

Understanding the stigma of leprosy

Edward Eremugo Luka MBBS, MscIH^a

Introduction

Leprosy is the oldest disease known to man. The earliest written records describing true leprosy came from India around the period 600 BC¹. Leprosy is caused by *Mycobacterium leprae*; the Norwegian, Dr Amauer Hansen, isolated the bacterium in 1873. Leprosy is also called Hansen's disease after him. Although it is the first human pathogenic bacterium to be defined, *M. leprae* is the only bacterium causing disease in man that has not been cultured in the laboratory².

Leprosy situation



Figure 1. Lepromatous leprosy patient presenting at leprosy clinic. Photo: Edward Luka

Leprosy is found throughout the Sudan with areas of concentration in the South, West and East. Sudan has achieved the elimination level of leprosy, defined as a prevalence of less than 1/10,000 population. At the end of 2008, the registered prevalence was 1,892 cases. The number of newly detected cases was 1,901, including data from Southern Sudan³.

Some studies have concluded that stigma affects many aspects of the lives of people affected by leprosy including "mobility, interpersonal relationships, marriage, employment, leisure activities, and attendance at social and religious functions"⁵.

Stigma process

Understanding how stigma develops is crucial for planning strategies to reduce it. Stigma associated with leprosy does not start immediately after the disease starts, but develops over time in 2 stages:

- Stage 1 - the cognitive dimension. This describes how much influence the disease has on the person's life. The patients pass through the concealability course, disruptive, aesthetic, origin and peril dimensions⁸.
- Stage 2 - the affective stage in which the social devaluation of the individual occurs.

Heijnders describes a similar process of stigmatisation. In her studies in Nepal, she noted that people with leprosy go through two stages in coping with their condition: the concealment phase and the exposure phase. In moving from one phase to the other, there are triggers to exposure and discrimination such as the visible signs of the disease. However, she found that in the process, stigma

Stigma of leprosy

The fear of leprosy leads to the stigma and discrimination and is due to lack of understanding and knowledge about leprosy - which increases misconceptions about the disease's transmission and treatment. The fact that most of those with untreated leprosy end up with severe deformities and disfigurements has contributed to the stigma⁴ - see Figures 1 and 2.

Definition of stigma

The commonly used definition of stigma is "the attribute that is deeply discrediting" and "that reduces the bearer from a whole and usual person to a tainted, discounted one"⁶.

Another definition states that stigma is "a social process that exists when elements of labelling, stereotyping, separation, status loss and discrimination occur in a power situation that allows them"⁷.

Stigma can be classified into three types:

- Enacted - the commonest type in which there are actual experiences of discrimination.
- Perceived - stigma viewed from the perspective of the patient. It is "the devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to oneself".
- Self stigma - the fear of being discriminated against⁵.

^a PHC Advisor in the Sudan Health Transformation Programme Phase Two (opikiza@yahoo.com) - see more details on p48.

enforces the inequalities that are found in the community with regards to gender, age and social class⁹.

The impact of stigma

Having a stigmatising disease like leprosy severely affects aspects of life such as social status, employment opportunities or jobs, marriage and family life⁷. These can be summarised as effects on:

- the individual
- the community
- public health programmes and interventions^{10, 11}.

Effects on the individual

As noted by Weis and Ramakrishna “the impact of the meaning of the disease may be a greater source of suffering than symptoms of the disease”¹². Individuals with leprosy have emotional stress and anxiety, which may lead to psychological and psychiatric morbidity^{13, 14}, as well as a decreased quality of life on the WHO Quality of Life Assessment BREF^b ¹⁴. They become isolated and lack motivation to continue treatment (if already started). There is a risk that the disease will progress with resultant disability and complications. Individuals may have decreased status in the community because of their conditions⁷. In the case of leprosy they may become destitute and resort to begging as the only way of survival^{4, 15}.

Studies have shown that these effects are greater in female than male patients¹⁶. A review of leprosy patients in South East Nigeria from 1988 to 1997 found that the effects were greater in women than men. The women also tend to present late, have complications and disabilities^{17, 18}.

Effects on community interaction

The social participation of persons affected by leprosy is much more distressing to them than their individual effects. It impairs their quality of life in various ways^{10, 12, 18, 19, 20}. Persons with stigmatising conditions experience problems in their marriages or difficulties in getting married and in their employment or getting employed. Their community interaction is affected, such as social relationships and friendships. Their families may experience reduced educational opportunities, leading to further inequities between those affected and those who are not. All of these negative effects result from poor community knowledge of the disease, and the misconceptions held about them.

Effects on public health programmes

The impact of stigma on public health programmes and interventions have been well documented and discussed^{10, 12}. People with the stigmatising conditions may conceal or deny their condition and delay seeking treatment – which may:

- result in the diseases getting worse and increase the risk of complications
- increase the transmission of the disease in the community
- make it difficult to trace contacts and those defaulted from treatment - important in leprosy and TB²¹.

Some patients may not adhere to treatment when diagnosed especially for treatment that takes a long time, like TB and leprosy¹². Risk of drug resistance developing is then very high. In general therefore stigma results in an increased burden on the general health services.

Fighting the stigma of leprosy

Fear and stigma are difficult to remove. They can only be dealt with through a combination of strategies. Heijnders and van der Meij¹⁰ described 11 levels of interventions and strategies that can be used to fight stigma. These focused on:

- changing the image of the diseases
- integrating programmes
- rehabilitating patients and
- media campaigns.

These interventions are now used in most leprosy control programmes.

WHO encourages integrating leprosy into the general health service. Leprosy patients should be treated in the same outpatient department as those with any other disease, showing the patients and their communities that leprosy is not a 'different' disease. Different countries are in different stages of implementing these interventions that have been shown to reduce stigma¹⁹.

Education and media campaigns help to correct false beliefs and raise awareness of new advances. They include information about leprosy and its treatment, context-specific media messages addressing misconceptions and traditional beliefs about leprosy, positive images of leprosy and testimonies of people successfully cured of leprosy²². Physical and socio-economic rehabilitation helps to restore self-esteem and status in the community, and assists patients to find employment. Most studies have shown that the stigma of leprosy is aggravated by the physical deformities associated with the disease^{19, 23, 24}. So programmes that prevent disabilities developing or identify patients most at risk of developing them, can reduce the effects of stigma^{20, 25}.

b BREF = Best Available Technique Reference document

Psychological or physical changes reported by the patients can predict development of participation restriction (i.e. the reduction of their involvement in life situations such as social, economic, civic, interpersonal, domestic and educational domains of daily living).

A study in Nepal showed that people affected by leprosy who were in the Stigma Elimination Programme (STEP) ²⁶ were less stigmatised and participated more in the community than those who were not. The assessment of the stigma in this study used the Participation Scale developed by van Brakel¹¹.



Figure 2. Persons affected by leprosy with disabilities in Mayo, Khartoum. Photo: Edward Luka

STEP participants were more empowered and become change agents in their own communities. This kind of intervention has been proven to be effective, as demonstrated in Ethiopia²⁷.

Social marketing strategies (the designing and implementing of programmes to bring social change by using the concepts of commercial marketing) can change community attitudes to leprosy. When used correctly, they can be highly effective at reducing stigma and improving the lives of patients. Social marketing can be done through mass media campaigns, schools and involvement of community leaders. These methods have been successfully implemented in Sri Lanka^{28, 29}.

Conclusions

Leprosy has always been linked with stigma. For many people stigma is synonymous with leprosy. This is due to:

- leprosy often causing severe disfigurement and disability
- lack of knowledge about the disease.

The key messages that can overcome stigma are:

- leprosy is curable
- drug treatment is available free of charge
- there is no need to discriminate against people affected by leprosy.

If the misconceptions about leprosy are not changed, it will be difficult to eliminate leprosy as a public health problem.

References

1. Browne, S. 'The History of leprosy', in Hastings, R.C. (ed.) *Leprosy*. Edinburgh: Churchill Livingstone, 1989; pp 1 -14.
2. Rees, R. 'The microbiology of leprosy', in Hastings, R.C. (ed.) *Leprosy*. Edinburgh: Churchill Livingstone, 1989; pp 31-52.
3. World Health Organization 'Global Leprosy Situation 2008', *Weekly Epidemiological Record*, 2009; 33: 333-340.
4. Navon, L. 'Beggars, metaphors and stigma', *Social History of Medicine*, 1998; 11: 89-105.
5. van Brakel, W. 'Measuring leprosy stigma – a preliminary review of the leprosy literature', *International Journal of Leprosy and Other Mycobacterial Diseases*, 2003; 71: 190-197.
6. Goffman, E. *Stigma: notes on the management of a spoiled identity*. New York: Simon & Schuster. 1963
7. Link, B. and Phelan, J. 'Conceptualizing stigma', *Annual Review of Sociology*, 2001; 27: 363-385.

8. Bainsong, K. and van den Borne, B. 'Dimensions and process of stigmatization in leprosy', *Leprosy Review*, 1998; 69: 341-350.
9. Heijnders, M. 'The dynamics of stigma in leprosy', *International Journal of Leprosy and Other Mycobacterial Diseases*, 2004; 72: 437-447.
10. Heijnders, M. and van Der Meij, S. 'The fight against stigma: an overview of the stigma reduction strategies and interventions', *Psychology, Health and Medicine*, 2006; 11: 353-363.
11. van Brakel W. 'Measuring health related stigma', *Psychology, Health and Medicine*, 2006; 11: 307-334.
12. Weis, M. and Ramakrishna, J. *Stigma interventions and research for international health*. 2001; Available at: <http://www.stigmaconference.nih.gov/FinalWeissPaper.htm> (Accessed: 16 May, 2007).
13. Tsutsumi, A., Izutsu, T., Islam, M., Amed, J., Nakahara, S., Takagi, F. and Wakai, S. 'Depressive status of leprosy patients in Bangladesh: association with self-perception of stigma', *Leprosy Review*, 2004; 75: 57-66.
14. Tsutsumi, A., Izutsu, T., Islam, M.D.A., Maksuda, A.N., Kato, H. and Wakai, S. 'The quality of life, mental health, and perceived stigma of leprosy patients in Bangladesh', *Social Science and Medicine*, 2007; 64: 2443-2453.
15. Harvinder, K and van Brakel, W. 'Is beggary a chosen profession among people living in "leprosy colony"?'', *Leprosy Review*, 2002; 73: 334-345.
16. Zodpey, S., Tiwari, R. and Salodkar, A. 'Gender differentials in the social and family life of leprosy patients', *Leprosy Review*, 2000; 71: 505-510.
17. Peters, E. and Eshiet, A. 'Male and female (sex) differences in leprosy patients in south east Nigeria: females present late for diagnosis and treatment and have higher rates of deformity', *Leprosy Review*, 2002; 73: 262-267.
18. de Stigter, D., de Geus, L. and Heynders, M. 'Leprosy:

- between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal', *Leprosy Review*, 2000; 71: 492-498.
19. Arole, S., Premkumar, R., Arole, R., Maury, M. and Saunderson, P. 'Social stigma: a comparative qualitative study of integrated and vertical care approaches to leprosy', *Leprosy Review*, 2002; 73:186-196.
 20. Withington, S., Joha, S., Baird, D., Brink, M. and Brink, J. 'Assessing socio-economic factors in relation to stigmatization, impairment status, and selection for socio-economic rehabilitation: a 1 year cohort of new leprosy patients in north Bangladesh', *Leprosy Review*, 2003; 74: 120-132.
 21. World Health Organization *Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities, (Planned Period 2006 – 2010), Operational Guidelines*. Geneva: World Health Organization. 2006
 22. World Health Organization *Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities, (Planned Period 2006 – 2010)*. Geneva: World Health Organization. 2005
 23. Pfaltzgraff, E. and Bryceson, A. 'Clinical leprosy', in Hastings, R.C. (ed.) *Leprosy*. Edinburgh: Churchill Livingstone, 1989; pp 164 – 174.
 24. Barret, R. 'Self-mortification and the stigma of leprosy in northern India', *Medical Anthropology Quarterly*, 2005; 19: 216-230.
 25. Nicholls, P., Bakirtzief, Z., van Brakel W., Das-Pattanayak, R., Raju, M., Norman, G. and Mutatkar, R. 'Risk factors for participation restriction in leprosy and development of a screening tool to identify individuals at risk', *Leprosy Review*, 2005; 76: 305-315.
 26. Cross, H. and Choudhary, R. 'STEP: an intervention to address the issue of stigma related to leprosy in southern Nepal', *Leprosy Review*, 2005; 76: 316-324.
 27. Benbow, C. and Tamiru, T. 'The experience of self-care groups with people affected by leprosy: ALERT, Ethiopia', *Leprosy Review*, 2001; 72: 311-321.
 28. Brown, W. 'Can social marketing change community attitudes towards leprosy?', *Leprosy Review*, 2006; 77: 88-98.
 29. Wong, M. 'Can social marketing be applied to leprosy programmes?', *Leprosy Review*, 2002; 71: 308-318.

*** About the author:**

Edward Eremugo Luka is a PHC Advisor in the Sudan Health Transformation Programme Phase Two (SHTP II), a USAID funded project in Southern Sudan. He previously worked for six years with The Leprosy Mission International Sudan Programme. The article, with updated data, is based on his Masters' thesis on the assessment of leprosy stigma in Sudan.

The need for culturally-relevant research

Two studies highlight the need local research (like the article above). These looked at the gap between research and practice in four areas of the Millennium Development Goals (malaria, contraception, childhood diarrhoea and childhood tuberculosis) across 10 low- and middle-countries. Results showed that:

- % of Healthcare providers who, at least once a month, read journals:
 - From their own country = 18%
 - From high –income countries = 5-8%
- % who would change clinical practice based on research from:
 - own country = 85%
 - own region = 66%
 - from high-income country = 56%

See: *SciDevNet* article <http://www.scidv.net/en/news/gulf-between-health-researchers-and-doctors-highlighted.html> and *Bridging the gaps between research, policy and practice in low- and middle-income countries: a survey of health care providers* <http://www.cmaj.ca/cgi/rapidpdf/cmaj.081165v1> and: *a survey of researchers* <http://www.cmaj.ca/cgi/rapidpdf/cmaj.081164v1>

Quiz: Do you know?

- Which five risk factors are responsible for 80% of all risks for stroke?
- Which is the most important?

Answers on page 59.