

## **A qualitative study of impressions and experiences of HIV in Zimbabwe**

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### **ABSTRACT**

HIV remains a significant social, political and economic problem in Zimbabwe however, few researchers have explored people's lived experiences of the virus in that country. This paper draws on qualitative interviews conducted with 60 people living in urban communities of Harare, Zimbabwe, to outline several conceptual contributions to understanding HIV in that country. Traditional and religious interpretations of illness, as well as the historical roots of the epidemic and deep rooted structural inequalities, shape the experience of the virus and HIV-related stigma. An exploration of intersections between sexuality, disease and culture among the participants indicates that an observable shift in attitudes, particularly with regards to patriarchal notions of sexuality and gender is underway. Furthermore, the spiritualisation of disease and the gendered mediation of HIV shape the uptake of Antiretroviral Therapy and other forms of bio-medical technologies. Finally, grassroots social activists contest and re-frame the HIV narrative through advocacy and informal and formal activism and organising to revindicate a series of human rights and social demands in support of people living with and affected by HIV.

### **Introduction**

In the 1970s a spike in rare medical conditions was experienced in the Democratic Republic of the Congo (Illife 2006), Zambia (Bayley 1984) and Uganda (Rees 2008) and in the early 1980s the same phenomena was noticed in Zimbabwe (Jackson 1992). After suddenly becoming ill with conditions such as Kaposi's sarcoma, lymphoma and cryptococcal meningitis most of these patients, often young and previously healthy, failed to respond to treatment and invariably died. Researchers later traced the outbreaks as they moved along trade and transport routes from Central Africa to the East Africa and then southwards to Zimbabwe and Mozambique (Illife 2006).

In 1981 a report on "cellular-immune dysfunction", which had been observed among several seriously ill young men in Los Angeles (Gottlieb 1981) drew resonance across the United States and subsequently Europe and Australia. However, the correlation between the symptoms causing concern in the Western hemisphere and those occurring in Africa was not immediately established. During these years the mysterious origins and associations with 'the other' meant that minority groups such as immigrants, sex workers, gays, injecting drug users were stigmatised and accused of spreading the so called 'plague'. The introduction of AIDS to the world, has thus generated a multiplicity of meanings in what Treichler calls an "epidemic of signification" (1999, 1). Zimbabwe, with its location in the epicentre of the epidemic and its complex geopolitical historical setting Zimbabwe presents an important site for understanding how these meanings and issues play out around as HIV as gone on to cause over 34 million infections and 30 million deaths.

### **Background**

Suspicious that the Kaposi's sarcoma and lymphoma being observed in Harare's public hospitals (Ministry of Health [MoH], 1988; Latif et al 1989) might have been AIDS were

confirmed in 1985 when nearly 3% of Harare's blood supply was found to be contaminated with HIV<sup>1</sup> (MoH 1988). With hysteria still gripping the popular imagination about AIDS in the western hemisphere it is perhaps understandable that most countries in Africa did not approach HIV as a serious issue. In Zimbabwe, the problem was minimised, denied or portrayed as only a predicament for the sexually deviant. This perception has persisted and having taken the form of social stigma has discouraged access to counselling and testing (e.g. Duffy 2005a; Sambisa 2010) and treatment (e.g. Genberg et al 2009; Maman et al 2009). In this situation the toll of deaths and infections has continued to mount. Since 1985 an estimated two million Zimbabweans have died from AIDS while an additional one million people have become positive to HIV (Ministry of Health and Child Welfare [MoHCW] 2009). However, by the late 1990s the epidemic in Zimbabwe started to turnaround (UNAIDS 2005). Prevalence, the total number of people living with HIV, almost halved over a 10 year period and HIV incidence (annual number of new infections) dropped from five per 100 persons to less than one in a hundred by 2009 (MoHCW 2009). This shift has generated considerable discussion about the effectiveness of the national response and the impact of death, disease, condoms and economic collapse on changing sexual behaviours (O'Brien & Broom 2011) as well as a level of political contestation and controversy (O'Brien & Broom 2010). Studies on HIV in Zimbabwe have tended to focus on the quantitative data gathered from ante-natal care clinics, demographic health surveys and specific population based studies (e.g. Gregson et al 2011; Halperin et al 2011; Tshabalala et al 2011; Rödlach, Dlodlo & Hwalima 2012). In recent years the research agenda has shifted towards exploring the lived experiences of HIV. Qualitative research has provided broader explanations for the decline in the epidemic (Muchini et al 2011) as well as the impact of antiretroviral therapy (ART) (e.g. Campbell et al 2011a; Campbell et al 2011b; Skovdal et al 2011c). This present study is conducted in the qualitative tradition. By focusing on the urban environment it seeks to add another layer of sophistication to existing work on lived experience HIV and provide a platform for informing the more effective delivery of social support and health interventions within communities in Zimbabwe.

### **Methods**

In-depth qualitative interviews were conducted in 2010 in partnership with four small AIDS service organisations (ASOs) linked through their involvement in the Zimbabwe Social Forum. The ASOs recruited respondents from their respective catchment areas: Chitungwiza, a satellite suburb 30 kilometres south of the Harare CBD; Glen View, traditional industrial working class heartland some 14 kilometres to the west; and Mbare an inner city area with informal markets and crowded tenements. The fourth and largest area is Epworth, a large squatter settlement on the eastern outskirts of Harare. Collectively referred to as 'high density areas', these locations are characterised by poverty, intermittent utility services, waterborne related diseases and large populations. Through purposive and convenience sampling respondents were invited by word of mouth to join the study on the basis of being affected or infected by HIV. Participants were not remunerated, but were reimbursed for their transport costs. Fifteen people from each of the four townships were interviewed: 25 men and 35 women, in 45 to 90-minute individual sessions. Follow-up interviews were conducted with three people in 2011 in order to clarify specific points made in the original meetings. The average age of the participants was 39: the youngest being 18

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<sup>1</sup> In accordance with UNAIDS terminology guidelines (2011) this paper employs the terms AIDS and HIV separately according to the specific context. HIV is regarded as a broader term than AIDS.

and the oldest 69. Most were in the 31 to 45 age group and 46 of the total revealed that they were HIV positive. Just over half were enrolled on ART and about the same number reported having been treated with traditional medicine for various ailments. It should also be noted that here I deal specifically with city dwellers (approximately 30% of the total population is urban) (Government of Zimbabwe [GoZ] 2010). While participants were not chosen on the basis of their ethnicity, all spoke Shona and understood English. Shona, the main language of northern Zimbabwe, is also spoken in parts of Mozambique, Zambia and Botswana. Eight participants reported that they had at least one parent or grandparent who had migrated from a neighbouring country and one person identified with a minority ethnic group.

I utilised a qualitative design, primarily because of the need to explore in an in-depth manner people's everyday lived experiences, and secondly, due to the emotive issue of HIV. The interviews were structured around the following broad themes: views and perspectives of HIV and AIDS, and the community context in which they were held; individual experiences of stigma and discrimination; access to treatment and understandings about transmission. In order to minimise fear and anxiety regarding dialogue about HIV status, the interviews were conducted in a trusted space, the offices of a legal aid NGO. Participants were not directly asked 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 is referred to by a unique pseudonym mainly drawn from the types of Anglicised names used by many people in Zimbabwe. Translation was provided where necessary and respondents were given the option of speaking in Shona. The interviews were conducted by Stephen O'Brien a researcher with several years' experience in Zimbabwe, and the research assistant (a Shona-speaking Zimbabwean). In accordance with a reflexive approach to data gathering (Ezzy 2002) the interview schedule and questions were semi structured, reviewed on the basis of emerging evidence and tailored to the situation of each person. Field notes were compiled and the discussions were recorded and transcribed in full. Ethics clearance was obtained from the author's university and the Research Council of Zimbabwe. During and subsequent to the fieldwork I systematically appraised the data, identified key themes and from these applied a series of codes to develop an overall generalised framework for its analysis within the interpretative traditions of qualitative research (Charmaz 1990; Ezzy 2002). In conducting this research I was aware that I was working outside my own culture in a fairly sensitive political environment. This methodology, and the various steps that I took to put the study into place (ethics compliance, cultural and language training, planning and familiarisation meetings with community leaders etc.) allowed me to conduct the study 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. This article is one of few explorations of the lived experience of HIV in Harare, an epicentre of the HIV epidemic internationally. I draw 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. 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, culture and structural violence***

The interviews reinforce the argument that HIV-related stigma in Zimbabwe is very much embedded in the ideologies and institutions that emerged at independence in 1980. Despite the occasional deployment of feminist rhetoric the leadership of the main ruling party the Zimbabwe African National Union-Patriotic Front has tended to hold patriarchal views towards the social and economic status of women. Consequently 'traditional' and religious derived beliefs about women and sexuality have become entrenched in State ideology and practice (Bassett & Mhloyi 1991; Schmidt 1992; Barnes 1999). As a consequence the perception that HIV is a predicament for the deviant has been created as illustrated by the following quote:

*Bea:...we were first taught that HIV and AIDS is contracted through prostitution so this has stuck in people's mind...in the early 90s we didn't have a clear understanding of how HIV is transmitted (female aged 35, HIV positive)*

Bea's comment about 'prostitution' also illustrates the fact that HIV is inherently gendered in Zimbabwe. While the post-independence period has redressed some legal anomalies these have not been enough to make up for the increased economic burden which has fallen on women in the transition from traditional society (e.g. increased responsibility for agricultural production but reduced control over land allocation (see Barnes 1999, Schmidt 1992 and Bourdillon 1997). As a result overall social disadvantage has deepened (Bassett & Mhloyi 1991; Nhongo-Simbanegavi 2000; Lyons 2004; GoZ 2010) and this has limited women's ability to refuse, or negotiate safe sex. The impact on HIV is accordingly seen in the fact that around 60% of the people living with HIV in Zimbabwe are female and young women are twice as likely to be HIV positive as their male peers (GoZ 2010). Intergenerational sex between older males (with likelihoods of greater incomes, sexual histories and rates of infection) and younger women has been reported to play a role in HIV transmission (Wyrod et al 2011). Multiple partner concurrency is also thought to increase infection risk (Mavhu et al 2011). Gender has been discussed in terms of inequality (e.g. Duffy 2005b; Masvawure 2010), gender roles (e.g. Montgomery et al 2012; Mugweni et al 2012) HIV prevention and treatment (e.g. Hageman 2010 et al; Skovdal et al 2011a; Skovdal et al 2011b) and gender based violence (e.g. Nyamayemombe et al 2010). Masculinity, especially the growing realisation that certain aspects of maleness carry adverse health consequences has also been a focus of research (Skovdal et al 2011a; Skovdal et al 2011b). Studies dealing with various aspects of reproductive health (e.g. Chiroro, Mashu & Muhwava 2002; Pearson & Makadzange 2008) and barriers to treatment (e.g. Skovdal et al 2011a) have also helped establish the gendered nature of HIV.

The interview participants talked about HIV in ways which reflect the persistence of gendered and spiritualised ideas about 'blame', 'transmission' and 'treatment' and utilise rhetorical devices which at times misrepresent the circumstances of infection, treatment and therapy. The following quote provides a good example

*Delia: I got the disease from my husband because when he was sick I had developed herpes and some of the symptoms that I now discovering on people who are HIV*

*infected but at that time my husband's relatives never thought of AIDS they were saying that my husband had been bewitched. (female aged 41, HIV positive)*

Despite the fact that the source of Delia infection is her husband's sexual history Delia is nevertheless stigmatised and accused of being a witch by her 'in laws'. The concept of social stigma is particularly useful for understanding such gendering of blame.

According to Goffman (1968 [1963]) 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 family, community and society. Consequently, when HIV appeared it was either misunderstood, ignored or constructed as a consequence of deviant practice (Sibanda 2000). The examples of Delia and Bea illustrates that such misrepresentations are still clearly present in participants' memories as most tied HIV to moral failings and the 'ills of the weak' (i.e. promiscuity, prostitution, gays, foreigners). Such discursive and rhetorical framings are difficult to shift from the public consciousness and popular culture especially when they are constructed around notions of morality and disease.

The discussions around sex provide a good example. Male participants generally assumed that having sexual partners was culturally sanctioned. For the women I interviewed – and single mothers in particular – such an admission was tantamount to being called a 'prostitute' and 'spreading' HIV - such an 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 about the implications of HIV status for their 'moral' standing. For men their concern about the stigma of HIV was related to their physicality and social standing, e.g. being mocked for being weak, sick or unable to work. In addition they tended to assume that HIV was something they 'caught' from women not something they had passed on. 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 common perceptions to the contrary male to female sexual transmission is much more efficient than female to male (Whiteside 2008). However, gendering also works in such a way that men are less likely to seek treatment than women - in other words men tend not to accept and live with their HIV status (Skovdal et al 2011a). This is a significant disadvantage when ART has meant that HIV no longer has to be death sentence.

While stigma has individual manifestations significant large scale drivers of discrimination, prejudice and disadvantage are the power differentials which exist in society (Link & Phelan, 2001; Parker & Aggleton, 2003). The high level complacency around uncollected rubbish, overflowing sewerage, polluted drinking water, structural unemployment and inadequate health care can cause individual and community harm and as such constitute forms of structural violence (Castro & Farmer 2005, 55). The dismantling of many public services built up during the early years of independence not only took away many health services but shifted the burden of health and caring for the sick onto the poor and female (Loewenson & Masotya 2008) just when HIV meant that they were more needed than ever. This disregard for public good in pursuit of broad political-economic objectives by the State became more

intense at various times. One significant event mentioned by participants occurred in 2005 when mass demolitions in urban areas uprooted some 700,000 people: including several participants. Again showing the pervasiveness of stigma the 'clean up' was justified in terms of the need to sweep away urban 'filth', i.e. the diseased and 'HIV infected' urban dwellers (Harris 2008).

### ***Culture and treatment***

Despite funding problems and economic crisis when the research was conducted in 2010 ART enrolment has increased to 280,000 people or almost half of those in need (Apollo et al 2010; Government of Zimbabwe [GoZ], 2012). However, despite this success the transparency of the national treatment programme has been seriously questioned (Amon & Kasambala 2009; Mundawarara & Mapanda 2010). In addition, biomedical approaches to HIV have faced contestation from traditional healing practices (e.g. Taylor et al 2009; Taylor 2010; Simmons 2011) as well as spiritualised approaches to healing and prevention (e.g. Gregson 1999; Mate 2002; Maxwell 2005; Rödlach 2006).

However, in terms of therapeutic responses to HIV in Zimbabwe biomedicine was somewhat of a 'late arrival' in the country. This was evident from the fact that almost half to the participants talked about their experiences with traditional healers and the faith healing practices of African Apostolic and Pentecostal churches.

The relationship between traditional medicine, spiritual healing and biomedicine obviously influences HIV treatment and prevention. In this context biomedical technologies are being inserted in an environment of significant diversity of belief and traditional practices. Patients with serious health problems in developing countries face varied structural, practical and cultural challenges. The resulting gaps in service provision may be filled (albeit at times problematically) by traditional medicine and spiritual healers. Consequently, given these shortfalls, limits to ART coverage and the historic presence of traditional medicine and spiritualised forms of healing many of the sick have adopted pluralistic health practices. Such approaches can both counteract or complement biomedical care and treatment and moreover reveal aspects of the lived experiences of HIV in Zimbabwe.

The perseverance of superstitious and existential 'solutions' may also be embedded in persistent misconceptions of transmission (e.g. personal responsibility, moral breakdown) and lack of structural support (economic deprivation, infrastructure limitations, technical shortages etc.). Certainly the persistence of traditional practices cannot be dismissed as merely a 'stage in development' phenomena. In Zimbabwe spirit mediums, diviners and traditional medicine were ascribed an important role in nationalist iconography during the liberation struggle (Lan 1995; West 2002) and illustrate the contradictory place of tradition within the political economy of the State. The examples provided by participants also reveal how culturally-derived ideas about HIV can be reconstituted in nuanced and 'acceptable' ways in order to make "behaviour and practices safer" (Gausset 2001, 512). For example, churches who eschew ART may, at the same time, preach messages such as "avoid drugs and beer halls and don't have many boyfriends" (Portia, woman aged 63, HIV positive) which helps to avoid risk. Moreover traditional healers might also encourage people to go for testing (medical complementarity).

Biomedical treatment is thus situated within a cultural context of strong persistent religious influences, structural and political problems and histories of care and value. While it was clear that drugs used in ART were pharmacologically potent their delivery was viewed as fractured and inefficient. Problems around drug availability and inadequate patient monitoring (structural violence) and cultural ideas about techno-scientific medicine may limit the 'on the ground' effectiveness of ART. Furthermore, the co-existence of different therapies, practitioners and models, based on the lived experience of recovery, can allow us to move beyond a largely epidemiological model of managing the epidemic. The lived experience helps appreciation of the complex intermingling of biomedicine (primarily ART and clinical surveillance) with traditional medicine and spiritual practices. While not always incommensurable, this certainly emphasises a local reality, often not acknowledged by public health programs, that barriers to implementation can lie very much in the forms of patient engagement that persist despite biomedical developments.

### ***Change, gender and grassroots activism***

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. However, prevailing over stigma is not just a question of providing ART. The large scale forces which exacerbate social inequality and perpetuate attitudes and actions which isolate, stigmatise and predispose the poor and the female to pathogenic vulnerability need to be overcome. While the Zimbabwean State has the key role to play in health service provision, national HIV coordination, monitoring and evaluation the capacity which it has to achieve this has deteriorated. A significant proportion of Zimbabwe's health funding, for example, now derives from external donors. However, even in this regard funding levels are well below that received by other countries in Southern Africa (O'Brien & Broom 2010). In addition, according to Loewenson & Masotya (2008) the biggest contributor to health funding in Zimbabwe is the household budget and moreover, since the 1990s most AIDS patients have been treated at home. Given the weaknesses of the public health system respondents looked to social movements, (community, non-government and faith based organisations) as well as informal networks in to help them access the health system, and work their way around its limitations and establish a sense of personal satisfaction:

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

The activities referred to by Isaac not only reflect how collective actions can shape a sense of community solidarity and generate agency but how they can also temper experiences of stigma and increase chances of survival.

A renewed international focus on community mobilisation around HIV has emerged out of the realisation that, if the shortfall in ten million ART places is to be met, then communities must be involved in promoting and managing HIV testing and treatment programmes. Theorising how to achieve such participation is often framed around the contested notion of social capital. This concept can be understood in various ways, collectively as the social good achieved through cooperation (e.g. Putnam 2000) or individually as a "network of

connections” (Bourdieu 1986, 52). The latter approach is helpful in understanding what social characteristics help a person navigate their way through the complicated processes of, for example, enrolling on ART.

In this sense some participants described how they remade and re-imagined their identities, Stan for example. Over an eight-year period he went from self-described ‘man about town’ to widower, ill and destitute beggar, finally transforming – thanks to ART and his community involvement - into a renewed, confident, healthy, remarried and proud father of a HIV negative baby born to a HIV positive mother. Other men redesigned themselves to incorporate HIV status and reconfigured ‘manliness’ (e.g. regaining social status, advocating safe sex behaviours). Similarly, many of the women were confident about being able to assert themselves in their relationships and lives regardless of their HIV status. This further illustrates that culturally-derived ideas about HIV, and about gender, can be reconstituted in nuanced, positive and meaningful ways.

However, not all States are interested in such social cohesion and social movement theory can help understanding of the dynamics of flexible organising. One trend in social movement theory, for example, emphasises the collective identities (e.g. global justice, treatment action) which have emerged as part of globalisation (Melucci 1985). The more activist oriented participants described their activities in ways which resonate with this idea of fluidity. People create formal and informal networks that remain submerged until economic pressures, shifts in legalities or other social triggers, allow new collective identities to resurface around narrower or broader aspects of HIV.

While participants complained against the power of landlords, customers, employers, unsympathetic relatives, and neighbours, a more nuanced criticism was thus also directed towards the power imbalances and structural violence inherent in the political and economic system. This view was evident in the participant’s willingness to challenge and reduce social stigma by favouring rights which they saw as complementing treatment. These included jobs, farming plots, food support, pensions, allowances, psychological support and the involvement of people living with HIV in all areas to do with their welfare, treatment, and in educating the public about HIV. These solutions challenge structural violence – but they also run the risk of inviting physical violence – the participants talked about how they walked this fine line in the context of the shifting legalities and political vagaries of the State.

While the ‘significations’ (Treichler 1999) created around HIV may silence and/or misrepresent the lived experiences of people who are living with HIV the rollout of new treatment therapies has allowed people who were previously marginalised to reassert their restored ‘healthy’ and ‘productive’ identities.

### **Conclusion**

In this paper I have summarised some key findings of a study which uncovers a complex intersection between traditional practices, modernism and bio-medical technologies which themselves are products of constantly contested and renegotiated cultural norms and community responses around HIV. It is important to also consider the ‘big picture’ of the international HIV response. The global rollout of ART is predicated on the basis of



communities taking on more of the functions of HIV treatment– in other words reduced levels of biomedical care in order to make drug delivery cheaper. However, the communities I interviewed already make a significant contribution to their own care, that of their family and their community. Also, in a broader sense if individuals and communities are stigmatised then Zimbabwe as a nation is stigmatised and this has deep consequences We have already noted the lower levels of funding received by Zimbabwe to roll out its RT programme. This needs to be understood in the context of what Mills et al (2011) have noted. In recent years Zimbabwe has lost the equivalent of at least \$US40 million through the migration of highly qualified and experienced healthcare staff to countries such as Australia. In addition, ART has been standard treatment in the West since 1996 – between 1996 and 2004 – when no ART was available one million Zimbabweans died of AIDS (MoHCW 2009). One serious concern that was expressed by several participants was that the ongoing Global Financial Crisis could mean that the ART drugs – literally their lifeline - will no longer be available.

In this paper I have summarised several aspects of my findings of the lived experience of HIV in Harare. Social stigma, structural violence, the gendered dimension of HIV indicate that health recovery is not just a question of drugs, but negotiating the right balance between competing therapies, and participating in forms of social solidarity which both offer mutual support but challenges stigmatising attitudes and social inequality that exist on a scale that extends far beyond the participant's communities.

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