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The impact of visa status and Medicare eligibility on people diagnosed with HIV in Western Australia: a qualitative report

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Abstract

Background: In Australia, temporary visa holders are ineligible for Medicare and subsidised antiretroviral drugs. Additionally, HIV testing is not mandatory for visas unless applicants seek work in the health sector. We sought to understand the impact of HIV and issues of access and adherence to antiretroviral therapy (ART) in people holding temporary visas and permanent residents. **Methods:** Data were gathered from interviews with 22 participants. Information concerning medication adherence, side effects, CD4 T-cell count, viral load and rate of response to generic drugs were collected. **Results:** The mean age was 33.4 years (\pm s.d. = 6.0), 21 out of 22 were from HIV-prevalent areas in East Africa and Asia, 14 out of 22 were on temporary visas, 12 were ineligible for Medicare, 14 out of 22 were diagnosed during health screening, 19 out of 22 risk exposures were in country of

origin, 8 out of 17 were taking generic ART at an average cost of \$180 per month, adherence was excellent and self-reported side-effects were relatively infrequent. Participants applying for visa continuations and permanent residency were fearful, believing their HIV serostatus would prejudice their applications. Patients cited belief in ART efficacy, were motivated to maintain therapy and were anxious about lack of access to treatment in their countries of origin. Conclusion: Adherence to antiretroviral drugs in Medicare-ineligible HIV-infected individuals is excellent despite limited access to treatment. The threat of visa non-renewal and the likely failure of applications for permanent residency result in considerable anxiety and confidentiality concerns.

Additional keywords: AIDS, antiretroviral therapy, generic drugs, guest workers, immigration, stigma.

Introduction

In Western Australia (WA), there has been a steady rise of HIV diagnoses in women and heterosexual men, against the previous trend of risk and transmission in men who have sex with other men.¹ This emerging trend reflects population mobility driven by international travel and work opportunities, and it is estimated that there are over 90 million people working outside their countries of origin.² In December 2010, there were just over one million temporary entrants in Australia, excluding an estimated half a million New Zealanders, made up of students, tourists and business visitors. One hundred thousand were guest workers as Business Long Stay visa (subclass 457) holders, 11 000 were from sub-Saharan Africa and of these people 30% were settled in WA.³ In WA, there is increasing reliance on guest workers to support the resource industry labour market, largely structured around workers who live in a major regional centre, usually Perth, but work in remote areas (fly in–fly out workers or FIFO). One-quarter of ~21 000 457 visa holders in WA worked in the mining, construction and manufacturing industries in comparison with other states, where most were working in the health sector.³ Successful application for permanent residency is contingent on satisfying the Health

Requirement⁴ under the 1958 Migration Act. This includes an assessment of the likely impact of the health of the applicant on Australian health resources. People diagnosed with HIV are not able to meet this requirement, which the Australian Government can waive at its discretion; however, the process is unclear and the outcome not assured. The Migration Regulations 1994 also accommodate a provision for a 'skilled health waiver' for suitably qualified applicants and employers. An important issue for those on temporary visas is the lack of Medicare cover, which, for residents with HIV infection, covers the cost of expensive antiretroviral drugs (ARVs). No generic ARVs are available for prescription in Australia because of international trade restrictions,⁵ but a limited range of generic formulations may be purchased from internet suppliers and legally imported. In order to establish the health care needs of these individuals and the wider implications for health care delivery, we sought to: (1) understand the impact of HIV diagnosis on visa holders and the broader implications that temporary resident status has for them and their families; and (2) describe the experiences and outcomes of antiretroviral therapy (ART) in those without Medicare access.

Methods

The study was conducted in the Royal Perth Hospital Immunology Outpatient clinic between April 2010 and August 2011. The Western Australian HIV Cohort includes 700 adults and, at the time of the study, ~10% held temporary visas and were therefore ineligible to receive Medicare benefits. Patients were invited to participate by the nurse researcher or the clinic nurse if they had been ineligible for Medicare at some stage; this status was determined from case notes on their attendance at the clinic. A qualitative research design was used to gather data from interviews, and was triangulated with case notes, results of investigations and the self-report Adult AIDS Clinical Trial Group adherence instruments and a side-effect questionnaire.^{6,7} Written informed consent was obtained at the time of the interview, which was arranged by appointment some time after the invitation to participate. The research was approved by the Royal Perth Hospital and Murdoch University Human Research Ethics Committees.

Sociodemographic, clinical and biochemical characteristics were collated. Professional activity, educational level, marital status, living arrangements, ethnicity and visa status were documented. Details concerning HIV disease status, place of infection, route of exposure, comorbidities and history of ART, were collected from the medical records. Pill burden, dose scheduling and medication adherence over the last month were discussed with the patient. Semidirected interviews of 40–90 min duration were conducted in English, recorded and transcribed. Questions were open-ended and based on topics and themes from a previous study including impact of HIV, treatment and stigma,⁸ and established cross-cultural approaches.⁹ Patients were encouraged to speak freely about issues important to them.

Data analysis

Transcripts from interviews were imported into NVivo 8 (QSR International Pty Ltd) for analysis by the first author, cross-checking of interpretation and analysis was carried out by the second author. Sociodemographic, clinical and side-effect information were entered into Excel and standard descriptive summaries used to characterise the data.

Results

Sociodemographic data

Interviews were conducted with 22 consecutive participants (10 women) fulfilling the study criteria. Table 1 contains the sociodemographic data. In summary, 12 interviewees were of East African ethnicity, either from Zimbabwe or Kenya, seven were Asian, two were from Oceania and one was European, ranging in age between 23 and 43 years (mean = 30.3, s.d. = ±5.8); seven were in relationships with Australians; and 12 were currently ineligible for Medicare but two more had interim access. Half of the sample had university or college education and the other half had completed secondary school or vocational training. All except the Thai women were fluent English speakers.

The median year of HIV diagnosis was 2007. Most HIV exposure was in the country of origin except for two men infected by other men (clade B) in Australia. Eight patients infected overseas had the clade C virus, one had the recombinant form AE and another had clade D; the rest did not have results available. A common reason for testing was health screening to obtain a visa or on application for permanent residency. Seven had a detectable virus; of these, four were treatment naive, one was not on current treatment, and two had been on ART less than four months and the virus was barely detectable (166–224 copies mL⁻¹). Comorbidities were: tuberculosis, hepatitis B, uterine fibroids, haemolytic anaemia, osteoporosis and dyslipidaemia (each comorbidity was found in 1 out of 22 patients). Depression was diagnosed and treated in one patient, and self-reported in another.

At the time of the study, 19 patients had prior treatment with ART via compassionate access or generic formulation (Table 2), including three women who had pregnancies managed with ART; 17 were on current treatment (range: 3–94 months, median = 19); the average cost of imported generic ARVs was AUD\$180 per month. One man diagnosed and treated in Africa, having missed 6 weeks treatment, consulted a GP seeking access to ARVs on his arrival in Australia. Another reported a 3-week interruption to a generic supply of Viraday (Cipla Ltd, Mumbai, India). Two patients with compassionate access to patented drugs experienced side-effects in the early stage of treatment, necessitating a treatment switch. Of the five patients not on treatment, only one was likely to be eligible for interim Medicare cover. All 17 on current ART demonstrated high levels of adherence regardless of whether they were taking generics or not: five patients reported never missing a dose, four >3 months ago and one <3 months ago). Where there was threat of treatment interruption, clinic staff sought (successfully) compassionate access to meet the shortfall. Patients reported few side-effects (5 out of 17 reported none, 11 out of 17 reported up to five and 1 out of 17 reported 10); the most usual were fatigue, pruritis, dry skin and bad dreams. The most common drug combination was emtricitabine, tenofovir and efavirenz (9 out of 17) co-formulated as the generic Viraday.

Interview data

ARVs, attitudes and access

Patients showed basic knowledge of HIV and treatment, cited belief in the value of ARVs and were motivated to maintain therapy: *'The moment that I knew I was HIV-positive, it was in my mind that if I get something to help me, I would adhere to that; I would stick to that.'* (African man, student visa).

There was also motivation to adhere and avoid drug resistance: *'[If] I have to start using the other medications, [it] is going to be even more difficult because the price and also the number of the drugs you need to take's going to be completely different.'* (Asian man, student visa). Most were concerned about access to treatment on return to their countries of origin and feared death from AIDS: *'I will not survive. It's really complicated, I think, to get the medicine in. You need a lot of money for that.'*

'Cause people trying to rip you off and then not every city got it and I'm not from a big city as well.'

That's why my cousin pass away 'cause he can't get access to medicine.' (South-East Asian man,

bridging visa). Two patients were relatively unconcerned about returning to their country of origin,

although their wives wanted to stay. One of these had experience of unfettered access to ART in

Africa and was sanguine about returning, stating: *'But now with this introduction of ARVs, you can really hardly tell now 'cause everyone is getting normal.'* (African man, 457 visa). Another

interviewee, whose HIV-infected spouse remains in East Africa along with their child, cited that ART was readily available from the local hospital.

Impact of HIV

The immediate reaction to diagnosis was distress: fear of death and fear of having infected others unknowingly. In addition, people feared deportation, which, in turn, had influenced willingness to be tested in the small number who suspected they were HIV-positive. One man on a 457 visa returned to Africa for testing: *'My worst fear was, if I do the test here [in Australia], we'll be deported.'* Some partners delay testing: *'She's lost three members of her family through HIV so she's not prepared to have a test.'* (African men). Generally, the interviewees diagnosed outside Australia received their results by telephone, unannounced, as one African interviewee explained: *'Cause I had friends [with*

me], *they couldn't hear what was happening on the phone. I had to pretend [to them], to have a smile on my face.*' However, those diagnosed in Australia received them in person from medically qualified personnel at Medibank Health Solutions (MHS), a hospital-based specialist or a general practitioner. In most cases, pre- and post-test discussion took place, although the quality of this is not known. In the case of MHS, patients referred to Royal Perth Hospital were seen as soon as possible – in less than 2 weeks but mostly within days – by either experienced nursing staff or the staff immunologist, who gave immediate support to alleviate distress and initiate HIV/AIDS education. One woman was glad she had been tested: *'I think knowing is a little bit better; at least, the disease, you can manage it with the medication.'* (African woman, 457 visa). Health screening for immigration or temporary visas in the country of origin can result in inadvertent disclosure to families and friends of applicants who fail the assessment, one African woman says of her 457 visa application process: *'It doesn't come out clearly that you'll be allowed to come. You know you'll be stopped. I'm already being told if you're HIV, you're not coming to Australia. That's how it looks.'* Serodiscordancy puts pressure on relationships, including when one partner cannot meet the Health Requirement. Although waivers are granted, there is no surety or consistency in the award and some choose not to risk the loss of the application fee that would offer them substantial support in their country of origin in the event that they were deported: *'So I'm thinking if I put in \$3000 and it goes like that, it's money that I can use for something.'* (African woman, 457 visa). Three participants articulated a sense of frustration, feeling that the situation was hopeless and they would give up trying to stay in Australia, but most persisted, with determination, by accessing migration agents or remote *pro bono* legal advice available from a Sydney law firm.

Confidentiality

Disclosure to family and friends

The impact of HIV was moderated by individual and situational characteristics of the participants. Family ties were strongly evident, as demonstrated by the frequency of contact with families in country of origin, some daily. Despite this, most families were not aware of the interviewees' HIV diagnosis. Five out of 22 participants only disclosed their status to selected members of their

immediate families – not including their partners – apart from the two women who disclosed to their Australian husbands’ families. The people with children were concerned about discussing their HIV serostatus with their children. The two gay men talked of their friendship with Australian gay and HIV-positive men, in contrast with the majority of African men who had not disclosed their serostatus to friends. Secrecy was relieved by nonjudgmental support from clinic staff and a sense of anonymity: *‘I’ll go to the hospital and I’m comfortable just because I know not so many people know me here and, yeah, will talk open. They’ll ask me a question I can tell even over the counter because I know the next person here doesn’t know me.’* (African woman, 457 visa).

Although disclosure was an issue for all but one of the participants, pragmatism was evident, particularly among men who viewed themselves as fit and strong. They considered that they should be treated *‘like normal’* as with medication they could work, remain well and protect their partners by practicing safe sex: *‘I don’t share anything [personal items], even my wife [and I], we use protection when we have sexual intercourse and, yeah, everyone is safe from me.’* (African man) Several people, particularly those who went on to become residents, talk of remaining positive: *‘I think the main thing is to keep it positive, very positive indeed and just not think about it.’* (African man, now a permanent resident). This attitude sometimes included avoiding thoughts about HIV: *‘I treat myself like normal. I don’t think about it.’* (African woman, spousal visa). Support was sometimes drawn from Christian and Buddhist sources and life partners: *‘What we’ve come to understand after going through all this, you know, with a visa [PR], with my condition, we’ve just come to learn that no need to stress; we just relax. We pray a lot as well.’* (African man, now a permanent resident). However, another African man on a 457 visa, representative of others in the group, put it this way: *‘So that’s where my life is affected the most because I can’t move; I can’t do anything; I’ve got this stigma.’*

Fear of transmitting the infection

There was a high level of anxiety relating to the fear of transmitting HIV expressed by many of the participants in this study. A Thai woman explains: *‘Before I not get sick, I have a lot of kids too, like to come to play with me and then I know I get sick, I don’t want to play with them I’m scared them gets HIV from me or something. I must be careful [if I] have any cut or something.’* For several

participants, this fear was out of proportion to the likelihood of the occurrence and did not seem to diminish over time.

Disclosure of HIV status is complicated by visa status

Disclosure of HIV status for people on visas takes on a new dimension: *'They write on the clause of the immigration document to say this person is a potential danger to the Australian community and society. So when such words are mentioned, you get even scared of going to the hospital or to any public centre.'* (African man, 457 visa). Interviewees limited the number of people aware of their HIV status to prevent disclosure within their 'cultural' communities: *'Nothing is confidential.'* (African man) Some believed that if they engaged in the research or commenced ART, they would become a 'burden' to the Australian community and therefore fail to meet eligibility criteria for a waiver of the Health Requirement. Some were also concerned about perceptions of the Australian community: *'But that's the other thing, how does the Australian public look at HIV? They don't have it. So in addition to me not being Australian, I have another disease. Maybe if somebody else knew it, you know, they might discriminate me more, so it's always that wondering what somebody else will think about it, that it's really a burden.'* (African woman, 457 visa). Once residency was granted, issues relating to disclosure stigma were attenuated for some people, although this may also be part of the adjustment process: *'Occasionally, I know some day someone will find out. Medical records, I know they in computers and all that. Someone will log in one day and find my name and have a look, but I think as day by day goes by, I grow stronger and stronger at heart.'* (African man, now a permanent resident). The six women married to Australasian men reported support from HIV-negative husbands and, in two cases, their families: *'Very good support, very, especially his mother, sisters.'* (African woman, spousal visa).

HIV and employment

Work opportunities can be prejudiced for those on 457 visas, since application for continuation requires disclosure of HIV status even when sponsored: *'The truth is... I'm locked with this company almost for life.'* (African man, 457 visa). Interviewees feared stigma and discrimination: *'I haven't*

talked to anyone in the company about these things. I don't want to talk to them.' (Oceania man, 457 visa). There was frustration that HIV disease limited the opportunity to stay in Australia: *'I'm not sick or anything. I'm fit for work; that's all they need.'* (African man, 457 visa).

Discussion

This is the first study to describe the experience and clinical outcomes of overseas-born, temporary visa holders with HIV infection in WA. The data gathered in this study illustrates that for people seeking to work or reside in Australia, a positive HIV test has wide-ranging implications, including aspects that can shape the futures of people affected and their families. Once diagnosis is established, declaration of HIV serostatus is mandatory for renewal of a 457 visa. Inability to meet the Health Requirement limits access to permanent residency, which might have otherwise been met by other attributes or those of spouses. Furthermore, Medicare ineligibility precludes temporary visa holders from accessing the same subsidised patented ARVs as Australian citizens. In this study, diagnosis made during visa screening in countries of origin also had implications for the interviewees, since they feared being exposed as infected in their own communities if the visa application was refused – which they believed was automatic.

Treatment with current ARVs can prevent HIV transmission, disease progression and death from AIDS.^{10,11} However, an individual must avoid missing doses and persist continuously to prevent virological failure.¹² Therefore, the clinical imperative is to ensure consistent access to potent drugs, and effective medical and psychological support. A major finding, in contrast with that of studies by Körner,^{13–15} was that temporary visa holders diagnosed with HIV in WA engaged with the WA health system, in spite of their lack of citizens' rights, via a simple chain of clinical care delivery from MHS screening to Specialist Tertiary HIV Services. They were also able to negotiate access to most commonly used generic ARVs. The participants' strong motivation to take ART – independent of their HIV clinical status – and their efficacy in executing the regimen overcame two potential barriers to adherence: (i) access to ART and, (ii) an interrupted supply. The immediate emotional impact of

HIV was moderated by the context in which the news was received, and timely post-test discussion attenuated distress with reassurance and education. Eligibility criteria for a long stay business or student visa require recipients to be proficient in English – although these skills may only apply to the primary visa holder and not to their spouses. Language proficiency may increase a person's capacity to act autonomously, access information and manage medication, and may be another point of difference between temporary visa holders, asylees and refugees. Indeed, health literacy and numeracy may have contributed to the successful medication adherence and persistence seen in this group, together with clinic protocols for adherence monitoring and counselling.^{16,17} Only one of the participants expressed concern that generic drugs might not be effective, since he was not experiencing the side-effects that he had when taking a patented combination. This is in contrast with a recent study by Bulsara and colleagues,¹⁸ who found that Western Australians were suspicious of foreign generic manufacturers and sceptical about generic drug bioequivalence. However, it was evident from the interview and self-report questionnaires that ARVs were believed to be effective. Lemoh *et al.*¹⁹ reported delayed diagnosis in half of the 20 African-Australian participants in their study, and clinical and virological failure in seven and five respectively. Arguably, in our setting, health screening identified asymptomatic HIV infection and prevented morbidity from delayed diagnosis. However, interviewees were concerned with threats to future health and longevity, since their HIV-positive status could prejudice applications for residency and necessitate a return to their countries of origin, where, despite the global scaling up of treatment availability, especially in South Africa, coverage remains patchy. In South-east Asia and Africa, corruption, the cost of drugs, low wages and local turmoil can result in an interrupted supply of ARVs.^{20,21} The participants in this study also pointed out that even if they had access to drugs, these would be limited to first-line treatments and should side-effects occur, then options would become limited.

In addition to the impact of HIV status on work visa and residency applications, perceptions of stigma, social and spiritual support moderated the experience of HIV. A number described how they drew comfort from spiritual sources, and most of the patients had current and sometimes frequent contact with family members in other countries; however few had disclosed their HIV status to their

families. The reasons for this appear, in part, to concur with Körner's study,¹⁹ which refers to the collectivist attributes of nonAnglo-Celtic cultures that emphasise the interdependence of families, for example, the desire to avoid causing the family distress from the burden of illness and the association with 'immoral' behaviour. Furthermore, patients perceived stigma stemming from their personal vicarious experience of HIV disease in their countries of origin. The stigma they felt, for the most part, did not diminish over time as might be expected.²² Some described an irrational fear of transmitting HIV, which may be a psychological response to internalised stigma.²³ The support received from the clinic staff was highly valued, but some participants were unsure about whether they would be viewed so compassionately by 'ordinary' Australians, their workmates or people of similar ethnic backgrounds outside the health system. Given the current laws and public dialogue around visas and immigration, their concerns are hard to dismiss.²⁴ These led them to exercise vigilance around their need for confidentiality and made them reluctant to access other health services. Despite this, some resilient attitudes reflected personal characteristics associated with recovery from stressful events, which have been reported in survivors of difficult circumstances.^{25,26} Additionally, strong support was drawn from spiritual sources and life partners. The HIV-positive gay men also had access to an 'alternative' community,¹⁵ potentially allowing them an identity free of family ties. However, their biological families' reactions to their sexuality and the circumstance of being gay and HIV-positive was another source of stigma.²⁷

Limitations and conclusions

The characteristics of the people in this study reflect the requirements of the visas that they hold. Therefore, the findings cannot be generalised to refugees, none of whom were recruited into this study. However, the interview material and triangulation with the clinical outcome data provide sound observations. Furthermore, the sample reflects the expanding Western Australian epidemic – 10% of the cohort at Royal Perth Hospital, in people born overseas and temporary visa holders from high prevalence regions – which has implications for service delivery across the state.²⁸ In particular, there has been a shift in the type of services and support that is required as a consequence of this

epidemiological pattern. For example, there are increased issues around pregnancy and serodiscordancy. In addition to standard HIV care, visa holders seek support for visa continuations and residency applications from outpatient services. Awareness over the perceived cost to the Australian community, which will have a bearing on their applications, appears to limit how and what health services are accessed. In theory, patients may actively avoid those from their own cultural communities because of confidentiality concerns. High visibility as ‘foreigners’ heightens anxiety about potential discrimination from Australians outside the health system. At a policy level, efforts to ensure the human rights of people living with HIV are respected and protected should be reinforced by continued research to ensure that individuals’ voices are heard.

Conflicts of interest

None declared.

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Table 1. Demographic characteristics of the sample (n= 22)

MSM, men who have sex with men; IVDU, intravenous drug use; FIFO, fly in–fly out

Characteristic	Number (%)
Age (mean ± s.d.): 33.4 (6.0)	
Median year of diagnosis: 2007	
Female	10 (45.5)
Living in a couple or family	17 (72.2)
Children	13 (59.1)
Serodiscordant	12 (85.1)
Living or working in a metropolitan area	10
Employment	
Student	3 (13.6)
FIFO worker	6 (27.2)
Full-time	14 (63.3)
Unemployed or home duties	4 (18.2)
Visa status	
457 long stay business visa	7 (31.8)
Student	3 (13.6)
Spousal	2 (9.0)
Other	2 (9.0)
Permanent resident	5 (22.7)
New Zealand citizen ^A	3 (13.6)
Indication for first positive HIV test	Number (%)
Illness or concern about symptoms	5 (22.7)
Health screening	14 (63.3)
HIV-positive partner	1 (4.5)
Risk exposure	2 (9.0)
Self-reported HIV exposure	
Heterosexual	17 (77.2)
MSM	2 (9.0)
Unknown	2 (9.0)
IVDU	1 (4.5)
Self-reported location of HIV exposure	
Country of origin	19 (86.3)
Australia	2 (9.0)
Abroad	1 (4.5)

^AAll East African ethnicity.

Table 2. Clinical and treatment characteristics of the sample (n= 22)

ART, antiretroviral therapy; OD, once daily dosing; BD, twice daily; ART, antiretroviral treatment; 3TC, lamivudine; FTC, emtricitabine; TDF, tenofovir; ABC, abacavir; AZT, zidovudine; EFV, efavirenz; NVP, nevirapine; LPV, lopinavir; RTV, ritonavir; ATV, atazanavir

Regimens	Number
FTC–TDF–EFV	9 OD
FTC–TDF–NVP	1 BD
FTC–TDF–LPV–RTV	2 BD
3TC–AZT–RTV–ATV	1 BD
3TC–AZT–ABC	1 BD
3TC–AZT–NVP	1 OD
3TC–ABC–NVP	1 BD
3TC–ABC–RTV–LPV	1 BD
Access and adherence	Number (%)
ART naive	3 (13.6)
No current treatment	2 (9.09)
On ART	17 (77.3)
Medicare ineligible	12 (54.5)
Generic ART	8 (47.0)
On patent ART ^A	9 (52.9)
CD4 T-cells mm ⁻³ (mean ± s.d.) ^B	578.95 ± 245.45
CD4 T-cell (%)	27.18 ± 9.2
Median CD4 T-cells mm ⁻³	623.5
Viral load ^C	7/22 (6093.3 ± 9667.7)
Self-reported adherence	
never missed	5 out of 17
missed >3 months ago	4 out of 17
missed <3 months ago	1 out of 17
Self-reported side-effects	
None	5
<5	11
10	1
Average cost of generic ART	AUD\$180 per month

^A Includes one patient on a spousal visa with interim access to Medicare.

^B The CD4⁺ T-cell lymphocyte count (per mm³) was measured using the current standard flow cytometry assay (FACScanto™ flow cytometer, Becton Dickinson, Sydney, NSW, Australia).

^C ≥40 copies mL⁻¹. The Taqman 48 assay (Roche, Sydney, NSW, Australia) was used to determine HIV RNA levels.