

A Qualitative Study of Impressions and Experiences of HIV in Zimbabwe¹

Stephen O'Brien
The University of Queensland

Abstract

The HIV epidemic, in Southern Africa in particular, has taken a significant toll on individuals, families and communities. In Zimbabwe this human tragedy has occurred in the context of an ongoing economic and political crisis that has constrained health service delivery and further complicated HIV care. This complex socio-political landscape constitutes the backdrop to this study's exploration of the impact of HIV on people who live in the high population density areas of Zimbabwe's capital, Harare. In order to explore the social dynamics of HIV I conducted qualitative semi-structured interviews with sixty people in 2010. In this article I draw on these interviews to examine how traditional and religious interpretations of illness, as well as the historical roots of the epidemic and deep-rooted structural inequalities, have shaped the experience of the virus and HIV-related stigma. The intersections between sexuality, disease and culture indicated that there was a shift in attitudes, particularly with regards to patriarchal notions of sexuality and gender among the participants. Furthermore, the study reveals how the spiritualisation of disease and the gendered mediation of HIV have shaped the uptake of antiretroviral therapy (ART) and other forms of biomedical technologies. Finally, I note how grassroots social activists have contested and re-framed the HIV narrative through advocacy and informal and formal activism in ways that have vindicated the rights of people living with, and affected by, HIV.

Introduction

Zimbabwe, with its location in the epicentre of the HIV epidemic and its complex geopolitical historical setting, presents an important site for understanding how HIV continues to impact on the lives of individuals and communities in Africa. The effects of HIV can be measured in

¹ This article is an updated version of Stephen O'Brien's paper presented at the AFSAAP Annual Postgraduate Conference held in Canberra, November 2012, which was awarded First Prize in the 2012 AFSAAP/Monash Postgraduate Prize Essay competition.

terms of foregone life years, lost economic productivity and a myriad of other equally serious consequences. However, in this study I was interested in examining the effects of HIV on people who have lived under its influence for most, if not all, of their lives. Hence, this study explores how the epidemic has impacted on self-perceptions, culturally-located understandings and the lived experience of health, illness and disease. It has sought to understand related social processes through the stories of a specific group of men and women from four townships of Harare, Zimbabwe's capital city. Some of these people were openly HIV positive. Others, while not public about their status, were nevertheless affected by HIV due to their close relationships with people who were HIV positive, or simply because of the endemic presence of HIV in their communities. The analysis of the interviews uncovered a rich complexity around the interrelationships between disease, cultural practices and social structures.

Background

In the 1970s a spike in unusual medical conditions, such as Kaposi's sarcoma and lymphoma, was observed in countries such as the Democratic Republic of the Congo, Zambia, and Uganda, in the early 1980s, the same phenomenon was noticed in Zimbabwe.² After suddenly becoming ill, these patients, often young and previously healthy, invariably failed to respond to treatment and soon died. Researchers later traced the illness outbreaks as they occurred along trade and transport routes from Central to East Africa and southwards to Mozambique and Zimbabwe.³ On the other side of the globe in the early 1980s, reports of immune dysfunction diagnosed among young men in Los Angeles and New York drew resonance across the United States (US), and subsequently in Europe and Australia.⁴ However, the correlation between the symptoms causing concern in the Western hemisphere and those occurring in Africa was not immediately established, and this confusion delayed the emergence of an effective response to HIV.⁵ In the US, the perplexing nature and mysterious

² John Iliffe, *The African AIDS Epidemic: A History* (Athens: Ohio University Press, 2006); Jacques Pepin, *The Origins of AIDS* (Cambridge, UK: Cambridge University Press, 2011).

³ Iliffe, *The African AIDS Epidemic*.

⁴ Paul Sendziuk, *Learning to Trust: Australian Responses to AIDS* (Sydney: University of NSW Press, 2003).

⁵ Paula Treichler, *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS* (Durham: Duke University Press, 1999).

origins of the new disease, as well as its associations with ‘the other’, meant that marginalised groups such as immigrants, sex workers, gays and injecting drug users were stigmatised and being accused of spreading the so-called ‘plague’.⁶

In 1985, suspicions that AIDS had also arrived in Zimbabwe were confirmed when nearly 3 per cent of Harare’s blood supply⁷ was found to be contaminated with HIV.⁸ With AIDS hysteria still gripping the popular imagination in the western hemisphere, it is perhaps understandable that countries such as Zimbabwe minimised, denied, or portrayed HIV as only a predicament for the sexually deviant.⁹ This perception has persisted, and where it has taken the form of social stigma, access to counselling and testing and treatment has been discouraged.¹⁰ Given this situation, the epidemic’s toll has continued to mount. In 2009 it was estimated that two million Zimbabweans had died from AIDS and over one million more had become HIV positive.¹¹ This occurred in a region, Southern Africa, where 11 million people, or one-third of the global HIV-positive population, are currently living.¹²

⁶ Treichler, *How to Have Theory in an Epidemic*.

⁷ Ministry of Health, *Medium-Term Plan for the Prevention and Control of AIDS, July 1988 to June 1993* (Harare: Ministry of Health, 1988).

⁸ In accordance with *UNAIDS Terminology Guidelines* (Geneva: UNAIDS, 2011) this paper employs the terms AIDS and HIV separately according to the specific context. HIV is regarded as a broader term than AIDS.

⁹ Alexander Rödlach, *Witches, Westerners, and HIV: AIDS and Cultures of Blame in Africa* (Walnut Creek: Left Coast Press, 2006); Sunanda Ray and Farai Madzimbamuto, “The HIV Epidemic in Zimbabwe—the Penalty of Silence,” *The Round Table* 95:384 (2006): 219-238.

¹⁰ Lynne Duffy, “Culture and Context of HIV Prevention in Rural Zimbabwe: The Influence of Gender Inequality,” *Journal of Transcultural Nursing* 16:1 (2005), 23-31; William Sambisa, Sian Curtis and Vinod Mishra, “AIDS Stigma as an Obstacle to Uptake of HIV Testing: Evidence from a Zimbabwean National Population-Based Survey,” *AIDS Care* 22:2 (2010): 170-186; Suzanne Maman et al., “A Comparison of HIV Stigma and Discrimination in Five International Sites: The Influence of Care and Treatment Resources in High Prevalence Settings,” *Social Science and Medicine* 68:12 (2009): 2271-2278.

¹¹ Ministry of Health and Child Welfare, *Zimbabwe National HIV and AIDS Estimates 2009* (Harare: Ministry of Health and Child Welfare, 2009).

¹² World Health Organization (WHO), UNAIDS, and UNICEF. *Global HIV/AIDS Response: Epidemic Update and Health Sector Progress Towards Universal Access: Progress Report 2011*. (Geneva: WHO, 2011), 24.

By the year 2000 the intensity of the epidemic in Zimbabwe had started to ease.¹³ Prevalence (the total number of people living with HIV) almost halved over a 10-year period and HIV incidence (the annual number of new infections) dropped from five per 100 persons to less than one in a hundred by 2009.¹⁴ This shift has generated considerable discussion and political contestation about the impacts of factors such as death, condoms and economic collapse on changing sexual behaviour.¹⁵ Studies on HIV in Zimbabwe have tended to focus on quantitative data gathered from sources such as ante-natal care clinics, the blood service, demographic health surveys and specific population-based studies.¹⁶ In recent years the research agenda has shifted towards qualitative research in order to seek broader explanations for the decline in the epidemic¹⁷ as well as assess the impact of antiretroviral therapy (ART).¹⁸ This study focuses on the lived experience of HIV in order to provide a platform for informing a more effective delivery of social support and health interventions within communities in Zimbabwe.

¹³ Simon Gregson et al., "HIV Decline in Zimbabwe Due to Reductions in Risky Sex? Evidence from a Comprehensive Epidemiological Review," *International Journal of Epidemiology* 39:5 (2010): 1311-1323.

¹⁴ Nicole Fraser et al., *Zimbabwe: Analysis of HIV Epidemic, Response and Modes of Transmission* (Harare: Republic of Zimbabwe, 2010).

¹⁵ Stephen O'Brien and Alex Broom, "The Rise and Fall of HIV Prevalence in Zimbabwe: the Social, Political and Economic Context," *African Journal of AIDS Research* 10:3 (2011): 281-290; Stephen O'Brien and Alex Broom, "The Prevalence and Politics of HIV/AIDS in Zimbabwe: Examining the Ideological, Political and Historical Factors Behind the 'Decline,'" *Politikon* 37:2-3 (2010): 309-328.

¹⁶ Daniel T. Halperin et al., "A Surprising Prevention Success: Why Did the HIV Epidemic Decline in Zimbabwe?," *PLoS Medicine* 8:2 (2011): e1000414.

¹⁷ Backson Muchini et al., "Local Perceptions of The Forms, Timing and Causes of Behavior Change in Response to the AIDS epidemic in Zimbabwe," *AIDS and Behavior* 15:2 (2011): 487-498.

¹⁸ Catherine Campbell et al., "A 'good hospital': Nurse and Patient Perceptions of Good Clinical Care for HIV-Positive People on Antiretroviral Treatment in Rural Zimbabwe—A Mixed-Methods Qualitative Study," *International Journal of Nursing Studies* 48 (2011): 175-183; Catherine Campbell, et al., "We, the AIDS People...": How Antiretroviral Therapy Enables Zimbabweans Living with HIV/AIDS to Cope with Stigma," *American Journal of Public Health* 101:6 (2011): 1004-1010; Morten Skovdal et al., "Contextual and Psychosocial Influences on Antiretroviral Therapy Adherence in Rural Zimbabwe," *The International Journal of Health Planning and Management* 26 (2011): 296-318.

Methods

In-depth qualitative interviews were conducted by the author in 2010 in partnership with community leaders from four locally-based HIV organisations who recruited the participants from amongst their networks. The participants had varying degrees of involvement in their respective groups. Each group was based in one of four locations which provided a cross-section of the lower socioeconomic areas of Harare. These locations included the old inner city (Mbare), the industrial residential (Glenview), the peri-urban informal (Epworth) and the satellite dormitory (Chitungwiza) areas. All of these locations are characterised by poverty, intermittent utility services, waterborne diseases and high population density. Through purposive and convenience sampling respondents were personally invited to join the study on the basis of being affected or infected by HIV. While participants were reimbursed for their travelling costs, they were not otherwise remunerated. Fifteen people from each of the four townships were interviewed: 25 men and 35 women, in sessions that lasted from 45 to 90 minutes each. The average age of the participants was 39, the youngest being 18 and the oldest 69, with most aged 31 to 45. Of the 60 participants, 46 revealed that they were HIV positive and of these two thirds (or just over half of the total number interviewed) mentioned that they were enrolled on ART. While participants were not chosen on the basis of their ethnicity, all spoke Shona, the main language of northern Zimbabwe, and were conversant in English. The four community organisations that assisted in this study were linked through their previous involvement in the Zimbabwe Social Forum (ZSF).

The research design adopted for this study, qualitative semi-structured interviews, was especially useful for exploring lived experience as it encouraged participants to talk and express “meanings and interpretations”¹⁹ in relation to HIV. Out of the research question, ‘What is the lived experience of HIV?’, I developed four themes: the social and community context in which the participants lived; stigma; access to treatment; and understandings about HIV transmission. A series of questions or talking points accompanied each theme, with the purpose of being either introductory, follow-up, probing, specifying or interpreting.²⁰ In order to minimise fear and anxiety regarding HIV

¹⁹ Douglas Ezzy, *Qualitative Analysis Practice and Innovation* (Crows Nest, NSW: Allen and Unwin, 2002), 3.

²⁰ Steinar Kvale and Svend Brinkmann, *Interviews: Learning the Craft of Qualitative Research Interviewing* (Los Angeles, CA: Sage Publications, 2009).

status, the interviews were conducted in a trusted space, the offices of a legal aid NGO. Participants were not directly asked about their status in order to respect the voluntary nature and confidentiality of disclosure in both the recruitment process and the interviews. In addition, each person was identified by a unique pseudonym mainly drawn from commonly used names in Zimbabwe. Interpreting was provided where necessary and respondents were given the option of speaking in Shona. The interviews were conducted by the author, a researcher with several years' experience in Zimbabwe, and a Shona-speaking research assistant. In accordance with a reflexive approach to data gathering,²¹ the interview schedule and questions were semi-structured, reviewed on the basis of emerging evidence, and tailored to the situation of each participant. The discussions were digitally recorded and transcribed in full. Ethics clearance was obtained from my university and the Research Council of Zimbabwe. During and subsequent to the fieldwork, I systematically appraised the field notes and transcripts, identified key themes, and from these applied a series of codes to develop an overall generalised framework for analysis within the interpretative traditions of qualitative research.²² This methodology, and the various steps I took to initiate the study (ethics compliance, cultural and language training, and planning meetings with community leaders etc.), allowed me to conduct this research—one of few explorations of the lived experience of HIV in Harare—with a better appreciation of both its limitations and potential.

Results

While epidemiology is key for estimating the extent and spread of HIV, such statistics by themselves reveal little about the social and cultural production of new infections, and the respective roles of social change and shifting notions of, and attitudes towards, risk. In this article I bring together aspects of cultural beliefs, stigma and therapeutic treatment in the context of changing behaviours, political action and social mobilisation, to focus on the personal problem or lived experience of HIV. Overall the research seeks to understand, describe and make wider generalisations concerning the complexities of how individuals, families and communities cope with HIV in their daily lives.

Stigma and Structural Violence

²¹ Ezzy, *Qualitative Analysis, Practice and Innovation*.

²² Kathy Charmaz, "'Discovering' Chronic Illness: Using Grounded Theory," *Social Science and Medicine* 30:11 (1990): 1161-1172; Ezzy, *Qualitative Analysis Practice and Innovation*.

The interviews reinforced the argument that HIV-related stigma in Zimbabwe is very much embedded in the ideologies and institutions that emerged or were pre-existing when the country became independent in 1980. Despite the occasional deployment of pro-feminist rhetoric, the leadership of the ruling party, the Zimbabwe African National Union-Patriotic Front (ZANU-PF), has tended to hold patriarchal views towards the social and economic status of women.²³ Consequently, traditional and religion-derived beliefs about women and sexuality have become entrenched in State ideology and practice, and this has influenced attitudes toward illness and interpersonal relations at the individual level.²⁴ This is evident in the following observations:

Sara: [my friend] suddenly got ill [she] went to a traditional healer to seek treatment but as she was told she had been bewitched by her relatives she couldn't go to them for help ...she died of meningitis.

(female, aged 32, status not declared)

Delia: ...I was pregnant when I discovered I was HIV positive. I think that there was AIDS before as when my husband passed away because he had developed some AIDS-related diseases and I developed herpes which, I now realise, is a symptom of HIV infection. But at that time people would hardly discuss HIV and AIDS so I didn't have enough knowledge about what it was. I got the disease from my husband but his relatives never thought of AIDS, they were saying that my husband had been bewitched.

(female, aged 41, HIV positive)

The accounts of Sara and Delia reflect the persistence of gendered and spiritualised ideas of blame, transmission and treatment. We see the consequences of what Delia referred to as not having “enough

²³ Josephine Nhongo-Simbanegavi, *For Better or Worse: Women and ZANLA in Zimbabwe's Liberation Struggle* (Harare: Weaver Press, 2000); Tanya Lyons, *Guns and Guerilla Girls: Women in the Zimbabwean National Liberation Struggle* (Trenton, NJ: Africa World Press: 2004).

²⁴ Mary T. Bassett and Marvellous Mhloyi, “Women and AIDS in Zimbabwe: The Making of an Epidemic,” *International Journal of Health Services*, 21 (1991): 143–156; Elizabeth Schmidt, *Peasants, Traders, and Wives: Shona Women in the History of Zimbabwe, 1870-1939* (Portsmouth, NH: Heinemann, 1992); Terri Barnes, “We women worked so hard”: *Gender, Urbanization, and Social Reproduction in Colonial Harare, Zimbabwe, 1930-1956* (Portsmouth, NH: Heinemann, 1999); M. F. C. Bourdillon, *Where are our Ancestors? Changing Culture in Zimbabwe* (Harare: University of Zimbabwe Publications, 1997)

knowledge” with the example given by Sara. Her friend is not only misdiagnosed but is estranged from her family, the people from whom she is most likely to receive help. Despite the fact that her husband is the source of her infection, Delia is nevertheless indirectly accused of being a witch by her in-laws, an accusation that can lead to a woman being denied access to her children and family property.²⁵ While the post-independence period has partially redressed some legal inequities, such as the right of women to own and inherit property, these have been insufficient to compensate for the increased economic burden that has fallen on females in the transition to modernism (e.g., increased responsibility for agricultural production but reduced control over land allocation).²⁶ As a result, overall social disadvantage has deepened and this has limited the agency of women, including their ability to refuse or negotiate safe sex.²⁷ The impact of this is attested to by the fact that around 60 per cent of the people living with HIV in Zimbabwe are female, and young women are twice as likely to be HIV positive than their male peers.²⁸

The concept of social stigma is particularly useful for understanding this gendering of blame. According to Goffman,²⁹ social stigma is created when a person’s identity is spoiled by association with negative social markers (e.g., immorality, disease, witchcraft). This process of discrediting (misrepresentation) not only impacts on social perceptions of HIV but restricts normal social interaction between people living with the virus and their families, communities and society. Consequently, when HIV appeared in Zimbabwe it was misunderstood, ignored or constructed as a consequence of deviant practice.³⁰ The cases of Sara, Delia and other participants illustrate that such misrepresentations are still clearly present in participants’ memories, and that once associations

²⁵ Kaori Izumi, “Gender-Based Violence and Property Grabbing in Africa: A Denial of Women’s Liberty and Security,” *Gender & Development* 15:1 (2007): 11-23

²⁶ Schmidt, *Peasants, Traders, and Wives*; Barnes, “*We women worked so hard*”; Bourdillon, *Where are our Ancestors?*

²⁷ Bassett and Mhloyi, “Women and AIDS”; Government of Zimbabwe. 2010 *Zimbabwe Millennium Development Goals Status Report*. (Harare: Government of Zimbabwe, 2010.)

²⁸ Government of Zimbabwe, 2010 *Zimbabwe Millennium Development Goals*.

²⁹ Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Harmondsworth: Penguin: 1963), 71.

³⁰ Rödlach, *Witches, Westerners, and HIV*; Ray and Madzimbamuto, “The HIV Epidemic in Zimbabwe.”

between morality and HIV become ingrained they can be difficult to shift from public consciousness and popular culture.

This point is further illustrated by the way in which male participants generally assumed that having more than one sexual partner was culturally sanctioned. On the other hand, for the women interviewed—and single mothers in particular—such an admission was tantamount to being called a prostitute and accused of spreading HIV. This accusation could lead to enacted stigma—losing customers from your street stall or being evicted by your landlord. Internalised stigma (low self-esteem) meant that women tended to be more concerned than men about the implications of HIV status for their moral standing. For men, their concerns about the stigma of HIV were related to their physicality and social position, e.g., being mocked for being weak, sick or unable to work. In addition, men tended to assume that HIV was something they ‘caught’ from women, not something they had passed on themselves. Most of the women who discussed the source of their positive status were, like Delia, quite specific in identifying their male partners as the source of their infection. Despite the general perception amongst the male participants that they contracted HIV from women, the reality is that female-to-male sexual transmission is much less efficient than male-to-female.³¹ However, gendering also works in ways that disadvantage men. Male participants, for example, reported that stigma contributed to men’s reluctance to seek ART,³² in other words, men tend not to accept treatment and to live with their HIV status.³³ This is a significant handicap when early diagnosis and treatment can significantly enhance the length and quality of life.

The ultimate drivers of the discrimination, prejudice and disadvantage associated with stigma are the power imbalances that exist in society.³⁴ In 2010, Harare was characterised by uncollected rubbish, inefficient sewerage disposal, un-clean drinking water, structural

³¹ Alan Whiteside, *HIV/AIDS: A Very Short Introduction* (Oxford: Oxford University Press, 2008), 30.

³² National AIDS Council and Ministry of Health and Child Welfare, *Overview of the State of the HIV Treatment and Care Programme in Zimbabwe* (Harare: National AIDS Council; Ministry of Health and Child Welfare, 2012).

³³ Morten Skovdal et al., “Masculinity as a Barrier to Men's Use of HIV Services in Zimbabwe,” *Globalization and Health* 7:1 (2011): 13.

³⁴ Bruce G. Link and Jo C. Phelan, “Conceptualizing Stigma,” *Annual Review of Sociology* 27 (2001): 363–385; Richard Parker and Peter Aggleton, “HIV and AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implications for Action,” *Social Science and Medicine* 57:1 (2003): 13-24.

unemployment and inadequate health care. This level of official complacency, along with the avoidable and systematic denial of access to the essentials of life—housing, health, education, nutrition, etc.—is a source of individual and community harm and as such constitutes what has been theorised as ‘structural violence’.³⁵ In addition, the dismantling of public services built up during the early years of independence eliminated many health services and shifted the burden of health and caring for the sick onto the poor and female.³⁶ This occurred just when the impact of HIV meant that the need for social services and education was increasing. The disregard for the public good in pursuit of political-economic objectives by the State intensified at various times, with the mass demolitions carried out in urban areas in 2005 being a case in point. Several participants mentioned how they had been among those who had lost homes and sources of income when the State launched a so-called ‘clean up’ against allegedly diseased and HIV-infected urban dwellers.³⁷

HIV and the clinic

It was evident in the interviews that the biomedical clinic had come to represent a crucial mediating factor in the experience of HIV in Zimbabwe. Around two-thirds of the participants were receiving ART in 2010, a year when 280,000 Zimbabweans, about half of those in need, were enrolled in treatment. ART has been standard treatment in the West since 1996—between 1996 and 2004, when no anti-retroviral drugs were available, one million Zimbabweans died of AIDS.³⁸ Prior to being able to enrol on ART, people who sought treatment had little option but to be careful with their diet or, as one half of the participants acknowledged, seek the counsel of traditional medical practitioners and spiritual/faith healers. Thus, when the new treatment technologies were finally deployed in Zimbabwe they did so in the context of pre-existing

³⁵ Arechu Castro and Paul Farmer, “Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti,” *American Journal of Public Health* 95:1 (2005): 53-59; Paul Farmer, Bruce Nizeye, Sara Stulac, and Salmaan Keshavjee, “Structural Violence and Clinical Medicine,” *PLoS Medicine* 3:10 (2006): e449.

³⁶ Rene Loewenson and Marie Masotya, *Equity Watch: Assessing Progress Towards Equity in Health in Zimbabwe, 2008* (Harare: EQUINET, 2008), 11.

³⁷ Ashleigh Harris, “Discourses of Dirt and Disease in Operation Murambatsvina,” In *The Hidden Dimensions of Operation Murambatsvina*, ed. Maurice Vambe (Harare: Weaver Press: 2008), 46-49.

³⁸ Ministry of Health and Child Welfare, *Zimbabwe National HIV*.

and well-established traditional and spiritual healing practices.³⁹ Also, ART was delivered amidst concerns about transparency (several participants mentioned their encounters with corruption and drug misappropriation) and negative experiences concerning patient monitoring, follow-up and drug availability. While it was clear that ART drugs were pharmacologically potent and, by promoting a return to health, helped people manage stigma,⁴⁰ their delivery was viewed as fractured and inefficient. This was manifested in some reservations about ART:

Wilbert: ...swallowing a pill every day is not easy. I had to go for counselling... psychologically it affected me... I didn't like the drug combination they gave so for five years I vomited. But the doctor said that my CD4 count was ok so they didn't have to change my drugs.

(male, aged 45, HIV positive)

Eric: ...people are not adhering to their antiretrovirals (ARVs) ...their prophet might say that they should stop their ARVs or others might go on prayer fasting and not take their ARVs and others ...will get medicine from the traditional healer that substitutes for ARVs

(male, aged 40, HIV positive)

Lucy: ...ARVs drugs are for life. When you go to [religious] gatherings you will be forced to swallow them at the regulated time even though you don't want people to know your status. ARV is a silent killer so I don't want to get on the ARVs until my CD4 count is down and I have no option. But now I try by all means ... to stay off them by maintaining my diet.

(female, aged 36, HIV positive)

Problems around confidentiality, side-effects, drug availability and patient care may thus limit the on-the-ground effectiveness of ART. Due to the unstable nature of the virus and the danger of drug resistance, ART requires an adherence level of around 95 per cent.⁴¹ As seen above, participants struggled with their pills, religious beliefs challenged

³⁹ Tonya N. Taylor, ““Because I was in pain, I just wanted to be treated”: Competing Therapeutic Goals in the Performance of Healing HIV/AIDS in Rural Zimbabwe,” *Journal of American Folklore* 123:489 (2010): 304-328.

⁴⁰ Campbell et al., “We, the AIDS People...”

⁴¹ Amir Attaran, “Adherence to HAART: Africans Take Medicines More Faithfully than North Americans,” *PLoS Medicine* 4:2 (2007), e83.

medication adherence, and in the case of Lucy she feared the unknown effects of drugs on her body. The cultural ideas about techno-scientific medicine expressed in these quotes resonate with reports that significant numbers of Zimbabweans believe that HIV can be managed without ART.⁴²

Traditional health practices in Zimbabwe are afforded a certain official recognition, partly stemming from the supportive role that spirit mediums and diviners played during the liberation struggle.⁴³ Also underlying the reliance on spiritual/traditional solutions is the continuation of misconceptions about HIV transmission (e.g., personal blame, immoral behaviour) and ongoing structural violence (poverty, inadequate drug and diagnostic technologies, etc.). In this sense the persistence of traditional practices cannot be disregarded as a stage in development. Consequently, given the aforementioned limits to ART, people who are in bad health may thus resort to better known and more familiar treatments, instead of, or in addition to, ART. This health pluralism can either counteract or complement biomedical care and treatment, and does not necessarily undermine medical treatment as Clarence, a traditional healer explains:

Clarence ...we are developing a relationship between traditional medical practitioners and western medical practitioners through the so-called joint approach to HIV
(male, aged 54, status not declared)

This example shows how traditional healers can provide a pathway to biomedicine and how their culturally-derived ideas about HIV can be reconfigured and gain acceptance in ways that are not incompatible with biomedical understandings of HIV.⁴⁴ Extrapolating from this example, churches who eschew ART in favour of faith healing may, at the same time, preach messages such as those related by Portia, “avoid drugs and beer halls and don’t have many boyfriends” (female, aged 63, HIV positive) which may help to avoid exposure to HIV. These examples show how accounts of lived experience help reveal how ART (patient improvement) and clinical surveillance (patient monitoring) need to

⁴² Rosemary Mhlanga-Gunda, *Factors Influencing Adherence to Retroviral Therapy in Rural Zimbabwe: Implications for Health Policy and Practice*. (Ph.D. Thesis: University of Melbourne, 2010).

⁴³ David Lan, *Guns and Rain Guerrillas and Spirit Mediums in Zimbabwe* (London: J. Currey, 1985).

⁴⁴ Quentin Gausset, “AIDS and Cultural Practices in Africa: The Case of the Tonga (Zambia),” *Social Science and Medicine* 52:4 (2001): 509-518.

engage with traditional and religious beliefs about healing and illness so as to reduce obstacles to the uptake of biomedicine. The overall therapeutic environment in Zimbabwe is thus a mosaic of religious influence, infrastructure weakness, traditional practices and political problems. Understanding how therapies, practitioners and models coexist can allow us to move beyond a strictly epidemiologically-focused model of responding to HIV.

Grassroots Activism and social movements

Despite the views expressed above by Wilbert, Lucy, and Eric, which were not uncommon concerns, the overwhelming response of the participants was that treatment, while not a guarantee to good health, had helped them to live with the disease and cope with its negative social consequences. It was evident, however, that recovery was not just a question of providing drugs and doctors. Good health also depends on dealing with the structural violence that exacerbates social inequality, and perpetuates attitudes and actions that isolate, stigmatise and expose the poor and the female to illness and disease. Isaac provides a rationale for this view:

Isaac: ...if you want to lead a real positive life you must participate in many programmes, it is not only that you have to look for medication, something to eat or wear, or accommodation but that you must be occupied doing something fruitful, something that has a future in your life.
(male, aged 40, HIV positive)

The “something fruitful” mentioned by Isaac refers to forms of collective action that shape a sense of community solidarity, generate agency, temper experiences of stigma and consequently increase chances of survival. This activist imperative was partly driven by the incapacity of the Zimbabwean State to provide the monitoring and evaluation needed for national HIV coordination, as well as to adequately deliver health services. For the powerless, there are few options for deflecting and reducing the impact of the pressures that ill-health can place on a person and that affect his/her ability to cope.⁴⁵ The fact that the sick basically pay for their own health care and are looked after at home was obvious from the narratives and is supported by the

⁴⁵ Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (Cambridge: Basic Books, 1988), 84-85.

literature.⁴⁶ In this context, participants looked to social movements and organisations (community, non-government and faith based), as well as informal networks, for help in accessing the public health system, working their way around its limitations, and establishing a sense of personal satisfaction and agency.

The advantages of collective responses are also acknowledged by a renewed international focus on community mobilisation around HIV. This has emerged out of the realisation that if the international shortfall in ten million ART places is to be met then communities must be involved in the promotion and management of HIV testing and treatment programmes.⁴⁷ Theorising how to achieve such participation is often framed around the notion of social capital. This concept can be understood in various ways, such as the collective good achieved through cooperation⁴⁸ or as an individual's "network of connections."⁴⁹ The case of Vernon provides a good example of how social relationships and support systems may operate. When Vernon began to fall ill his family suspected witchcraft and sought advice from a traditional healer. However, after Vernon developed tuberculosis (TB) and lost his job in a supermarket he turned to a HIV support group for help. He then enrolled on ART, regained his health and became active:

Vernon ...my group is a man's network we discuss how to care for our wives as men who are HIV positive and who have positive wives and we are taught on the use of protection and also receive encouragement to work for ourselves, so we [learn different ways to] get an income.
(male, aged 52, HIV positive)

As this example and other participants' stories indicated, such community involvement not only led to health recovery but also allowed participants to access forms of social capital, helped them regain their sense of personal direction, recreate their personal identities and, as seen in the case of Vernon, also develop less patriarchal attitudes.

The forms of community involvement mentioned by participants varied from the informal to the organised and from the consciously

⁴⁶ Halperin et al., "A Surprising Prevention Success"; Loewenson and Masotya, *Equity Watch*.

⁴⁷ World Health Organization, UNAIDS, and UNICEF. *Global HIV/AIDS Response*.

⁴⁸ Robert D. Putnam, "Tuning In, Tuning Out: The Strange Disappearance of Social Capital in America," *PS: Political Science & Politics* 28:4 (1995): 664-683.

⁴⁹ Pierre Bourdieu, "The Forms of Capital," In *Handbook of Theory and Research for the Sociology of Education* ed. J. G. Richardson (New York: Greenwood Press, 1986), 52.

apolitical to committed activism. Regardless of the origin or initial motivations of community organisations, it was evident that overlapping memberships and networks had allowed broader alliances around specific issues to coalesce. The anti-globalisation movement in the form of the Zimbabwe Social Forum (ZSF) was one such example. The Zimbabwean State, perhaps unintentionally, had become associated with the international anti-globalisation phenomenon in the early 2000s.⁵⁰ As this progressive image proved convenient, ZANU-PF tolerated the various ZSF mobilisations of up to several thousand people between 2003 and 2009. These meetings provided an opportunity for HIV activists, from different political perspectives, to come together, exchange information and formulate claims such as the following:

Jacob ...we are demanding more CD4 count machines in clinics, wards, hospitals etc. etc. and for a national HIV card ...we need to be enrolled on ART when we are still fit and before your CD4 blood cell count goes under 200
(male aged 41, HIV positive)

The ZSF, and the activities that emerged from it, also generated several street demonstrations around HIV and helped connect various groups such as those that participated in this study. The HIV and AIDS issue was the most visible cluster within the ZSF⁵¹ and at least several of the participants went on from this experience to intervene in the constitutional debate of 2009-2013 to advocate the inclusion of health rights in the new constitution. These overall processes led to the emergence of a network of movement intellectuals engaged in community praxis, of which some of this study's participants formed a part.

However, community mobilisation, even to support people living with HIV, is not always regarded benignly in a country such as Zimbabwe, and in this context the dynamics behind such organising and activism can remain obscure. Social movement theory helps to conceptualise the social undercurrents which are in play, as movements

⁵⁰ Ellen 't Hoen. "TRIPS, Pharmaceutical Patents and Access to Essential Medicines: Seattle, Doha and Beyond," In *Economics of AIDS and Access to HIV/AIDS Care in Developing Countries, Issues and Challenges*, eds. J-P. Moatti, et al. (Paris: ANRS, 2003), 27-46

⁵¹ Miles Larmer, "'More Fire' Next Time?: The Southern African Social Forum as a Locus of Social Protest 2003-2005," *Journal of Asian and African Studies* 42:1 (2007): 25-37.

wax and wane according to social and political conditions.⁵² As circumstances change activists may experiment with different organisational approaches and political orientations. The ideologies of social capital creation, civil society participation or more counter-hegemonic activity, such as intervening around constitutional questions, may appear attractive to activists at certain junctures. Social identities that have emerged out of discontent with globalisation (global justice, pro-feminism, treatment action, etc.) were also evident in the interviews.⁵³ This study's more activism-oriented participants described their activities in ways that resonated with the idea that formal and informal networks may remain submerged until economic pressures, shifts in legalities, or other social triggers, allow new collective identities, for example around HIV, to resurface.⁵⁴ As well as demanding access to affordable biomedical treatment, participants also argued in favour of those social rights and resources that can help address structural violence. These included employment opportunities, farming plots, nutritional support, the abolition of school fees, sickness allowances, psychological assistance and the involvement of people living with HIV in prevention and treatment programmes. This also led to nuanced criticism of the power imbalances that are inherent in the political and economic system as articulated here:

David: To get more acceptance we need a massive awareness programme from the political leadership where the political heads go for tests and the results are known publicly, politicians, cabinet, judges, bishops, priests.

(male, aged 51, HIV positive)

While these sorts of solutions and demands challenge structural violence, they also run the risk of inviting physical violence. Several participants spoke of how at various times, particularly during elections, they were warned off doing HIV-related community work by local ZANU-PF officials. They also talked about how they shifted the focus of their activities in order to manage the shifting legalities and political vagaries of the State. It was clear in this study, particularly given the biographies of the participants, that forms of politicised resistance, accompanied by significant mobilisation at a community level, were strongly defining the landscape of HIV. In this sense, the disease

⁵² Alberto Melucci, "The Symbolic Challenge of Contemporary Movements," *Social Research* 52:4 (1985): 789-816.

⁵³ Melucci, "The Symbolic Challenge of Contemporary Movements."

⁵⁴ Melucci, "The Symbolic Challenge of Contemporary Movements."

produced and articulated a broader tension between a rather absentee State in terms of health care (but highly visible in other ways), and engaged and active community/ies seeking to address the harsh impacts of the epidemic.

Conclusion

This article explored the ongoing impact of the HIV epidemic on Zimbabwe, a country that, although on the periphery of the world economy, has been for 25 years at the epicentre of one of the greatest health disasters to affect humanity. In this article I have summarised some key findings of a study which uncovered the complex intersection between traditional practices, modernism and biomedical technologies in the negotiation of AIDS in Zimbabwe. By transforming their personal concerns around HIV (issues relating to culture, stigma and treatment) into social problems, the praxis of some of the participants as social activists has at times taken on an anti-systemic edge that has tested the boundaries of the State's tolerance. Their efforts to assert rights around questions of income, democracy, gender-based violence and treatment as they relate to HIV are thus interwoven and speak to a broad range of issues; furthermore, questions of good health, challenging discrimination and accessing services are all examples of individual and collective agency which help to transform formal legal instruments from mere statutes into active guides for policy and action.

These findings also need to be placed within the overall context of the international HIV response. The global rollout of ART, an integral element of the increasing bio-medicalisation of HIV, is predicated on the basis of communities assuming more of the functions of HIV treatment; in other words, reduced levels of biomedical care in order to make drug delivery cheaper. However, the participants I interviewed already make significant contributions toward the costs of their own health care and that of their families and communities. A biomedical framing of disease both strongly defined the disease and illness experiences and also created important contrasts with localised conceptions of responsibility, causation and cure. That is, the clinic represented an important interface between the State, institutional care, localised beliefs and values, community-based advocacy, health workers and patients. In a sociological sense, the clinic was thus a site of contention between different conceptions of health and treatment, preventative and curative, technological and holistic, and privatised versus public care.

In this article I have articulated and described elements of the lived experience of HIV and in so doing illustrated the social and cultural mediators of disease, and the multifaceted nature of gender disadvantage. The article also uncovered the inter-relationships between traditional healing practice, spiritual care and biomedical technologies, in order to understand the context in which these forms of healing co-exist and how they might work together—or at least not against each other. I have also sought to summarise the aspirations of the participants in terms of what they see as key issues in relation to helping the HIV positive survive and reducing infections. The participants’ voices represent those of people and communities who have worked hard to save lives and prevent infections. They have generations of experience and know-how and an incredible ability to inspire, organise and educate for the common good. However, their energy is not inexhaustible and cannot be relied on to fill gaps in service provision indefinitely. It needs renewal, nourishing, support and a guaranteed freedom to organise without fear of the consequences when it identifies and exposes structural and other forms of violence.

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