The nature of stigma and new challenges of leprosy control

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Overview

Nature of stigma
- What is it?
- Leprosy-specific interests
- Other related health interests

Challenges
- Indicated goals
- Research and action
Goffman’s definition of stigma

“The situation of the individual who is disqualified from full social acceptance”

(Erving Goffman 1963, p. 9)

“Disqualified from full social acceptance” in 1950s-60s and denial of basic human rights today
Reformulation of stigma

Discrediting attribute (mark)

A mark of shame or discredit (Webster’s); disgrace or infamy (OED)

Social situation (disqualification)

Situation of the individual denied full social acceptance
From moral definition to social analysis and human rights

**Morality, religion, and bondage**
- Mark of shame, infamy or disgrace
- Brand, as on slave or criminal
- Victim blaming

**Social science**
- Disqualified from social acceptance
- Social response to deviance
- Labelling theory

**Human rights**
- Denied civil rights
- Complementary vulnerabilities
- Health system and social obligations
Various “burdens” of illness*

- **Defined burden** - Epidemiological account of morbidity and mortality with reference to disorders, DALYs and deaths
- **Undefined burden** - Emotional and socioeconomic impact on family and community
- **Hidden burden** - Humiliation, isolation, and social consequences (e.g., unemployment) arising from stigma and human rights violations

Configuring stigma for public health

- **Social disqualification and discrimination** that is medically unwarranted and unjust
- **Identity redefined** by a disease or health problem (pain of metonymy—*mistaking* a part for the whole)
- **Applied to not only to persons but also to the problem condition,** which affects health and social policy
- **Layered stigma** acknowledging synergistic effects on a person or group of multiple identities (e.g., ethnicity and social status)
- **Common and distinctive features** for various diseases and cultures
Public health impact of stigma

Features, burden and other impact

• Burden of illness-related stigma
  – Personal impact: social and emotional suffering (hidden burden)
  – Effects on family and community (undefined burden)

• Timely help seeking, adherence to treatment and quality healthcare
  – Delayed help seeking
  – Premature discontinuation of treatment
  – Integration of social and biomedical aspects of healthcare (biopsychosocial)

• Well-being in psychosocial and legal domains
  – Social and legal pillars of unfair stigma
  – Alternatives to stigma: acceptance and support (social); dignity and self-respect (psychological)
Conceptual framework for public health action
Extending hidden-distress model

Hidden distress model of stigma*

- Enacted
- Felt

Those who are stigmatized
- Enacted
- Internalized
- Anticipated

Those who stigmatize
- Enacted
- Endorsed
- Accepted

**Experience of stigmatizing and being stigmatized**

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<th>Domains</th>
<th>Enduring stigma</th>
<th>Perpetrating stigma</th>
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**Key interventions**

- **Socio-cultural norms & behaviour**
- **Support**
- **Law and normative behaviour**
- **Awareness, challenging sociocultural norms**
Features of leprosy stigma

- Cultural historical associations with sin and blame—as if culpable
- Exaggerated fear of transmission motivating irrational quarantine
- Sensationalist tendencies of mass media and social networks
- Legal system that has sanctioned and required exclusion
- Impact of deformities—layering of disease and disability
Intermingling of cultural, colonial and racist histories

- Judeo-Christian sources

- Hindu sources, including legal texts that deny inheritance, marriage and other rights to people with insanity, leprosy or epilepsy (unmāda, kushtha or apasmāra)

- First European study of Ayurveda by Orientalist HH Wilson was on the topic of leprosy
“I have thought an account of the Hindu notions, on the subject of Leprosy, might form a not unserviceable introduction to the more scientific enquiries, which the better opportunities and greater experience of other members of the society may enable them to institute. The advanced state of medical knowledge in Europe is a sufficient security, that the errors of these guides, imperfect as they undoubtedly are, will not lead us astray…”

At the end of the nineteenth century, India was Britain's largest and most important foreign colony. Furthermore, it was known to have a large leprosy population. In 1889, the National Leprosy Fund was established as a memorial to Father Damien. One of the very first tasks was to appoint a Commission, composed of three members from the Royal College of Physicians, the Royal College of Surgeons, and the Executive Committee of the National Leprosy Fund, to survey leprosy in India and formulate policies regarding the disease. Their Report, prepared in 1891, irrevocably dismissed the ideas of heredity, but considered that although

... in a scientific classification of diseases leprosy must be regarded as contagious and also inoculable, yet the extent to which it is propagated by these means is exceedingly small.\textsuperscript{26}

A Special Committee of the National Leprosy Fund was appointed to review the conclusions and recommendations of the Report. In a strongly worded dissenting opinion, they specifically disagreed with the above conclusions, holding, instead, to a much harder line on contagion.\textsuperscript{27}
“The period of the 1880's and 1890's and especially the years 1889-1891 (Fig. 1) were marked by an alarmist attitude...

“Certain races and peoples, notably the Chinese, Asiatic Indians, and Negroes—the Yellow and Black races—were coming to be identified as leprosy-prevalent populations...

“Compulsory segregation became the official public health model ... Many nations had already passed segregation laws before the First International Leprosy Conference met in 1897.”

Fig. 1. Number of references to leprosy in Index to the London Times, 1870-1930.

Passage and table from Gussow and Tracy 1970, p. 436-437.
Sensationalist American press fuels exaggerated concerns of contagion

from *The Star* of February, 1949, the official news organ of the leprosy patients at Carville, La. This quotation from *The Star* is entitled, “Ghost Of The Month:”

“One Chicago paper Headlined:

**LEPER FLEES IN FLORIDA**

*Miami, Fla. (UP)—Highway patrolmen and local police were on a statewide alert Saturday for a 40 year old victim of leprosy who escaped from Jackson Memorial Hospital Friday.... Walter Winchell beat tom-toms and used the yarn with trimmings on his Sunday, February 13, broadcast. He gave a detailed description of the man’s physical appearance and his wearing apparel, emphasizing that a “state police dragnet” had been laid out for the “escaped leper” even though the health authorities had labelled him as not communicable.... The former Carville patient left here

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Social impact of deformities

- Both functional impairment and a social response
- Social impact of leprosy deformities independent of, but synergistic with infection status
- Response to vitiligo (leukoderma) – biomedically unrelated, but historically linked
Segregating affected persons in leprosy colonies

- History of forced incarceration in sanatoria, hospitals and colonies
- Appeal of colonies and institutionalization for leprosy-affected persons: safe haven and respite
- Meeting in Delhi in 2005 representing 630 leprosy colonies in India, “Empowerment of People Affected by Leprosy.” (Jacob and Franco-Paredes 2008)

“Patients who were discharged from hospital had no option but to settle on any available land because they could not go back to their native villages or towns. The leprosy-affected gravitated towards places and people where they felt at home, and so colonies grew and absorbed the stigmatised.” (Infochange, Oct 2008)
Questioning coherence of “stigma” applied to diverse conditions

Stigma applied to diverse conditions, not just health problems (Falk 2001)

- Women
- Mentally challenged
- Homosexuals
- Single people
- Prostitutes
- Minorities
- Overweight
- Handicapped persons
- Successful people
- Et cetera, et cetera

“It is remarkable that those who live around the social sciences have so quickly become comfortable in using the term ‘deviant’, as if those to whom the term is applied have enough in common so that significant things can be said about them as a whole.”

(Goffman 1963: 167n)
Features of HIV/AIDS stigma

- Recent condition without long cultural history and legal entanglements
- Layered stigma (e.g., homosexuality, sexual promiscuity, drugs and poverty)
- Safe sex for prevention and exaggerated risks from casual contact complicate public health action
- Durban conference 2001 focused on stigma and motivated focus on human rights
- “Break the silence.” Dual personal and social interests of disclosure

Nkosi Johnson, Durban, July 2000.
Annual PubMed citations for “stigma”

Years 1965 – 2012 (excluding “stigma” plants and botanicals)
Leprosy and HIV/AIDS stigma

PubMed Citations for Leprosy and HIV/AIDS Stigma

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Leprosy, HIV/AIDS and All PubMed stigma

PubMed Citations for Leprosy, HIV/AIDS and All PubMed Stigma

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Distinctive stigma interests of various health problems

- Leprosy
- HIV/AIDS
- Tuberculosis
  - DOTS, gender, cultural history, association with HIV/AIDS
- Onchocerciasis
  - Advocacy for priority of ivermectin investment
- Lymphatic filariasis
  - Hiding deformed limbs and hydroceles complicates self-care and use of health services
- Mental health problems (e.g., schizophrenia)
  - Exaggerated dangerousness, cultural meaning, institutionalization
- Epilepsy
  - Exclusionary cultural associations, safety and risk (e.g., driving)
- Obstetric fistula
  - Primary gender issues and access to surgical health services

Onchocercal skin disease case history of Agnes, promoting awareness, research and public health action
Engaging diverse stakeholders for stigma of schizophrenia

- Journalists
- Students
- Employers and employees
- Clergy
- Police and criminal justice system
- Family and community groups
- Affected persons
New challenges for effective elimination of leprosy as a public health problem

• Monitoring and advocacy to remove or fix unreasonable laws

• Studies of stigma in endemic communities among leprosy-affected persons (LAP) and others for baseline, assessing needs (e.g., nearby access and priority of informing LAPs of their diagnosis) and tracking progress

• Integration of social and biomedical aspects of leprosy health care (e.g., analogue of VCT; vocational and livelihood interests)

• Promoting community and patients’ awareness, participation and support with new innovative resources (e.g., films and other media)

• Effective use of existing resources
ILEP Guidelines to reduce stigma (2011). Four volumes:

1. What is health-related stigma?
2. How to assess health-related stigma
3. A roadmap to stigma reduction: an empowerment intervention
4. Counselling to reduce stigma

<table>
<thead>
<tr>
<th>Level</th>
<th>Approaches</th>
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| Person           | • Treatment  
|                  |  • Counselling  
|                  |  • Cognitive-behavioural therapy  
|                  |  • Empowerment  
|                  |  • Group counselling  
|                  |  • Self-help, advocacy and support groups                                   |
| Between persons  | • Care and support  
|                  |  • Home care teams  
|                  |  • Community-based rehabilitation                                           |
| Organisation     | • Training programmes  
|                  |  • (New) Policies that are patient-centred and have integrated approaches   |
| Community        | • Education  
|                  |  • Contact  
|                  |  • Advocacy  
|                  |  • Protest                                                                   |
| Government       | • Legal and policy interventions  
|                  |  • Rights-based approaches                                                   |

*A brief description of each of these can be found on the supporting website

www.infolep.org/stigma-guides
Goals suggested by considering leprosy stigma

Transformations

- Enacted stigma
- Anticipated stigma
- Internalized stigma

Support from family, social and health systems
Anticipated acceptance
Empowerment, dignity, and self-respect