain divergences between the qualitative and quantitative data are explored. The paper concludes with a review of existing

explanations for alternative beliefs about HIV and highlights possible opportunities for future interventions to reduce mistrust in HIV science among this population.

Methods

This study was conceived as a mixed-methods sequential exploratory design, where the quantitative data collection and analysis preceded and informed the collection of qualitative data. In 2009, questions about alternative and conspiratorial beliefs were included in the 5th wave of the CAPS of 2905 individuals (Figure 1). The methods used to draw this sample are discussed in detail in Grebe and Nattrass (2012).

Figure 1: Questions about alternative and conspiratorial beliefs in 2009 CAPS

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

All CAPS respondents gave permission to be contacted for qualitative follow-up research. As a continuation of this study, qualitative data collection ran from June to August 2010 and involved 10 focus group discussions (FGDs) with

African CAPS respondents (n=47), five with men and five with women, to explore questions that arose from quantitative data analysis⁷. Four of the questions about alternative beliefs from the CAPS survey were used to inform the sampling for the focus groups:

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
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”. Respondents in ‘mixed’ groups were individually identified in the analysis as an endorser or non-endorser.

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 beliefs, African respondents disproportionately endorsed these statements as plausible. The restriction of focus group participants to African CAPS respondents was made both because African respondents were more likely to endorse these 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 and 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.

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

⁷ The focus group facilitation guide is available in Appendix 1.

changed or because they refused. Thus, these focus groups may not be representative of the entire African CAPS sample; it is possible that people with the most strongly distrustful beliefs avoided participating in a university-sponsored study.

All focus groups were conducted in Xhosa by a male or female research assistant from the University of Cape Town, and then transcribed and translated into English. Focus group discussions lasted from 40 minutes to 2 hours, depending upon the respondents. They were semi-structured and explored beliefs about the origins and spread of the virus, beliefs about the credibility of scientific information about HIV and AIDS, and trusted sources of information. All participants were provided free transportation to and from the study site, given lunch after the discussion, and received a 50 rand voucher for a local food store.

In-depth interviews with peer educators from the Treatment Action Campaign (TAC) office in Khayelitsha, which complemented the survey and focus group discussions, were designed to explore this topic from a distinct perspective⁸. Peer educators were asked about the types of questions and beliefs encountered in conversations with clients, including alternative and conspiratorial beliefs. Taking place between October and December 2011, these interviews provided insight into alternative beliefs about HIV and AIDS from the perspectives of those who are entrusted with publically disseminating scientific information about HIV and 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 and 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 and 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 and AIDS circulating within the

⁸ The interview guide for peer educators is available in Appendix 2.

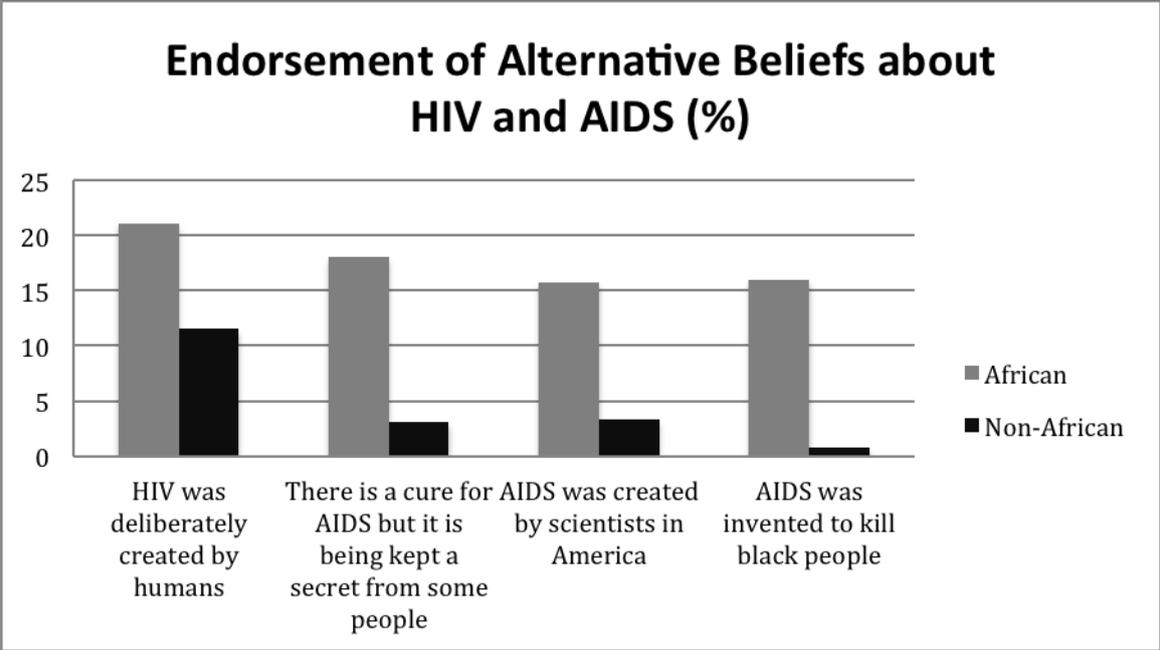
community – these interviews provided a check on data validity from the other two methods.

Ethical approval for both the quantitative and qualitative portions of this research was obtained from both the University of Cape Town and the London School of Economics and Political Science.

Results

In order to explore the prevalence of conspiracy belief among the CAPS sample, simple descriptive statistics were generated for the relevant questions. While a significant minority of respondents endorsed these conspiracy beliefs, African respondents disproportionately endorsed these statements as plausible (Figure 2).

Figure 2: Prevalence of alternative beliefs about HIV and 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. 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 above⁹. Other scholars have suggested that one of the legacies of Mbeki’s denialism may have been to create a deep-seated sense of uncertainty and confusion among the public (Geffen, 2010; Nattrass, 2012). This raises the question of whether uncertainty in this context can 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.

Some of the characteristics associated with alternative and conspiracy beliefs in this population have been explored elsewhere (Grebe and Nattrass, 2012; Nattrass, 2012), 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, 2012). To explore the prevalence and rationale for alternative beliefs further, focus groups were convened with African respondents only. The results from these focus group discussions are highlighted below.

Alternative beliefs about HIV and AIDS

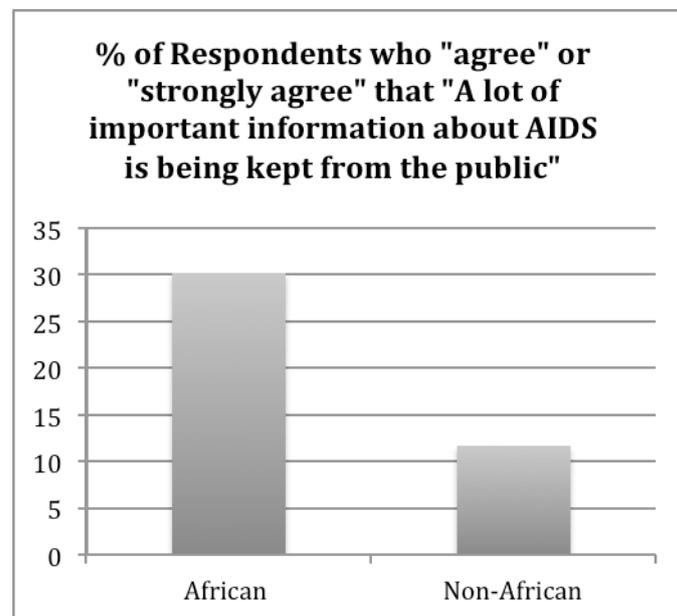
Though some conceptualisations of alternative beliefs have suggested that such beliefs constitute a rejection of scientific principles (Hofstadter, 1965; Thompson, 2008; Sunstein and Vermeule, 2009), the alternative beliefs discussed below do not stem primarily from an anti-scientific mindset. Nor do they reflect an explicitly conspiratorial outlook. Rather, they reflect careful observations about the way politics, the economy and public health are

⁹ To my knowledge, no studies exist that analyse mid-point responses on conspiracy belief scales. In a study measuring mid-point responses on other kinds of public policy questions, Sturgis and colleagues suggest that many mid-point responses should be regarded as “face-saving don’t knows”, that is, respondents picking a mid-point when they actually have no opinion on the issue. This is clearly different from a genuinely neutral opinion about a particular issue. This type of response was significantly associated with believing that one should have an opinion on important issues, suggesting that respondents were trying to avoid social embarrassment (2012). Future studies on conspiratorial and alternative beliefs could further investigate how respondents are using mid-point responses of this kind.

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 (Irwin and Wynne, 1996; Waters, 1997; Fischer, 2005; Wynne 2006).

In addition to the questions about alternative beliefs, 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 3).

Figure 3: 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 (discussed more below).

In the focus group discussions and interviews, both respondents and peer educators discussed alternative beliefs about HIV and 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 and 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 as found 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” (Roberts *et al.*, 2005), “confusion and disagreements” (Niehaus and Jonsson, 2005), and “doubts” (Posel *et al.*, 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 paper situates these disjunctures at the centre 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.

'Smoke in the sky': the origins of HIV

CAPS respondents' 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 clients¹⁰ about the origins of the virus.

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

Pemeido: Yah, a lot! [laughing] A lot. (Dec 7 2011).

Another peer educator confirmed the salience of this topic.

Nomandithini: They ask us a lot [laughing]. Yes, they ask us where HIV comes from. (Dec 7 2011).

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, Dec 9 2011).

When discussing the origins of HIV among CAPS 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

¹⁰ 'Clients' is the preferred term among TAC 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.

to prove – to show people that if he so wishes he could cure it’ (N1 female non-endorse FGD, 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 beings aren’t honest and that is the way in which they get punished by getting HIV and AIDS’ (N2 male non-endorse FGD, 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 FGD, 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 FGD, 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 (Dec 7 2011).

Lina: But most of them, they didn’t want to understand anymore because some they say, it comes from the foreigners (Nov 25 2011).

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 (Dec 12 2011).

One of the peer educators, 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, Dec 6 2011).

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 (2012: 17). Niehaus and Jonsson's ethnography of alternative beliefs highlight fears that in the mid-1990s, white farmers were dumping oranges that had been doctored with blood containing HIV at shopping centres and schools (2005: 196). Steinberg reports a discussion with the *Medecins Sans Frontieres* (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 80s, 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!' (Dec 9 2011).

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?' (Dec 12 2011).

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 (Dec 7 2011).

Although peer educators had heard people attribute HIV to a deliberate plot to harm Africans, this theory did not come up in the CAPS focus groups, even among 'endorser' respondents. Even though they had previously endorsed AIDS origin conspiracy theories when answering the CAPS survey, when prompted about their own views, no one argued that it was a deliberate plot. Rather, 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, as in this discussion between two female non-endorsers:

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 FGD, 21/08/2010).

Other CAPS focus group respondents attributed the virus to contact between humans and animals. While this drew on the notion that HIV originated as Simian Immunodeficiency Virus (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 FGD, 21/08/2010). Another stated, "HIV comes from an animal – like these Swine Flu. Swine Flu comes from pigs, right? So it too must have come from animals and was transferred to a human" (N2 female non-endorse FGD, 12/08/2010). Some respondents believed that an animal virus had infected white people or foreigners first, before being transmitted to black South Africans:

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-endorse FGD, 13/08/2010).

Some respondents suggested that scientists had experimented in laboratories, creating a new virus that was then spread to African people, echoing the survey questions "HIV was deliberate created by humans" and "HIV was created by scientists in America". In these explanations, scientists are seen as all-powerful individuals, capable of interfering with nature with both positive and negative results. A CAPS 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 endorse FGD, 11/08/2010).

A respondents from the ‘mixed’ group 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’ 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 in a lab and then I don’t know if it was the baboon’s blood or what’. (N3 female mixed FGD, 8/07/2010).

In the detailed account of why they found these beliefs plausible, CAPS focus group 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 endorse FGD, 11/08/2010).

This account emphasizes how scientific experimentation and innovation can disproportionately affect 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. Alternative explanations about the origins of HIV 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 focus group respondents, including the endorsers, were unwilling to suggest that scientists could have created the virus on purpose. Despite widespread discussions about the role of scientists in creating the virus, most respondents 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 CAPS survey question out of the four implied a specific intention to harm others, that “AIDS was invented to kill black people”. The maliciousness of this invention is disputed, as one non-endorser respondent states:

‘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 FGD, 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 FGD, 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. Perceptions of outright maliciousness were almost entirely absent from these discussions. Rather, they were probably 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 CAPS focus group participants 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 that alternative beliefs about HIV and AIDS often spring from a desire to attribute blame to an external source, either because of the psychological comfort this brings (Crocker *et al.*, 1999) or as a retaliatory reaction against stigmatizing discourses (Sabatier 1988; Farmer, 1992; Nations and Monte 1996; Briggs, 2004). 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 FGD, 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 FGD, 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 recognising 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 FGD, 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 CAPS focus group participants 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 CAPS respondents in the focus group discussions 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 FGD, 18/08/2010), an endorser in the same group stated, “I say AIDS goes alone – it is not together with witchcraft” (N3 female mixed FGD,

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?’ (N3 female mixed FGD, 18/08/2010).

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!’ (N3 female mixed FGD, 18/08/2010).

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, towards making a distinction between believing that witchcraft exists and subscribing to the notion that it causes HIV. Steinberg has called this “the fence around AIDS” (2008a: 119), serving to protect people from the notion that “neighbours and family are murdering one another in droves” (2008a: 132). Whether for this reason or not, another non-endorser respondent 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 FGD, 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 (Dec 12 2011).

Similarly, some respondents seemed unsure whether HIV was deliberately created or not. A CAPS 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 FGD, 28/08/2010).

Even in groups composed solely of those characterised 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 Azande¹¹, 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

¹¹ 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.

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 endorse FGD, 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', a Xhosa man who was exploring his fears and attitudes towards HIV and ARVs, 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" (2007). 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 lack of a satisfactory or conclusive explanation for the source of the disease constitutes a significant disjuncture in information about HIV. Several peer educators reported that they felt the issue of HIV's origins served as a distraction from other more important concerns:

'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"?' (Nonqaba, Dec 12 2011).

Another peer educator also urged people to move beyond these concerns:

'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 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?' (Pemeido, Dec 7 2011).

Yet viewing questions about the origins of HIV as a distraction may mean that these concerns are not taken seriously.¹² 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.

‘AIDS was invented for business’: the existence of a cure

There was considerable discussion among CAPS focus group participants about the existence of a cure. Peer educators noted that similar concerns arose in discussions with clients. The CAPS 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 Sizwe 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, Dec 7 2011).

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

¹² 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: colonisation, urbanisation 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).

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 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’ (N5 male uncertain FGD, 27/08/2010).

This was echoed by a peer educator, who observed that 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?’ (Dec 12 2011).

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’ (Dec 7 2011).

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-endorse FGD, 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 FGD, 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 up 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 FGD, 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 (Dec 6 2011).

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 FGD, 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 FGD, 21/08/2010).

At most, respondents believed 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.¹³ Some

¹³ Prevention of Mother to Child Transmission (PMTCT) involves a drug regimen of antiretroviral medication, given to HIV-positive women while they are pregnant and breastfeeding. In South Africa, the current guidelines recommend a triple-drug regimen taken during pregnancy and breastfeeding, with antiretroviral treatment continuing for women with CD4 counts of less than 350 (Bateman, 2013: 219). PMTCT has measurably reduced HIV transmission between mothers and their children; the rate of transmission was 8-20.2% before 2007, decreasing to 3.5% in 2010 (2013: 218). Although PMTCT is discussed in many web-based and printed health education materials, few clarify the exact mechanism for protection. One website www.PMTCT.org.za, explains that Nevirapine “rapidly crosses the placenta into the fetus with its effects lasting through the first week of life” (pmtct.org.za/docs/nevirapine.php). This does not explain, however, how it is possible for a mother and baby to appear to share the same blood supply for the entire gestation period without resulting transmission. A recent review of virologic and host factors contributing to MTCT acknowledges that “the mechanisms associated with transmission of HIV from HIV-infected mother to her infant are not fully understood” (Selvaraj and Paintsil, 2013: 93). Further clarity came from Dr. Jolanta Piszczek, a clinical pharmacy specialist with the Vancouver Island Health Authority in Canada, who explained that “maternal blood is not continuous with the foetus. HIV infected T-lymphocytes are not transferred through the placenta, and viremic blood for the most part does not mix with the fetus unless these barriers are compromised” (Personal communication, April 16 2014). This means that when

respondents viewed PMTCT as either impossible or a sort of ‘cure in disguise’, reasoning that it could only be a matter of adjusting 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 FGD 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 FGD, 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 (Dec 6 2011).

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

transmission does occur, it is “thought to be related to the breakdown of the integrity of the placenta, leading to microtransfusions of viremic maternal blood across to the fetus”. As a result, giving HAART to pregnant mothers can reduce the likelihood of vertical transmission by lowering the viral load, decreasing “the potential fetal exposure to the HIV virus during the third trimester and delivery when the placenta loses its ability to confer protection”. Essentially, a healthy placenta is the best line of defense, and ARVs taken during pregnancy and delivery can provide a secondary mechanism to protect the foetus and newborn baby.

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, it's 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 be gone? Because the ARVs can make your HIV be undetectable, but it doesn't mean it is gone'. But they ask the same question, like 'why it can't be mixed together'? (Dec 13 2011).

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 (Dec 7 2011).

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 (Dec 12 2011).

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 (Dec 13 2011).

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 (Dec 12 2011).

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? (Dec 7 2011).

A further issue that commonly arose in discussions with CAPS focus group respondents about a cure was controversy surrounding President Jacob Zuma's HIV status.¹⁴ Respondents observed that there is ample evidence that he has had unprotected sex, citing several well-publicised out-of-wedlock affairs and pregnancies.¹⁵ 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 reduce the change of infection (Evans and Wolmarans, 2006; Mail and Guardian, 2006). Respondents highlighted that Zuma had recently announced the results of his public HIV test as negative (Timse, 2010). 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.

¹⁴ Jacob Zuma was accused of raping a 31-year old, HIV positive family friend in November 2005. During the trial for rape in 2006, his HIV status was invoked in several instances. State prosecutor Charin de Beer questioned whether Zuma was, as he claimed, HIV negative, saying that his test result was not submitted to the court. Defence lawyer Kemp J Kemp retorted that the state would have to prove Zuma was HIV positive and that "that was why he could allegedly rape an HIV-positive woman". Kemp argued that Zuma was negative, and that he had judged the risk of HIV transmission during unprotected sex to be minimal (Evans and Wolmarans, 2006).

¹⁵ Zuma has fathered 20 children, some with his three wives and others with girlfriends or mistresses (Pillay, 2010a; 2010b).

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-endorse FGD, 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 (Dec 12 2011).

Snax: Yeah, because people, they say, after that shower thing, it was another challenge for peer educators (Dec 6 2011).

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' (Dec 7 2011).

Several respondents raised the question of whether Zuma was hiding his 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' (N female non-endorse FGD, 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 (Dec 13 2011).

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 man¹⁶ 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 endorse FGD, 11/08/2010).

Leadership

The possibility of a cure was obscured and complicated by contradictory claims from traditional healers, churches and culturopreneurs selling alternative HIV treatments (Nattrass, 2012), such as Matthias Rath.¹⁷ 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?' (Dec 13 2011).

A CAPS 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 FGD, 28/08/2010).

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

¹⁶ This comment is alluding to an earlier part of the discussion about the potential protective benefits of male circumcision.

¹⁷ 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).

Lina: 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 (Nov 25 2011).

A CAPS 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 endorse FGD, 11/08/2010).

Similarly, a male 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 FGD, 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 haven't 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 FGD, 15/08/2010).

These comments suggest how the disjunctures in information discussed above can be exploited by disingenuous people within the community and the state. As a result, 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 and 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 and 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, 2012), 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 and 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 and 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).

Discussion

In discussions of the origins of the virus and the existence of a cure, focus group respondents highlighted the salience of several previous explanations for alternative beliefs. The legacy of state-sponsored racism and historical abuse 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 (Wade *et al.*, 2003; Ataguba and McIntyre, 2012; Mills *et al.*, 2012; Saethre and Stadler, 2013). Though South Africans now live in a post-apartheid democratic country, many still experience and observe inequalities and injustices that can fuel speculations and suspicions about disparities in health care (Scheper-Hughes 1996; Scheper-Hughes 2000; Niehaus and Jonsson 2005; Saethre and Stadler, 2013).

CAPS focus group respondents also reflected on the ambivalent South African experience of globalisation 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 ventured 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 is “one in which the power of science [is]...being felt in more intimate ways” (Nattrass, 2012: 20). The exact mechanism for transmission of disease is not specified in these focus group 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, CAPS 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 – respondents also heralded the potential for scientists to innovate and invent. These observations highlight the mixture of “antipathy and respect” that can characterise people's approaches to modern medicine (Leach and Fairhead, 2007: 31).

In past studies, distrust and disjunctures in information have often been regarded primarily 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 respondents in this study highlight the influence of powerful individuals and reveal awareness of injustices and inequalities, they also 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 population.

Respondents demonstrated how they gauged the truthfulness of the biomedical consensus 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, there remains widespread uncertainty and confusion about the origins of HIV. Respondents drew on these different sources to account for the far higher rates of infection among the Black South African population.

CAPS respondents indicate that the official version of HIV science is not always perceived to align with respondents’ own observable evidence. The claim that no cure exists was refuted by respondents’ overly optimistic assessment of 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 ‘cure-in-disguise’ 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 personal statements and 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 may preclude their trust in HIV science. TAC has noted the difficulty of addressing some of these issues. In particular, TAC highlights the challenges of explaining PMTCT to the public, stating: “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). As with some peer educators’ responses to queries about the origins of the virus, TAC concludes their pamphlet on PMTCT 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, respondents may be more easily swayed by alternative explanations.

By focusing on persistent areas of confusion or doubt, this paper does not mean to suggest that the issue of alternative beliefs can be resolved simply by better education campaigns, as these can tend to represent respondents’ concerns about the trustworthiness of science as “irrational residues” that need correcting (Kaler, 2009). Instead, these beliefs should be viewed as important, “not just as roadblocks to effective public health campaigns but also as a form of local knowledge and “social imagining” (White 2000; Kaler, 2009: 1713). Most crucially for public health campaigns, taking alternative beliefs ‘seriously’ means openly acknowledging the historical and contemporary events that lend plausibility to these theories (Bogart *et al.*, 2008; Larson and Heymann, 2010; Larson and Ghinai, 2011; Nattrass, 2012).

At the same time, researchers and practitioners should address the substantial queries about aspects of HIV science that appear confusing or contradictory. The fact that common disjunctures reflect a disconnect between a respondent’s perception and the official scientific claim raises the possibility that additional information could resolve this confusion and increase respondents’ trust in biomedical claims. These persistent disjunctures include: the origins of HIV, the efficacy of PMTCT, the existence of a cure, and the veracity of HIV testing. Interventions should thus strive to recognize sensitive historical legacies while also paying special attention to the points of leverage indicated in these focus group discussions – that is, the areas where confusion or skepticism exists – and tailor interventions to respond to these suspicions or doubts. Respondents’ enquiries and doubts about the origins of the virus, existence of a cure, or the logic of PMTCT should serve as a reminder that science is constantly being reviewed and reinterpreted by this population using all available evidence.

Divergence and complementarity between qualitative and quantitative data

Though there are myriad examples of congruence between the qualitative and quantitative data in this study, several key divergences emerged, posing challenges in interpreting these data during analysis. For instance, 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 and 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” (2012: 22). That respondents who seemed strongly conspiratorial in the CAPS 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 Slonim-Nevo and Nevo note, divergences provide “information that might otherwise be lost, including possibly new theoretical perspectives on the phenomena under investigation” (2009: 110). 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’ observations 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 none may exist.

These findings are consistent with previous quantitative research in both South Africa (Bogart *et al.*, 2008; Tun *et al.*, 2012;) and the US (Bogart and Thorburn, 2005; Bogart, Wagner, Galvan, and Banks, 2010), wherein respondents were far more likely to endorse the idea that HIV was an accidental 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 the methods section, the composition of focus groups may have been skewed towards less conspiratorial people, as those who distrusted

scientific institutions more may have been 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, may have shifted their views in the interim or chosen 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 than in surveys. He hypothesized that 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. This suggests that respondents were sincerely describing the non-malevolence of alternative beliefs rather than simply moderating their opinions because they were part of a group discussion. 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 by 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, Wagner, Galvan, and Klein, 2010) or ethnography (Rodlach 2006; Steinberg 2008a; Wilson 2008; Kaler 2009). Steinberg highlights how long it can take to uncover a respondent's sincere beliefs when they feel cautious about revealing themselves. After knowing his protagonist for many months, they go on a trip together, at which point he writes: "For all our talk on the causes of AIDS, it had taken this trip to Nomvalo¹⁸ 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). In the current research, the inclusion of the interviews with peer educators was intended as a check on the cross-sectional nature of this study, by collecting data about clients' concerns, doubts and areas of confusion from 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 and confusion 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,

¹⁸ Nomvalo is a town in the Eastern Cape province of South Africa.

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 more complete picture of a population's beliefs about the trustworthiness of information about HIV. In the present study, measuring areas of confusion alongside mistrust and conspiratorial belief was also revealing. Respondents expressed mistrustful beliefs – such as the belief that a cure was being hidden from South Africans – as well as confusion or misperceptions – such as the lack of understanding of how PMTCT worked.

Conclusion

This paper highlights how young African men and women living in Khayelitsha account for the plausibility of alternative accounts about the origins of the virus and the existence of a cure. 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 and combined with awareness of certain aspects of HIV science that did not 'add up', fuelled respondents' beliefs in alternative views about HIV and 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; Leach, 2007; Larson and Heymann, 2010). 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.

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, 2009; Bogart, Wagner, Galvan, and Banks, 2010). Subsequent research could examine the extent to which various sources of information about HIV are trusted as a point of entry for future interventions.

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Appendix 1: 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 2: Peer educator topic guide

Introduction

Throughout this conversation, please adapt this guide in response to participants' comments. If the peer educator seems very comfortable speaking personally about their experiences and beliefs, ask them more direct questions. If the peer educator is self-conscious, ask more general questions. Above all, ask “why?” and “how?” as much as possible – as well as ask for examples – as that will help us understand certain experiences, opinions and behaviours more thoroughly.

Explain procedures

We are interested in asking you about your experiences as a peer educator. We will be taking notes and tape recording the discussion so that we do not miss anything you have to say. Everything is confidential, so we will not identify you by name.

General questions and themes

- Can you tell us about your work with TAC as a peer educator? How long have you been involved with TAC? What is your current job with them (are you a community health worker, a treatment literacy advocate or a different kind of peer educator?)
- How do you feel about the work that you do with TAC? Do you enjoy it? Is it difficult? Ask for examples about satisfying and unsatisfying parts of their job.
- What kind of challenges do you face in the course of your work as a peer educator? Tell us about some of these challenges, and please provide examples whenever possible.

[If peer educator includes ‘denialism’ of AIDS science (“sometimes people don’t believe that ARVs work”), or something related to this, probe in more detail. Ask for examples. Otherwise, continue to the next theme].

- Do community members ever question the accuracy of the information you are giving them? How often does this happen? What kinds of things do people have doubts about?

[If the peer educator does not have immediate examples, you can probe further – ask specifically “do people express doubts about ARVs/condoms/a cure/where HIV came from originally?”]. Ask for examples.

- When they are challenged by community members about their scientific accuracy, how have they responded? Do they explain again? How does that usually work? Ask for examples.
- How easy is it to convince community members about certain facts about HIV science? What techniques have they used to make their job of communicating complex scientific facts easier? Do they tell stories? Draw pictures? Get other people involved? Ask for examples.

Please thank them for their time and ask if they have any further questions.