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Understanding late HIV diagnosis among people from culturally and linguistically diverse backgrounds

Augustine Asante
Henrike Körner
Susan Kippax



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National Centre in HIV Social Research

National Centre in HIV Social Research
Faculty of Arts and Social Sciences
The University of New South Wales



Copies of this monograph or any other publications from this project may be obtained by contacting:

National Centre in HIV Social Research

Level 2, Robert Webster Building
University of New South Wales
Sydney NSW 2052 Australia

Telephone: +61 2 9385 6776

Fax: +61 2 9385 6455

Email: nchsr@unsw.edu.au

Website: <http://nchsr.arts.unsw.edu.au>

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Summary

Key findings

Four main factors were identified as contributing to late HIV diagnosis in the study population generally and in participants from CALD backgrounds in particular:

1. **Low perception of risk of HIV infection:** Participants, generally, did not perceive themselves to be at risk of HIV, in spite of experiencing seroconversion symptoms. For the vast majority, their HIV diagnosis was their first HIV test. Many CALD participants did not expect a positive test result, even those who experienced HIV-related illness such as tuberculosis, diarrhoea and persistent fatigue.
2. **Limited use of health services before diagnosis:** A significant proportion of participants in both cohorts rarely used health services before diagnosis even though the vast majority were entitled to Medicare. They believed they were healthy and did not need health services. In addition, only a small minority of participants from CALD backgrounds had a regular doctor.
3. **General practitioners not addressing HIV with their patients:** Some heterosexual participants presented with HIV-related symptoms to GPs but were later diagnosed in hospital.
4. **HIV-related stigma and fear of discrimination:** These were a concern not only for patients from CALD backgrounds but also for Anglo-Australians, although to a lesser degree. The biggest worry for CALD participants was confidentiality and rejection from their families.

Recommendations

Based on the findings from this study we recommend the following strategies:

1. Routine HIV surveillance data in NSW should continue to be analysed to monitor trends in later HIV presentation among PLHIV in NSW. This regular analysis can inform identifying priority CALD populations with the highest rates of late presentation and the targeting of responses to address late HIV presentation and barriers to HIV testing.
2. Education should target heterosexual couples from high prevalence countries. These campaigns should be designed to emphasise that HIV transmission within a marriage context is real. Education campaigns should also inform about early HIV-related symptoms and emphasise the need to seek medical care when people experience symptoms that can be HIV-related.
3. Health promotion interventions should be targeted to the communities with the highest rates of late HIV presentation and be tailored to the dominant modes of HIV transmission evident in these communities. These interventions should promote greater awareness of the benefits of regular HIV testing, services that offer HIV testing and common symptoms associated with late HIV diagnosis.
4. Education campaigns should encourage the effective use of health services, particularly by people from high prevalence countries, including sexual health and HIV-related health services.
5. HIV clinical services such as sexual health clinics should be supported to work more effectively with the communities most affected by later HIV presentation. Cultural competency may be an effective approach to support the development of the capacity of HIV clinical services so that they are more responsive to the communities with the highest rates of late presentation.

6. The capacity of general practitioners in areas with populations from high prevalence countries should be increased. This should include improved history taking, especially sexual health histories, and the ability to recognise symptoms that may be HIV-related. This could build on the existing partnership approach to professional development among general practitioners between the Multicultural HIV/AIDS and Hepatitis C Service and the Australasian Society in HIV Medicine and be geographically targeted to areas of highest need.
7. This research suggests that HIV related stigma and discrimination are pervasive among CALD communities, which can contribute to late presentation.

Health promotion interventions which involve partnerships between HIV stakeholders and CALD stakeholders should aim to promote community-level dialogue and address stigma and discrimination within HIV prevention interventions.

8. Further research should be conducted to investigate community specific factors that may work against using health services. Further research should also investigate the service development needs of HIV clinical services and professional development needs of general practitioners in areas with high migrant populations, especially migrants from high-prevalence countries.

Description of the study

Background

HIV treatment has advanced considerably in recent years. Many of the opportunistic infections associated with the virus can well be controlled with current medication (Castilla et al., 2002). However, for best possible treatment outcomes early diagnosis is essential. This is not only necessary for determining the best possible time to start treatment but also for preventing further transmission of HIV (Carpenter et al., 1997; Valdisseri 1997).

Late HIV presentation among migrants and ethnic minorities has been reported in hospital and population-based studies in the UK and elsewhere in Europe (Del Amo et al., 1998; Burns et al., 2001). In Australia there is increasing concern about patients presenting with advanced HIV/AIDS at sexual health and HIV clinics. A pilot study at Liverpool Hospital revealed that about 130 HIV patients who presented at the Hospital between 2003 and 2005 presented late. Of these, just under two-thirds were from English-speaking backgrounds (ESB), the rest were from culturally and linguistically diverse (CALD) backgrounds. Of the latter, the majority came from South East Asian and South American countries, and a small number from Eastern Europe. Information from health care professionals suggested that the major barriers to HIV testing for patients from CALD backgrounds included shame, stigma, fear of disclosure, and lack of information or misinformation about HIV/AIDS.

Aim

This project is an extension of the pilot study conducted at Liverpool Hospital in 2003–2005. The aim is to investigate and understand reasons for late HIV diagnosis in New South Wales with particular focus on people from CALD backgrounds in the Sydney metropolitan area. It is expected that data from this study will inform HIV education and prevention services and enable the development of culturally appropriate information campaigns and resources to encourage testing and prevent late HIV diagnosis particularly among people from CALD backgrounds.

Sample and recruitment

A total of 114 participants were recruited comprising 61 from CALD and 53 from Anglo-Australian backgrounds. The Anglo-Australian participants were recruited for comparative purposes only as the main focus of the study was on people from CALD backgrounds. The participants were recruited through health care workers at four sexual health and HIV clinics in the Sydney metropolitan region. All HIV-positive patients aged 18 years or older were asked to complete a survey during one of their follow-up visits after diagnosis. To ensure complete and accurate information, the questionnaires were administered by a researcher in a face-to-face interview. The questionnaires were linked to patients' HIV-related hospital records: CD4 count, viral load, and AIDS-defining illnesses at time of diagnosis. This enabled determination of whether a participant was diagnosed late and allowed comparisons between those groups of participants who presented late with low CD4 cell count of less than 200 μ l and those who presented with moderate to high CD4 count of more than 200 μ l. It also enabled the comparison between overseas-born patients and those who were born in Australia.

It was planned to conduct follow-up in-depth open-ended interviews with 15 to 20 participants from CALD backgrounds who had been diagnosed late to further explore some of the issues covered in the survey. Whilst ten participants initially agreed to participate in such an interview, only four actually did so. The reasons participants gave for not participating in the follow-up interview included not having enough time due to work and family commitments, and being unwell. Two participants arranged a time for an interview but did not show.

To deal with these difficulties we recorded any additional information that participants gave in response to the survey questions, for example, about circumstances leading to their HIV diagnosis, their use of health services, and perceptions of stigma. In this way, additional qualitative data was gathered simultaneously with the survey.

1 Demographic and socioeconomic characteristics

Age

The age profile of participants from CALD backgrounds was similar in several aspects to that of the Anglo-Australian participants. For example, the majority of participants in both cohorts were aged between 35 and 44 (Figure 1); 39.3% of participants from CALD backgrounds and 43.4% of Anglo-Australian participants were between 35 and 44 years. However, despite these similarities there were several differences between the two groups. The CALD cohort consisted of relatively younger and older participants; 18% were between 25 and 34 years and about 8% were above 65 years. In contrast, only about 9% of the Anglo-Australian participants were between 25 and 34 years and none was 65 years or more. The maximum age of the Anglo-Australian cohort was 58 years compared with 72 years for the CALD cohort.

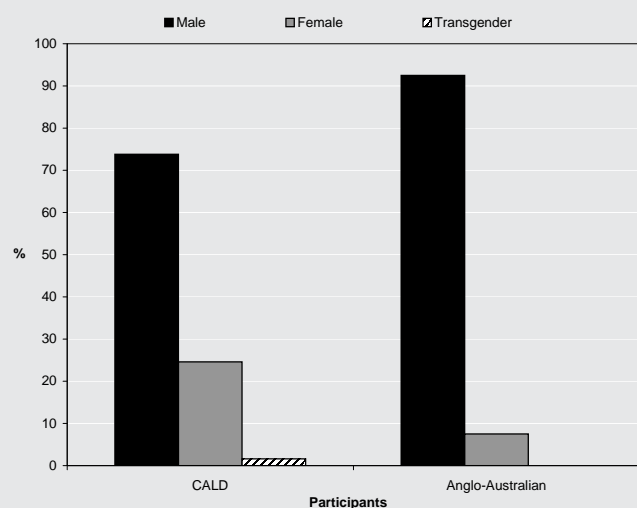


Figure 1: Age group

Gender

The gender balance of both cohorts was skewed in favour of male participants (Figure 2). Only about a quarter (24.6%) of participants from CALD backgrounds were female, 73.8% were male and 1.6% were transgender. The proportion of females in the Anglo-Australian sample was much smaller with only 7.5% of the total participants being female and 92.5% male. The high number of male compared with female participants was not related to difficulties in recruiting female participants as in some studies. Rather it was because there were not many female HIV-positive patients to recruit especially from an Anglo-Australian background.

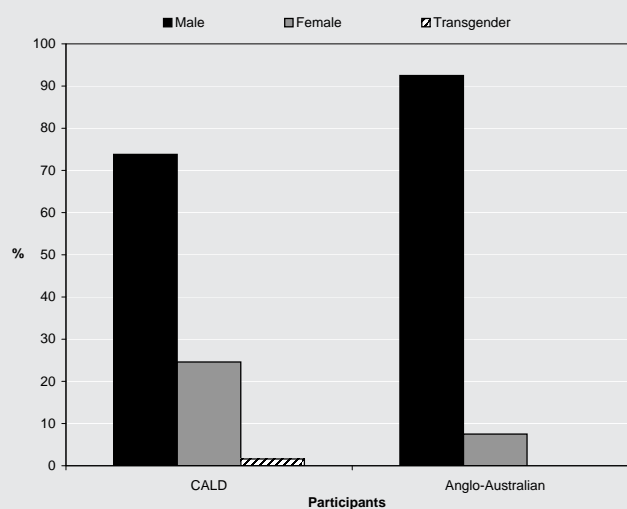


Figure 2: Gender

Sexuality

The vast majority of participants from CALD backgrounds self-identified as heterosexual/straight (Figure 3). Only 14.8% self-identified as homosexual/gay and about 7% were not sure of their sexual orientation or did not want to be labelled. On the other hand, the Anglo-Australian cohort was predominately homosexual; nearly 72% ($n = 38$) identified as gay and 22.6% as heterosexual. In both cohorts, less than 5% identified as bisexual (4.9% of CALD participants and 3.8% among the Anglo-Australian group). A tiny proportion of participants overall were not sure of their sexual orientation or did not want to be labelled (6.6% of CALD and 1.9% of Anglo-Australian participants).

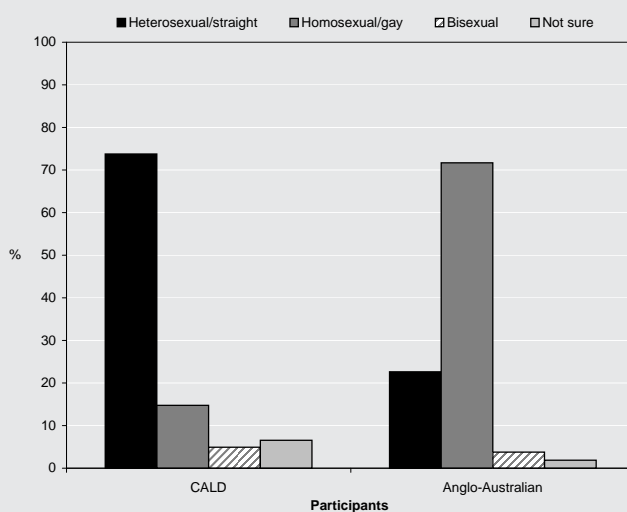


Figure 3: Sexuality

Relationship status

About 56% of participants from CALD backgrounds were in a regular relationship (married or had a regular partner) compared with 47% of Anglo-Australians. Within the CALD cohort, 60% of female participants ($n = 9$) were in a regular relationship compared with 53.3% of male participants ($n = 24$). The majority of participants in both groups who were in a relationship were between 25 and 34 years.

Living arrangements

The majority of participants from CALD backgrounds (36.1%) lived with a partner or spouse but nearly 28% lived alone (Figure 5). About 10%, mostly female, lived with their children while around 8% lived with parents. In contrast, a high proportion of the Anglo-Australian participants (43.4%) lived alone. Nearly 36% (the same proportion as CALD participants) lived with a partner or spouse. The proportion of Anglo-Australians who lived with friends was slightly higher (7.5%) than among participants from CALD backgrounds (4.9%).

Education

The level of education of participants shows some interesting variations between the CALD and Anglo-Australian cohorts. Among the participants from CALD backgrounds, nearly 33% ($n = 20$) had completed secondary school compared with 28.3% of Anglo-Australians (Figure 6). Eighteen percent of CALD participants ($n = 11$) were university educated compared with 13.2% of Anglo-Australian participants. A relatively high proportion of Anglo-Australians (26.4%) had attended college or TAFE. This was about twice the proportion of CALD participants with college or TAFE education. In both cohorts, there was a reasonable number of participants who left school at age 12 or earlier (i.e. at primary school) and those who left before completing high school (i.e. aged 13–17 years). In the CALD sample, the proportion of those with primary school education (23%) was significantly higher than in the Anglo-Australian sample (9.4%). However, more Anglo-Australians (20.8%) than CALD participants (13.1%) discontinued at secondary school level. In terms of gender, 40% of the female participants from CALD backgrounds ended their education at primary school compared with only 17.8% of males.

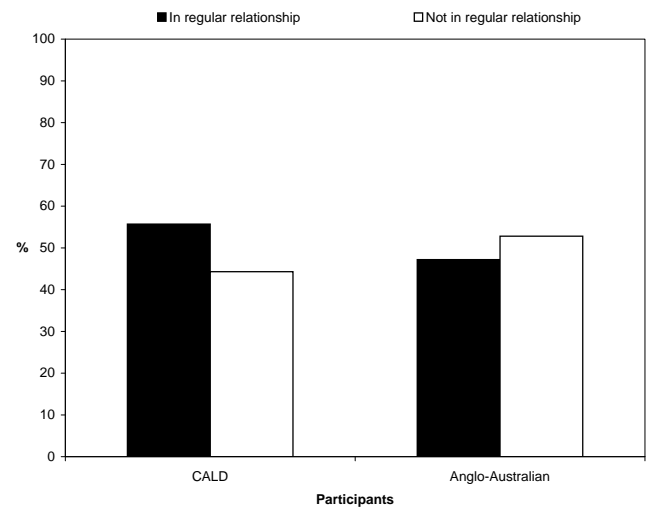


Figure 4: Relationship status of participant at time of survey

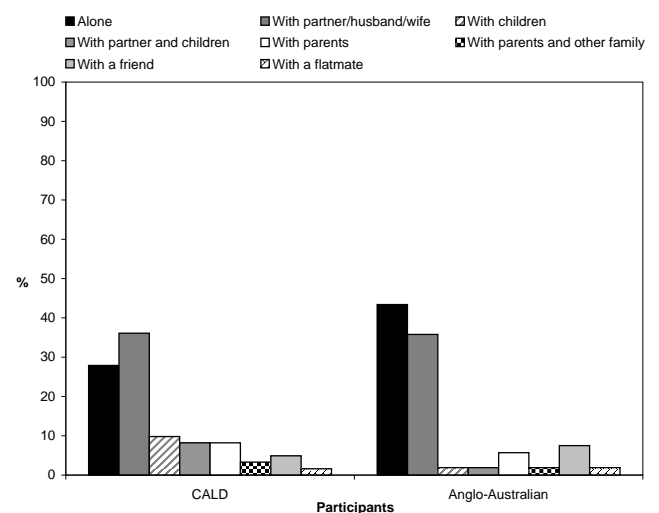


Figure 5: Person(s) with whom participants lived

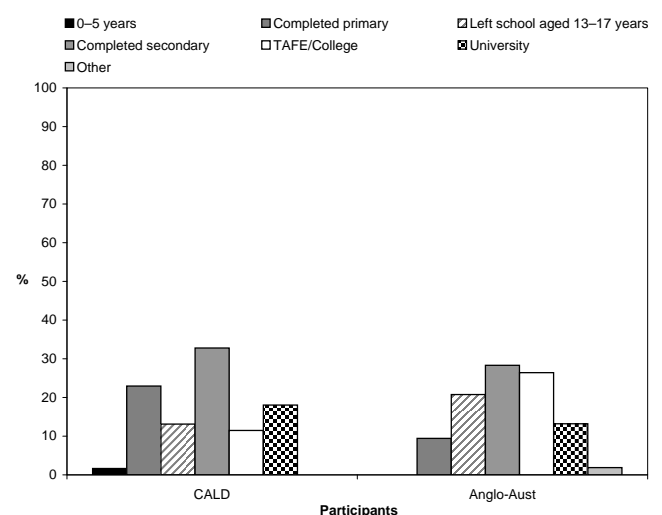


Figure 6: Education

Employment before and after HIV diagnosis

There were no major differences between the two groups in the employment status of participants before and after their diagnosis with HIV. Before diagnosis, 70.5% of participants from CALD backgrounds were employed, 4.9% were self-employed and 23% were unemployed. After diagnosis, the proportion of participants who were employed in the CALD sample dropped significantly to 42.6%, self-employment increased slightly to 6.6%, and unemployment more than doubled to 49.2%. A similar picture emerged from the Anglo-Australian data; before HIV diagnosis 84.9% of participants were employed, 7.5% were self-employed and 5.7% were unemployed. After diagnosis, however, the proportion of those employed almost halved (43.4%) while unemployment rose about 9-fold (52.8%). Although the study did not probe into how long after the HIV diagnosis participants left the labour force, psychological stress and ill-health may have contributed.

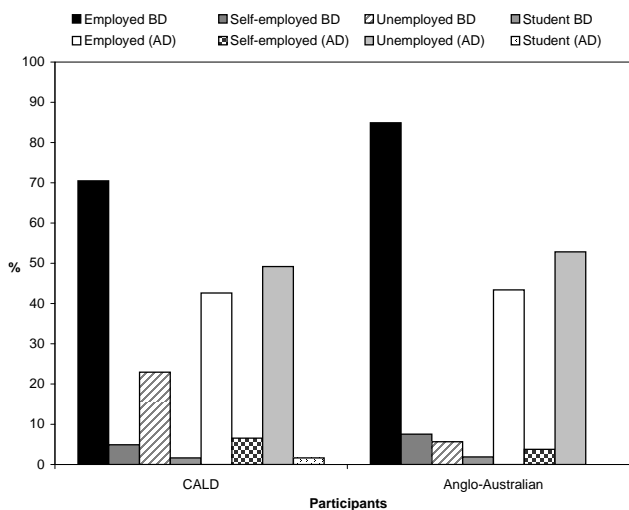


Figure 7: Employment status before and after HIV diagnosis

2 Access to and use of health services

Access to Medicare among CALD participants

About 79% of participants from CALD backgrounds had Medicare cards before they were diagnosed with HIV (Figure 8). However, 21.3% were without Medicare cards mainly because of their immigration status. The proportion of participants who had Medicare cards after their HIV diagnosis was much higher; about 90%. The small number of participants (9.8%) who had no Medicare card after diagnosis were mainly in Australia as temporary residents. Some were diagnosed whilst in the process of applying for permanent residency and were still awaiting the outcome.

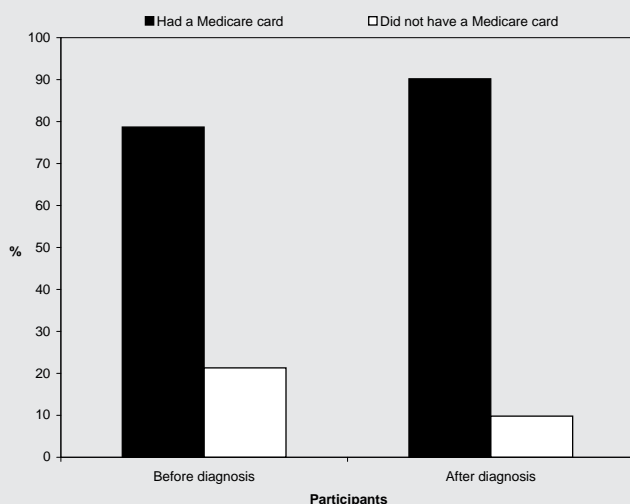


Figure 8: Participants who had and did not have a Medicare card

Sources of health care before diagnosis

Before they were diagnosed with HIV the overwhelming majority (about 90%) of both CALD and Anglo-Australian participants sought health care mainly from GPs (Figure 9). Only a small proportion of participants from both cohorts (less than 10%) sought health care from pharmacies and other sources. A tiny proportion (1.9%) of Anglo-Australian participants did not seek health care at all before they were diagnosed. The majority of CALD participants (65.6%) sought health care from GPs who were from different ethnic backgrounds; these were mostly Anglo-Australian GPs. Only 16.4% sought health care from GPs from the same ethnic backgrounds. After diagnosis, the main sources of health care in both samples were sexual health clinics. Only few participants from both cohorts had changed clinics over time due to change of place of residence.

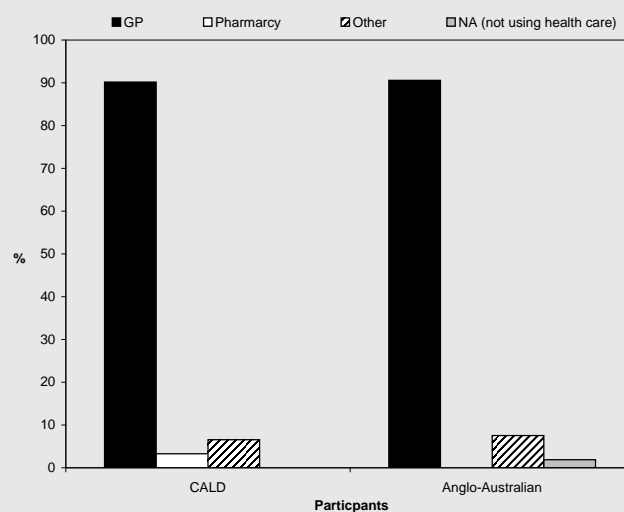


Figure 9: Sources of health care before diagnosis

How often participants used health services before diagnosis

A significant proportion of participants in both cohorts (69% of CALD and 57% of Anglo-Australians) rarely (less than once a year) used health services before diagnosis (Figure 10). Around 18% of participants in both samples used health services about once or twice a year. A comparatively higher proportion of Anglo-Australians (15.1%) than CALD participants (4.9%) used health services more than twice a year. Less than 5% of participants in both samples did not use health services at all before diagnosis. In the open-ended answers, participants gave different reasons for their use of health services. Most of them believed themselves to be healthy and therefore did not need health services. One woman who was diagnosed during antenatal care explained:

“Normally I didn't get sick. I saw a doctor for the first time when I was pregnant with my second baby [in Australia]. When I had a cold I just took lemon juice”. [CALD woman: diagnosed not late].

Of the 42 (69%) participants from CALD backgrounds who rarely used health care, 33.3% were between 35 and 44 years, and 26.2% were between 45 and 54 years. Of the 30 (56.6%) Anglo-Australian participants who used health care rarely, 43.3% were between 35 and 44 years while 30% were between 45 and 54 years. Thus, in both cohorts the majority of participants who used health care rarely were between 35 and 44 years. There were no major differences in terms of gender and use of health services among CALD participants. The proportion of male participants from CALD backgrounds who used health services less than once a year (68.9%) was almost the same as that of female participants (66.7%).

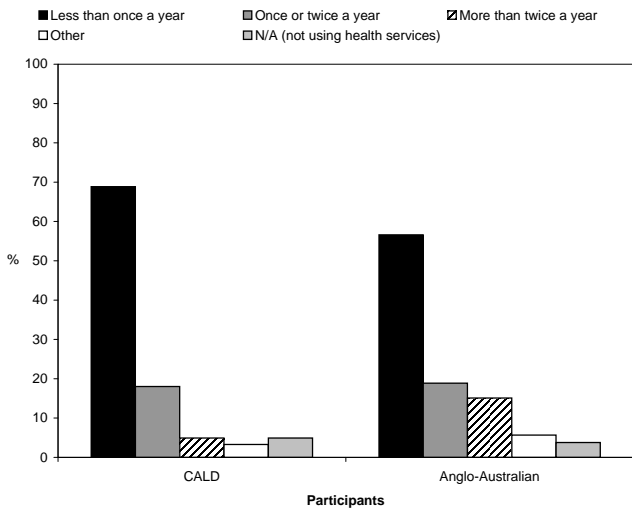


Figure 10: How often participants used health services before diagnosis

Perceptions of HIV treatment and services

In both samples participants rated current HIV treatment and services very highly. At all four recruitment sites, about 87% of CALD participants and 83% of Anglo-Australians rated the services as ‘very good’. Similar proportions (10% of CALD and 11% Anglo-Australians) rated the services as ‘good’. Only a small number of participants, about 3% of CALD and 4% of Anglo-Australians, rated the services as ‘not so good’.

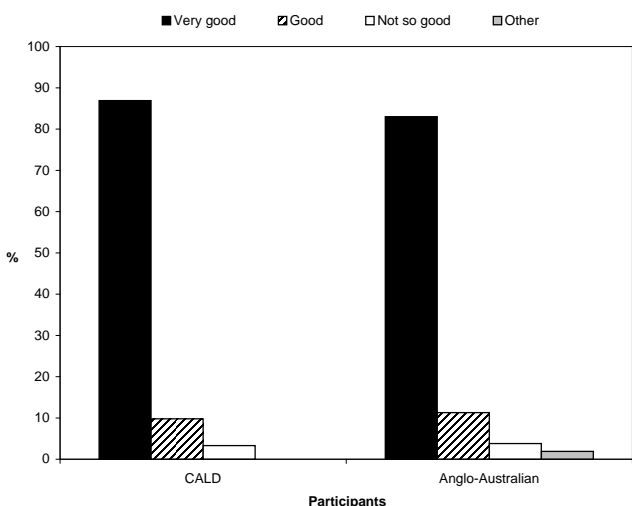


Figure 11: Rating of HIV treatment and services by participants

Suggested improvements

Participants were asked what improvements they would like to see in the HIV treatment and services currently available. About 67% of CALD and 55% of Anglo-Australians thought

the current treatment and services were excellent and saw no need for change (Figure 12). However, about 20% of CALD and 34% of Anglo-Australians mentioned the need for more after hours services for patients who are working. A small proportion (8% of CALD and 9% of Anglo-Australians) mentioned the need to reduce waiting time at the clinics. Other issues raised by a small number of participants, mainly from CALD backgrounds, included having a specific doctor, not calling out patients’ names in the clinic, and improving support networks for patients. Several participants elaborated on the improvements they wanted to see.

“It will be good if one can see the same doctor all the time. What I don't like is that you see different doctors and every time you have to repeat your story again and again. The doctors will not read the file and know what you said previously but will ask you. If it is the same doctor he won't ask you that again. The doctors need to understand that it is not easy to repeat the same story over and over again. If you have the same doctor looking after you surely that won't happen” .[CALD heterosexual man].

Improvement in medication [reduction in the cost of medication] is needed. I pay \$49.95 every month for the medication I receive. It's not much but if you are a low income worker it is still difficult to pay sometimes. [CALD woman]

The services are exceptionally good. The only problem I have is the location of the centre. I wish it is somewhere a little secluded or part of the main hospital. I always have to look around to make sure there is nobody I know watching before I enter. People know this centre is for HIV treatment so when they see you entering they think you have HIV. [CALD heterosexual man]

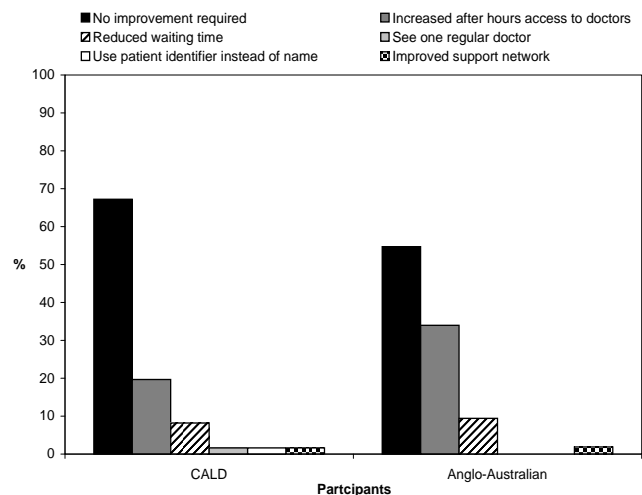


Figure 12: Improvements in treatment and services suggested by participants

3 HIV diagnosis

Time of presentation for HIV testing

Both cohorts had a significant proportion of late presenters as defined by CD4 count, viral load and/or presence of an AIDS-defining illness at time of diagnosis. About 59% of CALD participants compared with 50.9% of Anglo-Australians presented late (Figure 13).

There was an interesting pattern with regard to sexual orientation and late presentation. Self-identified heterosexuals from an Anglo-Australian background were more likely to present late than heterosexuals from CALD backgrounds. While 57.8% of self-identified heterosexual participants from CALD backgrounds presented late, a significantly higher proportion (83.3%) of self-identified heterosexuals from Anglo-Australian backgrounds presented late. Thus, self-identified heterosexuals from an Anglo-Australian background were more likely to present late than heterosexuals from CALD backgrounds. On the other hand, self-identified gay men from CALD backgrounds (77.8%) were nearly twice as likely to present late than their Anglo-Australian counterparts (39.5%). Finally within the CALD cohort, more male (66.7%) than female (40%) participants presented late.

In terms of age and late presentation, the majority of CALD late presenters were aged between 35 and 44 years (36.1%). This was not surprising as a significant proportion of CALD participants overall were within this age bracket. It was striking, however, that four of the five participants aged 65 or older presented late. In the Anglo-Australian cohort, by contrast, the participants who presented late were distributed across two main age groups; 35–44 (37%) and 45–54 (37%). Only 7.4% of late presenters in the Anglo-Australian group were aged between 25 and 34 compared with 27.8% in the CALD cohort.

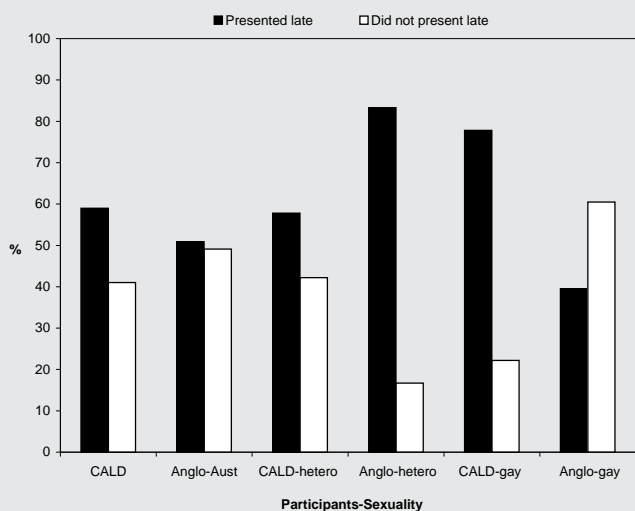


Figure 13: Participants who presented late for HIV testing and those who did not

Years since diagnosis

About half (49.2%) of CALD participants were diagnosed less than five years ago, 28% were diagnosed 5–10 years ago, and 18% 10–15 years ago (Figure 14). Only 5% of CALD participants were diagnosed more than 15 years ago. In the Anglo-Australian cohort, 32% of the participants were diagnosed more than 15 years ago, 21% were diagnosed 5–10 years ago, and 19% 10–15 years ago. A relatively small proportion of Anglo-Australians (about 28%) were diagnosed less than 5 years ago.

In terms of gender, the majority of male participants from CALD backgrounds (31.1%) were diagnosed 1–5 years ago, 28.9% were diagnosed 5–10 years ago and 20% 10–15 years ago. Only 6.7% of male participants from CALD backgrounds were diagnosed more than 15 years ago. In contrast, 60% of female participants from CALD backgrounds were diagnosed 1–5 years ago, 26.7% were diagnosed 5–10 years ago and 6.7% 10–15 years ago. No female participant from a CALD background was diagnosed more than 15 years ago.

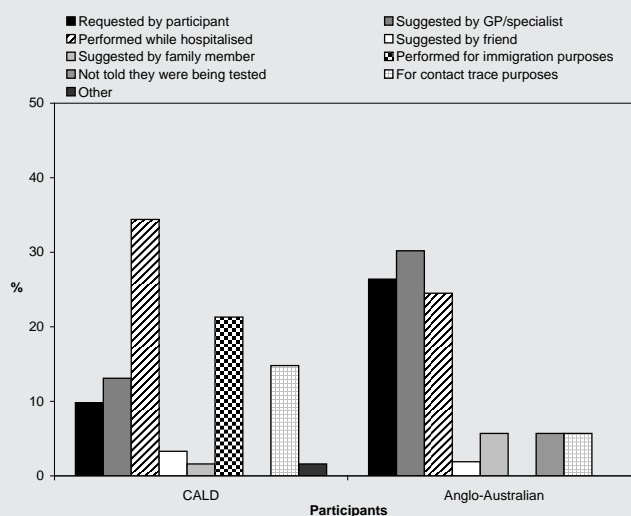


Figure 14: Time since HIV diagnosis

Reasons for HIV testing

There were some striking differences between the two cohorts in terms of reasons for testing. While about 26% of the Anglo-Australian participants asked to be tested, only 10% of CALD participants did so (Figure 15). The majority of CALD participants were tested because they were sick in hospital (34%), for immigration purposes (21%) or through contact tracing (15%). A reasonably large proportion of Anglo-Australians also tested because their GP/specialist suggested it (30%) or because they were sick in hospital (24.5%).

Participants' (particularly those from CALD backgrounds) accounts of the circumstances leading to their HIV diagnosis show that symptoms of HIV infection were often not recognized by participants and their GPs, for example:

"I had a bit of a cough and went to my GP. He did some test but didn't see what was wrong so he suggested I come to Liverpool [hospital] to get more test including HIV test" [CALD gay man: diagnosed late with TB].

"I was sick in hospital. It took a long time before my GP suggested an HIV test. I don't know why he didn't think about that early enough. I lost a lot of weight, I had diarrhoea, I lost appetite but he didn't figure out until it was almost too late for me. Any time I see him he tells me everything will be fine" [CALD heterosexual man: diagnosed late with CD4 80 and PCP].

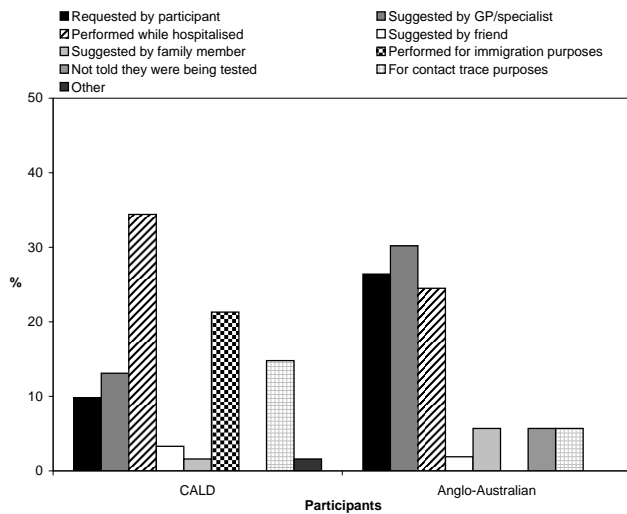


Figure 15: Reasons for HIV testing

Result expected from HIV test

About 77% of CALD participants never thought their test results could be HIV-positive (Figure 16). In comparison, 45% of Anglo-Australian participants thought the result could be positive, 8% were fairly sure it would be positive and 45% never thought the result could be positive. A tiny proportion (2%) of Anglo-Australians did not know they were being tested for HIV.

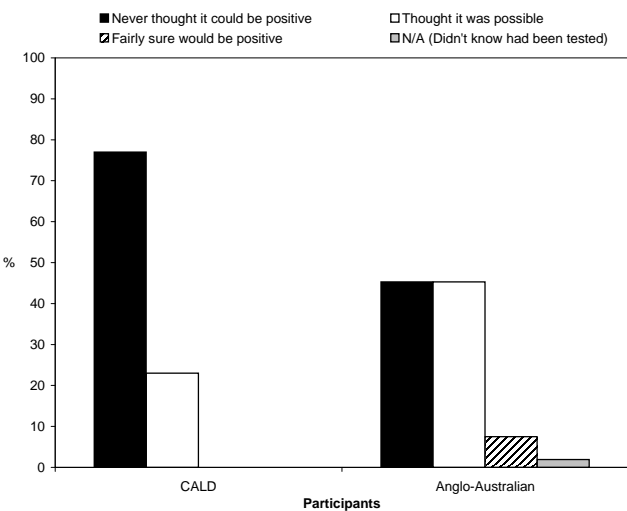


Figure 16: Result expected from HIV test

HIV-related symptoms experienced before diagnosis

Not all participants could recollect the symptoms they had experienced before diagnosis and others indicated not experiencing any symptoms. However, in both cohorts, the symptoms most frequently reported were fatigue and flu-like conditions (Figure 17). Forty-four (44%) of CALD participants and 64% of Anglo-Australians reported experiencing fatigue. There were slightly higher proportions of those who experienced flu-like symptoms (46% of CALD and 66% of Anglo-Australians). Skin rashes were reported by 31% of CALD participants and 26% of Anglo-Australians. Weight loss, teeth/gum problems and diarrhoea were reported by more participants from Anglo-Australian backgrounds than from CALD backgrounds. The duration of these symptoms varied considerably in both cohorts; 18% of CALD participants compared with 34% of Anglo-Australians experienced fatigue continuously.

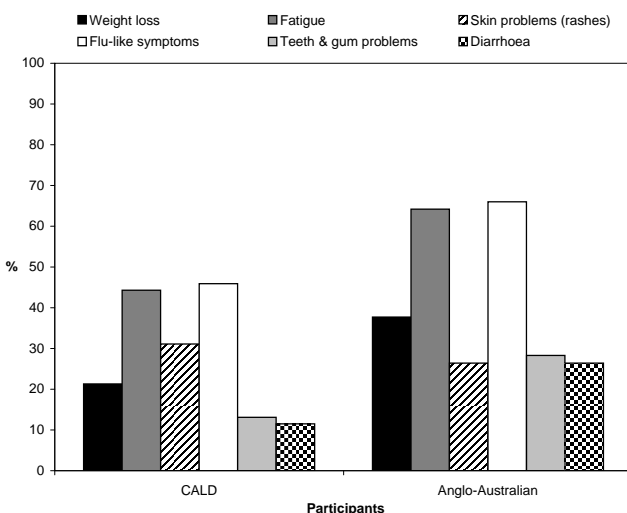


Figure 17: HIV-related symptoms experienced before diagnosis

Perception of risk

Several participants did not perceive themselves as being at risk of HIV infection in spite of experiencing symptoms. Some CALD participants explained they were 'not feeling sick' and hence did not think they could be HIV-positive. Those who experienced some symptoms explained these in the context of their everyday lives and never thought about HIV. Others thought they were not doing anything 'risky' as far as HIV was concerned. The comments below are examples of some reasons given to justify why HIV infection was not anticipated:

"I had no idea I have HIV because I have not been getting sick. When I feel tired I thought it is just because I work hard and probably don't sleep enough" [CALD gay man: diagnosed late].

"I never thought the result could be positive because I thought I wasn't doing anything stupid to put myself in danger. Although I used to play around a bit when I was quite young but I never thought it could lead to something like HIV" [CALD heterosexual man: diagnosed late].

"It was such a shock to me because I tested negative in 2004 and I don't think I engaged in any risky behaviour after that that should make me positive. I had a short relationship with a guy... but according to him he is still negative" [CALD woman: diagnosed late].

Previous HIV tests

The majority of CALD participants had not previously tested for HIV; for 72% their diagnosis was their first HIV test (Figure 18). Thus, only 28% ($n = 17$) had previously tested for HIV. Compared with the Anglo-Australian sample, 45.3% of participants had previously been tested for HIV but 54.7% had not. Of the 17 CALD participants who had had previous HIV tests, 47.1% were tested in Australia and 53% were tested overseas. Overall, more female participants from CALD backgrounds (33.3%) than male (26.7%) had previously tested for HIV. The reasons for any previous tests in both cohorts (CALD and Anglo-Australian) were not different from those given for the test that led to the diagnosis. Thus, most participants asked to be tested (for their own peace of mind) or were sick in hospital or tested for immigration reasons. The number of previous tests varied from once to several times in both samples.

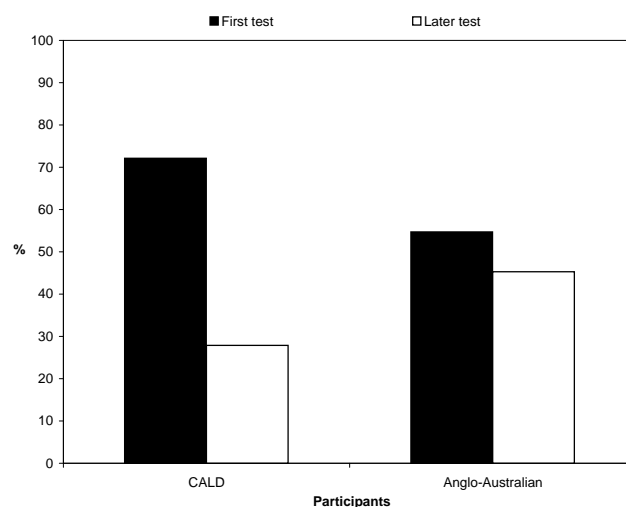


Figure 18: HIV diagnosis made at first or subsequent test

Main worries about HIV before diagnosis

There were both noticeable similarities and differences in the things that worried CALD and Anglo-Australian participants prior to diagnosis. The three main concerns in both cohorts were shame, confidentiality and fear of family rejection. However, the proportion of participants who had these worries differed between the two groups (Figure 19).

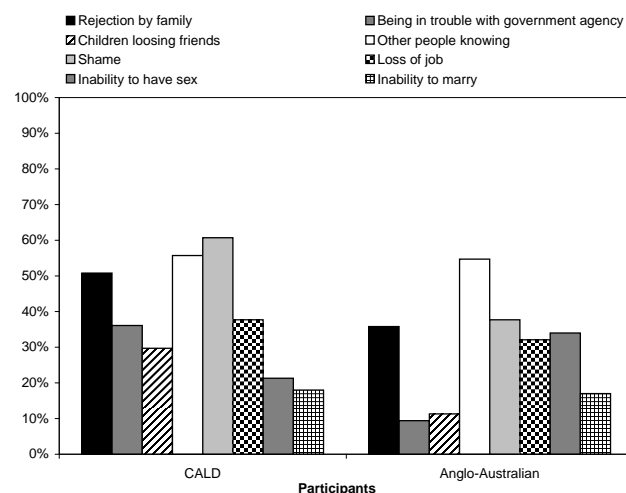


Figure 19: Main worries about HIV before diagnosis

Among CALD participants, 60.7% were worried that a positive HIV test would bring shame to them and their families. A lower proportion of Anglo-Australians (37.7%) felt the same way. The number of participants who were worried that other people would find out that they were

HIV-positive was almost the same (55.7% CALD and 54.7% Anglo-Australian) in both samples. A little over half of CALD participants (50.8%) compared with 35.8% of Anglo-Australians feared that they would be rejected by family members. The fear of losing a job was reasonably high in both groups; 37.7% of CALD and 32.1% of Anglo-Australian. A good proportion of CALD respondents (36.1%) were also worried that they might be in trouble with government agencies, for example, Centrelink, if they were HIV-positive. Only a small proportion (9.4%) of Anglo-Australians were worried about being in trouble with government agencies; rather, a good number (34%) were concerned that they would not be able to have sex if tested positive.

A small number of participants saw HIV/AIDS as a death sentence and were worried about dying more than anything. Some participants elaborated on their concerns.

“My biggest worry was that I was going to die soon. I have worked at the hospice before and have seen patients die of HIV/AIDS. So I was scared to death when I was diagnosed. I thought I was going to die. Then I started worrying about my kids and others. I sank into depression for a while but now I'm okay” [CALD heterosexual man].

“I was and still worried about losing my job because I know that if any employer finds out he will never give me a job. I'm healthy and working very well. My employer likes my work but if he should find out right now that I have HIV, he'll not give me work any more and most likely sack me from the work. It's not meant to be so but unfortunately that's the reality if you're HIV positive. That's why I don't tell anybody” [CALD heterosexual man].

“Other people finding out was my biggest worry. I had to move from my house to another area after the diagnosis because a nurse at the clinic which did the diagnosis happened to be my neighbour. I sold my property and moved out because of her. I knew she'll definitely tell her family at least” [CALD heterosexual man].

The gender dimension of concerns related to testing was explored in the CALD sample, which had a reasonable number of females. In general, female participants were more worried about the consequences of a positive test than their male counterparts. Across all the issues raised in the interviews, there were more females than males who were worried, except for two issues—‘losing a job’ and ‘being unable to have sex’ (Figure 20). Fifty-five percent of males compared with 80% of females were worried that a positive test would bring shame to them and their families. Similarly, 48.9% of males as opposed to 73.3% of females were worried about confidentiality. For women, the inability to have sex was the least of their worries, whereas for men, the least of their worries was the inability to marry.

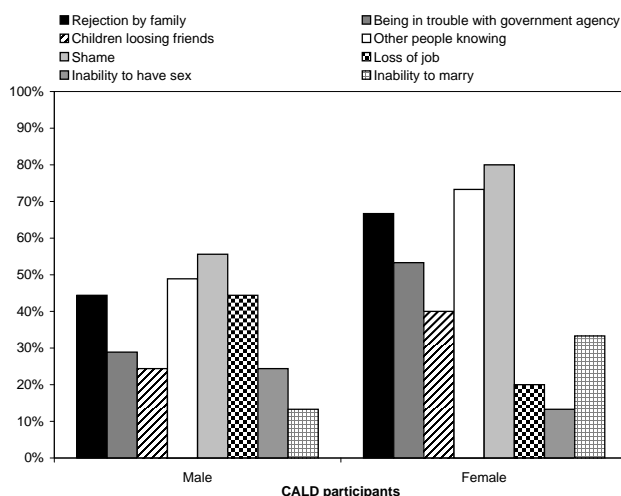


Figure 20: Main worries about HIV before diagnosis expressed by CALD participants, by gender

Where participants believed they had been infected with HIV

Of the 61 participants from CALD backgrounds, 44.3% ($n = 27$) thought they had been infected in Australia, 36.1% ($n = 22$) believed they had been infected overseas and 19.7% ($n = 12$) did not know where they had been infected (Figure 21). As expected, nearly three-quarters (71.7%) of Anglo-Australians believed they had been infected in Australia. About 6% thought they had been infected overseas, the rest (22.6%) did not know where they had been infected. In terms of gender, about 51% of male participants from CALD backgrounds believed they had been infected with HIV in Australia compared with 20% of females. Thus, 60% of female participants from CALD backgrounds thought they had been infected overseas. There were equal proportions of males (20%) and females (20%) from CALD backgrounds who did not know where they had been infected (Figure 21).

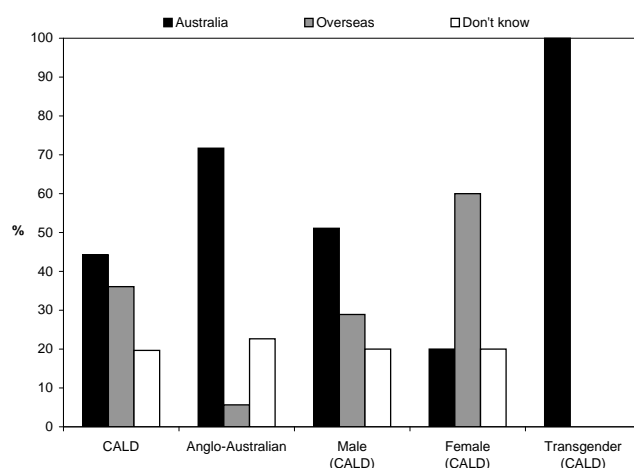


Figure 21: Where participants believed they had been infected with HIV

4 Knowledge and awareness of HIV/AIDS before diagnosis

Participants' knowledge and awareness of HIV/AIDS before they were diagnosed was explored to assess whether this may have contributed to late diagnosis. Overall, almost all participants in both cohorts had at least heard about HIV or AIDS before their diagnosis.

Knowing someone with HIV/AIDS before diagnosis

In the CALD cohort, only 31% of participants had known someone with HIV/AIDS before being diagnosed compared to 53% of Anglo-Australian participants. In terms of gender, more women (40%) than men (28.9%) from CALD backgrounds had known someone with HIV/AIDS before being diagnosed. None of the participants, neither CALD nor Anglo-Australian, reported that knowing someone with HIV/AIDS had influenced their decision to seek HIV testing. Sixty-three percent of participants from CALD backgrounds who had known someone with HIV/AIDS prior to being diagnosed presented late compared with 57.9% of those who had not know anyone with HIV/AIDS. In the Anglo-Australian cohort, 53.6% of those who had known someone with HIV/AIDS presented late compared with 48% of those who had not known anyone.

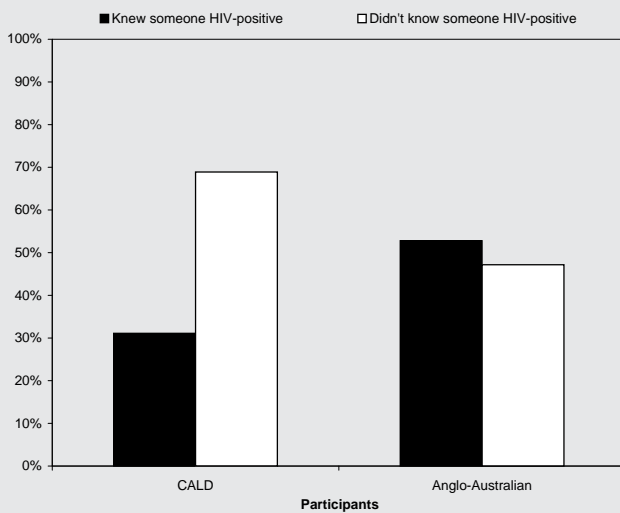


Figure 22: Participants who knew or did not know someone HIV-positive before being diagnosed

Knowing where to go for HIV testing

Despite not using health care regularly before their HIV diagnosis, participants in both cohorts knew where to seek testing. Nearly 79% of CALD participants and 87% of Anglo-Australians knew they could get a test from their GPs or at a hospital (Figure 23). Within the CALD cohort, about 10% more female than male participants did not know where to seek an HIV test. Overall, most of the participants who did not know where to go for HIV testing had been diagnosed at least 10 years ago.

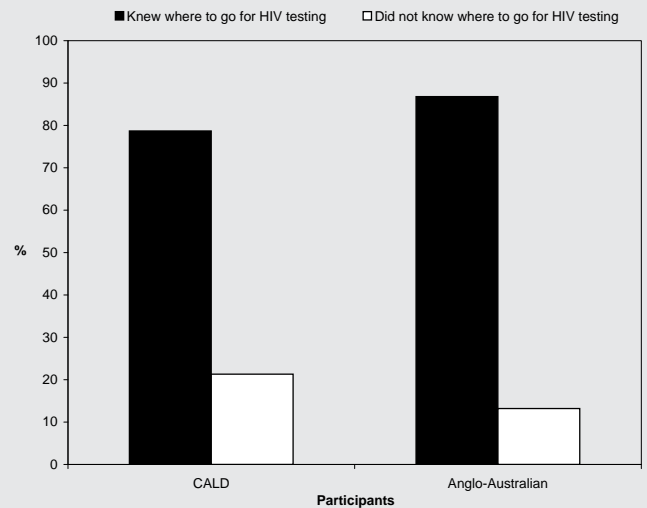


Figure 23: Participants who knew where to go for HIV testing

Participants who suspected being HIV-positive before diagnosis

In the CALD cohort only few respondents (13.1%) suspected that they could be infected before they were diagnosed. These were largely those with HIV-positive partners. About 85% did not suspect being HIV-positive before they were diagnosed. In the Anglo-Australian sample, on the contrary, 34% of participants suspected they were HIV-positive before being diagnosed; 62.3% did not suspect an HIV infection.

There was no evidence that being diagnosed late related to suspecting a positive test result. A significant proportion of CALD participants (62.5%) who suspected HIV infection were diagnosed late. A similar proportion (59.6%) of those who did not suspect any infection were also diagnosed late.

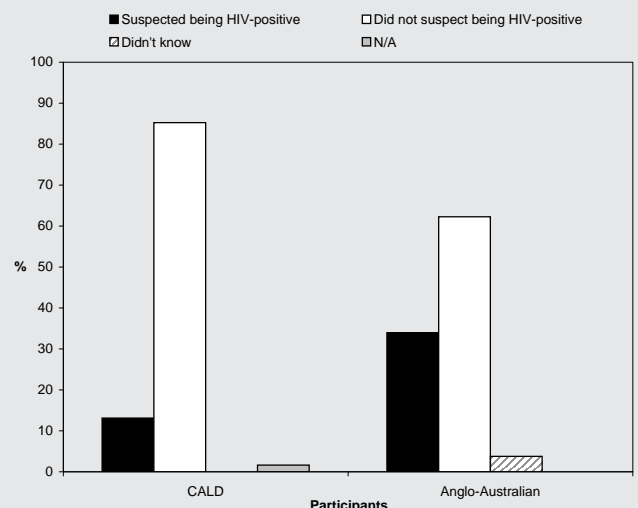


Figure 24: Participants who suspected being HIV-positive before being diagnosed

5 Disclosure of HIV serostatus

In the CALD sample, 72.1% of respondents had told at least one person about their HIV status (Figure 25). The proportion of Anglo-Australians who had disclosed to someone was far higher; 94.3% had disclosed to at least one person. In terms of gender, within the CALD cohort, more men (73.3%) than women (66.7%) had disclosed their HIV serostatus to another person.

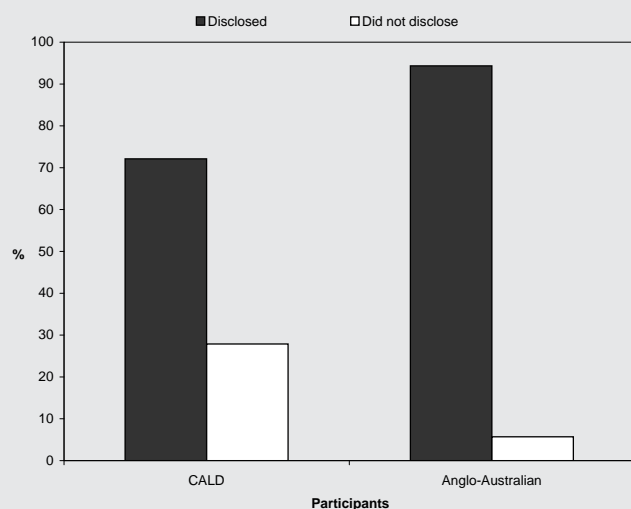


Figure 25: Disclosure of HIV serostatus to others

Pattern of disclosure

Participants were very careful and selective as to whom they disclosed their HIV serostatus. Among those from CALD backgrounds, 54.1% had disclosed to their partners, about 46% to their regular doctors (GP or family doctor), and 37.7% to a family member in Australia (Figure 26 upper half). A small proportion (4.9%) of CALD respondents had not disclosed their HIV serostatus to their partners and about 41% were not in a relationship. No CALD participants had disclosed his/her serostatus to a neighbour or a religious leader. The vast majority had also not disclosed to family members (85.2%) or close friends (95.1%) in their countries of origin.

The pattern of disclosure in the Anglo-Australian sample had some similarities and differences with the CALD sample. In the Anglo-Australian sample, a relatively high proportion (67.9%) had disclosed their HIV serostatus to their partners (Figure 21, bottom half). This was higher than the proportion of participants who were in a relationship at the time of the survey (49%), suggesting some may have disclosed to former partners. Only 1.9%

of the Anglo-Australians had not told their partners about their HIV serostatus. The overwhelming majority had disclosed to a close friend (83%), a regular doctor (77.4%) and/or a family member (75.5%). Similar to the CALD sample, only a relatively small proportion of Anglo-Australians had disclosed their serostatus to a religious leader (5.7%), a neighbour (24.5%), or a workmate (35.8%).

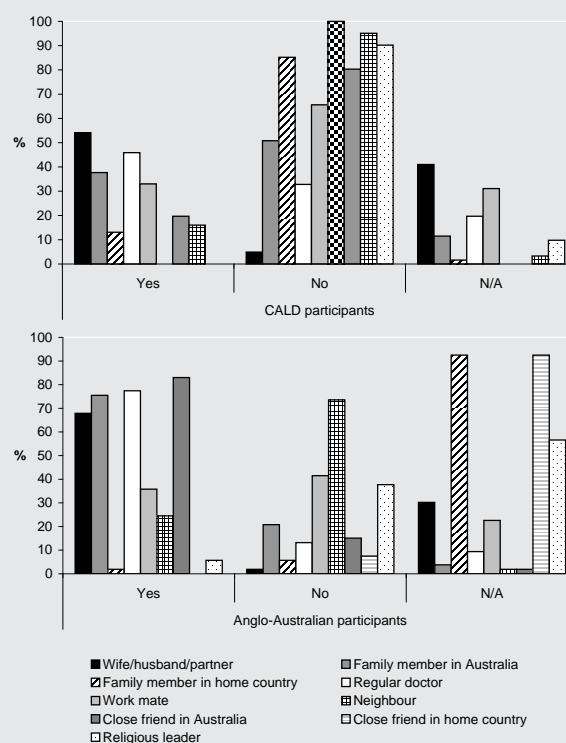


Figure 26: Persons to whom participants had disclosed their HIV serostatus

Length of time before disclosure

The majority of both CALD and Anglo-Australian participants had disclosed to a spouse or partner the day they were diagnosed; about 36% of CALD and 32% of Anglo-Australian participants (Figure 27). A slightly higher proportion of Anglo-Australian (7.5%) than CALD participants (4.9%) had disclosed within a week or two and almost the same proportions (6.6% of CALD and 7.5% of Anglo-Australians) had disclosed several years later. Those who answered 'not applicable' in both cohorts were either without partners, or did not remember how long it had taken to disclose.

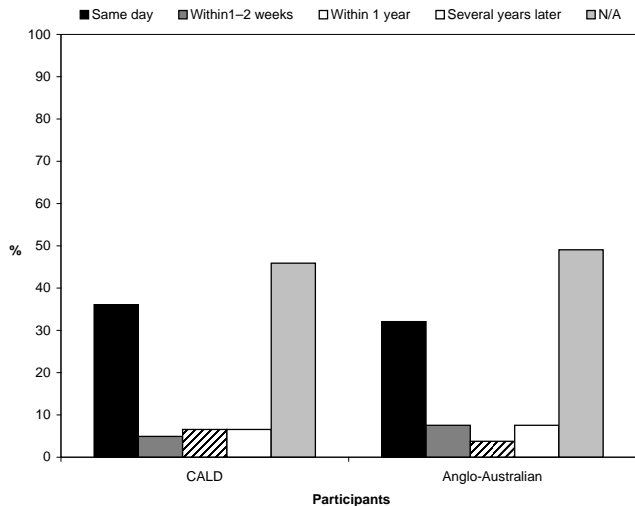


Figure 27: Length of time after diagnosis before disclosure to partner

Disclosing one's HIV serostatus to someone other than a wife/husband/partner took relatively longer for CALD than for Anglo-Australian participants. About 16% of CALD compared with nearly 40% of Anglo-Australian participants had told another person on the day they were diagnosed (Figure 28); 13.1% of CALD and 22.6% of Anglo-Australians had disclosed to another person within a week or two after diagnosis. The proportion of CALD participants who had disclosed within a year (16.3%) and several years (3.3%) after diagnosis was slightly lower than those from Anglo-Australian backgrounds who had disclosed within a year of diagnosis (20.8%) and several years later (7.7%). Just over half (50.8%) of the CALD respondents had answered 'not applicable' because they had either not told anyone beside their partner or did not remember how long it had taken to disclose to another person.

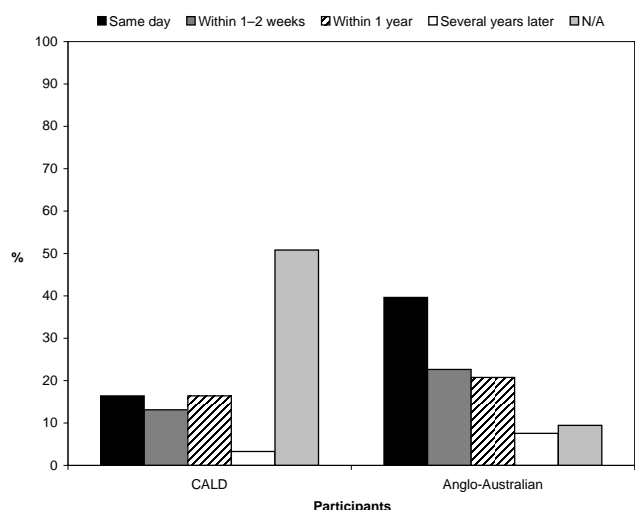


Figure 28: Length of time after diagnosis before disclosure to someone other than partner

Reasons for disclosure

Participants in both cohorts gave a range of reasons for the time they had taken to disclose or for not having disclosed at all. In general, the decision to disclose was influenced by a sense of obligation towards a partner, fear of rejection, stress on family, ignorance and stigma about HIV and needing time to come to terms with the diagnosis. The majority of participants in both cohorts who had disclosed their status to their partners the same day they were diagnosed thought they had an obligation to tell their partner straight away. Others (especially women from CALD backgrounds) went through the testing process with their partners. The few participants who could not disclose to their partners the same day mentioned the need for time to absorb the positive diagnosis. One CALD woman in a serodiscordant relationship made the following comment:

“He [partner] was the one trying to bring me to Australia. So I needed to tell him straight away although I was scared that he'll leave me but he was very kind and supportive. He is negative” [CALD woman].

Some of the CALD and Anglo-Australian respondents mentioned fear of rejection by partners, family members and friends as the reason for taking longer to disclose or for not disclosing at all.

“I don't think I need to tell people. I don't want people to start becoming scared of me and running away from me. I keep to myself. I have good relations with my friends” [CALD heterosexual man].

Another key reason for participants in both cohorts was the stress that disclosure would place on family and friends. They were concerned that people (especially parents and siblings) would worry for them and they wanted to protect them from that stress.

“I haven't told my parents. They'll be very worried and probably die early. It took them almost seven years to accept me when I told them I'm gay. The last thing I'd like to do is complicate things” [CALD gay man].

“Some close friends found out because I was sick and hospitalized. But for my parents and siblings I didn't tell them till about five years later. I was concerned about the pressure it will put on them and didn't want to put them through that worry” [Anglo-Australian woman].

“It's people's reaction. I've got supportive friends but I don't know how they would take it. I'm healthy. I don't want to make a big thing of it... When it gets bad then someone needs to be told. I'm not lying. I'm just protecting them... My mother is 79 and my father 80. They have high blood pressure. I don't want to put them through any stress” [Anglo-Australian gay man].

Ignorance and stigma about HIV were raised by several participants from CALD backgrounds as reasons for not disclosing to anyone. They felt disclosing in their ethnic communities could spell trouble for them.

“Our community is very ignorant about this disease. If I tell one person everybody will hear and they’ll talk a lot about me. My employer will hear and I’ll be kicked off my work. I’ll loose all my friends. Sometimes I find myself in the company of friends and the issue about HIV/AIDS will come up. They say a lot of bad things about people with HIV which are not true. I know they are ignorant and needs to be corrected but I know also

that if I try to correct them they’ll take it that I am probably one of the HIV positive people that’s why I’m defending them. I know how stupid these people can be in terms of jumping into conclusions. So I join them and talk as if I’m also ignorant just to avoid giving them clues” [CALD heterosexual man].

Ignorance and stigma about HIV/AIDS were also raised by several Anglo-Australian participants. However, it was no reason for not disclosing; many had already disclosed to close friends. The few Anglo-Australian participants who had not disclosed to anyone or only to their partners believed that their HIV status was ‘nobody’s business’.

6 Living with HIV/AIDS

Effect of HIV/AIDS on socialising

Sixty-four percent of the CALD cohort and 55% of the Anglo-Australian participants indicated that HIV had affected the way they socialised. In terms of gender, 80% of female participants compared with 58% of male participants in the CALD cohort indicated that they socialised differently because of their HIV serostatus (Figure 29).

The number of years that participants had been HIV-positive did not appear to have any significant impact on the way they socialised. In the CALD sample, the majority of participants who socialised differently had been diagnosed within the last five years (38.5%). This was not surprising as most participants in this sample had been diagnosed less than five years ago. Similarly, in the Anglo-Australian cohort, the majority of those who socialised differently had been diagnosed either 10–15 years (31%) or more than 15 years (31%) ago. Again, this was not surprising because the bulk of this cohort had been diagnosed 10–15 years or more than 15 years ago.

Participants who socialised differently elaborated on two key issues—the fear that people might find out about their HIV status and concerns about forgetting their medication.

“I feel uncomfortable with friends. I always feel that they know about my status so I try to stay away from them as much as possible” [CALD heterosexual man].

“I socialise with only few friends but most of the time I am on my own...Initially I had skin problems and didn't want my friends to see me with all those problems. I was afraid they'll ask me about it and somehow they will find out I have HIV” [CALD bisexual man].

“I don't want to socialise with friends that much anymore, I'm scared they'll find out [CALD woman].

“Due to the side effects of the drugs it is no longer easy to be socialising like before. You don't want to be drinking and missing your medication” [CALD gay man]

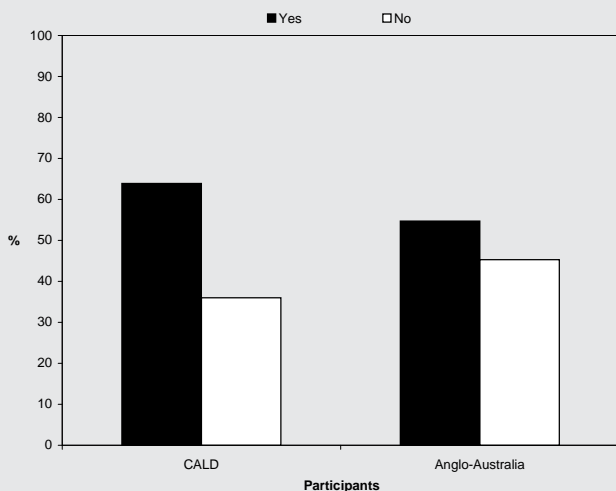


Figure 29: Did HIV/AIDS effect participants' socialising?

Changing attitudes towards HIV and people living with HIV/AIDS

On the issue of whether HIV is now less of a worry because of the availability of medication, 28% of participants from CALD backgrounds agreed, 54% disagreed, and 18% had no opinion (Figure 30). By contrast, in the Anglo-Australian sample the majority of participants (57%) agreed that HIV was less of a worry with medication, 40% disagreed, and 4% did not know. These differences between CALD and Anglo-Australian participants may be because more Anglo-Australians have lived with HIV and have had access to medication for a much longer time than the majority of CALD participants.

On the issue of whether people living with HIV (PLWH) are more accepted in their communities than before, only 5% of CALD participants and 38% of Anglo-Australians agreed. The overwhelming majority of CALD participants (87%) and a little over half (53%) of Anglo-Australians disagreed. Many commented that ‘there is still a lot of discrimination against HIV-positive people’. The high proportion of CALD participants who disagreed that PLWH were more accepted in their communities may be an indication of higher HIV-related stigma and discrimination in CALD communities than among Anglo-Australians.

Both CALD (92%) and Anglo-Australian (96%) cohorts agreed that early diagnosis of HIV was important. With regard to HIV and people's ability to work, 26% of CALD and 43% of Anglo-Australian participants agreed that HIV puts a person's ability to work at risk, although many participants remarked that HIV had not had any effect on their ability to work. Finally, with regard to living a normal life with HIV if medication is received, about 77% of CALD and 79% of Anglo-Australians agreed.

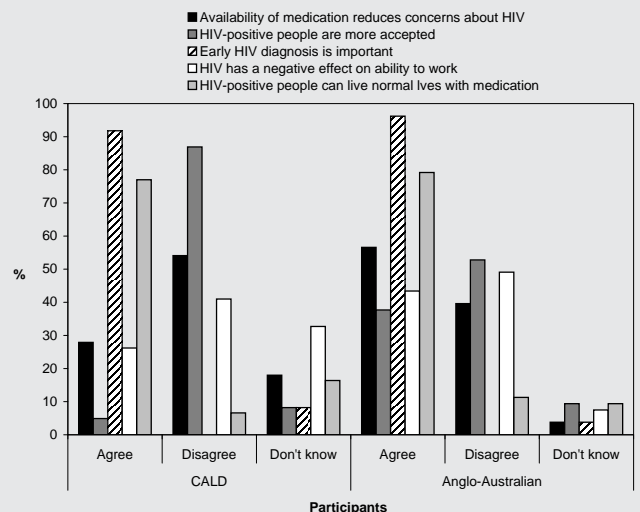


Figure 30: Changing attitudes towards HIV and people living with HIV/AIDS

Discussion

The findings of this study shed important light on why a large number of HIV-positive people in Sydney from culturally and linguistically diverse backgrounds are diagnosed late. Although late diagnosis is not peculiar to CALD patients, data from this study point to a relatively high incidence among participants from CALD backgrounds. Four main factors were identified as contributing to late HIV diagnosis in the study population generally and those from CALD backgrounds in particular. These were low perception of risk of HIV infection, limited use of health services before diagnosis, GPs not addressing HIV with their patients, and HIV-related stigma and fear of discrimination.

Low perception of risk of HIV infection has been highlighted in several studies as a major problem among migrant and other minority populations in the UK and elsewhere in Europe (Del Amo et al., 2003, Burns et al., 2001). Findings of this study are consistent with those results. The perception of risk among the CALD participants was relatively low. This is not only evidenced by the fact that the majority were diagnosed late, but for a considerable number their diagnosis was their first HIV test. In addition, the reasons for testing were, in most cases, either because the person was sick in hospital, needed to test for immigration, or because a partner had been diagnosed. Self-initiated HIV testing, which was high in the Anglo-Australian sample, was significantly lower among CALD participants. Furthermore, many CALD respondents never expected a positive test result and reacted with disbelief when notified. Even those who experienced HIV-related illness such as tuberculosis, diarrhoea and persistent fatigue did not connect these with HIV; most considered these symptoms as everyday health issues. Fatigue was explained by working night shifts, doing overtime or working in more than one job.

Being 'healthy' and being in a heterosexual marriage or relationship contributed to the low perception of HIV risk by many CALD participants. The majority of those

who reacted to their HIV diagnosis with disbelief thought they were healthy and could not be HIV-positive. Evidence from recent studies indicates that being married is fast becoming an HIV risk factor for women. An epidemiological study in Africa has found, for example, that approximately two-thirds of new HIV infections result from transmission within married or cohabiting couples (Rufagari et al., 2006). Especially some of the women from CALD backgrounds thought because they were married they were safe from HIV. It is essential that HIV transmission among married couples is made a priority in education and awareness campaigns especially in CALD communities.

Limited use of health services was also a major contributor to late HIV diagnosis. Many study participants sought to treat themselves at home for minor health issues with over-the-counter medications. This was the case not only for CALD participants but also with the Anglo-Australians, more than half (57%) of whom reported rarely using health care before they were diagnosed with HIV. For participants from CALD backgrounds their limited use of services cannot be attributed to access difficulties; nearly 80% had access to Medicare prior to diagnosis. Perhaps more than anything, the limited use of health services may be explained by the fact that most of the participants in the study were young and feeling healthy and therefore felt no need for health care. Studies have shown that young people in general do not seek health care even if they identify issues affecting their health (Booth et al., 2004; Milne and Chesson 2000). Another possible explanation for the limited health service use might relate to not having a regular doctor. While the overwhelming majority of participants appear to use general practitioners (GPs) as their main source of health care, only a few of them (particularly from CALD backgrounds) had a regular doctor. Having a regular doctor (i.e. a family doctor or GP) is generally perceived as important for timely access to, and use of, health services (Baker et al., 1994). Participants who had a regular doctor before diagnosis

in this study used health care relatively more frequently than those without a regular doctor.

Another important issue was that some GPs did not address HIV adequately with their patients. Several heterosexual participants presented with HIV-related symptoms to GPs, but were later diagnosed in hospital. This is, however, not peculiar to this study. In the UK, Burns and colleagues (2007) observed in their study of late presentation and health services utilisation by African migrants that many GPs were failing to address HIV with their patients. It is not clear whether not recognising HIV was due to a lack of adequate knowledge about HIV or a lack of confidence to handle sexual health issues. Since GPs remain the first point of contact with the health system, it is crucial that they are provided with the necessary training to handle HIV and other sexual health issues effectively.

Stigma and fear of discrimination provide another perspective on late diagnosis, particularly among people from CALD backgrounds. HIV remains one of the most stigmatised diseases despite education campaigns in the last two and half decades. Findings of this study suggest that stigma was not only a concern for CALD patients

but also for Anglo-Australians, although to a lesser degree. For example, 87% of CALD participants thought people living with HIV were not accepted in their communities compared with 53% of Anglo-Australians. Consequently, the biggest worry of most CALD participants was confidentiality and rejection from family members. Although there was no direct evidence that participants in this study delayed testing for HIV because of stigma, the majority of those who were diagnosed late, particularly in the CALD cohort, had strong concerns about stigma and discrimination. The effects of stigma on delayed testing among individuals who are at high risk of HIV infection have been demonstrated in several studies (Stall et al., 1996; Myers et al., 1993). A study of gay and bisexual men who were unaware of their HIV serostatus, for example, found that two-thirds of the participants were concerned about stigma and indicated that it was a reason for not getting tested (Stall et al., 1996). Burns and colleagues (2007) also observed that because of stigma people were fearful of presenting for an HIV test as the testing process itself carried an implication of blame. All these point to the need to effectively address HIV-related stigma especially in CALD communities.

Conclusion and recommendations

Late HIV diagnosis among people from CALD backgrounds presents a new challenge to Australia's successful HIV prevention program. The data from this study show that although the problem is not specific to CALD populations, it is more prevalent in people from these backgrounds than among Anglo-Australians, who were predominantly gay men. While there was no direct evidence that participants consciously delayed testing for HIV, it was clear that their perception of the risk of HIV infection prior to diagnosis, the way they used health services, the ability of some GPs to diagnose HIV, and the fear of stigma and discrimination played a vital role in late diagnosis. These issues therefore need to be addressed seriously both in policy and in practice.

It is especially necessary that education campaigns target heterosexual couples generally and CALD heterosexuals in particular, as the bulk of late diagnosed cases were among heterosexual couples from CALD backgrounds. Education campaigns must be designed to emphasise that marriage provides no immunity from HIV infection. Heterosexual couples need to be aware that HIV transmission within a marriage context is real and early testing where symptoms are present could save

their life. Encouraging effective use of health services particularly by people from CALD backgrounds has been highlighted in earlier reports, the current findings emphasise the need for better policy and strategic direction on the issue. With nearly 90% of the CALD participants in this study having Medicare, what appears to be lacking is not access but the knowledge and desire to use the services available, particularly HIV and other sexual health services. Investigating community specific factors that may work against using health services could be a useful starting point. It is also important that problems within the primary health care system, especially the ability of GPs to handle issues relating to HIV be properly investigated and addressed. People at risk of HIV infection are not medically trained and cannot diagnose themselves. Finally, there is the need for concrete measures to tackle HIV related stigma and discrimination in CALD communities. Mainstream education campaigns seem to have done little to reduce stigma in many of these communities. This study will provide a useful basis for responding to the challenges relating to late HIV diagnosis particularly in CALD communities and stimulates further research to expand our understanding of the issue in New South Wales.

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Appendix: Tables corresponding to the figures

Table 1: Age

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Under 25	2	3.3	1	1.9	3	2.6
25-34	11	18.0	5	9.4	16	14.0
35-44	24	39.3	23	43.4	47	41.2
45-54	14	23.0	16	30.2	30	26.3
55-64	5	8.2	8	15.1	13	11.4
65 and above	5	8.2	0	0	5	4.4
Total	61	100.0	53	100.0	114	100.0

Table 2: Gender

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Male	45	73.8	49	92.5	94	82.5
Female	15	24.6	4	7.5	19	16.7
Transgender	1	1.6	0	0	1	0.9
Total	61	100.0	53	100.0	114	100.0

Table 3: Sexuality

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Heterosexual/straight	45	73.8	12	22.6	57	50.0
Homosexual/gay	9	14.8	38	71.7	47	41.2
Bisexual	3	4.9	2	3.8	5	4.4
Not sure	4	6.6	1	1.9	5	4.4
Total	61	100.0	53	100.0	114	100.0

Table 4: Relationship status of participant at time of survey

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Regular relationship	34	55.7	25	47.2	59	51.8
Not in a regular relationship	27	44.3	28	52.8	55	48.2
Total	61	100.0	53	100.0	114	100.0

Table 5: Person(s) with whom participants lived

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Lived alone	17	27.9	23	43.4	40	35.1
With partner/husband/wife	22	36.1	19	35.8	41	36.0
With children	6	9.8	1	1.9	7	6.1
With partner and children	5	8.2	1	1.9	6	5.3
With parents	5	8.2	3	5.7	8	7.0
With parents and other family	2	3.3	1	1.9	3	2.6
With a friend	3	4.9	4	7.5	7	6.1
With a flatmate	1	1.6	1	1.9	2	1.8
Total	61	100.0	53	100.0	114	100.0

Table 6: Education

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
No formal education/less than 5 years of schooling	1	1.6	0	0.0	1	0.9
Completed primary	14	23.0	5	9.4	19	16.7
Left school aged 13–17 years	8	13.1	11	20.8	19	16.7
Completed secondary	20	32.8	15	28.3	35	30.7
TAFE/ College	7	11.5	14	26.4	21	18.4
University	11	18.0	7	13.2	18	15.8
Other	0	0.0	1	1.9	1	0.9
Total	61	100.0	53	100.0	114	100.0

Table 7: Employment status before and after diagnosis

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Before diagnosis						
Employed	43	70.5	45	84.9	88	77.2
Self-employed	3	4.9	4	7.5	7	6.1
Unemployed	14	23.0	3	5.7	17	14.9
Student	1	1.6	1	1.9	2	1.8
Total	61	100.0	53	100.0	114	100.0
After diagnosis						
Employed	26	42.6	23	43.4	49	43.0
Self-employed	4	6.6	2	3.8	6	5.3
Unemployed	30	49.2	28	52.8	58	50.9
Student	1	1.6	0	0.0	1	0.9
Total	61	100.0	53	100.0	114	100.0

Table 8: Participants who had and did not have a Medicare card

	Before diagnosis		After diagnosis	
	<i>n</i>	%	<i>n</i>	%
Had a Medicare card	48	78.7	55	90.2
Did not have a Medicare card	13	21.3	6	9.8
Total	61	100.0	61	100.0

Table 9: Sources of health care before diagnosis

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Doctor/GP	55	90.2	48	90.6	103	90.4
Pharmacist	2	3.3	0	0.0	2	1.8
Other	4	6.6	4	7.5	8	7.0
N/A	0	0.0	1	1.9	1	0.9
Total	61	100.0	53	100.0	114	100.0

Table 10: How often participants used health services before diagnosis

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Rarely/less than once a year	42	68.9	30	56.6	72	63.2
About once/twice a year	11	18.0	10	18.9	21	18.4
More than twice a year	3	4.9	8	15.1	11	9.6
Other	2	3.3	3	5.7	5	4.4
n/A	3	4.9	2	3.8	5	4.4
Total	61	100.0	53	100.0	114	100.0

Table 11: Rating of HIV treatment and services by participants

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Very good	53	86.9	44	83.0	97	85.1
Good	6	9.8	6	11.3	12	10.5
Not so good	2	3.3	2	3.8	4	3.5
Other	0	0.0	1	1.9	1	0.9
Total	61	100.0	53	100.0	114	100.0

Table 12: Improvements in treatment and services suggested by participants

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
No improvement required	41	67.2	29	54.7	70	61.4
More after hours access to doctors	12	19.7	18	34.0	30	26.3
Reduced waiting time	5	8.2	5	9.4	10	8.8
See one regular doctor	1	1.6	0	0.0	1	0.9
Use patient identifier instead of name	1	1.6	0	0.0	1	0.9
Improved support network	1	1.6	1	1.9	2	1.8
Total	61	100.0	53	100.0	114	100.0

Table 13: Participants who presented late for HIV testing and those who did not, by sexuality

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Time of presentation						
Late presenter	36	59.0	27	50.9	63	55.3
Not late presenter	25	41.0	26	49.1	51	44.7
Total	61	100.0	53	100.0	114	100.0
Late presentation, by sexuality						
Heterosexual/straight	26	57.8	10	83.3	36	63.2
Homosexual/gay	7	77.8	15	39.5	22	46.8

Table 14: Time since HIV diagnosis

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Less than 1 year	7	11.5	3	5.7	10	8.8
1–5 years	23	37.7	12	22.6	35	30.7
5–10 years	17	27.9	10	18.9	27	23.7
10–15 years	11	18.0	11	20.8	22	19.3
More than 15 years	3	4.9	17	32.1	20	17.5
Total	61	100.0	53	100.0	114	100.0

Table 15: Reasons for HIV testing

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Asked to be tested	6	9.8	14	26.4	20	17.5
GP/Specialist suggested it	8	13.1	16	30.2	24	21.1
Sick in hospital	21	34.4	13	24.5	34	29.8
Friend suggested	2	3.3	1	1.9	3	2.6
Family member suggested	1	1.6	3	5.7	4	3.5
Tested for immigration purposes	13	21.3	0	0.0	13	11.4
Not told being tested	0	0.0	3	5.7	3	2.6
Contact trace purposes	9	14.8	3	5.7	12	10.5
Other	1	1.6	0	0.0	1	0.9
Total	61	100.0	53	100.0	114	100.0

Table 16: Result expected from HIV test

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Never thought it could be positive	47	77.0	24	45.3	71	62.3
Thought possible	14	23.0	24	45.3	38	33.3
Fairly sure positive	0	0.0	4	7.5	4	3.5
N/A (Didn't know tested)	0	0.0	1	1.9	1	0.9
Total	61	100.0	53	100.0	114	100.0

Table 17: HIV-related symptoms experienced before diagnosis

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Weight loss	13	21.3	20	37.7	33	28.9
Fatigue	27	44.3	34	64.2	61	53.5
Skin problems (rashes)	19	31.1	14	26.4	33	28.9
Flu-like symptoms	28	45.9	35	66.0	63	55.3
Teeth & gum problems	8	13.1	15	28.3	23	20.2
Diarrhoea	7	11.5	14	26.4	21	18.4

Table 18: HIV diagnosis made at first or subsequent test

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
First test	44	72.1	29	54.7	73	64.0
Subsequent test	17	27.9	24	45.3	41	36.0
Total	61	100.0	53	100.0	114	100.0

Table 19: Main worries about HIV before diagnosis

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Rejection by family	31	50.8	19	35.8	50	43.9
Being in trouble with government agency	22	36.1	5	9.4	27	23.7
Children's loss of friends	17	27.7	6	11.3	23	20.2
Other people knowing	34	55.7	29	54.7	63	55.3
Shame	37	60.7	20	37.7	57	50.0
Loss of job	23	37.7	17	32.1	40	35.1
Inability to have sex	13	21.3	18	34.0	31	27.2
Inability to marry	11	18.0	9	17.0	20	17.5

Table 20: Main worries about HIV before diagnosis expressed by CALD participants, by gender

	Male		Female		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Rejection by family	20	44.4	10	66.7	30	49.2
Being in trouble with government agency	13	28.9	8	53.3	21	34.4
Children's loss of friends	11	24.4	6	40.0	17	27.9
Other people knowing	22	48.9	11	73.3	33	54.1
Shame	25	55.6	12	80.0	37	60.7
Loss of job	20	44.4	3	20.0	23	37.7
Inability to have sex	11	24.4	2	13.3	13	21.3
Inability to marry	6	13.3	5	33.3	11	18.0

Table 21: Where participants believed they had been infected with HIV, by background and gender

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Background						
Australia	27	44.3	38	71.7	65	57.0
Overseas	22	36.1	3	5.7	25	21.9
Don't know	12	19.7	12	22.6	24	21.1
Total	61	100.0	53	100.0	114	100.0
	Australia		Overseas		Don't know	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Gender						
Male	23	51.1	13	28.9	9	20.0
Female	3	20.0	9	60.0	3	20.0
Transgender	1	100.0	0	0.0	0	0.0
Total	27	44.3	22	36.1	12	19.7

Table 22: Participants who knew or did not know someone HIV-positive before being diagnosed

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Knew someone HIV-positive	19	31.1	28	52.8	47	41.2
Did not know someone HIV-positive	42	68.9	25	47.2	67	58.8
Total	61	100.0	53	100.0	114	100.0

Table 23: Participants who knew where to go for HIV testing

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Knew where to go	50	82.0	46	86.8	96	84.2
Did not know where to go	11	18.0	7	13.2	18	15.9
Total	61	100.0	53	100.0	114	100.0

Table 24: Participants who suspected being HIV-positive before being diagnosed

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Suspected being infected with HIV	8	13.1	18	34.0	26	22.8
Did not suspect being infected with HIV	52	85.2	33	62.3	85	74.6
Did not know	0	0.0	2	3.8	2	1.8
N/A	1	1.6	0	0.0	1	0.9
Total	61	100.0	53	100.0	114	100.0

Table 25: Disclosure of HIV serostatus to others

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Disclosed	44	72.1	50	94.3	94	82.5
Did not disclose	17	27.9	3	5.7	20	17.6
Total	61	100.0	53	100.0	114	100.0

Table 26: Persons to whom participants had disclosed their HIV serostatus

	Disclosed		Did not disclose		N/A	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
CALD participants						
Wife/husband/partner	33	54.1	3	4.9	25	41.0
Family member in Australia	23	37.7	31	50.8	7	11.5
Family member in home country	8	13.1	52	85.2	1	1.6
Regular doctor	28	45.9	20	32.8	12	19.7
Work mate	2	33.0	40	65.6	19	31.1
Neighbour	0	0.0	61	100.0	0	0.0
Close friend in Australia	12	19.7	49	80.3	0	0.0
Close friend in home country	1	16.0	58	95.1	2	3.3
Religious leader	0	0.0	55	90.2	6	9.8
Anglo-Australian participants						
Wife/husband/partner	36	67.9	1	1.9	16	30.2
Family member in Australia	40	75.5	11	20.8	2	3.8
Family member in home country	1	1.9	3	5.7	49	92.5
Regular doctor	41	77.4	7	13.2	5	9.4
Work mate	19	35.8	22	41.5	12	22.6
Neighbour	13	24.5	39	73.6	1	1.9
Close friend in Australia	44	83.0	8	15.1	1	1.9
Close friend in home country	0	0.0	4	7.5	49	92.5
Religious leader	3	5.7	20	37.7	30	56.6

Table 27: Length of time after diagnosis before disclosure to partner

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Same day	22	36.1	17	32.1	39	34.2
Within 1–2 weeks	3	4.9	4	7.5	7	6.1
Within 1 year	4	6.6	2	3.8	6	5.3
Several years later	4	6.6	4	7.5	8	7.0
N/A	28	45.9	26	49.1	54	47.4
Total	61	100.0	53	100.0	114	100.0

Table 28: Length of time after diagnosis before disclosure to someone other than partner

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Same day	10	16.4	21	39.6	31	27.2
Within 1–2 weeks	8	13.1	12	22.6	20	17.5
Within 1 year	10	16.4	11	20.8	21	18.4
Several years later	2	3.3	4	7.5	6	5.3
N/A	31	50.8	5	9.4	36	31.6
Total	61	100.0	53	100.0	114	100.0

Table 29: Did HIV/AIDS affect participants' socialising?

	CALD		Anglo-Australian		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Yes	39	63.9	29	54.7	68	59.6
No	22	36.0	24	45.3	46	40.4
Total	61	100.0	53	100.0	114	100.0

Table 30: Views of various statements about changing attitudes towards HIV and people living with HIV/AIDS

	Agreed		Disagreed		Don't know	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
CALD participants						
Availability of medication reduces concerns about HIV	17	27.9	33	54.1	11	18.0
HIV-positive people are more accepted	3	4.9	53	86.9	5	8.2
Early HIV diagnosis is important	56	91.8	0	0.0	5	8.2
HIV has a negative effect on ability to work	16	26.2	25	41.0	20	32.7
HIV-positive people can live normal lives with medication	47	77.0	4	6.6	10	16.4
Anglo-Australian participants						
Availability of medication reduces concerns about HIV	30	56.6	21	39.6	2	3.8
HIV-positive people are more accepted	20	37.7	28	52.8	5	9.4
Early HIV diagnosis is important	51	96.2	0	0.0	2	3.8
HIV has a negative effect on ability to work	23	43.4	26	49.1	4	7.5
HIV-positive people can live normal lives with medication	42	79.2	6	11.3	5	9.4