

# The effect of stigma on access to and use of TB services

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# Definition of health-related stigma

The social process of combining the presence of a biological disease in a person or group with a perceived notion of culpability

“Disease stigma is...negative social ‘baggage’ associated with a disease” [Deacon et al 2004:18].

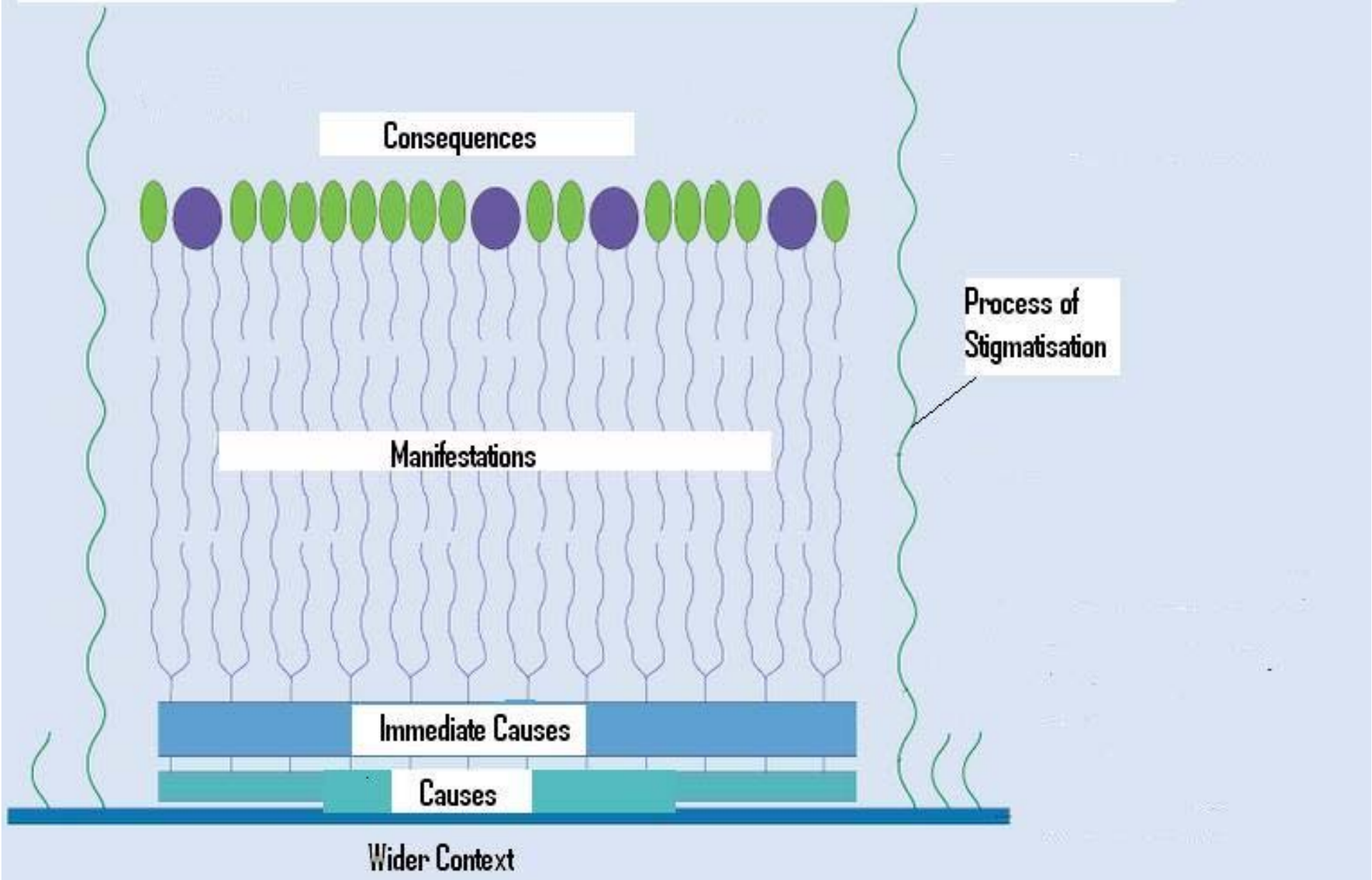
## Key elements of Stigma

- Stigma can be: “felt” (anticipated) and/or enacted and/or internalised [Brown et al 2001, Scambler 1998]
- Reinforces pre-existing inequalities and social divisions (deep rooted causes) [Parker & Aggleton 2003]
- Often multi-layered [Nyblade et al 2003]
- Culture specific, disease specific, though commonalities in experience and impact [Weiss et al 2005, Ogden & Nyblade 2005)

## Key elements of Stigma (continued)

- Used too loosely in public health – to explain too wide a range of negative actions, intentions & restrictions
- Can be unpacked into actionable, manageable parts
- Critical elements to consider:
  - causes,
  - experiences,
  - consequences,
  - coping strategies
- Part of a wider context

# Mycobacterial Cell Wall – A Schematic Model for TB Stigma



# Delayed health seeking & stigma

- Stigma shown to contribute to delayed health seeking (ie avoid TB diagnosis) - including shopping around for treatment from elsewhere (private clinics, traditional healers)
  - India [Atre & Mistry 2005, Atre et al 2004, Rangan et al 1998]
  - Bangladesh [Weiss et al 2005], Malawi [ibid]
  - Vietnam [Johansson et al 1999]
- Suspect TB patients more likely now to “*hide*” from the health services, go to traditional healers or elsewhere. (Zambian study (2001-2003), in context of high HIV prevalence)
- Recognition of consequence of this, that can “*die by hiding*”, [nurse counsellor, Lusaka, 2002].

# Denying or hiding TB diagnosis

- TB stigma feeds denial of TB diagnosis or leads people to hide diagnosis
  - India [Atre et al 2004]
  - Vietnam [Johansson 2000]
  - Thailand [Sengupta et al 2006, Ngamvithayapong et al 2000]
  - Pakistan [Liefoghe 1998]
  - Nicaragua [Macq et al 2005]
  - Mexico [Rubel and Garro 1992]

# Why Delay, Deny, Hide?

- Because of stigma: the fear of being thought to have AIDS, of being isolated, rejected, neglected, shamed (Zambian Study)

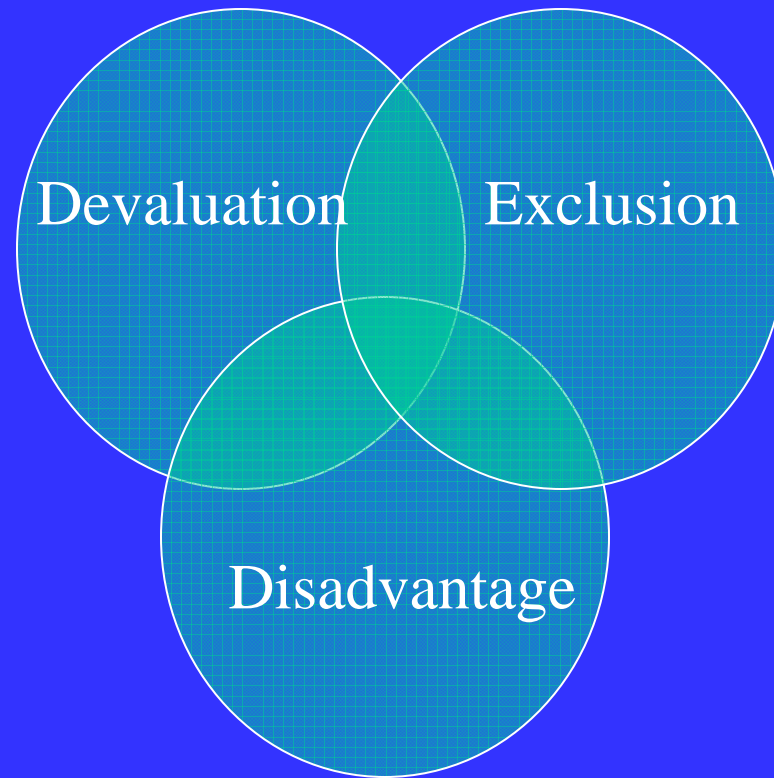
*“It is on rare occasions that TB patients tell their status because as a community when we see someone has TB, we say they have AIDS and so they decide to keep it to themselves for fear of being isolated”* [business woman, Lusaka, 2002]



*“There is a TB patient and the other 2 people are staying far away from the patient because they don’t want to be infected with the disease.”*

*Girl aged 14, Kamwala Street Children*

# Experiences of Stigma [Sartorius 2004]



# TB Treatment & Stigma

- Stigma has been one reason for:
  - interrupting treatment
    - In Vietnam, Mexico [Johansson *ibid*, Fox 1988];
  - Refusing directly observed therapy
    - In India, Pakistan [Weiss and Ramkrishna 2001, Liefoghe 1998].
- Health providers propagating stigma
  - Nicaragua, Zambia [Macq et al 2005, Bond et al 2004]
- Some TB prevention measures are unnecessary and prolonged and are stigmatising
  - Zambia, Vietnam & Mexico [Bond et al 2004, Long 2000]
  - E.g. In Zambia, being seen at the TB corner or with diagnostic symbols can lead to stigma & association with HIV can lead to either/both carers & TB patients '*giving up*' with treatment.

# Gender and Stigma

- Being identified as a TB patient had more negative consequences for women in India, Pakistan, Vietnam [Rangan & Mukund 1998, Liefoghe 1998, Long 2000, Johansson 2000].
- Women have more negative feelings at diagnosis [Liefoghe ibid], more scared of rejection [Long ibid]
- Men feel more to lose from loss of social status [Weiss et al 2005]
- Important to understand differences to design effective responses

# Reducing Stigma through...

- Structural improvements - improved services & access & outcomes & ARVs
- Developing specific, participatory anti-stigma education for TB programmes – for providers, patients, affected households, communities (especially critical for TB outcomes in high HIV prevalence areas)
- Addressing legitimate and non-legitimate fears of TB transmission (become more acute with HIV)
- Integrating anti-stigma education into a wider strategy of TB patient empowerment (see Macq 2006, STOP TB)

# Evaluating Stigma Interventions

Domains for diagnosed TB patients	Domains for TB affected households/community
<ol style="list-style-type: none"><li>1. Enacted Stigma</li><li>2. Disclosure</li><li>3. Internal Stigma</li><li>4. Coping with Stigma</li></ol>	<ol style="list-style-type: none"><li>1. Fear of casual transmission</li><li>2. Shame, blame, judgment</li><li>3. Enacted stigma</li><li>4. Disclosure</li><li>5. Association with HIV/AIDS</li></ol>

Developed by Bond for ZAMSTAR Study, adapted primarily from 'Can we measure HIV/AIDS related stigma & discrimination?', Nyblade & MacQuarrie 2006, & Weiss et al 2005, Van Rie et al 2006

# Conclusions

- Gap in research literature
- More qualitative & quantitative empirical evidence needed
- ARV rollout – how will this impact TB stigma?
- Need to adapt anti-stigma tools for TB & ‘TB/HIV’
- Need to further develop and pilot quantitative & qualitative evaluation tools to measure stigma reduction
- Decreasing stigma will lead to improved health outcomes - make having tuberculosis and HIV less dehumanising.

*“TB patients are also people because it is not that when someone suffers from TB they are not a person”* [HIV-positive woman cured of TB, urban household]

# Education message from 12 year old boy, Misisi, Zambia, 2002

[Clay, Bond et al 2003]

*“This message is targeted to those who have been victimized because of infectious diseases that they have caught.*

*TB is an airborne disease but a person cannot get infected once the patient is on treatment*

*Both TB and AIDS patients need proper care.*

*They don't have to be separated because of their status, they need encouragement and care.”*

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