

# Stopping ARV Treatment in Bali, Indonesia

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11<sup>th</sup> International Congress on AIDS in Asia and the Pacific  
18-22 November 2013 Bangkok, Thailand  
ICAAP2229-01019

## Background:

Access to ARV treatment in Bali is considered to be good, although never straight forward. Most people with HIV in Indonesia receive first line ARV treatment with a small number now accessing second line treatment. At the time of this study (September 2012) there were 6,500 people living with HIV in Bali, of which 2,103 were receiving ARV treatment. Little attention has been given to exploring why some people make a decision to stop treatment, with either the intention to resume at a later time, or to stop for good. The aim of the study is to explore why people decide to stop ARV treatment, their experiences during this time and reasons for starting treatment again.

## Methodology:

21 in-depth interviews were conducted from late 2011 until mid 2012 in Bali. These people have a history of drug use and were either currently not taking ARV treatment or had stopped treatment in the past for at least 3 months. Twelve of participants were on methadone treatment.

## Results:

### Experiences of ARV treatment:

Most were knowledgeable about HIV and were aware of their CD4 count. Nearly all participants talked about having a good rapport with their doctor and good experience accessing treatment. Most did not tell their doctor that they had stopped taking their medication, they continued to see the doctor and taking home the medicine. Bored with treatment was expressed by many of the participants.

*I deliberately didn't tell the doctor that I stopped ARV...You could say I have a good relationship with them. How could I put it? They are not formal, I can be really open with them...with Dr XX, I can tell her anything, I can tell her if I have been late taking my medication*  
(38yrs stopped for 3mths)

One of the Challenges of treatment was combining methadone and ARV treatment.

*No one influenced me to stop... I just felt bored and also with being on methadone. Methadone and ARV don't work well together. If I am on both I have feelings of withdrawal; I'm better off just stopping the ARV.*  
(33yrs, stopped for 4mths)

*I was taking the ARV at night, but every night I would feel heavy withdrawal, I felt really terrible; sweating and shaking. The doctor said that methadone contradicts with ARV. They couldn't provide me with a solution just that the methadone dose would have to go up to 180... But I really couldn't handle that situation... I was confused about having to choose between the two, to choose ARV or methadone...The dose of 180 was just too, too much...I was feeling high - like someone...way too wasted....so I asked them to reduce my dose and sometimes I wouldn't take the night dose.*  
(38yrs, stopped for 3mths)

### Why people stopped ARV treatment

People stopped treatment for different amounts of time and for a range of reasons - both negative and positive. The most common reasons mentioned were; pressures within the family, financial difficulties, side-effects of ARV treatment becoming too difficult to manage, viral load was at a low or undetectable level and health was good, knowing friends who had stopped treatment and were doing fine.

A few people had recommenced taking drugs which resulted in challenges with adherence which then led to deciding it was best to stop. Many participants told how they were engaged with their doctor and knew their viral load status and CD4 count. Some referred to their undetectable viral load along with a good CD4 count influencing their decision to stop treatment.

*I basically stopped taking therapy because I was feeling good. No virus. Two times I did a viral load test and it was undetected.*  
(43yrs, stopped for 10mths)

*I got slack with my meds...I had grown tired of it. I learnt that if CD4 is over 200 you don't have to take ARV anymore. You are in the clear - like past the critical stage; like a normal person.*  
(43yrs, stopped for 14mths)

Some talked about simply being 'over it'; they were bored or tired with ARV treatment. One person, who has a good relationship with his doctor and stopped four months ago, continues to pick up the medication and take it home. His wife and parents don't know he has stopped. He is feeling well, but knows he should be taking the medication. He plans to start again.

*I was very disciplined, never late. That is why I got sick of it...you have to take it forever... They explained that I had to take it my whole life... But over time I got sick of it.*  
(32yrs, 4mths, currently not taking ARV)

*I stopped because I wasn't adhering, because I relapsed into drugs... I knew that taking meds late could mean developing resistances and I didn't want that to happen, so I just decided to stop altogether.*  
(30yrs, stopped for 12mths)

Several participants talked about watching friends who had stopped ARV treatment and how they appeared to do well and so they believed it would not be an issue if they also stopped.

*At the time, how can I put it, I felt tired of it....and secondly because my CD 4 was already high...and thirdly, because I was looking to my friends as role models who had stopped and were doing really well, feeling really good after stopping therapy... I was deliberating over it for nearly a year before I stopped...I had started to feel tired of it...Sick of the routine, so I started to think about quitting... Yes...there were two reasons....one, I saw how well my friend was doing since stopping ARV and the second thing was that my CD 4 count was really high....So, I thought I would have a break for a while from the ARV.*  
(34yrs, stopped for 3mths)

## Conclusion:

Even with good access and good level of care in Bali people on ARV treatment still stop treatment. Ongoing support about the importance of treatment in the context of everyday pressures is vital. It is also very likely that people throughout Indonesia are unaware of the implications of stopping treatment and do make ill-informed decisions about their treatment.

### Further information:

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