

# LIVING AND AGING WITH HIV: HOW WELL ARE WE DOING ON THE 4<sup>TH</sup> 90? FINDINGS FROM THE LPQ STUDY

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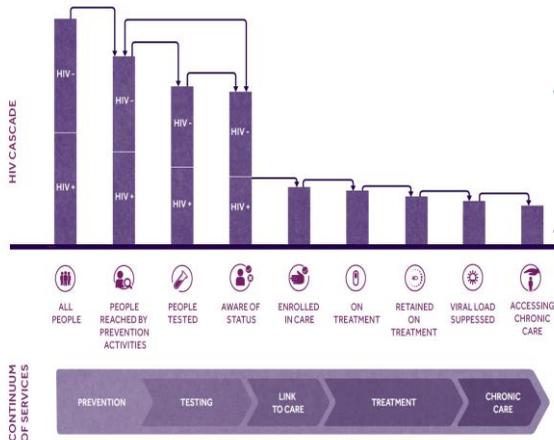
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## HIV as a chronic condition: The continuum of HIV services

Figure 5. The continuum of HIV services and retention cascade



- WHO: Attention to NCDs- mental health, pain management and pall care- and recognise stigma and discrimination as detrimental to wellbeing of PLHIV
- Lazarus et al (2016)- Serious NCDs-depression, anxiety, financial stress, HIV related discrimination- *prevent people from relegating HIV to periphery of daily life*
- Need for holistic person centred approach recognising NCDs and SDH – need a 4<sup>th</sup> 90 targets for quality of life for PLHIV

Global health sector strategy on HIV, 2016–2021. Available at: <http://apps.who.int/iris/bitstream/10665/246178/1/WHO-HIV-2016.05-eng.pdf?ua=1>. 2017.



## HIV and Aging

- 'Greying' of PLHIV = modelling estimates PLHIV in Australia over 55 years to 44% in 2020 (Jansson et al. 2012)
- Complex physiological and psychosocial issues
- Accelerated aging?
  - Premature age related comorbidities
- Stigma/discrimination/ Social isolation/Fragile support systems
- Social determinants of health (Catlan et al. 2017)

## HIV and Aging

- **“double jeopardy of ageism and HIV stigma = social isolation** (Emlet et al 2010;)
- Differences between HIV generations in experiences and needs (Owen et al. 2012; Emlet et al 2017)- importance of recognising life course perspective (Emlet et al. 2017)
- Differences across different PLHIV populations (women, indigenous etc)  
Sangaramoorthy, Thurka, Amelia Jamison, and Typhanye Dyer. "Intersection stigma among midlife and older Black women living with HIV." *Culture, Health Sexuality* (2017): 1-15.

### Aging successfully with HIV

- -individual characteristics/interpersonal relationships/environmental factors

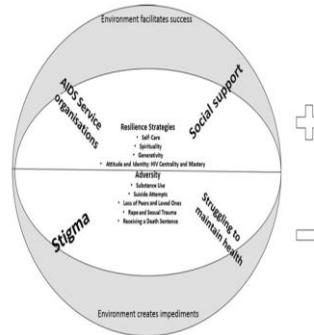
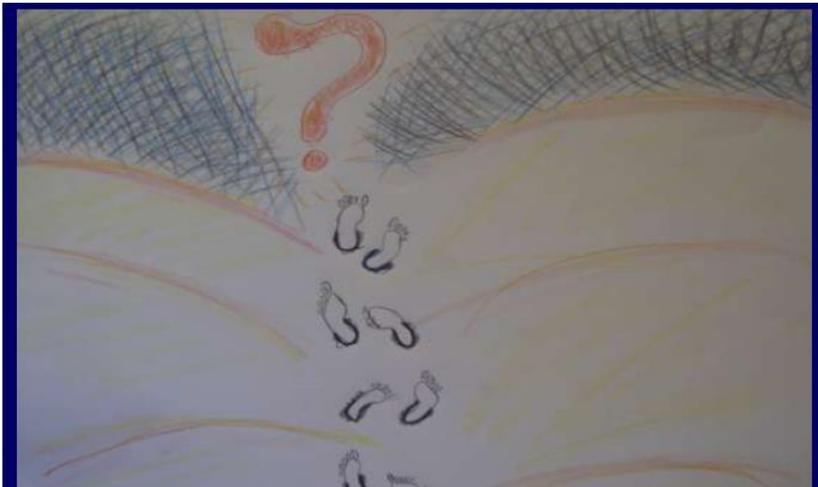


Figure 1. Successful aging among older adults living with HIV: resilience strategies, positives and negatives of life circumstances. Emlet, Charles A., et al. "I'm happy in my life now, I'm a positive person": approaches to successful ageing in older adults living with HIV in Ontario, Canada." *Ageing & Society* 37.10 (2017): 2128-2151.

“I don’t know what the future holds”



## Living Positive in Queensland: a qualitative longitudinal study of aging, place and social isolation (LPQ study)

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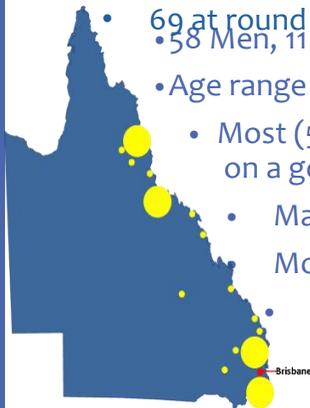


### The LPQ (2011-2017) study examined:

- Experience of aging
- Living in rural/regional communities
- Social networks and social support/social isolation
- Relationships, sexuality and HIV prevention issues
- Health practices
- Living with comorbidities
- Health care service experience
- Lived experience within a changing policy context (increased biomedicalisation of HIV prevention, funding cuts to psychosocial services)

## LPQ study participants

- Diverse cohort of 72 participants interviewed round 1 (5 participants have died)



- 69 at round 3
- 58 Men, 11 Women

- Age range 34 – 75 (48 over 45)

- Most (55) living on a govt pension

- Majority renting – or in public housing
- Most 'single'

- Living across Qld in rural, regional and outer urban area

Years lived with HIV	Number of participants
0-4 years	7
5-9 years	12
10-14 years	6
15-19 years	14
20-24 years	11
25-29 years	11
30-34 years	7
35+	1
TOTAL	69

## Example of our cohort: Tom

- Late 60s
- 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 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:	
Atropax 20mg Tablet	1½ In the morning
Astrix 100 100mg Tablet	1 Daily
Atenolol 50mg Tablet	1.5 Daily
Bacroban 2% Cream	PAA Three times a day
Benzhexol 2mg Tablet	¼ 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
Isoorbide Mononitrate 120mg Tablet	1 In the evening
Lipidil 145mg Tablet	1 Daily
Loperamide 2mg Capsule	1 Three times a day
Maldopar 125 100mg;25mg Capsule	¼ Three times a day
Maraviroc 300mg Tablet	2 Twice a day
Megafol 5.5mg Tablet	1 Daily
Nicotinamid 10mg Tablet	¼ Twice a day
Nitrolingual Pumpspray 400mcg/dose Spray	1 AD LIB
Normison 10mg Tablet	1 Before bed pra
Oxetelin Vitamin D 1,000IU Gel Capsule	1 Daily
Pantet 20mg Tablet	1 In the morning before meals
Plavix 75mg Tablet	1 In the morning
Raltegravir 400mg Tablet	1 Twice a day
Ramasec 10mg 10mg Capsule	1 Before bed
Sifrol ER 0.75mg Extended Release Tablet	1 In the evening
Tetrabenazine 25mg Tablet	¼ Daily
Truvada 300mg;200mg Tablet	1 Before bed with meals
Valtrex 500mg Tablet	1 Twice a day



## Preliminary findings

- Good HIV citizens –adherent to ARTs, resilient, self care
- Diversity of participants/intersectionality of identities  
BUT/Resiliency *in tension* with extreme suffering
- The lived experiences of PLHIV **complex** with multiple co-morbidities, disability, (past) trauma, limited resources, social stigma= HIV with its well funded clinical care system is often *'the least of worries'*
  - the accumulation of health issues interconnected with the social determinants of health (*Recursive cascade*)
  - *Shadow effect/cumulative effect* of intersectionality of issues- HIV/sexual identity/ethnicity/gender etc
  - *Social isolation and loneliness*, limited social and interpersonal resources and fragile social networks- reliance of formal networks for social support

## Preliminary findings

- **Mental health**, especially depression/anxiety. “Building resilience” and medication the dominant strategies to manage stigma, but how to tackle the entrenched social/self stigma associated with HIV and marginalised identities.
- While some participants are thriving (good social networks/well resourced), a significant proportion are not and are feeling **abandoned due to cuts in support services and ‘loss of community’**,
- There is little knowledge of or optimism the **aged care sector** is ready to respond to the needs of PLHIV over the next decade, and a number of participants express a readiness to end their life rather than endure suffering, or not to be a burden on health system.

## Changing discourses of what it is to be an HIV Citizen- focus on biomedicalisation= invisibility?

*Now it's about taking pills. And worse than that, it's about taking pills to keep the negative population negative. You know, there's a high degree of altruism required. We've been forced to be altruist – no, not forced, we've been pressured to be altruistic about it. I'm being pressured into this model and I don't fit well in there at all.*

- ... 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

## Biomedicalisation at expense of social determinants of health and community

• *One of the things that I think is happening in Queensland with this very medicalised view is that, what for me as a much broader and nuanced view of the way I experience my HIV is no longer being listened to, that it's being separated from a gay agenda.*

• *All this biomedical stuff is fabulous for us. It's making us live longer and it's preventing transmissions. It's fabulous. But for those people who are living with HIV, it's something that isn't really doing them any real good for their mental health, for their social lives, for their lives in general. So yes, I love the biomedical stuff but it should be hand-in-hand with social support as well.*

## Conclusions- where are we at with the 4<sup>th</sup> 90?

Normalising HIV *biomedicalisation* ... **HIV is different now** ...

- We may reach “the end of AIDS” but are people living long term with HIV becoming increasingly invisible ?
- Outside the clinical setting, precarity, disadvantage, uncertainty, stress, anxiety, depression, increasing comorbidities
- Recursive cascades of chronic illness/social determinants of health - where are the circuit breakers to this cascade?
- Is biomedicalisation and resultant policy/service provision funding tagged to 90 90 90 reinforcing disadvantage?
- How can we facilitate ‘successful aging’ in this current environment?- we need the 4<sup>th</sup> 90! And what about the 10%?
- Individualisation – what is the role of community?

## Acknowledgements

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