

# Personal decisions around anti-retroviral therapies: findings from the literature and from a qualitative longitudinal study with people living with HIV in regional Queensland, Australia



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## Background

The biomedical innovations in the field of HIV, including antiretroviral treatments (ARTs), have the potential to make healthy long-term living with HIV a reality, and to drastically reduce HIV transmission. With the current global focus on strengthening HIV prevention through greater testing and ART treatment uptake (Australian Federation of AIDS Organisations 2012; UNAIDS, 2011) it is increasingly salient to identify and address factors influencing people's abilities and decisions around adopting these biomedical innovations. Patient-centred care is the cornerstone of effective management of complex illnesses, yet little is known about personal decision processes around ARTs, especially among people living with HIV (PLHIV) in remote areas.

This poster presents selected findings from a comprehensive literature review and a qualitative study in regional Queensland, Australia, on the factors influencing initiation of and adherence to ARTs in the last 10 years. Pseudonyms are used thereafter to introduce select quotes.

## Methods

As part of her PhD study, the first author conducted a comprehensive literature review (published and grey, 2003-13) to summarize what was known about the factors influencing ART treatment uptake and adherence in Australia, Canada and the UK [under review with AIDS Care, AC-2015-03-0185]. Seventeen studies and 11 grey reports met the inclusion criteria for the review.

In addition, the narratives around ARTs were elicited as part of the ARC Linkage Project 'Living Positive in Queensland (LPQ): A qualitative longitudinal study of aging, place and social isolation, where 69 PLHIV over 35 from regional Queensland are being interviewed annually over three years. The LPQ Study was launched at a request of the leading advocacy groups serving PLHIV in Queensland. It follows recognition of the need to have Queensland-relevant research to inform service and support needs into the future.



In-depth interviews across regional Queensland once per year over three years

## Results

### Findings from the literature review:

We have found that factors influencing a person's abilities and decisions around ARTs are very complex, and understanding of these remains poor. A person's abilities and motivations (after Begley, McLaws, M.L., Ross, M., & Gold, J., 2008, we call them intra-personal factors, reported in 7 studies) around ART are influenced by a host of interconnected factors spanning relationship (inter-personal, reported in 3 studies) and broader socio-economic, political and cultural (extra-personal, reported in 15 studies) factors that are situated within social determinants of health.

### Preliminary findings from the qualitative study in regional Queensland:

Contrasting the binary view of being 'on' or 'off' treatment, ART adherence is on a continuum, ranging from delaying initiation of ARTs, irregular adherence including extended periods of not being on treatment, regular adherence with occasional treatment *breaks*, up to total adherence with no *breaks*.

#### Factors influencing weak ART adherence and taking treatment breaks

Common factors influencing weak adherence and taking occasional *breaks* in treatment, included side effects of treatment (i.e. nausea, kidney stones, high blood pressure and lipoatrophy) which impacted a person's physical and mental health.

*I just get sick of taking tablets all the time sometimes and if I go onto a new regime where I'm having side effects, I may decide to take a break....I didn't want to age before my time and I felt that this was happening as a result of treatment [lipoatrophy] and that was why I have taken at least one of the treatment breaks because not only were the side effects in terms of how I feel but also in how I looked and that impacted my self-esteem.* Gregory (gay man)

The role of important others in making a decision has also emerged as a common factor. Taking treatment *breaks* may have been influenced by the past HIV community discourse legitimizing taking the occasional *drug holiday*. Non-medical advice (from partner, friends) on whether to initiate or continue ARTs was also often sought when the health system was felt lacking.

*And so I took this drug holiday which was actually okay in those days, or thought to be okay.* Aleck (gay man)

There were also some distinct factors influencing taking *breaks* versus weak adherence. The latter included difficulties setting up and maintaining a routine around pill taking. Some would also discontinue ARTs when it was seen as 'polluting' the body, and instead engage in *cleansing* of the body using natural therapies.

*I have started to take the Gumbi Gumbi...instead of [ARTs]... one of the things that it does is it cleanses and helps to purify the body...*

*It's something I've thought about for a while and I don't like putting a lot of chemicals into my body, I never have, and thought that I will give this a try and to see how it goes.*

Hope (heterosexual woman)

In addition, structural barriers (out-of-pocket expense for ARTs, in particular if a person lost their pension) were experienced as compounding other barriers to treatment (i.e. drug side effects) and contributing to weak adherence.

*So when they dropped the medication, they dropped me off the pension and then I had to go back to paying for everything and it just got too expensive. And so I had a chat with the doctor and I said "Listen, basically I don't like taking the medication, I don't feel healthy on the medication, I am not prepared to pay hundreds of dollars a month for pills that make me feel sick so I said "I'm going off it"...So I went off the medication in '97 and I stayed off it then 'till 2010 until I came out of hospital.* Sebastian (gay man)

## Results continued

On the other hand, taking treatment *breaks* was seen as a means to forget, even if for a while, about the prospect of a lifetime of medication and the symbolism of *being sick* that accompanied it. *Breaks* would allow a person to temporarily regain a *sense of self*.

*I got tired of taking them, I'd look at the pills and they started carrying these messages around, you're sick.* Aleck (gay man)

Sometimes the narratives around one's total adherence and around 'scheduling' *breaks* alike were marked with a sense of pride and being in control of one's health. At times returning to ARTs was as planned (involving monitoring own CD4 cell count) as was the *break-taking*, a continuation of exercising agency around one's health.

*The T cells would drop but the viral load was still undetectable and then once it got up to about 10,000 so I thought "Okay, I'll go back on the medicine" after about an eight month break.* Sam (gay man)

Not all instances of going back on ARTs, however, would be monitored by the individual and associated with having a sense of control. Sometimes, returning to ARTs was necessitated by the severe weakening of one's immune system. Following hospitalisation individuals were made aware that further non-adherence would be fatal. To some, having this awareness has contributed to having a sense of destiny and a sense of choice.

*I guess with the warnings I've been given about going off my medication, I have a sense of my own destiny... So I'm aware of that and it has given me options but I don't consider it suicide if I stop taking the pills...As long as I'm happy, I'll carry on...I guess for me that's now a deciding issue.* Sebastian (gay man)

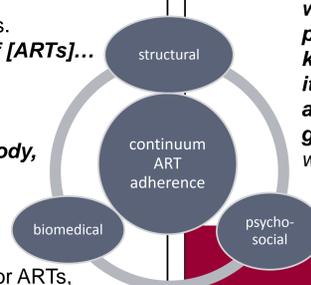
#### Factors facilitating ART adherence

Factors facilitating adherence included redefining the meaning of ARTs from that of a reminder of one's HIV status and *being sick* to that of being seen as a source of healthfulness and a means to a full life. This facilitated a grateful attitude towards ARTs, and better treatment adherence.

*I used to hate my medication ...it just reminded me that I was HIV positive. And now I just, I am very grateful of that it's there and that it works so well for me. And so I think I carry that over with the aging process is that I am very healthy, I feel very healthy at the moment.* Barry (gay man)

Other facilitating factors included having an active coping style (at times encouraged by a trusted health provider and peer advocates), seen as expressions of not succumbing to fear and stigma.

*Because the first thing I did after I was diagnosed was I wanted to meet someone else that was positive to tell me that it was okay, you know...She (peer advocate) has been living with it for more than 10 years...and she looked absolutely fabulous and I thought oh no, I ain't going to lay down and die.* Alison (heterosexual woman)



## Conclusions

Both the literature review and the qualitative study in regional Queensland have demonstrated that the key to understanding and addressing factors influencing adherence to ARTs is to acknowledge the intersectionality of the intra-, inter-, and extra-personal factors. PLHIV engage in a sophisticated analysis of the pros and cons of adherence, which considers the structural (financial barriers) and psycho-social factors (impacts of ARTs one's physical appearance, sense of *self*, mental health and ability to meet a partner) in addition to biomedical factors (including drug side effects).

Findings have implications for the management of HIV and other complex diseases in that patient-centred care needs to proactively move beyond purely biomedical considerations.