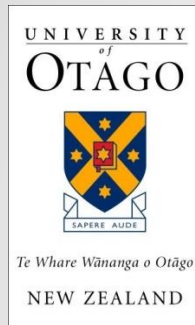


# **The 'lived experience' of HIV: Aging, place and social support**

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**Approved by the University of  
Otago Ethics Committee**

**Funded by Lottery Health**

- **Aim: to explore the experience of living with HIV in Canterbury across time**
- **Issues to explore: housing; access to health, social and support services; experiences of stigma or prejudice; and the impact of the earthquakes**
- **Semi-structured, face-to-face interviews 12-15 months apart**
- **Recruitment through the New Zealand AIDS Foundation**

**Study design**

- 12 males and 2 females
- Age range: 32-76
- Ethnicity: 13 NZ European, 1 African
- Sexual orientation: 2 heterosexual, 10 homosexual, 2 bisexual
- Employment: 7 full-time, 4 part-time
- Education: 8 tertiary, 5 secondary (> 3), 1 secondary (< 3)

## Participant demographic

- Earthquakes did not have any impact on the participants that differed from the general population
- No difficulties in access to health and social services
- Over half relocated – a representation of the reality in Christchurch

# Earthquakes 2010-2011

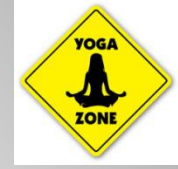
- **Attempt to control certain aspects of their lives**
- **Ways participants control presentations of the self, 3 aspects: the physical, the social, and the spiritual**
- **Post-diagnosis readjustment process involves the reconstruction of identity**

*...because HIV is one of those illnesses that it brings together all those taboos, you know, sex, drugs, all the things that as a society, you know, from Victorian ages, all those naughty things, you know. So there's that real stigma associated with it.*

## **Preliminary Findings - Control**



Gym & other forms of exercise:



Special Diets

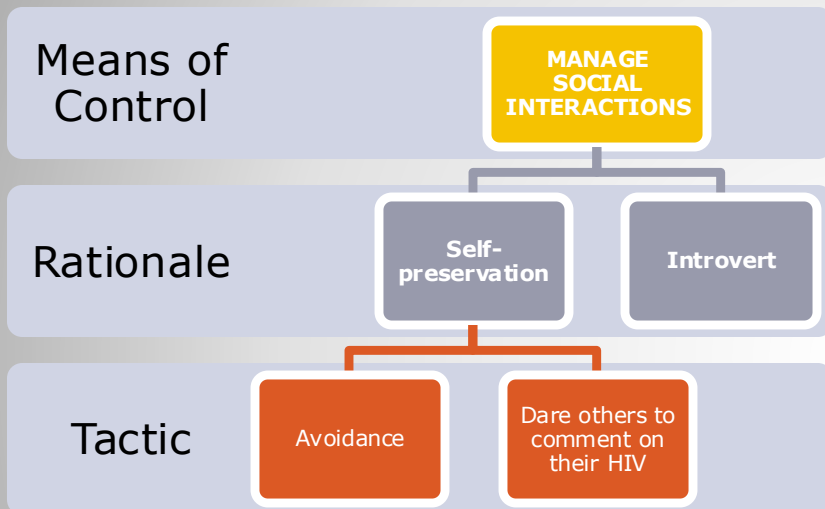


Strict medication regime or limit/avoidance



Procedures to enhance appearance

# Ways to manage physical presentations



## Intentionally self-isolate

*I must admit I've become rather reclusive.... I come home five o'clock or so I'd rather just sit down and have a couple of beers by myself and read or watch the telly. Going the other way then I also find it gets very lonely.*

## Introvert

*I'm just like that naturally that I just keep things to myself.*

*I feel in the time that I've lived in Christchurch somewhat beaten down a little bit by stigma and discrimination in Christchurch. And I'm less forthcoming than I once was.*

## Avoidance

*So I think it's just / I sort of got on with life in terms of I try to / I really isolated myself from anyone that's nasty or evil.*

## Daring others to challenge their status

*...I need some treatment on my teeth, I'm HIV positive, do you have a problem with that?*

# Social



# Varieties of self:



## “Getting on with it”

– unaffected: competent, in control, contributing members of society

*No, I haven't had any time off at all, I don't take time off really.*



## “Forgetting” HIV

- good grasp of disease management, chugging along....

*I get on with life and don't worry too much about it. It's not foremost on my mind at all.*



## Compares self to others with HIV

- to reflect on his/her own fortunate circumstances

*...some of them don't even need help with what I want help with, it may be an electricity bill that they need money to pay with. That's how poor they are.*



## Altruistic self

- managing well and willing to help others

*They've actually relied on me both for financial support and other support as well which I've no problems giving.*

## Limited social scene:

- Limited sites of social interaction – civic spaces, bars, restaurants etc.
- Post-earthquake lethargy  
*The lethargy here is a bit hard to get around. Just motivating everyone, especially after 2011, it's a bit harder.*
- Gay respondents - conservatism of Christchurch

## Older Age:

- Being social associated with a younger self  
*I think it's old age as well, you know, people don't / when you're young you do all that....*
- Aging with HIV  
*... the effect of it on my body of course has changed my whole energy levels and things so I've probably become a little bit more isolated than what I was*
- Aging as a gay man – invisibility  
*as one gets older in the gay community one becomes more transparent or something. People don't see you. You don't exist.*

**Perceived barriers to socialization**

- **Making or finding meaning through organized religion or other forms of spirituality**
- **Relinquish control to some extent as they learn to come to terms with the disease**

*I believe in Jesus Christ and he has helped me. He has helped me mentally.*

- **Spirituality has helped them through phases of readjustments**

*...accepting what is and when I do that I seem to stop fighting what is and accept it for what it is. And then find the beauty in what is so that's really kinda how I self-manage if you like...*

# Religion & Spirituality

## Timeline

- Further analysis of data
- Second round of interviews in winter 2014

**Where to from here?**