Disease-related stigma, the social construction of target groups, and South Africa’s programs for AIDS & TB

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Presenter Disclosure
Kathryn Quissell

(1) The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose

Research Questions

- Does disease-related stigma influence policy aggressiveness?
- What can we learn from AIDS & TB programs in South Africa?
### Disease-related Stigma

<table>
<thead>
<tr>
<th>Stigma Type</th>
<th>Description</th>
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<tbody>
<tr>
<td>Social Stigma</td>
<td>Association with pre-existing social inequalities e.g. poverty, inequality between ethnic groups</td>
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<tr>
<td>Symbolic Stigma</td>
<td>Harsh moral judgment, blaming &amp; shaming, often linked to behaviors e.g. sex, drug use</td>
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<tr>
<td>Instrumental Stigma</td>
<td>Fear of contracting the illness, often linked to prevalence, contagiousness &amp; lethality</td>
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### What is policy aggressiveness?

- Time from identification of problem to policy adoption
- Level of resources committed
- Reach of programmatic resources

### Case Selection – AIDS & TB

- They affect similar population groups, and often the exact same individuals because of co-infection
- Major difference is in gender: AIDS is more common in women, TB more common in men
- They differ according to:
  - Mode of transmission
  - Curability
  - Cost
Case Selection – South Africa

- The country with the largest number of people living with HIV
- It has the third largest number of people with TB
- It is a middle-income country and therefore has above-average resources to deal with these problems

Theoretical Relationship Between Stigma & Policy Aggressiveness

- Greater Social Stigma → Management as less deserving
- Greater Symbolic Stigma → Target groups are perceived as more deserving
- Greater Instrumental Stigma → Negative Policy Conflict

Methods

- Data sources: Press reports, Government documents, Advocacy publications, Interviews (31)
- Coding using NVivo 9 qualitative software
- Process-tracing, triangulation between different sources
Political Context

- Political transition at the end of Apartheid
- Concern over rising violence and threat of civil war
- AIDS epidemic struck at the same time ANC was challenging Apartheid regime. No real AIDS program under Apartheid. Issue was used to demonize ANC as “infected terrorists”
- TB program had been established under Apartheid

Narratives surrounding the diseases

- AIDS had first appeared in gay men, shifted from being seen as the “gay plague” to the “black death.” Used as another justification for racism under Apartheid. African origin of the disease.
- TB was known as the “white plague” and was largely thought to have been brought to Africa from Europe.

Preliminary Findings

Social Stigma

- AIDS
  - Gender, racism, underdevelopment
  - Created greater policy conflict

- TB
  - Racism, underdevelopment
  - Less policy conflict

Symbolic Stigma

- AIDS
  - Concern over sexual transmission
  - Stigma avoidance
  - Concern over cost
  - AIDS patients described as burdens on health system
  - Great policy conflict

- TB
  - No symbolic stigma, patients were not described as burdens but as needing treatment
  - Less policy conflict

Preliminary Findings – Symbolic Stigma

Instrumental Stigma

- AIDS
  - As epidemic grew, activist calls for policy change became more urgent
  - Lack of a cure initially created more policy conflict, but efficacy of ARVs changed this perception

- TB
  - Recognition of size of epidemic led to infact policy adoption & scale-up
  - Curability also supported policy adoption & scale-up

Policy Aggressiveness

- AIDS Treatment Policy
  - Delayed adoption of national ARV program (1999-2004)
  - ARV coverage 43% in 2009, 80% in 2012

- TB Treatment Policy
  - DOTS adopted in 1997
  - DOTS coverage 100% in 2006
Summary of Findings Related to Stigma & Policy Aggressiveness

Greater Social Stigma:
- Gender
- Race & Poverty

Greater Symbolic Stigma:
- Sexual transmission
- Cost

Greater Instrumental Stigma:
- Size of epidemic
- Curability

Reduced Policy Aggressiveness
- Shame & blame, target groups seen as less deserving
- Target groups are perceived as more deserving

Greater Policy Aggressiveness
- Less Policy Conflict
- Target groups perceived as burdens/less deserving

Implications
- Disease-related stigma does influence policy aggressiveness
- Social and symbolic stigma reduce policy aggressiveness
- Instrumental stigma increases policy aggressiveness when it is linked to the size of the epidemic, but it reduces policy aggressiveness when it is linked to curability
- For AIDS policy, the discourse on gender, moral judgment, cost, and lack of a cure were the key differences leading to reduced policy aggressiveness
- Created target groups perceived as burdens/less deserving
- Created greater policy conflict