

Asha Persson, Christy Newman, Myra Hamilton,  
Joanne Bryant, Jack Wallace & kylie valentine

## serodiscordance



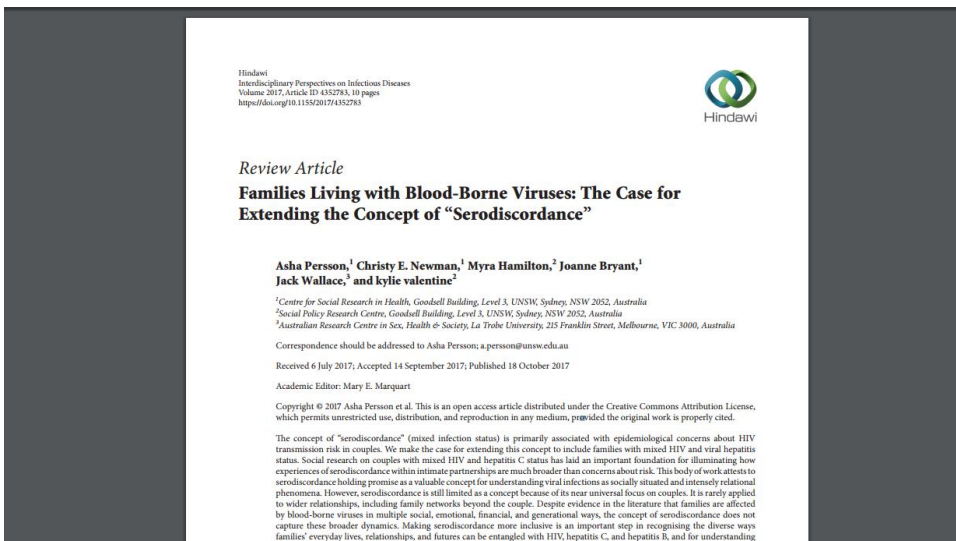
- Usually describes a **sexual/injecting relationship** with mixed status
- Primarily associated with HIV and transmission **risk**
- Social research on couples with mixed status (HIV and hepatitis C)
- Serodiscordance not reducible to risk, BBVs profoundly **relational**
- Concept still **limited**, overlooks relationships beyond couples
- **Discordance** = differing, **sero** = blood
- Recognise/understand **serodiscordant family life**



- **ARC Discovery**
- **3-year qualitative study**
  - Critical literature review
  - In-depth interviews with people with HIV, hepatitis C and/or hepatitis B (ongoing)
  - In-depth interviews with family members (ongoing)
  - Consultations with service providers (next year)
- **“Family” is self-defined** (e.g. partners, parents, children, siblings, extended family, pets, families of choice, affinity, or intimate connections)



## literature





## literature

- **HIV literature:** diagnosis can have profound effect on families
- Mainly focused on negative outcomes
- No attempt to extend concept of serodiscordance beyond couples
- **Hepatitis C literature:** only scattered references to families
- No attempt to extend concept of serodiscordance beyond couples
- **Hepatitis B literature:** mainly focused on biomedical descriptions
- Impact on families and intergenerational relationships unexplored
- Hepatitis B is essentially a disease of the family (transmission route)



## preliminary findings

- Aim to interview 50 people
- 24 interviews so far
- Diversity in age, sexual orientation, cultural background, geographical location, treatment experiences
- Family relationships affected in multiple social, emotional, financial and generational ways
- Common issues: disclosure, stigma, support, education, treatment, clinical management
- Two *over-arching themes* emerging





## health as a “family affair”

- **Disclosure to family** a pivotal issue, whether seen as obligatory, negotiable, difficult or unthinkable ...

“I really **hated the thought of [my parents] finding out** that I had this disease. And then also, yes, there was a shame to that. They’re wonderful people and they had great genes ... I really feared them knowing. I wanted to tell them when I was cured ... I was deeply ashamed of the lack of care I had taken for the, you know, **the body that [my mother] had given birth to** and nurtured, and I’d just treated so, like it was of no value. These moments are obviously very sad and stressful for, you know, for both parties, and [for] my mother and I, it was very, very sad, but **very bonding** at the same time” (Martin, 53 years, hepatitis C, cleared in 2016).



## health as a “family affair”

- **embodied connection** to family (through DNA, affinity, upbringing, co-habitation, etc)

“I think in our family, we’d always been really open about things ... So it was a natural thing for me to do... I mean it would **never be a thing in our family to keep a secret** like that [...] Your family members are the best source of support. And also, if you have an honest relationship with family members, then those are the most important **things that you should be discussing** with them” (Damien, 50 years, HIV and hepatitis C (cleared))





## health as a “family affair”

- Gathering the family to break the news
- Family’s “right to know”
- Secrecy; virus as a personal matter (generational effects)

“My parents, you know, they always said it’s a massive secret ... as a little kid, they’d say, “You’re not allowed to tell anybody. It’s a really big secret.” And **that’s kind of carried on to now...** I don’t think I could ever consider telling anybody other than very, very... [My daughter] was really upset and angry that I hadn’t told her sooner ... I tried to tell her, “Please don’t tell your friends.” I worry that she will be stigmatised. It’s my biggest fear ... I don’t like someone else having my secrets ... So yeah, I hate the fact that she has this knowledge ... It kind of bothers me. **It is a huge secret and it’s mine**” (Kiera, 33 years, hepatitis B).



## family connections

- Serodiscordance **strengthening or disrupting** family connections

“You know, when all your ailments and dramas can’t be shared with any family member, whether it be health-wise or incarceration, or whatever, life gets pretty lonely ... **I didn’t feel like I belonged** to anybody, you know ... And when Dad or when a member of my family started to take an interest all of a sudden ... it felt like for the first time for a long time **I had an arm around me shoulder**, if that makes any sense? ... So it felt good that I was actually sharing my health with my father ... It’s hard to explain, but the fact that Dad took an interest **made me feel part of something** I’d never really felt before” (Bradley, 61 years, hepatitis C, cleared 2016).





## family connections

“I would like them to be nice to them and don’t say stupid thing like “don’t share their cup” ... thing like that, you know? Because that person who hear it, they really hurt. They feel really bad. Because **they think they are not part of the family** ... like me, *I’m that person* (May, 66 years, born overseas, HIV-positive).

“I thought it was a death sentence until I got more information about it and read-up on it all ... [His siblings], **they’re frightened** of catching it and stuff like that ... [But] it’s not worried me any. I just get on with life ... ‘Cause I’m his mother. It’s just I love my kids. I mean it’s a **mother’s way of coping** with this ... Just to love them and let them know you love them, and be there if they need you” (Barbara, 73 years, mother of son with HIV).



## forthcoming analysis

- How do these over-arching themes intersect with:
  - *actual* support and engagement by families?
  - gender and power relations?
  - expectations around family obligations/generational contracts?
- How might a family’s health beliefs, communication patterns and degree of cohesion or conflict influence well-being and health outcomes?
- The role of treatment and monitoring in negotiating these dynamics?



## to conclude...

- Families matter in the context of blood-borne viruses, still...
- Families have to “co-create ... a new context for living” and for managing relationships within/ outside (Årestedt et al. 2015)
- Families as “emotionally co-infected” (Uphold et al. 2012)

Årestedt L, Benzein E, & Persson C. (2015) Families living with chronic illness: Beliefs about illness, family and health care. *Journal of Family Nursing*, 21(2);206-231.

Uphold C, Shehan C, McDonald Bender J, Bender B. Emotional bonds and social support exchange between men living with HIV infection and their mothers. *Am J Mens Health*. 2012;6(2):97-10

Rotheram-Borus M, Flannery D, Rice E, Lester P. Families living with HIV. *AIDS Care*. 2005;17(8):978-987.

## to conclude...

The case for extending the concept of “serodiscordance”...

- Decouple it from equation with “risk”
- Serodiverse relationships are not just about transmission
- Definition disregards other meaningful relationships
- Acknowledge a wider serodiscordant world

More to come ....



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