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# HIV and migration: two major uncertainties for people from culturally and linguistically diverse backgrounds

Henrike Körner

## Abstract

**Objective:** To describe the interrelationship between living with HIV, migrating to and resettling in a new country, and the Australian migration system.

**Method:** Key issues from the international literature on HIV-positive ethnic minorities in resource-rich countries are summarised. Findings are presented from semi-structured, in-depth interviews with clients of the Multicultural HIV/AIDS and Hepatitis C Service, and a sexual health clinic, both in Sydney.

**Results:** Three major themes interwoven with migration were identified: HIV diagnosis, access to care and support, and forming social relations. Participants who applied for permanent residency in Australia, rather than off-shore, were usually diagnosed by means of the HIV-test that is part of the health requirement for permanent residents. This jeopardised their prospect of staying in Australia and was at the same time a barrier to returning to their country of birth. It was also a major barrier to accessing health care and support services and a major source of uncertainty. Because of the stigma associated with HIV/AIDS, many had little or no contact with their ethnic communities. At the same time, they found it difficult to form new social relations in the English-speaking mainstream culture. A further problem was feeling torn between Australia and the promise of a better future, and the close emotional relationships with family and friends in the country of birth.

**Conclusion:** New migrants with HIV need to negotiate simultaneously two major life disruptions and two major uncertainties: migration and HIV infection. In the Anglo-Celtic mainstream, language, cultural and financial barriers to health and support services should be removed or minimised. In ethnic communities, HIV-related stigma needs to be addressed to enable new migrants to rebuild social relations with these communities and to rebuild their lives.

**Keywords:** People from culturally and linguistically diverse backgrounds, migration, health care, permanent residency, social relations, ethnic communities

## Introduction

In the *National HIV/AIDS Strategy 1999–2004*, people from culturally and linguistically diverse (CALD) backgrounds were identified as a group with specific needs for HIV/AIDS-related education, prevention and health promotion.<sup>1</sup> People born in non-English-speaking regions of the world accounted for 20% of HIV notifications in Australia in 2002–2003. There is also a higher proportion of heterosexual exposure in this group. People from CALD backgrounds also represent a higher percentage of those diagnosed with AIDS in Australia (20%), an increase from 13.3% in the period 1994–1998.<sup>2</sup>

There is a significant body of Australian research that provides insights into the experiences of people living with HIV/AIDS in Australia. However, there is no research that provides insights into the experience of people from CALD backgrounds living with HIV/AIDS in Australia.

Overseas research on people belonging to cultural and ethnic minorities in resource-rich countries suggests that they face a number of unique and pressing issues when living with HIV. Among Africans in the UK, fear of deportation and the impact of the migration

system contributed to high levels of uncertainty for those without permanent residency.<sup>3,4,5</sup> Fear of deportation and uncertainty about entitlements because of immigration status were also barriers to HIV testing and the seeking of general health care.<sup>6,11,12</sup> In the US, research established that the fear of deportation was a barrier to seeking health care among ethnic communities, as well as a barrier to disclosing HIV status to family and friends.<sup>7,8</sup> A New Zealand study described the twofold uncertainty and isolation of sub-Saharan refugees: of having lost home and country and of being HIV-positive.<sup>9</sup> For these refugees, a lack of English was also a barrier to seeking health care.<sup>10</sup>

This paper will report on the first study of its kind in Australia: a research project on the lived experience of HIV-positive people from CALD backgrounds in Sydney. Its aim was to investigate the intersections of living with HIV and belonging to culturally diverse groups outside the Anglo-Celtic mainstream. The focus was on common issues across cultures and ethnicities.

Interviews were conducted with 29 HIV-positive people from a variety of cultural and ethnic backgrounds about their experiences of

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migrating to Australia, being diagnosed with HIV, their access to health care and support services, their perceptions of HIV and perceptions of HIV in their ethnic communities, and disclosure of HIV status to family and community.

## Setting the context: migration in Australia

Migrants are a diverse group. Their reasons for migration and the circumstances under which they migrate are also diverse. However, they share the process of leaving behind their country of birth and their family and friends, and resettling in a new country with an unfamiliar culture. They also have to deal with a complex migration system. In addition to successfully passing the immigration selection criteria, all applicants for permanent residency must complete the health requirement of the Department of Immigration, Multicultural and Indigenous Affairs (DIMIA), which includes an HIV test.<sup>13</sup> While an HIV-positive serostatus does not necessarily mean that a permanent visa will be denied under Australian immigration policy, current practice is that HIV-positive applicants are usually rejected at the first stage.<sup>14</sup> Applicants who appeal against this decision are given one of a number of possible bridging visas, which have different restrictions and entitlements, such as the right to work and access to health care and other services.<sup>15</sup> This means that those who want to stay have to go through the uncertainty of a lengthy appeal before they can finally settle.

## Description of the sample

This paper reports on a subset of 17 HIV-positive migrants who applied for permanent residency while in Australia, and whose migration status was uncertain due to their serostatus. Their ages ranged from 29 to 49 years. In this group were four heterosexual women, four heterosexual men and eight gay men. One man provided no information about his sexuality. Participants arrived in Australia between 1994 and 2000 and were diagnosed with HIV between 1994 and 2003. All participants were born in non-English-speaking countries. The majority came from South East Asia, and smaller numbers from South America and Southern Europe.

Five participants had had uncertain immigration status when they arrived in Australia but were now permanent residents. One was on a temporary visa and had had his application for permanent residency, and his appeal, rejected. Two had had temporary visas when they arrived here but provided no information about their current immigration status. Nine were still uncertain about their status, usually because they were HIV-positive; they were on various temporary visas and each was awaiting a decision from a review tribunal.

Some participants had come to Australia under the program for skilled and family migration; others had come under the program for refugees and those in humanitarian need. Some had come to Australia intending to settle as permanent residents; others had come on various temporary visas and sought a change of their migration status after some time. Some had come with their families, some had joined family members

already in Australia, and some had come on their own. They were a diverse group but they shared the experience of having left behind a familiar culture and social relationships, and having had to start a new life in a culture that was new and unfamiliar.

## Results

### Immigration and HIV diagnosis

Three gay men had been diagnosed with HIV in their country of birth; the remaining 14 were diagnosed in Australia. Those diagnosed in Australia had found out about their HIV-positive status as a result of the HIV test that is part of DIMIA's health requirement at a time when their lives were already unsettled and they were uncertain whether their applications would be successful. In Australia, pre- and post-test counselling have been an integral part of HIV testing policy since the early 1990s. However, no one in this study who was diagnosed as part of the health requirement for immigration reported that they had had any pre- or post-test discussion.

I came to Australia as a [visa type] and then I applied to live permanently in Australia (...) At that time I applied that I want to take my visa, I want to take my children to continue their studies (...) in Australia. (...) And then the paperwork went through and then the last part they asked me to do the blood test and then one day they call me to tell me about my results and they told me that I'm positive with this and then I feel shocked. I fell unconscious right away. (...) I did not have any idea that I might have this. So unpredictable, it make me really shock.

(*Cambodian woman*)

Because of Australia's health requirement for all migrants, the diagnosis jeopardised participants' prospects of staying in Australia. At the same time it was now difficult for them to return to their country of birth for a variety of reasons: their HIV status, their sexual orientation, war and other forms of social and political turmoil.

CO-WORKER (translating): And then there was this great fear that his application would be rejected on the basis of his poor health. But he argued that if he goes back, basically he would be doomed because no medication, no access to health care. At the same time it was a war situation. He was at that time, like a Serbian in Croatia, which is, like he couldn't possibly go back, you know, like multi-ethnic, inter-ethnic problems and all that situation.

(*Serbian gay man*)

Some gay men had come to Australia to escape from repressive attitudes towards homosexuality and the stigma associated with HIV/AIDS in their country of birth. Those who were on antiretroviral treatment in Australia had to face the possibility that this treatment could be withdrawn from them at any time if their appeal were unsuccessful.

For those whose application for permanent residency had been rejected and who were waiting for the outcome of their appeal, the uncertainty of their migration status was

experienced as a bigger problem than their HIV-positive status.

If I got my residency I wouldn't worry anything (...) I'm going to look after me (...) It doesn't mean I can just have coffee, enjoy my life and government give me money. I'm not that person. I can work for myself. Just say, don't come lock me up and send me home. I can keep going. If I get sick I get to my treatment. And I still am going to live another fifty years!

(*Indonesian heterosexual man*)

### Immigration, health care and support

Access to health care was dependent on participants' immigration status. Those on certain temporary visas who were ineligible for Medicare had problems getting health care after they were diagnosed. Some clinics provided free care and treatment. Others did not treat patients without a Medicare card. For some, the only way to get antiretroviral treatment was to be enrolled in clinical trials. Others imported generic drugs from overseas, sometimes with the help of their doctor.

The uncertainty of migration status and the prospect of deportation affected treatment adherence for some participants. They saved any treatment they had in case they were deported, carefully monitoring their clinical markers and balancing the treatment needs of the future against their state of health at the time.

I am getting prepared (...) While the doctors were telling me very carefully not to stop taking your medication at the prescribed times and in the prescribed amount (...) I take half of the medication, of course with the risk of getting worse. But because I was having blood tests every four months and also I was, like, controlling my health condition, I saw that nothing like that was happening. So, in the end I have medication for a whole year.

(*Peruvian gay man*)

Those whose migration status entitled them to health care and support services still experienced difficulties in using them. Major issues here were language barriers, having to negotiate an unfamiliar system of health care and social services, and being referred between services, sometimes without knowing what these services were for. Participants also had to absorb vast amounts of information and medical terminology. They had to make decisions about their lives and their health in a culture that was still unfamiliar, without close friends to confide in. Some found this quite overwhelming.

For those whose migration status was uncertain, survival was precarious and access to support was limited. Some had to work in physically demanding jobs to support themselves at a time when they were physically and emotionally very vulnerable. Others, who were physically able to work and who wanted to work, were not allowed to under the terms of their bridging visa. This made them dependent on friends for basic survival needs. Being dependent on others when they wanted to be independent undermined their self-reliance and their

sense of self-worth. It also affected their mental health.

You can work because you're healthy but you're not allowed to work because you're on this visa. That's waiting far too long, more than half year (...) Waiting for—and not allowed to work. Last time I feel if I don't work, stay home, make me sick (...) makes me feel no good, worse, because I can work, I can help myself (...) Now I'm not allowed a visa I have got to ask somebody else to look after me (...) and I've got to thank these people very, very much. They do help me, you know. (...) Actually, I'm forty years old. I can look after myself.

*(Chinese gay man)*

Those who were allowed to work were proud of their independence. They were not only able to support themselves but as taxpayers they also felt they contributed to Australian society.

If Immigration come to lock me up because of my residency, I just say, 'Officer, one thing I want to tell you. You lock up the wrong person. Why? Because I'm HIV-positive? And I been on treatment, I think it three years already, been living, and I work, I make money, I pay tax, work for myself, I never done criminal, kill people or do something bad to people.'

*(Indonesian heterosexual man)*

Those who had arrived in Australia on their own had no one to turn to. They were also unfamiliar with community organisations that could have provided social and emotional support.

PARTICIPANT: The first year I was isolated completely by depression. I didn't talk with anybody at all. I came only to ACON once, after the Multicultural HIV Service, and that was after almost one year or less, eight months.

INTERVIEWER: So, for eight months, what did you do?

PARTICIPANT: I stay alone a lot. It was very hard. I become very skinny. Living in different place. The kind of job I was doing was very hard, physical work.

*(Colombian gay man)*

There was one barrier specific to the women in this study, both new migrants and those who had been in Australia for some time: access to the health care system was controlled by their husbands. New migrants with little or no English had to rely on their husbands or another English-speaking person to take them to a doctor.

I know that he [husband] came here to this [sexual health] clinic but he did not tell me what for and then a few times later when he was break down I know that he has some sort of health problem and myself one day I went to see my family doctor who can speak some Cambodian and I asked him to refer me to this clinic (...) I ask him [husband] to take me to this clinic. He refuse. So I try to come by myself and then after the test I found positive. He [husband] can speak English and I can't (...) [He] can speak English but I can't rely on him. He refuse to take me anywhere, even to come to this clinic. (...) So I ask someone else to take me here. After four

months in Australia I don't know anybody. I have no relatives at all.

*(Cambodian woman)*

### *Immigration, HIV-positive status and social relations*

The meaning of an HIV-positive diagnosis was grounded in participants' knowledge about HIV/AIDS from their country of birth and their experience there: HIV was the same as AIDS, a terminal illness. Most were familiar with AIDS prevention campaigns in their country of birth. However, they did not know about HIV and the difference between being infected with HIV and having AIDS. Therefore, the meaning of an HIV-positive diagnosis was 'having a terminal illness and dying soon'.

They did explain to me that I'm positive of HIV but I don't have the word for HIV in my language. We unfortunately presume that it's AIDS. Yeah, and he [doctor] tried to explain to me that 'Not yet, you just started.' When I was in Cambodia I saw the information, the brochure about this. They just call it AIDS (...) AIDS disease, not HIV, and we believe that it's terminal. It means when you've got it you won't live very long.

*(Cambodian woman)*

Also grounded in the culture of the country of birth were participants' perceptions of people with HIV/AIDS as 'immoral' and 'deviant'. While they did not necessarily perceive themselves in this light, they were acutely aware that they would be judged by their ethnic communities.

It's the cultural perception of people in my country, at least I believe, maybe all Asian developing countries, they a perception that if you get AIDS—they don't know about AIDS and HIV, you know, what is the difference. They don't know. So when say 'HIV'—'Oh, you will die soon. You are unclean person. You have to be gay or you have to go to a lot of prostitutes.' All negative perception, you know. They don't want to listen to you.

*(Thai gay man)*

In view of these meanings associated with HIV/AIDS, for many participants it was vital to maintain silence about their HIV-positive status. However, this could lead to considerable tensions: new migrants with HIV were alone at a time when they needed support.

[It was] terrible, because in that time I feel very isolated. I have no family, no friends, nobody here and I just apply for permanent resident. I end up having to wait for almost three years. The emotional situation was very bad (...) Because there was no support. That time I was living very hard. I can't express myself for example (...) Almost nothing. Just a few words in English and no more (...) Um, secondly, alone, with no family, no friends, nobody, to find out you are HIV-positive five years ago it was something that was a big scare. You feel like the whole world is going down, doing down. Very hard.

*(Colombian gay man)*

At the same time, the language barrier and the vulnerability after being diagnosed made it extremely difficult to establish new social relations in the English-speaking mainstream.

Then, for me, the second thing was the battle with English. It was very hard because I only just come here with a few expressions and then when you find out something (like HIV) you don't feel confidence in anybody. You don't feel that you want to—you want to talk with people but you don't feel confidence to talk. It's better to be quiet sometimes and don't talk.

*(Colombian gay man)*

Because they expected prejudice and stigma, some participants had no contact at all with their ethnic communities. However, they needed someone with whom they could communicate in their own language. This need was met by the bilingual workers of the Multicultural HIV/AIDS and Hepatitis C Service. They were from the same language and cultural background but without prejudice about people with HIV.

In those three months I was feeling so really homesick of not being able to listen to anybody speaking in Spanish. More than medication I was trying to find somebody who spoke my language and would be able to understand my tragedy (...) I was feeling like depressed and anguished and empty and this process went on for the whole of 2001 until I was able to find a way through my coordinator [co-worker], who was a Bolivian person.

*(Peruvian gay man)*

Participants with limited English had great difficulties in negotiating the Australian health care system after they were diagnosed. They also had problems understanding medical information and making decisions about antiretroviral treatments. The bilingual workers acted as brokers between clients and the health care system.

Living in Australia afforded participants the privacy and anonymity that protected them from the judgment and stigma they would have experienced in their country of birth.

I feel more comfortable to live here in Australia rather than in Thailand (...) Western culture they not care much about personal matter, you know. They don't have a gossip culture like Thailand. So I feel more comfortable here (...) and no one care about your personal life, you know, and they respect you more. Discrimination law here says so (...) In Thailand, even if one person knows, I can be on the front page of the paper because of [details withheld].

*(Thai gay man)*

However, there was also a feeling of being torn between living in Australia, where they had privacy, health care and support, and the close emotional ties with families and friends in the country of birth, even in the case of those who had settled in their new lives.

I miss my nephews, my mother. I love my country but I don't miss my country because I'm gay, because my culture and the life in Colombia is so difficult. Because we got a lot of problems: guerrilla, mafia, corruption. So you always scared about

someone behind you (sobs). It's not a happy life. Here is peaceful, everyone respect each other (...) I haven't got all my closest friends and family or my partner. So I feel alone. I know so many people but I haven't got real close friends. (...) I love this country. I got a lot of support but I don't feel able to go back and live there [Colombia]. (...) Yeah, you have to deal with that. Because it's impossible to have everything. I got a lot here but something is back home.

(Colombian gay man)

Some felt guilty because they were unable to care for their ageing parents in their country of birth, and women with young children missed the support of their extended families at a time when their own health would deteriorate.

## Discussion

Being diagnosed with HIV as part of the immigration process means having to negotiate simultaneously two major life uncertainties: the uncertainty of living with HIV and the uncertainty of migration. It means being diagnosed with HIV at a time when life is already greatly unsettled and affected by trauma. Living with HIV is generally dominated by uncertainties: about health, treatment success, the future and the meaning of HIV.<sup>16</sup> At the same time, people who migrate experience high levels of uncertainty: the uncertainty of their legal status, including the fear of deportation, financial uncertainty, lack of facility with English and barriers to the use of health services. As HIV is interpreted in terms of experiences in the country of birth (where HIV is stigmatised, access to treatments is limited and survival times are short), the uncertainty of migration status and the possibility of deportation foreclose the prospect of a better future. In their country of birth, HIV infection would also become a terminal illness. Thus, two major life uncertainties compound each other.

Migration, settlement and acculturation have been described in the research literature as processes involving considerable stress: stresses include past persecution, uncertainty about permanent residency, language conflict, loss of social networks, loss of social status, social isolation, unemployment, lack of money, and concerns about survival generally.<sup>17,18</sup> Prolonged uncertainty about permanent residency, especially, can have negative impacts on health.<sup>19-23</sup> A number of complex social and emotional tasks need to be accomplished as part of resettlement: learning a new language, finding accommodation and employment, building new social relationships. When migration status is uncertain, these tasks are more difficult. People who are diagnosed with HIV as part of the immigration process have to deal with this news at a time when they are already experiencing high degrees of stress. At the same time, an HIV-positive diagnosis makes these tasks more difficult.

For refugees and new migrants, rebuilding social relations with ethnic and cultural communities is a key factor in overcoming psychological distress.<sup>18,20</sup> New migrants with HIV, who are still in the process of settling and building new lives for themselves, are caught between two conflicting forces. On the one

hand they need to build new social relations with their ethnic communities, but at the same time contact with ethnic communities is avoided for fear that their HIV status might become public knowledge. Thus, secrecy is a major constraint on interactions with others. However, building new social relations outside of ethnic communities is difficult because of a lack of English. This can result in a form of 'double exile' from family and friends in the country of birth, and from ethnic communities in the new country.<sup>9</sup>

## Conclusion

The lived experience of people with HIV in this study shows up areas in which improvements are necessary to provide effective care and support. Language, cultural and financial barriers to health and support services should be removed or at least minimised. The routine rejection of applications for permanent residency of people diagnosed with HIV as part of the health requirement results in a lengthy appeal process and high levels of uncertainty. This practice should be reviewed. The federal government policy of refusing Medicare coverage to certain categories of visa holders, some of whom live and work in Australia for long periods, is a barrier to health care access. This policy too should be reviewed. For new migrants, the support of their ethnic communities is vital for successful settlement. Therefore ethnic communities need to examine their attitudes towards HIV and HIV-positive people. They need to address stigma and discrimination to enable people with HIV to build relationships within their communities and ultimately to rebuild their lives in Australia. Finally, DIMIA's practices of conducting testing without offering counselling, and disclosing test results over the phone, are striking departures from best practice and raise important questions about DIMIA's duty of care to migrants as they negotiate the immigration system.

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