

“Even if she’s sick at home, she will pretend that everything is fine.”

Reasons patients delay seeking treatment for advanced HIV in Kinshasa, DRC

Emilie Venables, Ilse Casteels, Maria Mashako, Eric Goemaere, Sofie Spiers,
Gilles van Cutsem

MSF OCB Operational Research Day
Brussels, 2017



Introduction

- Low HIV prevalence setting in DRC: 1.2%
- *Centre Hospitalier Kabinda* (CHK): MSF-run in-patient facility providing care for people in advanced stage of HIV
- Quantitative study (Mashako 2014):
 - High intra-hospital mortality: 22.6% of patients died after hospitalisation
 - 34% of deaths within 48 hours of admission
- Qualitative study conducted to ask “**why?**” this was happening...and how to prevent it

Methodology

- Qualitative study conducted in October 2016
- 24 interviews in French/Lingala with:
 - **Patients (7)**
 - **Care-givers (8)**
 - **Health-care workers (9)**
- Participant observation
- Transcripts coded and analysed using NVivo
- 4 interviewees died during 2 week fieldwork period



Multiple factors led patients to delay seeking treatment for advanced HIV

Individual

Community

Health-
care facility

Individual level challenges

- Lack of patient knowledge of treatment journey, diagnosis and treatment
- Lack of patient empowerment
- Self-stigmatisation
- Economic difficulties to pay for non-MSF care



Community stigmatisation

- HIV-related stigma remains extremely strong in Kinshasa
- HIV feared and equated with death
- Stigma prevents people from testing, seeking treatment, continuing ART and disclosing

*« Ils vont dire
que nous
sommes la
famille VIH »*

Influence of churches

- *Eglises du reveil*: strong theme throughout all interviews
- Religious beliefs lead people to seek alternative explanations and treatment for HIV
- Television and radio campaigns show people ‘*cured*’ of HIV through ‘*miracles*’
- Pastors tell patients to ‘*throw their treatment away*’

Certain religious beliefs stop people taking treatment

« She came late because of religion. Her pastor told her that she was cured. She only took her medication for 2 or 3 months at the end of her pregnancy... »

« My pastor told me not to take my treatment anymore. He told me I was cured. »

Economic factors: individual and health-care facility

- User-fees cause people to delay seeking health-care until they are seriously ill
- Paying for treatment for someone who may die of HIV is seen as *“a waste of money”*
- Health-care workers *“want to make money”*
 - Delay HIV testing
 - Send patients for unnecessary tests
 - Give TB treatment without HIV testing

*La clinique
c'est comme
une boutique.
It's like a
shop...*

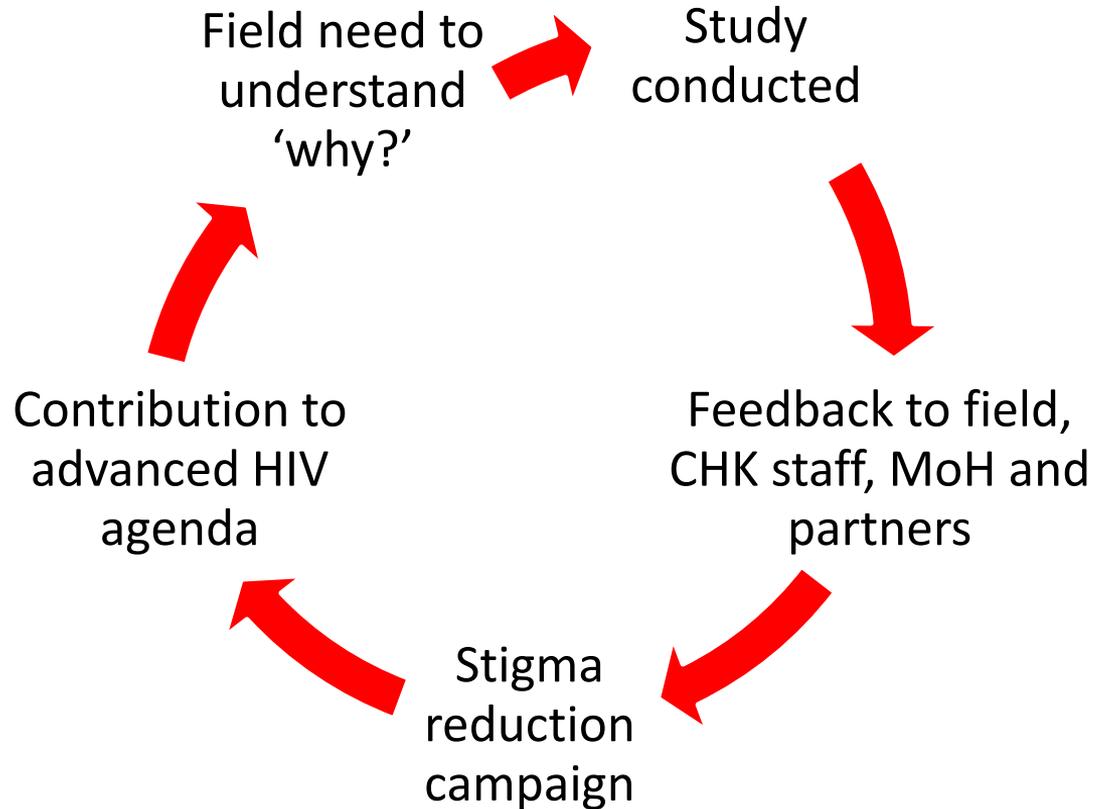


Conclusions

- The late arrival of advanced HIV patients leads to unnecessary deaths
- Lack of patient and health-care worker awareness and knowledge of HIV contribute to delays in seeking care
- Stigmatisation remains a major factor
- Many churches spread dangerous messages which prevent people from taking – or continuing – ARV treatment
- Cost remains a barrier for accessing health-care



Operational implications: research into action



Acknowledgements

- Elysée Manzias Sumbi, MSF Kinshasa
- The team from '*projet SIDA*'
- The psycho-social team at CHK
- All the patients, care-givers and health-care workers who participated in the study