

poslink

Issue 74
Spring/Summer 2016

CULTURALLY AND LINGUISTICALLY DIVERSE *'Equity and access'*



UPTAKE OF TREATMENTS IN CALD COMMUNITIES

Suzy Malhotra and Tony Maynard

As we approach the end of 2016, it's a good time to assess how well we have done in supporting all of our communities to have access to effective treatments.

The 2016 Annual Surveillance Report from the Kirby Institute, shows that the number of HIV notifications newly diagnosed in Australia has remained stable for the past four years, with 1065 notifications in 2012, 1030 in 2013, 1082 in 2014 and 1025 in 2015. The main route of HIV transmission in Australia continues to be sexual contact between men, which accounted for 68% of notifications in 2015. Overall, no jurisdiction has observed a long term decreasing trend in the past ten years, though very recent data from NSW and Victoria suggests that there has been a noticeable drop in new infections over the last two quarters as the various PrEP Trials have been rolled out.

One section of this national score card where we have room for improvement is with our cultural and linguistically diverse communities (CALD), and the Aboriginal and Torres Strait Islander (ATSI) population.

Of the 20% of new HIV diagnoses attributed to heterosexual sex, 19% were in people born in countries recognised by UNAIDS as having a national prevalence above 1% (high prevalence), and 17% in people with sexual partners born in high prevalence countries. This group also fared worse with respect to diagnosis,

treatment and care than their gay counterparts in that over the last five years the proportion of late diagnoses was highest in people born in Southeast Asia (48%) and Sub-Saharan Africa (46%). Among Aboriginal and Torres Strait Islanders, the rates of HIV infection was more than double the rate of Australian born, non Indigenous population (6.8 versus 3.1 per 100,000).

If we are to come close to fulfilling the 2020 UNAIDS targets that 90% of all people living with HIV will know their HIV status; 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy and that, 90% of all people receiving antiretroviral therapy will have viral suppression, then we need to engage better with these communities in providing culturally appropriate education and empowerment whereby they seek testing and treatment at similar rates to the rest of the community. In the 30 years of this challenging epidemic, there has never been a more hopeful time for PLHIV. We now have the data that proves that the earlier someone starts treatment the better it is for their health and the life span for PLHIV is equivalent to those not living with the virus.

Treatments themselves have undergone a revolution in recent times as well. Often the reluctance to start HIV treatment is driven more by the memories of the awful, toxic treatments before 2005. Today, most people can be prescribed a single-tablet regimen that is taken once a day and has very few, if any, side effects.

If there's one thing we would like to remind you during this festive and New Year season it's this: if you have ever been exposed to a high risk situation for HIV infection, get tested. And if the test is positive, it's not the end of the world. There are great doctors in Victoria who you can trust and will work together with you to find a treatment that suits you to get your life back on track.



COMPASSIONATE ACCESS TO HIV DRUGS

Tony Maynard

Tony Maynard is the former Treataware Project Officer of the National Association of People with HIV Australia (NAPWHA)

In early 2002, I was entering a new relationship and found out that my then HIV positive partner was here in Australia on a visa that did not give him access to Medicare. Although he was eligible to work and pay taxes which ironically included a Medicare levy, it didn't allow him to access the benefits of access to Medicare.

Due to my work in the HIV sector, I was able to connect him to a clinical trial of some new antiretroviral (ARV) therapies which, for the duration of the trial, would give him access to medication and HIV care and monitoring. Until then we had to personally import generic ARVs from a company in India known for being a reliable supplier that produced generic copies of the drugs with the correct amounts of active ingredients. This all required a huge leap of faith. I was working part-time at the National Association of People Living with HIV (NAPWHA) and in discussion with colleagues, we realised my partner's plight was far from being an isolated incident. In fact, surveys and estimates from around Australia showed that about 450 HIV positive people are in the country at any one time, residing legally on working and student visas with no access to HIV medications.

From this, the idea of setting up the Australian HIV Observational Database Temporary Residents Access Study (ATRAS¹) was formulated. Together the Kirby Institute and NAPWHA managed to reach an agreement with all seven of the pharmaceutical companies supplying ARVs within Australia to support a study of 180 Medicare ineligible HIV positive people for a four year period, follow up the outcomes over that period and supply them with the required ARVs free of charge. The aim was that over the duration of the study, the barriers to ARV access could be overcome at all levels of government and anyone who required access to HIV monitoring, care and treatment would be able to do so.

The study began in November 2011 and finished in November 2015. Many of the participants, due to changes in visa status, have become eligible for Medicare, become permanent residents or returned back to their country of origin. However, by the end of the trial, there were still more than 60 people left in the study who were still without access to Medicare and had very limited options to access ARV treatment.

State and territory health departments have all agreed in principle that these participants should have ongoing treatment access, although the specific mechanisms for achieving this still remain unclear. But the question remains - what are we going to do on an ongoing basis to treat not only the people left on this study, but any other HIV positive people residing legally in Australia that have no way of accessing HIV medication other than importing generic ARVs through online international distribution sites? Clinical trials of new medications were a way for these people to access treatment but right now there is a drought of new anti-HIV medicine trials. As a fall-back position, some of the pharmaceutical companies have responded positively to requests and pleas from individuals and their doctors, to provide them with drugs free-of-charge for some patients on humanitarian grounds. It is commendable that some companies do respond positively. Nonetheless, a number of pharmaceutical companies are now refusing to carry the responsibility for free access to medicines, saying (quite rightly in my opinion) 'that the responsibility for providing HIV treatments lays with the national government, not the pharmaceutical companies.'

The ATRAS has clearly shown in its mathematical modelling, that it makes good economic sense to treat all people with HIV to prevent onward transmission. If all HIV positive temporary residents who are ineligible for Medicare are successfully treated, estimates show that around 81 new HIV infections would be averted over five years. While this is a significant public health benefit of itself, it also means that those 81 people will not be facing the challenge of living with HIV and possibly having no access to ARV.

The cost of treating those ineligible for Medicare over five years would be approximately \$23.4 million corresponding to a median cost per infection averted of around \$320,000. However, the lifetime cost savings from the people who would otherwise have been infected results in a cost saving of over \$69 million!

The current unsatisfactory situation of not treating the 450+ people can no longer be ignored. Doing so will only prove to be more costly not only in terms of people wellbeing, quality of life and productivity, but also in terms of the lifetime costs of treatment and care of an ever growing number of people becoming infected with and consequently living with HIV.

Australia's Seventh National HIV Strategy has as one of its overarching goals, the virtual elimination of HIV transmission by 2020. This commendable goal will only have a chance of being achieved if treatment access is provided to all people who are living with HIV regardless of their visa or Medicare eligible status.

1 <https://kirby.unsw.edu.au/publications/australian-hiv-observational-databasetemporary-residents-access-study-atrasmar-2015>

CROSS CULTURAL RELATIONSHIPS

Peter Davis

I met my future wife in a community theatre production about a supermarket, in which I played the role of a shop thief and busker, while she was a checkout operator. I developed a crush on her during rehearsals but acted frigidly around her due to my being HIV positive.

Maria and I became very close buddies outside rehearsals but she did not know that I was HIV positive. I thought she was attractive but lacked the courage to ask her on a date. Due to my inner-stigma about being HIV positive, I never thought a woman would be interested in me particularly if she was HIV negative. It was 1990 and HIV/AIDS stigma was at an all-time high with the general public.

Meanwhile, Maria's parents were trying to arrange a marriage for her, as had been customary back in their small mountain village home in northern Greece. They had paid money to privately educate their daughters and held high hopes that they would marry a doctor, lawyer or accountant. They certainly wouldn't choose someone for their daughter like me – non-Greek, HIV-positive and on a gap year from an arts degree at university.

Two weeks before the play season began, Maria asked me to go out so we could rehearse our lines together. We met in the city and walked to the nearby Yarra River. When we got to the kissing scene, I sensed she gave more than just a peck on the cheek as the script required. Her intimate feelings were revealed through these pretend kisses. I felt wonderful, but I also felt the weight of when or how would I disclose my HIV positive status to her.

Once before in my life, I had tried waiting a few months to disclose being HIV with another girl I'd dated. She became angry that I hadn't told her before we'd even started to kiss. We never had sex but many people still didn't know HIV couldn't be passed on via social contact. After that experience I became celibate until meeting Maria.

I told her that I had feelings for her too. That same afternoon I also told her that I was HIV positive as we were saying goodbye under the clocks at Flinders Street Station. Maria looked shocked, went pale and was silent for a minute after my disclosure. She then told me she had no idea that I was HIV positive because I looked so healthy, but also that she needed to think and asked if we could speak later. I was still feeling elated at her declaration of feelings but also saddened by her swift departure.

Maria phoned the day before our next rehearsal and wanted to meet. When we were together she asked about the woman I'd been with in a relationship during my diagnosis and what had occurred after she then tested HIV negative? She asked, "Did you both continue to be lovers? Is that possible?"

I can recall all Maria's words that day. It was the most tender and straightforward conversation of my life. She asked, "Isn't there some way that we could be boyfriend and girlfriend, even if we just do some of the things that lovers do, I'd be happy. I love you." I didn't feel able to answer all her questions about safer sex with sufficient objectivity, so we visited a social worker and my doctor at Royal Melbourne Hospital. The social worker helped most because he'd researched

medical reports about the risks in HIV sero-discordant couples.

We were told that the risk was negligible with safer sex (using condoms and water based lubricant). In 2015, with an Australian HIV population nearly all having undetectable viral load, Maria's and my story about safer sex may seem unspectacular, but in 1990 this research was cutting edge. The first time Maria tested for HIV, she fainted in the clinic while waiting for her result. I realised then how much she'd kept her fears hidden. A year later, we were in Mexico and ran out of water-based lube and a condom broke, which became another nervous wait but she still remained HIV negative.

Our first year dating wasn't easy because we couldn't hold hands or cuddle in public. Maria feared people from a Greek orthodox background might see us and then tell her parents.

After a year of secrecy we decided upon a world trip together. Maria told her family she'd been selected for a field trip after graduation and her parents reluctantly gave permission. We were finally able to spend our first whole days and nights together.

It took another year for her family to accept our relationship. The night before our marriage, her father tried to bolt the house but Maria escaped through loosening a window. There were many people from my family at the wedding and Maria had support from her friends.

Maria felt her parents would freak if they knew I was HIV positive. She has never felt able to tell them. Her parents never learnt English

in decades of living in Australia, perhaps due to the lack of support services for migrants in that era. They also lived in a small social circle inside Melbourne's west with people they'd known from their Greek village and fellow immigrants who also worked in factories where not much English speaking was required.

After our son was born, Maria decided to tell her family that we'd used a sperm-donor program via hospital because I was infertile. Our boy is 12 now and has had to learn that some people know about daddy being HIV positive and that many others aren't informed. It is hard for him to learn and understand the stigma which surrounds HIV but he has gradually adjusted. I'm proud to say he was voted a school captain in his last year of primary school.

It is important to give families a chance to be supportive about HIV and to disclose. I believe in a CALD context, HIV disclosure would have been easier if we'd accessed interpreters who were also experienced HIV counsellors. Some families may react adversely to HIV regardless from a CALD background. My ethnic background is Irish and English and my father hasn't accepted or supported my being HIV for over twenty years. He is the only family member in my life that hasn't reacted lovingly.

Wherever there is passionate love there can also occasionally be passionate loathing. Normally family members do continue loving one another after HIV disclosure. People possess the same basic capacity to care; some just need time to adjust to information that is unfamiliar to them.

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