"IS IT HIV OR JUST OLD AGE?" UNCERTAINTIES OF 'SUCCESSFUL' AGEING WITH HIV

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- We especially acknowledge 6 participants of the LPQ study who died during course of the study, and whose voices can be heard in this important study.

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Partners

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- Queensland AIDS Council
- Positive Directions
- Queensland Department of Health

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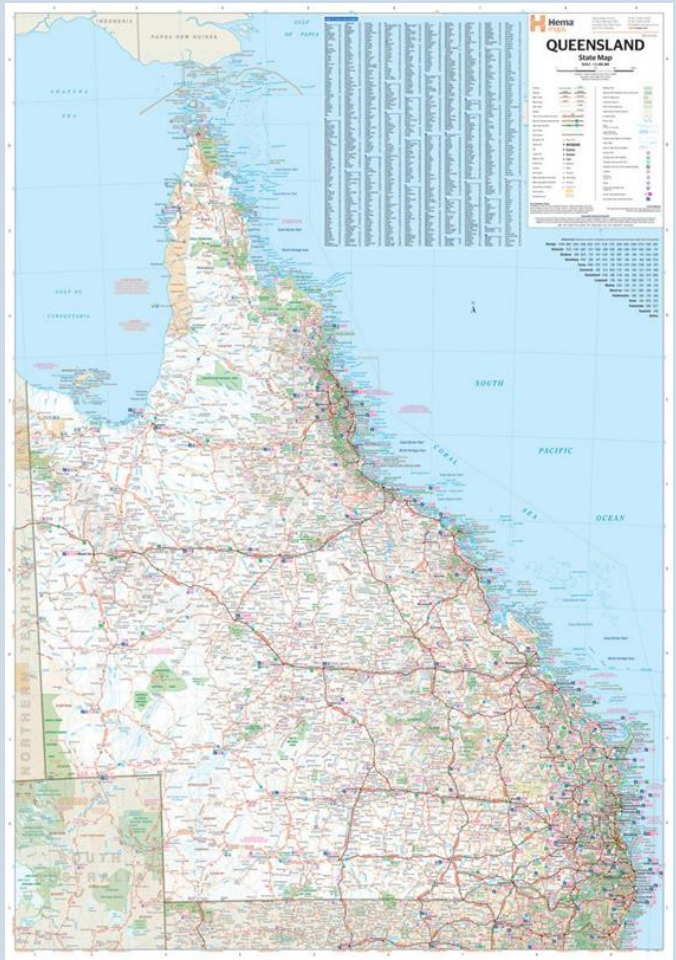
LIVING POSITIVE QUEENSLAND (LPQ)

- Explored social determinants of ageing and health, in particular locality/place, housing, precarity, stigma, social support/social isolation, access to services and support
- "Natural experiment" explored PLHIV over time, through significant policy and service provision change in Qld.
- Longitudinal/Life course approach- examining cumulative and complex lived experience
- Examined everyday strengths and resilience

METHODOLOGY – QUALITATIVE LONGITUDINAL RESEARCH

- Longitudinal research exploring experiences of PLHIV in a time of changes to services, funding, policy, and biomedicine
- Qualitative longitudinal research –temporal context.
- All interviews face to face, traversing the length of the state
- Developing trust and relationships with our participants over time
- Over 200 in-depth interviews in last 5 years



LPQ STUDY PARTICIPANTS

- 73 participants interviewed round 1 (69 R2; 67 R3)
- 62 Men, 11 Women
- Age range 34 – 75
- Living with HIV: 4 - 35+ years. Over 60% 15 yrs
- Most on a disability support pension
- Majority renting/public housing

Age	
18-34	2
35-44	10
45-54	35
55-64	19
65-74	6
75 and over	1
Years lived with HIV	
0-4	8
5-9	12
10-14	6
15-19	15
20-24	11
25-29	12
30-34	8
35+	1
Decade of diagnosis	
Pre-HAART era: 1982-1995	31
Post-HAART era: 1996-2009	33
TasP era: 2010-present	9

LPQ PARTICIPANTS - QLD'S REGIONAL 'ROUGH SAILORS'

- Diversity of participants/intersectionality of identities
- Resiliency *in tension* with (extreme) suffering
- Complex intersection of multiple co-morbidities, mental health, disability, limited resources, social stigma
- The accumulation of health issues interconnected with the social determinants of health (*Recursive cascades*)
- *Social isolation and loneliness*, limited social and interpersonal resources and fragile social networks- reliance of formal networks for social support
- Everyday strengths and resilience

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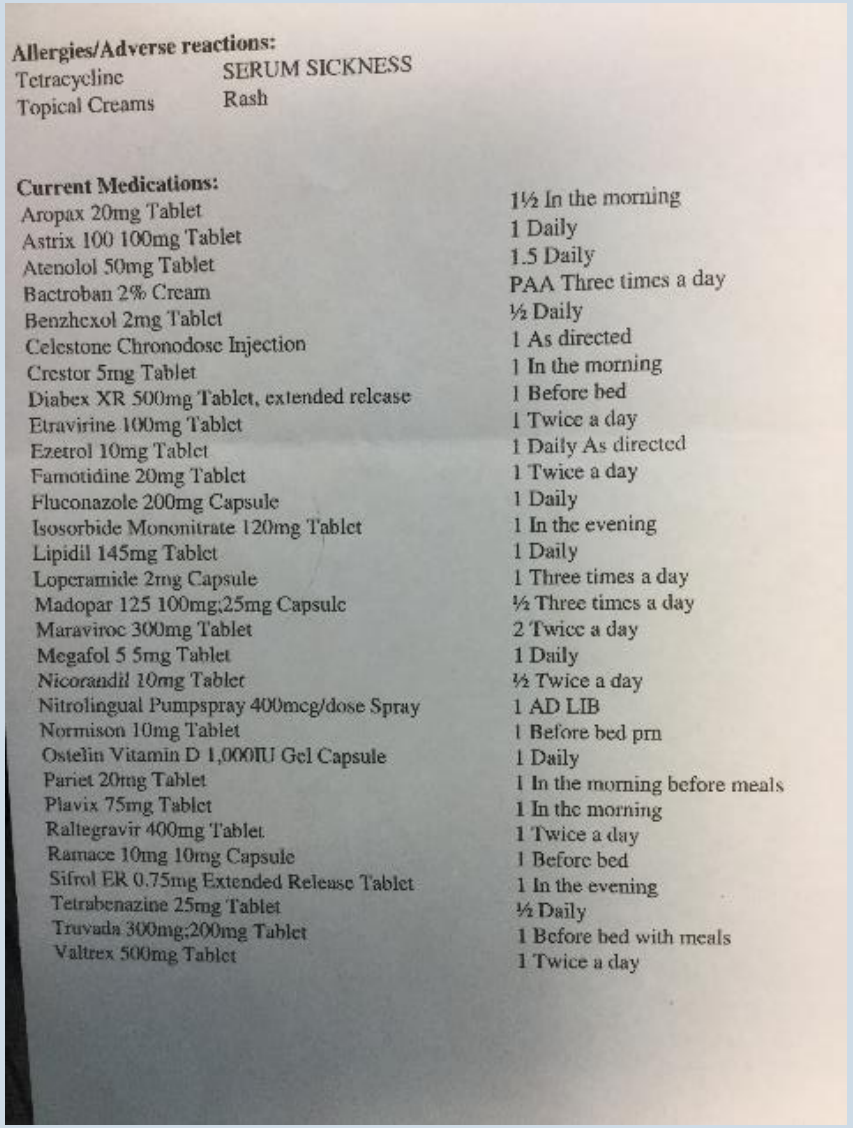
TOM

- Aged 68 -72
- PLHIV for over 30 years, life partner died of AIDS
- Social housing, govt pension, lives alone
- Multiple and increasingly complex co-morbidities over the 3-4 years of interviews

I go down in a bit of depression but I'm up now, only grieve for one day at a time and back on the boat…. I have a career, it's my health I work at not having negative thoughts… HIV aspect does not bother me at all in comparison with that.



Allergies/Adverse reactions:

Tetracycline	SERUM SICKNESS
Topical Creams	Rash

Current Medications:

Aropax 20mg Tablet	1½ In the morning
Astrix 100 100mg Tablet	1 Daily
Atenolol 50mg Tablet	1.5 Daily
Bactroban 2% Cream	PAA Three times a day
Benzhexol 2mg Tablet	½ Daily
Celestone Chronodose Injection	1 As directed
Crestor 5mg Tablet	1 In the morning
Diabex XR 500mg Tablet, extended release	1 Before bed
Etravirine 100mg Tablet	1 Twice a day
Ezetrol 10mg Tablet	1 Daily As directed
Famotidine 20mg Tablet	1 Twice a day
Fluconazole 200mg Capsule	1 Daily
Isosorbide Mononitrate 120mg Tablet	1 In the evening
Lipidil 145mg Tablet	1 Daily
Loperamide 2mg Capsule	1 Three times a day
Madopar 125 100mg;25mg Capsule	½ Three times a day
Maraviroc 300mg Tablet	2 Twice a day
Megafol 5 5mg Tablet	1 Daily
Nicorandil 10mg Tablet	½ Twice a day
Nitrolingual Pumpspray 400mcg/dose Spray	1 AD LIB
Normison 10mg Tablet	1 Before bed prn
Ostelin Vitamin D 1,000IU Gel Capsule	1 Daily
Pariet 20mg Tablet	1 In the morning before meals
Plavix 75mg Tablet	1 In the morning
Raltegravir 400mg Tablet	1 Twice a day
Ramace 10mg 10mg Capsule	1 Before bed
Sifrol ER 0.75mg Extended Release Tablet	1 In the evening
Tetrabenazine 25mg Tablet	½ Daily
Truvada 300mg;200mg Tablet	1 Before bed with meals
Valtrex 500mg Tablet	1 Twice a day

INVISIBILITY

- Invisibility in increased focus on biomedicalisation of HIV
- Invisibility due to social isolation in regional/rural settings exacerbated by stigma/precarity/poor health
- Ageism experienced in both gay and PLHIV cultures.
- Invisibility of complexities of managing chronicity- everyday work of aging with comorbidities, social precarity
- *…people don't see is the true lived experience of years of poverty, years of mental health issues, drug dependency, back like bone structure stuff, deformities in, either strokes or heart attacks or lung issues, cancers; the myriad of cancers that can now be you're at risk of, dealing with toxicity, they're not discussing that. And the moment you bring up that conversation you're closed down, you're shut down, you can't do that. Your voice as an older long-term is not acceptable to talk about that lived horrific experience (Hugh)*

UNCERTAINTY

- Uncertainty and ambivalence about ageing in the face of debates surrounding adverse HIV ageing discourses and unknown futures.

Is it my HIV having worn out my body early or am I just suffering from old age? … I've always had a belief that I'd probably wear out sooner because of the HIV and what it's doing to the immune system. So when I noticed these old men signs, if I can call them that, it does sort of freak me out a little bit and hypervigilance is probably not the – they're not necessarily real yet but they're certainly alarming me (Jack)

- Uncertainty about social determinants of 'successful ageing' including income, housing and access to care.
- *even if I lived to 70 … it's a long time to live if you've just got enough income to pay for basic groceries and rent and nothing else (Tim)*

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LOSS OF AGENCY AND CONTROL

- Older participants with the most complex health issues, fragile social networks and limited support, feared loss of agency and control.
- Discussions of the future - apprehensions about not wanting to be a 'burden' on others or the healthcare system, retaining some control over life and death.
- Lacking confidence in aged care options- 'back up plans' including treatment refusal or non-adherence:

I don't want to get to a stage where people have got to wipe my bum and that's time to check out. I don't have a safety net…I know then if things become unbearable there's an exit … if I can just stop a couple of pills. It's only an escape hatch if things become unbearable. (Tom)

APPREHENSIONS OF AGED CARE

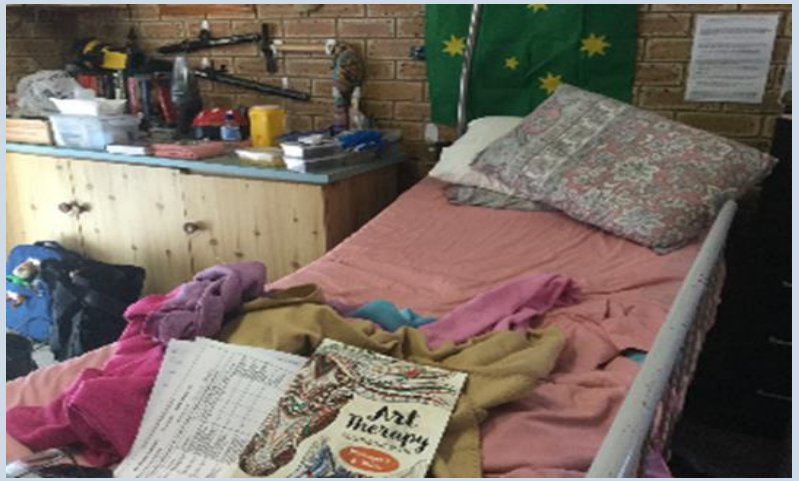
- Many anxious about their capacity to live independently in the future.
- Care for older people synonymous with residential aged care.
- Having experienced stigma and discrimination in healthcare settings, concerned about stigma and discrimination in aged care settings and fear that the aged care sector not ready to respond to the needs of PLHIV

- *I'm still absolutely paranoid about the response to people when they know and I was actually thinking about that other thing, going into a nursing home, I'd want to pick it very carefully to know that there was acceptance and understanding. Even saying that sounds scary. (Warren)*

RESILIENCE/GENERATIVITY/AGENCY

- Individualised
- Generativity, volunteering, socialisation and sharing of experiences

Over time as you grow you look at things differently … once you start to get to our age, you just look at things differently and you just have to accept things. You just have to because nothing is – especially with this, it's not going to be any different. So when you accept it, it's just so much easier … And that's what I'd like to do with my Positive Speakers role, to be able to stand in front of people [with HIV] … and give them hope. (Xavier)



- Opportunities for volunteering, socialisation and sharing of experiences unmet, impacted by service cuts and fracturing of communities.

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POINTS OF DISCUSSION

- Ageing with HIV is **biosocial,** lived within diverse intersections of embodied experiences of HIV, generational, social, and locational contexts.
- **Generativity** – the opportunity share wisdom, to support other PLHIV
- ***Recognition, respect and support.***
- Biomedicalised, individualised approach to funded services and care and individualised successful aging discourses. Fracturing and dismantling of 'community' networks that served as a resource for care. **Where is the collective support for older PLHIV?**
- **Successful ageing is not individual-its relational, social connections matter.**
- Cost effective social, peer support, HIV and ageing literacy, quality and culturally competent aged care services for PLHIV; and coordination and partnership between disability and aged care sector and HIV community.
- Stigma remains a key issue

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