The many (interconnected and relational) strands of HIV: Qualitative insights from Australia and Papua New Guinea

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The bounded, autonomous body?

HIV as relationally embodied

Serodiscordance (mixed infection status)

Guiding concepts: embodiment, intersubjectivity, intercorporeality

Three qualitative studies in Australia and Papua New Guinea
• 38 HIV-positive and HIV-negative people in serodiscordant gay and heterosexual relationships in Australia (2014-2016)
• 25 couples represented in the study
• Completed 2016, Centre for Social Research in Health (UNSW)
• https://csrh.arts.unsw.edu.au/media/CSRHFile/YouMeHIV__Final_Report.pdf (STUDY REPORT)

relational entanglements...

Sex
Communication
Privacy and disclosure
Health & treatment
Testing & monitoring

Treatment-as-Prevention (TasP)
risk/infectiousness
reproduction
normality & legitimacy
future
relational entanglements...

- Stigma affected broader relational connections
- HIV-negative partners also “embody” HIV
- HIV as “our” issue

“It’s as much your issue as it is their issue. If you just treat [HIV] as their issue, you’re gonna fail. It’s a shared thing. It’s not just about someone having a disease and you not having a disease. It’s actually about sharing the problems [of that] together” (Charlie, 48 years, gay, HIV-negative).

**YUMI ("us")**

- HIV serodiscordant couples and biomedical technologies in Papua New Guinea
- Longitudinal anthropological study (2017-2021)
- Interviews with 90 men and women in mixed-status relationships (Goroka & Port Moresby)
- Kirby Institute (UNSW), PNG Institute of Medical Research, Centre for Social Research in Health (UNSW)
**complex embodied connections**

- Polygamy
- Different households
- Extramarital relations common
- Shifting constellations of serodiscordance
- Not all partners are always aware who has/hasn’t HIV

**vibrant entanglements**

- Local/global dynamics
- Rapid roll-out of treatment
- Overstretched, under-resourced healthcare system
- Faith-based service providers
- Economic instability
- Post-colonial legacies
- Gender inequity and violence
- Vast cultural diversity
- Gender inequity and religious faith

**vibrant entanglements**

- Male violence affecting women’s ARV adherence
- HIV as a catalyst for change
- Turning to God
- Living healthily & “responsibly”
- Mutually supportive life
- Christianity plays powerful role
- Multiple health/healing systems

**God, HIV & ARV**

- Being “faithful” to HIV treatment
- HIV infection ultimately God’s will
- Living a righteous life
- Faith in God’s power to heal through medicine

“Yes, I am taking my HIV medicine, but sometimes I have thought of going without it … I have faith in the Lord that I have been healed, but He wants me to just continue with my treatment … [My husband and I] have committed everything to the hands of our good Lord, so we never use condoms or anything for procreation … He sees that I am fully committed to the Lord, so he is not afraid of the HIV virus. He knows that he won’t be infected” (Rhonda, 25 years, Mount Hagen).

- treatment stock-outs, lack of viral load testing, public transport difficulties, etc impact adherence
- Serodiscordant unions not recognised as a priority population

*Kelly-Hanku et al. (2017) I shouldn’t talk of medicine only: Biomedical and religious frameworks for understanding antiretroviral therapies, their invention and their effects. Global Public Health 13[16].*
We have been interviewing (mainly in metropolitan & regional 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, families of choice, affinity, or intimate connection*

**Health as a “family affair”**

- Disclosing diagnosis to family = pivotal issue
- Embodied connection to family (through DNA, affinity, upbringing, co-habitation, adoption, etc)
- Fear of losing family “belonging”
- Privileged access to personal information
- Family support commonly expected (hurtful when not available)
- “We” voice – HIV as a “shared diagnosis”, “family status”

“[My husband and I] were actually on a caravan trip, going on a holiday … We just turned around and came straight back. It was just too, it was too huge to possibly carry on with normal activities. She needed someone to help immediately, to support her, which is exactly what we did. We all needed to cry together, in fact” (Rosemary, 70s).
family matters

- Diagnosis had a galvanizing effect on family members
  “[My] 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” (Step-father)

- “Having an arm around my shoulder”, “[someone’s] got my back”

- Families matter in the context of stigmatised condition

- Families have to “co-create ... a new context for living”

- Important anti-stigma advocates in society

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Serodiscordant families

[Review Article]
Families Living with Blood-Borne Viruses: The Case for Extending the Concept of “Serodiscordance”

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concluding reflections...

• Global advances in biomedical treatment
• HIV continues to be experienced and negotiated through embodied connections to significant others
• Recognising the many interconnected, relational ripples of HIV in the Asia-Pacific region
• Families, partners, close friends also “live with” HIV
• Strengthening the “many strand of the one rope” can strengthen their contribution to treatment, well-being and prevention practices

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We have no other disclosures of interest to report
want to hear more....?

Sex, gender and health in the Asia Pacific
4-6.15pm (Gallery 3), Proffered Paper Session 3

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Kia ora rawa atu!