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Peer educators' responses to mistrust and confusion about HIV and AIDS science in Khayelitsha, South Africa

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Abstract

Peer educators are on the front lines of communication between sources of scientific authority about HIV and AIDS and target populations. This study focuses on a group of peer educators from the Treatment Action Campaign working in Khayelitsha, South Africa (n=20), highlighting perceptions of their treatment literacy activities and the challenges faced in these encounters. In order to maintain clients' trust in themselves and their information about HIV, they employ various "rhetorics of persuasion", including accurate mobilisation of biomedical facts, personal testimonies, and figurative language such as parables and metaphors. These tactics build on community members' everyday observations and experiences and draw from peer educators' own credibility and trustworthiness as TAC members, and as members of the community. This paper draws attention to the ways in which peer educators' personal agency and judgement are brought to the task of peer education, as well as the implications for future programmes using treatment literacy to advocate on behalf of biomedical facts about HIV and AIDS.

Introduction

Doubts, uncertainties and alternative beliefs about the origins, spread and treatment of HIV and AIDS, have been documented in numerous countries (Farmer, 1992; Bogart and Thorburn, 2005; Burns *et al.*, 2007; Bogart *et al.*, 2008; Robins, 2009a; Grebe and Nattrass, 2012; Rubincam, 2014). In South Africa, the country with the largest absolute number of people living with HIV, a significant minority of the black South African population have been documented as having alternative beliefs about HIV and AIDS (Grebe and Nattrass, 2012; Rubincam, 2014), and have been associated with lower levels of condom use (Grebe and Nattrass, 2012), lower levels of reported HIV testing (Bogart *et al.*, 2008; Tun *et al.*, 2012), and lower reported adherence to antiretroviral medication (Bogart *et al.*, 2010).

In response to these beliefs, some scholars have recommended enlisting trusted sources of information, namely community leaders (Bogart *et al.*, 2010; Larson and Heymann, 2010) and peer educators (Bogart and Thorburn 2005; Bogart *et al.*, 2010; Bogart *et al.*, 2011) to build trust and understanding within target populations. Peer educators are anticipated to employ their significant social and cultural capital with peers to act as "antennae" (Dickinson, 2011) within their communities for beliefs expressing mistrust and confusion. Once such beliefs have been identified, peer educators can act as "brokers" on behalf of biomedical science, by employing various "rhetorics of persuasion" to disseminate scientific information, reiterate the reliability of key sources of scientific authority, and clarify uncertainties (Robins, 2009a).

There are good reasons to believe that peer educators could be helpful allies in efforts to spread biomedically sound, culturally-appropriate information about HIV and AIDS. The use of peer education in HIV prevention interventions is common, with one study estimating that 60% of major HIV prevention NGOs carry out peer education (Kelly *et al.*, 2006). On the principle that "learning occurs most efficiently when individuals are trained by their 'near peers'" (Rice, 1993), peer educators are recruited from the same communities in which they are expected to serve so that their messages are more culturally resonant (Bastien, 1990; Standing and Chowdhury, 2008; Vale, 2012). Peer educators build on their existing trust and credibility with the target population, with whom their familiarity is assumed to foster greater trust (Mitchell *et al.*, 2006; Dutcher *et al.*, 2011;). Some peer-based programmes have had measurable impact on knowledge about HIV (McKirnan *et al.*, 2010). For example, a meta-analysis conducted on peer education in HIV prevention and treatment programmes in developing countries showed a significant effect on improving HIV knowledge and condom use (Medley *et al.*, 2009).

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

"friction" in their interactions with the targets of these interventions (Robins, 2009a).

Whereas in some cases resistance may arise because their message is deemed unreliable, in other cases peer educators themselves may be deemed illegitimate or untrustworthy. In such circumstances, peer educators' familiarity and informal status within the community, indicated through their lack of "symbolic markers of authority", such as uniforms and technical instruments, may make their authority suspect to both clinical professionals and patients (Vale, 2012: 2). If peer educators are viewed as less knowledgeable than formal health workers, they may struggle to achieve authority and maintain credibility about scientific facts in the eyes of the very people they strive to influence (Standing and Chowdhury, 2008). Other factors affecting their trustworthiness include whether they are seen as exemplary or hypocritical; for instance, peer educators who counsel others on drug abuse yet continue to use drugs themselves may be deemed less credible (Mitchell *et al.*, 2006).

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

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

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

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

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

Given the central role peer educators are expected to play in promoting trust in, and understanding of HIV science, it is important to consider how they approach this task and navigate these various challenges. The purpose of this paper is to explore how peer educators working with the Treatment Action Campaign respond to mistrust, confusion and alternative beliefs about HIV in Khayelitsha, South Africa.

This paper is divided into three main sections. After a discussion of the methods used to collect and analyse the data, the results section focuses on the content of interviews with peer educators, highlighting the perceptions of their treatment literacy activities, the challenges faced in these encounters, and their responses to questions, doubts, and confusion. The discussion section suggests that peer educators are frequently called upon to advocate on behalf of HIV science, necessitating accurate mobilisation of biomedical facts and personal testimonies alongside creative discursive strategies. This section draws attention to the ways in which peer educators' own agency and judgment is brought to the task of peer education as well as the implications for future interventions of this nature.

Methodology

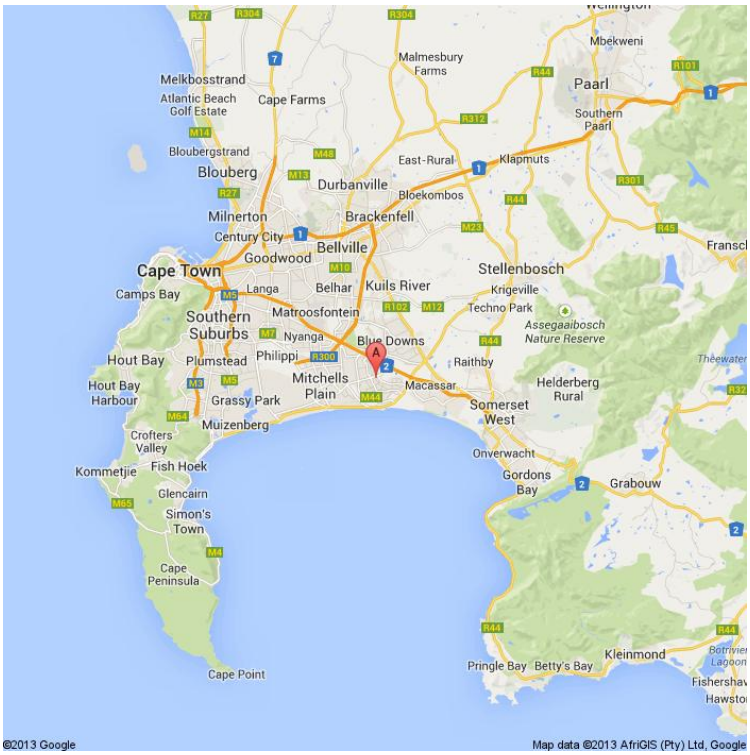
Study setting

Research for this study was conducted in Khayelitsha (Figure 1), a township located approximately 30 km outside of Cape Town. It was created artificially in the 1980s by the apartheid government, separated by distance and poor transport links from the white suburbs and the city bowl. Often said to be the fastest growing township in South Africa, it has a population of 406,779 (as of 2005), making it the 20th largest city in the country. Over 95% of its inhabitants identify themselves as Black African and 96.8% speak Xhosa as their first language. Approximately 62% of its residents originate from the Eastern Cape province making Khayelitsha a city of people who have made the rural to urban transition[1]. Economically, Khayelitsha remains very poor, with approximately

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

70% of its residents still living in informal houses, and over 50% of residents being unemployed.

The Treatment Action Campaign (TAC) became involved in Khayelitsha shortly after its founding on the steps of Cape Town's St George's Cathedral in 1998. The intention was "to establish volunteer-run branches in Cape Town's poorest townships to educate people about AIDS and alert the rest of the organisation to problems at their local clinics and hospitals" (Geffen, 2010: 52). Khayelitsha's clinics, in partnership with Medecins Sans Frontieres (MSF), piloted ARV treatment in South Africa in 2001[2]. By 2011, over 20,000 people had been put on ARV treatment in Khayelitsha (Treatment Action Campaign, 2012). The attention devoted to Khayelitsha's ARV programme and the resources from MSF make the public health facilities in Khayelitsha better than in most public clinics in other areas, though long queues and wait times are still part of the norm (Geffen, 2010).



Source: Google Maps, 2013.

Figure 1: Location of Khayelitsha, South Africa

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

Starting in 2002, the TAC's Treatment Literacy Programme (TLP) became one of the most prominent and developed programmes of its kind[3]. It was designed to mobilise against the government's AIDS denialism by teaching HIV science to the public. Conducting widespread instruction on how HIV works, as well as how ARVs operate, enabled the TLP to demystify HIV science to people with limited formal education (Steinberg, 2008; McNeill, 2009). TAC has described the importance of understanding all aspects of HIV treatment:

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

In teaching people about HIV, the TLP "tries to change the idea that understanding scientific and medical information is only the business of healthcare workers, scientific researchers or trained traditional healers" (Treatment Action Campaign, 2006: 3–4). Geffen highlights the centrality of local TAC branches, particularly their treatment literacy programmes, 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 realise that the denialist message, promoted by Mbeki and filtered down through the ANC's structures, was wrong" (2010: 192). The success of earlier experiences of Treatment Literacy activities worldwide were important to TAC's approach in that these activities show "that 'ordinary' people have made it possible for poor people to access these medicines and information about them in a way that governments would never have done" (Treatment Action Campaign, 2006: 4). This treatment literacy model was based on the activities of US activist organisations such as Gay Men's Health Crisis (GMHC) and ACT-UP, who came to South Africa in 1999 to train local HIV activists in their techniques (Heywood, 2009: 17).

Two types of peer educators operate within TAC's organisation. Treatment Literacy Practitioners (TLP) are TAC volunteers who have been trained and have passed an examination of techniques for disseminating HIV information

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

(Heywood, 2009). Community Health Advocates (CHA) organise public health education and advocacy campaigns (TAC, 2009). In the Khayelitsha office, the key distinction between these two types of TAC employees was that TLPs educate the public in health clinics and CHAs conduct door-to-door educational activities.

Methods

Community Health Advocates (CHA) and Treatment Literacy Practitioners (TLP) – hereafter referred to collectively as peer educators - who work for the Treatment Action Campaign in Khayelitsha township were interviewed in 2011. In-depth interviews were conducted to provide insight into alternative beliefs about HIV/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. The range of questions covered in one-on-one interviews included:

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

Twenty in-depth interviews with peer educators were undertaken, 13 with female peer educators and 7 with male peer educators, including two with the leaders of the Treatment Literacy Programme and the Community Health Worker programme. Five were current or former CHAs, 14 were current or former TLPs, and 1 worked as a condom distributor. They ranged in age from 24 to late-40s and had worked for the TAC for between 1-7 years. The characteristics of the peer educators in this sample are set out in Table 1.

All participants were given the opportunity to select a pseudonym in order to shield their identity. Interviews were tape recorded, transcribed and, if conducted in Xhosa, translated into English. Research ethics for this project were reviewed and approved by the Centre for Social Science Research at the University of Cape Town and the London School of Economics.

Table 1: Peer Educators from TAC Khayelitsha Office

Number	Pseudonym	Type of peer educator	Language of Interview
1	Lina	CHA	English
2	Velile	CHA	English
3	Sobza	CHA	Xhosa
4	Sonia	Trainer CHA	Mixed
5	Abongile	CHA	Xhosa
6	Nthabiseng	TLP	English
7	Snax	TLP	English
8	Pretty	TLP	Xhosa
9	Andile	TLP and Trainer	English
10	Pemeido	TLP	English
11	Nomandithini	TLP	Xhosa
12	Lloyd	TLP	English
13	Neliswa	Former TLP, now District Coordinator	English
14	Chunyiswa	TLP	English
15	Bonelwa	TLP	Xhosa
16	Nonqaba	TLP	Xhosa
17	Poppy	TLP	English
18	Isaac	Condom distributor	English
19	Ntombekhaya	TLP	Xhosa
20	Amelia	Coordinator of TLP	English

Analysis

Qualitative data analysis of both the fieldnotes and interviews with peer educators was facilitated by the use of Nvivo software (Nvivo, 2009). Data was analysed using open-coding (i.e., identification and categorisation of recurring patterns), and axial coding (i.e., re-examination of categories to see how they are linked), marginal remarks, comparisons, and memo-writing (Strauss and Corbin, 1990). Initial analysis was approached as an interactive process, with data abstracting, coding, and categorisation as a simultaneous enterprise for the purpose of identifying and/or confirming major themes and patterns. The research assistant who assisted in interviews was involved in reviewing the transcripts, discussing emerging concepts, and triangulating across perspectives to compare interpretations and impressions of the data (Denzin and Lincoln, 1998).

Results

Questions, Doubts, and Alternative Beliefs

Peer educators reported hearing a range of questions, doubts, and alternative beliefs about HIV and AIDS. These results have been discussed in detail in Rubincam (2014) and will be briefly summarized below.

One of the most common queries peer educators reported hearing from clients focused on the origins of HIV. One peer educator stated that "they asked us a lot!" (Nomandithini) while another claimed that the question came from people all around them, including familiar sources, "even my daughter, even my sons!! Even our cousins!" Some peer educators reported comments about the role of westerners and white people in the spread of HIV. One peer educator explained, "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" (Bonelwa). Another confirmed, "Yes, there also people who say that it came with white people, because many people who are HIV positive are people who are black" (Nonqaba).

When asked where they thought these kinds of beliefs came from, several peer educators connected it to the history of apartheid in South Africa. "Some they just say 'whizt, this is a disease from white people from apartheid, you know?'" (Xoliswa). Another peer educator thought "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 (Loiso).

Some people blamed foreigners for the origin or spread of HIV – although the most commonly blamed group was not westerners, as some conspiratorial explanations would suggest, but rather people from other African countries.

> Nomandithini: If you notice there will be someone who is dating a Nigerian or a foreigner. They get stigmatised along the lines of "You sleep with a foreigner! You are you going to get HIV! There's their HIV" and there's this thing that their HIV is different – it's not the same as ours, although we know that there is only one HIV.
>
> Snax: Most of them they say it's like Zimbabweans.

In addition to probes about the origins of HIV, peer educators identified other common areas of confusion, doubt and mistrust that their clients raised in their interactions. Many reported that clients asked about whether a cure currently existed for the virus.

> Nomandithini: And that [a cure] also comes up a lot – people ask us a lot and people say "the cancers were there and they have cures and other sicknesses have cures. But what's wrong with HIV?" and we usually explain to them that HIV is the strongest virus.
>
> Nonqaba: Yho! [exclaims] They are always asking about it [a cure] – 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?"
>
> Loiso: Exactly, they are asking about that cure. When, why there is a treatment but there is no cure?

While some clients merely wondered why a cure had not yet been discovered, others believed that it already existed but was being withheld.

> Pam: A lot. A lot of, 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'.

Some churches were adding to the confusion by claiming to cure the faithful.

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

Connected to the skepticism about a cure was the issue of Prevention of Mother to Child Transmission (PMTCT). Peer educators recounted how their clients expressed confusion 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.

Similarly, the revelation that patients could exhibit undetectable viral loads 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 mind-set that 'It's not the ARVs, it's the pastor's prayer!' and so that's one of the big challenges that we get.

Another common topic focused on the controversy surrounding Jacob Zuma's rape trial and his subsequent HIV test[4]. Zuma's public pronouncement during his rape trial in 2006 that he had showered after having unprotected sex with an HIV positive woman in order to protect himself from infection was viewed as particularly problematic. Peer educators stated that they faced numerous questions about 'the shower':

> Interviewer: Yes, about uZuma and the shower?
> Xoliswa: Alright. He confused so many people about that statement he made about it. Yes he did.

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

[4] Jacob Zuma was accused of raping a 31-year old, HIV positive family friend in November 2005. During the trial for rape in 2006, he notoriously said that rather than use a condom, he had showered after having sex with the woman in order to reduce the change of infection (Evans and Wolmarans, 2006; Mail and Guardian, 2006). His HIV status was invoked throughout the trial 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).

Coupled with confusion about 'the shower', peer educators reported that Jacob Zuma's public HIV test in 2011 also raised doubts in people's minds about whether the test had occurred at all, and whether the results could be trusted. Peer educators reported that President Zuma's contradictory behaviour and public statements led clients to doubt the veracity of public statements about HIV. 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-counselling and post-counselling, everything, and then the prick, and then the results on the blood is there.

In short, peer educators reported common topics of confusion, doubt, and alternative beliefs among their clients, including questions about the origins of the virus, the existence of a cure, the logic of PMTCT, and the public disclosure of Jacob Zuma's HIV status. Their strategies for addressing these topics and others are presented in the next section.

Rhetorics of Persuasion

Given the fraught terrain in which they operate, where scientific information about HIV is greeted with doubts, confusion and skepticism, peer educators are keenly aware of the need for clarity and consistency. They report using various "rhetorics of persuasion" (Robins, 2009a) in their attempts to build public understanding of, and trust in, HIV science. These include providing straightforward scientific explanations for various concepts, exercising judgment about what facts to share and how to share them, drawing examples from their personal experience while taking into consideration the experiences and observations of clients, and using stories and metaphors to clarify uncertainty and confusion.

Scientific Explanations

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

Pemeido: So the big words, the scientific big words, the bombastic[5] words, sometimes people get confused, so you have to clarify each and every, define each and every word and try to make people understand what you're talking about, and try to differentiate the virus and the bacteria. So people can understand what exactly you're talking about.

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

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

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

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

In trying to clarify clients' persistent questions about the origins of HIV, peer educators describe the explanations they provided, drawing on the training they

[5] This word was sometimes used by TAC peer educators to describe scientific terminology. This raises the question of the extent to which this word represents scientific terminology as pompous, overbearing or exaggerated. This is not the only time scientific vocabulary has been termed as such; in a critical analysis of Beckett's *Waiting for Godot*, Velissariou states, "Didi and Gogo play incessantly with words; they treat the same word as its opposite, they find synonyms, they use scientific terms because they sound bombastic, they rhyme". In doing so, they dismantle and parody "the pretentious rhetoric and logic of conventional philosophical thinking" (Velissariou, 1982). Rather than this wholly derogatory connotation, however, a former TAC employee thought that this usage among peer educators signalled that "the terms are difficult and exclusive, not accessible" (Personal communication).

received from their supervisors and the staff at MSF, as well as their own research.

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

> Snax: There was Dr. Dave, we were having a training at UCT, and we asked about 'where does HIV come from, please won't you tell us', and Dr. Dave tells us that HIV is from the chimpanzee. Because, I say "okay, how did we get it from the chimpanzee", animals?

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

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

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

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

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

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

> Nomandithini: When you have sex, HIV stays in the blood and in your bodily fluids – we know this. It won't just go away by washing. We have washed for years and people have taken showers for years. If that were the case then I would simply have to take a shower after having sex. So which means we wouldn't have as much HIV then. You see?
>
> Chunyiswa: It lives in the blood and if you go to church, you heal your spirit not the blood.
>
> Lloyd: We cannot worship so that the illnesses go away. But spiritually, we can go to the church and worship so that you can be cured spiritually. Not physically.

Experiential Proof

Whenever possible, peer educators spoke to respondents' "street-level epistemologies of trust" (Hardin, 1992), drawing on experiential aspects of everyday life in Khayelitsha in order to lend practical plausibility to their claims. As Robins observed in his study of HIV advocacy in rural South Africa: "There appears to be an agnostic and experimental attitude towards both modern medicine's 'magical drugs' and the claims of traditional healers and diviners", necessitating "concrete, observable evidence" of the truthfulness of any claims (Robins, 2009a: 102). In order to buttress their assertions, peer educators constantly referenced their own experiences as people living with HIV, pointed out illogical aspects of myths and misinformation, and used easily observable data to prove their argument. When one peer educator was asked whether her clients trusted the information she gave them, she answered, "Yeah, they do. Because we are telling them about the practical things that they see. So they do. They do" (Chunyiswa).

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

trust us. We give them detailed information. We don't just give and leave them.

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

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

Peer educators were conscious of the importance of maintaining their credibility and described instances when they had doubts about the information they were sharing. This was particularly the case when it came to discussions about the origins of HIV.

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

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

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

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

> Isaac: It's simple, the research is been still going on, they can't say at the moment that HIV is coming from where.
>
> Bonelwa: But then we answer then and say that no one knows quite exactly where HIV comes from – there are various stories – what we are still getting are just stories, that it came from animals, so some people have differing information and some people say it came from white people and some say it came from this and that place – so there isn't yet a tangible response to where HIV came from.
>
> Lloyd: Ah, HIV, the first case of HIV was found in Egyptian mummy[6].
>
> Nthabiseng: I also heard a story that there were hunters up in Africa, whereby the hunters used to go and take months away from home, and then a hunter met a chimpanzee and sort of had sex with a chimpanzee, not knowing that the chimpanzee had this virus on it. And then it's whereby a human had this virus from a -- I sort of told them they got it from a chimpanzee. It's whereby, because the person came back home, and he slept with his wife, and then it's starting to spread.

In such situations, peer educators fell back on their scientific training and their own personal experience. Though peer educators in this study were not always completely certain about their information, they claimed not to hesitate from seeking help when they felt they did not know the answer to a client's question. Every peer educator interviewed spoke unselfconsciously about searching for new evidence, exploring better ways of explaining things, and seeking clarity on difficult topics from fellow educators, trainers, doctors or the internet.

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

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

> Akhona: I tell them that I am going to go do some research on it. No, I am very open with them and I tell them that "I do not know the answer to this one – give me a chance – tomorrow I will come back with the answer, or if you are not here tomorrow, the next time you come back for your appointment, just call me and I will respond to you!".
>
> Bonelwa: I will answer the ones I can answer and the ones I do not know I won't answer, and questions that concern the doctor I will go ask the doctor for them or I will go get the information myself from the doctor. Do my own research and bring back the information.
>
> Nomandithini: And with information – yes, we have it, but there are some things which we find we don't know and we can't say to the people when they ask us questions – we can't lie. We can't lie because that lie might backfire on some other day.
>
> Nonqaba: Most of the information I have I get from TAC – at MSF, at those workshops and then at the trainings.

Peer educators in this group felt that asking for help boosted their credibility with their clients, by showing that they would not pass along information of which they were unsure. Having explored instances where peer educators were uncertain about how to convey scientific information, discussion will now turn to certain occasions when peer educators engaged in more deliberate shaping of their messages around HIV.

Exercising judgment

Peer educators were concerned about revealing certain types of health information to their clients when they worried that it would have unintended consequences. They were also mindful of the need to remain trustworthy to their clients, and sought to manage the dissemination of information in ways that would not undermine this trust. According to them, the recurring examples of difficult issues were undetectable viral loads and alcohol use among HIV positive patients.

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

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

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

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

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

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

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

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

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

Pemeido: Yeah, we were keeping the information before, until recently, when we went to a training and the doctors told us that it's

> very much important for us to tell the people, you know, because we need to be transparent, we need to tell them everything. Even though we didn't tell them, but they knew because they were reading it on newspapers and in books and stuff, and even Equal Treatment, that we distribute in our clinics, it had the same information. So now we tell them.

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

> Snax: Nah, I release it into the community. I say that, if the doctor says that your viral load is undetectable, meaning that there is no virus, so meaning your CD4 count is 100% good, that doesn't mean you must stop your ARVs.
>
> Bonelwa: We tell them. Because these news comes out even on the TVs and radios – or it just written about in the newspapers. We tell them.
>
> Poppy: No, I do tell them, because I want to encourage them to take their treatment. So that their virus can be undetectable. And I tell them, if your virus is undetectable, it doesn't mean that you are cured. It means that it has been suppressed by the ARVs. That's the evidence of the ARVs.

These peer educators were acutely aware that information about undetectable viral loads was unlikely to remain private for long; it would only undermine their credibility and trustworthiness if they failed to disclose this information to their clients.

As with undetectable viral loads, peer educators faced challenges while advising clients about mixing alcohol with antiretroviral medication. Alcohol use was cited as an impediment to proper adherence and defaulting. All peer educators felt that mixing the two substances created the possibility for a drug interaction with potentially harmful consequences[7]. However, they also recognised that

[7] There is no scientific evidence to support a total ban on alcohol use by people using ARVs. Rather, as Steinberg highlights, peer educators and other community members have sometimes used their authority to prohibit alcohol use among HIV-positive people. Eric Goemaere, head of MSF in South Africa, reported to Steinberg that the prohibition on alcohol use was created by activists and lay counsellors: "If you want to create a club, you must create

clients would frequently default from their treatment if they were drinking. Peer educators spoke about the difficulty of banning all alcohol consumption. Many preferred to engage with the practical realities of daily life in Khayelitsha, advising clients to enlist the help of a friend to ensure they continued to take ARVs even if intoxicated.

Several had been urged by doctors and nurses to embrace a position of compromise, whereby clients would be told to drink in moderation while remembering to take their ARVs. This seemed to reflect a change of policy, from one of warning of the dangers of mixing alcohol and ARVs to recognising the inevitability of alcohol intake. Again, peer educators were in the center of this debate, and were involved in communicating this change of policy to clients and community members. This sometimes placed peer educators in awkward positions vis-à-vis their clients.

> Pretty: So some will ask – "Can we drink alcohol?" and we tell them "Don't drink whilst you're on ARVs!" and the sister in charge, Sister Mpumi from Ubuntu [clinic] came out and told them outright that "Dear people we know it's holidays and you will be heading home – you are going to get drunk. Get drunk! But make sure you take your ARVs!" and I could see that they were all interested in what Sister Mpumi was saying. And they were all saying "Really? Really?" and yes, fine, we'd heard about this thing that "if you drink alcohol you can still take your ARVs", but we never put it out there. So now, we had no choice – because Sister Mpumi had let it out and we were forced to speak about it, "No, she is right – if you're going to drink alcohol make sure you take your ARVs though!" So now we are promoting that people continue drinking! You see?
>
> Bonelwa: Well, I haven't spoken about the issue of ARV and alcohol. Because it confuses people. Because we just told the people recently – that alcohol and ARVs don't mix. And so I haven't spoken about this issue of alcohol and ARVs. I still stop them from indulging in alcohol. Because if we release it, they are going to see that alcohol does nothing when I mix it with ARVs.
>
> Nomandithini: What happens is that we advise them and we show them the danger of drinking and at the same time we advise them to

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rules. Because otherwise everyone is in, which means nobody is in. It is amazing: they set up artificially a number of rules; it was never pushed by us. And they give challenges to each other" (Steinberg, 2008: 181).

take their pills even if they have drunk alcohol. But at least they must have limits.

As with the issue of the cure, peer educators were keenly aware that clients gathered information from their own experiences and used it to challenge inconsistent claims.

> Nonqaba: Ja, the challenges are adherence, alcohol and ARVs – there, there is also a conflict that exists. Because there is a side of people who say they've been using alcohol since they started ARVs and they have no problems. So they are sharing stories – that you are trying to give information to new clients, so they come with their old stories that "I have been taking these ARVs and drinking alcohol and I am still alive! So this thing you're saying – I won't understand! And I do test my blood and it's undetectable! So you are talking nonsense!" So it becomes challenging in that sense.

The use of parable and metaphor

In this context, where complex scientific information needs to be conveyed so that it can be easily understood, some peer educators reported using creative strategies to explain difficult concepts or to make an emphatic point. Many said that they employed figurative language such as parables or metaphors to clarify a concept that was not easily accessible on a purely scientific level. In doing so, they attempted to build the public's trust in HIV science by rendering its concepts more accessible to people with limited science education.

Metaphor is described by Aristotle as "giving the thing a name that belongs to something else" (Aristotle, 2004: 32). This study follows the distinction made by Lakoff and Johnson between two different types of metaphor (1980). While 'conventionalised' metaphors refer to those expressions that have become so commonplace as to enter into everyday usage without deliberate thought (e.g., the leg of the table; the eye of the storm), the more noteworthy category of 'conceptual' or 'novel' metaphors is seen as a device to expand language so as "to create new ways of understanding" (Kirklin, 2007: 12). Thus, while the former type of metaphor is a figure of speech, the latter creates new meaning "to fill a semantic lacuna" (Kirklin, 2007: 12). Parables are extended metaphors, used allegorically, in which one thing is described as another in a short story (Dickinson, 2011).

In this study, peer educators used metaphors and parables to clarify crucial facts. One of the recurring challenges for the peer educators were defaulters, people

who would begin ARVs when they were ill yet would stop treatment once their health was restored. In communicating with and about such patients, several peer educators used a snake metaphor to reiterate how important it was to continue treatment once it had been started:

> Bonelwa: Ja, well I do have my own example for the pills. I usually say take a snake, place a rock on the snake and when you remove that rock off the snake – the snake moves fast you know – so it will have energy and anger to the extent that it will want to bite you now. And then now if that rock on top of that snake stays there – that snake doesn't have the energy to bite you. So it's also like that with HIV – if you take your pills you are suppressing HIV so that it won't rise or duplicate itself with you.
>
> Nomandithini: For example, like in Xhosa I usually make an example – particularly for those who default. A person just says, "No, I am tired of these pills I won't take them! I see no difference whether I take them or not!" and then I make an example of a snake – if you place a rock on top of a snake and it doesn't die and wakes up, once that snake wakes up, it'll wake up stronger and even if I the person who place the rock on it ran away – you the person who was just walking along the road innocently, it'll just come to you with the anger I caused it. You see? And it'll just destroy everything much much more than it did before the rock was placed on it. Maybe it hadn't done anything before you put the rock on it, but after the rock it wakes up much more angry. And it wakes up much stronger. So I give them that example in the side of defaulters.
>
> Nonqaba: The snake is your threat. So if you want to protect or fight safely with that snake you must get a stone and put it on top of it – because you won't be able to kill it if you don't have the strength to kill it. So for you to be safe, just at least take a rock and press it down there.
>
> Chunyiswa: I use a good example of a snake, that if you find a snake, then you take a – sorry, my English is bad – you take a stone, and you put it on a snake. Then that's how ARVs work. But if you stop them, then you are lifting up the stone and then the snake will be dangerous and come and bite.

Individual peer educators would vary the snake story in small ways, but all who used it had the same underlying point: stopping antiretrovirals after you have started them carries great risks. Similarly, when trying to explain to clients how

HIV enters the body and operates with impunity against the body's immune system, peer educators repeatedly told a story about an outsider, sometimes a 'thug' or criminal, trying to gain entry to a school. Recognising that entry would only be granted to those wearing identical uniforms, the thug steals or otherwise obtains a uniform, enters the school in disguise, disables the school principal, and is therefore able to enact his malicious plan.

> Pretty: Like for example, I like to use – like when I am trying to show them how HIV enters the body – like for example I usually make an example with school, the Masiyile School, when you are at that school you wear a brown school uniform and then once someone from Matthew Goniwe [a nearby school] wearing a grey uniform and enters this school – if he wants to cause trouble and make the school corrupt he will get a brown uniform too, so as to blend in as well, and others won't know he's not from Masiyile. Because if he comes in wearing the Matthew Goniwe uniform they will see that he is not from here. So he'll wear a brown uniform and then start influencing all the other children inside to do as he does. And then all the children become rebels. So it's like HIV when it enters the body – it comes in and camouflages itself and looks like your body's soldiers and once it looks like them it starts eating those soldiers in your body. And then it becomes clearer for the people then. Whereas if you are going to talk about DNA and this and that about the condom and so on – you have already lost them.
>
> Nomandithini: You have to first have to get a school uniform that is going to look like that of the other children, and then you can come in and see all the things that are inside. Like HIV enters it comes in and checks out the security of the body or you just kill the security guard and wear its uniform.
>
> Lloyd: And when you are inside, you can change the whole school, to do your focus, because you are not having the same focus as the people at this school. But you came as an opportunist. That's how HIV attacks our CD4 cells. So I make those stories, I create those stories so that people can have a broader picture of what we are trying to educate them.
>
> Neliswa: We are at school, and then there is this guy who wants to come, maybe a gangster who wants to come and kill somebody in the school. But because of that particular gangster is not wearing our same uniform, he can't be allowed to get inside to do whatever he wants to do inside.

As with the snake parable, though the level of elaboration and certain details changed with each peer educator's unique telling, the overall message of the story was the same. It is similar to a metaphor used in a TAC pamphlet to describe how HIV interacts with the immune system. Entitled, "HIV, the thief", it states:

> 'HIV is a thief that comes to a house (CD4 cell) and has a master key to open the door lock. The thief will come and open the door and see what is inside the house that s/he wants. The thief will look around the drawers, everywhere, sit on the chairs and make him or herself feel at home. Then, s/he will take all the things s/he wants and destroy the house. When the thief leaves the house, s/he goes to find another house that has not been robbed. The thief breaks into this house, takes what s/he wants and destroys the home. All the homes in the neighbourhood are soon robbed by the thief and his or her friends. So they go to other neighbourhoods and rob those homes. Eventually, all the homes are destroyed by the thieves. Similarly, this is what happens when we have been infected with HIV. Our immune system makes many CD4 cells – the home in our example – because we are trying to kill off the virus' (Treatment Action Campaign, 2006: 18).

Given the evidence that a high level of congruence and cultural understanding between patient and metaphors is needed if this is to be an effective communication strategy for medicine (Fuks, 2009; Fuks *et al.*, 2011), it is not surprising that the metaphors and parables found effective by peer educators contain some familiar objects, events and experiences from everyday life, such as schools, snakes, crime, and, as discussed below, football. In a 2006 pamphlet for treatment advocates, TAC highlights how a metaphoric explanation could be used to explain how the immune system works. Under the heading "Immune system is like the Bafana Bafana team", it states:

> 'In a football team, there is a coach, the CD4 cell (T helper cell), who works out ways in which the team can be successful and win its matches. It also co-ordinates and keeps watch that each person is playing their role and understands best what is each player's weakness and strength. Then there are the player categories: the midfield or defenders who make it hard for the other team, HIV, to come close to a place where they are likely to score a goal, there are the strikers who try to score goals for their team and run fastest, there is the goalie who makes sure that even if the other team has managed to go past the defender and come into the territory of his team to score a goal he tried to prevent them from doing so. So, you can see that each person has their role and sticks to it and that everyone works together as a

> team to achieve the one goal – to win the match! A similar process happens with the immune system' (Treatment Action Campaign 2006, 13).

In his work documenting stories and parables used by peer educators, Dickinson points out that "a noticeable feature of the stories is the relevance of the plots and contexts to the target audience" (Dickinson, 2011: 338). A meta-analysis of the influential effects of metaphor found that "the persuasive impact of metaphor is maximized when the audience is familiar with the metaphor target", suggesting the need for shared social and cultural experience (Sopory and Dillard, 2002: 413).

Though these metaphors could potentially enhance understanding of scientific concepts, peer educators also spoke about the possibility of creating further confusion. This was the case even with the simplest metaphor, as when the immune system was described as the 'body's soldiers'[8]. This metaphor was used by TAC (referring to '*amajoni omzimba*' as "soldiers of the body") in official pamphlets in order to explain how white blood cells function[9] (Treatment Action

[8] The origin of the depiction of the human immune system as 'soldiers' has been debated. Ashforth and Nattrass discuss the claim that this is an ancient Zulu notion but conclude that, "It is, most likely, a Zulu translation of the concept of immunity. "*Amasojha'* is, after all, a phonetic rendering in Zulu of the English word 'soldiers'" (2005: 286). Henderson describes how "as HIV takes its toll, it is said that the soldiers of the body are no longer strong enough to fight off invading viruses and germs. In isiZulu, the common phrase for such depletion is 'amasotsha omzimba aphelelwe amandla' (the strength of the soldiers of the body has come to an end) (2005: 27). An adherence counsellor in Steinberg's ethnography in Lusikisiki uses the term "*bala amajoni*" to instruct patients about CD4 count. Literally, to "count your body's soldiers" (Steinberg, 2008: 188).

[9] There is a significant body of literature critiquing military metaphor usage in relation to disease and, in particular, cancer and HIV/AIDS. Sontag (2001) argues that, "the effect of the military imagery on thinking about sickness and health is far from inconsequential. It over mobilises, it over describes, and it powerfully contributes to the excommunicating and stigmatizing of the ill" (Sontag, 2001: 182). Similarly, Fuks contends that "the military metaphors that pervade medicine undermine the ability of physicians and society to deal with the burgeoning burden of chronic illness" (Fuks, 2009: 1). In their instructional pamphlet, TAC notes that "TAC and the activists who wrote this handbook do not endorse or believe in violence or wars and therefore do not like this example. We use the example because it is the one most people will be familiar with, but we prefer the one of a football team explained above" (Treatment Action Campaign, 2006: 13). However, Henderson argues that military metaphors of soldiers, war, invasion, and annihilation "resonate deeply with a social history where a series of political and economic dispossessions related to the social polity were made possible prior to, during colonial rule, and up until and during the apartheid era" (2005: 27). She observes that it is not surprising that there are important parallels between the ways in which people in rural South Africa are taught about how HIV operates within their bodies and their experiences of disenfranchisement and dispossession in the modern South African state.

Campaign, 2006: 11). One peer educator recounted how she used this figurative construction to explain how HIV deactivates the 'command centre' in the body:

> Pemeido: You know we have a soldier in our bodies, the big one, the CD4 cells issues commandments in our body, so what does HIV do, it attacks the commander, the CD4 cell. You know? So when it attacks the commander, you know the commander gives the instructions to the other soldiers, so who is going to give instructions to other soldiers if the commander is dead, you know?

However, she also explained that sometimes this metaphor was taken too literally by some of her clients, causing additional confusion:

> Pemeido: You just have to make it that way, to make it a little bit simple, because sometimes the clients will ask you 'where are the soldiers in my body?', and you'll be like 'woah'…-- [laughs]
> Interviewer: [laughs] 'Are there actually little soldiers…?'
> Pemeido: Yeah, you have to explain that, you have to say 'no, I'm talking about the cells'.

At times, the use of metaphor became too cumbersome for some, losing its effect by being unclear or confusing.

> Isaac: Why are you wearing your jeans sitting on the chair? There's something that you're preventing. What is it? Can you explain it? Then the answer that you'll get is that 'I'm wearing the jeans because I'm preventing something'. So that is why I'm saying to you, if you're preventing this HIV from this chair, or from this jean that you are wearing, it's not going to follow you. Because you're preventing it.

Although there were occasional failed or inappropriate uses of metaphor, on the whole peer educators felt that this technique rendered scientific information more accessible to their clients. One of the TAC trainers explained it as a strategy to represent science in familiar terms:

> Lloyd: I communicate that training that I do with TAC, that scientific training, in the Xhosa language, so that those who are not educated, they can understand. And we relate HIV scientific training with things that are happening. We transform HIV as soldiers that attack the human immune system. So if we are creating that story, one can have the picture of how the soldiers attacked, so if they can make that picture in their minds, they can be aware of what we are trying to educate about HIV. So that's how I handle the difference between the

> scientific education, the scientific training with the public who is not well educated.

In sum, peer educators used stories, metaphors, and parables as a creative way of introducing complex information that might otherwise be difficult to convey.

Discussion

In his study of HIV activism by the Treatment Action Campaign, Robins concludes by wondering about the role TAC and MSF will play in promoting "universalist biomedical understandings of 'disease' and 'illness' in South African communities where there are competing explanations for misfortune and ill-health" (Robins, 2004: 671). This paper explores these dynamics by examining the experiences of advocating on behalf of HIV science by peer educators in Khayelitsha, South Africa.

TAC peer educators in this study were able to act as "antennae" in their communities, providing a detailed account of the sources of medical mistrust. Though the Khayelitsha MSF/TAC office is in many ways exceptional (Robins, 2005; 2009a) with long-standing provision of ART to community members and regular advocacy around HIV issues, it is notable that peer educators still routinely encountered HIV-specific questions, doubts, and mistrust. Common topics causing persistent confusion and mistrust among clients included the origins of the virus, the existence of a cure, and Jacob Zuma's HIV status, all of which echo the issues voiced by focus group respondents from the same geographic area (Rubincam, 2014). Peer educators also highlighted how their client population is challenged by rapid changes in HIV policy – the revelation about 'undetectable viral loads', for example, created particular challenges for them.

The results of this study echo previous studies showing that peer educators "encountered numerous obstacles and challenges during their daily attempts to implant these [scientific] 'facts' in the hearts and minds" of their clients (Robins, 2009b: 29). In responding to key areas of controversy, doubt and confusion, peer educators experienced their role less as a neutral bridge between science and the target population. Rather, they acted more as a mediator or broker, compelled to make their own judgments about how to explain certain topics and whether clients could handle the truth about scientific developments in all their complexity. This suggests that peer educators in this context are rarely operating in purely didactic environments, and more frequently must actively engage with the questions and debates of their target audience.

In this task peer educators reported using various rhetorics of persuasion to boost their clients' understanding of, and trust in, HIV science. These ranged from relating and reiterating biomedical facts about HIV to employing creative story-telling techniques to illustrate key scientific concepts. They also drew upon different sources of credibility in the face of doubts and mistrust. One technique was to highlight evidence that was apparent to clients in everyday life. This was deemed appropriate in situations where clients' questioned something in the public sphere, such as the potential existence of a cure, or the 'shower' claims of Jacob Zuma. Peer educators reiterated that a cure would be plainly evident if it existed, and that people had been showering for years with no discernable effect on rates of HIV infection. Another technique was for peer educators to draw on their own history and experience as HIV positive people. As someone who had experienced testing, counselling, diagnosis and treatment just like their clients, peer educators could claim to have 'walked the walk' and possess the authority to advise others.

This conceptualisation of peer education as a complex activity involving mediation, agency and judgment also highlighted the uneven dynamics of power present in these peer education interactions. Though the premise of peer education is that "similarity between message source and recipient is vital to the ultimate impact of the message" (Wolf and Bond, 2002: 362) so that they can impart credible socio-culturally resonant information, in reality peer educators tend to differ from their peers in important dimensions. As James observes, the model of peer education posits two seemingly contradictory sets of qualities: the "egalitarian and non-authoritarian character of a relationship between equals with a more hierarchical relationship in which knowledge…can be passed on from the informed to the ignorant" (James, 2002: 15). The comment of one of the peer educators in this study that one must "select your group, then you select your words" illustrates how conscious she is in determining appropriate language for her target group, which may or may not be identical to her own.

By virtue of their education, status, and training, peer educators are set apart from others in their communities and positioned to impart the "correct" basis for decision-making about HIV care. This creates tension between peer educators and their clients, particularly when peer educators believe that certain information should not be openly discussed, and raises the question: How much discretion are peer educators expected to exercise in their decisions about education and advocacy? These findings suggest that TAC peer educators perceive themselves as differentiated in significant ways from their peers, by virtue of their training and education. While some believe in complete transparency around all scientific issues, all were cognisant of the challenges bound within the process of imparting complex scientific information to an audience that, in general, lacked a high-level of scientific education. In practice,

peer educators must balance the inclination to withhold information with the danger that clients will discover their dishonesty. If clients believe that there are inconsistencies between the information they receive from TAC peer educators and what they hear and see in their communities and the media, peer educators risk losing their trusted status in the community.

Metaphors and Parables

Along with imparting biomedical facts and drawing on personal experiences, peer educators also described using parables and metaphors to explain aspects of HIV science that remained confusing for their clients. They served similar purposes to the parables and metaphors recorded by Dickinson (2009; 2010b; 2011) in his work with peer educators at a South African mining company. Though few studies have discussed this method of communication among peer educators, numerous studies have demonstrated the widespread use of metaphors in business, politics, education and medicine to assist in both communicating new information in familiar terms and challenging existing mindsets (Hutchings 1998; Arroliga *et al.*, 2002; Reisfield and Wilson 2004; Periyakoil, 2008; Wortmann, 2008; Fuks *et al.*, 2011; Krieger *et al.*, 2011). Common medical metaphors include the pumps and pipes of the circulatory system, the circuits and wires of the nervous system (Arroliga *et al.*, 2002; Periyakoil, 2008; Fuks *et al.*, 2011), the fog and immobilising experience of mental illness (Rhodes, 1984), and military metaphors of battle, survival, fighting, and defense (Fuks, 2009).

The use of metaphors and parables, however, is not without the potential for misunderstandings or misappropriation (Rhodes, 1984; Bedell *et al.*, 2004; Periyakoil, 2008). Perhaps the most vehement critic of metaphorical use in medicine is Susan Sontag. In *Illness as Metaphor* and *AIDS as Metaphor*, Sontag argued that "illness is not a metaphor" and that disease should be spoken about purified of "metaphoric thinking" (Sontag, 2001: 3). To think of disease as a metaphor too often turns into blame for the affliction based on the personal characteristics of the afflicted[10].

[10] Thus, the tubercular patient of the 19th century is viewed as passionate, melancholy, creative, and romantic, whereas the cancer patient of the 20th century is perceived as repressed, angry, and emotionally inhibited. Such negative characterisations, Sontag argued, "deformed" the patients' experiences of their affliction, convinced them that they were disgusting and their situation hopeless, and ultimately, discouraged them from seeking appropriate care. Thus, she argues, "metaphors and myths, I was convinced, kill" (Sontag, 2001: 102).

Using figurative techniques to enhance the public's understandings of science also carries the risk that the scientific meaning will become less accurate as the metaphor evolves. In the example discussed above, it is possible that the snake used in peer educators' discussions may shift into a positive symbol rather than a dangerous or undesirable object, with implications for people's understanding of the value of ARVs in halting the progression of the virus. Snakes can take on different meanings depending on varying cultural traditions in southern Africa (Ashforth and Nattrass, 2005). While for some groups in southern Africa, snakes can symbolise "bodily power and purity" (Green, 1996) or the power of divine healing (Henderson, 2005), they can also be seen as the "familiar dispatched by a witch in order to cause harm and misfortune" (Ashforth and Nattrass, 2005, 289).

This potential for a medical metaphor to obscure rather than clarify scientific concepts is further highlighted in Ashforth and Nattrass' (2005) analysis of a video designed by a Yale University medical student and used by the South African Department of Health (Wong, 2004; Wong *et al.*, 2006)[11]. In it, the metaphor of a snake is employed to represent HIV, while the idiom of 'poison' is used to refer to the power of antiretrovirals. An excerpt from the script reads as follows:

> 'Your body's immune system – or *amaso tsha amzimba* (sic) is an army of soldier cells that guard your body from sicknesses like HIV. But HIV is a particularly bad sickness because it not only fights your body, it fights CD4 soldier cells. HIV is like a poisonous snake, sneaking up to the CD4 soldiers while they are sleeping and killing them' (Wong, 2004).

The video then expands on the metaphor to explain how ARVs work:

> 'This is where ARVs come in. ARVs can prevent the multiplication of the HIV virus. It is as if the body's soldiers could find the HIV snake nests, and pour poison[12] on the snake eggs to keep the eggs from hatching. However, ARVs are a kind (sic) poison that only works for a limited amount of time. They must be taken every day, in the morning and evening, otherwise the HIV virus has a chance to reproduce itself' (Wong, 2004: 59).

[11] The video can be viewed via a link at the bottom of this page: http://cushing.med.yale.edu/greenstone/cgi-bin/library.cgi?a=d&c=ymtdl&d=etd-08202004-175255html (Accessed May 15 2013).

[12] In the final version of the video, currently available online, the word 'poison' is replaced with 'drug'. The author does not comment on which version was circulated by the Ministry of Health in South Africa, nor on why this substitution occurred.

Ashforth and Nattrass note that 'poison' is a common translation for *idliso*, a form of witchcraft. Thus, "a video embracing both the image of the snake and the idiom of poisoning", the authors argue, "is entering a cultural zone where interpretations of meaning cannot easily be predicted" (2005: 289). This is particularly problematic in South Africa, where the former Health Minister depicted ARVs as 'poisonous' and toxic on numerous occasions (Geffen, 2010). The deployment of the snake and poison metaphor in this video risks reinforcing denialist representations of ARVs as toxic for humans[13].

A further challenge in using metaphors to communicate science is that some metaphors can "freeze", becoming "part of the language system to which the terms making up the metaphor belong" (Fricke, 1998: 3). For instance, when a war metaphor is used to describe cancer, there is a risk that "all the facts and knowledge related to warfare are thought to apply entirely to cancer therapy as well thereby resulting in errors in inference and the resultant desire to 'fight to the bitter end'" (Periyakoil, 2008: 843). While this limits the creative use of metaphor, the opposite tendency – that a metaphor will fail to adapt to changing circumstances – is also present. Though the image of the thug using a disguise to enter the school is dramatic, one wonders how this parable will evolve to incorporate and articulate new scientific information about HIV, such as the discovery that ARV treatment, administered rapidly after birth, may be able to prevent HIV infection in newborn babies (Dolgin, 2013; Guardian, 2013; McCartney, 2013). In short, metaphors and parables can evolve in an unpredictable and inaccurate manner, freeze in meaning or fail to adapt to changing circumstances as needed. When this occurs, they can increase rather than diminish ambiguity and uncertainty.

Perhaps the strongest caution against the uninformed invocation of metaphors can be found in recent psychological research showing that metaphors shape the way people "forage" for information and how they generate strategies to deal with real-world problems (Thibodeau and Boroditsky, 2011). Moreover, people appear to be influenced by metaphors without being conscious of their

[13] These objections may seem petty given the recorded improvement in ARV access and adherence knowledge among participants in Wong and colleagues' study. However, it bears noting that, given the pre/post study design, the study did not compare exposure between a health literacy approach and the 'culturally-sensitive' video designed by Wong. Rather, the study measured whether there was improvement in knowledge *before* the video was screened compared to *after;* it established that the video did not measurably *decrease* ARV-related knowledge. Failure to use the 'best available standard of care' as a comparison (such as the *Beat it!* materials noted in the introduction), as would be the case in a randomised control trial, leaves open the question of whether this video is actually an improvement over existing materials.

persuasive power (Thibodeau and Boroditsky, 2013). These "covert" effects make it even more crucial that metaphors are used carefully and strategically.

If deployed appropriately and sensitively, metaphors can augment understanding and clarify concepts that might otherwise be difficult to understand (Arroliga *et al.*, 2002; Bedell *et al.*, 2004; Reisfield and Wilson, 2004; Krieger *et al.*,2011). The results from this study suggest that all metaphors and parables should not be assessed under the same rubric. Though metaphor usage may be universal and ubiquitous (Lakoff and Johnson, 1980; Geary, 2011), certain stories work better than others. As Robinson argued in response to Sontag's *AIDS and Its Metaphors*, "The correct question to ask regarding the way we think about AIDS is whether its metaphors are well or ill chosen" (Robinson, 1989). Dickinson found that while some parables and stories succinctly and dramatically conveyed the importance of certain behaviours, others served to reinforce a misconception about HIV rather than challenge it (Dickinson, 2011). The straightforwardness and stickiness (Gladwell, 2000; Wortmann, 2008) of the 'snake and the rock' parable stands in contrast to the complex and contradictory meaning contained in the 'snake and poison' story used by Wong (2004; 2006).

Though the relationship between metaphors and scientific explanations is sometimes represented as oppositional and hierarchical, with educators forced to make a choice between competing approaches, and with health literacy positioned as the preferred method (Krieger *et al.*,2011), this study suggests a more complimentary use of such techniques (Kirklin, 2007). TAC peer educators have been well trained in biomedical explanations about HIV; these interviews suggest that they have found figurative language to be a useful and perhaps even necessary adjunct strategy. By using both orthodox scientific educational techniques – where a CD4 cell is identified as such – as well as more creative, story-based descriptions, TAC peer educators feel themselves better able to communicate with their clients. That this has been noted in other studies of peer educators suggests that it may be a common strategy for communicating biomedical information to the public (Dickinson 2007; 2011). Peer educators' ability to alternate between these techniques in communicating with clients is testament to their expertise and training, as well as their commitment to their work.

Implications for Policy and Practice

In challenging the conceptualisation of peer educators as people engaged in vertical communication with passive recipients of a focused, stable, scientific message, this study reiterates how peer education in this context frequently involves horizontal communication with active, engaged receivers of complex,

changing facts and understandings. As described in other studies of this more engaged, horizontal form of peer education (Robins, 2009b: 29), equipping such peer educators to work in the field will require more than just training in good scientific literacy. To be comprehensively trained as a peer educator will necessitate instruction in how to manage contentious communication with peers, how to steer a discussion towards a productive end, and how to employ creative tactics to best effect. Moreover, given that some peer educators in this study felt that they needed to withhold certain information from their clients, comprehensive training should include open discussion about the appropriate balance of transparency versus discretion.

Training could also improve peer educators' use of metaphors and parables in their explanations. Though there is a clear instinctual skill in telling stories, peer educators could be guided in how to deploy a sufficiently complex story to accurately represent a scientific concept without creating additional confusion. As Aristotle observes, "Metaphors must not be far-fetched, or they will be difficult to grasp, not obvious, or they will have no effect" (Aristotle, 350AD; Barnes, 1995: 265).

It is also noteworthy that although various metaphors were deemed useful by peer educators, none addressed any of the key sources of confusion or doubt that were raised by their clients (discussed in more detail in Rubincam, 2014). These include: the origins of the virus, the existence of a cure, the trustworthiness of Jacob Zuma's HIV test result, and the logic of PMTCT. This may be because these topics are complex and difficult to capture succinctly in a story or metaphor. It may be difficult to pithily and concisely explain why Post-Exposure Prophylaxis (PEP) and Pre-Exposure Prophylaxis (PreP) are preventive measures not cures, how PMTCT works, or why it is possible that Jacob Zuma is HIV negative even after having unprotected sex with an HIV positive woman. The difficulty in conveying these concepts, however, should not dissuade peer educators from trying to generate explanations that satisfy clients' curiosity and confusion.

In addition to training in these figurative techniques, it should be recognised that scientific accuracy is a necessary, if not sufficient, component of a good peer educator's skills. Though peer educators in this study were not always completely accurate or certain about their information, most of their errors were minor in nature. This is consistent with other studies of peer education showing that gaps in knowledge about HIV exist, even among experienced educators (Tobias *et al.*, 2010). The exceptions in this study were peer educators' responses to questions about the origins of HIV. Though peer educators' uncertainty about this topic may simply reflect the newness of scientific inquiries into the origins of the virus (Pepin, 2011; Timberg and Halperin,

2012), or the complex detail of the scientific account, it should be addressed with clarity and consistency as it remains a key topic of concern to segments of the South African population (Rubincam, 2014).

Study Limitations

The Treatment Action Campaign is a high profile, extremely well co-ordinated organisation that has achieved international and national recognition, and as such, the experiences of peer educators working for TAC may not represent the experiences of other peer supporters in South Africa. Moreover, the TAC Khayelitsha office is unique in both its history and its current role (Geffen, 2010; Nattrass, 2012). The findings from this study should not be generalised beyond the immediate study site.

Conclusion

This paper suggests that in response to alternative beliefs about HIV/AIDS, peer educators employ various rhetorics of persuasion to augment clients' understanding of, and trust in, HIV science. They make use of their scientific training from TAC, recognising the importance of harnessing concrete observable data from everyday life and using the easily grasped nature of stories and metaphors to communicate intricate concepts. The success of these tactics can be enhanced with even more training and guidance on the appropriate ways of mobilising peer-to-peer communication for the challenging task at hand.

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