

Assessing Social Preparedness for Antiretroviral Therapy in a Generalized AIDS Epidemic: A Diffusion of Innovations Approach

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Abstract Researchers conducted focus groups in the Eastern Cape Province of South Africa concerning AIDS and treatment options. Constituent groups included adults aged 25–45, HIV/AIDS caregivers, HIV-positive adults, nurses, rural elders, teenagers, and traditional healers. This pilot work aimed to gather early evidence on perceptions about the government's rollout of antiretroviral treatment (ART), identify potential barriers to success, and inform a subsequent pilot survey. Diffusion of innovations theory was used to interpret the data and helped identify potential obstacles to the ART rollout. AIDS stigma and a weakened healthcare system were negatively impacting the program. There was a lack of accurate knowledge about HIV/AIDS and antiretroviral treatment, with wide disparities among groups. Many people were not convinced that antiretroviral treatment is superior to other treatments, and a few people were afraid it was poisonous. There was no evidence that people were aware of the long-term difficulties of adherence to the regimen.

Keywords AIDS · South Africa · Antiretroviral therapy · Diffusion of innovations · Traditional medicine

Introduction and Background

Southern Africa has been heavily impacted by the global AIDS epidemic, and South Africa has not been spared. An estimated 10.8% of its population aged 2 years and older is living with HIV/AIDS (Shisana et al. 2005). South Africa is experiencing a generalized epidemic and its prevention and treatment efforts must acknowledge existing norms, perceptions and practices in order to be successful. This study uses diffusion of innovations theory to assess social preparedness for publicly-provided antiretroviral therapy (ART) in three locations in the Eastern Cape of South Africa.

Before 2004, ART was only available to South Africans who could pay for it in the private sector, those who were part of employer-offered programs or those in a few small, pilot programs being offered by non-profit organizations. The South African government previously questioned the link between HIV and AIDS under the leadership of President Mbeki and has suggested that ART might pose risks that outweigh its proven benefits. However, in the context of persistent protest and legal action by political action groups such as the Treatment Action Campaign (TAC) and intense public debate, the government commenced roll-out of its ART program in May 2004. The program began at a limited number of sites with a select group of patients and is intended to expand to provide ART to all South Africans who need it. It was at this time that ART became available through the Department of Health in the Eastern Cape Province, the location of this research. At the time of our pilot study in late 2004, the Eastern Cape had 2,147 patients receiving ART in the public sector,

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compared to an estimated 59,646 who were in need. (Estimates of those needing ART were calculated as 10% of the estimated provincial prevalence in 2004 that was produced by Actuarial Society of South Africa modeling (ASSA n.d.)).

According to the National Antiretroviral Treatment Guidelines (Department of Health 2004) adults are eligible for ART if they meet medical criteria and psychosocial considerations. The medical criteria include (1) having a CD4 count <200 cells/mm³ or (2) a diagnosis of World Health Organization (WHO) Stage IV disease, irrespective of CD4 count. The psychosocial considerations include (1) demonstrated reliability, i.e., patient has attended three or more scheduled visits to an HIV clinic; (2) no active alcohol or other substance abuse; (3) no untreated active depression; (4) disclosure of HIV status to at least one friend or family member OR joined a support group; (5) insight into the consequences of HIV infection and the role of ART before commencing therapy, and acceptance of one's HIV-positive status; and (6) transportation to the treatment center on a regular basis. In addition, the program in the Eastern Cape Province requires a designated treatment support person—a family member or friend who volunteers to remind the patient to take medication.

Diffusion of innovation theory studies the adoption of a new innovation in terms of the characteristics of decision-makers, society, and the innovation itself (Rogers 2003). It is particularly useful as a framework for assessing how a new practice or innovation diffuses through a given social system and whether the new practice is rejected or is accepted and becomes the new social norm. It considers the decision-making and communications processes. It tracks the adoption of new innovations (or lack of thereof) from knowledge-gathering to decision-making and on to the consequences, including refinements or alterations of the original innovation. All of these aspects of diffusion can be assessed in order to gain a better understanding of why an innovation is accepted or rejected.

Looking at the individual decision-maker's role in the process of diffusion, we can enumerate several stages in Rogers' (2003) theory of the process. The theory begins by identifying the characteristics of the individual decision-maker and the social system that necessarily impact the decision-making process. The stages in the innovation-decision process include (1) knowledge, in which decision-makers gather and evaluate knowledge related to the innovation; (2) persuasion, when they begin to form an opinion of the innovation; (3) decision, when they begin to take steps to make a choice; (4) implementation, when they begin using the innovation and possibly adapting it; and (5) confirmation, in which they re-evaluate their decision and perhaps reverse it. Likewise, the perceived attributes of the innovation play an important role in the rate of adoption.

These attributes include relative advantage, compatibility, complexity, trialability, and observability.

Previous applications of diffusion of innovation theory to HIV/AIDS have focused on prevention rather than treatments. Rao and Svenkerud (1998) found that AIDS organizations that applied social marketing and diffusion of innovation concepts to their work in HIV prevention had more successful programs, as evaluated by the groups themselves. Bertrand (2004) makes the case that it is very difficult to have successful HIV prevention programs because many of the structural and environmental factors identified by the diffusion of innovation model as necessary for success do not apply to safe sexual practices.

The diffusion of innovations theory has not, as far as we are aware, been used to understand ART programs. We use it to understand the significance of perceptions relating to ART in the Eastern Cape Province, thereby hoping to highlight issues that need to be addressed in optimizing public access to and use of this program.

In spite of the intense national and international media attention paid to the decision to undertake government provision of antiretroviral treatment in South Africa, there has been little research attempting to capture and document attitudes toward ART in the general public. Gebrekristos et al. (2005) interviewed patients in TB clinics in Durban in 2002–2003. They found little awareness of ART. Nachega et al. (2005) surveyed HIV clinic patients on knowledge, attitudes, beliefs, and practices related to HIV and antiretroviral therapy in Soweto in 2002. These patients had received counseling on HIV and treatment options at their initial visit to the clinic and again every 3 months. They found most people believed in the effectiveness of ART and were not concerned about side effects, and most had correct knowledge about the importance of adherence. While these results are encouraging, they do not tell us about attitudes in the general population.

Chopra et al. (2006) interviewed nearly 200 people in 3 South African locations where antiretroviral therapy had been available at least 6 months. The majority of subjects were HIV-positive and over half of those were on ART. Overall, they found more enthusiasm for traditional medicines and dietary supplements than for ART, and subjects seemed to view ART as just a variation of those treatments. Those on ART were more enthusiastic than others and pointed to positive results. The authors reported that less than 30% of their sample of community members knew about ART, and even nurses administering ART were not excited about it.

The research presented here provides a snapshot of the situation within 6 months of the beginning of the government program in the Eastern Cape. It provides a key benchmark of attitudes in the early days of the ART

program, and offers an opportunity to anticipate future problems as the program expands to new locations.

Method

As a pilot study aiming to establish baseline attitudes about ART in the early months of the government program, it was important to convene a broad base of constituents in multiple types of locations, including some where ART was available and some where it was not. Focus groups were conducted in late 2004 in three locations in the Eastern Cape: a large urban area, a town, and a rural area. ART was available at select locations in both the urban area and the town, but not in the rural area.

Participants

A total of 62 participants were recruited for seven focus groups. Since the aim was to provide a diversity of perspectives on which to build in future work, each group was recruited from a particular pre-determined constituency, specifically: adults aged 25–45, HIV/AIDS caregivers, HIV-infected adults, nurses from a public clinic, rural elders, teenagers, and traditional healers. Recruitment of convenience samples was done with the assistance of various professional groups, associations, health clinics, and a school. In the case of the group of adults aged 25–45, participants were recruited by word-of-mouth. Due to an error in recruiting, a few of the participants in the rural “elders” group were volunteer health educators.

The focus groups were conducted by a facilitator in the language or languages most comfortable for the participants: English, Afrikaans, or Xhosa. Facilitators came from the groups’ respective communities and used a common set of questions (available from the authors) to lead the discussion for each group. Focus groups lasted between 90 min and 120 min. Participants were served tea and light refreshments but not offered monetary compensation for their time.

After obtaining consent, a facilitator and one or two co-facilitators led each group through a discussion of the impact of AIDS, methods of coping with AIDS, and treatment of AIDS. Facilitators asked participants to report about perceptions and experiences of AIDS in the general population in addition to their own direct opinions and experiences.

Data Analysis

Audio recordings of the sessions were translated into English (where necessary) and transcribed. Transcriptions were read by all team members. One person inductively

generated an initial summary of major themes that was distributed to all team members. Another team member then did detailed coding of all focus groups using software for qualitative data analysis, expanding on the previously-identified themes. Each transcript was coded a total of three times so as to incorporate newly-added codes into all transcripts and to ensure accuracy. Codes were then grouped into families that captured the elements of the diffusion of innovations theory.

Analysis began by identifying important social forces and institutions discussed in our groups that would impact individuals’ decisions to adopt ART as a treatment. Then *Knowledge*, the first step in the process of adopting or not adopting an innovation, was considered. We identified all codes relating to knowledge (or lack of knowledge) and considered the pattern of responses across the groups.

Themes relating to *Persuasion* were considered next. These relate to various attributes of ART as perceived by our participants, and results were grouped according to the types of attributes used in diffusion of innovations theory. For *Relative Advantage*, the focus was on the extent to which ART was perceived to be superior to other treatments. In the case of ART, it may seem obvious to Western observers that this innovation is vastly superior to any other treatment available, but it cannot be assumed that ordinary South Africans will reach the same conclusion. Themes for *compatibility* relate to the extent to which ART fits into the existing culture, habits, and attitudes of the population. Themes relating to difficulty in using or accessing ART were grouped under *Complexity*. *Trialability* was considered as a potential factor, but ART is extremely ill-suited to trial use. First, temporary use of the medication is likely to harm rather than improve health and is not advisable on medical and epidemiological grounds as it can increase resistance to ART. Second, difficulties in accessing the treatment mean that trial use is unlikely to be practical. Most people will therefore rely on observing the experience of others as a substitute for trying it on a temporary basis. Our final attribute, *Observability*, reflects how easily one can learn about the innovation from following the experiences of others.

Because the government rollout of ART was in its early stages at the time of our focus groups, we have restricted our attention to the Knowledge and Persuasion phases of the diffusion of innovation model. Only four participants (all being in the HIV-positive group) identified themselves as eligible for or currently on ART in the discussions.

Results

Figure 1 summarizes the issues that arose in the focus groups and their relation to the diffusion of innovations theory. These findings are discussed below.

Social Structures

We identified four important social forces and institutions that will impact individuals' decisions to adopt ART as a treatment: AIDS stigma, social support for individuals with AIDS, the South African healthcare system, and the legacy of apartheid.

Perhaps the strongest theme in the focus groups overall was AIDS stigma. We found evidence of AIDS stigma linked to norms about sexuality, a fear of contagion, secretive behavior and self-stigma. It was mentioned several times in our groups that many people resist getting tested and seeking treatment partly because they are afraid they will be seen at the clinic or that clinic staff and other visitors will gossip about their test results or treatment.

It was widely believed that social support is necessary for living positively with HIV. Some families are very accepting and supporting of HIV-positive family members, while others are rejecting and blaming. Many respondents commented that both types of responses are commonly seen. Likewise, many faith-based organizations (FBOs) are reportedly very supportive of persons living with AIDS (PLWAs). However, there were some reports of negative reactions in FBOs, such as refusing to sit near a PLWA during services or refusing to allow the cause of death to be discussed at a funeral if it was AIDS.

Problems with the healthcare system as a whole may also impede access to and uptake of treatment. The nurses were most vocal about these problems. They include hospitals sending people away once they are past a certain stage of illness progression, insufficient numbers of staff, ART being offered only at selected clinics that not everyone can get to, that the staff trained in HIV/AIDS are not

necessarily the ones dealing with HIV/AIDS patients, and that not enough AIDS medication is stocked at the centers. The 25–45-year-old group discussed problems with the clinics lacking proper HIV counseling. Counselors were said to be sometimes indifferent, insensitive or unknowledgeable and there was one accusation of favoritism in the allocation of ART.

Two people in the groups mentioned a link between AIDS and race. One man in the rural elders group was adamant that AIDS was part of a racist plot by whites to kill off blacks. He had been heavily influenced by a radio program he had heard in which the author of a book proclaimed that whites had specially developed HIV so that they could pass it on to blacks through sexual intercourse without being infected themselves. Others in the group argued strongly with him about this, but he remained convinced of a racist plot and returned to this idea at the end of the session. One participant in the teenage group suggested there are a lot of racist people who are a happy for blacks to get AIDS and die.

Knowledge

At the outset of this research, we were primarily interested in knowledge about ART. However, it was difficult to overlook evidence that knowledge was lacking in more basic AIDS matters. For instance, the traditional healers personally expressed some doubt that HIV causes AIDS, and that AIDS is really one disease. This group also was very interested in learning more about AIDS from the facilitator (though this was discouraged). One traditional healer put it this way:

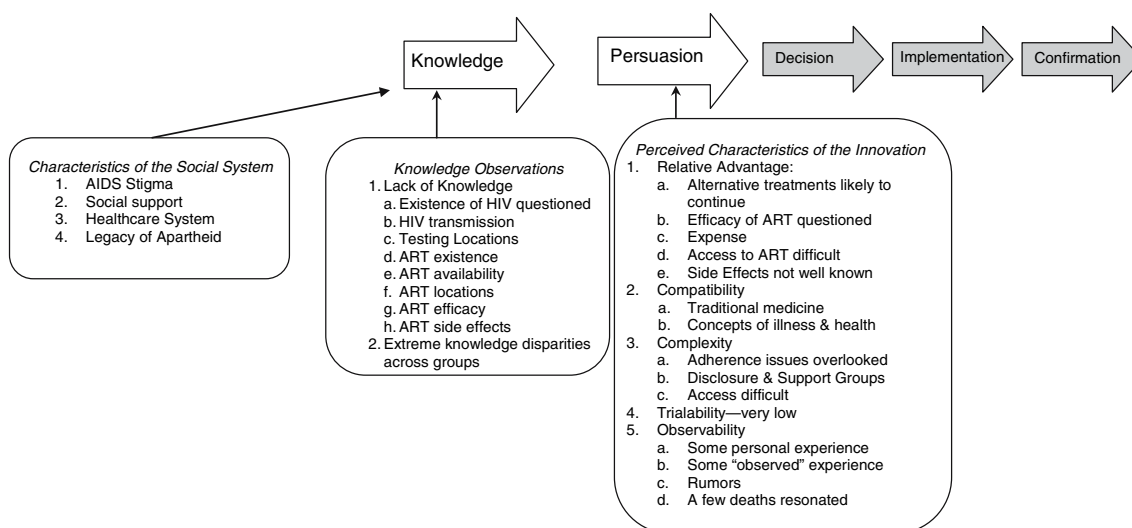


Fig. 1 Schematic of findings. Adapted from Rogers (2003)

But with AIDS, it manifests itself in many forms. A person can develop skin diseases or rashes, a person develops a continual cough, a person develops many other aspects and all of those aspects of sicknesses are associated with this virus, like diarrhea and loss of weight. And so - is there certainty that it is caused by a single virus? The question is, is there a single virus or is there a multitude of different viruses that are causing differing reactions to a person's body? This is where the problem lies in terms of this question, is there certainty?

The nurses clearly felt there were many people who, like the traditional healers, doubted the existence of AIDS, doubted that HIV causes AIDS, and doubted that one virus could account for so many different symptoms. One reference was made to President Mbeki's widely publicized earlier questions about the link between HIV and AIDS in the group of adults aged 25–45, noting that, "a large number of people believe that, well, if he says it doesn't cause the disease then it doesn't."

Facilitators inquired about the extent to which people know where to go to get tested and get treatment. Most groups felt that many people do not know where to get tested. The nurses were the only group convinced that everyone knows where to get tested. When asked about whether or not people know where to get treatment, most responses indicated that while some people do know, others, particularly the less-educated, do not.

Not everyone knew that ART was available or existed, even though the government was providing it at some clinics and hospitals in our urban and town locations. The adults aged 25–45 group in the town did know about ART, but early in this discussion one person incorrectly mentioned that the government was not offering antiretrovirals because of the expense. Despite repeated prompting for discussion of how to manage AIDS in the group of urban traditional healers, only a few references were made to ART. ART was unavailable in the rural area, and our group there, which included four volunteer health educators, knew almost nothing about ART availability. Extensive prompting about the program yielded just one person who said he/she had heard about it on the radio. Participants who were aware of ART expressed a variety of inaccurate perceptions about it.

Persuasion and Perceived Characteristics of ART

Relative Advantage

The participants suggested that the main alternatives to ART were treatments for opportunistic infections (such as antibiotics), taking dietary supplements, using a traditional

healer, having a healthy lifestyle and having a positive attitude with good support systems. The volunteer health educators participating in the rural elders group were recommending a range of dietary supplements, including Cellfood, a heavily-marketed, commercial dietary supplement; grape leaves; guava leaves; garlic; *Inongwe* (African potato); and *rooi* water (an indigenous root preparation), but they were not sure whether they worked and wanted to know. They did not know about side effects of ART, since they were barely aware it existed. When the caregivers group was asked what they recommend to people with AIDS, they cited Cellfood, a healthy attitude, and garlic. They did not seem to perceive ART to be a superior treatment, as shown by this exchange in the group of caregivers:

Facilitator: Can we look at what we consider to be most helpful treatment options?

Participant: Coping with stress, eating right, good support structures....

It is possible that they do not recommend ART because so few people are being treated at this time. Overall, however, they were hopeful that ART might work but seemed to consider it unproven as of yet. Some of the caregivers in this group apparently deal directly with ART patients, since they mentioned that they count tablets to monitor adherence as part of their home visits. Yet these front-line volunteers were as yet unconvinced that ART is an important breakthrough.

Interestingly, although the caregivers suggested dietary supplements to AIDS patients, they saw traditional medicine as harmful. They expressed exasperation that a few traditional healers claim to be able to cure people, and said that people travel long distances to be treated by them but they die anyway.

The nurses unanimously agreed that ART works, provided it is begun early enough. They believe that if treatment is delayed too long it will be ineffective. But they, too, emphasized that a healthy lifestyle and positive outlook with good support are also important. They did not mention any of the dietary supplements such as Cellfood or garlic that were suggested in other groups.

The traditional healers were quite anxious to have their treatments tested in a drug trial so as to prove their efficacy. They explicitly said that they could not cure AIDS, but they did believe that they could offer significant help with symptoms. A few people in the other groups also expressed a desire to know whether alternative treatments (traditional medicines as well as dietary supplements) were effective or not.

Alternative treatments were noted to be affordable, as the supplements are quite cheap and some of the traditional remedies are found in the wild. Antiretrovirals are free for those in the government's ART program, but for those

purchasing them privately they are expensive enough to be beyond the reach of most South Africans. To purchase the standard first line package of three drugs a day privately they would need to pay the equivalent of about US\$200 per year, which is more than a month's salary for the lowest paid workers.

Rationing or limited access to ART was mentioned in all groups except the rural elderly group, which had almost no knowledge of ART. In addition to medical criteria, before being accepted into the government ART program patients must satisfy psychosocial conditions (detailed earlier). Disclosure, attending a support group, needing a designated friend or relative to serve as treatment support person, and not using alcohol were each mentioned at least once in the focus groups as being barriers to access.

Most of our groups were not particularly aware of or interested in discussing the side effects of ART, an exception being the HIV-positive group. The nurses said that the side effects of ART are unknown among the general population because of a lack of experience with it. One nurse told a story about a patient who felt sick upon beginning ART. The patient's mother convinced the patient to discontinue the treatment on the grounds that it was making her sick. The nurse relating this story noted that discontinuing the therapy once started was likely to be harmful.

Compatibility

As mentioned above, it seems that most people view ART as a complement to alternative treatments, including dietary supplements and traditional medicine. Perhaps the biggest question for compatibility, then, is the extent to which ART is compatible with these alternatives.

One concern with traditional medicine in this context is that it often uses purging (induced vomiting and diarrhea) as a way to rid a body of disease. One of the traditional healers in the group noted that feeling worse with such a treatment does not mean that it caused or worsened the illness—that is part of the cure. However another healer thought that purging was unlikely to help those with AIDS, and that for them he/she would try to reverse symptoms such as a cough or diarrhea and stabilize the patient. The emphasis on purging in traditional medicine is one reason that its use is discouraged by Western doctors and nurses. This disapproval was mentioned a few times throughout the focus groups. In fact, when the facilitator for the HIV-positive group asked why nobody had mentioned traditional medicine yet, the reply was that they knew from counseling that it was frowned upon. This exchange from the caregivers group illustrates this tension.

Participant: It sometimes turns out that they are using traditional medicines, on the sly. Some may be open

about it—then you can tell them that when they are as sick as they are they shouldn't be using the stuff. But the next time you come back you will [find] evidence of the stuff they use even if they tell you otherwise. Facilitator: So they tend to do it behind your back. Participant: They don't realize that it is what kills them.

It is easy to see why Western doctors and nurses prefer that their patients take only the medicine prescribed and not dabble in alternative treatments that might confound the effects of ART, but it appears that at least some patients will be adding ART as a treatment without giving up other remedies. The situation with dietary supplements is similar to that of traditional medicine. One of the caregivers wondered whether garlic could be used safely with ART. There is clearly considerable uncertainty about the reasons for not mixing traditional and Western remedies.

One traditional healer noted that sometimes patients present believing that they are bewitched and therefore they believe that Western medicine will not be effective in curing them.

Complexity

When combination therapies were first discovered to be more effective than single drugs in combating HIV one of the major adherence issues was the challenge of taking several pills, several times a day. Fortunately the drugs being prescribed in South Africa are already formulated in combination and need only be taken once a day. Nobody mentioned any examples of patients having trouble adhering to the medication. Issues addressed in most groups mainly related to finding out about it, accessing it, and qualifying to receive it. These issues may be eased as the program grows.

Some in the HIV-positive group were unhappy with the support group requirement, as vocalized by one participant:

...one cannot get ARVs [antiretrovirals] unless they are part of the group. You can't force people to attend; it should be up to the individual. There is supposed to be confidentiality and if you're forced to join a group then that is taken from you. If you're not ready to disclose then it's your right, it does not mean you should be barred from getting treatment....

Observability

With the rollout only in its initial stages, we were interested in how much experience participants had with ART, either

directly, from observation, or from hearsay. The town groups were most able to speak about actual experiences of people on ART, particularly the caregivers and the HIV-positive group. The rural, elderly group was nearly unaware of ART and did not offer any anecdotes about its use; likewise the traditional healers did not mention any personal observations of ART use.

The adult group had some reports of ART experiences. One person knew someone who had “recovered” on ART. The teenagers reported only the most tenuous direct experience with ART.

The nurses reported that out of 75 people on the program, 2 had died. There was no doubt among the nurses that ART is effective. They mentioned that one patient responded so well that when she changed clinics and presented at a new clinic for the first time, she was sent away because nobody there believed she had AIDS.

The caregivers in the town spoke about having an initial bad experience with ART after two early adopters died (though one of these patients had had a CD4 count only equal to 1). They are more hopeful about ART now. But the early deaths in the program have apparently created some lasting impressions. A caregiver noted:

Some will agree to go on the program but when you visit them later they will have heard these terrible stories and will tell you that their mother has said they shouldn't go on the program because the treatment is fatal. We then try to clarify the facts with them.

Some in the HIV-positive group said they did not qualify for the program. One person in the group is in the process of getting the necessary medical tests to determine if he/she qualifies. Another person had been delayed because he/she lived alone and needed to find someone to agree to provide treatment support. Two people in the group were already in the ART program. Another participant noted that one of them had been very ill before beginning treatment and was now looking very much better.

Discussion

The diffusion of innovations (DOI) theory has proven to be a valuable conceptual approach in assessing key obstacles to a successful ART program in South Africa. The DOI model asks us to begin by considering the individual's knowledge of the innovation. We found widespread lack of knowledge or misinformation relating to every aspect of HIV/AIDS prevention, testing, and treatment, including ART. The social forces identified using DOI, specifically AIDS stigma, problems in the South African healthcare

system and the legacy of apartheid help us understand how such a widespread lack of knowledge can persist. AIDS stigma makes it difficult to make inquiries about testing and treatment. A strained healthcare system that is rationing ART may perceive little reason to communicate information about where to seek treatment and testing.

The legacy of apartheid may be causing government leaders and ordinary citizens alike to be suspicious of information about HIV, AIDS, and ART coming from Western sources. One rural person strongly believed that AIDS is a racist plot, some people did not believe HIV causes AIDS, and some people believed that ART had caused the death of a few early adopters. Research by Campbell et al. (2005) in KwaZulu-Natal province found variations of these racial themes, including the theory that whites are infecting blacks in order to reduce the numbers of black voters. These beliefs may have a direct influence on the credibility of the government ART program, so it will be important to track and counter them in appropriate ways as the program expands, especially into rural areas. The model thus identifies the knowledge gap and suggests some underlying reasons for it.

The model characterizes the *persuasion* stage as a time when individuals will think about the relevant characteristics of ART: *relative advantage*, *compatibility*, *complexity*, *trialability*, and *observability*. To consider the first, *relative advantage*, we must take the perspective of the decision-maker. The nurses were the only group firmly convinced of the efficacy of ART. To the ordinary person, and even to volunteer healthcare workers, ART remained an unproven experiment. These results are strikingly similar to those reported in Chopra et al. (2006).

In addition to efficacy, one aspect of relative advantage could be expected side effects. The program could be at risk if people conclude that ART makes people sick instead of well. The mention of a person who ended ART because of the mother's fears shows that they must be taken seriously. It is interesting to note that traditional medicine may also make one feel worse at the beginning of treatment, which may provide a cultural background for accepting the side-effects of ART. This is a potential building block for educating the public about what to expect from ART.

When we considered the *compatibility* of ART with the culture and lifestyles of the decision-makers, we uncovered a contradiction: many perceived ART to be compatible with alternative medicines, whereas the “experts” were telling them they were not. There is clearly a lack of knowledge and confusion about interactions between ART and traditional medicines and dietary supplements. Given the evidence that many people will continue using traditional medicine and dietary supplements, it would be very helpful if information were available to them about what common remedies are helpful or harmful, alone and with

ART. There is only a small literature on this, (see Mills et al. 2005; Tshibangu et al. 2004) and what little is known does not appear to be trickling down to ordinary healthcare workers or patients.

Our subjects recognized the *complexity* of ART in terms of it being difficult to access and requiring disclosure or attendance at a support group, but they were not attuned to long-term adherence issues. Even in this environment of mistrust of experts and a lack of information, people still might be willing to experiment with the innovation. But *trialability* is extremely low with ART, as temporary use can accelerate drug resistance and it is difficult to access. Unfortunately, there are serious private and public health consequences to discontinuing ART once it has commenced.

Finally, observing the experience of others might be another way for people to get information about ART. Unfortunately with ART, there is something of an asymmetric quality to *observability*. Successful ART adopters might wish to hide their treatment because of AIDS stigma, whereas unsuccessful adopters (such as those discontinuing due to side effects or those who died) might be readily discussed as a warning to others.

The model has thus identified some important lessons. In this environment, expert evidence of the superior efficacy of ART compared to other HIV/AIDS treatments had either not filtered throughout the general public, or had not been believed (the nurses were an exception to this). What outsiders might perceive to be the biggest advantage to adopting ART had not registered yet with our participants. At the same time, there was no evidence that the general population was concerned about the issues troubling public health experts, such as side effects of ART and difficulties with long-term adherence.

How useful was the diffusion of innovations model for this research? Some of our results would have been obtained by any careful study of the data. The prevalence of AIDS stigma, the problems with the healthcare system, the lack of knowledge, the widespread use of traditional medicine and dietary supplements, and the suggestion that continuing racial suspicions are affecting the epidemic fall into this category. The model has been most helpful at identifying the “missing pieces” in the decision-making process. Specifically, these are the ambiguity about whether or not ART is compatible with alternative medicines, the complete lack of trialability, and the asymmetric nature of observability.

Limitations of the study are that it was based on a convenience sample rather than a representative sample, and that only one focus group was convened for each constituency. This means that our findings might be idiosyncratic to our participants. Another limitation is that the study was not focused on people trying to make decisions

about ART, which means that some issues important to the decision-making process might have been overlooked.

The study has suggested several avenues for exploration in future research. Further investigation of the decision, implementation, and confirmation parts of the DOI model is warranted. Given *trialability* and *observability* are largely lacking with ART, will people be likely to stop treatment, once begun? These results also suggest that in-depth studies of how traditional medicine’s conceptions of illness and health relate to AIDS and ART will be directly relevant to the success of the ART rollout. Finally, a solid understanding of how health messages are understood in a context of longstanding racial mistrust could be invaluable for designing culturally-appropriate public health campaigns.

A few remarkable recovery stories were reported along with a few deaths of early adopters. It is notable that isolated incidents become particularly salient in a context where there has been remarkably little attempt to educate the general public about treatment. Any evidence, no matter how exceptional, weighs heavily when the general stock of public knowledge is poor, and this may be particularly true if it confirms lingering racial suspicions. There has to date been little to no recognition that ART knowledge needs to be developed for the population as a whole, and not only for those receiving information when they directly need it at medical facilities. Traditional healers, friends, family members, colleagues and caregivers need to be clearly informed about a wide range of issues relating to ART provision and the conditions of efficacy. If this is not done then it can be expected that the epidemiological and personal health risks of discontinued treatment will become a reality.

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