The lived experience of long-term survivors ageing with HIV in regional Queensland: Preliminary findings of a longitudinal study

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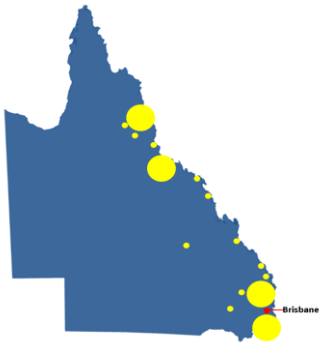
Cohort

- **72 participants, diverse but majority gay male long-term survivors**

(16 hetero, 11 women, 8 indigenous)

- **33 diagnosed before mid-90s ART breakthrough**
- **50 on DSP, aged pension or unemployment benefit**
- **20 in a relationship**



Qualitative longitudinal methodology

- **QLR accompanies participants across time**
- **Annual face-to-face interviews usually at home X 3**
- **Standard questions across time points, plus new questions**
- **Ethnographic field notes**
- **Thematic analysis at each time point, and then cross cutting over 3 time points.**
- **So far, 1st level thematic scan informing 2nd round interviews that are near completed (100% retention).**

Rural Location

- Mobility a feature (paper pending)
- Origin usually not rural – push and pull factors
- Local involvement: non-disclosure precaution
- Most have been significant contributors before this 'quiet life'

"Just the psychiatrist. I don't talk to anyone about anything…they don't want to hear, they don't care…all they want is to talk about the weather and the grandkids."
(60+ yrs, living with HIV since early 80s)

Adaptability

- Grit and persistence.
- Not thinking about the future and ageing.
- Part-time work a bonus re quality of life (risks review).

Caring for health:
"I see that as my primary job. I'm the CEO and my health is the bottom line of my company."

(50+ yrs, living with HIV 28 yrs)

Service changes – natural experiment

- Loss of a trusted individual to turn to, and a safety net.
- Continuity breakdown

"…whenever I needed dental work done they (PD) used to fund it in a way and that…now I've got to try and get into a hospital…when they folded they sort of sent this letter out saying blah, blah, blah; so that was a bit of a tail spinner."

(50+ yrs, living with HIV 30 years, drug related cognitive damage)

- Loss of volunteer opportunities and mobilised community context.
- Cultural lag – attitudes, behaviours, legal frameworks not keeping pace with biomedical advances.

Mental health

- ***'With undetectable viral load HIV treatment is the least of my worries'*** – common theme. Yes, "HIV is Different Now", but beyond the clinic door there are still significant life challenges for many long-term survivors.
- Anxiety and depression - complaint about HIV and LGBTI competence of many mental health services, and mismatch to the depth of trauma involved.
- Anti-depressants have 'taken the edge off' but not solved social and emotion suffering – stigma, isolation, sexual apartheid, poverty.

"Too much traffic, way too much traffic. It was like instead of sitting on the footpath of the Sydney Harbour Bridge during peak hour, it was like sitting in the second lane from the footpath. Everything was just, like, too much traffic and it was just – yeah. I just couldn't function".

(50+ yrs, living with HIV 28 yrs)

Preliminary conclusions

- **As comorbidities increase engagement with a broader range of specialists is required, but hostility is still encountered.**
- **Medical aspects of HIV are generally well managed, but non-medical aspects are foregrounded in the lived experience. Can clinics be expected to provide psycho-social supports?**
- **Rural living involves constant vigilance to remain 'socially undetected'.**
- **Mental health is a major challenge, and widespread prescription of anti-depressants alone is an inadequate response.**
- **Many on DSP at 'last resort' financially, few options for solving problems that arise.**
- **Cuts and uncertainty experienced as 'a kick in the guts' for people who have contributed a lot to the response.**

Recommendation

- Queensland needs a new model of **<u>community care</u>** to complement the models of
  - prevention
  - testing
  - treatment

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In memory of the three participants who died during the 2nd year of the study