



WITS REPRODUCTIVE HEALTH & HIV INSTITUTE

# Gossip, Rumor and Medical Research: Some Findings from VOICE C

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# Does the truth matter?

- Rumors are more than just wrong or incomplete information; *they are socially constructed, performed and interpreted narratives, a reflection of beliefs and views about how the world works in a particular place and time*

**A I D S R U M O R S**  
Rumors about disease and illness draw on the rich symbolism of the body and are a way for social groups to express concerns about their relationships to the community and state. The Indonesian “AIDS Club” rumors are part of a corpus of contemporary legends about AIDS that have circulated globally. In their local form, however, they speak to particular concerns that urban Indonesians have about modernity and the power of the Indonesian state. [*AIDS, rumors, Indonesia, New Order, disease and illness, violence, body politic, somatization*]

**I** Deficiency Syndrome (AIDS) that emerged in my field site of Surabaya, East Java, Republic of Indonesia, during late 1996 and early 1997. Rumors are more than just wrong or incomplete information; they are socially constructed, performed, and interpreted narratives, a reflection of beliefs and views about how the world works in a particular place and time (Brunvand 1981; Fine 1992a; Kapferer 1990; Perice 1997). Rumors about disease and illness, in particular, draw on the rich symbolism of the body and are a collective way for groups to work out concerns about relationships among the individual body, the social body, and the body politic (Douglas 1991; Scheper-Hughes and Lock 1998). The rumors that circulated in my field site arguably belong to a corpus of contemporary legends about AIDS that have emerged in many parts of the world. They share elements

social and political conditions in urban Indonesia during the late 20th century. I argue that these particular AIDS rumors are a kind of “somatization”

# Rumors as critical commentary of bioethics

*rumors enable people to debate current events and concerns... they make use of their own models and terminologies to express and debate their concerns*

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## **Editorial: Popular concerns about medical research projects in sub-Saharan Africa – a critical voice in debates about medical research ethics**

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# Blood theft: Colonial rumors

The blood-thieves were white people, used European technology (cars, fire engines, torches, medicines, electricity, syringes) to extract blood from local people, which they then either sold or transformed into other commodities, such as medicines.



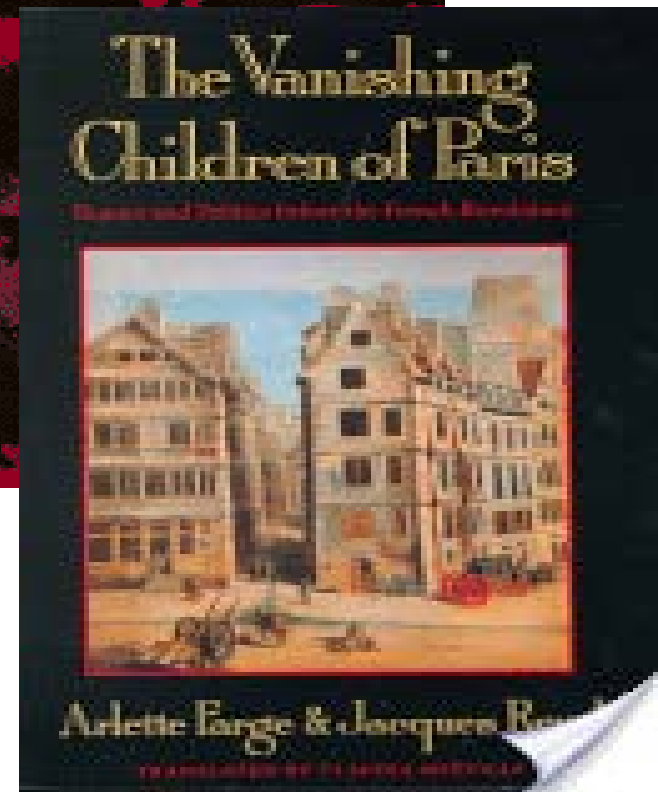
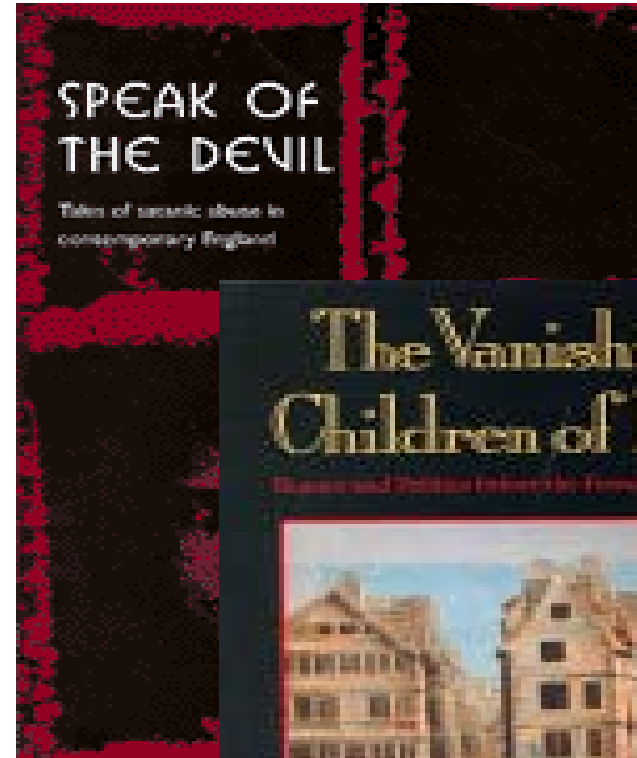
# Blood theft: a contemporary rumor

Friction and confrontations between researchers and parents of children in Western Kenya following tales of blood theft

field staff, assisted by pupils, arrange some of the few available desks for the physical examination of the children and the collection of stool and blood specimens. The teachers and field staff speak Luo (*Dholuo*) to the children, and English, which few children understand well, with the non-Luo researchers. Accompanied by a field technician, the headmaster interrupts the lesson of the classes that will be examined. The names and numbers of the children enrolled in the study are read out from a list. The children stand up, respond 'Present!' and leave the classroom. Outside, they are lined up in the order of their study numbers and wait to be individually measured, given stool containers, or have their blood taken. The team members note results and collect specimens, which are labelled, numbered and stored in cool-boxes. Although they are given a soft drink, most of the children fear giving venous blood, but none of them runs

# Rumor and Moral Panics

Moral panic:  
'the construction  
of a social  
problem as  
something more  
serious than the  
routine issue of  
social control'



# Gossip

- Gossip provides a way of talking about AIDS in a context in which secrecy prevails

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**RUMOR, GOSSIP AND BLAME:  
IMPLICATIONS FOR HIV/AIDS  
PREVENTION IN THE SOUTH AFRICAN  
LOWVELD**

Jonathan Stadler





**Preliminary findings from in depth interviews with enrolled women in Johannesburg**

<b>Group and Mode</b>	<b>Total # interviewed</b>
<b>Enrolled Women In Depth Interviews</b>	41
<b>Enrolled Women Ethnographic Interviews</b>	21
<b>Enrolled Women Focus Group Discussions</b>	40
<b>Male Partners of Enrolled Women In Depth Interviews</b>	14
<b>Male Partners of Enrolled Women, Focus Group Discussions</b>	8
<b>Community Advisory Group Members, Focus Group Discussions</b>	17
<b>Community Stakeholders, Focus Group Discussions</b>	23

# Rumors about VOICE in Johannesburg

- In Depth Interviews with enrolled women (n=42)
  - We asked: ‘What have you heard about VOICE in your community?’ and ‘What influence has this had on your adherence?’
  - Many had not heard anything,
  - Some referred to rumors about clinical research in general
  - Four (N=41) said that rumor / gossip influenced their adherence

# Rumours about VOICE

- Intentional harm
- Greedy women
- VOICE women are HIV positive

# The trial causes harm

She heard a woman talking on the radio that the gel infects women with HIV.

women who enrolled in the trial were given the gel and instructed to have sex with HIV positive men to see whether the gel can prevent HIV.

participants will fall sick because if HIV positive people default on their treatment, they die.

# Greedy women

When she told the women who attended her church [Zionist Church of Christ] about her participation in VOICE they ridiculed her and said she was greedy because she received reimbursements.

# HIV positive

she is concerned that people in her neighborhood may spread rumors that she is HIV positive if they see that she is taking tablets. When she had TB she overheard older women spreading rumors that she was HIV positive.

# Implications for Adherence

Even though her friends at work teased her for taking ARVs, this helped her adherence because they always reminded her to take her treatment.

Some started a rumor that she is HIV positive. Even though she felt bad about the gossip she continued to take her tablets. She even taunted her colleagues, saying that she was in a better position than them because she is aware of her HIV status.



# So, do rumors really matter?

- Perhaps as a form of dialogue, engagement, communication
  - Medical research is a metaphor for anxieties about gender relations
- Implications for adherence:
  - Secrecy and concealment of participation and product use

# Summing up

- Rumors are important but not to be taken literally as misinformation or a lack of education
- Rumors about VOICE not instrumental in shaping adherence
- ... but the fear of gossip and rumor contribute significantly to secrecy and non-communication

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