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Analysing Longitudinal Population-based
HIV/AIDS data on Africa

When 'bad' patients transform into 'good' patients: mediating agency in the therapeutic alliance to overcome bottlenecks along the HIV cascade of care

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Introduction

- Notions of 'good' or 'bad' patient behaviour affect patient-provider relationships in the domain of HIV care.
- Little is known about the role of these social and moral representations in shaping access throughout the cascade of HIV services.
- **Aim: explore factors that mediate bad and good patient behaviour, and examine how these mediation processes could serve to overcome barriers along each stage of the cascade.**

Theoretical Framework

Social-Cognitive Theory

- Person
- Behaviour
- Environment



Methods

- A qualitative study done in seven demographic surveillance sites
- Purposive-sampling of health workers and PLHIV
- In-depth interviews conducted and analysed inductively, with constant comparison
- Ethical approval in all countries, and individual informed consent all participants

	HCW	Diagnosed no ART	On ART	No longer in care
Kisesa (Tanzania)	8	6	18	5
Karonga (Malawi)	5	9	27	4
Rakai (Uganda)	6	16	14	6
Kyambaliwa (Uganda)	5	8	16	4
Kisumu (Kenya)	8	10	15	6
Manicaland (Zimbabwe)	4	13	35	11
uMkhanyakude (South Africa)	18	10	17	6
TOTAL	54	72	142	42



Results

“A bad patient?... A person who never comes to the clinic on his appointment date ... Now you just wonder, ‘where is he getting the treatment he is taking?’ That person is a bad patient because even if he is sick, he never comes to clinic...”

GOOD PATIENTS

- Disclose HIV status,
- Attend clinic regularly
- Adhere to medicines,
- Remember what providers teach
- Report new problems
- Follow instructions
- Are open about their HIV
- Timely initiated
- Virally suppressed
- They love themselves
- Love their lives

BAD PATIENTS

- Do not meet above
- Are uncooperative

CHALLENGING THE NOTIONS OF ‘BAD’ PATIENTS

- Labels of 'challenging' or 'difficult' instead of bad patients.
- “Bad” patients have social circumstances that hinder behaviour
- Providers implicate social determinants, e.g. poverty, stigma, as contributors to “bad” behavior.
- These may be seen as unintentional, beyond patient control, and need special services.

TURNING ‘BAD’ PATIENTS INTO ‘GOOD’ PATIENTS

- Tracking (telephone and home visits) systems for missed appointments
- Treatment delivery in the households by community health workers
- Treatment collection by family members for sick and working patients
- Alliances with patients to support testing of sexual partners

Conclusions

- Providers are shifting away from notions of ‘bad’ patients for PLHIV, and rather label some as ‘challenging’ patients
- Blame is increasingly placed on the responsible personal and socio-contextual factors, and less on the patients
- These shifts necessitate stronger therapeutic alliance between patients and providers to jointly identify and overcome barriers
- Success in mediating agency and ‘good’ patient behaviour will depend on mutual understanding between providers and patients

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Thank you