

“I won’t die with the cause of AIDS”:

Testing, initiation and adherence experiences of people on ART since the implementation of South Africa’s national HIV treatment programme

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Background

- South Africa's ART program has been ongoing for over ten years
- Universal Test and Treat has compressed the HIV care cascade, removing several key barriers to initiation
- Implementation of differentiated care means increasing number of patients now being supported outside of the facility
- Wealth of research investigating short-term clinical outcomes
- Long-term outcomes (retention and viral suppression) critical to achievement of 90-90-90
- Opportunity to learn from patients' long-term treatment experiences

Methods

- Mixed methods study
- Large urban public-sector HIV clinic located in Johannesburg, South Africa
- Objectives:
 - Describe 10-year treatment outcomes of a cohort of HIV-positive patients (Quantitative cohort analysis)
 - Explore experiences of those receiving ART since the first years of SA treatment program (Qualitative)
 - Identify barriers and facilitators to continued care throughout the different stages of the care continuum (Qualitative)

In-depth Interviews

Inclusion criteria:

- HIV-positive South African adults (≥ 18 years old)
- Initiated ART between April 2004 and March 2005
- Active in care between October 2015 and March 2016

In-depth interviews:

- Interview guide incorporated themes around facilitators, barriers and experiences at testing, initiation and on treatment, quality of life and hopes for the future
- Purposively selected 24 adult patients during routine visits
- Conducted in English
- Analysed using Nvivo 10
- Initially used deductive, pre-assigned codes then inductive code development

Results:

Interview Patient characteristics

	N (%)
Sex	
Male	9 (37.5)
Female	15 (62.5)
Age at interview	
25-44	10 (41.7)
45-54	12 (50.0)
55 or older	2 (8.3)
Has spouse/partner	22 (91.7)
Has children	21 (87.5)

	N (%)
Employment	
Full-time	7 (29.2)
Part-time	6 (25.0)
Self-Employed	3 (12.5)
Unemployed	7 (29.2)
Missing	1 (4.2)
Pregnant at ART initiation	3 (20.0)
At least one drug reaction	21 (87.5)
Stopped treatment at least once	6 (25.0)
Disclosed HIV status to partner / family member	24 (100.0)

The clinic environment: a facilitator

- Clinic provided emotional and psychological support as treatment became available
- Regular visits
- Supportive counselling
- Informal support groups
- **Crucial link to initiation**



38 yrs

...when I'm coming to [the clinic], they welcome with open hand, you know that welcome. I was so happy getting counselling, true counselling, getting the treatment, no problems.

The clinic environment: a barrier



- Increased patient volumes
- Staff shortages and change in staff attitude
- Long queues and having to return for medication
 - **Emotional and psychological impact and a barrier to continued care**

Sometimes you come here, you don't get medication, you have to come back tomorrow because it's late... they couldn't finish all the patients.

49 yrs



57 yrs

And the staff were kind of busy, and sometimes they get violent. They get angry because people were many by that time... They were always shouting and cross, angry...

Gratitude and good fortune: a facilitator

- Once treatment became available, participants felt ready for treatment
- Felt 'blessed and honoured' to be among the first treated
- Many had already lost loved ones to AIDS
- **Facilitators to initiation and adherence**



54 yrs

After my husband passed away, my daughter passed away, I - a lot of people in my community passed away because of HIV positive. So I think I'm lucky to have the, the treatment. So I'll never leave the treatment.

Family and children: a facilitator



- The need to support and provide for family financially was a **strong motivator for initiation and adherence**
- Females participants in particular expressed a strong parental need to survive for their children



54 yrs

Because I have to maintain family. If I don't get anything, I feel that some part of my body its left somewhere.



54 yrs

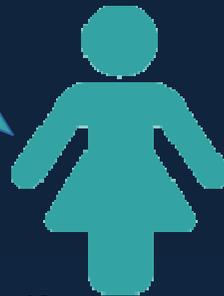
It was not an easy job, but because I want to live for my children, I, I thought it's a good idea

Disclosure and support networks: a facilitator and barrier

- A strong support network was crucial to retaining hope and continuing in care
- Other participants reported that disclosure resulted in them being shunned which made continuing in care more difficult

...I never forget that day she gave me a hug. I think after some years she never gave me a hug, but that day my mother gave me a hug. And said don't worry, we'll go through this together.

45 yrs



57 yrs

So I have to move from his shack because I could see now that he doesn't even want to see me anymore. Or talk to me for that matter, or it was like I came with a bulk of HIV.

Reasons for Gaps in Care

- 6 participants reported stopping treatment at least once
- 4 reported gaps ranging from two weeks to six months

- Reasons included:

- Severe side-effects
- Travel
- Domestic abuse



38 yrs

I didn't know that he is a violent man... I go to the room, to the wardrobe to take my bag, take my tablets, it's time... He broke my hand...it was a serious case because he broke my leg, my hand..



45 yrs

I went away [for work] for a month, and then where I was, there's my treatment finished and I couldn't come back to the clinic.



Long term retention & adherence

- Feeling healthy and happy and hope for the future
- Hope for a cure
- The opportunity to help others
- Motivation to live a healthy lifestyle and have a family
- **Key motivators for long term retention and adherence**



45 yrs

One thing that motivates me...if I didn't have my treatment I think I was supposed to be passed away a long time ago. I even have kids after I was diagnosed...two beautiful daughters

...I tell myself that if I die today, tomorrow they say now there is a something that will stop the HIV, finish and all this thing.



40 yrs

Study limitations

- Only spoke to people who had successfully navigated treatment at one facility for over ten years.
 - The SA HIV Treatment Programme's "success stories"
- We do not know about the people who transferred out or who dropped out of care completely
- Recall bias – asking people to remember details from ten years ago

Conclusions

- Participants reiterated much of what we know in terms of reasons to initiate and adhere to treatment
- In the era of 'treatment for all' some of these factors may be less pertinent and others more important
 - For example - those who are obviously sick may be more likely to disclose because it is harder to hide; also more likely to experience rapid health improvements from treatment
 - Disclosure and support may become less likely
 - Less likely motivated by the impact of treatment

Conclusions 2

- As new strategies and policies are implemented e.g. Guidelines for differentiated care, these interventions need to focus on two key issues:
 - **Establishing support networks and ongoing support**
 - e.g. adherence clubs, ongoing counselling
 - **Addressing clinic level barriers (e.g. waiting times and resource issues) to adherence and retention**
 - e.g. Decentralised medicine delivery
- Critical to achieving and sustaining 90-90-90 targets

In closing:

“My future is bright... I’m not saying it will happen, [but] if I may die, I won’t die with the cause of AIDS. Do you know that? I might die with something else? But not with this.” (Male, Age 54)



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