

The (Multi-) Cultural Dynamics of Disclosing HIV Status and Implications for Support

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The National HIV/AIDS Strategy acknowledges that people from culturally and linguistically diverse backgrounds may belong to one or more priority groups

- gay and homosexually active men
- injecting drug users
- people living with HIV/AIDS.

But it is also acknowledged that they have specific requirements concerning HIV/AIDS-related health promotion.

This study is a collaborative project between the National Centre in HIV Social Research and the Multicultural HIV/AIDS and Hepatitis C Service.

[slide: Aim]

The aim is to investigate the lived experience of HIV-positive people from culturally diverse backgrounds, that is, the intersections of living with HIV and belonging to ethnic and cultural groups outside the Anglo-Celtic mainstream.

The focus is on common issues across and cultures or ethnicities and risk exposure categories.

[slide: Method]

Participants were recruited among the clients of the Multicultural HIV/AIDS and Hepatitis C Service and a sexual health clinic. Data were collected through in-depth semi-structured interviews.

In this paper we focus on the social and cultural dynamics of disclosure in families

and ethnic communities, and implications of this for practical and emotional support.

[slide: Demographics]

- 28 interviews
- 7 female, 21 male
- 8 participants had children
- Median age: 38 (range 29 to 58)
- Median year of arrival in Australia: 1995 (range 1973 to 2001)
- Median year of HIV diagnosis: 1997 (range 1984 to 2003)

[slide: Country of origin]

Participants were born overseas, predominantly in countries in South America and Asia. One gay man was born in Australia and identified as Greek Australian.

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- Education ranged from no formal education due to war to postgraduate
- 20 participants worked (including home duties) or studied, or did both
- 11 lived alone, 16 lived with a partner, family, flatmates/friends, children

Culture is a very complex issue and I don't even want to attempt to give a definition here, but I do want to raise a couple of issues as they are relevant to migration:

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- Cultures are not static elements but dynamic, and some aspect of a culture change more than others, some change faster, others more slowly, and some don't change at all. And this applies (1) to the culture in the country of origin, (2) to the culture of the new country, and (3) the ethnic culture in the new country.
- Secondly, ethnic cultures and communities in Australia are not necessarily homogenous and unified structures but there is diversity within ethnic communities; and
- Thirdly, we move – to varying degrees – between our cultures of origin and our "new" culture, and we move between mainstream and various subcultures, depending on what we're doing, with whom and why.

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We want to argue here that disclosing and not disclosing HIV status is purposeful. "To disclosure or not to disclose" is motivated by the interdependence of individuals and their social environment, especially the family. If disclosure threatens the equilibrium of existing social relations, participants choose not to disclose. But they form new social relations outside their existing networks which can provide the support they need.

One very important element in the decision about disclosure is interdependence with family. For example, when a parent was in a difficult situation where they needed support from their children, participants chose not to tell them about their HIV diagnosis. Non-disclosure here had an altruistic motivation: The parent's problem was put ahead of one's own problem.

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- One gay man was diagnosed with HIV at the same time as his mother was diagnosed with cancer. The family gathered around her.
- Another gay man's mother begged him not to get tested. The man's sister had died already and a brother had committed suicide. The mother couldn't bear the thought of losing another child. He did not tell her about his test result.
- Another gay man thought about telling his father that he had HIV when he returned home for his mother's funeral. But he didn't feel strong enough to support his father after the disclosure.
- A Cambodian woman's mother arranged her marriage to the husband who infected her with HIV. The mother had raised five children on her own in very difficult circumstances. She did not tell her mother that she had HIV because she didn't want the mother to blame herself for a bad choice of husband.

Interdependence means that one person's HIV status affects the whole family. In communities where HIV is associated with shame, this means that the whole family is morally tainted, irrespective of their own action, even very young children. So, non-disclosure becomes a vital mechanism to protect children.

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... it's a shame to have this illness. ... When I was in hospital, there was a pastor. He came and visited me, and he disclosed my problem to other people. That caused a lot of rumour. ... I respect whatever happened, but I'd like my son to be protected. I don't want to have another disclosure. ... When I took my child to church, other children said, "Oh, this person has HIV" and they ran away.

This man does not attend any family support group events for fear that his young child might be affected by his "shame".

Interdependence also means protecting the family name. In cultures where HIV is associated with shame, one person's infection brings shame on the whole group. One Chinese man told us this story, how "shame" is enacted in his family. This is a summary of what he told us.

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The whole family used to get together once a week to share a meal. Since they found out about "his condition", his brothers and sisters have turned their backs on him. They don't come around to see him anymore and merely exchange polite greetings in public. They feel he brought shame on the whole family. One of his siblings with whom he runs a business wants him to hand over his share of the investment because they cannot plan a future for the business with a partner who is sick. Handing over his investment would jeopardize his business visa, which is a temporary visa, his application for permanent residency, and his young child's future.

The importance of family relations is stated explicitly by the following participant:

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My sister-in-law is a very old-fashioned type of person and she worries about everything and she has two sons and I worry that she will worry for me. I don't want my problems to affect our relationship.

And finally, there is interdependence with ethnic community generally. All participants in this study experienced their HIV diagnosis as a terminal illness. When they were diagnosed, they were not aware of the difference between HIV and AIDS.

This is also the general attitude towards HIV in ethnic communities: HIV equals AIDS and AIDS equals death. In this context, not disclosing to anyone is for many participants a vital mechanism to focus on living rather than dying:

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... if people find out I've got HIV, people talk about HIV and, you know, and I might become depressed because of hearing people getting worried about [me] and, you know, always talk about it.

However, the sense of interdependence with family can also be the reason for disclosure, for example, if a positive son is unable to meet his duties in the family. Again, the family's needs are bigger than the needs of the individual, which in this case facilitates disclosure:

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Having thought about it in great detail I decided that I should inform someone and therefore the first person I decided to tell – to disclose – that will be a family member. I told my elder sister and also my second elder brother. They are both in Hong Kong. Because I thought that I have the obligation to inform them of my problem because I have to take care of my mother.

Where voluntary disclosure happened in the family from a sense of "I need support", it was typically to siblings. The important question here is: "If I tell, can they handle it? Can they do anything?" If the answer is No, disclosure serves no purpose.

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I only have an elder brother and a younger brother here. ... Only my younger brother knows but my older brother he is quite old fashioned. Even if he knows he can't give me any help. ... Financially I get support from my elder sister [in Hong Kong] they support me financially as well as psychologically. Mentally my second eldest brother as well as my younger brother gave me a lot of support.

However, siblings are under the same cultural restrictions and even if they want to provide support, they are not always able to do so:

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They [brothers] told me, "José, you are our brother. You have our support." ...
But you see, for them was very difficult too, because again culture. So they
couldn't talk with anybody and I didn't talk with my brothers about it. Obviously
"Are you okay? Are you fine? Are you healthy?" And that's it.

However, disclosure practices vary as people move between cultures and between
communities. People balance the priorities of interdependence, which means to keep
quiet, and their priorities as individuals who need support, which requires disclosure:

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If it concerns privacy and it affects my family I keep it to myself. But if it
doesn't affect my family then I will talk openly.

Interpreter: He also says that in that respect he thinks more like a Chinese.

When he speaks openly he is more like an Australian.

Decisions whether to disclose are made dependent on social context: Whom will I
tell? What do they know about HIV? Why do they need to know that I have it? And,
What can they do for me? The important factors are: knowledge and understanding,
otherwise – what's the point?

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I keep everything confidential to myself. I don't show to anyone. If I can share
it's alright, I don't mind. If it's like this study, or [clinic], or ACON, I don't mind,
I'm open, I talk to people or I'm close to people. But people who can't
understand, I don't share it with them.

Some participants who experienced cultural constraints on sex and sexuality in their
cultures of origin do not feel the same constraints when they move in Sydney's gay
community.

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I'm very happy here. I can talk about my HIV. In Colombia I couldn't do it ...
Because of religion ... and just the culture. 99 per cent of Colombians are

catholic. So you can't talk about sex ... and safe sex.... My experience here is I don't care anymore. More of my close people here know that I'm HIV. If I have sex with somebody I can talk about it, "I have HIV" and I don't feel discrimination.

If participants are not certain whether it's safe to disclose, some test the water first before they jump in. This can reveal people's knowledge and attitudes towards HIV.

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In the Chinese community it's quite difficult to accept [HIV]. I found this out when I called my sister. I did not mention that I have this problem, but I just mentioned HIV, and they think that it is a terrible thing. ... I think among the Chinese community, once you have HIV they think that you have abused a relationship, you know, that you're probably not a good person. ... And they think that this is a shame.

However, not making a formal statement of disclosure to family and friends does not necessarily mean that they don't know about someone's HIV status. There is a difference between knowing about someone's HIV status and acknowledging it. In some families there seems to be an unspoken "Don't ask, don't tell" agreement, something along the lines "We know that you have HIV but we don't want to hear about it and we don't want to talk about it." This means, if a family member's HIV status has no official acknowledgement in the family and in the community, the family remains free from shame and social relations are able to continue.

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co-worker: They [family] all know about her partner's illness and what he died from [AIDS] and a couple have sort of mentioned to her, asked her questions "Did he really die from this illness?" And you know, she hasn't talked to anyone, she doesn't admit to it. And she thinks they'll know if she does get sick, visibly sick, that's when they'll know but right now – She thinks they feel bad, it'll be bad for the family and that sort of thing.

This "I don't know anything" attitude extends even to adult members of the same household.

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co-worker:

She thinks like her older son [age 24], ..., he's sort of heard about her partner and what he was sick from and what he died from [AIDS]. And you know he'd put two and two together and if she got really sick then he'll know what it is and it will be really hard for him too.

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So he knows that you're HIV positive?

She thinks that maybe he knows but he hasn't said anything to her but he puts two and two together, like she comes here [clinic] every three months and he lives at home, the medicine.

What does this mean for support?

Group meetings with other positive people are not popular at all with our participants. First, there is the fear of gossip and forced disclosure through others, and that did happen to some participants, as we saw earlier.

Secondly, support groups for gay men were described by those participants who had tried them as 'unfriendly' and 'clicky'.

I went to the [positive group] ... but I feel they are not for the Asian type of people, I think. They group each other and I don't feel comfortable at all.

Can you try and describe why you don't feel comfortable there?

I think they talk to each other. Australian talk to each other. ... Yeah, all Australian. Only one Asian. So I feel isolated.

For those who do attend groups and find them helpful, cultural commonalities, shared values and mutual understanding are important:

Starting from seven years ago I attended a group, Asian group. We get together and of course we talk and that's where I get most of my support and found out where I can get help. ... Asian, all Asian, from all parts of Asia.

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How important is culture in this? ... What is it that you have in common?

... important because Asians are more conservative and also not as open as westerners. ... The people in the group will feel more easy. ... A group, if you are all Asian or got the same cultural background you can talk freely. There is no boundary in the culture.

Thirdly, people don't want to be reminded of their positive status. They want to concentrate on the here and now, and their state of health rather their illness. This is also coloured by the perception that HIV equals AIDS and you'll die.

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The one-to-one service [MHAHS co-worker] is best ... Many people try to invite us [to attend groups], "Think about it." ... Ah we find people worse than us. I don't know. ... We looking. We saw is like they say "Be careful ... This will happen to you ... That's where you're heading." That's the message.

Some participants also share the attitudes and prejudice of their ethnic communities about people with HIV, where some people are guilty, and some are innocent victims, and these two groups should not be mixed.

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co-worker:

She doesn't get comfortable [with other positive people] and she really doesn't want to talk about her illness at all. ... It would be okay to have something where women can meet other women who are in a similar situation, like they've been infected through their partner. But she wouldn't want to go where there's women, for example, that have got it through sex work. She wouldn't want to meet with prostitutes. ... She would want people in the same situation as her.

So, how can the competing demands of interdependence with family and community through non-disclosure – and getting support, which requires disclosure, be reconciled? Support needs to represent closeness and distance simultaneously: closeness through one-to-one support, in the mother tongue and from the same cultural background; distance through being outside the familial and relational network.

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No, friend cannot know. Family no ... not at all ... close friend, no. ... You see, it's like everything is in my brain. ... And I speak only that one time in Melbourne [with a Thai health care worker] and here only with [Thai co-worker]. That is the first person I tell. You see, it's so important for this organisation [MHAHS] to have someone because if only one who I can tell everything about ... that I can talk in Thai ... and he, I think, that he signed that he cannot tell anyone else about my – Then I tell everything.

This form of support enables people to talk about their concerns and at the same time maintain social relations with family, friends in the country of origin, and ethnic communities in Australia without suffering discrimination.

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So why have to tell bad thing to them? Why have to tell something that's bad image to their perception. So it's better to cut and only, put only good things to them so they think only good thing to me. And I tell all bad thing to the one [Thai co-worker] [laughs]. He's the only one I can tell, only one that I tell thousand things.

The multicultural co-workers provide support in several domains: they are a link with the English speaking world through someone who speaks the mother tongue and is from the same cultural background. They give practical support. And they provide a substitute trusted family member: some participants referred to their co-workers as "Mum", "Grandma", "sister". They are a member of the same ethnic community but without their prejudice and without the gossip; confidentiality is assured through a written agreement. For some of the participants their co-worker was the only person outside the Australian health care system who know about their HIV status in whom they could confide.

In conclusion,

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People with HIV from CALD backgrounds are not passive victims who suffer in silence. They actively assess their social environment and decide about disclosure according to this environment. Basic cultural institutions such as family cannot and

will not be challenged.

Disclosure is purposeful. People with HIV from CALD backgrounds are creative and use cultural diversity to position themselves and their families in a way which enables them to maintain interdependence with family and ethnic communities, to protect themselves and their families from prejudice and discrimination and, at the same time, to obtain the support they need to get on with their lives.

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