



“STANDING IN THE FIRE”

Experiences of HIV Positive Black African
Migrants and Refugees Living in New Zealand



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**“Standing in the Fire”:
Experiences of HIV-Positive, Black African Migrants
and Refugees Living in New Zealand**

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EXECUTIVE SUMMARY

Introduction

HIV-positive, Black African migrants and refugees present as a group of growing interest in Aotearoa New Zealand. This is a low-incidence country in respect to HIV with a cumulative total of 3,474 people ever having been diagnosed with HIV at the end of 2010. A range of factors, outlined in this report, has resulted in an increase in the numbers of HIV-positive Africans seeking medical and social services, and there is growing public awareness of their presence. A population shift in those living with HIV challenged existing HIV infrastructure and existing service provision in NZ:

- New AIDS service organisations emerged, including Positive Women (1990), Body Positive (1992), both peer support groups for HIV-positive persons and INA (2008) that caters to Māori and South Pacific peoples.
- Existing groups expanded and the New Zealand AIDS Foundation (NZAF) began an African services initiative in 2001 in response to the changing demographic profile of HIV. The caseload of Positive Women is currently 35% African women, compared with 45% “New Zealander” or “European”.
- The Ministry of Health’s HIV Action Plan (Ministry of Health New Zealand, 2003) identifies “refugees and migrants from high-prevalence countries” as a target group, but does not specifically cite Africans.

Although there has been academic and Government research attention focused on refugees’ and migrants’ experiences of settlement and, particularly, their labour market outcomes, research on the needs of this HIV-positive population group is limited.

Method

This qualitative project explored the lived experiences and social service needs of affected or at-risk Black African migrants, refugees and their family members in New Zealand. In this report, we use the word *migrant* to describe the collective group of African migrants and refugees who settled in New Zealand. In-depth interviews were conducted with 13 HIV-positive Black African individuals between July and August 2010. These interviews were recorded and transcribed and data analysis was managed with ATLAS.ti©. The opportunity for the research was created by a Fulbright Senior Specialist Fund Grant in partnership with the University of Auckland. The research comprised close collaboration with HIV community groups in New Zealand, including Positive Women, Auckland Hospital and the NZAF.

Findings

This report presents the findings of this qualitative study of HIV-positive, Black African migrants and refugees to Aotearoa New Zealand. We aimed to present the stories from the participants in order that care providers, employers and people living in New Zealand would begin to understand this relatively new community of people. One of the main themes that emerged from the data is HIV-related stigma and the profound ways it affects participants’ lives—including the ways they access care for HIV disease. “Standing in the fire”, one participant’s report of how HIV infection is referred to in her country, is a powerful image of the experiences of all of those living with HIV interviewed for this report. The metaphor not only represents the experiences of living

with HIV, but also of other losses that the participants have survived, such as political repression, arrest, torture, refugee camps and relocation into an entirely foreign culture. While participants may now be in a more secure physical and political environment in Aotearoa New Zealand, in many cases their experiences of marginalization and discrimination continue as migrants and Black Africans and because of their HIV status.

However, fire can also create something new and another major theme that emerged from the data relates to participants' courage, integrity and their challenge of stigma. Participants wanted to tell their stories in order to make things better, not only for themselves and for people in their situations, but also for their new country. These stories identify the need for service providers to take care of HIV African migrants and refugees who are less successful, less resilient and more isolated. Clearly these changes need to occur not only in the traditional HIV service delivery organisations, but also in employers, medical and social care agencies, educational institutions, and in faith communities.

Completion of the descriptive and interpretive analysis of the data led to the identification of the following patterns, discussed in detail in the report: African heritage as strength; African heritage as profound challenge; Resettlement and reconstruction; Enforcement of African community boundaries in New Zealand; Reconstructing boundaries; and HIV service provision. Naturally, 'Africans' represent a very diverse group of countries, languages and cultures and these patterns are a reflection only of the voices and experiences of the participants. However, the patterns resulted from issues clearly and repeatedly stated by different participants, and different kinds of participants.

Conclusions and Recommendations

The participants made positive reference to the support they received in New Zealand and expressed appreciation for being valued as people when receiving care and support. This highlights that service providers need to be sensitive to care needs of the whole person more than a HIV-infected individual.

Although the sample did not reflect experiences nationally, specialist knowledge about HIV and access to services in rural areas is a concern—not only for this population, but for all people infected with HIV. Care needs to be standardised throughout the country.

It is clear from the experiences related by participants that education of health care educators, human resource managers and nurse managers is urgently required in order to protect the legal and human rights of participants who reported frequent and gross breaches of their privacy and confidentiality on their jobs that had nothing to do with their ability to perform their jobs. Furthermore, HIV-related education must also be provided to health professionals who live and work with this population outside the offices of the HIV specialty providers.

Peer support organisations need to be accessible. HIV/AIDS organisations including the New Zealand AIDS Foundation, Body Positive and Positive Women were reported as valuable for peer support and social contact with people living with HIV. Migrants and refugees coming from a collectivist culture found themselves re-establishing a new collective identity based on HIV and support organisations are crucial in this resettlement.

INTRODUCTION

This report presents the findings of a qualitative study of HIV-positive, Black African migrants and refugees to Aotearoa New Zealand. The participants' willingness to access health and social care is influenced by a number of factors, and perhaps foremost among these is stigma. Stigma negatively impacts how people access care. One of the things that we heard very clearly from participants in this project is that stigma affects their lives in profound and important ways, including the ways they access care for HIV disease. However, the impact of stigma is only part of the story. Another compelling aspect of the story this report presents is the courage and integrity that participants have shown, simply by living their lives. Their courage challenges the stigma that they experience. A primary goal of this report, then, is to tell the story of these migrants and refugees, to make these hidden stories more visible in order that care providers, employers and people living in New Zealand will begin to understand this relatively new community of people.

Although Aotearoa New Zealand is a small island nation, with an estimated resident population of 4.4 million people, it is a popular tourist destination and migrant settlement. The country also accepts an average of 750 United Nations quota refugees annually (Refugee Services, Aotearoa New Zealand, n.d.). The term *migrant* usually refers to individuals who choose to migrate freely, and may consist of those who seek personal convenience absent compelling factors (UNAIDS/IOM, 1998). Generally the term excludes refugees or those fleeing economic, political, or social persecution, but as emphasised by The International Federation of Social Workers (IFSW) (2005) *migration* is "... a complex social, cultural and political process." As most participants reported migrating to escape political conflict in their countries of origins or to seek economic opportunities in New Zealand, this IFSW definition of migration captures their lived experiences more accurately. A *refugee* refers to a person outside of their country of nationality due to a "well founded fear of persecution for reasons of race, religion, nationality, membership of a particular social group, or political opinion" (United National High Commission for Refugees, n.d.). In this report, except where the distinction is important, we will generally use the word *migrant* to describe the collective group of African migrants and refugees who settled in New Zealand regardless of their status and regardless of why they migrated to New Zealand. We hereby acknowledge that some of our participants migrated to New Zealand as voluntary migrants, but many of them were on the run from war and torture.

Data from the 2006 Census¹ suggest 22.9 percent of people usually living in Aotearoa New Zealand (or 879,543 people) were born overseas, with an estimated 37 percent of people in the greater Auckland region being overseas-born. Between 2003 and 2008 there were 411,400 arrivals into and 355,300 departures from the country, resulting in a net in-migration of 56,100 people during this time (Statistics New Zealand, 2006).

Similarly, Aotearoa New Zealand's ethnic make-up has continued to change. According to 2006 Census results, "European" remained the largest of the major ethnic groups, with 2,609,592 people (67.6 percent of the population) in 2006. The indigenous Māori ethnic group is the second largest, with 565,329 people (or 14.6 percent). Of the major ethnic groups, the Asian population grew the fastest between 2001 and 2006, increasing from 238,176 people in 2001 to reach 354,552 people in 2006 (an increase of almost 50 percent). Middle Eastern, Latin American and African (MELAA) groups totalled 0.9 percent (34,743 people) of Aotearoa New Zealand's usually resident population. Within the MELAA grouping, there were 17,514 people who identified with Middle Eastern ethnic groups, 6,657 people with Latin American groups, and 10,647 people with African groups (although it should be noted that this number is contended).

Aotearoa New Zealand is a low-incidence country in respect of HIV (UNAIDS, 2010). At the end of 2010 a cumulative total of 3,474 people had ever been diagnosed with HIV, according to the AIDS Epidemiology Group (AEG), (2011). Of these, it is estimated that 1,800 people are currently under treatment for HIV (AEG, 2011). Nevertheless, HIV disease in New Zealand has followed the infection pattern that occurred in most developed nations, appearing first in gay male communities (Dickson & Paul, 1996; Mann, Tarantola, & Netter, 1992), and it was these communities that mounted the first comprehensive approach to prevention (Dickson & Davidson, 2006). This early response to HIV in New Zealand included the establishment of the now venerable New Zealand AIDS Foundation (NZAF) in 1985 by members of gay communities, their supporters and allies who had been affected in some way by AIDS (Lindberg & McMorland, 1996; Parkinson & Hughes, 1987). It is widely believed that the early response of the gay male communities in New Zealand contributed significantly to the relatively low incidence of HIV in this country. New Zealand was one of the first countries to experience a levelling of AIDS cases by 1995 (Sharples, Dickson, Paul, & Skegg, 1996).

¹ The New Zealand Census 2011 was cancelled due to the Canterbury earthquake.

However, beginning in 1998, New Zealand began to experience changes with regards HIV diagnoses. From 2000–2005 the number of newly identified HIV infections nearly doubled (Dickson & Davidson, 2006). These new infections occurred not only among men who have sex with men (MSM), but included heterosexuals. Furthermore, the infection pattern of heterosexual transmissions was quite different from that of MSM: while nearly three-quarters of MSM diagnosed with HIV in 2005 were reported being infected in New Zealand, 88 percent of heterosexuals identified that year reported being infected overseas. This latter pattern remains relatively stable; in 2010, of the 90 MSM newly diagnosed with HIV, 64 (71 percent) were domestic infections, while of the 35 reportedly heterosexually acquired new infections, 23 (66 percent) were acquired overseas (AEG, 2011); these overseas-acquired infections were predominately among Asian or African migrants (Ministry of Health New Zealand, 2007). These epidemiological data, which signalled important shifts in the nature of New Zealand's HIV situation, triggered questions about the nature of changes in health care and social service delivery.

The arrival of African migrants in the period beginning in 1992 coincided with significant political, economic and social upheaval in many parts of the African continent. Civil war in Somalia arguably began in 1991, and continues to the present. The Rwandan genocide occurred in 1994; the flow-on effects of this genocide spilled into the armed conflict in Zaire—later the Democratic Republic of the Congo—which also continues to the present under extremely militant regimes, and has been associated with evidence of routine torture and murder. Fast-track land reform and resettlement in Zimbabwe was ramped up beginning in 1999, and political repression and instability remain, resulting in the greatest number of new asylum-seeker applications from any nation in the world, as reported by the United Nations High Commission for Refugees [UNHCR] (n.d.); 90 percent of these new Zimbabwean claims were lodged from South Africa. Unemployment in the Black population of South African increased dramatically in the period 1994–2003. All of these factors are examples of forces that have resulted in significant population movements in Africa, both internally and internationally, and have created displaced people and refugee populations. In 2010 the UNHCR estimated that there were nearly 2.2 million refugees and displaced persons in Africa, an increase of 5.3 percent over the previous year (UNHCR, n.d., p. 13).

Spiegel (2004) writes that armed conflict in migrants' homelands may render populations more vulnerable to HIV infection, and that the presence of HIV/AIDS may

also reduce the coping mechanisms and the resilience of populations affected by such conflicts. Sub-Saharan Africa accounts for more than 70 percent of all HIV and AIDS cases in the world (International Centre for Research on Women [ICRW], 2003) and AIDS is the leading cause of death there. More specifically, life expectancy decreased in the region from 62 to 47 years of age (ICRW, 2003). The adult prevalence of HIV infection was greater than 15 percent in southern African nations (including Zimbabwe, Zambia, Namibia, Mozambique, South Africa and Botswana), and very high in many central African nations. HIV infections in younger people, particularly females, have consistently been higher than males of the same age (Joint United National Programme on HIV/Acquired Immune Deficiency Syndrome, 2002).

Between 1992 and 2001, approximately 3,000 refugees, immigrants, or asylum seekers from the Horn of Africa settled in New Zealand (Worth, Denholm, & Bannister, 2003). In addition, New Zealand's 2004 Special Zimbabwe Residence Policy, along with a subsequent 2006 waiver allowing HIV-positive Zimbabweans to apply for residency, resulted in close to 1,000 Zimbabweans applying to remain in New Zealand (Joint United National Programme on HIV/Acquired Immune Deficiency Syndrome, 2008). These trends have resulted in an increase in the numbers of HIV-positive Africans seeking medical and social services, as well as public awareness of their presence (Worth et al., 2003).

There has been a great deal of academic and government research attention focused on refugees' and migrants' experiences of settlement and, particularly, their labour market outcomes (see e.g. Department of Labour, 2011). Attention has also centred on how principal applicants and their children fare in making the transition to inclusion within New Zealand society, as with the NZIS Longitudinal Immigration Surveys (Statistics New Zealand, 2010). The findings of these and other studies (e.g., Dickson & Davidson, 2006) indicate that new migrant populations are particularly vulnerable to stigma. New migrant populations that have been heavily affected by HIV are particularly at risk for stigmatisation. People with HIV are reported to feel that they are blamed for having this disease and that they somehow deserve it (Worth, Reid, Ackroyd, & Tamirite-Bowden, 2001).

The New Zealand Ministry of Health AIDS Action Plan (Ministry of Health New Zealand, 2003) stressed the importance of social attitudes to HIV; attitudes affect prevention, intervention and quality of life in people living with HIV disease (Grierson et al., 2008). Stigmatisation of people with HIV disease remains a troubling reality (Miller,

2010; Grierson et al., 2008). In 2011, the United Nations commemorated three decades of HIV infection awareness, noting that no country has escaped the devastating effects of the pandemic. Acknowledging important accomplishments in medical treatment and human rights recognition, the report of the Secretary-General called these successes “insufficient and in jeopardy” because stigma and oppression continue to undermine efforts to achieve prevention, testing, care, and treatment goals (United Nations General Assembly [UN], 2011, p. 1). Calling for sustainable responses, leadership, accountability, bold decisions, political commitment, and global solidarity, the UN calls HIV an urgent international issue and declares “the HIV response faces a moment of truth” (UN, 2011, p. 3). The current research will show that these HIV-infected migrants and refugees and their putatively transgressive identities (i.e., identities that do not appear to fit expectations) are also stigmatized within their own cultural communities, and often choose to remain separate, silent and hidden. This stigma-induced isolation has an inevitable personal, social and health toll on the lives of new migrants living with HIV.

Because of all of these factors, new migrants and refugees from African nations have altered the profile of HIV in New Zealand and challenged existing service providers. Organisations historically affiliated with MSM communities have had to make decisions about whether HIV outreach prevention and services delivery is primarily to the gay/bisexual/MSM communities which founded them or to all HIV-infected communities and individuals. New AIDS service organizations emerged from this debate, including Positive Women (1990), Body Positive (1992) (both peer support groups for HIV-positive persons), and INA (2008), that caters to Māori and South Pacific peoples (Miller, 2010). NZAF began an African services initiative in 2001 (initially called the Refugee Health Education Programme, changed to the African Health Promotion Programme in 2005) in response to the changing demographic profile of HIV. The caseload of Positive Women is currently 35 percent African women, compared with 45 percent “New Zealander” or “European” (Miller, 2010). The New Zealand Ministry of Health’s HIV Action Plan (2003) identifies “refugees and migrants from high-prevalence countries” as a target group, but does not specifically cite Africans as a specific group (pp. 13–14). It is thus clear that HIV-positive, Black African migrants and refugees present as a group of growing interest in Aotearoa New Zealand, yet there is very little information on the social service needs and daily lived experiences of African migrants or refugees living with HIV in this country.

It is within this context that a research study was launched, and we report the initial findings in this document. We intend this report to be accessible to a wide range of readers, some of whom we hope were participants in the study and some who may be participants in future studies—being designed as we write this report. We also anticipate that an array of more focussed articles and presentations in traditional scientific formats will emerge from the study, although we have included references to some of the relevant literature in each section. In this report we sought to achieve a balance between letting the participants speak for themselves and finding a way to put those individual stories into a larger context and narrative. We hope that this report will be useful to health and social services providers who work with HIV-positive Black African migrants and refugees to Aotearoa New Zealand, so that they will understand the complex and difficult histories that these people bring with them and develop approaches to service delivery that will address the particular needs of this growing community.

METHODOLOGY

Interviews for this study took place in New Zealand in July and August 2010. The project was funded through two research grants from Fordham University (United States), with supplemental funding from The University of Auckland and research staff support from Massey University. Initially, the researchers drafted interview questions based on a review of the literature. This draft was refined and expanded based on significant input from staff at NZAF. Priority was given to topics addressing the main areas of interest and needs of the NZAF and the researchers. Institutional Review Board (IRB) and Human Participants Ethics Committee approval was obtained respectively from Fordham University, The University of Auckland and Massey University prior to the study beginning.

Our focus was on HIV-positive, Black, African migrants and refugees living in Aotearoa New Zealand. Participation was elicited by a flyer that was distributed through two community-based agencies and one of the major hospitals in New Zealand. Because of this recruitment strategy, all of the participants were receiving some form of HIV-related care at the time of the recruitment. All participants were offered a NZ\$50 voucher for their participation in the study.

A total of 14 participants initially agreed to take part in the study, and one withdrew after the interview. Of the 13 remaining interviewees, nine were females and four were male. All were adults and almost all reported finding out their HIV-positive

status either upon entry into New Zealand or in refugee camps prior to relocating to New Zealand. The participants' length of stay in New Zealand at the time of the interviews ranged from less than two years up to nine years. Eight participants migrated to New Zealand from Zimbabwe, and the others from other eastern African nations. All of their countries of origin had histories of conflict or political unrest. Five participants were UN quota refugees accepted by New Zealand.

Individuals wishing to participate in the study called the mobile phone of the principal investigator to schedule an appointment with one of the researchers. Interviews were conducted by the non-African researchers rather than by African peers at the strong suggestion of a Black, African key informant at NZAF. (This informant stressed that potential participants would be less comfortable speaking to Black African peers.) Three interviews were conducted by phone, and all other interviews were conducted either in the homes of participants, or at a place they chose.

With one exception, interviews were digitally recorded and transcribed. (One participant requested that the interview not be recorded, although allowed extensive notes to be taken during the interview.) All transcriptions were reviewed by the interviewer and sent to the respective participants. Most requested changes were deletions of material that participants felt might identify them either to their communities or to authorities in their home countries. The fact that the participants had input into, and final control over, the content of the transcribed interviews is regarded as a strength of this design. Initial (descriptive) data analysis was managed by the US-based research team with a computer-based analysis tool (Atlas ti 6.2). Initial coding developed based on topics outlined in the interview guide and from key themes in the interviews. A codebook emerged with 65 codes. Each incidence of coding was reviewed by two researchers to enhance the reliability of the coding.

Following completion of the descriptive and interpretive level of the research in the United States, the full team jointly identified and named patterns, (discussed in the next section): *African heritage as strength*; *African heritage as profound challenge*; *Resettlement and reconstruction*; *Enforcement of African community boundaries in New Zealand*; *Reconstructing boundaries*; and *HIV service provision*. The major strength of this relatively small exploratory study is that it helped to augment the voices of these participants, members of a hidden population of HIV-positive migrants and refugees who might not have come forward to participate in a large survey. We acknowledge that 'Africans' represent a very diverse group of people, countries, languages and cultures and this research is a reflection of the

voices and experiences of only a few participants. However, the patterns resulted from issues clearly and repeatedly stated by different participants and different kinds of participants and are worth noting.

FINDINGS: THE JOURNEY

African heritage as strength (“In our culture we grow together...”)

Most participants described traditional African culture as a place where families, groups and communities were most important. On the other hand, post-colonial New Zealand—although it is multi-cultural—has been heavily influenced by prevailing Western values of individualism, autonomy and self-determination. Caldwell-Harris and Aycicegi (2006, p. 335) explain that New Zealand is a country with “Horizontal individualism”, where the “individual is allowed to pursue their own goals without undue obligation to their in-group”. They note the shortcoming of this is social isolation. Most African nations would be considered a “vertical collectivist” one, where individuals subordinate their own desires to those of the group leaders.

Participants noted both positive and negative aspects of African and New Zealand cultures. Nine participants described positive statements of African culture because of its emphasis on the importance of groups, such as families (Adele², Anna, Joe, Lisa, Mary, Pat, and Rute) and communities (Adele, David, Jane, Mary, and Rute). Pat related the contribution of groups to Africa’s “strong” culture. Rute best exemplified this positive contribution when she compared her homeland with New Zealand:

In our culture we grow together, we are close, we can live forever. If you are my age and not married, it doesn’t matter. We live together. We are happy to be together. It is very hard for us to live here, like you guys.

Participants also described negative aspects of their collectivist culture. Since the group is emphasized over the individual in many African countries, Adele feared rejection from her group and losing social support from them if she asserted her individuality or independence. Adele noted:

And women, because of our culture women are supposed to be submissive to their husbands so you can be abused and you can live a life which is very difficult and not be able to talk about it or to do anything about it because you won’t be getting any support.

² All names in this research are pseudonyms and each participant chose his or her own pseudonym.

Because African family and community are so important, participants struggled with separation from their families in the more Western-influenced culture of New Zealand; this separation can lead to feelings of isolation and loneliness. In respect of their relationship with their families in Africa, participants have adopted a stance of waiting:

I mean, it's something that you think of every day but you get to an extent—I do think about it but there's nothing much I can do. It's pathetic, it's sad. But I suppose that's life. What else can you do? They are just surviving, that's what I know. You just thank God for each day when you hear they're still there, they're still alive, but it's like living in limbo. You just expect anything anytime. Just wait for phone calls. When the phone rings, [you] get a fright first and then you answer it and if everything is okay then you smile. (Lisa)

This collective identity is self-reinforcing. One of the most important things African migrants to New Zealand have brought with them is their lengthy history of African traditional and post-colonial religion. Aside from their value in providing meaning and purpose to life, these religious and spiritual traditions are ways of creating communities and enforcing boundaries and social norms. Van Wyk (2006), for instance, writes that most African societies regard their social morality as a gift from their ancestors, and these ancestors guard this morality: “They punish those who do not respect the accepted morality by bringing all kinds of calamities and misfortunes onto them” (p. 708). The community also enforces these moral norms:

Most of the time, Africans make limited use of corporal punishment. They, however, regard other forms of punishment as necessary for the proper upbringing of a child. They also know that the functioning of “common law” is necessary to uphold public order. Strategies such as the intimidation of people through public opinion and public mockery, as well as isolation, excommunication and deportation, all contribute towards the enforcement of the accepted morality. (p. 707)

This enforcement of morality is found particularly within the church: Chinouya and O'Keefe (2005) found in their study of HIV-positive African migrant women in a small town in the United Kingdom that the church was simultaneously construed as a threatening space marked by lack of confidentiality and a site for the generation of stigma. The arrival of Christian missionaries in Africa with their legacy of colonialism fitted within this traditional paradigm of the enforcement of moral behaviour. Maboea (1994) writes that missionaries carried the legacy of Puritanism where “saving souls” was a primary objective, rather than understanding indigenous cultures (p. 127). The teaching

of Christianity, then, became a manual of behaviour, something imposed on daily living, whereas traditional African spirituality was fully infused into the life of the community.

Despite, or because of, the compounded adversity and suffering participants had experienced, including their HIV disease, conflict in their countries of origin, migration experiences, and other traumatic experiences, participants displayed individual strengths including altruism and ability to access resources of support. These strengths appeared to the researchers to foster happiness and psychological, spiritual, and physical well-being. Seven participants (Adele, Ivy, Jane, Joe, Lisa, Mary, and Pat) expressed an altruistic desire to protect others from issues related to HIV disease. They expressed a desire to diminish the fear of many Africans that HIV disease was a death sentence. When participants disclosed their HIV status to others, especially their family members and sexual partners, they felt that they protected them and diminished those fears. Participants believed that their altruism lessened the physical, psychological, and spiritual impact of HIV disease and the stigma surrounding it.

Participants also found strength in reconstructed communities. Several participants talked about how living with HIV disease encouraged them to access the resource of social support from others who are also HIV positive. These relationships served as opportunities for mutual support. Adele commented:

I have joined [Agency Name]. They are very supportive and that's where I've managed to meet some friends who are also HIV positive as well. [Interviewer: And you feel that makes a difference?] Very much, because when I am with them, I can be myself. I can talk about anything, whether I'm feeling depressed or low or whatever. I am free because they've been there and they know what I'll be talking about.

Social support appeared to foster a sense of freedom and happiness in Adele. Joe, Mary, Pat, and Rute also found social support from other Africans. These participants expressed how their collectivist culture fostered altruism and closeness with others, which brought them happiness. Adele and Mark suggested that their strengths surrounding social support appeared to have the outcome of reducing HIV stigma. For example, Mark noted,

If someone walks past that maybe is frail and looking sick, maybe you would just say, maybe he has got HIV or talk like that, you know. But after the experience of living with someone, a family member having HIV, you find—I don't think I'll be doing the same thing now.

Participants' strengths created positive futures not only for themselves but for many people in their lives. Saleebey (2009) confirms, "The central dynamics of strengths discovery and articulation lies in hope and possibility; the vision of a better future or quality of life" (p. 9). In sharing their stories participants found a profound strength that serves to enrich and help their friends and family who are infected with, and affected by, HIV disease.

African heritage as profound challenge ("...it was slightly difficult, yes. And I probably got some scars")

The psychological label *trauma* was not used by these participants to describe what they had survived. In fact, only twice was the word trauma used by participants, and in both cases it was used to refer to the impact the disclosure of their HIV status would have on their child. Nevertheless, lived experiences of trauma and suffering clearly underpinned participants' stories of the past and their longing for better lives. So palpable were participants' experiences of suffering that each of the researchers noted at some point during interviews or analysis that, in their years of social work experience, they had never encountered a group that had suffered more. While these findings are based on the interview transcripts, participants requested that many of the most traumatic experiences related in the original interviews be removed from the transcripts out of fear that they or their families might be identified and again put at risk. Although we cannot report these events, we can say that this group of individuals has lived through utterly unspeakable suffering in their home countries. And, it should also be noted that their ongoing concern for the safety of their families is one of the lingering effects of oppression.

Current research on trauma indicates that the majority of individuals experience at least one event in their lives that could be judged as traumatic, and that the majority of people recover from such events (Bonanno, Westphal & Mancini, 2011). Within the 13 interviews that comprise this study, the number of events which could be judged as potentially traumatic was extremely high and the severity intense. Participants originally reported experiences that included arrest and imprisonment, torture, seeing family members murdered, leaving their culture and country (probably) for ever, living in refugee camps, multiple losses of family and friends, loss of their communities, as well as the experience of being diagnosed with a highly stigmatized, chronic, possibly fatal, illness.

To develop effective and culturally competent interventions with different cultures and with cumulatively traumatized individuals, we need a deeper understanding of the culture and its relationship to identity and to identity development as well as to identity and non-identity traumas (Kira, 2010, p. 128).

Erikson's concept of collective trauma references traumas that move "slowly and even insidiously into the awareness of those who suffer from it, so it does not have the quality of suddenness normally associated with 'trauma.' " (Erikson, as cited in Kira, 2010, p. 4). Thus, it makes sense that they may not have labelled these experiences as "traumatic". In addition, Kira's (2010) work on the impact of cumulative trauma within collectivist cultures speaks to the impact of these experiences on identity and on culture. It would be reasonable to suggest that the events outlined above have had a substantial impact on the culture of this group of African migrants. These events have now been paired with the impact of finding they are HIV positive and the location to a different culture in New Zealand. The impact of this cumulative trauma on individuals who are separated from their collectivist culture deserves further exploration as work with this community continues.

While the participants in these interviews readily spoke of the impact of political, economic and ethnic turmoil on their lives, they did not dwell on the past. This is not to say that the participants are not still affected by these experiences—they clearly are. However, the researchers were impressed by the resilience of these individuals based on the types and amounts of suffering they had endured. Participants had gone on with the business of creating a new life and future in New Zealand despite the atrocities they had experienced.

Interview participants recalled many factors relating to why they had to leave home; many of these related to significant political, economic and social upheaval. Lisa said,

There were a lot of factors—political, economic, a combination of both.

She stated that she had to leave because of her family's opposition to the political and economic policies in Zimbabwe. She reported that a lot of her family is no longer in Zimbabwe,

...especially my generation, five years older than me and the younger ones.

These political situations have led to the displacement of massive numbers of people within families and the disruption of normal family and community life.

All participants referred to the losses of family, community, and ties to their countries of origin. Most said that, if it were safe to do so, and if their medical needs could be met, they would choose to return to their home countries. Joe said,

Maybe some people would say they want to go back to Zimbabwe or whatever and maybe people ask you about it you would think maybe if I say “no, I don’t want to go back”, maybe there is something that—because we have got this problem (HIV) you think that people would think that the reason why I don’t go back. [I: So people in Zimbabwe are saying “oh, it’s better now, you can come back” and you’re thinking “well, I’m not sure I’m going to do that”.] Yes. [I: Do you want to go back?] Yes, because we still have got family there.

Participants also referred to the number of people they have lost to conflicts and genocide in Africa. Mary said,

[I’ve lost] my father, my two brother(s), my second husband ... they were all killed.

Jane explained,

You see your family, whole families are finished...Especially coming after the war because the whole country was destroyed. Many people were already dead so you didn’t know even if you were to survive...Imagine three million people dying in front of you, then you survive.

She said that it is hard to get away from the past:

Every time I tell someone I’m from Rwanda they want they will say, “Oh, were you in the war?” I say “yes”. They ask me—because we have two ethnics so always they are interested to know which one I am—“Are you Hutu or are you Tutsi?”.

As survivors of political conflict, many of the participants report having endured or witnessed torture. Jane stated matter-of-factly,

During the war all the girls were raped.

David reported being under house arrest for more than a year and enduring ... severe torture at times.

And Joe said,

Yes it was slightly difficult, yes. And I probably got some scars [reaches to his shoulder].

Jane related,

If you are from Rwanda we meet each other, if I meet a person who is a Tutsi I will ask that person how she survived because I know it was harder to survive. I will say, “what happened, how did you survive?” So she can tell me where she was hiding or

who helped her. It's the same like people who are asking here so you understand. Sometimes it's emotional when you go through the time, what happened but you get used to it.

Resettlement and reconstruction (“I need someone to talk with ...”)

The decision to live in New Zealand led to critical separations from loved ones. Participants consistently said that it was extremely hard for them to bear this separation. They reported missing key life events in their families: for example, Adele reported that she hadn't seen her daughter (in Africa) in five years; Rute lamented not getting to see her mother before she died.

Even two days before she died she said, 'I want to see my daughter before I leave', she said, "before I die." [I couldn't return to Africa] because of my paper for my residency, so I can't. She passed before I saw her.

The immigration process was characterized by participants travelling to New Zealand without members of their nuclear and extended families to escape conflict or an ailing economy. While for some participants it was a relief to leave the conflict and trauma of their country of origin, the move into the refugee camps or life as an urban refugee was difficult. Mary recalled,

In Ethiopia when I was there they don't have camp. They just [have] urban refugee. You are like an urban refugee who gets a small amount just to eat. You are not allowed to work, you are not allowed to do anything.

Their migration and resettlement in New Zealand appeared to be a source of stress for them, having been raised in a collectivist culture, and experiencing isolation and the absence of needed social support for their HIV disease. Ten participants (Adele, Anna, Jane, Lisa, Marie, Ivy, Mary, Pat, Paul, Rute) immigrated to New Zealand without key members of their families. Pat exemplified this experience as a stressor when she stated that,

You miss your family, at times like this...you miss your family but you can't do anything, especially, with me, I miss my Mum. She has always been my pillar of support...

Rute responded to an interviewer's question, “So it's even more important for you now to have family here?”

Yes, because I have depression sometimes, no-one to talk. I need someone to talk with ...

Not all study participants experienced separation from all of their families. Some participants (Adele, Ivy, Lisa, Marie, Mary, and Rute) migrated to New Zealand because they had family members already residing here. In contrast, Lisa, Paul, and Pat tried to bring immediate and extended family members to New Zealand, but experienced challenges that they attributed to the country's immigration policies. Lisa reflected on her challenges when she stated,

I mean, I do understand that they do have criteria for HIV people; obviously you can't let them into the country or whatever. But it feels really sad, because this is my mother because I have come here and I now call this a home, and if my mother can't come to my home, it's not a home for me, because my Mum is something to me. [She weeps]

This challenging resettlement as individual is eloquently explained by Zahan (1970/1979):

To define the self, we separate it from the other, whereas in Africa the opposite is the rule; nowhere is the African psyche ever limited to "that which is not the other and does not come from him." On the contrary, the African carries within himself psychologically and psychically, his own genitors and their respected ascendants. His self is thus more "social" than "individual"; he defines himself precisely by that which he receives from others at any moment (p. 9).

HIV diagnosis as challenge ("It's almost like a life termination...")

All of the participants report that they were diagnosed with HIV either in a refugee camp or when they were applying for residency in New Zealand. One participant reported that they had been tested for HIV in the military of his home country and had been told he was HIV-negative when he was, in fact, positive. The participant believes this is because the government finds it too expensive to treat the illness.

When I left the (Zimbabwe) army I was tested and they said, "You are not HIV." [I: And that was in the nineties?] No, that was [mid-2000s]. Whether that was true or not I don't know because the law of Zimbabwe and Zimbabwe National Army is if someone is terminally ill when he retires the person should be kept under government list for treatment. [I: So, it was for the government's benefit to tell you that you were negative?] Yes, I suppose. I cannot substantial that but only when I came here to New Zealand, that's when I got told I was HIV. (David)

This type of betrayal from authority figures can lead to betrayal trauma – a type of trauma secondary to violation by people or institutes that we depend on for survival

(Freyd, Klest and Allard, 2005). This betrayal trauma typically has lifelong consequences because it reflects the added shock of having assumptions of safety, justice and protection shattered (Indart, 2011).

For the participants in this research, being diagnosed with HIV was life-changing. Paul recalled (regarding his diagnosis),

Yes. It's very difficult; it's not an easy thing to handle. If you are told ... it's very difficult to explain the feeling, what it feels like. In short, it's really a simple shock. You actually lose it; you run out of ideas; you can't decide anything. It's almost like being told that you are going to be hanged tomorrow at twelve o'clock. You can imagine what that feels like. It's almost like a life termination.

Possibly because of the stigma attached to an HIV diagnosis in Africa, many of the participants reported that they viewed it as a death sentence. Adele stated,

I didn't see any life at all. I just thought like, "Oh, I'm dying." There was no need for all that—because I thought I was going to die.

In response to a question about whether HIV plays a role in his decision about where he lives, Joe stated,

I would say so, ... in Zimbabwe it's fairly difficult to get medication and if a person is HIV positive it's going to be very difficult for that person so you would want to live in a place where you get medication.

Enforcement of African community boundaries in New Zealand ("It becomes like a gossip")

Participants also noted some differences and some similarities between African and New Zealand culture in regards to privacy, HIV stigma, and HIV discourse. Anna, Ivy, Jane, Joe, Marie, Mary, Pat, and Rute experienced or observed HIV stigma and breaches of HIV confidentiality among Africans that resulted in the community gossiping about or shunning the infected person. Because of this, Mary and Pat commented that Africans are "reserved" about communicating their HIV status. Mary said,

If they know that there is someone with HIV, it becomes like a gossip. So that's why you find people, when they find out that they are HIV they want to keep it a secret, they don't want to share it with anyone.

As a result, two participants (Anna, Mary) expressed that there was a need for emotional and physical privacy. Anna noted that emotional privacy is characteristic of African

culture, as they do not talk about problems outside of their family. However, physical privacy was discordant with the African collective culture. Mary stated that,

You have to keep people out of your house. And it's not you. I don't choose this life. I don't choose to be alone but I have to be that to keep my privacy. ... When you want people to come here, play, sleep over, that's African. They can come, very time sleep over. But you have to stop everything. I am not a secret woman. No. I want to laugh, come and sleep over, do everything, go, but it's like something stopped inside me. We are not like everybody.

The disclosure of participants' HIV status by another person appeared to have limited open discussion of their disease to immediate adult family members (Jane, Marie, Pat) and prevented open discussion in employment and with health care professionals. Mary noted that:

I don't trust Africans, yes. They can go and gossip about you behind your back and come before you and laugh with you, and I don't trust anybody.

David and Joe also noted that a person's HIV status in New Zealand is "quite confidential", and Adele felt HIV was not a topic of general discussion among Africans in New Zealand.

Three participants mentioned being victimized by community gossip from other Africans. These incidents were harrowing and disturbing to them. Rute confided in an African friend who told other church members. Mary's best friend, in the refugee camp, spread the word about Mary's being HIV-infected, leading to Mary's being avoided. There are people from that refugee camp living near Mary now, and she feels that they have continued to spread that gossip among the community. Paul felt so pressured by people talking about his HIV status that he left one town and moved to another, and does not socialise with other Africans:

When I arrived [in New Zealand] I was staying in [another town] and I lived there for a while. Then some people came to know of my health status and the information was just spread around and it became a very difficult time for me to keep on socialising with people because the moment they discover what you are, it becomes a nightmare, honestly. So I hardly communicate with people from my own country. I don't socialise much, just because of that. ... The rest of the community got the information from somebody else. ... it was very difficult...you could tell, you can feel it, you can just tell by how people are acting towards you. You can tell that there is something not right here. So I simply noticed that it was becoming more and more difficult to continue in that community and I actually had to move on.

It appears that HIV stigma exists in African communities both in African countries and New Zealand. The participants report it is enforced by gossip. HIV-infected people respond to that stigma by remaining silent, and isolating themselves. This atomisation of HIV-infected persons prevents their full affiliation with a community, which also contributes to their isolation. Adele supported this observation when she stated,

I understand there are quite a number of HIV-positive people, especially from my country and other African countries in New Zealand. But as we can't talk about it, I don't know whether they are having the same problems I am having or they are okay with what they have, I'm not quite sure really. I just don't know what can be done for the African community to be able to come out and speak up and support each other.

The destructive effect of HIV stigma was a common topic in these interviews. Three women (Anna, Mary, and Pat) said that they were socially isolated due to HIV stigma and secrecy, and highlighted the need for support. Mary did not want to join a support group because of her fear of seeing someone there that she knows, and she did not date so that she did not have to disclose her HIV status and risk being judged. Pat articulated that hiding one's diagnosis has emotional consequences, especially regarding depression and loneliness:

I think for those people like me who can't come out, I think we need more support. It's not because I don't want to be around people, but I just haven't gained the confidence of doing that. ... You need someone to talk to ... when you think about it you get depressed. You don't know when your days are going to end, so these are some of the things that you think about, and you think about your family, what will happen. Like if I'm gone, what will happen with my children? So you really need people who can support you with that. Last year I had some problems with my boyfriend, so we were apart for some time, and that's when I found I was really, really lonely. It was just me and my kids and I was really struggling, but I didn't have anyone to support me. But then I couldn't come out to say, this is what is happening to me. [I: You were completely alone.] Yeah. In my own shell.

The writing of Zahan (1970/1979) seems a relevant reminder that an African's esteem for someone is a function of his ability to dominate his passions, emotions, behaviour and actions.

The word "stoicism" comes naturally to the memory of those who have long been witnesses to this quality of the African soul...In all cases a single rule governs the human being's education; this is the stoic bearing of pain which is felt to be the best training in self-mastery. Self-mastery thus becomes a real factor in the social integration of the individual who is accepted by the group only to the extent to which he acquires a great

facility for inhibiting the reflexes of affective sensitivity. Thus the real *homo socialis* is a closed being; he does not show himself on the outside. The “virtue” to which he aspires and which he must practice above all else, makes him a being who is indifferent, who does not betray any emotion, feeling or disturbance. (Zahan, 1970/1979, pp. 111–112)

Discrimination (“I can’t tell a lie. I don’t want to”)

Participants frequently reported incidents in New Zealand of medical and employment discrimination, and spoke of being socially isolated, and having their confidentiality violated. Despite legal sanctions protecting confidentiality, Paul noted that his employer disclosed his status without his consent to other co-workers; Julius and Anna told of experiences of HIV stigma in health care settings.

The participants attributed unjust or disadvantaging treatment attributable to HIV stigma. Three people (Anna, Adele, and Julius) reported experiencing or witnessing clear HIV discrimination in medical or dental settings, such as the breaking of confidentiality about HIV status or taking unnecessary and unreasonable safety precautions upon learning of the participant’s HIV diagnosis. Participants volunteered examples of encountering HIV discrimination in a church (Adele), a bank transaction (Julius), and a neighbourhood (Paul).

One of the most disturbing types of discrimination accounts concerned employment. Seven people (Adele, Anna, David, Jane, Julius, Marie, Paul) offered long narratives about feeling that their privacy and wellbeing were at risk in their workplace. Adele reported that she has been struggling to renew a work permit because she has HIV. Anna encountered direct, invasive questions about her HIV status during a job interview as well as an illegal disclosure (against her will) of her HIV status when she was working on a job. Julius called workplace discrimination “insidious” because, he said, although one cannot be outright penalised, employers and co-workers find covert ways to mistreat or get rid of people with HIV. Paul told of one co-worker who betrayed his medical confidentiality in the workplace, and a second who then harassed and verbally abused him about his HIV status. Jane recounted that, during her professional training in health care, a tutor told her to change professions because of her HIV diagnosis. She says that official policy may be anti-discriminatory, but individuals are still able to make HIV-positive persons feel unwelcomed and unwanted. David makes the point that, even though there are laws against discrimination, employers still have the power to screen

you out, pretending there is another reason for the rejection, if HIV status is asked on the forms:

*When you say you are HIV they don't want to take you... [I: Well, you know that there are antidiscrimination laws in place?] I know it could be illegal but you see here is someone who is empowered to employ. He will only say, "No, sorry."
...Getting it off the form is better because if we say we cannot discriminate and you put it on the form. [I: Do you answer it when it's on the form?] When it is there, if you don't answer it they will say why didn't you answer? [I: You say because it's not legal to ask the question.] It's not legal but it's already there. ...[I: So for you, getting that question off job application forms would be important?] Yes.*

Marie reported several examples, all work-related. She spoke about being asked specifically about medications on a job application form, then watching the human resources interviewer going from office to office to show her list of HIV medications to others; then she was told they could not process her application. In another incident, while at work she thought she was having a serious medication reaction and asked her manager for assistance, fully disclosing her diagnosis and medications. She learned later, when she was transferring to another department, that the manager had recorded her HIV diagnosis in her personnel file. Thirdly, her supervisor at her current job told her that she takes too many sick leave days to go to the doctor and case manager, even though Marie has taken well under the allowed amount. Through this confrontation, Marie realized that her HIV status was known:

She started shouting at me. She said I had bad behaviour and she even said "I know you have got an underlying condition, you are always going to the hospital." That's what she said to me. Then I realised she knew when she said that. ... I realised my current manager knows so I don't know who else knows but I think quite a number of people there know.

These repeated experiences made Marie feel stuck in her current job, unwilling to apply anywhere else for fear of what she will go through:

I cannot look for a job anywhere else because I already have a picture of what will happen to me. I just have to stay there because I know if I decide to go and work I won't even get the job if I apply. The way they ask it, "Are you HIV positive? Are you taking any medications?" If I say "yes", then you just know. ... So now I can't even look for a job elsewhere because I just know that the whole thing will be repeated over and over again and at the same time I can't tell a lie. I don't want to.

Although interviewers did not inquire about the reasons for HIV stigma, the topic arose spontaneously in many interviews. Participants thought that negative notions and actions stemmed from *blame, lack of information or experience, African norms*, or from HIV's *association with illness and death*.

- **Blame** (“*You are already dead to them*”). Ten people linked stigma to blame or judgment of the HIV-positive person, primarily censure for sexual behaviour. The picture that emerges from the data is: HIV tends to be associated with sex outside of marriage, multiple sexual partners, or sex workers, which in turn leads to attribution of blame, which in turn leads to stigma, nondisclosure, isolation, and lack of support. People are thought of as either guilty or innocent—this division is so stark that Julius and Marie actually used the words “bad” and “good” to describe these categories—and the guilty deserve to be sick. Adele’s phrase for deserving illness was “payback for your sins.” The understanding of this blame for having HIV causes the profound silence about one’s illness (nondisclosure).

Joe and Mary explained that in African culture when a person is known to have HIV, or is seen to be sick, others assume the cause is having sex with a prostitute, being a prostitute, or having sex with many people. Adele, Anna, Ivy, Julius, and Pat connected the attribution of blame to having multiple partners; what they labelled “sleeping around” or “promiscuity”. Marie, as seen in the excerpt below, described the assumption that an HIV-positive woman was a prostitute:

Most people, they do have it [HIV] but they just hide it because of stigmatisation. People will judge you; if you are a woman they think you are a prostitute. Because it is a condition for prostitutes but if you are married and then you get it, still you lose your status in the community. People start looking down at you. You are already dead to them....Even if you are a married woman, people will still look down on you.

Paul said that HIV could not be discussed because it is “shameful”. Jane also specifically linked the attribution of blame to nondisclosure:

It's like they say you deserve that. They say maybe you ask for it. They don't ask you how did you get it or what happened. They will judge you straight away... I can hear how they are judging others, then I say, “Oh my gosh, if they know I am HIV they are going to do the same for me.” That is why I don't tell anyone.

- **Lack of information/experience** (“*They don’t even greet you*”). Seven participants attributed stigma to not knowing or not experiencing enough about HIV, a situation which can lead to, as Anna said, “fear of the unknown”. David said that the lack of education about HIV transmission and disease course is the biggest problem in Africa. Joe said that misinformation and lack of information about how HIV is transmitted, as well as the lack of knowing people who have disclosed their HIV diagnosis, leads to the shunning and blaming of HIV-positive persons. Adele, Anna, Jane, and Pat brought up education about HIV as a need in New Zealand as well as Africa. Rute describes the dire situation for Africans both in her home country and in her new country:

[I: What do you think the attitude of {people from your home country} is about people who have HIV?] *Now I think they understand a little bit, but before it was very hard. They don’t even greet you ... They are scared or maybe they cover with the hand like this. They don’t have much education about it. Before if you have HIV they will fire you from your job, from your work. ... Even here, I hear one of the ladies, she’s hanging up herself and she die. She’s from [my home country]. Because people, when she goes to someone’s house they say, “Don’t touch our kids.” They are still afraid. That’s why she brings some rope and she kill herself.*

- **African norms** (“*I don’t trust in Africans*”). Six respondents tended to link the shame and blame of HIV with their cultures of origin. HIV stigma and silence was the norm in African communities, and they expected to be shunned or gossiped about if they disclosed their HIV status or were suspected of having HIV. A dichotomy emerged from the participants’ description: Africans tended not to talk about HIV, but they did tend to talk about people with HIV. David was one of several participants who spoke about both sides of that coin: information and education are scarce, but gossip is plentiful. We have seen how Pat used the words *reserved* and *ashamed* when describing the reticence to disclose, *gossip* as a consequence of suspicion or disclosure, and *outcast* to describe someone thought to have HIV. Anna said that HIV is *taboo* in her society:

Nobody talks about it, even if you know people have it.

Adele also mentioned the silence about HIV:

My own community, they know but they want to pretend like they don’t know.... It’s kind of very lonely.

Joe said explicitly that silence about HIV was the norm among Africans: “I have never heard anyone talk about it. I think people are not free to talk about their HIV status.” Mary was clear about the fear of gossip:

African people, they are talking. Talking, talking. ...I don't trust in Africans. They can go and gossip about you behind your back and come before you and laugh with you, and I don't trust anybody. That's why I don't want to have any friend....because of my condition [HIV] I'm happy [here in New Zealand]. Because if it was in Africa, everyone would start to gossip, start talking, “she's HIV,” or laugh on you. But here, nobody knows your life.

- **Association with illness and death** (“*Standing in the fire*”). Six persons thought that HIV was almost always associated with immediate loss of function and life. We should remember that this fear is a rational one, based on observation, for people coming from areas without health care, food security, and medicine. Adele and Ann spoke of their own fear upon testing HIV positive that they were dying soon. Julius said:

Somebody who breaks the news [about having HIV] for the first time, they still believe it is a death sentence even though there have been many changes. There is still stigma.

Joe and David both expressed the belief that, in Africa and for Africans, frail or sick people were assumed to have HIV, and HIV was assumed to mean death. Rute expressed this powerfully:

HIV is the end of the world; you're going to die. Someone, they said last time I went to someone's house, they said someone is “standing in the fire” they said. I said “Why are you saying that?” “Because...she have that sickness.”

Generally, participants gave the impression of being secretive about having HIV, expressing unwillingness to be open and distrustful of others. Yet most of them had told someone (researchers had reached all of them, after all, through a hospital, support group, or social service organization). A picture emerged of an unusually hidden and isolated group of people who made measured decisions about who to tell and who to trust.

Reconstructing boundaries (“It’s easy to tell someone ...not part of your community”)

In order to maintain, or regain, control, participants had to make a decision about disclosure of their HIV status. The choice to disclose or not was carefully considered, and individual, relationship and social contexts were included in the decision process.

Non-disclosure of HIV status (“You have to keep that secret for your life”)

Twelve of the 13 participants spoke of keeping secret their own and/or their children’s HIV status from family members in their home countries, from their offspring, from community and faith group members, from co-workers, from schools, from flatmates, from neighbours, and from friends. They related making careful, considered decisions about who to tell, and the number of people who knew the true struggle of their lives was severely limited. This comment from Mary is illustrative:

If you have HIV it is hard ... You have to keep that secret for your life. Even from your family. Very hard when you have to keep some kind of secret ...I can talk with my doctor, my social worker, only. The only person who knows about HIV is my interpreter... because she has confidentiality, she can’t tell anybody, she is the only one who knows about my HIV here in New Zealand. Even my friend, I have to keep it secret.

Participants offered reasons for their choosing nondisclosure of HIV: they had already experienced or witnessed HIV stigma in action; it was hard to tell who could be trusted; silence about HIV is the norm among Africans; they wanted to protect themselves, a partner, and/or their children from others’ judgment or pity; they feared employment discrimination; they feared deportation or their residency application being turned down; or they wanted to save others from worrying about them.

Disclosure of HIV status (“It’s nothing for me to be quiet about”)

All 13 participants also talked about telling others, usually people who had been carefully chosen, intimates or professionals who could be trusted. Adele and Pat told their adolescent or adult children. David, Joe, Mary, Pat, and Rute disclosed to their partners and received support in return. Marie told her brother and sister; Jane told her mother and brother; and Pat told her mother, all receiving support. Anna and Jane both told New Zealander friends, who reacted with affection and concern. Pat told an African friend, who was respectful and encouraging. Jane, Julius, and Lisa told their pastors and found those disclosures to be helpful. Anna, Adele, Jane, and Marie had disclosed to

others living with HIV, the first three in a HIV support group, and Marie to her sister after her sister had first disclosed her diagnosis.

Several participants reported that they had disclosed to professionals with no difficulty and no negative consequences. As mentioned earlier, Mary told her doctor, social worker, and interpreter, and mentions that the interpreter must keep things confidential—a strong reason why it is safe to disclose to professionals. Rute said that a social worker and doctor know her diagnosis, Paul says that only his doctor and medical staff know; Jane said that only her doctor and mother know, and Ivy said that she received good treatment at a hospital when she disclosed. When Joe was asked what it was like to disclose his diagnosis to the interviewer, he explained that it is easy to disclose to people who know about HIV, who are not part of one's community, and who may be able to help:

It's easy to tell someone [your HIV status] when you know he is not part of your community, so it's easy for that. Like people who are doing research and doctors, you find it easy to talk to them about HIV because they probably have dealt with people with HIV and maybe they will have information that might be beneficial to you. So it's easy for you to tell them that you are the one who is positive.

When participants explained why they had decided to come out about having HIV, the reason was always to help or protect others. Mary disclosed immediately to her partner so that he would get an HIV test. Adele discloses on medical forms because she believes she is protecting the personnel who are “looking after me.” Pat said that she told her teenage daughter so that she can be aware of HIV and its dangers. Lisa is contemplating becoming a public speaker to have an effect on others' lives:

Probably in future I'll come out, for me it's like nothing for me to be quiet about. ...it's a huge negative impact but it can be turned into a positive input into other people's lives. By sharing the experience.

HIV service provision (“They do what they can, everything possible”)

As indicated earlier in the report, the participants were all recruited through two community-based HIV service agencies and one of the major hospitals in New Zealand. Because of this recruitment strategy, all of the participants were receiving some form of HIV-related care at the time of the recruitment. Almost all of participants identified the high quality of HIV-related care in New Zealand; three specifically reported better care in New Zealand than in Africa. (These comments appeared to be related to fears of losing care if they were deported.) Mary states,

I am so lucky to be here.

And, David concurs,

In Zimbabwe if you're HIV, even if you get a cold you'll die straight away, if you get anything you'll die straight away, you cannot be treated... I want to thank (my doctor) so much because she sat down with me and talked to me ... (she said,) I want to tell you that you will not die of this.

The majority of the participants report receiving their HIV-related medical care through a system that included a General Practitioner (GP) working with an HIV-specialist. Participants state that the GP handles most of their medical care, and visits to specialists are limited to once per quarter or once a year. The frequency of these visits appears to be based on the individual's disease process; those who are relatively healthy stated that they have the least contact with the specialists.

Participants identified the HIV specialists and his or her staff as one of the major avenues for both social support and information on the disease. For the participants, scientifically accurate information on HIV is highly valued; Ivy stated that specialists supply them with "facts". Jane noted that specialists update them on drugs or other new information about the virus. Paul stated,

They will give you the basics in terms of, scientifically what it is ... They will simply explain everything in full details and then you understand. ... They simply give you the facts from the group and they make sure you understand everything and if you have any questions then you ask them.

Specialists and staff are also highly valued for their support and for the fact that they do not stigmatize those with HIV. Paul appreciated this,

It's only my medical specialist and his supporting staff [that I talk to]. ...psychologically, they are trained to remove that feeling from you instantly. ... They do what they can, everything possible. They supply you with the right medicine—they choose something that will work for you ... they can actually monitor the situation and you find that at the end of the day you see the results are very positive. So that support alone, it was phenomenal.

*I haven't had a situation here where I was treated differently. (Anna)
...the doctor I have, he's good. He's never discriminated me. (Ivy)
They care about me. I didn't see it from other people in all of my life, I didn't see this kind of thing. They are very special ...they are very kind. I say God thank you.
Even I have this punishment but God, he brings someone (Rute)*

Participants also identified that the HIV specialty staff maintained their confidentiality about their HIV status:

The doctors are no problem. So far I haven't had any cause to be scared information will come out (Ivy).

Nursing and social work services received through the specialists are important. Nurses are valued for their ability to educate about the disease:

Like every time I go for my appointments, there is always a nurse specialist, they always talk about blood. (Anna)

Social workers appear to fulfil several roles within the care system: outreach worker, source of referrals to medical and social services, and providing a capacity to listen. Anna relates how one social worker searched for her and her child to assure herself that they received the medical care they needed. Anna notes that this occurred even though she was scared and tried to avoid everyone trying to find her.

[She – the social worker] said, "Where are you? I've been looking for you?" ... And she was looking for me and I told her that I was in the South Island and she managed to get hold of a doctor in the South Island. ... After that I met a social worker, she was really friendly so after some time I started opening up. She used to come see me and my son. We just used to stay indoors. But...I had a good relationship with my social worker. She helped me a lot. I started opening up and there were a lot of things I didn't know, that I could have access to.

Equally important to the participants were the community-based agencies and the services they provide. Adele stated,

I've got a lot of support from Positive Women. ... They are very supportive and that's where I managed to meet some friends who are also HIV positive as well.

The participants identify the community agencies as providing advocacy, information, newsletters, retreats and a connection to others living with the virus. Most importantly, they report a sense of empowerment, of getting a normal life back through encouragement received in these settings. Said Adele,

...because when I am with them, I can be myself. I can talk about anything. I am free because they have been there and they know what I'll be talking about. ... We're going through the same thing so we can relate and comfort each other.

Mary concurred:

I was quite empowered there because when I went to attend, I didn't know you could actually have children when you are HIV positive....Some people would say, "I bought a new car; I bought a new house." I learnt a lot because me, I was just waiting to die. So, I started saving my money and I bought this place. ... I started living.

Unfortunately, the participants' experiences with other medical professionals were not as good. Two participants noted unacceptable discrimination from dentists and dental staff members:

The dentist I see here, on their questionnaire they asked me if I have a communicable disease so I opened up and wrote that I am HIV positive and when they read it, they just did see me quickly and hurried me off and within two weeks they filling they did just came off meaning they didn't do a thorough job because they thought that they would get it from me. (Adele)

Stigma is the same across the board. I remember I had to get a tooth extraction, and there's question on the medical form about HIV. I answered the question and submitted the form to the receptionist. ... I saw her response. She reacted – I saw her facial expression. I saw her whispering to her colleagues around the office. (Julius)

Julius also recounts an experience of discrimination from a phlebotomist:

I went to the lab for testing—viral load, that kind of thing. Maybe it was the first encounter for the phlebotomist, but I was made to be the last person of that day—even though you're supposed to be see[n] in the queue. I had to wait 40 to 50 minutes.

IMPLICATIONS FOR SERVICE PROVIDERS

The participants spontaneously made reference to the support they received in New Zealand. Some of the comments were more personal rather than care-centred, but indicative of the importance they placed on being valued as a person and valuing personal relationships in receiving care and support. This appreciation is clear from the following comments:

The doctor is really supportive. (Ivy)

... How they are treating me, like I'm important person. They care about me; even my family doctor and the specialist, they are very kind. (Rute)

The health systems seem to be mostly efficient, with Rute's comment illustrative of experiences in this regard:

If you are handed over to the specialist like my current doctor and his supporting staff, they can actually monitor the situation and you find that at the end of the day you see that the results are very positive. So that support alone, it was phenomenal.

David reiterated this by stating:

The good thing is - here it was very fast, my doctor made an appointment and the same week I went to a specialist. He assured me (they) have enough resources to make sure

that you live like anyone else; you are better off because you are checked every now and then, better off than a person who isn't checked.

These responses may have to be assessed against the backdrop of the specific meaning of HIV and resources available to refugees in their countries of origin. As mentioned by Worth et al. (2003), the physical experiences of HIV and AIDS are often quite different in New Zealand as opposed to the respondents' countries of origin, based on the absence of medications and treatments. This is evident by a comment from Mary:

If I was still in Africa, maybe I would not be alive today.

Some offered suggestions for improvement, such as:

There are a number of ways that New Zealand is lacking behind other Western countries, particularly in the medication available. New Zealand is often the last to get medications. Government needs to put more HIV drugs on the list.

Although the sample did not represent experiences nationally, one of the respondents reported regional differences that may be indicative of a larger problem.

In the South Island the specialist that I used to see was—I think she was a specialist in oncology. And even the doctor who used to see my son ... I think maybe we were the only ones in that situation. (Anna)

Specialist knowledge about HIV and access to services in rural areas is a concern—not only for this population, but for all people infected with HIV. Similarly, this raised concerns about confidentiality and discrimination as in this statement by Anna:

I think other people working in smaller towns, they had problems, they had issues like information leaking out without consent. I think the doctors here are different—there seems to be a lot of support at Auckland Hospital.

However, not all of this has been positive, with Anna remembering her experiences when hospitalized for TB:

... me and my son were put in a single room and we were put in isolation and they had all these stickers outside the door. I understand now it was hospital protocol but nothing was explained to us so I had no idea what was going on. I had no-one to talk to and I was really scared of asking questions.

It is clear from the experiences related by participants that employer education is urgently required, particularly, and disappointingly, in the public health care sector. For example, participants reported that non-specialty medical professionals try to “protect” themselves

from exposure to HIV. However, these ineffective (and in this case riskier) practices also signal to those with HIV that they fear them:

...they can double-glove themselves but not when one is touching my dry hand. I've got no wound, there's nothing wrong with my hand and someone is putting on double gloves. (Adele)

In addition, although only two participants spoke about difficulties with medication adherence and indicated some confusion regarding the roles of various medical providers, these issues should be explored in further research.

Education of health care educators, human resource managers and nurse managers is clearly urgently required in order to protect the legal and human rights of participants who reported frequent and gross breaches of their privacy and confidentiality on their jobs that had nothing to do with their ability to perform their jobs.

References to other support services included HIV/AIDS organisations, namely the NZAF, Body Positive and Positive Women. Grierson et al. (2008) highlighted that treatment advice was a commonly used service at HIV/AIDS organisations, but these services were also reportedly valuable for peer support and social contact with other people living with HIV. This was also true in this study.

I was on the internet looking for a way to get my HIV problems addressed when I found Body Positive. I called them, and then went there. They referred me to a GP who had been trained in HIV. My GP is great, and referred me to the specialist. Then I met the social worker there. (Julius)

So the Foundation [NZAF] was there to support what our specialist was doing. They [NZAF] will come – ... to meet some of the people who are also in the same situation as me and to explain their situation. Some of them had been living with the virus for over fifteen years now. And talk about how they are managing and they are giving encouragement. (Paul)

Consistently, support with work permits, residency applications and dealings with immigration seemed to be an issue where support from these agencies was sought and valued.

I am in the process of applying for my residents permit and [the worker] said she would help me... (Ivy)

Other support that participants valued and utilised included pamphlets, newsletters, support groups and retreats.

I was quite empowered there because when I went to attend, I didn't know you could actually have children when you are HIV positive ... Some people would say, "I

bought a new care, I bought a house.” I learnt quite a lot ...When I went there I was empowered so I started saving my money and I bought this place. (Mary)

So I went to a retreat for one weekend and it was really good. I made some friends and for the first time I could actually talk about it. (Anna)

So the Foundation was there to support what our specialist was doing ...They will come...to explain their situation. Some of them have been living with the virus for over fifteen years now. And talk about how they are managing and they give encouragement. (Paul)

However, treatment advice did not continuously meet the respondents’ needs.

Yeah, I think I can do with more information because the information I got was the first time when I was diagnosed and that was all. (Pat)

I know they exist but I don’t know what they can do or what they can help. (Jane)

It was not easy to initially make contact with these organisations, as stated by Mary:

I remember the first time when I phoned there was no-one in the office, I couldn’t even leave a message because it took me a lot of courage to phone. So when I finally did, there was no-one answering the phone so I didn’t leave a message, I just put the phone down.

However, the value of peer support and social contact was very important as illustrated in the following statements:

At Body Positive there is a lot of peer support, what’s new, new research, new medications. I go to the peer support meeting once a month. We talk about everything. (Julius)

They [Positive Women] are very supportive and that’s where I’ve managed to meet some friends who are also HIV-positive as well. When I am with them, I can be myself. I can talk about anything, whether I’m feeling depressed or low or whatever. We are going through the same thing so we can relate and comfort each other though we are in different phases. Some have got support and they’ve managed to overcome other things so they can actually give you good support as well. (Adele)

It’s just another world when you attend the women’s retreat. You just don’t want to go back home. (Mary)

Community support, as mentioned previously, was very limited due to trust and confidentiality issues, which limited sharing of knowledge and accessing services:

I don’t trust Africans, yes. They can go and gossip about you behind your back and come before you and laugh with you, and I don’t trust anybody (Mary).

That's why I don't want to have any friend. I never tell anybody. I don't trust anybody.
(Rute)

If they know that there is someone with HIV, it becomes like a gossip. So that's why you find people, when they find out that they are HIV they want to keep it a secret, they don't want to share it with anyone. (Pat)

Thus, the connections gained through support groups at community-based agencies becomes even more important to allow for the social support that is so critical to healthy living while HIV-positive. Unfortunately, the view that African community members could not trust each other with HIV disclosures is grounded in real experiences and as already mentioned previously, linked with incidents of diagnosis disclosure. Anna, Ivy, Jane, Joe, Marie, Mary, Pat, and Rute experienced or observed HIV stigma and breaches of HIV confidentiality among Africans that resulted in the community gossiping or shunning the infected person. Paul added:

... some people came to know of my health status and the information was just spread around and it became a very difficult time for me to keep on socialising with people because the moment they discover what you are it becomes a nightmare honestly. So I hardly communicate with people from my own country.

Some reported support from church leaders and church groups, although this was often fraught:

Like there is a prayer team, there is a couple that do prayers so they know and the priest knows.
Someone coming from Fiji has healing gifts and I said I want to go up to be healed.
"Why? Are you sick?" ... I told her, my friend she tell him about me and [later] he [the preacher] was preaching about me. (Lisa)

Others, like Adele reported going to church, but without anyone knowing her HIV status. Some report having close friends and in some instances these are very supportive, such as for Pat, stating, "*she's always been there for me, even on my operation she went with me*", but mostly, social contact is limited. Mary's comment is powerful in this regard:

I'm either at work or at home. Those two places. That's where you'll find me.

And Anna claimed:

The only friends I have now is when I go to the meetings at Positive Women.

Many participants acknowledged that their own attitudes limited access to services:

I've always been somebody who, I can do things by myself, but that's what I was telling Jane, that sometimes we don't realise that we need support. (Lisa)

There are always social workers but I don't know how a social worker would help me really, talk about what? (Anna)

It's not anything to be discussed. That becomes more of a disastrous thing to do I think. (Paul)

Considering these data as they are reported, participants felt that their health care was adequate, but reported better care when managed by an HIV specialist.

My GP is not very good. It's a clinic so you just meet any doctor and some of them are very negative about HIV. (But) just a note of appreciation to my specialist physician: he is a good man. [I: And you've said that you had some really good service and support from him.] Yes. I see my HIV specialist every three months. If I have a problem in between I can go to my GP. [I: And you feel that's a good service?] Sometimes you're really not sure if what you are getting is what you need. It's kind of tricky really. I'm trying to say – sometimes you think you are getting enough services but you may not even know what is available to you. You may not know the options. (Adele)

The literature on the care of individuals with HIV disease supports this assertion. Provider experience treating those with HIV is positively associated with better health outcomes. However, the literature supports the fact that quality outcomes can be achieved through co-management by a GP and a specialist in HIV (Grierson, et al., 2008; New York State Department of Health, 2008; United Nations General Assembly Special Session, 2010). This may mean that education for the non-HIV specialists on better communication, ways to allay fears regarding confidentiality, and on the specific needs and available community resources for those living with HIV might strengthen the support available from the GPs, the first level of existing care in New Zealand.

The disparity in care by region is concerning, as is the difference in access to HIV-related information and support outside of Auckland. Not all the respondents—people already in care—found it easy to access information about support services, nor was it easy to make initial contact with support groups such as Positive Women, Body Positive, and NZAF. And, it should again be noted that the respondents are a population who are already receiving some level of care. Thus, it is imperative that this information be more widely disseminated so that all people living with HIV have access to the available supports.

Some of the most valued supports, including retreats, are limited, and access to support and information for children is particularly scarce. On-going issues with immigration (e.g., work permits, residency status), provide on-going challenges. If we explore these responses on a deeper level, what is clearly important is that participants were attended to as individual persons, not simply as patients with a disease. People want to be seen in their wholeness, not as blood-test results. It is the integration of HIV into the self-identity, and the reconnection with a community which is important, and all providers need to have that in mind—even though that is a process that service providers can facilitate more than perform. African migrants come from a collective context, where membership in a community is the norm. Being infected with HIV can separate the individual from the collective.

Among many of the participants we found a subtext where, for those who have found other people infected with HIV, HIV became a way for finding or reconstructing a community based on that infection. This makes affiliation with peer support groups such as Positive Women and Body Positive even more important in the lives of our participants because, as we have seen elsewhere, they have become separated through stigma from their cultural communities. In a sense, then, these participants were in the process of re-forming their identities as a member of a different kind of collective—this one made up of people from many different cultures and nations, affiliated only by a virus. Of further note, the apparently natural interest our participants had in the latest treatments and pharmaceutical interventions is actually quite significant. If HIV is constructed as a *punishment* (by ancestors or a divine being) for behaviour that is perceived outside community norms (whether or not that behaviour actually occurred), then to seek treatment for HIV infection is to act against the will of the ancestors or the divine. This in itself is a radical action which suggests that some participants were beginning to adopt a different, individuated identity.

CONCLUSION

There are a number of observations and reflections from the research that the authors would like to underscore as we conclude this report. When the researchers reviewed the interviews with participants there was immediate agreement on what the title of this report should be. “Standing in the fire”, one participant’s description of HIV status, is a powerful image of the experiences of all the participants. The image describes not only the experiences of HIV, but also the survival experiences of the participants, many of whom have endured unimaginable histories of loss, political repression, arrest, torture,

refugee camps and relocation into an entirely foreign culture. Many of them have stood in the fire and have looked at death in the face of their torturer. We heard from people who were still too afraid to have their voices recorded, lest they be discovered by political operatives from their home countries. We heard from people who have isolated themselves from their communities, families of origin, and their own children because of their HIV status. We also found, however, that, while participants may now be in a more secure physical and political environment in Aotearoa New Zealand, in many cases their experiences of marginalization and even discrimination continue. We heard from participants who have experienced continuing stigma from New Zealanders as new migrants and as Black Africans, and people who have felt marginalised and isolated in their own cultural communities because of their HIV status. We have heard experiences of overt and covert discrimination in employment, and in access to care. The experiences of social isolation and exclusion, including racism, unemployment and underemployment, and economic hardship related by our participants are consistent with other people with HIV living in the Black African Diaspora throughout the world (Patten, n.d.).

It would be easy to erroneously conclude from this report that we have heard from a group of poor, sick, broken African migrants and refugees whose lives are filled with unremitting misery and despair. But these difficulties are far from the whole story told by these individuals. In addition to destroying, fire both refines and creates something new: African faith healers use ash to purify and cleanse, as it has itself been purified by fire (Maboea, 1994). As researchers, we heard from a group of courageous participants who wanted to tell their stories in order to make things better, not only for themselves and for people in their situations, but also for their new country. Admittedly our participants were successful survivors: they had migrated, settled, and were in care. But this reality only makes their stories more urgent. These stories identify the need for service providers to take care of HIV African migrants and refugees who were less successful, less resilient and more isolated. Our participants wanted to improve New Zealand by challenging discrimination, and by supporting their communities. We heard from people who have children and new relationships; who play soccer and go to school, church and work; people who support others and find support from others. We heard from people who are planning their futures and who want the best for their communities.

I'm going to die here by myself, I said. And then God assured me, "No, you have longer life", he said. He show me. (Rute)

I am quite positive. Even when I plan my things I don't say "I don't know whether I am going to survive to this". I just plan. I am living my life... (David)

I work long hours and I support people... I'm standing up to say here I can, I can do this for you so you can live your life. (Adele)

Jane, who was denied the opportunity to be a nursing student because of her HIV status, exemplifies this movement toward life. She now wants to take advantage of her status to be a peer advocate and health educator:

If I get a chance and- if I get a job and then they say okay, here are [HIV] positive people there, whatever they are asking me to do with them, do you think these people they will not be happy? I think they will.

For these participants, as difficult as the past has been, the future holds possibility and hope. The researchers have been affected and changed by the stories we heard. Because we are social workers we also want to ensure that these stories provide the context and motivation to create appropriate policy and practice-level change. Clearly these changes need to occur not only in the traditional HIV service delivery organisations, but also in employers, medical and social care agencies, educational institutions, and in faith communities. We have proposed that more HIV-related education be provided to employers and service organisations, including, and perhaps *especially*, the health professionals who live and work with this population outside the offices of the HIV specialty providers: social workers, nurses, general practitioners and dentists.

More than anything, however, we hope this research creates opportunities for further conversations about HIV-positive Black African migrant and refugee experiences in Aotearoa New Zealand. Breaking through the fear and stigma that surrounds HIV will ultimately create occasions for healing not only for HIV-infected individuals but for HIV-affected communities.

I hope and I pray one day African people understand HIV and accept HIV. Because I accept HIV... I think stuff can change one day... If you talk, you open your heart.... If I'm talking about my HIV I'm feeling in peace. Even you don't give me a cure but I'm feeling okay. Just talking about it opens your heart. (Mary)

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