

Treatment Failure and Adherence in Second-Line Patients.





Results from an interview and photo-based research study looking at barriers and facilitators to adherence for second-line patients.

### What is treatment failure?

- What is Viral load?
- When?

■ What is high viral load

- Following 1 high viral load, patients attend adherence counselling and a follow-up viral load is taken after 3 months.
- Treatment failure

#### What is treatment failure?

- What is Viral load?
- When?

4 and 12 months following treatment initiation.

- What is high viral load
- >1000 copies/mL
- Following 1 high viral load, patients attend adherence counselling and a follow-up viral load is taken after 3 months.
- Treatment failure = 2 consecutive high viral loads, need to change medication



#### Adherence and resistance



■ What is Adherence to ARV's?

■ What is Resistance to ARV"s?

# \*What is 2<sup>nd</sup> line ARV's

■ lst line

Efavirenz or Nevirapine

■ 2<sup>nd</sup> line

Aluvia or Kaletra

■ 3<sup>rd</sup> line

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## Background: Ubuntu Clinic

#### Patients on second-line:

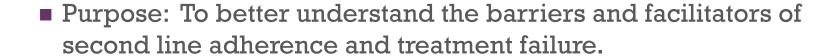
- At the end of 2011, 6296 patients were receiving ART & 463 (7.4%) were on 2<sup>nd</sup> line treatment
- Currently 20 new patients per month are starting second-line ART

#### Second-line treatment failure:

- After 5 years on ART, an estimated 14% of patients experienced laboratory virological failure & 12% were switched to second-line treatment
- Second-line failure rates as high as 33% and 40% have been found in South Africa.



## Study Purpose & Significance



#### ■ Significance:

- As more HIV+ persons begin to take ARVs, rates of failure are increasing.
- Treatment failures have no public option beyond second line ART in SA.
- Patients who remain successful on first line often experience fewer side effects.
- Addressing sub-optimal adherence early increases efficacy of treatment and decreases morbidity of patients.

## **Study Structure**

- Interviews both staff and patients at Ubuntu clinic were interviewed regarding their experience with second line ARVs
- Staff interviews 11 nurses, counselors and clinicians were interviewed
- Patient interviews 10 patients who had at least one high viral load on second line ARVs were interviewed.
- Photovoice 11 patients were asked to take photos of issues, situations and people in their lives affecting or affected by their medication.

# + Summary of Barriers by Respondent

Patient Cited Barriers		Key Informant Cited Barriers	
Issue	Frequency	Issue	Frequency
Not condomizing	3	Drinking	9
Timing of medication	3	Disclosure	8
Side effects	3	Not condomizing	6
DDI/one hour delay	3	Pill Fatigue	5
Pills too large	3	Forgetting	5
Forgetting	2	Not honest with clinic staff	3
Life stress	2	Stigma	3
Drinking	1	Side effects	3
Gave up	1	Lack of food in home	2
Haven't accepted HIV+			
status	1	Life stress	2
Disclosure	1	Insufficient support	2
		Treatment partner not	
Life Stress	1	working	1
Unable to keep appt	1	DDI/one hour delay	1
Pill fatigue	1	Denial	1
		Feeling better	1
		Embarrassed about	
		defaulting	1
		Timing of medication	1
		Staff shouting	1

- Lack of comfort/communication between staff & patients
  - "If you ... are this formal person, then I won't be open with you because you are too formal for me. But if you are a down to earth person and understanding people for who they are, then its easy for people to just be comfortable and share."
- Patients experience problems that are not addressed.
  - "It was getting so difficult to take second-line. It was a big pill and I decided to stop."
  - "I have this diarrhea in my stomach and it's cramping ... it started my viral to go up and up because I skip now"



- Education/miss-understanding of medication:
  - Many patients initially default on first line due to missunderstood medication parameters.
  - "Before they said to us, if you used to take your tablets at 8 o'clock in the morning or night you can't take it at 9 o'clock because it's too late. But [later] said it's not late, you must take the tablets. If you forget, maybe it's two hours or one hour, you can take your tablets."



■ Re counseling: "It's not enough... for those who are starting, they really need that 45 minutes or more, which we don't get."

- Significance of relationships between staff and patients:
  - When relationships between staff and patients were good, it seemed to facilitate adherence and addressing problems.
    - "They got a big heart, you know, when you've come to tell them what's going on with you. They advise and then you believe it, that advice."
  - However, where bad could affect a patients outlook on treatment.
    - "Then maybe it happens that day when you go to the clinic and then the nurse also doesn't have a good day and then that clash would make us feel like I'm not going back."

- Need for positive support/encouragement:
  - Re counseling: "Its about preparing you for what you mentally are going to get into... it has to prepare you for whatever situation you get into."
  - Re support group: "Knowing that we are all attending for second line, its easier to share ... then I crave to see them because I know I will get positive response when I meet them."

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# **Photovoice Themes**

■ The table below lists frequency by main theme of photos shared during the photovoice workshop.

Main Photo Theme	Frequency
Support of family/friends	12
Importance of treatment in lives	5
Gratitude toward MSF staff	3
Difficulty of treatment	3
Religion as source of strength	2
Overcome drinking problem	2
Poor living environment	2
Food insecurity	1
Regret for losing previous wealth	1

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#### **Key PhotovoiceMessages**

- Overall message from photos was positive
- The most recurrent negative aspect was the difficulty of continuing on treatment
- The most important single idea communicated was the importance of a support structure (friends/family)
- Patients used the exercise as a platform to share struggles and successes, highlighting the importance of having a forum for sharing their experiences with ARVs/treatment



#### **Patient Profile**

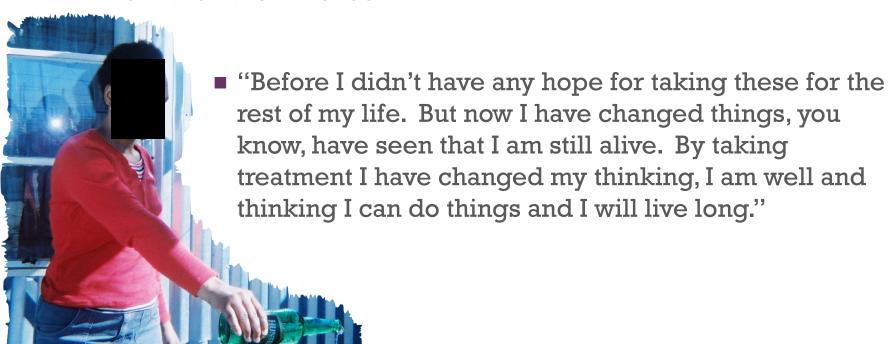
■ "My husband passed away in 2006. He was sick and then he passed away... then in, I think it was November 2007, I went for my first chemo. The other difficult thing ... was when I was disclosing to her and her brother, because he was asking why is she always sick, so I had to site down and disclose and that was the toughest day of my life."

"I realised that there are parts of my life that I just blocked off and never faced ... but now I have that mind that is telling me that I can face them again."



#### **Patient Profile**

■ She was diagnosed with HIV in 2006 when she came to the clinic with TB. While on first-line she drank alcohol to help with the stress. Its now only herself, her sister and her two children. She is the breadwinner in the family but her sister gives emotional support. Both children are in school.



# Misconceptions about ARV's

- Dosing times
- Missing your time
- Alcohol
- Condoms
- Diet

## Recommendations – TAC's Role

- "The last decade was about access, this one is going to be about adherence."
- Educate patients on what treatment failure isand why it's important
- On-going education and support for patient adherence
- Clear up common misconceptions about taking treatment
- Promote good communicationbetween patients &healthcare workers