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

Jonathan Stadler
Wits Reproductive Health and HIV Institute
Johannesburg
South Africa
Women used as Aids guinea pigs

'Study to prevent Aids left me infected'

ROBERTO ABADIE

THE PROFESSIONAL GUINEA PIG

Big Pharma and the Risky World of Human Subjects

It has knocked out this woman! Now the creature of evil is trapped!

Smallpox vaccine ‘triggered Aids virus’
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.

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 show 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

Tropical Medicine and International Health

Volume 11 No 7 PP 975–982 July 2006

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

P. W. Geissler¹ and R. Pool²

¹ London School of Hygiene and Tropical Medicine, London, UK
² Centre for International Health, Hospital Clinic, Barcelona, Spain

Keywords Africa, medical research, science, blood, rumour, ethics
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 away.
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

© 2003 The Guilford Press

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
<table>
<thead>
<tr>
<th>Group and Mode</th>
<th>Total # interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enrolled Women In Depth Interviews</td>
<td>41</td>
</tr>
<tr>
<td>Enrolled Women Ethnographic Interviews</td>
<td>21</td>
</tr>
<tr>
<td>Enrolled Women Focus Group Discussions</td>
<td>40</td>
</tr>
<tr>
<td>Male Partners of Enrolled Women In Depth Interviews</td>
<td>14</td>
</tr>
<tr>
<td>Male Partners of Enrolled Women, Focus Group Discussions</td>
<td>8</td>
</tr>
<tr>
<td>Community Advisory Group Members, Focus Group Discussions</td>
<td>17</td>
</tr>
<tr>
<td>Community Stakeholders, Focus Group Discussions</td>
<td>23</td>
</tr>
</tbody>
</table>
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.
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.
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
Acknowledgments

• In Hillbrow:
  – VOICE C participants, partners and community members
• At WRHI:
  – Sello Seoka
  – Busisiwe Magazi
  – Florence Mathebula
  – Ndangano Makongoza
  – Gusta Fransisco
  – Thesla Palanee
• At RTI:
  – Arian van der Straten
  – Liz Montgomery
  – Miriam Hartmann
  – Helen Cheng

• At MTN:
  – Sharon Hillier
  – Ian McGowan
  – Ronda White
• At FHI:
  – Katie Schwartz
  – Kat Richards
• At DAIDS:
  – Lydia Soto-Torres