The relationship between risk perception, health conceptions and stigmatization in the case of HIV/AIDS – Research results from urban Ethiopia and rural Malawi

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Development Geography

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Geographisches Institut der Universität Bonn
Structure

1. Problematization / Theory
2. Case Studies
   a) Methodology
   b) Case study: rural Malawi
   c) Case study: urban Ethiopia
3. Conclusion
Problematization

Globalization / Modernization

Local Culture
The African society is in a process of fundamental transformation, that affects all parts of society.

- education
- gender role patterns
- communications norms

Problematization
Problematization

Globalization / Modernization

Local Culture

HIV / AIDS
Problematization


▪ AIDS as a „plague of modernity“: due to an increase of spatial and social mobility

▪ AIDS is fought with means of modernity: biomedical understanding, setting up of medical health facilities

▪ thus: AIDS in itself is contributing to modernization
Overall assumption:
The perception and interpretation of a risk influences the selection of coping and adaptation strategies.

Globalization / Modernization

HIV / AIDS

How is HIV and AIDS perceived?

How does this perception influence the treatment of PLWHA?

→ stigma can be interpreted as the discrepancy to the culturally accepted “normality”
Social construction of AIDS in Sub-Saharan Africa (Benn 2002, Winkelmann 2010)

a) Biomedical Discourse
   Transmission: HIV as a virus
   Prevention: Abstinence, Be faithful, Condoms
   Cure: So far none, but ART-medicaments

b) Religious Discourse
   Transmission: AIDS as punishment of god, sexual misbehaviour
   Prevention: Living monogamous and according to rules of the bible
   Cure: Believe in God

c) Traditional Discourse
   Transmission: Witchcraft and Punishment for breaking cultural rules, Curses
   Prevention: Avoidance of jealousy and breaking cultural rules
   Cure: Traditional Healer

‡ in reality, discourses intermix and overlap with each other
Structure

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Methodology

The research was conducted by mainly using qualitative methods

- Participatory Rural Appraisal (PRA)
- Semi-structured Interviews
- Participatory Observation

- quantitative survey (n = 270) in Ethiopia

<table>
<thead>
<tr>
<th>Country</th>
<th>Research period</th>
<th>Semi-structured interviews</th>
<th>PRA group discussions</th>
<th>Quantitative survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Malawi</td>
<td>4 months in 2004</td>
<td>55</td>
<td>24</td>
<td>-</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>11 months between 2007</td>
<td>90</td>
<td>89</td>
<td>270</td>
</tr>
</tbody>
</table>
The case study Malawi

Malawi Research Locations

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The case study Malawi

History of AIDS in the research location Chambwe

1934 founded from former Chewa slaves

1970/80ies: Chambwe as the “headquarter of smuggling”

“People never slept at night. There was a lot of dust because of the incoming and outgoing trucks.” (Woman in Chambwe)

1982 first STD cases

1985 first AIDS case (reconstructed)

1995 in 3 months, 26 people were dying of AIDS in Chambwe

2004: 6-8 AIDS-related deaths per year in Chambwe (800 inhabitants)

ca. 4-6 AIDS-related deaths in Kamkundi (300 inhabitants)
Social construction of AIDS

Phase I: 1985 – 1994

- increased number of people sick with a combination of locally known illnesses

  “In 1984 women were getting sexual transmitted diseases, in many cases, they also spread it to the men. After they were healed, after a few years, these persons started to get sick regularly and got unhealthy hair and were getting skinny.” (Chief M’taya, Chambwe)

- decrease of solidarity in the village due to a suspicion of witchcraft

- no discrimination of AIDS-sick; they were considered as victims of witchcraft
The case study Malawi

Social construction of AIDS

Phase II 1994 – 2001

• since 1994 intensive HIV/AIDS campaigning in the radio
• people realized, it was a sickness but misunderstood the ways of transmission: touching, breathing, shaking hands
• being sick as the result of “misbehaving”
• massive stigmatization of suspected AIDS victims

• Chambwe itself was stigmatized: “Nakongwa” (as if you are shivering)

“If people from Chambwe were coming to a funeral, they were not greeted anymore by shaking hands.” (Evelyn Mackson, 44, AIDS worker from Chambwe)

“We could not marry people from Chambwe. The one person said “You have AIDS” and then the other one said: “You have AIDS.” We were afraid of each other.” (Chief Chidula, 49, Kamkundi)
The case study Malawi

Social construction of AIDS

Phase III  since 2001

• 2001 training of an AIDS Worker from Chambwe by GTZ and Ministry of Health
  • Teaching about AIDS in local language and translation/integration in local culture

• perception of AIDS as a sickness (STD) is dominating
• being HIV-positive is associated with “misbehaviour”
  • rigid communication norms prevent an open discussion on personal level
    “I don’t know [how I got the big cough]. But I never did prostitution or went into bars.” (dying HIV-positive woman in Chambwe)
    “Never ever someone admitted that he had AIDS. This can not happen here.” (Man from Chambwe)

• low discrimination of PLWHA in the village
Social construction of AIDS

- PLWHA are reintegrated in village life

- reduction of discrimination of the village Chambwe
  a) “Now it seemed as a natural thing, everyone was dying of AIDS.”
     (Chief Selemani, Male)
  b) increased level of knowledge about HIV/AIDS in surrounding villages

- Chambwe still has a bad reputation, but marriage into other villages is possible again
### The case study Malawi

<table>
<thead>
<tr>
<th>Time</th>
<th>Political System</th>
<th>Social construction of AIDS</th>
<th>Solidarity in Chambwe</th>
<th>Segregation of PLWHA in Chambwe</th>
<th>Segregation of Chambwe</th>
<th>Number of AIDS deaths in neighbour villages</th>
<th>Number of AIDS deaths in Chambwe</th>
</tr>
</thead>
<tbody>
<tr>
<td>before 1985</td>
<td>Dictatorship</td>
<td>-</td>
<td>strong</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1985 – 1994</td>
<td>Witchcraft</td>
<td>low</td>
<td>none</td>
<td>none</td>
<td>none</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1994 – 2001</td>
<td>dominant: Witchcraft; some Religious, Biomedical</td>
<td>low</td>
<td>strong</td>
<td>very strong „Nakongwa“ bad reputation</td>
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<tr>
<td>2001 - 2004</td>
<td>to the same amount: Witchcraft Religious Biomedical</td>
<td>strong</td>
<td>low</td>
<td>low bad reputation</td>
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</table>
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The case study Ethiopia

Map: GoogleMaps 2007

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## AIDS in Ethiopia

1984  first official HIV-infection

1998  first national AIDS-prevention campaign; start to address in radios

2008  national prevalence rate: 2.2 %

Addis Ababa: 11-16 %

## AIDS in the research locations

1999  first official AIDS case

estimated HIV-prevalence rate: 15-20 %
Social construction of AIDS in Addis Ababa

a) Biomedical Discourse
Transmission: HIV as a virus
Prevention: Abstinence, Be faithful, Condoms
Cure: So far none, but ART-medicaments

b) Religious Discourse
Transmission: AIDS as punishment of god for disregard of the bible, doubts in God
Prevention: Living according to rules of the bible, strong believe in God
Cure: Believe in God, Holy Water

c) Traditional Discourse
not relevant for transmission

d) Lay Concepts
- “Sharp things”
- “Jumping virus”
- mentioning “AIDS” can lead to get sick with it
Which HIV-prevention strategies work to avoid an infection? (n = 225, multiple responses possible)

<table>
<thead>
<tr>
<th>Dis-</th>
<th>Biomedical discourse</th>
<th>Religious discourse</th>
<th>Lay concepts of health</th>
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</thead>
<tbody>
<tr>
<td>course</td>
<td></td>
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<tr>
<td></td>
<td>Condoms</td>
<td>Abstinence</td>
<td>Be faithful</td>
</tr>
<tr>
<td>Percentage</td>
<td>78,7</td>
<td>95,6</td>
<td>95,6</td>
</tr>
</tbody>
</table>

**Sharp things**

a) effort to translate biomedical concepts in local health concepts

b) rigid communication norms
Social construction of AIDS

Phase I: 1997 – 2001
- information about HIV/AIDS starts to spread
- people do not perceive a personal vulnerability

Phase II: 2001 – 2005
- number of AIDS cases are rising
- local population starts to realize, that there is a new sickness
- religious interpretation: AIDS is the devil, PLWHA are demons
- in media: PLWHA are depicted as skeletons, “as the living dead”

“The media only showed horrible pictures of AIDS. I was so much terrified, that I tried to commit suicide.” (HIV-positive man, 45)
Social construction of AIDS

Phase II: 2001 – 2005

- strong discrimination of PLWHA

„Now I have told the owner of my current apartment, that I’m HIV-positive and he rented me his house. Before they wouldn’t have accepted me. Before people changed the ropes when I hung my clothes to get them dry. They didn’t want to share toilets with me. But now it is better.”

(HIV-positive woman, 31, Mekanisa, 2007)

2003: start of public events at local level, organized by the city administration

2003: founding of HBC groups
Social construction of AIDS

Phase III: since 2005

- ART drugs accessible

  "They started to use the medicine and take good care of themselves; they look even much better than us plus we think of our future: "If we discriminate and stigmatize them, what would happen to us in the future?" (woman, 30, from Mekanisa)

- PLWHA and HBC are going public to educate their neighbours
- religious discourse: AIDS as a punishment of God,
- good knowledge about HIV/AIDS in local population, except for the uneducated
- discrimination of PLWHA is a bit reduced
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Conclusion

- risk perception is influencing agency in context of HIV/AIDS
- social construction of AIDS matters!
- stigmatization reflects the internalized health concept of those that stigmatize
- for effective HIV prevention, an insight into local health concepts is unalterable
- bottom-up approaches, e.g. the use of peer educators, are most effective to inform people, to change communication norms and to reduce stigmatization
Thanks a lot for your attention!

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References quoted in this presentation