

Curing the stigma of leprosy

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Summary The stigma of leprosy is a real phenomenon in many people's lives that affects their physical, psychological, social and economical well-being. There are many causes for this damaging image of leprosy. There is no one easy answer to dispelling this image; it is something that has to be done in partnership with communities and patients. Many papers document the effects of stigma, but few discuss or trial solutions. Education and media campaigns counteract false beliefs about leprosy and raise awareness of new advances in the field. Leprosy care is increasingly provided in an integrated setting showing patients and their communities that leprosy is not a disease apart. Physical and socio-economic rehabilitation is worthwhile in restoring self worth and status in the community and helps patients to find employment. Group counselling can allow those with leprosy to talk about their feelings and experiences to empower one another. Gradually attitudes towards leprosy are changing, but there is still much to be done if the underlying menace of stigma is to be dealt with. We as health professionals must be prepared to make the first move and give that first touch. Certainly more research is needed. In the highly endemic countries the road to elimination may yet be long. Perhaps with effort we will one day be able not only to treat the disease, but also to cure the stigma of leprosy, and make that road an easier one.

Introduction

In the last century, the understanding and management of leprosy has advanced greatly. With multi-drug therapy becoming widely available, hundreds of thousands worldwide have been cured of leprosy and its elimination is no longer unrealistic. For the first time in 1997, the number of registered cases globally was less than 1 million¹ and of the 122 countries where leprosy was endemic in 1985, 108 have now eliminated it as a public health problem (defined as a prevalence of the disease of less than 1 case per 10,000). There are realistic hopes that by the end of this century, leprosy may no longer exist. Leprosy can be treated medically and cured in a year² and patients can return to normal life provided that its complications are not disabling.

However, there is much more to a disease than just its pathological processes. Leprosy is a complex condition that not only affects patients physically; it has social and psychological

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implications that must be considered if cure is ever to be complete. The World Health Organization describes health as not merely the absence of disease, but 'a state of complete physical, mental and social well-being';³ therefore, we ignore the wider issues involved in leprosy to our (and the patient's) peril. As scientists, it is difficult for us to deal with something as indefinable as stigma and ostracism; they are less comprehensible than cellular and biochemical processes. But, as human beings, we need to understand what leprosy means to our patients and their communities. For holistic care, we must never forget the impact leprosy can have on a patient's psychological and social well-being.

More than any other disease [except perhaps acquired immune deficiency syndrome (AIDS)], leprosy has a very negative image. In literature, outcasts are treated like lepers; leprosy and stigma have been almost synonymous. For centuries it was a feared disease, the very word invoking shame and disgust. Stigma is hard to define and measure, being a 'complex reality made up as it is from a mixture of belief, attitudes and behaviours'.⁴ For many sufferers, however, it is the hardest part of the burden to bear.

This essay seeks to explore the problem of the stigma associated with leprosy, its causes and some possible solutions.

Effects of stigma on people with leprosy

Researchers have shown that leprosy and its stigma have a pervading affect on a patient's life, affecting marriage, employment, interpersonal relationships, leisure activities and attendance at social and religious functions.⁵

In Nepal, people with leprosy are often ostracized by their communities, reporting insults, rejection and hate.² One study found that one-third of leprosy patients were left by their spouses.⁶ Many places where leprosy is prevalent, such as South Asia, have a strong culture of belonging to one's family and community. More than in the individualized West, people's identity is bound up in their role in their family and wider community. For leprosy suffers to lose this is to lose a large part of who they are. One patient summed it up like this, 'We can endure losing fingers and toes, eyes and nose, but what we cannot endure is to be rejected by those nearest and dearest'.

People with leprosy may lose their employment because of their disease, the disabilities associated with it and negative attitudes of employers. When this happens, they lose the means of supporting their families and often the respect of their communities, with loss of self-esteem. There can be severe financial burdens to bear. A study in India found that 16–44% of those with leprosy reported a fall in their income because of their disease.⁷ Younger people who develop leprosy may find it restricts their education,² with schools being unwilling to admit them or placing limitations on what they can do.

Women are a particularly vulnerable group of leprosy patients. Studies show they are more affected by leprosy and its stigma, suffering more isolation, loss of touch, and rejection and have more restrictions placed on them than men with the same level of disease.¹ If a mother has leprosy, the health and well-being of the whole family can suffer. Fear of passing on the disease can prevent emotional closeness and bonding with her children and also reduce positive health behaviour. In Nagpur, India, 49% of breast-feeding mothers with leprosy stopped breast-feeding their children.¹

Sometimes the stigma and ostracism of leprosy can affect the psychiatric state of the patient.⁸ Leprosy itself attacks the peripheral nerves; the brain and central nervous system,

however, are not damaged. Yet many patients are affected mentally, not because of the disease, but because of society's rejection of them. One third of black patients in studied in South Africa were found to have contemplated suicide after their diagnosis of leprosy.⁶

Negative attitudes towards people with leprosy act to destroy the patient's psychological and social health, but also can affect them physically. The shame associated with this disease can prevent people from seeking treatment until significant disability has occurred, while those who have been treated may never be cured in a truly holistic way nor be accepted back into society.

Effects of stigma on treatment and cure

Stigma causes problems for treatment of leprosy. Often, to prevent discrimination, patients try to hide their disease by not immediately seeking medical help on finding signs of leprosy.⁹ When they do, they may have significant disabilities and deformities.¹⁰ This in turn makes the stigma of leprosy worse and perpetuates the cycle.

Once treatment for leprosy has commenced, patients may stop going to clinics or taking their medication (non-compliance)² because of fear of rejection by their community or a lack of acceptance of the condition. Non-compliance with treatment is a major problem in some areas; for example in East Nepal, the non-compliance rate for the leprosy control programme is greater than 40%.²

Even if patients are cured of their mycobacterial disease, the stigmatization can remain an insurmountable obstacle to the resumption of a normal life. Negative perceptions of leprosy still can be a barrier to the process of reintegration into their families, jobs and wider society. Complete cure requires that the barrier be overcome.

Causes of stigma

Many factors contribute to the stigma of leprosy, and these vary across continents and communities. In each community, there is a complex mix of reasons why leprosy is a feared and shameful disease. Some of the commoner reasons are discussed below.

BELIEFS ABOUT THE CAUSATION OF LEPROSY

Beliefs about the causation of leprosy have differed over time and between places. These beliefs affect how the disease and those who have it are perceived. Some groups believe that leprosy is a judgement from God or the gods for wrongdoing either in this¹ or a previous life.¹² Those with leprosy are avoided as they are seen as sinful, and those around them do not themselves want to incur that wrath.

Likewise, those with leprosy may be avoided in places where leprosy is viewed as a sexually transmitted disease,¹³ as something contracted by victims of witchcraft,⁶ or as something that witches themselves have.⁶ More recently, in some areas traditional beliefs about how diseases are caused are giving way to a fear of infection by germs'.²

Although there is no one common perceived cause of leprosy, all the beliefs described above are negative and usually imply that the sufferer has done wrong and brought the disease upon himself.

DEATH SENTENCE

Another factor feeding in to the folklore of leprosy is that until the 1940s, there was no effective cure. This meant that contracting leprosy was a death sentence, with disability and deformity progressing until one finally succumbed. Man's failure to master leprosy added to its fear.

FEAR OF CONTAGION

Behind the ostracism of those with leprosy lies the fear of infection. In the past, in certain epidemiological settings, leprosy ran in families to the extent that many authorities considered it an inherited rather than an infectious disease. So marriage into a leprosy family was forbidden. Once infection had been established as the cause, by Armauer Hansen in 1873, patients with leprosy were further shunned. Later, it became clear that contact with a person with leprosy, even if intimate and prolonged, was not essential to contracting the disease, although it did increase the risk. Despite extensive health education that leprosy cannot be caught through touching someone with leprosy or sharing utensils, in many societies this reality has yet to lead to behavioural change.

There are traditional and historical reasons for this fear of infection. In the past, those with leprosy were isolated from the rest of society to try to stop its spread. Often this was against the patient's will and in many countries, such as Japan in 1953, laws were passed allowing forced hospitalization of those with leprosy. This law was still in place until 1996.¹⁴ It is now accepted that enforced segregation is a violation of the patient's human rights, after a case won in 2001 by Japanese leprosy patients.

The fear of contracting leprosy was sometimes perpetuated by methods of tackling the disease. Treating leprosy apart from other diseases in separate programmes and hospitals unfortunately sent out the message that leprosy is somehow different and more infectious than other diseases. Many people still hold this belief and want those with leprosy to be treated away from their communities to avoid others getting the disease.²

DISABILITY AND DEFORMITY

Another reason for the stigma associated with leprosy is the deformity and disability caused by the disease. In lepromatous leprosy, there is a characteristic facial appearance that marks out a patient as having the disease as the skin becomes ridged and thick and the nose wider. This means that at first glance other people can see they have leprosy. It is common for patients to request surgery for facial deformities and facial appearance is often the thing patients would most like to change back to its pre-leprosy state. Research in Myanmar found it was believed all leprosy patients would inevitably end up with some deformity,¹⁵ which increased the dread of the disease. In India, the greater the disability the greater the level of stigma.⁷

ODOUR

Some patients with leprosy may have a distinctive odour caused by infected ulcers. This smell can be nauseating and is made worse in cases when their communities do not allow people

with leprosy to wash in communal water, as in Madhya Pradesh, India.¹⁶ As well as making them outcasts, bad odour can affect the patients' sense of worth and dignity.

SELF-STIGMATIZATION

Self-stigmatization is a very real issue. People with leprosy may become ashamed, possibly because of local attitudes and deformity, and may isolate themselves from society, thus perpetuating the idea that leprosy is something shameful to be hidden away. Patients may find it difficult to value themselves and have a positive self-image. The self-loathing associated with leprosy can be permanent, persisting after the disease is cured.⁶

It can be hard for some patients to accept that they have leprosy. They may never be able to come to that point, refusing to believe it is true,⁶ while others may not believe they are actually cured after treatment.¹⁷

Solutions to stigma

Despite great advances, leprosy is still a problem in many countries. It is estimated that between 11 and 12 million people living in the world today have suffered from leprosy.⁶ Although most of that number will not now have active disease, for many the stigma of leprosy is still real and needs to be addressed. It is simply not enough for the medical profession and society to treat the disease and ignore the patient as a whole person. Many, despite their leprosy being dealt with, are still living a subexistence, mere shadows of their former selves and their true potentials.

There are two components of the approach to tackling stigma in leprosy: to help those actually affected by stigma and to prevent stigmatization of others in the future. It will be more satisfactory and efficient to prevent stigmatization than to try to reintegrate patients already rejected.

TREAT LEPROSY LIKE OTHER DISEASES

There is a growing awareness among health professionals involved in providing leprosy care that it does not help to treat leprosy differently from other diseases. Dr David Heyman, Executive Director of Communicable Disease Programmes at the WHO, says, 'Diagnosing and treating leprosy through the public health system is vital if we are to avoid continuing stigma and prejudice against leprosy patients. Continuing to treat leprosy patients through expensive and separate programmes has been shown to be the wrong approach - for health systems and for the patients they look after.'

A study in India¹⁸ showed differences in attitudes towards leprosy in areas where leprosy treatment was integrated in the local healthcare programme alongside other diseases, compared with areas where it was treated separately. The social stigma of leprosy was rare amongst patients and in the communities using the integrated approach. In contrast, areas where leprosy was treated separately had more self-stigmatization among the patients themselves and high levels of social stigma in their communities. Patients in villages with the integrated approach were more open about their disease and willing to discuss it with others. Integration into general health services may have other benefits for patients such as shorter distances to travel for treatment, earlier diagnosis and therefore reduced disabilities.

EDUCATION

Much work has been done to educate people about leprosy and decrease the false beliefs that underlie its associated stigma. As can be expected, stigma is much more prevalent among those who are uneducated.¹⁹ Education needs to be three-pronged, teaching patients, their peers and young people. Teaching those with leprosy about their disease enables them to be empowered in their treatment and to have the confidence and knowledge to counteract opposition they may face from others. This can help acceptance of their condition and decrease self-loathing. It is not enough to educate only patients; their communities need to be educated as well. Education should be tailored to suit the particular community, taking into account local cultural and religious beliefs. Ideally, a local person aware of beliefs and issues in the area should be the educator as communities are more likely to listen to and believe one of their own rather than an outsider. New advances in leprosy need to be explained because much has changed in a relatively short space of time. These advances alter the outlook for patients and their communities; for example with MDT, people are no longer infectious within a few days of starting treatment. Education must be easily understandable, addressing real concerns. Sometimes targeting information at a particular group may help, for example village leaders. It is important not to undermine their authority. Educating the leaders may affect their decisions and allow appropriate information to filter down.

One of the best ways to prevent stigma occurring in the future is to educate young people about leprosy. Children are receptive to information and it is relatively easy to teach them about leprosy in schools and youth clubs. Hopefully, as they grow up, their generation will have a different perspective on leprosy. Teaching children has a double benefit, as they tend to pass on what they have learnt to their parents, thereby educating the whole family.

CHANGING THE IMAGE OF LEPROSY

One way of changing perceptions of leprosy is by using the media. In Sri Lanka, the Department of Health worked with a group of charities and a public relations company to change the public image of leprosy. Leprosy was portrayed as just another disease and people were encouraged to come forward when they developed suspicious lesions. All components of the media were targeted, including radio, TV soaps, music, jingles, billboards, buses and walls posters. Instead of the previous negative portrayals of leprosy on TV, it was shown in a positive light with people being happily cured. This approach, together with skin camps, increased detection by 150%. These types of campaigns are expensive, but as shown in Sri Lanka can reach a lot of people and be effective in changing attitudes.

PHYSICAL AND SOCIO-ECONOMIC REHABILITATION

Much has been done to rehabilitate those affected by leprosy. To be accepted in their community, the disabled must be trained to overcome their disabilities and do every day things again. Programmes that teach new skills and trades to people affected by leprosy help this acceptance. One lady with leprosy in Maharashtra state, India, who was selected to be trained as a village health worker reported the changed attitudes of her neighbours: 'The community are very loving towards me now. They realize I have medical knowledge since being trained'.²⁰

Training may also help to prevent further disability and deformity. In one group studied in India, 39% of females felt they needed to change their occupation (usually household and agricultural work) to protect their hands and feet.⁷ Rehabilitation schemes involving training and setting up small businesses have proved successful, with about half the participants being restored to their initial economic status.⁷

It is important to rehabilitate those with leprosy alongside those with disability from other diseases in order to help them reintegrate into their original societies, rather than stay in the confines of a leprosy community. Rehabilitation enables patients to regain their self-esteem. No longer are they the village leper, rather the village health worker.

COUNSELLING

People affected by leprosy may benefit from counselling to help them cope with their disease and avoid self-stigmatization and empower them to face discrimination. Individual counselling, however, can be a slow process benefiting only a few patients because of financial and personnel constraints. A better alternative may be group counselling. This has been shown to help by ensuring that those affected by leprosy do not feel alone, as well as helping them understand and overcome the damaging effects of stigmatization.²¹

ATTITUDES OF HEALTH PROFESSIONALS

The attitudes of health professionals can influence how patients and communities perceive leprosy. It is assumed that health professionals would have a positive attitude to leprosy. However, this is not always the case. There are reports from India for example of some doctors refusing to treat people with leprosy.⁶ This problem needs to be addressed, perhaps with more leprosy awareness training during initial education and as part of ongoing professional development. Healthcare staff are in a respected position in a community and their reaction to those with leprosy can have a major positive or negative effect. When Jesus cured the leper,²² he did not simply banish his disease; he touched him restoring his self worth. Probably this was the first touch this man had received in years. For many people with leprosy, it is healthcare professionals that provide that first touch.

References

- ¹ Zodpey SP, Tiwari RR, Salodkar AD. Gender differentials in the social and family life of leprosy patients. *Leprosy Review*, 2000; **71**: 505–510.
- ² Stigter D, de Gaus L, Heynders M. Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal. *Leprosy Review*, 2000; **71**: 492–498.
- ³ Collier J, Longmore M, Brown TD. *Oxford Handbook of Clinical Specialities*. Oxford University Press, Oxford 2001.
- ⁴ Romero-Salazar A, Parra MC, Moya-Hernandez C, *et al.* [The stigma in the social representation of leprosy] (in Spanish). *Cad Saude Publica*, 1995; **11**: 535–542.
- ⁵ Van Brakel WH. Measuring stigma – a preliminary review of the leprosy literature. *Int J Lepr Other Mycobact Dis*, 2003; **71**: 190–197.
- ⁶ Scott J. The psychosocial needs of leprosy patients. *Lepr Rev*, 2000; **71**: 486–491.
- ⁷ Prabhakara Rao V, Rao IR, Palande DD. Socio-economic rehabilitation programme of LEPRA India – methodology, results and application of needs-based socio-economic evaluation. *Lepr Rev*, 2000; **71**: 466–471.
- ⁸ Bharath S, Shamasundar C, Raghuram R, Subbakrishna DK. Correlates of psychiatric morbidity in patients with leprosy. *Ind J Lepr*, 2001; **73**: 217–228.

- ⁹ Bekri W, Gebre S, Mengiste A, *et al.* Delay in presentation and start of treatment in leprosy patients: a case-control study of disabled and non-disabled patients in three different settings in Ethiopia. *Int J Lepr*, 1998; **66**: 1–9.
- ¹⁰ Meima A, Saunderson PR, Gebre S, *et al.* Factors associated with impairments in new leprosy patients: the AMFES cohort. *Lepr Rev*, 1999; **70**: 189–203.
- ¹¹ Jopling WH. Leprosy stigma. *Lepr Rev*, 1991; **62**: 1–12.
- ¹² Stigma and challenge of leprosy. Available at <http://www.nlt.org.uk/background.shtml>.
- ¹³ Gilman SL. Disease and stigma. *Lancet*, 1999; **354**: SIV15.
- ¹⁴ Kukuchi I. Hansen's disease in Japan: a brief history. *Int J Dermatol*, 1997; **36**: 629–633.
- ¹⁵ Myint T, Thet AT, Htoon MT, Win M. A comparative KAP study of leprosy patients and members of the community in Hlaing and Laung-Lon townships. *Ind J Lepr*, 1992; **64**: 313–324.
- ¹⁶ DANLEP, Madhya Pradesh. *Combating Leprosy*. Published in WHO Special Ambassador's Newsletter No. 3, 2003 August 1. Available at www.nippon.zaidan.info/seikabutsu/2002/00637/contents/006.html, accessed 3 May 2005.
- ¹⁷ Ben Naafs. Viewpoint: Leprosy after the year 2000. *Trop Med Int Health*, 2000; **5**: 400.
- ¹⁸ Arole S, Premkumar R, Arole R, *et al.* Social stigma: a comparative qualitative study of integrated and vertical care approaches to leprosy. *Lepr Rev*, 2002; **73**: 186–196.
- ¹⁹ Kushwah S, Govila AK, Upadhyay S, Kushwah J. A study of social stigma among leprosy patients attending leprosy clinic in Gwalior. *Lepr Ind*, 1981; **53**: 221–225.
- ²⁰ Hill J, Tearfund UK. Report. *Teartimes Magazine*, Winter 2004.
- ²¹ Floyd-Richard M, Gurung S. Stigma reduction through group counselling of persons affected by leprosy – a pilot study. *Lepr Rev*, 2000; **71**: 499–504.
- ²² Bible, Luke 5, v 12–13.