

## Research paper

# Zimbabwean cultural traditions in England: *Ubuntu–Hunhu* as a human rights tool

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### ABSTRACT

This paper is based on the argument that inside evolving African cultures, there are resources that could be useful human rights and ethical tools. These cultural resources can be harnessed in conducting research on sensitive topics such as HIV or used to deliver health promotion interventions. A key cultural resource, based on evolving Zimbabwean cultural traditions, is the notion of *Ubuntu–Hunhu*, which is grounded in respect, humanity and the interconnectedness of beings. This concept can be a useful resource in upholding confidentiality, a central requirement in research ethics and the deliverance of health promotion interventions.

The aim of this qualitative study was to explore the meaning of *Ubuntu–Hunhu*, and the applicability of this concept in helping those with HIV. Thirty HIV-positive Zimbabwean men and women living in London and the surrounding area were interviewed and then invited to take part in focus groups to discuss their experiences as migrants to the UK. All data were transcribed and a grounded

theory approach was used to identify three themes: the meanings of *Ubuntu–Hunhu*, *Ubuntu–Hunhu* as a basis for privacy, and *Ubuntu–Hunhu* in clinical settings. Although all the respondents reported that they were aware of the concept of *Ubuntu–Hunhu*, not all were aware of the meanings of confidentiality as used by Western health and social care providers. Our study shows that the use of *Ubuntu–Hunhu* concepts that link the entitlements of individuals with communal responsibilities and duties provides an important ethical tool for clarifying what research participants understand confidentiality to be. Using the *Ubuntu–Hunhu* framework, confidentiality in HIV emerged as crucially important, not only for the individual but also for those connected to the person living with HIV, including sexual partners. This has important implications for public health.

**Keywords:** confidentiality, HIV/AIDS, human rights, Hunhu, Ubuntu, Zimbabwean diaspora

## Introduction

The Declaration of Commitment, adopted in 2001, by UN General Assembly Special Session (UNGASS) on the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) identifies human rights as one of five areas of commitment deemed essential to stem the negative impact of HIV/AIDS on wellbeing. It asserts that lack of confidentiality ‘undermine[s] HIV prevention, care and treatment, and increase[s] the impact of the epidemic on individuals, families, communities and nations’ (UN General Assembly Special Session on HIV/AIDS, 2001, para 13). It commits states to enforce laws, regulations and

take other steps ‘... to ensure all their rights – in particular, their access to education, inheritance, employment, health care, social services, prevention, support, treatment, information, legal protection, privacy and confidentiality ...’ (UN General Assembly Special Session on HIV/AIDS, 2001, para 58).

However, vulnerable populations are often not engaged or consulted about the conceptualisation and implementation of human rights and HIV programmes. Recognising the limited engagement of vulnerable populations in HIV and human rights work, the UNAIDS Global Reference Group stresses

the importance of engaging vulnerable populations in HIV/AIDS responses (UNAIDS Global Reference Group on HIV/AIDS and Human Rights, 2004). Within human rights discourse, the right to the preservation of confidential information is a standard requirement of medical care and research ethics procedures. The limited involvement of vulnerable populations poses questions, overlapping with those raised by some scholars, about the universality of rights, indicating that rights discourse may be grounded in dominant Western cultural assumptions. Service users, for whom rights discourse might be expected to have the greatest importance, may themselves find this discourse alien. If so, the sense of its alien nature may have health-damaging consequences for such service users, especially if this sense is shared within a community facing enhanced risks. There is evidence that this is so among the African diaspora in the England affected by HIV infection (Chinouya, 2002).

This paper, based on qualitative research with and for HIV-affected migrant Zimbabweans in England, argues that inside changing, traditional non-Western cultures, there are norms that are useful human rights resources. The paper describes *Ubuntu–Hunhu* found in the world view of Zimbabwean migrants affected by HIV in England. It shows how normative materials embedded in *Ubuntu–Hunhu* have provided a useful way into the language of human rights, in particular the right to confidentiality for this population. We argue that the cultural resources offered by *Ubuntu–Hunhu* enable Zimbabweans to activate their specific meanings of the right to confidentiality, and exercise this right in their everyday lives as well as during research. The use of *Ubuntu–Hunhu* has involved the development of research methods which operate through reconstructing mechanisms in which secrecy is traditionally policed, deliberately grounding those mechanisms within a normative framework with wide currency and suitable for work on human rights. Crucial to this is the need to find out what people understand *Ubuntu–Hunhu* to be, and what they think *confidentiality* means as they encounter it in formal settings such as healthcare clinics and the informal settings in which they live their ordinary lives. The research presented here addresses these questions. In so doing we found that Zimbabwean women and men had complicated needs in respect of confidentiality regarding their own positive diagnosis. There were indications that confidentiality was both desirable and problematic. For them, confidentiality had a wider boundary than just themselves as individuals. They wanted partners to know their diagnosis, and had proposals about how clinicians should be actively involved in ensuring that partners could be more open with one another, especially in cases where the woman was pregnant.

## Confidentiality

In an early anthropological book that deals with Shona cultural traditions, top of the list of what constitutes a 'bad Shona character' is *makuhwa* (gossip) as this often leads to defamation of character (Gelfand, 1973). Preserving one's confidentiality is hence of great concern to individual service users in relation to specific conditions. This is the case in respect of HIV, as unsolicited disclosure of a positive diagnosis often leads to stigmatisation. This is understood and accepted by health professionals and researchers in England. Hence, the right to privacy/confidentiality is central to healthcare and research ethics, with all information collected during these interventions being protected from disclosure to third parties without consent of the participants.

User concern for confidentiality for them as individuals is put at risk in accessing treatment and support. At least they can count on professionals maintaining confidentiality, but there may be no safeguards against disclosure by their peers. People suspect or indeed know each other's diagnosis by virtue of meeting in places such as support groups and specialist HIV clinics, or encounter one another in research exercises, such as focus groups, which they know to be devoted to the study of those with a positive diagnosis.

Worries about confidentiality amongst Africans in England impact on their willingness to take part in research. The experience of carrying out epidemiological studies of African communities affected by HIV has presented challenges for recruiting research participants and led African researchers to seek practical strategies to engage communities. Several health and social care needs assessments, essential for evidence-based service planning, have been made possible through the construction of research methods which draw on cultural materials derived from African traditions such as the *Padare* (see Box 1; Chinouya and Davidson, 2003). A preoccupation throughout was to create an environment in which participants understood that they were entering a normative environment in which each would be entitled to have

### Box 1 *Padare*

The *Padare* is a confidential traditional space in Zimbabwe where men discussed male issues such as sex, gender relations, etc. The concept of a confidential space offered a niche for researchers to recreate the *Padare* as a non-gendered space that allowed the study of sexual lifestyles of London based HIV-positive Africans (Chinouya and Davidson, 2003).

her/his secrets kept, and each would be obligated to keep the secrets of others. The *Ubuntu–Hunhu* framework made this possible. In so doing, it provided a culturally competent conduit for what is understood by health professionals in formal settings as *human rights*. These initiatives were carried out using the framework as process on the basis of the principal investigator's judgement about what would work in practice with these communities, without doubling back to explicitly explore the meaning of the framework for research participants themselves.

### Rights as 'Western'?

The desire and need for confidentiality are of great importance to individuals living with HIV. They permeate an infected individual's life within the immediate and extended family, in ordinary life within African diasporic networks, and within the wider community. However, this concern for individual confidentiality need not be interpreted using a human rights framework.

It has been argued that Western cultural traditions provide the basis for human rights, thus creating fatal objections to their claim to universality. Some clinicians working with ethnic minority groups in the UK argue that dominant rights discourse is individualistic, with potentially health-damaging consequences, and should be replaced by a culture of obligation (Tamimi and Sami, 2005). The African Charter on Human and People's Rights (ACHPR) is commended for placing duty as central and the family as the natural basis for society (O'Keefe and Chinouya, 2004).

The language of rights may not be understood or shared by lay communities from non-Western backgrounds (Chinouya and O'Keefe, 2004). Young African Londoners affected by HIV because of their parent(s)' positive status have the right to information that HIV affects them. A study with these young people reported that although they wished for information on matters affecting their lives, including the presence of HIV in their immediate family, they expressed concern over the language of rights (Chinouya and O'Keefe, 2004). They perceived this language as too individualistic, resulting in behaviour incompatible with respect for their parents. Harnessing cultural resources that make sense to communities is key to their participation in research on matters that affect their health and wellbeing. We have argued elsewhere that it is correct to give greater prominence to duty or obligation, but that this can and should be done within human rights discourse, which brings duty and entitlement into balance with one another. Such discourse is not sitting there waiting to be used. It is a

*project*. Our work using the *Ubuntu–Hunhu* framework is part of such a project.

### The *Ubuntu–Hunhu* framework

The words *Ubuntu* and *Hunhu* are, respectively, Ndebele and Shona, two Bantu languages spoken by some people who identify themselves as Zimbabweans in their homeland and in the diaspora. The word *Ubuntu* is also found among Zulu-speaking populations of South Africa. The use of both Shona and Ndebele was an inclusive way of combining some of the Zimbabwean languages in a health-promoting/research programme that targeted Zimbabweans in the diaspora. The words *Ubuntu* (Ndebele) and *Hunhu* (Shona) signify the activity of *being human* or *humanness*. Ramose (1999) argues that *Ubuntu* is the fundamental ontological and epistemological category in the African thought of Bantu-speaking people. The idea of *humanness* is grounded in mutual care, interdependence, initially within families, and is foundational for duties and obligations amongst kin and non-kin. Others argue that *Ubuntu* highlights the group solidarity and care essential for the survival of marginalised or poor communities wherever they are in the world (Mbiti and Marea, 1995). This commitment to group solidarity is encapsulated in the Ndebele or Zulu aphorism *umuntu ngumuntu ngabanye* (one is a person through others). Another aphorism describes human beings as *being with others* and encourages respect, dignity, solidarity, survival and compassion for others (Ramose, 1999). This ethic enjoins active participation in acknowledging the needs of others and mutual support. Mutuality is the touchstone of *Ubuntu*, especially, but not exclusively, in conditions of shared adversity, including those brought by health threats and the conditions of a marginalised life as found in the African diaspora.

The concepts of *Ubuntu–Hunhu* have universal leverage, as dispossessed groups wherever they are have their own versions of *Ubuntu–Hunhu* that promote group survival, making the concept a resource in empowering marginalised communities in the West. The concepts of *Ubuntu–Hunhu* that are related to respect, dignity and communal responsibilities have been used as research ethics tools amongst African migrants affected by HIV in England (Chinouya *et al*, 2003). The use of these concepts was designed to enable researchers to employ research participants' own social meanings regarding confidentiality to carry out culturally competent research. However, this was carried out on the assumption made by the principal investigator about the meanings that these cultural resources had for the participants. The research reported here directly addresses questions about whether and how this framework operates among research participants.

This paper should be understood within a context in which HIV brings complex human rights challenges amongst Zimbabweans in their homeland and England. The exodus of Zimbabwean professionals to live in the diaspora helps citizens of developed countries such as Europe and the United States to realise their rights to health, while leaving a gap in the source country. Zimbabwe, with an estimated population of 11.6 million, has around 1.8 million people living with HIV.

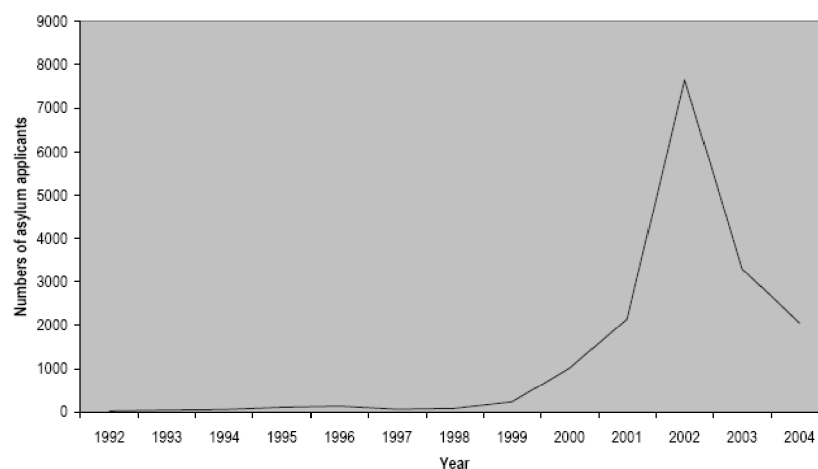
According to the UK Collaborative Group on HIV and STI Surveillance (2005), in 2004 there were approximately 58 300 adults living with HIV in the UK. The group reports that the increase in reported HIV cases is marked by a geographical shift in the distribution of HIV cases in the UK, with regions outside London also reporting an increase. The group also reports that there are more heterosexually contracted HIV diagnoses (64%) than found amongst homosexual men (32%), because most people infected abroad, in particular Africa, are diagnosed in the UK for the first time. In 2004, there were 17 900 African-born people living with HIV in the UK, accounting for 60% of heterosexuals in the country. There has been a shift in the nationality of people diagnosed with HIV in the UK. In the early 1990s it was people from Uganda who were the largest affected group, but in recent years it has been other countries, especially Zimbabwe, that have come to the fore (Medical Foundation for AIDS and Sexual Health, 2002). In a world where the rates of HIV infections show a gendered pattern, over 50% of the people living with HIV are female in both developing and developed countries. The increased gendered vulnerabilities to HIV become more salient for migrants to the UK, as HIV testing remains largely associated

with an individual's sexual health history or self-perceived risk, a strategy that may be inappropriate given the potential for onward and vertical transmission (Fenton *et al*, 2002). However, fear of stigma and discrimination was reported as preventing Africans in the UK from presenting for HIV testing (Elam *et al*, 2006).

## Background: Zimbabweans in the UK

It is difficult to give the exact numbers of Zimbabwean migrants living outside their home country, as the process of documentation for tracking migrants is often inaccurate. Estimates have a wide range from 280 000 to 1.2 million (Mbimba, 2004). Health workers and students are prominent amongst immigrants. In 2003–2004, 391 Zimbabwean nurses joined the UK Nursing and Midwifery Council register and as of 2004, about 117 Zimbabwean doctors also joined the UK medical register ([www.who.int/countries](http://www.who.int/countries)). Others are refugees and asylum seekers, groups with increased vulnerability to HIV. Figure 1 shows the estimated numbers of Zimbabwe-born asylum seekers in the UK.

The number of Zimbabweans claiming asylum in the UK rose sharply from 2000 and has been steadily decreasing from 2003. In 2002 a visa obtained from Zimbabwe was required before entry to the UK. This new visa requirement increased the cost of travelling to the UK, and closed down all legitimate routes out of Zimbabwe (Ranger, 2005). The presence of asylum seekers and economic migrants generally, especially



**Figure 1** Zimbabwean asylum applications to the UK 1992–2004. Reproduced with permission of ICAR from ICAR Statistical Snapshot Series [www.icar.org.uk/?lid=2409](http://www.icar.org.uk/?lid=2409)

those who are black, currently constitutes a moral panic in the UK, in particular when HIV is added to their situation in the UK.

Zimbabweans and other Africans affected by HIV in the UK and who have compromised immigration status have reason not to take part in research for fear of being exposed to authorities. African migrants are subject to symbolic AIDS stigma; that is to say, when AIDS operates to express hostility toward groups that were already stigmatised on grounds other than the epidemic itself (Herek, 2002). This makes the project of being invisible and remaining uncounted an important everyday exercise. The project of being a migrant living with HIV has added costs: Africans are more likely to be living in poverty compared to HIV-positive non-Africans (Weatherburn *et al.*, 2003). Africans often present late with AIDS-related complications, and are subject to various forms of discrimination. Engaging such communities in ethically sound research and healthcare interventions requires culturally competent resources that offer confidentiality and harm reduction.

## Aim of the study

Focusing on Zimbabweans living with HIV in England, this qualitative study explored the meanings of *Ubuntu–Hunhu* and the applicability of this concept in human rights discourses. The study objectives included investigating how the concept of *Ubuntu–Hunhu* might help to offer a human rights approach for those living with HIV and its transferability to non-health settings.

## Methods

This was a qualitative study conducted after a research ethics committees granted ethical approval. Thirty HIV-positive Zimbabwean men and women were interviewed about living with HIV and their understanding of *Ubuntu–Hunhu* as well as their experiences of telling others that they have been diagnosed with HIV. Thirty respondents aged 22–52 years were recruited from support groups in London ( $n = 15$ ) and its suburban hinterland ( $n = 15$ ). The respondents included 22 females and eight males. Posters and flyers about the project were displayed in support groups. All the index cases recruited in support groups had to be Zimbabweans, who had a positive diagnosis. All non-Zimbabwean support group members were excluded from the study.

Potential respondents contacted the researcher and discussed the dates, times and venues where a one-to-one audiotaped interview would take place. In one-to-one

interviews, demographic characteristics were collected including information on migration histories. In addition, respondents were asked how they got to know that they were living with HIV, their understanding of confidentiality and *Ubuntu–Hunhu*, as well as disclosure. None of the respondents chose to be interviewed at home. Almost half ( $n = 14$ ) were interviewed at the university, and another 16 in support group settings. Most of the respondents who came to the university were also keen to discover ways of connecting with the university and finding opportunities for studying and getting away from the sick role. Similarly, in support groups, some participants were also keen to know more about the university where the researchers were based, and also how they could be part of the university community as students.

After a one-to-one interview, respondents were asked if they wished to take part in a focus group discussion. The aim of the focus groups was to discuss their views regarding being a Zimbabwean migrant living in the UK, HIV and the way the virus was affecting people in their networks, how Zimbabweans understood and made sense of the concept of *Ubuntu–Hunhu* in the UK, and confidentiality. Asking the respondents after the interview if they wished to take part in focus group discussions was a way of preserving their right to confidentiality, as participating in a focus group was a form of disclosure to the group about one's HIV status. Respondents were aware that they were selected from the support group database, and as such reported that they did not mind meeting their peers in focus groups as they regularly met in support groups and were already aware of the HIV status of other participants. Three focus group discussions were held: one at the university and two in support group settings. Focus groups allowed the researcher to engage participants to discuss, share and challenge one another on the meanings of *Ubuntu–Hunhu* within the context of living with HIV. All the interviews and focus groups were transcribed verbatim and analysed using a grounded theory approach.

## Findings

Three themes emerged from data analysis: the meanings of *Ubuntu–Hunhu*, *Ubuntu–Hunhu* as a basis for privacy, and *Ubuntu–Hunhu* in clinical settings. Each is discussed below.

### The meanings of *Ubuntu–Hunhu*

Respondents referred to HIV as *chirwere* or *umkhuhlane* (illness or disease). This is how one female described how she found out her husband was positive:

'His body was finished a long time ago [slim]. I never thought that he was being finished by *chirwere*.' (A mother)

The use of words such as *chirwere* or *umkhuhlane* was said by some to 'lighten the burden' of living with HIV, as they construed themselves as people who had an 'illness'. In addition, respondents were asked in focus group discussions and individual interviews about their understanding of the words 'Ubuntu' or 'Hunhu'. Central to their answers was the idea that *Ubuntu* or *Hunhu*:

'... was part of our culture ... as Africans ... and Zimbabweans.' (A mother)

*Ubuntu-Hunhu* was also construed as being transmitted across generations as noted by one mother:

'Hunhu I can say is the way you control yourself. Also coming from the way you grew up. Like how did you parents grow you up ... as the child will copy from the older person who is close and doing at that time. So it is our duty that we us adults we should have *Hunhu*.' (A mother)

Another female respondent reported that *Ubuntu-Hunhu* was related to behaviour and respect for others:

'For me *Ubuntu* is being an African and character, how you carry yourself as a woman ... You must have respect for yourself and other people ... not sleeping with loads of men ...' (A mother)

Others viewed *Ubuntu-Hunhu* as related to culture and rights, as one male respondent noted:

'Maybe the way I behave ... respecting other people. The way I take things as they come. Maybe the way I understand more and more of maybe my rights ... maybe the same time ... my taking into consideration culture.' (A father)

### *Ubuntu-Hunhu* as a basis for privacy

During this study, participants were also asked their understanding of the word 'confidentiality'. Some when interviewed said:

'It means don't go outside and don't tell another person ... It's important because it can ruin a relationship of two people ... trust goes.' (Female)

A few did not understand the meaning of the word but reported that they had heard it repeatedly in healthcare settings and in support groups. One mother said when asked about her understanding of confidentiality:

'It means things that [you] are confident ... as a woman ... you can stand up for yourself.' (A mother)

Breach of confidentiality led to ruined relationships and stigmatisation of the person living with HIV. Others were keen to draw on Zimbabwean proverbs

that pointed at confidentiality as one male respondent said:

'*Chakafukidza dzimba matenga* [what covers houses are roof tops] ... You will never know what is happening in someone's family. Even some people in those families will not know. There are things which do not leave the house. But the family will be aware of it. But even in the *musha* [family or household] there are some people who don't know what is going on.' (A father)

Further, confidentiality as understood by Zimbabweans was layered with various levels of confidentiality and privacy within the family and other networks. The management of confidentiality and privacy was viewed as a social contract between the person who had the information about their HIV status and them, as persons living with the virus. There were settings such as clinics where these contracts were documented and signed providing written evidence of its existence. For example:

M: 'In the clinics what do they say confidentiality means?'

R: 'They say it's between you and the clinic. They will not leave room for other people.'

However, confidentiality, as when a person shares their diagnosis with kin or friends in non-formal settings such as homes, was often characterised by its non-written contractual character. People who knew someone's HIV status in non-formal settings had no legal basis for upholding confidentiality, but relied rather more on family contracts, to reduce harm as rooted in obligations and duties towards one another, as one respondent commented:

'Confidentiality means it stays within the family and like I am saying I am not upset that my brother knows but had he told a cousin or an uncle ... it would be different. It means sometimes we do not tell our extended family.' (A father)

The obligatory nature of confidentiality in non-formal settings and networks of Zimbabweans living with HIV was based on an inter-subjective notion of respect. The respondents described this activity as grounded in behaviours and gestures that express a sense of being with others through politeness and respecting other people. *Ubuntu-Hunhu* was the basis of this, as being with others meant respecting their secrets. One HIV-positive Zimbabwean female put it this way:

'*Ubuntu* is the way you live with others ... when you hear other people's stories, in particular immigration status and HIV ... and someone says this is for your heart, it means this is for your heart. It should not grow and go other places. It should stay with you.' (A mother)

People living with HIV often meet one another in various settings such as support groups. Confidentiality outside these settings was reported as sustained by the practice of *Ubuntu-Hunhu*. Others described

*Ubuntu–Hunhu* as the contractual basis for managing secrets outside formal settings such as in their homes:

‘I talk to other people who are living with HIV. They call me at home ... but I would not call other people and say can you imagine so and so has tested positive ... if someone trusted them I should not betray that by telling other people. So *Ubuntu* is about not gossiping.’ (A mother)

The concept of *community* and preserving secrets became important because of the devastating effects of gossip on group cohesion:

‘They will hear of it in Zimbabwe. You may have a relative who may gossip and things will get there ... and my parents will be blamed as they are the ones who brought me up ... my wrongs will touch my mother.’ (A father)

As noted from the above text, the inability to hold confidential information often led to parents back home in Zimbabwe being stigmatised, as they are the ones who imparted the values of *Ubuntu–Hunhu* during the process of bringing up the respondents.

### *Ubuntu–Hunhu* in clinical settings

The dominant Western notion of human rights presents the individual as an autonomous being with rights to information on matters affecting their health, including the presence of HIV in their bodies. In formal settings such as clinics, disclosure of HIV is to the person living with HIV, as such information should not be passed on to a third person without expressed consent. This helps people who are living with HIV not to be subject to stigmatisation. However, the interconnectedness of persons, namely the person identified as living with HIV and their emotionally close other, became problematic, especially for women who reported that they were in steady relationships and became aware of a positive diagnosis during pregnancy. These women reported that they wished for their male partners, where appropriate, to be engaged and be part of antenatal care, including the HIV testing process. In England, an opt-out HIV testing programme is available to all pregnant women. In focus group discussions with men and women, it was suggested by participants that expectant fathers must be part of the HIV testing programme and jointly informed about the diagnosis, ways of reducing the risk of re-infections and mother-to-child transmission. Some of the women had taken their partners to the antenatal programme, expecting joint care but had been tested individually for HIV, and when the disclosure of their diagnosis happened, they were alone with the nurse advisor. This was surprising, as noted by one:

‘They called me. What surprised me is that they called me alone.’ (A mother)

Another female who found out her diagnosis while pregnant recalled:

‘So I could not believe that was the issue, so I began to cry and then I said “You must phone my husband and ask him to come to the hospital and tell him. Because for me to go home and tell him this story I don’t think he is going to understand. So you must tell me when he is there. It will be better for me ...”, they told him and gave *baba* [husband] a letter to go and be tested ... I would not do that!’ (A mother)

Another woman reflected on the moment she was given the results, while pregnant, alone, in the absence of the expectant father:

‘Then we were all quiet. They then gave me time. Because in most cases when they tell you that kind of news I think they also find it hard. So I said “What do I do now?”. And “Ahhh ... me, it’s not only me”. I held my self [-control]. I did not become hysterical. I just received it as it had come. I then asked for one thing. I said yes I have heard what you have told me. I am asking for one thing. What? Can you please tell my husband. Call my husband and tell him. They said “Do you agree with that ... do you agree with that? Do you want to talk to him alone?”. I said “How do I begin to tell him? Please tell him for me. If I say I will talk to him at home the way I will talk ... I may talk as if I am running away from the news. It’s not possible. You will have done a job if you tell him when I am here as well. Alright.” So they called him. They sat him down. They said “We have to stress one thing. You need also to be looked at [tested] so that we know what to do”. The main thing is that these things [HIV] are now here ... So the idea of pointing fingers to say so and so, it’s gone and we don’t want to hear of it. The main thing is surviving with what we have. I thank God here as he understood me. He did not argue or anything. He said “OK look at me too [test me]”. He said “One thing, my wife I love her and I have always love her with or without HIV”.’ (A mother)

Some women who were told of their HIV status during pregnancy, in the absence of their sexual partner, reported that when they disclosed to their partners, the partner did not believe that the women had had a positive diagnosis. One put it this way:

‘He just said “don’t worry you know sometimes these machines make mistakes” [laughs].’ (A mother)

The women who had requested that their partners told by medical staff of their diagnosis reported that this made it easier for the women as the medical staff recommended that the men receive an HIV test, something which the women found difficult to do. During a focus group discussion, respondents were asked whether they thought that HIV testing and subsequent disclosure of HIV should focus on the individual. Respondents reported that, where possible, joint HIV testing for sexual partners should be encouraged with expectant fathers and mothers, along with active engagement in maternity care and the

prevention of mother-to-child transmission. The women were adamant that people should be encouraged to have joint HIV testing as the silence brought about by preserving individual confidentiality in the clinics was dangerous. As they put it:

'Confidentiality at times ... when you tell [the] person alone ... is killing us.' (A widowed mother)

## Discussion

As these narratives indicate, *Ubuntu–Hunhu* is rather complex to define and is embedded in rapidly changing cultural experience. Culture provides a toolkit for a people's world view (Swidler, 1986), from which actors select lines of action, which shape behaviours enabling them to articulate meanings of obligation and entitlement, including those with respect to confidentiality. Tradition is central to cultures but is subject to change, with human agents selecting between continuity and creative alternatives from their cultural toolkit as cultures are passed on from one generation to the other. As they migrate, Zimbabweans bring to the host nation some of their cultural traditions that they have deployed in the management of their everyday lives, including the notion of *Ubuntu–Hunhu*. Our findings resonate with cultural practices in HIV prevention strategies in Kwazulu province prior to the implementation of individual rights-based confidentiality protocols in post-independence South Africa. Under the earlier arrangements, bounded confidentiality was maintained where the infected individual was entitled to confidentiality if he or she wished, but encouraged to share the diagnosis with kin and community to destigmatise the condition, to reduce onward transmission and to engage community support in resource-poor rural areas. Its use in Kwazulu was explicitly based on '*Umuntu, Umuntu, Ngabantu*' (in Zulu), i.e. 'a person is a person with the people' (Seidel, 1996). London (2002) points to this as an analysis which makes sense of subsequent 'preoccupations among health-care providers in the rural KwaZulu-Natal Province [which] have undermined traditional communitarian responses to illness by preventing HIV from being treated in an open manner'. These preoccupations emerged when shared confidentiality was replaced by a more adamant focus on individual confidentiality.

### *Ubuntu–Hunhu* doing 'human rights work'

The *Ubuntu–Hunhu* framework has several features which make it a possible candidate for human rights work. To do human rights work, a cultural complex needs to apply to all human beings, and be seen by lay people to be obligatory and apply in the informal

settings where ordinary life is lived and legal procedures rarely penetrate. *Ubuntu–Hunhu* meets these criteria. It is not just a discourse used by the professional educated elite. It is the ordinary moral argot of oral culture. It is not confined to particularities; that is to say, just to those who are emotionally important to us through family, friendship, clan, nationality or other ties of particular identity. It is potentially cosmopolitan, is pervasive within the cultures of sub-Saharan Africa, and is foundational to moral judgements. Not confined to formal settings such as those in healthcare clinics, it applies to the informal spaces where we ordinarily mingle and gossip: home, place of worship, pub, market place or supermarket.

The notions of *Ubuntu–Hunhu* that place emphasis on the family as the transmitter of principles of respect and solidarity are congruent with the articulations of the African Charter on Human and People's Rights (1981) that places duty and the changing family as central and the natural basis for society. The kinship patterns and the community accord rights which are duties of other kin and community members. The literature on family life positions them as complex exchange networks of goods and services across and within households, with obligations and reciprocities as their basis, contracting individuals with respect to normative behaviours. These family contracts are not formalised but shape expectations and behaviour. The normative relations amongst kin are based on obligatory help and what is considered the 'proper thing to do'. *Ubuntu–Hunhu* extends beyond the family to include people that one is not biologically related to. It places duties and obligations both inside the family, to blood relatives, and outside the family, to neighbours, friends and the community, as the basis of this social obligation that enables us to respect and treat others with dignity and humanity.

As we have seen, *Ubuntu–Hunhu* is grounded in three notions: humanity, respect and interconnectedness. The first two are acknowledged by all versions of human rights. The notion of interconnectedness is prominent in human rights discourse associated with underdeveloped countries. Interconnectedness is increasingly recognised as crucial by feminists who are critical of rights discourse taking the unencumbered male as the starting point, and by those committed to the full panoply of rights, including economic and social rights (O'Keefe and Scott-Samuel, 2002). Noting that *Ubuntu* appears in the preamble to South Africa's human rights-based constitution, Dickenson (2004) treats *Ubuntu* as an example of a non-Western rights concept. The Africa Commission Report devoted to eradicating the scar of poverty in Africa calls for a move beyond charity:

It is about a journey from charity to justice or what in Zulu and other Bantu languages is called ubuntu which insists



that the very identity of each person is bound up with others in a community of all. 'I am what I am because of who we all are.' In a globalised world our sense of ubuntu must extend across the planet. (Commission for Africa, 2005)

## Conclusion

This paper began by considering the premise that inside some non-Western cultures there may be human rights concepts that form part of their cultural framework which can promote shared understanding of ethical codes of conduct, a key to high-quality research on sensitive topics. The use of *Ubuntu–Hunhu*, concepts that link entitlements of individuals with communal responsibilities and duties, proved an important ethical tool for clarifying what research participants understand confidentiality to be, between the researcher and the researched, among people who are living with HIV, as well as between health workers and patients.

A lack of respect for human rights fuels the spread and exacerbates the impact of the disease, while at the same time HIV/AIDS undermines progress in the realisation of human rights. This work has demonstrated the importance of engaging with ethnic minority or marginalised populations in taking a rights-based approach to health. Such an approach needs to incorporate a concept of rights that is shared and grounded in the ways of knowing of the target population. Confidentiality can be understood by a marginalised ethnic minority population using concepts taken from their traditions. The moral values grounded in *Ubuntu–Hunhu* have offered a niche for explaining harm reduction and a shared understanding of confidentiality.

This research suggests that procedures for ensuring that health and social care service users are simultaneously treated with respect and supported to prevent onward transmission of HIV infection are less than straightforward when it comes to African communities' experience of confidentiality. While emphasis on individual confidentiality is taken as a cardinal feature of good-quality service provision, African service users are challenging providers to work with them to construct safe structures in which information can be shared in an effective and timely manner amongst affected significant others. *Ubuntu–Hunhu* presents a challenge to think hard about the default position which encourages each of us to carry on our lives, including our sex lives, defensively protecting ourselves in our encounters and exchanges. Some members of African communities expect that we should protect one another, and they would like to see procedures that make it easier to share information amongst significant others. Further research would be

in order to explore models which protect individual rights while actively encouraging such information sharing.

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#### CONFLICTS OF INTEREST

None.

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