

“We, the AIDS people. . .”: How Antiretroviral Therapy Enables Zimbabweans Living With HIV/AIDS to Cope With Stigma

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We studied the impact of antiretroviral treatment availability on HIV/AIDS stigma through interviews with 118 antiretroviral treatment users, HIV/AIDS caregivers, and nurses in Zimbabwe. Treatment enables positive social and economic participation through which users can begin to reconstruct their shattered sense of social value. However, stigma remains strong, and antiretroviral treatment users remain mired in conflictual symbolic relationships between the HIV/AIDS people and the untested. To date, the restoration of users' own sense of self-worth through treatment has not reduced fear and sexual embarrassment in framing community responses to people living with HIV/AIDS. Much remains to be learned about the complex interaction of economic and psychosocial dimensions of poverty, treatment availability, and conservative sexual moralities in driving HIV/AIDS stigma in specific settings. (*Am J Public Health*. 2011;101:1004–1010. doi:10.2105/AJPH.2010.202838)

How does antiretroviral treatment (ART) affect the ability of ART users to cope with HIV/AIDS stigma? Stigma is a key driver of the HIV/AIDS epidemic, particularly in low-income settings.^{1,2} Psychologists have dominated discussions of its causes, foregrounding individual-level explanations, which include unrealistic fears of contagion and social embarrassment of the sexual nature of HIV transmission.³ The greatest challenge to this dominance comes from Castro and Farmer. In their classic 2005 article, they argue that stigma is determined more by lack of effective health services and treatment than by psychological factors, particularly in resource-poor settings where the sick and dying drain scarce community resources.⁴ They argue that access to ART enables people living with HIV/AIDS to regain potential value as economically and socially competent citizens and that as ART becomes universally accessible, stigma will gradually disappear. Since this 2005 article, ART has been slowly rolled out,⁵ transforming HIV/AIDS from a tortuous death sentence to a manageable chronic illness and providing researchers an opportunity to explore Castro and Farmer's arguments in specific contexts. We investigated the impact of ART on users in rural Zimbabwe to explore how treatment availability affects stigma in this setting.

Goffman emphasizes the need to use the “language of social relationships rather than the language of attributes”⁶ to understand stigma. Viewing stigma as negative social representations of HIV-infected people, we examined the processes through which people living with HIV/AIDS internalize or resist it, leading to positive or negative social identities. We understand social identity in terms of Cooley's notion of the looking glass self⁷ and Mead's observation that social identities are heavily determined by how others view us.⁸ A vital precondition for human well-being and agency is the recognition of people as having value by those around them.⁹ Stigma arises when people are denied such recognition. We examine the extent to which the availability of ART opens up new modes of positive social recognition for treatment users.

At the time of our late 2009 study 34% (2010 WHO guidelines) of those needing antiretroviral drugs in Zimbabwe were receiving them (compared with an average of 37% across sub-Saharan Africa).^{5,10} Many people living with HIV/AIDS remain visibly ill and dying, health services battle with the complex demands of ART rollout, and the long-term future of heavily donor-sponsored ART services remains uncertain. Although it is too early to offer definitive comment on Castro and Farmer's

claims at this early stage, our study provides useful preliminary insights into potential pathways between ART use and stigma.

EXPLANATIONS OF STIGMA

The HIV/AIDS stigma literature is vast^{3,11} and incorporates 4 broad trends. Three give primacy to psychosocial factors, the fourth to socioeconomic factors. The first views stigma as the result of ignorance, which leads to exaggerated fears of physical contagion. The second roots the othering of people living with HIV/AIDS in unconscious anxieties about the uncertainty of the human condition. The third links these unconscious processes to wider power relations.¹² With its link to illicit sex and drugs, HIV/AIDS is argued to constitute a symbolic threat in contexts requiring the control of irrational human impulses for efficient economic production.¹³ In contexts of conservative sexual moralities, stigma is conceptualized as society's symbolic punishment for those who have challenged the sexual and gendered status quo.¹⁴

Although psychosocial explanations dominate, a fourth countertrend focuses directly on socioeconomic and structural factors, arguing that poverty and lack of access to basic health and welfare services drive stigma.⁴ This line of argument holds that people are most likely to extend compassion to the sick when they have the resources to offer effective assistance.¹⁵ In resource- and service-poor areas, HIV/AIDS stigma may be driven by the hopelessness of supporting a dying person, the costs of whose care compromises the well-being of others. Hopelessness may also drive health workers to assign stigma where there is little they can do to alleviate patient suffering.¹⁶ It is predicted that HIV/AIDS stigma will disappear in contexts of effective treatment access. Castro and Farmer discuss the case of a Haitian living with AIDS, Samuel Morin.⁴ As his health deteriorated, he became unable to support

his family, who eventually left him. Once on ART, he was able to resume a normal and economically productive life. His family returned to him, and he was reintegrated into his community as a respected, productive person.

A recent Tanzanian study did not support the argument that ART availability reduces stigma but found that although ART contributed to a degree of normalization of HIV/AIDS-affected people, HIV/AIDS continued to be stigmatized as a “moral disease,” a label which undermined disclosure and voluntary counseling and testing.^{17,18}

COPING WITH STIGMA

The literature on how people living with HIV/AIDS cope with stigma is often descriptive, presenting lists of coping mechanisms. An African 5-country study¹⁹ lists emotional and problem-focused coping strategies that people living with HIV/AIDS use (e.g., turning to God, rationalizing one’s situation, helping others). We seek to move beyond viewing coping in terms of decontextualized individual-level strategies and conceptualize it in terms of people’s embeddedness in wider social relations, particularly their opportunities to engage in forms of social participation that enable them to (1) access formal and informal social support, (2) live productive and socially valued lives, and (3) construct positive social identities.^{20,21} Viewing stigma as a negative social identity arising from the participation of people living with HIV/AIDS in social relationships that devalue them, what opportunities does ART use open up for new forms of social participation that enable people living with HIV/AIDS to have a more positive and empowered sense of self? HIV-infected persons with positive identities are most likely to be able to resist stigma, as are those in supportive families and communities and trusted networks.²²

Several studies document ART users’ responses to stigma, some reporting the development of stigmatized identities,^{23,24} others highlighting resistance or management of stigma.^{24–27} However, there has been little analysis of the pathways between ART availability and resisting stigma. One exception, resonating with our own conceptualization of coping, argues that people are able to resist stigma to the extent that they have access to

social roles, identities, and group memberships to which they can ascribe positive value and meaning.²⁶ This insight offers a springboard for our investigation of whether and of how improved ART availability provides people living with HIV/AIDS with resources and opportunities for social participation through which they can demonstrate their social value. The advent of ART has already been found to rebuild the hope and motivation of demoralized South African nurses.²⁸ How has ART affected people living with HIV/AIDS in Zimbabwe? What pathways has it opened for more empowering and identity-enhancing forms of social participation?

METHODS

Zimbabwe is a landlocked country in southern Africa that transitioned from colonial to African majority rule in 1980. Initially, it experienced an annual gross domestic product growth of 5%, free primary education, and improved health services.²⁹ However, from 1999, it experienced political and economic turmoil. The gross domestic product declined by 8.0% in 2001 and 18.5% in 2003.³⁰ Conditions have improved slightly since mid-2009 but remain unstable. AIDS shifted life expectancy from 61 years of age in 1992 to 42 years of age in 2010.^{31,32} The epidemic has recently stabilized, with HIV prevalence declining from 26.5% in 1997 to 14.3% in 2009³³ following reductions in high-risk behavior.³⁴

The past 6 years have seen a gradual ART rollout. Zimbabweans on ART increased

from 99 500 in 2007 to 148 100 in 2008 and 218 600 by the end of 2009, an increase which represented only 34% of those who needed treatment.¹⁰ Funding has been chiefly provided by an expanded program of support coordinated by the United Nations and financed by bilateral donors as well as the Zimbabwe government. The Zimbabwe government provides financing through the National AIDS Trust Fund via a 1% tax levy ring-fenced for HIV/AIDS management.

We conducted our research in Manicaland, eastern Zimbabwe. This rural province had an HIV prevalence rate of 16.5% for men (17–54 years of age) and 20.5% for women (15–44 years of age) in 2005.³⁵ We recruited 53 patients, 40 guardians caring for a child on ART, and 25 nurses from 3 locations. We sampled patients and pediatric caregivers with snowball (using village guides), opportunistic (self-selected informants), and typical case (adherers to ART) sampling. We recruited nurses according to their willingness to participate.

Four experienced Shona-speaking fieldworkers conducted 58 individual and 8 focus group discussions in late 2009 (Table 1). Semistructured topic guides focused on informants’ health, career, or caregiver histories and experiences or views of HIV/AIDS and ART, stigma, and health service and treatment access. Individual interviews averaged 1 hour and group interviews averaged 2.3 hours. Group interviews followed a similar topic guide; in addition, the interviewer invited participants to role-play a typical

TABLE 1—Study Participant Characteristics: Evaluating and Enhancing HIV/AIDS Treatment Services Study, Manicaland, Zimbabwe, 2009

Study Characteristics	Patients	Pediatric Caregivers	Nurses	Total
Research participation type				
Individual interview, no.	19	21	18	58
Focus group, total no. (no. of groups)	34 (4)	19 (3)	7 (1)	60 (8)
Total participants, no.	53	40	25	118
Average age, y	44	54	41	46
Women, no.	32	38	11	81
Men, no.	21	2	14	37

patient-nurse interaction in the ART context.

We recorded, transcribed, and translated the interviews. Thematic network analysis³⁶ generated 225 codes clustered into an increasingly inclusive set of 22 basic and 4 global themes that reflect the pathways through which ART enables users to cope with or resist stigma (Table 2).

Given that research participation was voluntary with recruitment from clinic settings, our sample was probably biased toward regular, highly motivated clinic attendees who had overcome multiple barriers to access and adherence (including stigma, transportation costs, opportunity costs, and high consultation fees: US\$1.00 per month, where the average person lives on less than US\$2.00 per month; M. Skovdal, C. Campbell, K. Nhongo et al., unpublished data, study completed in 2009). As social constructionist researchers,³⁷ rather than seeking to generate stereotypical characterizations of all members of a statistically representative sample, we sought to produce a fine-grained study of the diverse ways that 1 group of ART users was responding to stigma in 1 setting.

RESULTS

Although ART opened up many opportunities for people living with HIV/AIDS to resist stigma, our research participants emphasized that stigma remains powerful and that coping with it presents a constant and formidable challenge. Contrary to Castro and Farmer’s findings,⁴ informants explained stigma in terms of the 2 factors most frequently mentioned by psychologists: a deep fear of infection and the sexually transmitted nature of HIV/AIDS. The latter often led to deep humiliation from the loss of dignity that “promiscuity” implies in this context. In abject poverty, with little access to material sources of social status, social respectability plays a key role in the construction of social value and personhood and is closely linked to a conservative sexual morality. Although there was a degree of tolerance for sexual transgressors, people were expected to be discreet in their transgressions. Those who were not were subject to varying combinations of delight at their misfortune, gossip, denigration, or outright

TABLE 2—Pathways Through Which Antiretrovirals Empower Users, by Global Theme: Evaluating and Enhancing HIV/AIDS Treatment Services Study, Manicaland, Zimbabwe, 2009

Basic Themes	Organizing Themes
Improved HIV management (global theme 1)	
Improved ART availability.	Availability and quality of HIV services.
More people test for HIV.	
Many people living with HIV/AIDS are satisfied with the quality of health services.	
Following counseling, ART users are more likely to disclose and live positively.	Patient satisfaction, disclosure, confidence
Being able to offer effective help to people living with HIV/AIDS motivates nurses.	Nurses feel motivated by ART.
Many nurses take pride and pleasure in seeing patients progress.	
ART users actively participate in HIV management (global theme 2)	
ART users strive to work with nurses on achieving treatment goals.	Patients engage with support services.
ART users participate in support groups.	
ART users comply with health services to qualify for food aid.	
ART users negotiate support from nongovernmental organizations.	
ART users have considerable knowledge about AIDS and ART, which they use to educate others.	Give advice and encourage testing
ART users actively encourage others to get tested and help them come to terms with their status.	
ART users lead normal and productive lives (global theme 3)	
The livelihoods of ART users are often sustained through subsistence farming.	ART users are economically active and can sustain themselves and contribute to society.
Many patients take pride in their ability to actively engage in formal or informal work.	
Patients see themselves as living normal lives and capable of doing the same things as uninfected people.	ART users seek to normalize their circumstances by rejecting differences between ingroup and outgroup
Many patients repeatedly emphasize their capacity to engage in microfinance and farming activities.	
ART users construct positive identities (global theme 4)	
Acceptance by many ART users of their own and their infected children’s HIV status feeds into positive living.	ART users seek to resist stereotypes.
ART users want to display their positive living skills to challenge stigma.	
ART users avoid exposing others to the risk of HIV.	ART users construct themselves as responsible, valuable citizens.
ART users depict themselves as competent and active participants in community life.	Positive identity construction by asserting differences between ingroup and outgroup.
ART users compare their enhanced control over their health with those who have not yet been tested.	
Many ART users feel confident enough to reject stigmatizing comments and attitudes of nontested people.	

Note. ART = antiretroviral treatment.

hatred. The sexual element lay at the root of what was widely regarded as the “laughable” fall from grace of people who had, in their pre-HIV/AIDS lives, been “proud” and behaved “as if they were worthy of respect and dignity.”

They laugh at us behind our backs, saying, “Look they used to be pompous, to think that they were ‘a somebody’—now they are paying the price!” (Telder, patient)

Men experienced this loss of status as particularly devastating.³⁸

I did not want to be tested because I would lose my dignity as a father to my kids. I would also lose respect from my wife and the community, who would view me as a promiscuous and useless man. The pride we have of being father and head of family—an HIV-positive result washes away all that respect. (Jotan, patient)

However, while emphasizing ignorance and sexual embarrassment as drivers of stigma, people often spoke of how ART enabled the economic rehabilitation of people living with HIV/AIDS, giving them the confidence to resist stigma and to restore their own, and sometimes the community’s, sense of themselves as dignified persons of social value. Our data suggest an interaction between the economic and the psychosocial in shaping peoples’ fall from social respect as well as the possibility of its restoration. We follow the structure of Table 2 in developing these points.

Improved HIV Management

Unsurprisingly, the availability of lifesaving drugs that transform HIV/AIDS from a slow and often agonizing death sentence to a chronic and manageable disease has provided patients, caregivers, and nurses a renewed trust in their health services.

The availability of ART has transformed how HIV/AIDS is viewed. People feel able to disclose their status because they know drugs will be given at no cost. Before this, people viewed HIV sufferers as people merely waiting to die. (Farisai, patient)

Despite carrying heavy responsibilities in a context where doctors are in short supply, nurses welcomed the job satisfaction and positive nurse-patient relationships enabled by ART.

One guy who first came in a wheelchair is now walking and looking fit. It is very satisfying to work with HIV sufferers on ART. We build

relationships with them because they come back every month, and we see them progressing towards recovery. (Esther, nurse)

Most ART users spoke of outstanding service from nurses, commenting on their concern, patience, and interest in prioritizing patients living with HIV/AIDS.³⁹

Antiretroviral Users Actively Participate in HIV Management

ART rollout opens opportunities for users of antiretroviral drugs to participate in HIV/AIDS management. Such involvement not only allows the best possible outcomes for their own health but also helps them support others, providing them with a platform to exercise agency, build social capital, and renegotiate stigmatized identities. ART users’ interaction with nurses is a particularly important area in which the agency of ART users is played out. ART users are fully aware of how nurses perceive “a good patient” (e.g., one who attended on given review dates, adhered to treatment plans, and answered nurses and counselors truthfully during review meetings), and many worked hard to fulfill this role to ensure optimal care.

If the nurse thinks you are not a good patient, they will not even listen to what you have to say. (Grace, patient)

When I was in hospital, all the nurses wanted to serve me, they would always rush to my bed. They enjoyed talking to me because I obeyed what they were saying. (Rufaro, woman patient)

Patients also worked actively to negotiate support from community-based services (e.g., disclosing their status to nongovernmental organizations to access food aid). Ironically, their right to access this prized assistance in a poverty-stricken community elicited envy from others and gave them a degree of social status.

When food donations came, they asked for verification of people’s HIV status. Those who were sick and had not gone to the hospital rushed to the hospital to get tested. (Karren, patient)

The uninfected feel jealous that we get this food assistance. (Mercy, patient)

Several patients repeatedly referred to their positive engagement with community-based support groups that nurses, HIV/AIDS counselors, and patients established to facilitate optimal ART adherence. Group members

supported each other and advised new ART users on coming to terms with their status and rigid treatment plans and on how to access help. Groups also provided patients and pediatric caregivers with opportunities to meet similar others and participate in joint income-generating activities.

In our support group, we share ideas and our experiences on how to take care of these children properly and how they can live longer. We also have different projects to raise income and to generate things for domestic use like chicken and rabbit rearing. (Marie, pediatric caregiver)

Many spoke of their duty to disseminate understandings arising from their own experiences, processed through dialog with support group peers, to educate and support community members who still saw HIV/AIDS as a terminal illness and refused to be tested. This role gave them a positive sense of performing a vital and lifesaving community service.

Antiretroviral Users Lead Normal and Productive Lives

Informants repeatedly spoke of how ART had enabled them to regain their physical health, allowing them to participate in economic activities that challenged people’s perceptions of people living with HIV/AIDS as a drain on society. The opportunity to prove their economic competence dramatically reformed their perceived social value.

People still do look down upon us. If we can engage in income-generating projects, they will see that even though we are ill, we are still productive. We can grow all the vegetables we need and feed our chickens and sell them. (Everline, patient)

ART enabled some informants to resume or begin formal employment—as a police officer, tailor, bus driver, and nurse. Although most users engaged in subsistence farming, several were actively seeking nongovernmental organization support to establish additional income-generating activities. These endeavors would not only cover the costs of monthly ART reviews, food, and medicines for opportunistic infections but also help them prove their worth, not least through being able to contribute to family support. ART users emphasized that living with HIV/AIDS did not diminish their relationship with their family and linked their ability to participate in

productive activities to their family's long-term well-being.

Antiretroviral Users Construct Positive Identities

In striving for normalization and proof of their social worth, ART users worked hard to resist society's efforts to depict them as "devalued others." They spent a lot of time discussing the boundaries between "us" (people living with HIV/AIDS) and "them" (those without HIV/AIDS) to construct positive identities and resist stereotypes. However, the process was often defensive, with people either repeatedly asserting that they "didn't care" what others thought of them or responding to perceived insult or denigration through a process of counterstigma. This involved the often very intensely felt vilification of "the untested" who sought to stigmatize them. In this way the newly empowered identities that ART use enabled were often counteridentities built on the continuation of ill will rather than representing the restoration of ART users' dignified place in a harmonious social order.

Before examining the conflictual nature of some coping responses, we emphasize the very real sense of empowerment people repeatedly mentioned.

Personally I don't really care, and I don't really view it as an issue when people refer to us as "those people with HIV/AIDS." If they say that in my presence I just say, "Here I am, I am one of those people, and I have accepted my situation and I am ready to let everybody know." (Stephen, patient)

To be honest we "the AIDS people" no longer care, and we don't really mind what they say; in fact we even find it funny that some people refer to us that way—we often laugh about it. It is actually helping us to cope. (Florence, patient)

Not everyone was able to dismiss stigma as confidently however; several stressed that HIV/AIDS-affected people should actively strive to counter negative stereotypes, work hard to look fit and healthy, and avoid behaviors that might alienate others.

We shouldn't be among those AIDS-affected people who people see as "about to die." We should be seen to have good health so people are surprised when we tell them we are HIV positive. (Karren, patient)

When your body has sores and you are bleeding, it's best not to touch other peoples' food even if you want to, because it gives people a reason to complain. (Jane, pediatric caregiver and patient)

A key identity-strengthening strategy that "we, the AIDS people" (as ART users often describe themselves) use is their confident assertion of their superior courage compared with those they dismissively referred to as "the untested" (Violet, patient). They proudly depicted themselves as those who had the courage to overcome their fears and take action against HIV/AIDS—assuming that many of the untested were also likely to be HIV positive. Their characterization of themselves as a small, socially responsible elite who had taken control of their health status provided many with a strong sense of positive agency. Furthermore, support group members said being open about their status had gained them significant and welcome support from similar others. They no longer felt isolated, proudly styling themselves as educated through having acquired health-enhancing knowledge compared with those who deliberately chose not to know this.

I am now happy and feel I have regained my social position. My only plea is for continued HIV awareness to enlighten those blind people. By these I mean those untested people who like to think they are OK. I call them blind because they would rather wait until they fall ill to find out the truth of their situation. (Violet, patient)

I don't really care what these people say because if somebody says something degrading to me, I ask them whether they have been tested for HIV. If they have not been tested, then they don't know their status and that makes me better than them because I already know mine. I have taken that responsibility. (Caroline, patient)

This pride in knowing their status helped many turn the tables, mocking or pitying the untested who would unnecessarily die of AIDS. Having "made the right decision" (Caroline) enabled them to "laugh at those who sought to laugh at us" (Florence).

We were tested in 2003, and that's when we started ART. There were people who thought I was not going to last long. Yet I was already on ART and recovering well. Some of the very people who laughed at me have themselves already died, and yet I am here (general laughter). (Stephen, patient)

Other community members noted their growing confidence and refusal to be ashamed.

You hear people making sarcastic comments like "These AIDS people are now parading their status, as if having AIDS were beneficial" . . .

people even accuse us of bragging about our AIDS. (Florence, patient)

DISCUSSION

Viewing coping in terms of opportunities for positive social participation,²⁰ we have examined how treatment availability may open up forms of positive community engagement that enable people living with HIV/AIDS to repair their shattered social identities. Many ART users have successfully built rewarding and positive relationships with motivated and supportive nurses, enabling them to gain optimal benefit from the health care system. They have also derived a sense of agency, and material benefit, through successfully negotiating with nongovernmental organizations for food parcels in a community challenged by poverty and hunger. They have given and received vital information and social support through participation in support groups as well as deriving the will and confidence to act as positive health advocates to other community members. Their improved physical health means both they and others can see they are capable of living economically productive lives, which is vitally important in conditions of tremendous poverty. Their sense of having some kind of control over their health enables people to construct an empowering distinction between "us" (the self-identified "AIDS people") and "them" (the often hostile and untested other).

Treatment availability gives many ART users a renewed sense of social value, including confidence in their previously compromised abilities to engage in housework, subsistence farming, or formal work where available. To this extent our findings strongly echo the views of Castro and Farmer.⁴ However, stigma continued to be rife in our study community, with fear of infection and sexual embarrassment still cited as powerful drivers, even in the face of growing evidence that ART offered the possibility of restoring the abilities of people living with HIV/AIDS to function as socially productive members of society, no longer necessarily a drain on scarce resources. Furthermore, ART users often responded to HIV/AIDS stigma using strategies of defensive

counterstigma, rather than feeling that ART had restored their acceptance as valued community members.

Given that the process of ART rollout in Zimbabwe is still relatively recent and partial, it could be that as greater coverage is achieved over time, gains in economic competence associated with ARV use will progressively overshadow the role of fear and sexual embarrassment in driving stigma. However, given the complexities of the human emotional response to sexuality and the predominantly sexual mode of HIV transmission, it seems likely that the positive effects of economic empowerment will always be tempered by psychosocial factors in shaping both community responses to HIV/AIDS and the likelihood of stigma.^{13,14} Here we emphasize that we are in full agreement with Castro and Farmer's emphasis on the vital role of treatment availability in stigma reduction and their insistence on the role of economic and structural factors in shaping community responses to illness. We would certainly not seek to deny the role of poverty and of lack of treatment in shaping such responses; however, psychosocial factors will always mediate economic determinants of community responses to HIV/AIDS. Much remains to be learned about the complex interaction of the economic and the psychosocial in driving HIV/AIDS stigma in conditions of poverty. ■

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Contributors

C. Campbell was the research leader of this study; supervised research design, data collection, and analysis;

and wrote the final version of the article. M. Skovdal managed the data set, conducted the data analysis, and wrote the first draft of the article. C. Madanhire and C. Nyamukapa managed and conducted the fieldwork. O. Muguruni facilitated access to the research site. S. Gregson was the principal investigator of the overall Manicaland Project, which hosted this research. All authors were involved in ongoing discussions of the research and write-up.

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