

Positively identified

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Do you think being HIV positive is a part of your identity? Part of who you think you are as a person – or something less significant, a medical condition that you live with comparable to say, asthma or [diabetes](#) [1][Diabetes mellitus] A disorder in which sugars in the diet cannot be metabolised into energy due to a lack of the enzyme insulin. Late-onset diabetes mellitus may be a long-term side effect of some anti-HIV drugs.?

I asked this question of twenty of my HIV-positive friends – some quite connected to HIV organisations, some not at all; some older, some younger (although only one was under 30, unfortunately); some who have been quite ill with

Of the 15 responses, 11 said that they had an HIV identity, two said they used to but it had waned considerably post [HAART](#) [2]Highly Active AntiRetroviral Therapy ??? aggressive treatment of HIV infection using several different drugs together., one felt that it no longer existed (he had “moved on”) and another said that the [virus](#) [3]A small infective organism which is incapable of reproducing outside a host cell. had never meant anything to his identity.

I’m not going to claim some scientific validity to this straw poll, but identity is a highly personal thing and if intelligent people whom I respect believe they have an HIV identity for very lucid reasons (as you will see) then that needs to be treated seriously in my opinion. As do the opinions of those who believe it doesn’t exist, or has ceased to exist in the world post HAART where crucial issues which might lead to the need to identify with other people with HIV – such as facing up to your mortality, trying to cope with a highly stigmatised condition (particularly in the eighties and early nineties) and dealing with the grief and loss from the deaths of so many friends – are no longer part of the landscape for people who are newly diagnosed with the virus. There may be implications of any changes in thinking around this identity question for the ‘ PLWHA movement’ as it exists today and for service providers in the sector.

NAPWA board member Brent Allan described the way he sees a positive identity. “All identities are fluid, they change over time and are influenced by contexts and relationships inherent in those spaces. Sometimes I feel very poz, such as when I’m around other poz people, other times it barely registers. When I am sick I’m poz; when I disclose I’m poz. Most of the time I feel like me – a mixture of identities, Canadian, gay, middle child, poz, married, stubborn and so on.”

Ian, an Aussie working with the World Health Organisation overseas, agrees that it is only one element of his identity but an important one. “There are a number of reasons why I feel I have a positive identity. It’s partly metaphysical – coming from the experience of having faced one’s mortality and survived so far. It’s partly practical – coming from the shared experience of taking pills, monitoring one’s health and other aspects of treatment and care. It’s also partly shaped by social attitudes to people living with HIV/ AIDS (both positive and negative) and to those groups it so often affects (often marginalised groups such as gays and injecting drug users). And there’s the political aspect in the form of the international movement that people living with HIV/AIDS have created for themselves over the last twenty years. All these factors have combined so that no matter where I travel around the world I feel a kinship, a powerful sense of belonging with other people with HIV.”

Arthur is more reserved about its impact but acknowledges its importance. “I have a HIV-positive identity but only when I chose to or when I use it so that it doesn’t control me in any way. I control it! To me identity is about something that you are proud of and what is reflected in your personality, behaviour and belief systems – how I think. I don’t think my HIV status does affect those things in the same way as being a gay man or being from an Italian background does. These things affect the way I feel about the world or my perspective on life. I suppose my

For those heavily involved with HIV activism, there is often a necessary association with HIV identity. NAPWA’s International Portfolio Co-Convenor John Rock says, “In my case my HIV identity developed as I became more personally involved in voluntary HIV work. If I did not have this identity I would not be a credible advocate and not open enough to do the work I do.” John believes that if you are ‘out’ about your HIV status and particularly if you are publicly identifying as HIV-positive (such as through advocacy work) then you have an HIV identity. Even so John acknowledges that as he is on [salvage](#) [4][salvage therapy] A treatment strategy for managing HIV in people who have developed resistance to existing therapies. therapy and still has a real concern about his treatments

future, it is harder for him to see HIV as a small part of his life – which people newly diagnosed or having few complications with the virus may be able to. He thinks that ‘moving on’ from concerns about HIV in your life is harder if you are not doing so well clinically.

However one friend, who has had HIV since the early nineties and who was involved with the HIV sector for a number of years, vehemently disagrees with the concept of an HIV identity. “It’s about self oppression and victimisation. There is a difference between openly acknowledging being a person with HIV and having that as an identity. Defining oneself by a virus seems to me to be oppressive,” he says.

Different for the Newly-Diagnosed?

Stephen Gallagher, a former treatments advocate and policy adviser with ACON, says that for most of the newly-diagnosed clients he has seen in his work, the notion of identity based on HIV status is absolutely foreign to them, compared with clients he was working with back in the mid-90s. “Even though many of them have positive friends, HIV discussions do not occur and for the most part they made an appointment with me because of a referral from their GP or clinic. They usually stated that they didn’t need the services of ACON or PLWHA NSW because they’re well and don’t feel the need to network with other people living with HIV.”

In ‘Genesis’ groups for the newly diagnosed, the participants frequently distance themselves from those positive people whose identity is pronounced. “They associate HIV identity with age, having been sick and/or being on a pension,” says Stephen. Their concerns lie more with non-health related concerns, he explains. “They worry about travel restrictions, insurance, career planning and goals, mortgages and the legal requirements to disclose to sexual partners.”

Glenn Flanagan runs an after-hours drop-in group with PLWHA NSW. He believes in the value of peer support for newly diagnosed guys. “They come to our group, desperate to ‘normalise’ the experience of living with HIV but soon work out that it isn’t always an easy task,” says Glenn.

“They want it to be just like any other manageable chronic illness but realise that there are moral issues and a stigma associated with HIV that can make it different. It is also hard to ‘normalise’ HIV in your life if you don’t know much about it. One of the reasons pos guys came to peer groups is to try to do this by sharing their experience with other guys of the same status.”

For some newly-diagnosed then, the experience of mixing with positive peers is still a valuable one – whether this in itself leads to a greater identification with being HIV-positive is perhaps not so clear.

Greg, who has been HIV-positive for over 20 years, says that the changes that HIV brought into his sexual life were profound. The realisation that he had a serious communicable disease curtailed some of his sexual activity, he says. “Even today when treatments have made us less infectious, having to curb sexual practices, one of the most basic urges for most people, will always have a debilitating effect on you. I believe I have an HIV identity because HIV has changed me, changed my relationship with my HIV-negative partner, changed the person I am today. Having to leave work because of the virus for a time, and then returning to the workforce along with losing so many friends in the nineties; it all has a massive effect on who you are.”

Research on Identity

There is little in the way of research about HIV identity, particularly in the way it may have changed post HAART. Perhaps the most pertinent is a research paper by Michael Bartos and Karalyn McDonald from the [Australian Research Centre in Sex, Health and Society](#) [5] (ARCSHS), published in *AIDS Care* in 2000¹. The authors interviewed participants from the [HIV Futures](#) [6] study in 1997, and concluded that those people who were most tied to an HIV identity tended to be gay men who conflated it in with being gay and part of the gay community (talking about ‘coming out as HIV positive’ but not believing in an ‘HIV community’). These people were less likely to see the possibility of a cure for AIDS – in fact a cure would somehow defeat the importance of their identity. This suggests that these people had a fragile sense of their own identity (although being gay was central) until HIV

The research found that there was also a group, often heterosexuals with HIV/AIDS, who saw HIV as an

experience (albeit one that would probably last forever). The infection was an ‘accident’ that did not integrate into their sense of self. However the one heterosexual in my interview group, Adam, who has had HIV for many years, does feel he has an HIV identity because of the strength of peer support he got from other positive people. “We both have a common assailant that has disturbed our peace and happiness,” he says.

There was a third group in the ARCSHS study for whom HIV was all-consuming, who believed it was an aspect of identity but who separated that from the self because involvement with HIV was ‘something you do’ or a career. They were very likely to believe in the existence of an HIV community and a potential cure.

These research findings have to be tempered with the knowledge that in 1997 when the interviews took place, the success of treatments was still unclear. Interviewees would have been more likely to be unwell and to have difficulty believing that the [effectiveness](#) [7](Of a drug or treatment). The maximum ability of a drug or treatment to produce a result regardless of dosage. A drug passes efficacy trials if it is effective at the dose tested and against the illness for which it is prescribed. In the standard procedure, Phase II clinical trials gauge efficacy, and Phase III trials confirm it. of treatments – and a sense of future hope – would be sustained.

The first group in the ARCSHS study – those who most clung to the concept of an HIV identity – do not seem to fit with the views of the people I interviewed above. All of my interviewees today believe that treatments will give them a prolonged life. They seem to have assimilated an HIV identity into their lives in a functional way unlike the earlier

So what conclusions can we draw? My views were mixed when I came to this topic because, like Arthur, I have thought of identity as something you like about yourself, something integral to your personality and belief systems. I wasn’t sure that something negative like HIV was capable of doing that. But like Greg, I had to admit the changes

If there was ever a time that I was making a statement about being HIV-positive it was when I stood before the television cameras from most of Melbourne’s TV stations representing PLWHA Victoria in 1989, speaking against a local council’s refusal to grant a planning approval for our Positive Living Centre. What followed over the years was many media interviews, talks to schools and community groups, articles on HIV for this and other papers which have probably tagged me as some kind of public HIV identity.

The need for representation

HIV-positive people will need representation of some kind for as long as we need access to treatment, welfare or care and support, or experience stigma and discrimination. No matter what happens to people’s fluid personal identities around HIV, as long as there is a perceived need for conditions to improve in society for positive people there will be a need for an HIV organisational identity of some sort, I think.

If newly diagnosed HIV-positive people do not wish to identify as HIV-positive, would they still not wish to have someone advocate on their behalf if HIV transmission laws were to be made even harsher, to have visa entry regulations into countries like the USA changed, to have their superannuation laws altered so that they can qualify in the future?

There is one issue on which I believe all positive people will acknowledge a kinship, and that is sex. The simple fact of our HIV-positive status changes the way we view sex with others – and the way we are, in turn, viewed ourselves. We have all had to face up to issues around disclosure, potential rejection and the pressure to not to transmit HIV to others. It makes you different from other people in an important way given how fundamental sex is to the expression of who we are. But does it make for an HIV-positive identity? Probably not in itself – there has to be a significant other level of experience (things like a real threat to mortality, grief and loss, long term survival or some involvement with the HIV sector) to make this more fundamental as a concept.

It probably doesn’t really matter whether you identify as HIV-positive or not but I think it is probably important that there are others who do – or who at least have a strong enough commitment to people with HIV that they support PLWHA organisations in their work. There is also something compelling in Ian’s statement that he feels an almost metaphysical connection with the other positive people wherever he travels around the globe – a kinship or powerful connection because we have been through such a deep, life-changing experience. I know what he means but it’s OK if you don’t. Identity is, after all, a very personal thing.

¹ Bartos, M. and McDonald K., “HIV as identity, experience or career”, *AIDS Care* 2000 (Vol 12, no 13, pp299-306)

- [newly diagnosed](#)
- [living with HIV](#)
- [Gay and bisexual men](#)
- [social research](#)
- [stigma](#)

Links:

[1] <http://www.napwa.org.au/glossary/term/95>

[2] <http://www.napwa.org.au/glossary/term/96>

[3] <http://www.napwa.org.au/glossary/term/125>

[4] <http://www.napwa.org.au/glossary/term/111>

[5] <http://www.latrobe.edu.au/arcshs>

[6] <http://www.napwa.org.au/?q=taxonomy/term/293/9>

[7] <http://www.napwa.org.au/glossary/term/486>

[8] <http://www.napwa.org.au/glossary/term/477>