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BRIEF REPORT

‘A Virus and Nothing Else’: the Effect of ART on HIV-Related Stigma in Rural South Africa

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Abstract While the World Health Organization acknowledges the potential of antiretroviral therapy to reduce HIV-related stigma, few studies examine the nature of this linkage. This article discusses the connection between ART and HIV-related stigma, using qualitative analysis of interviews with HIV-positive adults at a rural South African clinic. The data has two main implications for ART’s role in stigma reduction: it strengthens the plausibility that ART can reduce stigma through weakening HIV/AIDS’s link with disfigurement and death, and shows that ART enables the establishment of spaces for support, which reduce stigma through normalization of the disease.

Keywords HIV · Stigma · Antiretroviral therapy · South Africa

Introduction

In 2003, the World Health Organization (WHO) published a report calling for the urgent scale up of antiretroviral therapy (ART). In this report, the WHO declared that increased availability of ART could reduce HIV-related stigma, arguing that, “as HIV/AIDS becomes a disease that can be both prevented and treated, attitudes will change, and denial, stigma and discrimination will be rapidly reduced” [1]. While confidently asserted, the WHO does not provide justification, nor does it elaborate on the pathways through which ART availability and stigma reduction may be connected. In fact, very few studies exist which closely examine the nature of this linkage. This is a critical gap in our understanding of the impact of ART on HIV/AIDS, as ART coverage increases worldwide.

While few studies have measured directly the effect of ART on stigma, an exploration of stigma literature reveals that ART has strong potential to cut stigma at its sources. Much literature exists surrounding questions of why HIV/AIDS is stigmatized in the first place, and can be divided into four main explanatory threads, including (i) interaction with pre-existing stigma, including marginalization of women, impoverished groups, homosexuals, etc [2–4]; (ii) utilitarianism, whereby people living with HIV/AIDS (PLHA) may face growing resentment in resource-poor settings because of the expense of their treatment incurred by the government and/or by society, and the perception that these individuals are no longer contributing members of society [5]; (iii) lack of HIV-related knowledge, whereby individuals’ misperceptions of HIV transmission (for example a belief that HIV can be transmitted through casual contact), leads to discriminatory attitudes towards PLHA; and (iv) the link between HIV/AIDS and imminent death. This last source pertains to social interpretations of the disease as disfiguring, debilitating and leading to certain death. Considering the fact that no treatment existed for HIV before the mid-1990s, and that many still lack access to ART, many understand the disease to be an inevitable progression into a humiliating loss of bodily control [6], as well as a death sentence [7]. These views can lead to an overestimation of personal risk due to heightened

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fear of the disease, as well as to avoidance or 'giving up' on an HIV-positive individual because the aesthetic of the condition is deemed by some to be offensive to inherently human judgments of cleanliness and normality [6].

ART may be able to disrupt three out of four of these sources of stigma. Briefly, as ART reconstitutes the immune systems of PLHA, HIV/AIDS is transformed from what was once a "disfiguring and consumptive disease," into a manageable condition, largely invisible to the outside world [8]. This transformation may reduce stigma, as social interpretations of HIV/AIDS shift away from imminent, unaesthetic death, and towards invisible, chronic condition. This transition constitutes the normalization of HIV [9], and can reduce stigma by cutting the association between HIV and death. The ability for PLHA to live longer, more productive lives can also cut stigma by reducing utilitarian concerns.

ART can also lead to the dissemination of HIV related knowledge, as rollout of ART has been the impetus behind the bolstering/expansion of voluntary counseling and testing (VCT) programs, as well as support groups and education campaigns which spread information about the modes of HIV transmission and prevention practices. This dissemination of correct information may reduce stigma by addressing misperceptions in HIV-related knowledge.

Thus, ART has the potential to target stigma at three out of four of its roots, which would make it a critical component in an effective stigma-reduction plan. This potential needs to be more closely examined, given the severity of the HIV/AIDS epidemic and the stigma that enshrouds it. In this regard, this paper examines real-life accounts of such stigma among PLHA in rural South Africa, which serve to corroborate the pathways proposed above. This article begins by examining the plausibility of the connection between ART and stigma reduction, then presenting qualitative analysis of a series of interviews with 32 HIV-positive adults in a rural clinic of South Africa, to discuss the ways in which the experiences of these patients sheds light on the pathways between ART and stigma.

Methods

Study Setting

Bushbuckridge is a municipality in the North East of South Africa. With a population of 523,000, 52% of people in Bushbuckridge live on less than R800, about \$130 per month, and the unemployment rate is 80%. Antenatal HIV prevalence is $\sim$35.5%, as compared to 29.3% in the country as a whole [10]. While more than 7,000 HIV-positive patients in Bushbuckridge are receiving ART, it is estimated based on national guidelines that over 20,000 are in need of ART [11]. As further ART scale up is clearly a necessity in Bushbuckridge, it is important to understand the issues facing patients on ART to ensure that future rollout is effective. With ethical approval from University of Witwatersrand and Brown University, interviews were conducted over a 10-month period from 2006 to 2007.

Sample

The study included 32 HIV-positive adult participants selected at the HIV clinic of the local hospital through purposive sampling methods. 1 month before the interviews began and following informed consent, the interviewer and local interpreter sat in on clinic support groups, which are offered to all HIV-patients at the clinic, in order to observe the participants' behavior and recruit a diverse sample for the study. The vast majority of patients attend the groups, and 32 were selected to represent a range of ages, and a mix of genders, experiences of treatment failure versus adherence, extrovert or introvert behavior, and a status of ART-initiated or non-initiated. The sample includes 20 females and 12 males, (proportions in line with the gender breakdown of the national ART program), and an age range of 25–57 years. 23 of 32 participants were unemployed. At the time of the first interview, 24 participants were ART initiated, and five patients initiated ART over the course of the study.

Data Collection

Once participants were selected and consented, they were interviewed privately, between 3 and 7 times each. An average of four interviews per participant were conducted, in both English and Shangaan, using an interpreter. Interviews took place in a variety of locations, including a private room of the clinic, the hospital courtyard, and at the participant's home. Privacy remained a high priority throughout the interview process.

During the interviews, which lasted between 20 min and 2 h, one interviewer and one interpreter took notes, which were combined, crosschecked and typed into an electronic file directly following the interview. Most patients opted out of voice recording, so no recording took place during the interviews in order to keep the data collection consistent across participants. As such, the data collected is not word-for-word transcriptions of the interviews, but detailed notes of the participants' answers. The data analyzed did not include any personal identifying information.

Data Analysis

The interview notes were typed up and imported into NVivo software where they were coded by two separate researchers based on demographic attributes and themes arising from a close read of the data. Any coding differences were discussed and rectified.

Results

Qualitative analysis reveals two main implications for the role of ART in stigma reduction. First, ART has the potential to break down the perception among community members and PLHA themselves that HIV is linked with death, as HIV-positive individuals begin to live longer, asymptomatic lives. Second, ART enabled the establishment of the clinic treatment support group, which can reduce stigma through normalization of the disease.

Breaking Down HIV/AIDS's Link with Disfigurement and Death

A dominant theme throughout the interviews is that community members have a general misunderstanding of HIV/AIDS, which leads to stigmatizing attitudes and behaviors towards PLHA. The most common perception of HIV/AIDS reported in the interviews is that the virus is linked with imminent death, a view that many of the participants also held at the time of their test. Two participants spoke about understanding HIV in this way when they first found out their status. According to the notes of one participant:

> "When she arrived at Tintswalo, the physician recommended that she test for HIV. The subject was hurt when the doctor first suggested this; she kept thinking about death. She thought that people with HIV die within three months"
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> Another participant's notes echo this sentiment:
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> "Approximately two months after she had separated from her husband, he called her and told her that she was going to die because she has AIDS. She was hurt, and she thought that she was going to die."

In these and other examples, the perception that HIV/AIDS is a death sentence had negative emotional consequences for both of the participants, and in the latter case, also delayed her decision to test and access treatment.

Four participants spoke about community members' perception of HIV/AIDS as linked with imminent death; one cited this as the reason why she does not want to disclose her young daughter's status to her. Another participant spoke about how "his family no longer stays with him because they think he is going to die." A third participant believes that families "do not want to talk about HIV" because of a perception that it "kills."

Four participants recounted stories about how their family and friends did not believe them when they disclosed, simply because they were not visibly ill, and thus did not fit into their preconceived notions of what PLHA looked and acted like. For one participant:

> "Her family was shocked, because the subject looks healthy, and they didn't really believe her. The subject had to show them her clinic card before they believed her."

The experience of another participant who reported disbelief as a reaction to her disclosure speaks to a different set of assumptions. According to the interview notes,

> "Her boyfriend didn't believe her, and he still does not believe her, because he believes that people who are HIV positive wouldn't tell other people."

This situation reveals the boyfriend's deeply ingrained assumptions of HIV/AIDS as something that must always be kept a secret, as if a great source of shame.

Several participants reported that community members are fearful of HIV, and subsequently overestimate their risk of contracting the disease. Four participants talked in their interviews about people's unwillingness to come into contact with PLHA, for fear that they will become infected "just by touching." Another participant discussed the perception she has encountered from community members that PLHA are dirty, "because they have diarrhea."

Overall, these interviews point to the existence of pervading beliefs that HIV is blame-worthy, highly contagious, and linked with imminent death. Heightened fear and overestimation of risk can lead to discrimination and alienation of PLHA. For example, four participants noted that community members "shout at others who are HIV positive," while eight reported that alienation of PLHA is a common reaction of community members. One participant reported that, "at the beer hall, some of the patrons say that they will not sit with people who are HIV positive. These people are some of his former friends." Another participant shared that his friends "have been treating him differently lately: they keep quiet when they are around him." Two participants reported that community members hesitate to share things, such as utensils, with PLHA, and one spoke of how HIV-negative individuals do not want PLHA to "touch their things."

Similar events were reported to occur among family members of PLHA. Three participants reported being abandoned or alienated by family members after disclosing to them. One participant noted that his family "no longer stays with him" since he disclosed to them, and another claimed that after disclosing, her family "began to neglect her and her children." Yet another reported that some of his family members no longer "want to be near him" since they know his status.

The associations demonstrated through the interview notes corroborate HIV's link with disfigurement and death as a significant source of stigma, increasing the plausibility that ART, with its life changing potential, may be able to disrupt stigma and the negative perceptions of HIV/AIDS. But the interview notes also demonstrate concrete ways in which starting on treatment has already begun to shift these perceptions, particularly for the participants themselves. Many participants' stories show that starting on treatment, and realizing that they could live healthily with HIV, has led to a reduction in perceived sigma in their lives. One participant explained that he "now feels comfortable disclosing his status to the community because he is on treatment and doing much better than before." Several other participants had similar experiences, where they were able to accept their status once they realized they had a chance to live. When commenting on the clinic support group, many participants noted that they were relieved to learn that HIV does not mean imminent death, and were comforted by the fact that they could witness many others living healthily with HIV.

Another way that ART facilitates a reduction in HIV-related stigma is that, in regaining their health and their confidence in the community, PLHA were able to become advocates and sources for support for other PLHA. One participant explained that, in his community, he counsels people who want to get tested. According to his interview notes,

> "In general, he feels comfortable disclosing to other people who are also ill, and if he sees parallels between his situation and theirs. People approach him about where he was able to go to get help. He counsels them, and accompanies them when they do VCT."

He also visits families "on behalf of someone he has counseled, and says to them, 'I have HIV. You should not be afraid of me…I am here today because you do not support [x person]'" This participant acts as a positive role model and advocate for others who may be HIV-positive, helping to reduce self stigma as well as family-level enacted stigma.

Several other participants report taking on similar responsibilities in their communities. One participant reported comfort in "disclosing her status because she is able to help others in disclosing, especially people who are ill." She reported having helped a young pregnant girl get to the clinic to test, and that the girl is now "doing well." Another participant disclosed to members of the community in order to educate them about HIV, and one participant reported that, although he is uncomfortable disclosing to his community, he wears his Treatment Action Campaign "HIV positive t-shirt" in public, "with the idea that people might see him wearing his t-shirt and then themselves will feel more comfortable testing and/or disclosing their status." Even when disclosure is not a viable option, this participant still advocates for stigma reduction and the empowerment of PLHA.

New Spaces for Support

In addition to enabling PLHA to lead healthy, asymptomatic lives, the data shows that ART reduces stigma since rollout of ART was the impetus for the establishment of treatment literacy courses and treatment support groups at the clinic. These courses and groups allowed participants to discuss issues and form bonds with other HIV-positive people with whom they could identify.

At the clinic, patients were encouraged to have a treatment supporter—family members of friends designated to remind the participant to take their treatment correctly. Interview notes show that these supporters provided important practical support to many participants, and played an important role in the participants' adherence to treatment. One participant reported that her family members "will not go to sleep unless they have watched her take treatment." Another noted that her son "plays an active role in reminding her to take her treatment." Thus, treatment supporters help PLHA stay healthy, which, as discussed above, is a crucial component in the reduction of stigma. But more than that, given their close proximity to the respondents, treatment supporters may also represent a significant source of emotional support for PLHA. While we do not know the extent to which this is the case, treatment supporters do have potential to provide both emotional and practical support, and further research into their role in stigma reduction should be conducted in the future.

The clinic support group also provided participants with a strong support system. Almost all participants spoke favorably of the clinic, as it is an important supportive space for the participants in several ways, stemming from its combination of HIV/AIDS education, emotional support, and its formation of positive group identity and solidarity amongst attendees. Fifteen participants reported that they first learned about HIV at the clinic. Within the support group, participants learned concrete tips for living healthily with HIV/AIDS. According to one participant,

> "Within the sessions, they discuss protecting themselves with other partners, keeping themselves healthy by not drinking alcohol or smoking, taking treatment on time, and they discuss potential ways to conceive and give birth in the future."

Other participants reported learning “the importance of eating a balanced diet,” the importance of eating food before treatment, the side effects one can expect from taking ART, and how to interpret CD4 counts. One participant spoke about how the clinic is “a great space to ask questions.”

But the interview notes show that the clinic space has importance beyond dissemination of facts. One participant mentioned that the support group taught attendees “how to accept their status and how to take care of themselves” while another spoke about how “he learned that there was nothing ‘wrong’ with ART as people sometimes imply.” The lessons about HIV and ART show participants that they can live normally with HIV. One participant reported that he learned at the support group that “HIV is a virus and nothing else.” The normalization of HIV/AIDS, with a focus on healthy and productive living, is crucial to a reduction in stigma.

Several participants reported a positive change over time in their acceptance of their status due to the support group. According to the notes of one patient,

> When he tested, he asked how he contracted HIV, and the clinicians didn’t know. He was very scared, and he thought about killing himself. He began to attend the support session, and he eventually accepted his status.

This account is a clear indication of how the support sessions made HIV more manageable for one participant. The normalization of HIV/AIDS in the clinic space changed this participant’s outlook on life. In a similar manner, another participant “was told that if he accepted his status, being HIV positive is not a death sentence.”

It is not just the discussions of how to live healthily with HIV/AIDS that contributed to an improvement of participants’ outlooks on life. A common theme in the interviews is that the clinic support group made participants feel less alone, because it opened up a space for HIV-positive people to meet and talk to one other. One patient “realized how many people were living with HIV” which “helped him to accept his status.” Another patient did not believe his status until he attended the support group and began “listening to others who described the symptoms of being HIV positive.” The interview notes demonstrate that having other HIV-positive people to discuss issues with is important not only because they are able to share concerns and advice, but because it demonstrates to the participants that there are many people living healthily with HIV/AIDS. The simple fact that the support session is full of other PLHA is an important contributor to the normalization of the condition, and may lead to reductions in stress, fear and feelings of isolation. One participant came to realize that “many people his age ($\sim$55 years old) are infected” since “he encounters so many of his peers at the support sessions.” Another participant reported feeling “free and less stressed” because “she is with other people who she can identify with,” a sentiment echoed by several others.

What’s more, four different participants reported finding relationships through the clinic. According to one participant’s interview notes:

> “His current girlfriend is also HIV positive and they have disclosed to one another. He disclosed the same day that he met her, and she revealed that she had seen him in the support group, but he had never seen her. She had been there to test (for HIV). She accepted him when she learned his status; she had been looking for someone who would understand her.”

Although it is not clear whether the participant met his partner at the clinic itself, the fact that they both attend the same clinic, and that they are both HIV-positive, seems to have been a catalyst for the formation of their relationship, and a continued source of support for them both.

The data shows that ART can reduce stigma because rollout of ART in the clinic was the impetus for the establishment of treatment literacy courses and treatment support groups. These sessions have been shown to have many benefits for the patients, as attendees were able to gain knowledge and make connections with other people with their condition. This solidarity and support helped to normalize HIV/AIDS for many of the patients, leading them to accept their status, and improve their outlooks on life. In this way, the normalization of HIV/AIDS is not merely associated with HIV-negative people realizing that PLHA can live healthy lives, but also with PLHA, themselves, realizing that they can live healthy lives. The clinic space enabled many participants to come to this realization, which leads to a reduction in the shame and self-loathing associated with self stigma. But the normalization of HIV can also lead to a reduction in enacted stigma, as the participants’ acceptance of their own status can lead them to be advocates and counselors for others. One participant cited her realization that “we are many” as the motivation for disclosing to others in the community. It is plausible that her disclosure could help someone else to seek testing and support at the clinic.

While ART has been associated with a decrease in perceived stigma in many of the participants’ lives, one important exception deserves notice. According to this participant:

> “He feels comfortable disclosing his status to the community, but he does not feel comfortable telling people that he is on treatment, because he fears that the community will not want to interact with him

> since ‘people on treatment have AIDS’. He feels comfortable disclosing his status within the community, especially when people see his HIV ribbon pendant. He does not feel comfortable telling others that he is on treatment”.

In this case, the respondent feels that ART is equated with late stages of AIDS, and therefore with death, such that being on treatment is what is stigmatized rather than only being HIV-positive. While other participants did not report this view, the potential for ART to increase stigma cannot be discounted, and must inform any future research concerning ART scale up and/or HIV-related stigma reduction.

Discussion

Limitations

This study of the effect of stigma on the lives of PLHA has several limitations. The study was conducted over a 10-month period when rollout of ART was relatively new and coverage was limited, so examples of change in stigma over time are scarce. It was also beyond the scope of this report to examine the differences in experiences and perceptions between ART-initiated and non-initiated patients. Further research should focus on these differences, as they may provide greater insight into the ways in which ART can reduce self or experienced stigma.

As previously mentioned, the interviews were not voice-recorded, and thus the data may have omitted parts of a participant’s response. However, two sets of interview notes were crosschecked during the data collection process comprised of several follow-up interviews. In addition, the sample of participants in this study was purposive, not random. As such, we cannot generalize the findings to the population of South Africa, nor to HIV-positive individuals as a whole. However, the findings will speak to the experiences of other HIV-positive individuals in South Africa, particularly those in rural settings and those who seek treatment in the public sector.

The rollout of ART is relatively new and far from complete; as rollout continues, it is crucial to conduct more studies in order to understand the challenges arising from the provision of ART. There is a particular need for longitudinal studies to better understand the effect that rollout of ART has on perceived and experienced stigma over time.

Conclusion

Qualitative analysis of interviews with 32 HIV-positive adults at the local clinic in Bushbuckridge, South Africa has two main implications for the role of ART in stigma reduction. First, the data strengthened the plausibility that ART can reduce stigma through a weakening of HIV/AIDS’s link with disfigurement and death, as participants reported that community perceptions of disease often aligned with this source of stigma. The data also demonstrated cases where this plausibility became reality. Many participants were able to accept their status once they realized that HIV was not a necessary death sentence; others even became advocates and/or counselors for other PLHA. Secondly, ART enables the establishment of new spaces for support, including the clinic treatment support group, which was shown to reduce stigma through normalization of the disease. While contextual variability limits the generalizability of any studies of HIV-related stigma situated in one place or at one point in time, this may inform studies across contexts since the theoretical underpinnings of ART’s link with stigma are applicable to communities across the globe.

This article should be the beginning of an in depth conversation on the importance of ART for stigma reduction. ART can turn HIV/AIDS into an invisible and chronic condition, thus creating a normalized picture of the disease, and enhancing positive messages of hope and health for both infected and non-infected individuals. This shifted perception of HIV/AIDS is a significant and necessary component of successful approaches to stigma reduction, such that a lack of access to ART could likely undermine other efforts to reduce HIV-related stigma. ART’s implications for stigma reduction reinforce the urgent need for continued ART rollout around the world.

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