

Living with HIV and cultural diversity in Sydney: migration, gender and sexuality

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MONOGRAPH 1/2013



Living with HIV and cultural diversity in Sydney

migration, gender and sexuality

Never Stand Still

Faculty of Arts and Social Sciences

National Centre in HIV Social Research

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MONOGRAPH 1/2013

Living with HIV and cultural diversity in Sydney: migration, gender and sexuality

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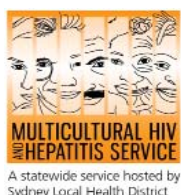
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Background

The aim of this study was to explore how living with HIV and being a migrant from an ethnic minority background interact and how these contingencies intersect with gender and sexual orientation in shaping the lives of individuals. It was a follow-up study to an earlier study which investigated the interrelationship of living with HIV and belonging to culturally and linguistically diverse groups outside the Anglo-Australian mainstream (Körner, Petrohilos, & Madeddu, 2005).

Some issues are faced by all HIV-positive migrants. Insecure residency status, language difficulties, and lack of familiarity with healthcare systems can pose structural and cultural barriers to healthcare for gay men, heterosexual men and women alike, and migrants with little or no English are less involved in making decisions about their treatment (Körner, 2007a). Furthermore, HIV-positive status disrupts social relations with family in the country of origin and with ethnic communities in the country of resettlement, and knowledge about HIV from the country of origin as well as culture and belief systems continue to strongly influence migrants' experience of living with HIV (Åsander, Belfrage, Pehrson, Lindstein, & Björkman, 2004; Körner, 2007a). People from culturally and linguistically diverse (CALD) backgrounds are also more likely to be diagnosed late and testing is more other-initiated than self-initiated (Asante, Körner, & Kippax, 2009; Körner, 2007b).

There are, however, differences according to gender and sexual orientation in the way people living with HIV (PLHIV) use health and social services. In a US study, for example, Caucasian gay men were more self-directed in their use of such services, while for Spanish-speaking Latina women access to services was driven by agencies (Takahashi & Rodriguez, 2002). In a Sydney study, women's use of health and social services was motivated by the collectivist notions of self-reliance and interdependence, while gay and heterosexual men drew on collectivist and individualist cultural norms in different contexts and for different reasons (Körner, 2010).

Another aspect of living with HIV that is intensely related to ethnicity, gender and sexual orientation is disclosure of HIV status. For women, disclosing HIV status is particularly problematic because of the stigma attached to HIV, concerns about burdening others, and concerns about discrimination (Körner, 2007c). African women in the UK who disclosed their HIV status experienced violence from their families (Anderson & Doyal, 2004). Black-Caribbean gay men in the UK, African-American gay men and Spanish-speaking Latino gay men in the US have much lower rates of disclosing their sexual orientation and/or their HIV status, especially to their families, than Caucasian gay men (Kennamer et al., 2000; Keogh et al., 2004; Mason et al., 1995).

Methods

Participants were recruited through the Multicultural HIV and Hepatitis Service (MHAHS), The Western Suburbs Haven, and word of mouth.

In semi-structured in-depth interviews we explored reasons for coming to Australia, use of health and social services, HIV diagnosis and treatments, social networks and relationships with family and ethnic communities, hopes and expectations for the future. For heterosexual participants we also explored experiences of parenting, and for gay men their experiences of being gay in the country of birth and in Australia. Interviews were conducted in participants' language of choice. Those who wanted to conduct the interview in their mother tongue could have assistance from an MHAHS co-worker. With participants' permission the interview was audio-recorded and interviews were transcribed. Participants chose or were given a

pseudonym and identifying information was removed from the transcripts. All names mentioned in the interviews were changed. Healthcare services and HIV organisations were de-identified to preserve confidentiality of the individuals who used these services as patients or clients. As the number of participants from each country was small, we replaced country of birth with regional descriptors, for example, Africa, Middle East. Transcripts were coded for major themes (Braun & Clarke, 2006). These themes form the basis for this descriptive report.

The study was approved by the Ethics Review Committee (RPAH Zone) of the Sydney South West Area Health Service, the Research Ethics Review Committee of ACON, and ratified by the Human Research Ethics Committee of The University of New South Wales. Written consent was required for participation.

Description of sample

Twenty-seven participants agreed to participate: 12 gay men, 7 heterosexual men, 7 heterosexual women, and 1 transgender woman. It was a very diverse sample. Participants came from 18 different countries of birth: 12 from countries in Asia, 6 from South America, 6 from Africa, and 3 from Southern Europe and the Middle East. Age ranged from 22 to 59 years, with a median of 43 years. Participants had arrived in Australia between 1978 and 2009: 2 came in the 1970s, 4 in the 1980s, 10 in the 1990s, and 11 in the 2000s. Three participants had lived in New Zealand before they came to

Australia. Participants came to Australia under very different circumstances and for many different reasons: as adolescents with their families; as skilled migrants; to study; to join family members; to join a partner; as refugees. They wanted new experiences in a new country; a better future for their children; and some gay men left their country of birth because homosexuality was socially unacceptable or against the law. At the time of the study 21 had permanent residency or Australian citizenship and 6 were waiting for a decision about their application for permanent residency.

Findings

1. Access to services

1.1 Health services

1.1.1 Testing and diagnosis

The vast majority of participants were diagnosed in Australia. Five participants were diagnosed overseas: during return visits to the country of birth, in refugee camps, and during pregnancy. Two gay men had been diagnosed in the 1980s, 11 in the 1990s, and 14 since 2000. There

My sister told me to make a test because, 'I don't know what happen with you.' And that time I lost too much weight. And that was the reason. ... My sister say to me, 'Come clinic health [Sexual Health Clinic D].' (Pedro, GM)

Only some of the recently diagnosed gay men described symptoms of seroconversion and requested an HIV test of their own accord.

I always got sick if I went on planes ... the flu and whatever you get, I suffer. ... And my throat usually, everything ends up in my throat. And I thought that's what it was but after having a really strong dose of antibiotics and antiviral medication I thought, 'I'm gonna go to my proper doctor,' because I went to the local doctor in [western suburbs] and, of course, they have no clue. ... My doctor is in [high HIV case load general practice]. ... So when I went to my doctor and gave him the symptoms, he knew. ... But anyhow, the next day we found out that it was, or the next two days that it was, yeah. (Diego, GM)

At the time of the study six participants did not have permanent residency. An HIV diagnosis on its own causes considerable trauma, however, for participants who did not have permanent residency the trauma of a diagnosis was compounded by the uncertainty of their residency status and the implication that HIV-positive status would have for their future in Australia. They felt paralysed and unable to make decisions. Returning to the country of birth was not an option. For example, there were obligations to the family.

I was too depressed and I even thought of committing suicide because that's my motive to come to Australia to become a [health professional]. Now I don't know what my future is. The main thing I'm still alive is my family. I just want to be there for my family. So I came back to Australia and I thought of applying for immigration but there's a problem with immigration when you're HIV-positive. They refused my application. (Surush, HM)

'It became all about the residency. ... So it was very hard to kind of grieve about your diagnosis ... and at the same time think about logistics and think about immigration.'

was little evidence of self-initiated testing among those who were diagnosed in Australia. Testing usually happened either as part of the health requirement for a visa, or in hospital with HIV-related illness. In addition, for women one reason for testing was issues around a husband's HIV status.

He didn't tell me and say, 'I have HIV-positive.' But he give me. Some people tell me, say, 'This man have disease.' I say, 'You have disease?' He say, 'No.' 'People tell about you. Say you have disease. You say no.' I run to my doctor. I say, 'Please doctor, I need check.' He take blood test. After I sit down my house at ten-thirty, telephone, ring me. He say – I'm surprised. 'What's wrong today? My family doctor ring.' He say, 'Come down.' I know it. I have this disease. I run to doctor. Doctor say, 'You have HIV-positive.' I collapse. I didn't know what I – I go to [Hospital H]. He admit me. He say, 'Again, another blood test.' Same. He say, 'Sorry.' (Aysha, HW¹)

Another route to HIV testing when someone experienced health problems was through a family member who knew where to get a test.

1 HW = heterosexual woman; GM = gay man; HM = heterosexual man; TW = transgender woman

Another matter of great concern was the lack of appropriate care and medication in the country of birth.

You get the worst class of medication there and they don't get a lot of funding for medication from the government. And it's a battle, really. Socially and medically, and everything it's a battle. So the option of going back to [Middle East] was definitely something that I was not thinking about at all. (Youssef, GM)

In addition to the practical considerations related to residency status there were psychological consequences; the concerns about residency disrupted coming to terms with an HIV diagnosis.

It kind of interrupted me from grieving about the fact that I'd just got a disease and that I have to look after myself health-wise. It became all about the residency. It became all about where I'm gonna be in the next couple of years. Am I gonna go back to [Middle East]? ... So it was very hard to kind of grieve about your diagnosis and the stuff that needs to come up when you actually get a diagnosis and at the same time think about logistics and think about immigration. It was really, really, really frustrating and very painful. (Youssef, GM)

1.1.2 Access to healthcare

All participants, irrespective of their residency status, had an HIV doctor. Only a few of the gay men used general practice clinics with high HIV-caseloads. The vast majority of participants attended HIV clinics in hospitals and sexual health clinics. Some participants had had only one doctor since their diagnosis and had very long standing relationships with their HIV doctors. Continuity of care was important to all participants. They wanted to be with one doctor who knew their history, especially their history of HIV treatments and other medications.

I have seen different doctor most of the time [at the clinic]. ... I wish I have the same doctor but because of the service they're changing. Every doctor who came to see me always ask me what sort of medication I'm taking and I don't know the name. I can't tell them. If I knew the different doctor I have to take all the name of the medication with me. So hard for me. ... I used to take for my palpitation medication. And they ask me how many gram. How do I know? (Sophy, HW)

About half the participants had a general practitioner for their general health needs, had informed their GPs about their HIV status and had good relationships with their GPs.

He trust me. For example, I'm not sick but if I don't wanna go to work, my body sometimes, really so hard. So I never lie to him. Just, 'Today I'm tired.' 'Okay, you need a rest. How many days do you need today?'

So he trust me. And before we start about the health conversation he tell about his mum, his wife, his daughter. Just have been holiday. 'How was your week? How have you been?' ... We always talk about our daughters. (Liya, HW)

The remainder used their HIV doctor for all health needs. One reason for this was ignorance about HIV among healthcare professionals and potential stigma.

[Doctor at high HIV-caseload practice] is my GP as well. ...

So you don't have a local doctor?

No, no I wouldn't. I wouldn't. There is a lot of ignorance out there with doctors when it comes to HIV. It's just amazing. Even emergency departments. ... Doctors, they have no clue, no clue. So now I restrict all my medical visits to my doctor [at high HIV-caseload practice]. (Diego, GM)

One gay man did, in fact, experience ignorance about the transmission of HIV from his family GP after he was diagnosed.

My GP ask for test for everyone at home. So HIV test for my sister, my brother-in-law, my two nieces. ... my sister inform me that all at home need a test because the doctor asked for that test.

Was that a GP?

Yes, my GP. GP of my sister and my family here too. ...

Was that an Australian doctor?

Yes. Australian doctor. At first I was very annoyed for that but I was thinking about that. I think, I strongly believe that it was my brother-in-law or my sister who asked for that test. They wanted to offend me. (Enrique, GM)

While all participants received medical care for HIV, other health needs could only be attended to after participants had permanent residency, which in the following case took 14 years. Access to Medicare made a big difference to the kind of care and services that were available.

You have residency you don't worry anything. And I got a green card [Medicare card]. Anytime I go to GP, go to seeking for the doctor, I don't have to worry I don't have money to pay. Just put my card, Medicare. And like I say, I'm lucky. A lot nice people, good people around me. ... And in the hospital, if I got a problem like this no good that no good, my tablet no good or whatever, then also good, you know. ... So seems like everything is going smooth. I'm getting exciting. My bottom gonna get cut [surgery] and my teeth gonna get fix. So I think is so exciting from that point of view. (Johnny, HM)

1.1.3 Relationship with healthcare professionals

Participants had good relationships with their doctors. This encompassed medical care but also social and

‘I think I die in the hospital. So when I say to the doctor, “I die,” the doctor said, “No, I’m not going to let you die.” ’

interpersonal matters. One important issue here was being treated by the doctor with respect and without moral judgement.

Good. ... I feel very confident. I feel very comfortable. They ask me with respect. I feel not discriminate, you know. That was very important for me. So I’ve been well treated. Yes, I feel very good. Very good, yeah. Positively. Yeah. (Enrique, GM)

The positive experience with doctors in Australia was quite a contrast compared to experiences with doctors in the country of birth.

Is good. I like because I have experience, I have experience about this now in my country. In my country is very hard because I, I ...

Co-worker translating: In [South America] was different because ... I fight. I argue with all the doctors and nurse. But here it’s completely different. I don’t feel well because in that time I saw people dying in [South America]. Go to the clinic and wait for a long, long time. And at that time make stress to me a lot because I was there and I tried to get some service but I didn’t get really quick. That made me to be, feel more stress. Here it’s totally different. ... Here the doctor are very, very professional but the doctor I saw in [South America], he was very strict and, with all the medication, everything. (Pedro, GM)

Participants appreciated that doctors talked to them on a basis of equality rather than from a hierarchical perspective. They felt their doctors listened to them and respected their decisions.

She talk to me ... is like sister. She’s talk to me say politely, ‘Aysha, this, this, this.’ ... She say, ‘Do like this, like this. You don’t die.’ ... She good for me. Until I meet him [her] from day I’m positive ... Very good for me. Yeah. ... I talk to her. I say, ‘I’m not going [to counsellor].’ She say, ‘That is your right.’ She say, ‘Don’t go.’ She say, ‘Okay.’ (Aysha, HW)

Participants also felt that their doctors took their concerns seriously, which gave them reassurance and certainty.

The doctor, both of them very helpful. ... When I feel worried about something, for example, with the bones, for example, when I went to the GP, say, ‘I want to do the bone density because I want to be sure. I have this worry.’ He say, ‘Okay, that’s fine.’ They please to me in that way. Then I feel comfortable.

So when you have a problem, they take it seriously?

Yeah. Not only problem. When I have a doubt about something, I worry about something, they want me to feel, they want to be clear that nothing’s wrong. At the same time they want to please me that way because I’m going to make the test and after the test I know nothing is wrong. I feel more happy with myself. And that is very important. (Roberto, GM)

Those participants who were diagnosed in hospital when they were seriously ill and who did not have permanent residency felt they were not being abandoned at a time of existential distress in spite of their uncertain residency status. Their doctor, literally, saved their life.

I think I die in the hospital. So when I say to the doctor, ‘I die,’ the doctor said, ‘No, I’m not going to let you die.’

co-worker translating: So he was very touched. (Bob, GM)

Some participants discussed only health and medical matters with their doctors, including those who had long-standing relationships with their HIV doctor. For others, the relationship with their doctors encompassed also psychosocial and practical life issues. Doctors were an important source of support and for some new migrants this included settling into a new life in an unfamiliar culture and a new language, and again, this happened from a position of equality rather than hierarchy.

She’s my doctor, just like my mum. ... She change me a lot. ... I’m not speak English in the beginning. So I was very shy. ... When she come to me, she’s not coming like a doctor. She come just friend. So she start to try to make me close to her. And I used to use interpreter in the beginning. So she stopped doing that. She tried to, she give me time to find me, yeah. So she really care about my health. Yeah. If I say something, she try different things. ‘Okay, try this.’ Try the counselling thing about my daughter. Everything. All my life. Not only my health. ... She’s the one, she guide me, you know. (Liya, HW)

Two of the women had had babies while living with HIV and one was pregnant again at the time of the study. They were very happy with the ante- and post-natal care.

I like them. [Hospital F] they’re good. There is no stigma there. I never seen anyone, like, who doesn’t want to touch me or what because I’m HIV. No. ... In the first time when I came in 2008 it was C-section because I came here late and they didn’t know how the

‘When she come to me, she’s not coming like a doctor. She come just friend. So she start to try to make me close to her.’

doctors were treating me back in my country. ... I came with my pregnancy when it was like seven months. So they think that that maybe will be dangerous. It’s good for me to have C-section. But now they say that I can have normal birth. So I’m going to have a normal birth with this. And I’ll not breastfeed. (Margaret, HW)

Negative experiences with HIV doctors and regular GPs were extremely rare. Only one participant reported that her concerns about having tuberculosis were dismissed by her HIV doctor. When she kept insisting on a test she was indeed diagnosed with TB. There were, however, some reports about stigma and discrimination from other healthcare providers: dental care, elective surgery, hospital emergency departments, and mental health services.

Some participants used mental health services and found counselling useful. This was particularly salient for those who had to deal with an HIV diagnosis, the uncertainty of their residency status and the uncertainty of their future in Australia. Counselling was also useful for some to deal with family problems, work, domestic violence, and disclosing HIV status to children. However, counselling was not experienced as useful by all. One problem was the perceived focus on negative aspects of life.

Sometime I feel if you go to, the more you go to see counsellor, the more you get depressed. It’s opposite. ... I don’t know. When you go to see them, they try to make all the negative point, make you feel sorrow, make you feel sad. And you get more deep down and when you ignore, when you ignore them, you don’t see them, and you put it behind. ... The more you doing it the more it make you feel you are not right, you are not normal. ... They always ask you the bad thing and when you talk about a bad thing, you start more sad. (Anh, GM)

There was also a clash between the line of conversation that a counsellor wanted to pursue and what a participant was really concerned about. In this case the MHAHS co-workers filled the role of a trusted confidante.

My counsellor is very rude. I don’t want to talk to him. Man, he talk too much. My head is not coping. ... He think another thing. ‘All my children.’ All the time, ‘Who look after my children?’ ... My head it work in this one. He talk too much. I say, ‘I’m stop now. I’m not going.’ Only with Lateefa [co-worker] Yeah, she good person. I meet her. She [I] work with her and my doctor. (Aysha, HW)

1.1.4 HIV treatments

With one exception only, an African woman, all participants were on antiretroviral treatments. Starting treatment, especially for those who had experienced ill health before they were diagnosed, was a real turnaround. Participants experienced a rapid improvement of their health; they felt that HIV was under control and that they could have hope for the future. With their health under control, a degree of normality had been restored and with that a sense of future.

But to my health, in two, in two months now I feel much better. Like my, I got energy back. I think that the, with the improvement in, in the medical, I think one day that they will kill my illness, I will get better. Yeah. (Hung, HM)

For some the decision to start treatment was easy. It meant better health and a longer life expectancy.

co-worker translating: When she went there, she didn’t know anything about the disease. So that doctor explain her about the disease or illness, about the HIV. And then she suggest the treatment but she didn’t press her to take it. ... She said to her that it was her decision about the treatment, but at the same time she said that the treatment give her more years of life or something. ... She wants to live more. (Monica, HW)

A powerful motivation for women to start treatment was the need to stay alive, and to stay strong and well for their family.

I was in shock. ... and at that point I thought, ‘I don’t want to live.’ [If] I chose not to take medication, I would be gone. ‘Maybe that’s the best way,’ I thought. But again, I have these small, my children were small when I came to Australia. And I have another four children ... And they all waiting for me. ... At that time, they were in Africa with my mum. So I had deep thoughts and I thought, ‘No, I can’t do it, you know. I have to stay alive for my children. I’ll have to stay alive for my mum. If I go, my mum, she will drop dead.’ ... And I start medication. (Mizy, HW)

However, there was also a perception that taking treatment meant being ill and being ill meant death was imminent. This was grounded in the experience of HIV in Africa and was a powerful barrier to treatment for one woman.

I saw in many people taking this medication ... kidney, liver, is people weak, bring down. That’s why I’m scare. Now my kidney fine. My liver fine. My heart fine. If I’m start medication maybe like those people, I have too weak. That’s why I’m scare. I pray Allah. I’m Muslim. I pray for Allah. I say, ‘Please, before I take medication, please kill me. I don’t want to suffer in pain.’ ... Doesn’t

work [Africa]. [Africa], no food. No water. No shelter. Is no work for that people. If you take that medication, if in your stomach is no food, ... it didn't work for that people. That medication, it kill people. [Africa] is poor country. In all Africa, poor country. This, most of them, HIV kill people in Africa. (Aysha, HW)

'At the time when I was waiting there was this theory that if you don't have to take the medication that it will cost Australia less. So it's actually stronger for your case. ... So we got to the point like I waited till the last basically, you know, last minute.'

Participants received HIV treatment irrespective of their residency status. For those who were not entitled to Medicare their doctors found other sources of treatment. However, access to treatment for those who were not on Medicare was precarious and could cause considerable financial strain.

co-worker translating: [The doctor has] basically knocked on every door he knows around to get him free medication up to December this year. So his medication is free until December this year.

And what happens after December this year?

He'll have to get them himself. The doctor said to him that there is a program that will be able to fund medicine for non-permanent residents for free for them. So, but they are still waiting on confirmation of that. He doesn't know yet. But if that's not the case then he'll have to pay for the medicine himself. (José, HM)

Uncertain residency status did have some effect on the decision to delay treatment in order to improve the chances of meeting the health requirement for permanent residency.

At the time when I was waiting there was this theory that if you don't have to take the medication that it will cost Australia less. So it's actually stronger for your case. ... So if you don't need meds it's actually really good. So that was in my mind in a way and I'm like, 'Okay, well, I shouldn't be taking meds so my case for the immigration will be stronger.' But, at some stage, I actually really needed meds. So I was kind of like, 'Alright, what do I do now? If I start taking meds, is it gonna really affect my case?'

Did you discuss that with your doctor?

I have, yeah, yeah. So we got to the point like I waited till the last basically, you know, last minute. And then I had to kind of start medication because my, my body was telling me that I should be starting medication. Having that stress as well to start medication or not to start medication was also – (Youssef, GM)

Uncertain residency status and not having access to Medicare also played a role in the kind of medication a participant could obtain, and what was available in the circumstances was not necessarily the best medication for an individual's circumstances. With access to Medicare, there were more treatment options available.

And they put me now on the new medication, fairly good quality, which is because I have Medicare and I am a resident. I have to pay some money. It's 133 dollars as the other residents or citizen. So is fair. Everybody have to pay. But I believe the quality that I have for many, many years, more than ten years, this one is more easy to take and I think it's more powerful. (Johnny, HM)

Most participants, especially those who had been diagnosed more recently and who were on the newer drug regimens experienced few or no side effects, or no serious side effects. They reported that they tolerated the medication well and had no problems taking their medication.

co-worker translating: Just the first day when he started taking them. ... The one, the medication he takes at eleven pm, the first night he had it he felt dizzy and the whole room was spinning around. ... He had already been warned that this may happen, so – The doctor was quite surprised because normally most people who go on the treatment, the side-effects last for a week but in his case it was only one day. (José, HM)

However, gay men who had been diagnosed in the 1980s had had very bad experiences and painful memories.

My doctor every time I see him he beg me to take the trial for medication ... And when I started my life is completely upside down. I vomiting and – Do we have to talk to the past? It's really dreadful. (Anh, GM)

Adherence was perceived to be easy. Participants emphasised that they were conscientious in taking their medication. It was a habit that was incorporated into their daily schedules.

I'm never forget my medication. I'm always taking it. ... I never forget. I think maybe once, that's it. But the doctor say once is okay but not quite often. And I always take it on time. You don't have to but I prefer

to take it on time. Like now, if I go to start [my shift] one o'clock and finish like whatever finish, I'm take it with me, my medication, and take it there [at work]. (Greekboy, GM)

However, taking medication was also a daily reminder of HIV: 'Every day. When I take my medication. Every day. It's sad.' (Liya, HW)

Only a few participants, all gay men, took the initiative to inform themselves about treatments and side effects, either from the internet or from their doctors.

That was another worry as well. Am I gonna get side-effects? Am I gonna be feeling terrible for the rest of my life taking medication? But it's actually really good. I don't, actually since, even from the first time I took them, nothing at all. And I think I take the kind of the new class of medication. And, as I said, also I was lucky to be working in [organisation] ... And so I was aware of what studies were going on and stuff for naïve patients. And that's one of the studies I was enrolled in. ... And yeah, so I'm still taking the same medication and I'm doing well. (Youssef, GM)

Some of the gay men were very involved with their doctors and proactive in decisions about treatment and their health generally

I do ask him if he suggests something and sort out pros and cons. What if I don't do it? What if I do it? So, and he's very honest about that. And he doesn't try to paint any nice pictures, you know. I mean he's – and then you make a decision, and if you don't believe it or you don't want to, you don't want to. (Diego, GM)

Heterosexual participants were tentative in that respect. For them this mode of decision making was still quite new. However, they were taking steps into that direction.

Doctor never push me. They help me. They explain how good or, you know, the good outcome if taking medication and I take it. And they never push me. ... like sometime the doctor mention to me about detox with drugs. They never push me but they explain to me it would be better for my health if I just quit, something like that ... we're talking drugs and cigarettes as well. I just say, they just give me – How do you say? 'If you stop smoking, what would happen.' And I say with drugs it's easy, it's easy, with drugs I can do it. But with cigarettes it might be difficult for me to quit so I cannot promise. But that is my choice. ... I decide to try for the detox, yeah. To start with I take the medication for the detox. (Tuan, HM)

And some were happy to leave decisions to their doctors.

I trust the doctors very much, so I just leave them to do their job. (Lucky, HM)

1.2 Social services and HIV organisations

Those who had been living with HIV for quite a long time and received the Disability Support Pension were very happy with the services they received. Their health and financial needs were met, they had secure and affordable accommodation, and social workers and case workers attended to a person's psychosocial needs.

I'm quite happy. I'm very happy how the Government look after the person like me. Still somebody comes see me and like everything alright. Things like that, you know. If I got something, a problem, I just tell them. If I don't have anything happen, we just enjoy each other's company. Go and have coffee. (Sarapong, GM)

Those who were entitled to social services from government and non-government organisations used these services selectively; they were willing and happy to work and provide for themselves if they were able to do so. Service organisations were used to fill the gaps that participants could not manage themselves.

The housing issue, those girls who are in [HIV organisation E] ... and also Marina and Maureen, they are still giving me ongoing support. So, in matters regarding contacting services like Housing, if I have any doubt about what's going on, I just go, or ring them and tell them and then they'll do that. That's what they're helping me. Otherwise the rest of the things I can do myself. I can do them.

What kind of things do you do yourself?

Well looking, for example, looking for a property, where to find it ... to rent. And regarding Centrelink issues and all this. So I don't need any social worker and the other thing, my psychologist at [sexual health clinic C] can also function the same thing whenever I have a problem. She can also do. But most cases I don't have that problem at all. (Robert, HM)

For new migrants and refugees social workers and case workers were important to provide information about services and entitlements, to connect and refer to services, and to help with paperwork.

I got a case manager ... So sometimes I used to call him for discussion and all that. ... He ring the doctor and find out how the treatment or the medication's going. If I need any help like accommodation assistance, all that. And he help me to apply for housing and all that (David, GM)

New migrants and refugees needed help in the beginning to enable to them negotiate organisations and services such as health, banking, accommodation, and social security in a society that was unfamiliar to them and very different from the countries they came from.

The first thing, the social worker, she helped me a lot. A lot, a lot. I told you, not communication, not nothing. She just know what I need that time. ... Someone has to guide me. So they found this person, the one, she's my family now. And then she's volunteer to help me. After work she take me how to use ATM. Like Medicare, what I, where I need to go. What I need. You know, just everything. ... So just yeah, these two people, they change my life. (Liya, HW)

Once these initial hurdles had been cleared, participants emphasised their independence of government assistance and their ability to support themselves.

I don't need [Centrelink] because I'm working. I don't want. ... No. (Liya, HW)

Those who were new to Australia and not entitled to social services because of their visa could be referred to organisations and services where they could get the support they needed irrespective of their residency status, and get support in their mother tongue.

Pedro: I start to see the social worker. Before I saw only the doctor. But then I started to see the social worker because back then I was so depressed and I didn't really assist the situation. Then I need to talk to someone. And then for that reason I start to see the social worker. ...

co-worker translating: I talk to her about the situation but she don't explain. She don't speak Spanish. So we look for interpreter. ... I told her that I don't have job. I just study but I don't have job. But the job is very important, very essential, and I don't have one. ... And she advised to me and she contact the Multicultural HIV Service here. (Pedro, GM)

The need for support and assistance with legal, practical and financial matters reached across gender and sexuality. Assistance with their application for permanent residency was of utmost importance for those whose residency status was uncertain. However, with regard to psychosocial

'I want to say that such service like Multicultural and the National Centre, that the way you guys doing things make me feel very warm. You are very careful about what you say, what you do. And then make me feel belong.'

support, gay men, heterosexual men, and women used HIV organisations differently. For heterosexual men contact with organisations for PLHIV was minimal and

revolved around legal and financial assistance. The only other contact was their MHAHS co-worker, and this one connection was very important.

I want to say that such service like Multicultural and the National Centre, that the way you guys doing things make me feel very warm. You are very careful about what you say, what you do. And then make me feel belong. ... Sometimes I do feel ... I don't feel lonely but I know people sometimes feel lonely. So those services actually make people feel belong. ... I think normally the people with HIV, they, because the HIV virus they actually feel quite alone. But with your services and the way you helping the people, that's why those people won't feel alone anymore. (Lucky, HM)

For some without extended family in Australia, their MHAHS co-worker was a substitute family, acting 'as a sister, mother, grandmother' (Lena, HW): discussing problems with adolescent children, supporting a women through her pregnancy and with a new baby, acting as a link between a woman, her children's school and the education system more broadly.

Co-worker: Mostly she ask me everything. Even read the letter from school. I explain to her about the school, how the school runs, everything. ... They come from a really completely different way of living. (Sophy, HW)

For others without family in Australia, the staff and clients of organisations for PLHIV had become a substitute family.

Before I don't have here [HIV community organisation E] I'm upset. I'm so lonely. I have HIV and no-one talking to me. And then I'm go to hospital ... So she pick me up to come here. I have fun here 'cause they're my family here. I have got problem I can tell them. ... [Maureen] help me everything. I got problem to see doctor she can talk to the doctor for me. Like this. (Samnang, TW)

One reason why most of the women in this study stayed away from organisations for PLHIV was the fear of gossip and having their HIV status disclosed. There was also a reluctance to associate with other PLHIV because they were a reminder that their own health might deteriorate.

In here, yes, it don't kill you but you suffer. Some people I saw [HIV community organisation A]. ... I saw people has brain damage. ... 'My goodness!' I say. That's why I stop now. I don't wanna go because I don't wanna see those people. If I see those people for one month, two months, I'm depressed. (Aysa, HW)

One notable exception here were a couple of African women. They used a variety of services provided by organisations for PLHIV to look after their physical, social and emotional wellbeing, for example, learning from other women how to look after their health.

I always tell them, 'You should not sit in the house and isolate yourself. ... They have women groups. Go there. Sit there. Listen. They are going to change your life.'

Isolating yourself is not good. Is so bad because if you isolate yourself you don't want to listen to others, how are you going to learn, you know? How are you going to learn how to take care of yourself? What to eat? ... How will you know what the best exercise to do? You should learn to them. You should learn. How did you live? How did you live with this virus for all those years, if you don't talk to them? (Margaret, HW)

Social contact with other women living with HIV was also considered important to combat social isolation and depression.

And then if you isolate yourself, you get, how is it called? Depression. You get depression in the house, you know. You feel sorry for yourself. And then, you know, it's not good to feel sorry for yourself. ... And that's what I always say to women. I always tell them, 'You should not sit in the house and isolate yourself. If you've heard of an HIV group, go there. Ask them if they have groups. They have women groups. Go there. Sit there. Listen. They are going to change your life.' (Margaret, HW)

Solidarity with other women was also a way of dealing with stigma that is still pervasive in ethnic communities.

Every time we meet there will be one person who's new, and pretty much destroyed. Still crying. But as soon they arrive there, have two times coming back, three times, they start to bubble, start to change. Start to, 'Oh my God, I'm not alone! We all together.' We support each other. But every day there is new story. Every day there is that stigma. Every day somebody saying, 'I'm scared to go outside. People will know that I'm HIV.' 'Who would say? It's not been written in your face, you know!' And they think, the isolation, you know. Scared to talk to their own people, or scared being discriminated because of their, their illness is there even though we are here in Australia. It's a lot of discrimination still going on, especially among families and the community. (Mizy, HW)

These African women were not content to look only after themselves; they actively encouraged others to participate in services and activities for PLHIV.

I help a lot of client who go to [HIV community organisation D], to tell them that they can have massage, free massage, free yoga, acupuncture. ... They also have ... women's day in [HIV community organisation D], which I did bring a lot of people. [laughs] I talk to people a lot. I convince them to come because I don't like people to be in depress. I see many people are really depressed and I'm like, 'Oh why do you have to be depressed when you can have people you can talk to, or when you can have somewhere you can cry as much as you want to and nobody will hate you for your tears? You will just get comfort. So come here!' I keep telling them. 'Come on!' (Mizy, HW)

It should be noted, however, that not all African women in this study participated in these activities (see, for example, Aysha above). For some, the fear of stigma and disclosure was stronger than the desire to meet other women living with HIV. They limited their contact with HIV services to their MHAHS co-worker.

Some gay men were very connected with organisations for PLHIV, but for others their only connection was through working for an organisation. For gay men who had complex health needs in addition to HIV, community organisations played a vital role in day-to-day functioning.

How long have you lived in this house?

This house, two years, approximately. ... I need to apply my case manager. ... [HIV community organisation A]

Do you get any services here in the house?

Yeah. ... My carer will cook for me from three o'clock to six o'clock ... Monday, Tuesday, Wednesday, Thursday, Friday. That's all. I will cook myself on the weekend and I will prepare my own lunch.... [HIV community organisation B] will drive me to various places, and [local government organisation A] will drive me to various places also. Appointment, gym appointment, physiotherapy appointment, hydrotherapy appointment, and doctor appointment, and eyes clinic, optometrist. (Stephen, GM)

For recently diagnosed gay men workshops for gay men living with HIV provided an opportunity to come to terms with their diagnosis, to gain a sense of hope for the future, and to connect socially with other gay men in the same situation.

I went to the workshop ... That was very good for me. Give me strong support when I need it. ... I think that was the most important thing that I did in my, all this time, yes. Yes, I strongly believe it. Yes, yes. When you are overseas, ... well it was in English, of course. But you need to speak with someone. That is what I need. I couldn't speak with my sister because, emotionally, I

wasn't, I needed someone who help me with his words. I need words to tell me, 'Look, there are possibilities.' I need that. So I found it.

Are you still in touch with any of the people from the workshop?

Yes. Yes, yes, of course. Actually, yesterday I meet with two of them. Yes. I went for dinner. Yeah, so it was a funny time. Yes, yes, we had a good time. Amazing. Amazing, yeah. (Enrique, GM)

'It was good for me because to speak with someone ... in my own language ... It's like all your ancestors is with you ... in my own language, it's more, it's deep. The emotion is deeper.'

However, language was a problem, and that's where the MHAHS co-workers fulfilled an important role.

It was good for me because to speak with someone in, in my own language is, is – what do you say? Different. It's – there's so much – your rules. The sound of your – if we say, look, I understand you. But in your own music. You know? It's like all your ancestors is with you. ... All your family, your brother, all your blood is here with you. Support you. That is why – And in English, well, it's a different language but I can't experience something like that. ... I think, in my own language, it's more, it's deep. The emotion is deeper. (Enrique, GM)

For recently diagnosed gay men whose permanent residency was in jeopardy because of their HIV status, a multi-pronged approach encompassing cultural support, legal advice, medical care and mental health was essential.

Okay, Multicultural Service in HIV and Hepatitis C. ... And then, well, a little bit with [HIV community organisation C]. Not much but more [HIV community legal centre G]. And [HIV health centre A] for medical advice. And also counselling as well. I saw a psychologist there on a regular basis, especially during the time when I was in limbo. She helped me a lot, deal with stress and anxiety around that stuff and cope with my life. Because I wasn't really feeling very well. And being in limbo also affected my health because of being in stress and the kind of waiting for the unknown and not knowing where my life was heading was actually really affecting my health. And I was actually sick most of the time, really. Not knowing whether I was sick because of depression or was it sick because, you know, my mind is affecting my body in a lot of ways. (Youssef, GM)

Some gay men who had been living with HIV for a long time had attended groups for PLHIV in the past but felt culturally alienated among Anglo-Australians. Simply having the same HIV status was not enough to connect socially and emotionally with others.

I did went to [HIV community organisation C]. And when you go there you get more isolated. ... Because even they are positive like you but they're not, they're not tell you anything and you don't want to tell them anything. Only the, the one who, who, who invites you to have a coffee and thing like that, they know you. ... You go there, you get more depressed too. Because I been there twice but I never, one of my friend told me go there. He's positive too. ... And I feel very terrible, depressed. Probably maybe different culture. They are almost western people or Australian people or whatever came from. But only two of us Asian. And you went to that positive centre, is you feel horrible. Very cold. ... That's why I never come back. (Anh, GM)

For some of the gay men in this study, the only connection with HIV services was through their work as employees or as volunteers, or through their HIV doctor. They had no other connections with the HIV sector and did not want such contacts. Social support revolved around family and close friends.

I've got my support around me. I don't need, I don't know that they genuinely care. Not that those people wouldn't care. It's another form of support, you know. A situation with somebody that's going through the same thing but I just, I guess I never had the need to. (Diego, GM)

2. Social relationships

2.1 Ethnic communities

Some participants who had not lived in Australia very long had extensive contact with others from the same ethnic backgrounds. These relationships revolved around friends from work or college and everyday social activities.

Pretty much everybody, at work, at school [is from South America]. ...

What kind of things do you do with other South American people?

Play soccer. ... Play volleyball. ... Activities at my house. Barbeque. (José, HM)

Social contact with others from the same ethnic background was also important for participants who had lived in Australia for some time but for whom English was a language barrier.

Did you have much to do with the Vietnamese community or other Vietnamese people in Sydney?

I met them a lot because I went to Cabramatta where is a lot of Vietnamese. So that's how I meet lots of Vietnamese there.

And what about Australian people?

Because I don't speak the language. So not really. (Tuan, HM)

In spite of frequent and close contact with others from the same ethnic background, no one had disclosed their HIV status. This was in part for cultural reasons, but in part also because of feeling good and healthy.

I don't really feel anything different. ... Because HIV is something I have to deal with it, so I didn't think it's necessary for my friends to know. All I concern is, for example, how the HIV actually pass on. So as long as I know how that works and how the things I don't really, yeah, tell my friends. And I think it's sort of in Chinese culture, you don't tend to say bad things to other people. So, for example, drug users, they don't normally tell other people they're drug users. So that's probably a similar scenario. Yeah, that's why I don't feel I need to talk to them about it. (Lucky, HM)

The MHAHS co-workers were a person whom participants could trust and in whom they could confide. This enabled them to maintain social relationships with others from the same language and cultural background and receive HIV related support in their own language.

co-worker translating: As for Multicultural, he's very happy that he has me because he finds a friend in me who he can trust and talk whenever he feels he needs to talk with somebody. (José, HM)

Some gay men socialised with others from the same ethnic background to some extent but were very wary of the stigma attached to homosexuality and to HIV in their ethnic communities and therefore kept these relationships to a minimum.

Not too much. Of course, friend of my sister or my brother, I visit them or they visit my sister, so I get on with. But I never speak about my condition. Obviously, I think they are homophobic.

Your 'condition', is that the fact that you are gay or that you're HIV?

Gay. ... As a gay man. ... And as HIV, it would be worse. So there are a lot of ignorance in my country. Especially my country. I don't know here but I guess there is a little bit of ignorance too, or lack of information about HIV condition. (Enrique, GM)

Some participants had little or no contact with individuals from their ethnic backgrounds but still participated in cultural activities, traditional celebrations and social events at the Buddhist temples in southwest Sydney. They observed customs such as offering food to the monks for the benefit of the ancestors' spirits and attended teachings.

I go to temple to learn about god. ... Talk about god, when to die, you make wrong, you good, if you good, you die you can go to heaven. ... I learn like that, yes. Don't make bad for someone. ... One days a week, the meeting. ... you know, every Saturday, Sunday. One days a week. ... Yeah, to learn and talking about the monk. The monk explain about 'Do like this, like this, like this.' (Samnang, TW)

And some stayed away from their ethnic communities altogether, had no social contact with individuals and did not participate in cultural activities and events. There was great fear about gossip in the community and disclosure of their HIV status.

Have you thought about moving to [city] and living with your family?

I don't want to because there is a big [African] community there. So most of them they came from refugee camp. And they know each other. We know each other. So they always think, 'She HIV-positive.' ... Because if you're, my family, they're allowed to come to [Australia]. They know if you fail the process it's because of the health. ... for me it's so hard. I got a lot of hurt in seven years in [refugee camp]. (Liya, HW)

Some had actually experienced disclosure of their HIV status in their ethnic community. One woman described how she was confronted about her status and how this shaped the relationship with her ethnic community.

I was replaced in immigration houses in [western suburbs]. I was living with other, three flatmates and they were all from detention centre. ... It was difficult to keep it from people. I had – we lived together. I don't have something to close the suitcase or something like that. So some of them I think started to read some papers and saw something about HIV, and they just went, tell everybody. And a man from [African] community who knows me ... he came and tell me, 'I heard you have AIDS.' I was so upset, you know. I said, 'So what? And if I have AIDS, what does it do to you?' We have an argument and I say, 'You know, that's not, it's inappropriate for you to come straight away and ask me if I have AIDS. It seems like a little bit of discrimination.' But I said, 'Look, I don't need to say anything to you and I don't need to prove anything to you, so, so be it.' So from then I thought, 'I have to stay away from my people.' (Mizy, HW)

While withdrawing from the community was a means of protection, there was also a sense of loss.

Do you miss contact with your own people?

Yes, yes, yes, I do, I do. And people really do respect me a lot here because I came with different attitude ... And I become really popular in [African] community. A lot of them knows me. Even some of them I don't know them, they already know me. So – but I just have that feeling, I better keep my distance. Just once in a while being with them it's a very good, it's a very good – I mean I will have a good connection in that time, good, respectful with the people. But I don't want to be often being with them. Of course I miss that. (Mizy, HW)

Some participants elaborated on the cultural values that worked against engagement of PLHIV with their ethnic communities. Asian cultures were centred around family and the collectivist notion of interdependence (Körner, 2007c).

I still think Asian country still learn from western, more open mind in the way like society and generous. ... See, I can talk to you more openly from my heart but I couldn't talk to my sister or my mother like that. ... I mean what the point you tell them? You make them worry. Because if you tell them, say, 'Look, I run out of money. Can you lend me five bucks or ten bucks?' that is you should tell them because you know they will give you, they will lend you. But something you tell them they can't help you and you can help yourself, what the point? You're wasting. You know what I mean? So if you have something good cooking, you have something, barbeque, whatever, you invite them, share with, you talk about bullshit thing and laughing, and keep them a good memory. But you cannot tell, 'Come down here. I've got HIV-positive.' You make them more miserable. And then when they're more miserable, they cannot keep it. They tell somebody else. And you rat shit. And they rat shit too. ... That is the culture of the Asian people. (Anh, GM)

In African cultures, values of Christianity and Islam and the notion of 'sin' were a strong force that worked against PLHIV engaging with their communities.

I tried to help him [ex-husband in Africa]. I talk to him. I told him, 'Go to see a doctor. Check yourself.' ... and he was like, 'Oh, no, no, no, no, no, no! I'm not a sinner! That's an illness for the sinner!' I said, 'Is not an illness for the sinner.' ... I think he knew. He just didn't want to say it. ... He just proud, you know. Didn't want to accept. You know, men in Africa, most of them, they are ready to die to keep their dignity instead of saying, 'I got HIV,' and start to find medication or the treatment. No, that is too much because everybody will know,

you know. And so they keep it until they get sick. Just passed away, you know. (Mizy, HW)

There were, however, also reasons unrelated to HIV and stigma for not engaging with ethnic communities. One such reason was cultural change in the country of birth, which had not filtered through to the ethnic community in Australia.

I find it very hard to connect with the [Middle Eastern] community here, especially people who actually were born here. ... I find the [Middle Eastern] community here in Australia very kind of attached to old values and old-fashioned kind of thoughts. And because they came ages ago and so they kept their kind, their values. And they're attached to old kind of cultural thoughts and stuff whereas being born in [Middle East], [the country] is evolving with time ... so I find it very hard to connect with the [Middle Eastern] people here. ... Countries change but the [people] here haven't changed. (Youssef, GM)

Another reason to stay away from ethnic communities was the desire to practise English, learn the Australian way of life and integrate into Australian society.

Mostly Asian people looking for a job a company belong to Asian people. But I'm totally the other direction. I'm mostly involved with Australian community or mix with European. That's how I can practising my English better. Yeah, I learn more Australian way than learn more bloody Chinese way. ... I don't like people come from overseas or even come from [Asia]. They don't bloody learn how to live in Australia. That's why I don't like. (Johnny, HM)

2.2 Family

Some participants had very close relationships with their families in Australia and overseas, irrespective of their sexuality and disclosure. Some had disclosed to some family members but not to others because they expected rejection. And some had experienced total rejection, for example, in African countries where homosexuality was illegal.

My family is in [Africa] ... No contact since I left ... I lose contact with them because ... I was gay and my family neglected [rejected] me. ... So I have to live by myself ... When you're gay your family, nobody accepts you ... They find out. That's why I was sent from home ... Nobody will even talk to you when they find out you are gay. (David, GM)

For other gay men, however, their sexuality was never an issue for parents and siblings. There was unconditional acceptance.

My parents never gave me a hard time. It was quite open. And in fact my mother, this happened way back in [Europe], my mother talking to, I don't know if it was a friend or my brother ... and she was saying, 'I wouldn't care if my child was gay.' I guess that stuck in my mind. Forever, really. (Diego, GM)

This unconditional acceptance by family was of central importance. In fact, family was more important than gay community or positive community.

What's more important in your life now?

My family. My family, my friends. I have very little patience for people that I wouldn't, like I have a simple question: Would I like this person in my life? To the same degree or to the same level that I have my friends of twenty years or my family? No. Okay. There's no middle ground there. (Diego, GM)

In this scenario, not disclosing HIV was motivated by consideration for the family. There was the stigma of HIV as a terminal illness and fear, but there was no stigma for the person living with HIV and no fear of rejection.

They would be very supportive. The real reason I don't tell my ... when you've got a mother, a [Latino] mother ... I ring every day, okay the first thing she says is, 'What did you eat? How are you?' ... and when she's like that, can you imagine me saying, 'Oh, by the way, I'm HIV-positive,' you know? 'AIDS! AIDS!' She will worry. She will die. ... To her it's got that stigma. Not because she would love me less or anything like that, no. She would just be so worried about me ... any cough ... we were having a bit of a hard week [at work] ... and I rang her today and she noticed from my voice that I was a bit down. She said, 'You look after yourself. Cheer up,' and all that. ... So you can you imagine if she knew I'm HIV-positive? No. I couldn't. No. That's the only reason I won't tell her. For her own sanity. Not because she wouldn't talk to me or anything like that.

And your brothers?

Just the same thing. The same thing. My family don't need to know and I'm healthy. ... I just get tired. ... But, you know, mum just says, 'You need to sleep more. You're working too hard.' It's like, 'Yeah, mum.' (Diego, GM)

A parent's perception of HIV as a terminal illness and worry was evident in Mizy's account of her relationship with her mother.

My relation with my mum is great, absolutely great. My mum she has no problem. She doesn't complain so much. She, I don't like the way she treat me. She treat me like I'm really, really sick, you know, which I don't like to be treated like that. Otherwise, she's fantastic. (Mizy, HW)

'... his wife was a great support for him because she made him realise that they had more in life to fight for, that the children were the reason ... and that they had to move on.'

Similar unconditional acceptance and support from parents, siblings and wife were forthcoming for a heterosexual man after his diagnosis. The family was sticking together, and apart from the MHAHS co-worker, his family were the people whom he could trust. Family unity was more important than HIV.

co-worker translating: At the beginning it was shocking. It had never crossed my mind that I was gonna be HIV-positive. ... he went ill for a week after he got the bad news. But then after a week of sulking and going sad he, his wife was a great support for him because she made him realise that they had more in life to fight for, that the children were the reason, and that that wasn't the end of the world, and that they had to move on. Also his family, his mother came to being great support because she said to him, 'No matter what happens, we're always here for you at all times.' (José, HM)

For some who did not have extended family in Australia, regular travel back to the country of birth was important to maintain the connection with the family.

I go back every year. I go back again at the end of November. ... I just wanna go away to catch up with all my nephews and nieces, and my sister, my brother, my cousins. ... Always [go] out. I got a big family. (Pablo, GM)

two years ago I'm go. ... visit my sister one month. ... I like it to see family and eating with my sister, my nephew. I'm very happy. (Samnang, TW)

While some had unconditional acceptance from their whole family, others had to be selective in whom they could confide. They had great support from some family members but were also concerned about disclosure by others, which would make a return to the country of birth impossible.

All my family has supported me. All push together. My brother. I have good family. ... is two brother in here I have. ... One he knows. One he helping me now. ... He give me some money. Now even he buy for me ticket to go to overseas with my children. He say, 'You happy. Before you die, I need helping my sister,' because he cry always. He say, 'Only me girl from all family.' ... Because if he lose me he don't have any sister. Forever.

And the other brother ... does he know?

No. He have bad wife. I didn't tell him. ... Because she's talking. She tell for people secret. She can't keep a secret. That's why to my brother, I didn't tell her. Say, 'Don't tell her.' Because she call in [Africa], she call, she tell her family. I can't go to [Africa]. People you can't shake your hand. You're scared from you to pass for people. That's what you do. Otherwise [I] can't go to see my family. That's what my brother say, 'Keep in your heart.' (Aysha, HW)

Having their HIV status disclosed by others with negative reactions was actually experienced by some. For example, there was avoidance because of the fear of transmission through social contact.

co-worker translating: It was her husband, the one who call her [cousin] and tell her about that. ... the cousin called her and asked her if it was true or not. And she said, 'Yeah, yeah, it's true.' So then ... the cousin was very sad and their relationship it wasn't like before. So [Monica] said that [the cousin] doesn't invite her to her home. So she said that after she knew that she invite her once and she was like with care about the plate in that she had the food ... And she was like washing the plate very careful because she was like scared about that. And she was, Monica was feeling very sad. (Monica, HW)

'I do feel the responsibility taking care of my parents ... I never stopped. Regularly I send money back home. So I do take care of my parents.'

Those who had regular contact by phone and email with family overseas chose not to disclose their HIV status. There was no need to disclose as they were healthy and able to fulfil their social obligations.

I often call my parents. I have quite good relations with them. ... I didn't tell them about HIV but they knew I was ill. They knew I got TB, yeah, but I didn't tell them about HIV. ... I don't really think my parents will understand much about HIV. I think that normally people will think HIV is actually deadly disease. Once you have HIV you are basically dead. So I don't really want to worry them. And obviously that's what other people think, and that's how I feel towards to my parents. ... I do feel the responsibility taking care of my parents and then that's what I'm doing now. I never stopped. Regularly I send money back home. So I do take care of my parents. (Lucky, HM)

2.3 Being gay

There were considerable challenges for gay men in their countries of birth. In some countries in Africa and the Middle East homosexuality was against the law and there were reports of having experienced physical violence and social ostracism.

Being gay in [Africa] is illegal. ... Being gay, when they catch you, you either go to prison, two years in prison or you'll be killed. ... Or attacked by any community people. People come [and] attack you and beat you up.

Has that ever happened to you?

Yeah, there were several times but I tried to escape and I find somewhere to hide until I left [Africa]. ... If you are gay nobody will like hang out with you, like friends or something like that.... they don't like it. Because they are scared. So they will not even come close to you. ... they will not even talk to you. Their family will not allow them to be friends with you because you are gay. ... Being gay in [Africa] is dangerous. You can go to prison at any time or be attacked any time. So it's very risky. (David, GM)

In some countries homosexuality was not against the law, however, the social stigma of homosexuality was huge. Heterosexuality was the social norm and middle-aged, middle class men were expected to be married and to have a family.

What was it like to live as a gay man in [South America]?

I think it's a little bit hard. Especially for people like me who belong in the middle class, who's a professional. ... it's something unthinkable that I'm a gay man. Especially because gay community there is not as open like here. Of course, they are not prosecuted. ... But socially is punished. Socially people don't think good about homosexuality or being gay. ... That is one of the reasons that I left my country too. ... society expect I've successful economically, have a family. It's not a law but ... the society expect from you be married with children, well established economically, you know. That is normal. That is, that is the correct. ... So it's quite problematic. (Enrique, GM)

Coming out to a parent could be highly problematic, however, over time there could also be change and, eventually, acceptance and a good relationship.

And it was even harder for my mother to accept. ... it was a big shock for her.

How did she react when you told her?

Very dramatically. She was very dramatic about it at first but then she got used to it with time. And the idea of me leaving [Middle East] kind of helped her, it eased

her pain a little bit. But it also changed her a lot. Like she's a different woman now, today, than the way she was when I first told her that I was gay. I mean I'm very positive about it. I see it as a, you know, a cathartic thing, in a way. ... And it opened her up to other things, to new thoughts, to new ideas about life for sure. (Youssef, GM)

When they came to Australia gay men appreciated the difference between the gay community in Sydney and their country of birth. They felt free, could be open, and did not stand out.

How do you feel about living as a gay man in Sydney?

co-worker translating: The difference is huge. You feel free. You don't feel any pressure. In [South America], the capital, the people is cold, is no friendly. But here is really friendly.

Pedro: I don't know. When I go different place, I saw different people like me, no? Doesn't matter. The people is no different but is, is good. Now when talk ... anything no is different. I like Sydney.

co-worker translating: I feel very good here. (Pedro, GM)

However, connection with the gay community could also be fraught with problems and ambivalence. While the gay community was important initially for living openly as a gay man, its importance decreased over time and more diverse social relationships became more important.

At the beginning, when I first came to Australia ... all my life was around that. It was around partying and going out and connecting with gay people and stuff because I kind of needed that. I needed to be accepted and, I needed to belong somewhere I guess, belong to a community. But it kind of faded through time. And I think I'm less part of one community. I'm more part of different kinds of communities. I'm part of a community at work, I'm part of a community, my friends, a bit of heterosexual, homosexual community. (Youssef, GM)

A similar attitude could be found among gay men who had come to Australia at a young age and had grown up here.

I've got my clinic, [general practice clinic A] there. That's my contact with it [Oxford Street]. Yeah. ... I might go for a stroll while I'm waiting for my doctor appointment. I don't know. It's all the same. ... Nothing's changed. Maybe different people, people have got a bit older. It's like 'That person shouldn't be doing this still,' you know. They should age dignified, with dignity.' So yeah, no, it's interesting, very interesting. ... oh look, we all have to experiment to get it out of our system because, you know, it's bad enough growing up. I think it's a matter of wanting more substance in your life I think. You know, it's a matter of having more important things in your life. (Diego, GM)

There was some connection with the gay scene through the pubs and bars on Oxford Street but not much social interaction with individuals at these venues.

co-worker translating: He goes to a bar but there's not much interaction. He's more in a way passive. If someone approaches him he's happy to talk but he's not very active in that sense. So in that way he doesn't feel discrimination or people avoid [him] or nothing serious like that.

Bob: When I go there I don't care who they are. ... They also don't care who am I. ... like you go there, have fun, everybody go there have fun. Maybe I'm interested in you. That's okay I just talk to you, like you don't, I don't talk to you, there's no point. ... Or maybe people just quite friendly, smiling. ... Like some people quite friendly. Just smiling. Then even though doesn't talk, then 'hello' and when you go to the bar all the time still see the people around, the same person. Say 'hello'. (Bob, GM)

Not all attempts to socialise in the gay community were successful, and as men got older and were living with HIV patterns of socialising changed and there were concerns about having to disclose HIV status.

The gay community in the beginning it was trying to get my friends in that area but right now I don't know, I really cannot do it. Before I was trying to go to bars, drink one beer and socialise with my friends but I don't know. Nothing really happened. ... I like socialise less than before. When I was twenty, I like to celebrate with everyone, going to parties all the time and I had more fun. Now I think all that change completely.

Do you think it has to do with the fact that you're now older or are there other elements?

There are other elements. One is older. Another one is my health. I'm HIV-positive. That change a lot, a lot, a lot in many ways. Then I think that's the reason because sometimes people ask me about my health or why I'm not working full-time. Then I have to lie all the time. I have to hide why not working full-time or why this, or why this, or why that. And I think that make me to hide myself. (Roberto, GM)

Some stayed away from gay community and other gay men altogether and preferred low-key social activities with straight friends.

I'm sort of gay but I play with straight person. [Play] like friend. ... talk to friend. Friendship. Most of the time I have straight [friends]. I don't really call it 'gay' you know. I go sometime but not all the time. I prefer to play with straight people. Because like too much gay, everybody know me one day ...

What do you do with your Australian friends when you play?

Just go visit, have lunch together. Go Paddy's Market and whatever. Just go for walk, things like that. Keep each other company. (Sarapong, GM)

2.4 Children and parenting

Children were a central concern and of central importance in migration and living with HIV. Some participants were separated from their children during the refugee process, and this was a source of considerable uncertainty and distress in addition to coping with HIV. Keeping the family together was very important for those who had a choice.

co-worker translating: If he had migrated [earlier], he would have had to leave his children behind and he didn't want to leave them behind. So he waited until the last moment ... and then once all of his family was here then he decided to move to Australia. (José, HM)

'What keeps him going is that he knows he has to get through somehow. And his main focus and strength are his children.'

On the one hand, the need to care for their children was a source of strength and the motivation to keep going, but at the same time worry about the children's future was also cause of considerable stress.

These two came, they came first. They were young. ... And my other kids came from 2002. They started to come one by one. Every three months. So yeah, I was absolutely difficult. I mean I, I had a great time when my children came but, at the same time, I was off my head. I could not think, you know. I couldn't – I used to smile a lot. I used to laugh a lot in my life but I lost all those kind of things. (Mizy, HW)

Disclosure of HIV status to children was a major issue and a difficult decision. For some, disclosure was out of the question. Disclosure of a parent's HIV status could have negative consequences for the children, but there was also great fear of negative reactions from children. This was, in fact, the experience of one woman whose adult children shared the common stereotypes of women living with HIV as promiscuous and morally deviant. However, with counselling and appropriate support, disclosing HIV status to a child could have positive outcomes. (For a more detailed discussion of women's experiences see [Körner, 2012]).

Three of the heterosexual men had children. Where the family was intact, the children motivated a man to stay strong and keep going.

co-worker translating: What keeps him going is that he knows he has to get through somehow. And his main focus and strength are his children. They are his strength.

What would you like for your children?

I like my children to have the opportunity to stay in Australia, them to become residents and to become professionals later on in life. (José, HM)

Other men became separated from their children after their HIV diagnosis, with no means to maintain contact.

I came to [country] and married my wife. ... My wife have my child in [country]. When my wife and my child reunite with me in Australia my child is about a few years old. ... then I have the HIV. When my wife find out I have HIV, she doesn't want to live with me anymore. ... Not legally divorced because when I sick my wife just took my child and walk out of the family. Then after that, I don't know where my daughter. I never contact with my wife after that. (Hung, HM)

3. Personal lives

3.1 Perceptions of health

Those who were diagnosed early and received HIV treatment perceived their health as being no different from their health prior to HIV infection. Once the shock of diagnosis had subsided and participants had been plugged into the healthcare system, life was perceived to be normal.

My health is perfectly alright now. I don't have any problem. I look perfectly normal and I live a perfectly normal life. And I don't feel any different. I don't have any complications. (Suresh, HM)

With accurate information about HIV infection, healthcare and psychosocial support, there was a feeling of control and some sense of return to normality.

co-worker translating: When she first knew that she was HIV she thought that was the end. But now she feel like everything is under control and she can do her life like normal person. Because ... the doctors and all, everybody spoke to her and said everything was gonna be fine. And they give information, the social worker, the doctors, so she feel that support from them. ... So at the beginning she thought that she was unable to live with her daughter but after all of this information she know that she can live with her. (Monica, HW)

Those who had experienced symptomatic infection experienced a marked improvement of their health after they received treatment, and with improved health there was a new sense of optimism.

I'm basically quite positive about the situation, So, my recovery is considerably quite quick. At the time I had HIV and TB medications that was the time I actually felt a bit more miserable. I didn't really feel very good. But once the TB finished I'm actually feeling quite good.

When you say you weren't feeling good, was it not feeling good physically or was that more mentally or emotionally not feeling good?

I basically just feel sort of physically I don't have enough energies and I was still coughing. And then at that time the only worry I had was that I didn't have a job. So I was trying very hard to get better and go back to work and make some money and make the situation better. (Lucky, HM)

‘... to be honest with you, from 2002 I don't think HIV is no longer is issue, in my point of view. ... [Now] the issue is the living, not the virus.’

For the gay men who had been diagnosed in the 1980s, there was no such sense of normality, however, there was a sense of stability and control.

I'm happy where I am now. I'm still alive. I always eat my food anyway, you know. I'm still, my T cells are undetected. Always controlled. (Pablo, GM)

An important step in living with long-term HIV infection was a shift away from the HIV virus to a focus on simply living.

How is your health now?

Extremely good. I got no cholesterol, no nothing at all. ... since 2000, 2001, or 2002, from now on I don't have any cold, flu, anything. ... I look better than before. ... to be honest with you, from 2002 I don't think HIV is no longer is issue, in my point of view. In my thinking it's no longer issue. [Now] the issue is the living, not the virus. (Anh, GM)

While some participants living with long-term HIV infection needed and received the Disability Support Pension, others rejected the need for a pension, indeed

rejected the very notion of ‘disability’. These participants were not only able to work, they wanted to work. There was a perception that only people who were really sick did not work. Healthy people could and did work.

I can't get that [Disability Support Pension]. I don't even want. I don't think of that. Disability? No, I have no disability. [laughs] ... I have some of my friends in African group. We always say we don't have disabilities. We are strong. We don't get sick. We don't have disability. We need work. ... when I was not pregnant, I was working as a cleaner. ... If you see me working there is no difference between me and someone who's not HIV. (Margaret, HW)

In addition to rejecting the label ‘disability’, for heterosexual men there was also the role of provider for the family.

In the first place, I don't want to be dependent. I want to get a job. I don't consider myself as a disabled person. I wouldn't like to be called ‘disabled’ and ‘invalid’. When I first see the letter written to me as a disability support pension, there's a word included in bracket ‘invalid’. I'm not invalid. [laughs] I say to myself, ‘I'm not a disabled person. I'm still able. I can work and earn and support myself.’ And I still have a vision not only to support myself, but to support others too. (Robert, HM)

A good health status was also used to counter gossip about a person's suspected HIV status and to confront ignorance about HIV as a terminal illness.

If they come to ask me [about my HIV status] those are the questions I'll ask them. ‘For how long have you known me? How many years?’ ... And then, ‘So, have you ever heard that I'm admitted to the hospital because I'm very, very sick, I'm dying? You only just come to see me in the hospital if I'm having a baby, that's all. But without that, no.’ (Margaret, HW)

However, while participants generally felt their health was good at present, there was also a concern that this might not last.

[If] I'm very sick, maybe I move from Cabramatta. Maybe I live around here. But now I'm still okay. If I'm very sick, ... maybe just come in here. ... I think in the future maybe I'm very sick. What can I do? Nothing. ... The same my sister. She work so hard. She work, leave [country] 1975. ... she got cancer lung ...

And she died from that?

Yeah. Look, for nothing, is gone. In the future, my sister doesn't know. Same me too. (Samnang, TW)

3.2 Outlook for the future

With their health being under control, there was a general sense of optimism about the future. Some participants had specific plans. Others focused on the present; the future would take care of itself.

I don't really think about that much. I feel like every day is a good day. And then I think that will make me, make myself happy every day. ... No, I don't really think about that much in the future. As I say, every day is a good day. I'm just sort of enjoying myself and then obviously Australia is a new country and I'm still trying to get used to the lifestyle and that sort of stuff. But no, I don't really think about, too much about future. (Lucky, HM)

I think I'm gonna have a really good life. Hopefully. And I see myself healthy for very long time. I don't think I'm gonna die with HIV anytime soon.

Specific plans for the future involved looking for work and getting Australian qualifications for a new career.

I'm studying ... I just finish, last semester I finish and I passed all of my subjects. ... Just start slowly by slowly and you move slowly by slowly because I want to do [health profession]. I want to be a [health professional]. I talk to my doctor and she said, 'No problem. You can be a [health professional]. Don't worry. Just go for it.' So that's what I want. (Margaret, HW)

Optimism reached beyond a person's own future to include using their own experience to help other PLHIV who were less fortunate.

I think I'm gonna have a really good life. Hopefully. And I see myself healthy for very long time. I don't think I'm gonna die with HIV anytime soon. And hoping, I'm hoping my job to pick up. I like to work. I like to be busy. I like to do something good for other people. That's my dreams. I like to help people with HIV. I like to move on little bit higher, maybe even to be able to have my own maybe organisation maybe to help children with HIV, to help women with HIV from here, Australia, to overseas. If it happens, you know. That's my dreams. (Mizy, HW)

For heterosexual participants a positive outlook for the future also involved new intimate relationships. Some had already found a new partner and had plans for a shared future.

I meet him [country]. ... I go in hospital, in HIV place. I saw him. He, he's shy and because he's, he's sick, he's shy. And I say, 'Don't shy.' I say, 'What's wrong with you?' [laughs] He say, 'No, nothing.' He say, 'Why you come here?' He say, 'I'm TB.' He say, 'No, this place is not TB. This place is this disease [HIV].' 'What's happened to you?' I say, 'I'm car accident,' he say, 'blood share,' you know. ... He get from that one. He say like this, I say, 'Okay.' So we talk from 2006 or 2007 by telephone. Finally my mum she say, my mum she knows I have this disease. She say, 'Marry this guy to live with him because you alone is no good,' she say. (Aysha, HW)

Others realised that they would be living with HIV for a long time, so they wanted a partner to share their lives with.

If you think about like you look at me today ... Okay, I'm HIV-positive. But anything wrong with me? Nothing wrong. I have my hand. I have my mind. I have my eyes. Everything. I have my heart. I still have my genetic or some stuff like that. I still can make baby. Nothing wrong. The only thing I just have to have a good, safe sex. That's all the point. I don't give my blood to you. Simple. I'm human being. I can give you the love more than people can give you. So what's wrong? Okay, you say, 'You are sick. I'm worried.' Come on! We live in Australia! Fourteen years I can survive. You worry I gonna die in next two years? I don't think so. This country look after me very well. (Johnny, HM)

However, starting a new relationship with a partner from the same ethnic background was also problematic because of disclosure and the perceptions of stigma in the community.

co-worker translating: She would like to remarry and has discussed this [with her MHAHS co-worker]. But he has to be 'Mr Right', and the problem is disclosing her status. Finding someone is not a problem. The problem is when and how to disclose. (Lena, HW)

However, while the outlook for the future was generally positive as far as health and physical wellbeing were concerned, the uncertainty of residency was a considerable obstacle to feeling positive about the future.

I went through fourteen years in my life by myself. I feel a lot painful, until today I can feel joyful, you know. So I will do anything. I'm tough enough. I used to don't have money. I used to eat instant noodle a week. I used to move from [northern suburbs] to [western suburbs], to [inner city] anywhere. So that's why is my dream, I want to have one house, even a small one, that's my own house. And if I can make it true, I think I can enjoy my life in peacefully. No-one annoying you. You

don't have to move. You can start buying thing to put in your own house. You don't have to thinking next time you have to move, next time someone kick you out or whatever, you know. But that is a bit hard to make it happen I think. (Johnny, HM)

Years of uncertainty about permanent residency also meant that any professional plans had to be put on hold. With residency resolved, thinking about the future and how to define oneself professionally had to be worked through.

I think HIV and my diagnosis and the whole immigration chaos that I experienced before was like an interruption of a process that I was going through. ... like a bad accident that happened. And that's why having my space at the moment, it's allowed me to reconnect with myself and try to figure out what I wanna do in life. ... Although I've got a good job and stuff like that and I'm really enjoying it at the moment but I haven't really defined myself professionally yet. And I may, I may not, you know. I might just need to accept the way things are but ... I would like to professionally, mainly, to have a little bit more clarity about my role here in life. (Youssef, GM)

However, while participants were generally optimistic about their health, there were concerns about their ability to provide for their children's future.

My future might not be that bright because I can't go to work. I don't have enough money to buy a house. I wish I can have a house and keep it for my daughter. At the moment, I try to save up bit by bit. (Sophy, HW)

3.3 Self-care and coping

Strategies to look after physical health and wellbeing included eating healthy food; exercising, even if it was only walking; getting enough sleep; not smoking; drinking no or very little alcohol; no drugs; no late night partying; avoiding stress, and taking HIV medication. A central theme here was routine, and HIV medication was integrated into this daily routine.

In the morning, I go to swimming pool. To swim, do something in the water, exercise in the water, yeah. Only thirty minute and come back, drink coffee and take tablet. ... Every, every day. (Samnang, TW)

Exercise also played a role in recovering physically and psychologically from HIV-related illness.

I'm doing the gym at the moment. ... Earlier when I was a bit ill [with TB] and when I was on the medications, I try to walk long distance, to exercise. So I'm trying to keep the exercise going. And then I can manage to have a better health. And the same time when I was the

driver [when I had a car] ... certain times I decide not to drive. So I would walk long distance as well. Just keep the exercising going. So, for example, when the time I was quite ill on the medications, even though walking stairs that was quite difficult. So I actually try to push myself walking stairs more. ... That's how I trying to push myself to exercise more. ... So now, everything is quite good. I can actually run now. ... I can jog. I love exercise a lot but before, because I was ill, but now I'm getting everything back. (Lucky, HM)

'I'm not going bad place ... to depressed. I have to look after myself. ... I say, 'It's happen. It can't go away from [it].' ... I have to accept this disease.'

Acceptance was one important step in regrouping after diagnosis and thinking how to live life with HIV. It involved accepting the fact of being HIV-positive, and accepting oneself. For gay men who had usually practised safe sex accepting their HIV-positive status was a difficult step but one they knew they had to take.

I always was very care about my health. Previous all my test was negative. But here something was wrong. ... So I say, 'Oh my god, why? Oh my goodness me! No, it's not possible!' Sometimes I can't believe it. That it has happened to me! No, no. But it's a fact. I accept my reality. ... I have to accept my reality that I'm HIV-positive. Yes. That is the best thing that I have to do. Accept my condition. (Enrique, GM)

However, acceptance was not passive or fatalistic but the foundation for dealing with HIV and looking after their health for men and women alike. Acceptance would lead to agency.

As for the HIV virus, I'm basically just face it. It's the thing I have to deal with, that I have to make sure I'm getting help and healthier. ... In the beginning I'm taking about twenty or more than twenty a day! So, but it's, what I think it's attitudes and mentality towards to the disease. And ... I just have to deal with it. That's all. I was very, very skinny. I was under forty-five kilos at that time. So I looked like, you know, those refugees in Africa? That's how I looked like. (Lucky, HM)

Now I stop any medication for depressed. ... But I'm no going bad place ... to depressed. I have to look after myself. I have to tell for myself because I say, 'It's happen. It can't go away from you.' What do you do? I have to accept this disease. (Aysha, HW)

For gay men acceptance involved not only acceptance of their HIV-positive status but also acceptance of difference: their sexual difference as gay men, and their ethnic difference among Anglo-Australian gay men.

How do you feel as a gay man from an Arabic country in the largely Anglo-Australian gay community?

Now I feel great about it. I feel like I'm proud of it in a way. ... I'm proud of my, the fact that I'm different now. But also I'm proud of the fact that I've kind of, I think I have more personality now ... it sounds a bit weird but I kind of, I appreciate myself a little bit more. Because I went through a phase where I hated myself and I like the fact that I'm different, you know. Not just different, not just different because I'm [Arabic] but also different because I'm a different [Arab]! Because I feel different even in my [Arabic] community in Australia. So yeah, I've kind of learned to [laughing] to be more accepting and liking myself a little bit more. (Youssef, GM)

While acceptance of HIV status was important for dealing with living with HIV, thinking about HIV and worrying about it was considered to be avoided. The focus was on not thinking about HIV and living like a 'normal' person. However, this insight did not come easily but only after years of living with HIV.

I didn't want to keep in my heart that I'm HIV. I try to put away, not to think about it, which it did help me a lot. I think many people with HIV, they do go down when they think always that they are HIV. 'Oh, what is gonna happen next?' Or, 'How long I'm gonna stay alive?' That was not in my head. Maybe at the beginning, yes, but later on I learned that I'm fine. I have to take out that HIV words in my head. I have to live like a normal person. Just not to think like I'm HIV. When I get flu I know I will be like double sick like as a normal person. But again I will just think, 'Oh it's just a flu,' you know. Not because of HIV. Of course I get really painful more than other people, sometimes, but I'm trying not to think HIV. Take it out of HIV, you know. It helps me a lot not to think about HIV. Just go on, move on with my life. ... I know I have to take my medication. I'm thinking my medication – somebody told me a while ago, 'Just think you are taking vitamins.' So I'm always thinking, taking vitamins, that's all. So I'm not taking medication of HIV, just take medication, your vitamins, daily vitamins. It helps me to go on. (Mizy, HW)

The thing is I only can tell, I can tell this service or tell this subject, to advise someone who got to live with strong mind, positive thinking. And do not think you carry the virus. You have to thinking what you carry to do for the next morning. But you do not thinking you are carry the virus in your blood. If you want to, if you

really down, you go out, take a walk. And thinking lots of thing or even you sit down and have coffee, and then you go and turn the music on or you go to movie. Or you find someone who really close friend, sit down and talk. And enjoy coffee or even have a dinner. And then the next morning you feel okay. ... You don't need to tell them you got a virus or anything. And day after day you will forgot about who you are and you think you just back to normal. That's what I learn for last ten year. (Anh, GM)

Participants emphasised that they focused on the positive things in their lives. They considered themselves lucky for many reasons. They felt lucky to be living in Australia without war, civil war, street violence, a country with political and economic stability and a country where gay men could be gay without fear of persecution.

Life here, like I told you before, I just try to adjust and try to be positive think here. I can go outside. No one will steal me my watch or nothing. No one will offend me in the street or nothing. It's safe. Then I think one of the ways I try to see then in some countries it's not like that. There are some countries in a very bad situation. (Roberto, GM)

Participants also felt lucky to be living in a country with a healthcare system that cared for people and kept them alive.

I try to think like this. If I were in [Asia], I might die already. But I'm lucky that I can have a chance to be here and receive treatment. And now here, in Australia, not only me who have this problem. A lot of other people having a positive as well. So I have to cope with my life. But I'm happy so much that I'm here in Australia. (Sophy, HW)

Participants who were in relationships also felt lucky to have loving partners who cared for them and about them.

And I believe [pause] I'm the most lucky people in the HIV people because I got more love than anybody else to support. And I really very well protect everything. (Anh, GM)

And finally, participants felt lucky for having survived against the odds and having received help and support while they were in limbo for years, waiting for permanent residency.

I believe in God. I believe everywhere I go, everything I do, everything I ask for, I believe he look after me. ... I become a real Christian when I was really sick and my pastor come and pray for me. Since that time on after I recover I went to the church to get baptised. So I think this is my commitment in life the rest of my life. This is who I believe. So even until today I'm not saying I'm

proud because of myself. The first thing maybe because my life, I'm lucky. Because everybody, as far as I know, is always saying, 'You are very lucky person.' Even I never win Lotto but they always say, 'You are very, very lucky person.' And, if I think about that, I believe I'm very, very lucky person because the first thing how this place look after me as well, which is I've been provided love. Someone who take care of me. Someone who listen to me and someone to help me, and someone to give me direction even sometime get involved in my life, what I better to do. (Johnny, HM)

Being diagnosed with HIV was not the first and only major challenge for many. Participants who came from countries affected by war and other disasters drew on previous experiences that gave them the strength to deal with HIV. They had survived war, civil war, and other potentially fatal illnesses.

Last year I was almost dead. Actually, I'm a survivor for many times. Even when I was first diagnosed in Africa the nurse who did the diagnosis told me if I am lucky I would stay for two years from thereon. 'Oh that's good,' I said. Because instead of just living this type of life it's better to die. ... And even I have taken some other steps to die, how to die and where to die but that didn't work. ... When I fell ill from malaria, I think, 'Oh this should be the last and then I'll be just gone.' Nothing would happen. Within a week I just get well and then – it's amazing. So that was the first time and last year was another time I survived. (Robert, HM)

Women drew on the cultural values that had been instilled in them in their country of birth to cope with the many challenges in their lives.

I said [to my psychiatrist] 'Look, I don't know, but I think deep inside I got this strong mentality.' I think it comes from my mum. I've seen my mum in abusive relationship and she was really, really patient. She doesn't complain. She always teach me to be patient. She used to tell me being patient, always patient, will give you a good result. She always tell me that. So I learn being patient since I was young. I was married [when I was] twelve years old. So I was patient with my first husband even though he was abusive as well. But again, I'm not like my mum completely. I have this little bit of being villain and, you know, try to fight back. (Mizy, HW)

There was a strong emphasis on 'don't feel sorry for yourself' and focusing on the things that participants could do instead of the things they could not do.

And you do not let the thing you know is not right to pressure you or to give you worry because you have

to find something more productively to live on and to move on. I mean whatever happen, you sorrow or you sorry, or you sad, that's still in your blood. It can no longer get out. So what the point you worry about it? Why now is medical technology, everything gets so much quick. ... So, think of what can you do now but don't think what I can't do. You just think what I can do now. You do it. (Anh, GM)

There was also an attitude of seeing things in perspective and focusing on the good things and the good fortune that participants did have in comparison to others who had less and who were worse off.

And I told him the reason why I'm sad now because we lose the house where I live. Now we have to move to the [area], which is out of touching and inconvenient. Then I think of people next door to me. They have got no house and they are old, and they not go anywhere. So why should I sit there miserable for day after day. You waste your life. (Anh, GM)

One source from which some participants drew strength and comfort was religion and spirituality. Some participants attended the churches, temples and mosques of their faith. Being in these places, prayer and quiet contemplation calmed the mind. Others just prayed at home by themselves.

Sometime I'm crying. My life still from young up to now, my life it didn't change. Nothing. All crying. That happen. God, he testing me. ... My dad, he kill in front of me, [country] Government. My family suffer. ... come to here, fall down. ... [God is] important for me. Time I'm sad I go to clean myself and pray. He helping me. I'm forget everything. I go my track. (Aysha, HW)

Before I used to go to temple but now I go to church as well. ... I feel better that way. ... pray to God, Jesus, Mother Mary.

I saw the big poster [of Jesus] there.

In my bedroom is better there because every time I sleep, I look at it and pray in my sleep. Sleep very well. ... Before, I go to temple all the time. Buy fruit, flowers, offer to the Buddha. But now I haven't got a friend [from country] to go with me and I just go to the church. ... I feel good. Like pray and come out. You feel nice. (Sarapong, GM)

Some participants rejected institutionalised religion but still found some aspects of traditional religions useful for coping with stress and for looking at life more generally.

I guess, if anything, Buddhism or some aspects of Buddhist philosophy. Yeah. I reject anything that becomes religion. ...

Which aspect of this philosophy do you find helpful?

You have to keep reminding yourself that nothing lasts forever. ... What's the point of spending thirty years paying for a house. You're just borrowing ... It's just things like that. And then attachment to things, you know. Very easy to say, 'Well no, it's a THING,' you know. You don't wanna get attached to a THING. Yeah, but the main thing is ... that we're not here forever.

We're just passing through. (Diego, GM)

As far as relationships with other PLHIV as a means of coping were concerned, opinions were divided. Some participants emphasised normality and stayed away from other PLHIV.

Those people who are there [at the charity shop], they're very nice people. ... They more catholic, more religious people. They very nice. But that sort of people you should contact more often because they make you feel comfortable. But if you meet someone who keep talking about HIV, that make you crazy, I think. (Anh, GM)

Others, however, found it important to connect with PLHIV. Maintaining social relationships with peers was an important antidote to social isolation and depression.

If you isolate yourself, you get, how is it called?

Depression. ... You feel sorry for yourself. And then, you know, it's not good to feel sorry for yourself. Because some people are innocent like me. I was innocent. I didn't go to work in the streets and sleep with everyone to get it. They bring it to me, the father of my daughter. So I'm innocent. So I should not feel sorry for myself. I should work hard. I should be strong. And that's what, that's what I always say to women. I always tell them, 'You should not sit in the house and isolate yourself.

If you've heard of an HIV group, go there. Ask them if they have groups. They have women groups. Go there. Sit there. Listen. They are going to change your life.'

(Margaret, HW)

Discussion

This was a highly heterogeneous sample with regards to country of origin, history and experience of migration, residency status, and length of period living with HIV. Similar to studies among African migrants in the UK (Anderson, 2008; Anderson & Doyal, 2004; Doyal & Anderson, 2005) migration and residency status played a central role in the experience of living with HIV and reached into many aspects of life, most importantly participants' entitlement to access healthcare services, Medicare, and receiving subsidised anti-retroviral medication. There were no barriers regarding ethnicity, gender or sexual orientation with regard to access to health services and treatment. Participants received, or were offered, treatment according to clinical needs.

While all participants did receive healthcare and ART, residency status could affect the kind of medication a person was able to get and whether health issues unrelated to HIV could be attended to. There is also evidence in this study that residency status and the fear of having an application for permanent residency rejected may delay uptake of ART even when it is clinically indicated.

While structural barriers to ART could usually be overcome with the help of committed and creative healthcare professionals, the unwillingness to start treatment due to cultural barriers such as fear, which were grounded in experiences from the country of birth, were more difficult to overcome (see, for example, also (Anderson & Doyal, 2004)). On the other hand, the need to stay alive and stay strong for dependent children was a powerful motivator to start treatment for those who initially did not want to consider treatment (Körner, 2012).

There were varying levels of involvement in making treatment decisions, and here there were differences according to gender and sexuality. Only gay men actively sought information about ART from a variety of sources, were involved in treatment decisions, and accepted or rejected a doctor's advice. However, this may be due to length of time living with

HIV, and length of time living in Australia. For heterosexual men and women, and for participants who had not been living in Australia for very long, this was a new way of interacting with a doctor and they were still feeling their way into this form of decision making. However, with support and encouragement from their GPs some men and women were taking steps in that direction.

Health services were very highly rated and participants reported very good relationships with their HIV doctors and their GPs for those who had a family GP in addition to their HIV doctors. Participants certainly valued their doctors' professional knowledge and skills, however, personal characteristics such as friendliness, kindness, respect and patience were more highly praised than medical knowledge. To some extent, healthcare professionals, social workers and MHAHS co-workers have a compensatory function, filling a gap in disrupted social networks and taking on a role of substitute family (Åsander et al., 2004).

The fear of disclosure and the need for secrecy were major constraints on social interactions with ethnic communities, including the fear that information about HIV status would get back to the family overseas (Anderson & Doyal, 2004). This was a major concern especially for participants from Africa. For others, however, social relationships revolved predominantly around people from the same cultural background, usually because of English language barriers. The MHAHS co-workers played an important role here, providing support in the mother tongue and language assistance in interactions with English-speaking mainstream health and social services.

Acceptance of HIV status as a coping strategy and the basis for managing life as a person living with HIV was also found across gender and sexual orientation. So was focusing on the positive aspects of life and of living in Australia, where people had access to treatment and care, and where they could live in a safe and peaceful environment. Spiritual beliefs, both within organised religion and at a

personal level were a source of coping for some gay men and women. However, religion could also be a source of stigma—the stigma of homosexuality, the stigma of HIV, and the double stigma of being a gay man living with HIV.

Attitudes towards and experiences with gay community and positive community diverged widely, and across gender and sexuality. Gay men's involvement with gay community was more prominent in the early stages of migration and at the time of coming out but faded considerably or stopped completely over time in favour of more diverse social networks that included family and heterosexual friends. Involvement with positive community revolved mainly around practical aspects of living with HIV, especially financial support and legal help with residency matters. Preferred social networks consisted of people unrelated to HIV such as family, neighbours, work mates, friends from college. However, there was also a small number of African women who participated extensively in groups for PLHIV and whose preferred social networks were other PLHIV. This is in contrast with earlier findings, where women had little or no connection with HIV organisations (Körner, 2007c, 2010).

There are some limitations to the study. Firstly, the target sample was ten gay men, ten heterosexual men, and ten women. However, we were unable to recruit the target numbers of heterosexual men and women. This suggests that there are considerable barriers for heterosexual men and women from CALD backgrounds to come forward about their HIV status. Similar obstacles were encountered in a previous study (Asante et al., 2009).

Secondly, the vast majority of participants were recruited through a health service and a support centre for PLHIV. A very small number were recruited through word of mouth. Thus, the vast majority of participants were connected with HIV-specific health and social services already.

Conclusion

Living with HIV, cultural diversity, gender and sexuality is a highly heterogeneous phenomenon. It cuts across gender and sexual orientation, it varies according to gender and sexual orientation, and it varies within gender and sexual orientation. As our sample has been drawn from 18 different countries of birth we cannot say whether there is also variation according to ethnicity. At the most basic level, migration and residency status determine whether a person can receive healthcare and treatment, and what kind of care, treatment and support they can receive. Also essential is to what extent and how settled people are in their new environment. Meeting survival needs is the most important task before health needs can be taken care of. Once these needs have been met and people have been connected with health and social services, gay men, heterosexual men and women can live a mode of existence that allows them to take care of their own, personal needs and to fulfil their social obligation, notably to their families. Therefore, there can be no one-size-fits-all approach to care and support for PLHIV from CALD backgrounds. It needs to address health needs and social needs within the cultural frameworks that can enable some but constrain others and vice-versa.

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