Arts & Social Sciences
Centre for Social Research in Health

Exploring the role of families in HIV treatment narratives, decisions and practices

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Acknowledgements and disclosures

Many thanks to **all of our participants** who generously shared their stories, including people living with HIV, who were willing to be incredibly open and honest with us

Very grateful to the *my health, our family* **investigator team** and **advisory committee**

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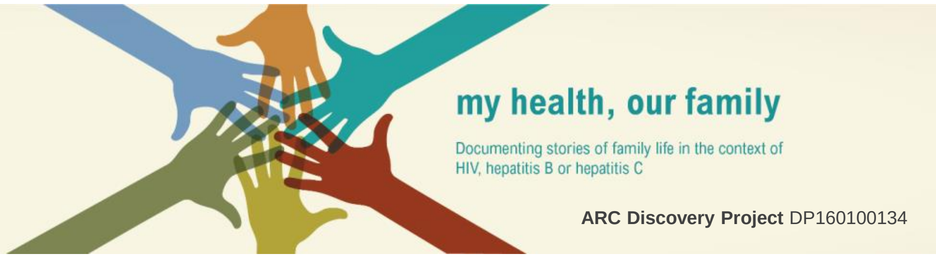
We have no other disclosures of interest to report

Background

The management of blood borne viruses has undergone rapid change: but *where are the stories of families living with and affected by HIV?*

In an increasingly individualised and biomedicalised response to HIV: *can we learn from and build on the contributions of families to enhance the prevention, management and treatment of HIV and related infections?*

Almost no literature on the role of families in the contemporary treatment era in settings with ‘robust’ health systems, like Australia…



ARC Discovery Project DP160100134

We have been interviewing (mainly but not only in NSW):

- people with a primary lived experience of HIV, hepatitis B or C
  - people with a family member who is/has been affected
    - stakeholders in the health and social policy, care and advocacy sectors

Definition of family deliberately open, eg. partners, parents, children, siblings and extended family, as well as families of choice, affinity, or intimate connection

Participant sample (HIV)

May 2017-Sep 2018	Totals
Primary perspective	15
Family perspective	10
Primary AND family persp	10
	35

Age: **15-61 years**; teens (5), 20s (2), 30s (3), 40s (6), 50s (9), 60s (6), 70 and over (4)

Diagnosis year (primaries): **1984-2017**; childhood (2), 1980s (3), 1990s (5), 2000-09 (11), 2010+ (4)

Currently living: Metro (21) NSW (14), Qld (4), Vic (3); **Regional (14)** NSW (7), Qld (4), SA (2), WA (1)

Gender identity: **female (19), male (16)**

Sexual identity: **heterosexual woman (16) or man (6), gay man (9),** lesbian (1), bisexual woman (1) or man (1), not provided (1)

Region of birth: Australia (20), Africa (6), another English-speaking nation (5), Asia (2), Europe (2)

Languages spoken: English-speaking background – speaks English only (20), speaks English and 1-3 other languages (6), **Non-English-speaking background – speaks English & 1-3 others (9)**

Relationship to person living with HIV (families only): same-sex partner (male) (4), mother (3), daughter (3), opposite-sex partner (3), sister (3), step mother (1), step father (1), son (1), close friend (1)

Mode of interview: face-to-face (15), phone (20)

Missing perspectives: ATSI-identified, trans or gender diverse-identified, father/brother perspectives

Families can be engaged with (effective) treatment narratives

I told everyone, all my family, within a week […] I said, "I found out I have HIV but it's all good. I'm on medication. I should be undetectable soon. Undetectable means I can't pass it on to anybody else. I shouldn't have any health problems from it. I won't get AIDS." […] I just armed myself with information [because] I knew the top concerns were: "Am I going to die? Will it affect my health? What does it mean to me?" […] and I sort of made sure I answered that really fast [Jason: 20s gay man, born in Australia, diagnosed 2014]

My big uncertainty was telling Mum […] But my brother [just] blurted it out, thinking, you know, that, "Alf's gonna die!" And Mum asked me outright and I said […] "I'm gonna be here forever and a day." […]I was quite open and honest with [my kids]. I've given them the information […] And they said, "Will you die?" I said, "Yeah, I'll die eventually but not from HIV. I'll die from a bloody heart attack probably or bad eating, but not from having the virus in me blood." […] I mean if [you're] on effective treatment of antiretrovirals and […] that's working […] There's no big deal. [Alf: 50s heterosexual man, born in Australia, diagnosed 2004]

Families can help support treatment initiation

When I first was deciding if I was going to take the medication, I discussed it with my nan […] Because I was upset that I was going to have to take a medication for the rest of my life […] They were asking what I wanted to do. And I didn't know […] And then, once I spoke to my nan and she explained it to me, it changed the way I saw it […] Doctor-speak confuses me and that's part of the problem. Sometimes the doctor forgets to swap back into "English". [Lauren: 20s heterosexual woman, born in Australia, diagnosed 2017]

I always discuss with [my uncle] because I don't have any other one to discuss … I talk with specialists. Then I'll come back and I will and, yeah, we discuss it […] The second time treatment, we really discussed, because the second medication was […] like if I lose my Medicare, I can't get the same drugs, I can't afford that […] But then again like, you know, he's happy. Like, you know, he advised me, "Just go with whatever the specialist said." [Rohan: 30s bisexual man, born overseas, diagnosed 2011]

Families can help maintain treatment adherence

And my other sister […] she sort of understands it better. She looks out for my medicine. She tries to make sure I'm always taking it and having the right food with it […] [She] just doesn't want me to forget. She knows I won't, but she sort of also looks after me. [Thandiwe: late teens heterosexual woman, born overseas, diagnosed 2002]

I'm the one that tends to make medical appointments […] [My partner says], "Can you make an appointment? Can you call up the hospital and arrange […] for us to get our six-monthly check-ups?" […] We tend to go to these appointments together. You know, a bit like husband and wife just going to the clinic together. You know, the doctor wanders in. He says, "Alright, who wants to come in first?". [Richard: 60s gay man, born in Australia, diagnosed 2008]

But family involvement isn't always helpful…

Once I told Dad, [he] jumped on the Internet and started researching, and sent me emails about treatment […] I'd sort of come to terms with it a bit more and I just didn't want them to be involved […] Dad's very proactive. And like wants to understand [and] he tries to be helpful and just ends up being pretty fucking unhelpful. I'm going, "Dad, I'm dealing with it, I'm seeing a doctor." [Luke: 30s gay man, born overseas, diagnosed 2007]

My family come from, we have a background of natural therapies […] But they were very respectful of that decision [to start treatment] and, yeah, they were really quite loving and comforting […] [Although] my parents would admonish me to do my research and take into consideration the toxic, long-term side effects […] But really those decisions are, I'll communicate those with my family, more than them being involved in it. [Sarah: 50s heterosexual woman, born in Australia, diagnosed 1998]

Emerging conclusions

While HIV treatments can provide family members with a concrete strategy for demonstrating care and support, which we can build on in our health and other support services, family involvement is not welcomed by all.

Some of the most valuable contributions from families included:

- *Taking the initiative to do own research and stay informed*
- *Checking in now and then to see how health and treatments are going*
- *Recognising and celebrating the successes of treatments working well*
- *Pitching in when things don't go well, whatever form of support is required*
- *Leaving you alone to manage things yourself if that's what you prefer*

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Understanding divergent family responses to a blood borne virus diagnosis

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Participant sample
(family perspectives)

May 2017-Sep 2018	Totals
HIV	17
HCV	7
HIV and HCV	3
HBV	1
	28

Age: **15-89 years**

Relationship to person living with BBV: **opposite-sex partner (7), same-sex partner (male) (4), mother (4), sister (4), daughter (3), step parent (2), son (1), close friend (1), brother (1)**

Currently living: Metro (16) NSW (11), Vic (3), Qld (2); **Regional (12)** NSW (8), Qld (4), SA (2)

Gender identity: **female (17), male (11)**

Sexual identity: **heterosexual woman (15)** or man (7), gay man (4), lesbian (1), not provided (1)

Region of birth: Australia (16), Africa (4), another English-speaking nation (4), Asia (2), Europe (2)

Languages spoken: English-speaking background – speaks English only (16), speaks English and 1-3 other languages (5), **Non-English-speaking background – speaks English & 1-3 others (7)**

Mode of interview: face-to-face (13), phone (15)

UNSW SYDNEY

Reactions and support

- Shock and sadness
- Not surprised
- Feeling left out
- Expectation to be told – family business
- Different notions of “support”
  - Intimate involvement
  - Not getting involved
  - Carry on as “normal”

The relational ripples of BBVs in family contexts

[M]y immediate reaction was 100 per cent to support her mother, so that she in turn can 100 per cent support “Melissa”. That was the initial thought … My second reaction was, “I need to find out more about [HIV] myself … How can we do this together to find out what we can do, and maybe get through this … [I]t has been a shared journey with [Melissa] and with my wife … I’ve grown from it I’m sure. It’s made me a better person in that [I] better understand how relationships work in crisis … There’s a sense of closeness to come out of it *(Trevor, 70s, step-father to a bisexual woman diagnosed with HIV in 1997)*

Emerging conclusions

- It is critical we better recognise and strengthen the role of families in supporting people with a BBV, given the uniquely persistent contribution of family relationships to health and well-being over time.
- Our findings remind us that family responses are divergent and shaped by pre-existing relationships and communication styles, and time since diagnosis.
- This highlights the importance of understanding the factors that can influence family responses to disclosure and diagnosis, to avoid a one-size-fits-all approach to supporting families affected by stigmatised, transmissible infections. This knowledge can also help families figure out how to best support each other in a way that works for them.
- Detailed analysis of potential differences in family responses to the three viral infections will be forthcoming. Though we can't say much about hepatitis B – unfortunately we couldn't get more participants.

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Please contact us for more information or to be added to mailing list:

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