Prohibitions Related to Treatment of Sleeping Sickness in DRC: Origins and Implications for Disease Control

( Mpanya A, Hendrickx D, Baloji S, Lumbala C, Kande V, Boelaert M and Lutumba P.)

ISCTRC
8th-12th September 2013 in Kharthoum, Sudan

Alain Mpanya: PNLTHA R.D Congo
Introduction

- HAT: major public health problem in the DRC (5983 new cases in 2012)

- Strategies of disease control: screening, treatment and vector control.

- Treatment:
  - Stage 1: Pentamidine
  - Stage 2: Arsobal (before) and NECT (currently)

- Operational effectiveness of screening and treatment depends on the involvement of communities (community participation)
Introduction

- Participation of the community is influenced by the beliefs of communities on treatment.

- Prohibitions related to sleeping sickness treatment were found to be a strong impediment to disease screening and treatment (Robays et al. 2007, Mpanya et al. 2012).

- The origin and rational basis for these prohibitions is not well known.

Objective

Gather information on the origin and find the rational basis of these prohibitions
Methods

- Study site: Bandundu and East Kasai (DRC)

- Methods
  - 9 Focus Group Discussion (FDG) with former patients
  - 25 Interviews: Patients, Care providers and coordinators of disease control

- Materials
  - FGD and Interviews were recorded on a digital support, transcribed and translated
  - Atlas ti software was used for analysis
Results

- Perception on drugs received during treatment

1. Arsobal:

Perceived to be very strong, not good for the human body (drug with many prohibitions).

“But the medication that we took Arsobal is too strong. As soon as it was injected, you feel your mouth getting very hot and you feel downgraded” (FGD_3)

"Ah, it was fear, Arsobal, the patient wonders ‘will I get out alive?’ and the nurse giving treatment wonders, ‘will the patient react?’” (INT_28).
Results

2. Eflornithine / NECT:

Perceived to have low toxicity, good for the human body (with only one prohibition)

"DFMO abolishes the prohibitions of Arsobal, you can walk under the sun, work, eat hot fufu ..." (FGD_4)

"... the only prohibition is not to have sexual intercourse, for other things, you can do it if you have the strength ..." (FGD_3)

“But the major prohibition is not to have sexual intercourse for 6 months.” (FGD_6)
Burden of the prohibitions

Occurrence of serious adverse events (death): associated with non adherence to prohibitions by the patient

"If someone is not observed, he is doomed to die. The people who received treatment, those who do not adhere to the rules, most of them are dead ... « (FGD_5)

"We fear the recommendations because we fear death and because we saw many deaths among those who have not respected that. " (FGD_1)

"... That rest, it frightens people and people are avoiding to take the sleeping sickness drugs" (FGD4)
Origin of prohibitions

A. Prohibitions from the Medical side:
- Avoid fatigue, no alcohol and no tobacco: Burke, 1976
- No heavy work, no sexual intercourse, no walking under the sun: heads of mobile team

"The nurse will administer the drug and tell you that when you take these drugs, the major prohibition is to avoid sex with your husband." (INT_9)

"Sexual intercourse for example, health workers on the ground have experienced it." (INT_26) [commenting on: people dying after drug treatment]
Origin of prohibitions

B. Prohibitions from the Community:
Alimentary prohibitions (not eating hot food, peppers, sour foods,...)

“Sorrel, mangoes, this is what I respect, people who have taken drugs have told us, not the nurse.” (FGD_7)

“Rumours from the village state not to eat hot food, it comes from the village.” (INT_21)
Food is prohibited

Food is not prohibited

Prohibitions

adverse events: severe, and each patient is at risk

Refusal to screening

Fear of treatment

Community

HAT Patients

Treatment centers

mobile team

Explicative model of prohibitions related to treatment
Conclusion

It is possible to reduce prohibitions and to increase adherence on screening and drug treatment when acting on:

1. Medication with low toxicity

2. Minor adverse events

3. Awareness (Key messages)

Community

HAT Patients
Thank you for your attention

PNLTHA
ITM Antwerp
Strategic Network Neglected Diseases