SPECIAL PAPER

Leprosy Stigma: Ironing out the creases

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Accepted for publication 25 May 2011

Summary  Oft-cited as a deterrent to elimination of the disease, stigma is still a critical feature of the leprosy landscape leading to ostracism, loss of employment, loss of housing, ridicule and rejection from society. The reason for leprosy-stigma rests historically and culturally on the mythology about the disease’s origin and transmission, and its aesthetic features such as the enigmatic physical disfigurement, and the distinctive ulcers consequent of untreated leprosy. While the literature on leprosy has been consistent in showing that stigma is a social complication of the condition worldwide, there is seldom recognition of processes of stigmatisation in broader contexts. Effective and sustainable interventions directed at curbing leprosy stigma and so improving its social course must, however, be informed by an appreciation of such contexts; particularly in the light of the goal to eliminate the disease worldwide. Examining stigma in the broader contexts of historical, social, economic, political contexts is the aim of this paper. The paper also has implications for broad ranging intervention efforts aimed at de-constructing leprosy-stigma in order to craft a more accommodating ambiance of acceptance, care and support for people affected by leprosy.

Introduction

Stigma is a central feature of the social impact of leprosy.1 The far-reaching and unfavourable impact of leprosy stigma leads to avoidance of healthcare services, deterioration of personal health and socio-economic status; and reduced quality and effectiveness of public health programmes in controlling the disease.2–4 It also feeds upon and strengthens existing social inequalities and is manifested at all levels: individual level, in families, institutions and the wider society.5–11 Moreover, it takes place over time as a process. According to Baison and Van Den Borne,12 the first stage explains how certain leprosy cognitive scopes result in a range of affective responses towards the disease. The second stage involves how these affective responses contribute to social devaluation of the leprosy patient and consequently, the adoption of negative behaviours towards them.

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The eventual manifestations of leprosy stigma process are status loss and discrimination. By extension, the stigma process crystallises into different types of stigma which, according to van Brakel, include self and public stigma respectively. While public stigma is discernible in evasion, social distancing, repugnance at disfigurement and lack of social support, self-stigma results in diminished self-esteem. People with self-stigma are less likely to socialise with other people. This is substantiated in research on leprosy-infected Taiwanese women by Shieh et al. which reported that these women exhibited self-inflicted stigma by avoiding close contact and sharing household items with family members; and also by avoiding social functions.

Research in leprosy has been quite consistent in showing that stigma is a deterrent to leprosy elimination. However, this research has seldom explored the dynamics of leprosy-stigma in its socio-cultural, economic, historical, and political contexts, and this consequently impairs the design of effective and sustainable interventions to tackle leprosy stigma, particularly in the light of the goal to eliminate the disease worldwide. Herein lays the importance of this paper. It examines leprosy stigma in the socio-cultural, historical, economic and political contexts; and the implication of this for interventions.

LEPROSY STIGMA IN VARIOUS CONTEXTS

Various writers have implicated historical events and practices in leprosy stigma. Firstly, biblical teachings perpetuated by missionaries associated leprosy with sin and uncleanness; and people with leprosy came to be considered outcasts as a consequence. Secondly, the related concepts of contagion and aesthetic features of leprosy induced fear. Finally, twentieth century western policies advocating incarceration of people affected by leprosy at various leprosaria due to the social constructions of the disease; also induced fear and ultimately stigma.

Social constructions of leprosy are commonly guided by cultural, traditional and religious beliefs or myths about disease and illness, not least in low resource settings like India and many African countries. Too often, leprosy infected people are thought of as cursed or victims of witchcraft, or as blameworthy / immoral; and their disease well deserved. The social constructs and myths of leprosy are knotted with high rates of illiteracy and misinformation about the disease. Leprosy stigma is not only produced by local beliefs about the disease, however. The wider social, political and economic contexts are also significant. In many previously colonised countries, government policies and laws on leprosy have lagged behind scientific breakthroughs. An example worth mentioning is the slow pace of changes in Indian leprosy legislation, despite the rapid decline in leprosy prevalence rate from 50.2 per 10 000 in 1994 to 6.2 per 10 000 in 1996. In the case of Japan, some government policies and laws such as the Japanese isolation policy had once favoured leprosy stigmatisation. The human rights of leprosy patients were violated as they forcefully underwent abortions, sterilisation, and isolation in remote islands long after the development of MDT. Japan’s isolation policy, albeit withdrawn in 1996, had real-time cost - a bequest that keeps on affecting the decisions made by leprosy-affected people. In addition, the problem of leprosy-stigma has not been explored in the policy debates of some countries due to the erroneous impression that the disease has been eliminated and no longer a public health problem in such countries. Consequently, governments shy away from enacting legislation in favour of leprosy patients; and when enacted, implementation is an uphill task because of budgetary famine.
In an economic context, leprosy stigma results in social instability which in turn curtails economic growth and impoverishes previously self-sufficient communities, and worsens conditions for those already poor. People with leprosy may be refused employment or lose their jobs because of their disease, and associated complications with consequent brutal financial burdens.\(^5\) For example, in an Indian study by Prabhakara et al.\(^7\) they found that 16–44% of leprosy patients experienced a fall in their income. Furthermore, in a South African study of the psychosocial needs of leprosy patients, Scott\(^8\) found that the subjects all feared losing their jobs and 17 out of 30 concealed their disease from their employers. Infected people may lose their jobs even earlier than they develop labour-impaired disabilities (due to late or no treatment) which lead to poverty. A set of operational rehabilitation principles for leprosy affected people by Nicholls and Smith,\(^30\) points out that many people affected by leprosy live in conditions of extreme poverty with few opportunities of earning income and may turn to begging as a last resort.\(^31–32\)

Overall, the ways in which leprosy stigma is explicitly or secretly expressed are shaped by a range of social, cultural, political, and economic factors. Addressing these broader social and economic forces can improve the health outcomes of people with leprosy while helping to curb stigma.

MANAGING LEPROSY STIGMA

The journey so far

It would be wrong to think that there are no intervention efforts against leprosy stigma so far. The existing interventions point to two major strategies. The first is information-based awareness programmes to dispel misconceptions and traditional beliefs about leprosy as well as to raise awareness of new advances at individual and community levels.\(^33–34\) However, providing people with disease facts, according to Hayes et al.\(^35\) does not lead to widespread stigma reduction. The second strategy is the instituting of favourable policies and anti discrimination legislation as safeguards or to compensate leprosy patients from stigma in public settings.\(^36\) This is exemplified by the landmark judgment resulting in court-awarded compensation of US$29·1 million to leprosy patients incarcerated for many decades due to the Japanese government’s isolation policy.\(^37\) This strategy is admirable, but stigma is often outside the reach of legal constraints, given that it is deeply-seated and its manifestations are subtle in most cases.\(^38\)

Further, evaluations of most of these interventions are not only limited by fairly short-term assessments, but also by the use less rigorous studies.\(^24\) Most of these studies report evidence of superficial attitudinal changes but limited change in deep-seated fears.

Way Forward

Although the aforementioned strategies are vital elements in the fight against stigma, on their own, they are inadequate in the anti-leprosy stigma cause. Leprosy stigma is rooted in various contexts, and therefore effective and sustainable interventions should have sound theoretical underpinnings with attention to these contexts. Interventions to reduce leprosy stigma are likely to be more effective if they are rapidly adaptable to the prevailing socio-cultural, economic, and political contexts; and are multi-strategic. According to Floyd Richard and Gurungu,\(^39\) holistic multi-strategy programmes are more effective in tackling stigmatising
attitudes than are single interventions and are therefore needed to address leprosy stigma in broad contexts. Interventions must be participatory, targeting individual, community and policy levels. Comprehensive needs assessment must precede programme planning which in turn must use appropriate planning models that encompass the community’s concerns.  

At the individual level, educational programmes must be targeted at health care professionals to address their prejudiced attitudes, and at people with leprosy and their family members. This is essential as there is evidence that when the family members of a person with the stigmatised condition are misinformed about the disease, it hampers the coping and adjustment abilities of the infected person. Likewise, the powerful effect of counseling people with leprosy is important. Group counseling of people with leprosy has been shown to be time-efficient and productive in tackling leprosy stigma. Further, inducing empathy, according to Batson et al., for a stigmatised group member - in this case is a leprosy affected person - can ultimately help to improve attitudes towards the whole group.

The impacts of the bodily disfigurement of leprosy on leprosy stigma have been widely documented, so development of leprosy control programmes that specifically target disability prevention will be a critical response to a widely appreciated need of reducing the effects of leprosy stigma. In addition, interventions that involve socio-economic rehabilitation of leprosy patients are very important.

At community level, health education campaigns must shed light on leprosy through messages that sensitively deal with the local community’s beliefs and misconceptions while driving home the right information about leprosy to the people. The messages must be structured to make sense within the logic of the peoples’ worldviews whilst they tackle leprosy stigma in broad contexts.

At policy level, advocacy efforts must centre on a supportive, enabling environment that favours legislative and policy change. To ensure organisation of various information into a logical structure advocacy efforts must use a target-specific stigma-change framework. There is also a need to pay greater attention to the human rights violations faced by people affected by leprosy. Finally, implementation of leprosy stigma intervention programmes does not only require diverse and joint skills, but must also be commensurable with access to health care.

Conclusion

This paper offers a snapshot of the conceptualisation and dynamics of leprosy stigma in various contexts. For people affected with leprosy, stigma remains a persistent predicament and control efforts so far have not adequately controlled the pervasiveness of the problem.

The struggle of successfully overcoming leprosy-stigma lies in understanding it in broader contexts, and continually exercising targeted strategies – normalisation, neutralisation and de-construction of stigma, all based on solid theoretical foundations and empirical evaluations. The key to success in all these efforts will be a coordinated inter-sectoral approach matched by massive commitments by those affected by leprosy, along with governmental and non-governmental organisations. The involvement of these organisations will be a function of the economic, political, and cultural contexts.

Finally, it is important to entrench the anti-leprosy stigma cause in broader equalities and human rights activities. Until patients with leprosy are treated as equals, the goal of leprosy elimination will remain evasive.
References


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