

Are you clean?

Created 26 Feb 2010 - 3:11pm

It has become a favourite on online dating sites as the 'polite' way to ask about HIV status. Just for the record, it is not polite. It is both stigmatising and discriminatory.

A friend said to me recently that he thought stigma and discrimination against HIV positive people must have decreased in recent years in direct proportion to the way our treatments and prognoses had improved.

My friend is well-connected. He has supported many of us through our trials and tribulations over the years while managing to remain HIV negative himself.

'Surely society is more accepting of people with HIV in an era when it is not such a fearful disease and when people are more out about their status?' he asked.

I would like to agree with him. But while acknowledging that things are generally better in the lives of HIV positive people, recent research into levels of stigma and discrimination against us suggests that in some ways, it may actually have got worse.

A report prepared by consultants for [AFAO](#) [1] Australian Federation of AIDS Organisations. AFAO is the peak non-government organisation representing Australia's community-based response to HIV/AIDS. AFAO's work includes education, policy, advocacy and international projects. and NAPWA last year came up with some rather startling findings about the attitudes of HIV negative gay men towards people with HIV. [1](#)

These findings were supported by a survey conducted by NAPWA and co-authored by Ronald Woods and myself. The survey found high levels of stigma were still being experienced outside the gay community, and that many felt that negative attitudes had not changed much in the last twenty years. [2](#)

The consultants' report surveyed approximately 90 gay men from metropolitan and regional locations, used discussion groups and some telephone interviews. Some groups were segmented according to HIV status, others according to age and some included HIV positive and negative men together.

The consultants found a particular lack of awareness and knowledge of HIV amongst gay men in their early twenties, and this only changed for people in their late twenties and older if they knew people with HIV. According to the report, 'those who claimed to have little or no personal experiences of anyone living with HIV were often openly negative and discriminatory in the way they discussed [PLHIV](#) [2] Person (or people) Living with HIV. This term is now preferred over the older PLWHA..' [3](#)

Most HIV negative men readily admitted to being aware of a labelling and stereotyping of HIV positive men among gay men generally. Many younger men in particular believe they can identify someone as HIV positive by their physical appearance, strongly believing in the stereotype of an older thin man with sunken cheeks.

Many readily articulated an 'us and them' attitude. Some negative men openly refuse to engage with positive men via the Internet and try to avoid any physical associations with them. The language they use clearly differentiates us, associating positive men as belonging to different 'clubs' or 'teams'. [4](#)

The consultants found that it was common to identify HIV positive men as 'unclean', and to liken sexual interactions with them to 'loaded guns', 'playing Russian Roulette' and 'poison'. In the view of the consultants, this language likens HIV positive men to criminals, and as a criminal would be marginalised from mainstream society and stripped of certain rights, so are some HIV positive men in the view of others. [5](#)

It is not surprising then to hear that the positive men surveyed reported that within the gay community, discrimination occurred in sexual situations (both potential or realised) more so than elsewhere. This discrimination occurred with both physical rejection and within the language used to ask about serostatus, with many believing that there was an increasing prevalence of other men asking 'Are you clean?'

Some HIV positive gay men also spoke about having their status discussed as a warning to others at a venue. And that the prospect of these details becoming known amongst gossiping gay men in their social circles was possibly a greater fear than one-on-one rejection — a form of social ostracism that could lead to feelings of shame and low self-esteem.

One of the few bright notes to come out of the discussions was when participants admitted to being in a serodiscordant (positive-negative) relationship. Both HIV positive and negative participants were surprised to hear these revelations and it seems the ability of some people to have successful relationships with someone of a different status had a positive influence on changing some attitudes.

Why could stigma and discrimination be increasing?

When I read the above report, I was quite shocked about its findings. Personally, I don't feel this level of ostracism from the gay community or society in general. I think that most HIV positive people feel safer and more accepted now, compared with the early years of the epidemic. HIV is treated far more sympathetically by the media these days and there is less general fear about the ways it is transmitted.

The problems though, as the consultant's report points out, are in the climate of sexual negotiation for HIV positive people — where the stigma about revealing your status is still a major issue.

The consultants give their reasons about why they believe stigma and discrimination is increasing. They suggest there is less need for gays and lesbians to come together as a community. Greater social and legal acceptance means we mix more freely with mainstream society, including at social venues — and that this leads to less exposure to HIV positive people.

There is also the impact of the Internet, where gay men are much more likely to meet a sexual partner online than at a gay venue. This anonymous environment makes it easier for people to express opinions and to discriminate against those who are prepared to identify as HIV positive. (It must also be said that the online environment can make it easier to meet someone of the same serostatus and to 'serosort' which can be useful for positive people who want to meet other positive people.)

The consultants also suggest that the improvements in HIV treatments — and the reduction in their side effects (such as the tell-tale signs of lipodystrophy) — have possibly contributed to HIV positive people not feeling the need to tell others about their status. If you can't tell by looking or you are not likely to become seriously ill with HIV, do you need to tell the world?

In my opinion, this is where the implications of stigma and discrimination really impact. If it is increasing against positive people and the acceptance and experience of HIV positive people is also diminishing in the gay community, there must be implications for HIV transmission as a result. If you are not going to disclose for fear of very negative repercussions then you are caught in a bind if an episode of unsafe sex happens, maybe by accident for instance. If you get serious with a sexual partner, there is no hiding the need to disclose at some stage in your relationship.

The psychological effect of holding secrets inside you can be detrimental. I'm not suggesting that everyone needs to come out to all and sundry (as I have done over the years, with no real regrets) but having a good group of friends (and family) who know and who are supportive is a wonderful backstop in your life. It can give you the confidence to accept being HIV positive and to not to develop feelings of shame or worthlessness because of your status — negative sentiments that some of the participants in the survey above expressed.

Many of us have built up such a fear about people's reactions if we disclose that we imagine all sorts of repercussions that are not likely to happen at all.

Living with HIV outside the gay community

NAPWA asked Ronald Woods and me to interview a range of HIV positive people around the country to complement the research done by the consultants on gay men. We conducted 20 in-depth interviews with representatives from the following affected communities: women, heterosexual men, people from a culturally and linguistically diverse (CALD) background, Aboriginal and Torres Strait Islanders and people with haemophilia.

Our interviews produced no brighter revelations than the consultants'. In fact, I think our interviews revealed that a more pervasive stigma and discrimination is still being experienced by people living with HIV outside the gay community. Without the awareness in the broader community created by prevention campaigns about HIV, positive heterosexuals report a much greater sense of isolation about their HIV status and a great fear of increased stigma and discrimination if these details were to become known.

Positive women still have to deal with ill-informed medical professionals making judgments about their lifestyle when told about their status. Positive heterosexual men we interviewed expressed the huge difficulty they experienced finding partners with whom they felt confident enough to disclose.

People from CALD backgrounds live in constant fear of rejection by their families and communities if their status becomes known, with parents refusing to seek out childcare or translators from their communities in case details of their HIV are somehow revealed.

People with haemophilia and HIV will often not tell anyone but their immediate family for fear that they will be ostracised by their community. Most people with haemophilia are not HIV positive (with the blood supply now protected) but misinformed community perceptions from the eighties still affect this population.

How can we change this situation?

Many interviewees we spoke to said there had been no mainstream anti-stigma and discrimination campaigns around HIV since the early nineties and they think the time is ripe to remedy this situation. AFAO and NAPWA are working with the Federal Government to develop responses that will address the issues during the implementation of the next national HIV strategy.

What form these responses will take and what outcomes they will deliver is going to be a major talking point for HIV sector agencies over the next year or so. The consultants suggest that, to begin with, the equation of 'HIV=Prevention' which has so dominated AIDS Council campaigns for years needs to be changed in subtle ways so that the negative perceptions of HIV do not include people with HIV. Basic information about how HIV is transmitted and the experience of people living with HIV needs to be included in these messages. A staged campaign, which sets about showing people the ugliness of HIV-related stigma and discrimination, could follow with messages that promoted inclusiveness and openness amongst gay communities over the issue of serostatus.

Turning around societal attitudes is never simple.

I was heartened to see a website called StigmaWatch developed by SANE Australia to try to combat the stigmatising descriptions and portrayals of mental illness in the media – and to read that, by using personal stories from a number of celebrities and others, the experience of living with depression has become more accepted by the community than in the past.

Maybe it will be possible to influence broad community perceptions and ignorance around HIV as well through similar means?

I do think that any campaign must also concentrate on giving positive people the confidence to tackle their own internalised sense of stigma about having HIV. Many of us have built up such a fear about people's reactions if we disclose that we imagine all sorts of repercussions that are not likely to happen at all.

Despite the negative emotions expressed by some people in the surveys above, there are many people who will be totally supportive if you reveal details of your status.

If AIDS Councils, PLHIV organisations and other HIV sector agencies can come up with ways to support people on disclosure, people may find it easier to get rid of their own sense of stigma about having HIV.

1. [1.](#) V. Parr, C. Burkitt, and A. Jennings, Formative Research for the National HIV Stigma and Discrimination Precampaign Development, Qualitative Research Report prepared for AFAO and NAPWA, GfK bluemoon, August 2009
2. [2.](#) R. Woods and D. Menadue, Stigma and Discrimination towards HIV-positive people in diverse communities around Australia, Report to NAPWA, October 2009
3. [3.](#) Op cit. Parr et al, p 6
4. [4.](#) Ibid. Parr et al pp 6 and 7
5. [5.](#) Ibid. Parr et al, p 7

- [living with HIV](#)
- [disclosure](#)
- [discrimination](#)
- [relationships](#)
- [stigma](#)

Links:

[1] <http://www.napwa.org.au/glossary/term/385>

[2] <http://www.napwa.org.au/glossary/term/689>