

**GUEST EDITORIAL**

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**DESIGNING PROGRAMMES TO ADDRESS STIGMA IN LEPROSY:  
ISSUES AND CHALLENGES**

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**ABSTRACT**

*Leprosy stigma is still prevalent in both endemic and non-endemic countries, and is a major factor leading to delay in patients seeking treatment. This paper reviews studies on factors influencing stigma in leprosy and the effectiveness of programmes targeting it. Most research showed that high level of knowledge of the curability and non-infectiousness of leprosy was not correlated with more positive attitudes and acceptance of leprosy patients. The mixed effects of interventions ranging from worsening stigma, to no change or slight change in positive attitudes suggest that stigmatising attitudes are difficult to change. There is a need for more integrated psychosocial, cultural and behavioral studies to identify important independent predictors of stigma. More rigorous study designs are needed to evaluate intervention programmes targeting stigma to provide evidence on what approaches work and what do not work.*

**INTRODUCTION**

The implementation of multidrug therapy since the mid-eighties has been highly effective in curing patients and reducing prevalence of leprosy. Registered cases have fallen from 5.4 million worldwide in 1985 to below 1 million in 2000(1). Presently, the global prevalence of leprosy is less than 1 case per 10,000 people. However, in many developing countries, a significant number of cases remain undetected or are detected late. WHO estimates that during the period 2000-2005, about 2.5 million people affected by leprosy need to be detected and treated. Stigma still remains a major factor leading to delay in patients seeking treatment (2). Stigma towards persons affected by leprosy and their families has also adversely affected their quality of life due to its impact on their mobility, interpersonal relationships, marriage, employment, leisure and social activities. Recent studies indicate that leprosy stigma is still a global phenomenon, occurring in both endemic and non-endemic countries. This paper gives an overview of factors influencing stigma in leprosy and reviews the effectiveness of programmes targeting stigma. It concludes with a discussion of the issues and challenges in designing programmes to reduce stigma.

The word 'stigma' was first used by the Greeks to denote bodily signs that expose something unusual and bad about the moral status of the signifier. Goffman (3) defines stigma as an attribute that is deeply discrediting, and the stigmatised individual is one who is not accepted and not accorded the respect, rights and regard of his peers; one who is disqualified from full social acceptance. He describes three groups of factors leading to stigma: physical abomination, blemishes of individual character, and tribal stigma. If this is applied to leprosy, we can see that all three groups of stigma are encompassed by this one disease - leprosy.

With regard to the group with physical deformities - there are the visible deformities of a leprosy patient; in the group with blemished character is the belief that leprosy patients are of blemished character and hence the disease is a punishment for their sins; and in the group with tribal stigma, leprosy is looked down upon as the disease of poverty or of a person 'of a inferior class'.

## **RESEARCH ON STIGMA**

The operational definition of stigma varies across studies but most of them examined at least one of the following negative attitudes or behaviours towards leprosy patients: (i) refusing to eat food with persons affected by leprosy (ii) not allowing them to enter one's home (iii) segregation (iv) social-public restrictions such as not allowing them to use public facilities or go to school and (v) expressing hatred at them.

### **Prevalence of stigmatising attitudes**

Although some studies have shown that stigmatising attitudes are on the decline (4,5), research over the last decade generally showed that prevalence of stigmatising attitudes toward leprosy is still high with some countries reaching levels as high as 80%.

Most studies (6,7,8) also showed that high level of knowledge of the curability and non-infectiousness of leprosy was not correlated with more positive attitudes and acceptance of leprosy patients. A study by Croft et al in Bangladesh (8) showed that 90% knew that leprosy was curable, yet about a quarter would not eat with leprosy patients.

### **Factors associated with stigma**

Studies have also been carried out on factors associated with stigmatising attitudes, and these may be categorised into mediating (direct) factors and indirect factors.

Mediating factors are those factors directly related to peoples' attitudes of fear and to their rejection of people with leprosy.

All the following four categories of mediating factors, namely (i) visible deformities (ii)

perceived incurability and chronic course of disease, (iii) perceived infectiousness and (iv) perceived 'bad' origin of disease have led to people's fear, rejection and hence stigmatisation of leprosy patients (9).

Why have visible deformities led to stigma? Some researchers (10) have explained that this was due to the fact that punishment for crimes in ancient society was dismemberment of parts of the body, consequently mutilations produced by the disease were associated with retribution for sins in the human mind.

Beliefs about the contagion of leprosy are still prevalent among most communities. A recent community survey in Singapore in 2002 (unpublished data) found that about half (41.3%) of adults still believed that persons always have deformities and that leprosy spreads easily, and about one-third (32.3%) believed that leprosy is incurable. Misconceptions regarding the infectiousness or contagion of the disease could have been perpetuated by past practices of institutionalisation and the enforcement of the Leprosy Act in some countries to segregate people affected by leprosy.

The perceived bad origin of leprosy may be attributed to cultural beliefs that leprosy is a punishment for sins and that it is hereditary. Most of these misconceptions were found to be rather similar across wide geographical and cultural backgrounds. The Hindus (11) consider deformity resulting from leprosy as divine punishment and the Chinese (12) believed that leprosy is sexually transmitted by contact with a prostitute and hence a punishment for immoral behaviour. The belief about heredity of leprosy is prevalent among communities in India (3), Malaysia (13), China (12) and Africa (7). Ironically, even in Norway (14) where Hansen identified the leprosy bacilli, the medical profession firmly believed that leprosy was hereditary and promoted the idea of segregation to prevent procreation.

Other factors that have led to stigma included the depiction of the horrors of neglected leprosy and the use of the words "leprosy", "leper", or "leprous" to imply something evil, degrading or immoral by writers, journalists and even politicians.

The mediating or direct factors leading to stigma are in turn influenced by indirect or socio-demographic factors and the findings appear to differ from one country to another. Studies in India found that stigmatising attitudes were associated with older age (6) but in Tanzania it was associated with younger age (7). The study in India (6) also found that stigmatising attitudes were associated with lower educational level, lower socio-economic status, female gender, and the muslim religion. Another study in India (15) found lower acceptance of deformed and handicapped patients by families of the lower caste groups (54%) compared to higher caste families (80%). Some studies in Africa found stigma to be higher among Christians than Muslims (16). While Christians perceived it as a punishment for their sins, Muslims believed it is God's will. This may explain why leprosy patients are better accepted

by Muslims compared to other religions. Stigmatising attitudes were found to be more prevalent among rural communities in India but in Myanmar stigma was more prevalent among urban communities.

The stigmatisation in leprosy is frequently extended to the families having members suffering from leprosy. A study revealed that families with a patient who had deformities faced ten times more societal problems than those having patients with no deformities (15).

### **Level of awareness of leprosy among health care workers**

Misconceptions about the causes of leprosy, that could have perpetuated stigma, were also prevalent among health care providers. In a study in Nigeria in the early eighties (17), about two thirds (65%) of final nursing students said that leprosy was highly infectious and that deformities were inevitable in leprosy. Another study in Philippines around the same time (18) found that while 88.4% of the health service providers agreed with the germ theory of disease, about 70% believed leprosy to be highly contagious and a small but significant (11.6%) proportion believed leprosy to be caused by “unclean blood” and witchcraft. In a study among health workers in Botswana (19), more than a third of respondents believed that patients should be isolated and treated.. A more recent study conducted among health care workers in Guyana (20) in 2000 still found a low level of knowledge: half of the respondents did not know that leprosy was curable and 15% thought it could be spread by touch.

### **Intervention programmes to reduce stigma: current strategies**

Since the seventies, governments and non-governmental organisations have implemented measures to reduce stigma.

Efforts at policy level included the use of non-discriminatory terminology such as Hansen’s disease to describe people with leprosy. In Brazil, the use of the word ‘lepra’ which means dog mange is discouraged by law. More support and rehabilitation services have also been provided to patients and their families. In some countries, leprosy control programmes have been integrated into the general health care system. As stigma may be perpetuated by the negative attitudes of health care providers themselves, many leprosy programmes have also focused on training health care providers to be more sensitive and empathetic to leprosy patients’ concerns.

To dispel the fears about the non-curability and infectiousness of the disease, community health education programmes have stressed on the following main messages: (i) Leprosy is 100% curable (ii) Leprosy does not spread easily as 99% of people have resistance to immunity to leprosy (iii) Deformities do not occur with early treatment and (iv) Patients are not infectious once they have been started on treatment.

Recently, some countries have used the mass media to disseminate more positive messages about leprosy. Instead of showing a child or mother with facial deformities, pictures showed a healthy, normal and happy child or mother with no deformity as a result of seeking early treatment. A public education programme in Sri Lanka (21) showed a perfect hand of a leprosy patient holding a flower instead of depicting a hand with unsightly deformities. Many countries such as Malaysia (13), China (12) and Botswana (19) have also involved traditional healers, community leaders and community in disseminating health messages on leprosy and facilitating early detection and treatment.

### **How effective are current interventions targeting leprosy stigma?**

Very few studies have been conducted to evaluate the effectiveness of intervention programmes targeting leprosy. The best evidence of programme effectiveness comes from randomised controlled trials. However, none of the studies used a randomised control group design, probably due to the fact that it is often not feasible to use this design in community settings.

Where randomisation is not feasible, the greatest evidence comes from quasi-experimental study designs in which the intervention group or community is compared with a concurrent comparison group or community without the intervention on prospective measurement of exposures and outcomes (22). In this review, only those studies with a comparison group were considered.

Croft et al (8) used a post-intervention control group study design to evaluate the effectiveness of a community health education programme in Bangladesh. Markedly lower levels (28-30%) of prejudice were found in a rural intervention community of 50 household respondents provided with community education compared to another similar number of households in a comparable rural community without the health education programme. In the village that had not received health education, over 75% of the families reported that they would not share a meal with a leprosy sufferer and 94% cited that they would not permit their son to marry a girl who is cured of leprosy, compared with 28% and 30% respectively in the intervention community. Another study in Bangladesh (23) also found that overall knowledge in leprosy and positive attitudes towards leprosy patients were significantly higher in a slum area of 200 household respondents that had received a community health programme compared to another comparable control slum of 200 household respondents which had not received the programme. More respondents (60%) in the intervention community reported that they would eat with a leprosy patient compared to 38% from the control community. However, as baseline data on stigmatising attitudes and behaviours before the intervention were not available, it could not be ascertained whether the two communities had similar levels of prejudice before intervention.

A seven-year intensive community health education campaign on leprosy in Tanzania (7), also using a post-intervention control group study design, did not find a significant improvement in knowledge or attitudes of the general adult population or health staff in the intervention community receiving the intensified health education programme compared to a control neighbouring district that did not receive the health education programme. However, the campaign had a favourable effect on knowledge and attitudes of schoolchildren. Slightly more than one third (38%) of children in the intervention area were willing to share food with a person affected by leprosy compared to 21% from the control area. The case detection rate in the intervention area was also higher in the intervention area (2.4/10,00) compared to 1.3% from the control area.

A study in India (24) showed moderate increase in level of knowledge but no detectable change in expressed prejudice towards people with leprosy after a community health education campaign. Another study in India, found no change in negative attitudes of children towards leprosy patients after health education, but showed increased fear towards leprosy patients (6). Thus an increase in knowledge per se may not lead to positive change in attitudes, and can in fact, have serious detrimental effects on attitude.

A qualitative study in India (25) compared acceptance of leprosy patients in a village, in which leprosy control activities were integrated with primary health care services, with a socio-demographically comparable village with the vertical approach. Focus groups and observations were used to assess specific and actual practices related to stigma such as relationships with specific family members, economic and social interaction such as whether they were gainfully employed, received economic support from service providers, got invited to social functions and have access to local services. Patients from the integrated care village faced less discrimination and stigma with regard to social acceptance compared to those from the village with vertical care. However, this study was conducted on only 24 families.

## **DISCUSSION**

### **Summary of findings**

A review of the literature showed that causes of stigma are multifactorial and misconceptions and negative attitudes towards leprosy patients are still prevalent. The varying success rates in interventions, ranging from worsening stigma, to no change and slight and moderate change in positive attitudes, indicate that attitudes related to stigma are difficult to change.

### **Gaps in knowledge**

Gaps still exist in our current knowledge on causes of stigma in leprosy. There is considerable research on the descriptive aspects of stigma such as the frequency distribution of cultural beliefs and stigmatising attitudes but there is a lack of analytical research on the independent associations or interaction between various beliefs and stigmatising attitudes. Data are still lacking on the relative importance of the various cognitive dimensions or mediating factors influencing stigma in leprosy. For example, which of these factors: disfigurement or beliefs on bad origin: is a more important determinant of stigma in leprosy or is the stigma due to a combination of both factors? If it is disfigurement that leads to stigma, why is a condition like Rheumatoid Arthritis less stigmatising than leprosy? Is it because it does not cause facial deformities like leprosy or is leprosy stigma due to the interaction or combination of beliefs about its infectiousness and bad origin, and deformities. These issues have not been addressed yet by research.

It is also unclear what interventions work best in reducing stigma as there are few rigorous studies that evaluated the effectiveness of the intervention programmes. In addition, the effects were mixed with some showing reduction in stigma while others reported an increase in stigmatising attitudes. It is not known what led to these differential effects as qualitative analysis and process evaluation of programme activities were not described in-depth in these studies.

### **RECOMMENDATIONS**

#### **Designing programmes to reduce stigma**

Research has shown that it is difficult to change people's attitudes and that high knowledge of the curability and non-infectiousness of leprosy did not necessarily lead to more positive attitudes towards persons affected by leprosy. This could be because beliefs about the bad origin of leprosy are so deeply rooted in people's culture that a simplistic approach of just presenting the scientific facts may be ineffective in addressing their concerns and beliefs. Community health education campaigns should therefore provide accurate knowledge of leprosy by working their way around the local community's cultural beliefs and misconceptions rather than denouncing them outright. For example, the message that is often used – 'Leprosy does not spread easily' – may be too simplistic. It is important as well to talk about local beliefs and change them gradually through exploration and clarification and in consultation with local community leaders.

The challenge for health educators is to get the right mix of traditional beliefs and modern theory of medicine which neither offends community sensitivities nor compromises on the accuracy of the message.

More holistic multi-component programmes are needed to address stigma, with interventions targeting individual, interpersonal, health system, community and policy levels. Discriminatory attitudes of the health personal should also be addressed.

We should use comprehensive planning models and conduct needs assessment before planning programmes. Assessing local educational needs is very important as needs and factors associated with stigma have been found to differ among countries.

A well-planned needs assessment will also help in designing more appropriate health education strategies and more specific and relevant messages that relate to the community's concerns.

### **Research**

An understanding of the determinants of stigma and the process of stigmatisation is an essential step towards developing effective interventions to address stigma. There is a need for more rigorous research such as the application of a holistic framework of psychosocial, cultural and behavioral models and theories, and the use of multivariate statistical techniques to identify important independent predictors of stigma and the relative importance of each of these factors.

Cross-cultural studies should be also carried out to compare factors that have led to the differing attitudes towards leprosy patients in different countries. We can learn from communities with more favourable attitudes and adapt what we have learnt from them, to less favourable communities.

While many health education programmes have been implemented with the goal of reducing stigma, few have been evaluated to assess their impact. A validated stigma scale should be developed to assess and monitor the effectiveness of such programmes. Data obtained with such an instrument would not only be useful in monitoring and evaluation of interventions against stigma but also in needs assessment to determine factors influencing stigma. The findings would help in more effective programme planning and advocacy work.

More rigorous study designs are needed to evaluate intervention programmes targeting stigma. This will provide evidence on what approaches work and what do not work. If it is not feasible to use randomised controlled trials in community settings, quasi-experimental designs should be used to compare changes in attitudes and practices from pre-intervention to post-intervention between an area with the intervention and a socio-demographically similar area without the intervention. Both outcome and process evaluation are needed to evaluate programmes on their effectiveness. While outcome evaluation assesses the effectiveness of a programme, process evaluation will explain why a programme failed or succeeded in reducing stigma. This information would help leprosy programme managers to plan better programmes.

For example, detailed information of interventions such as to how and why they work in a particular context will enable programme managers to replicate or adapt successful, sustainable interventions to their own setting.

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