

## Reducing Stigmatisation of Leprosy: What is Being Done?

Costa Bastos Castro JM\*

London School of Hygiene and Tropical Medicine, London, UK

### Abstract

When we hear about Hansen's disease, commonly known as leprosy, there is an image that is immediately catapulted to our head of limb deformities and skin lesions. Although treatment for the disease is highly effective and able to reduce the symptoms and keep them under control, this disease still brings a lot of suffering to people affected due to the stigma associated. A lot has been done in the research field on this disease which, although fatal a few decades ago, is highly curable nowadays, but whose atrocious effects in the past remain in people's memories and is the cause of the great level of stigmatization the people affected with leprosy face to this day.

Leprosy has faced ostracism for centuries and this has more to do with wrong cultural beliefs and lack of knowledge than with the risks of transmission and the morbid-mortality of the disease.

This article is a literature review of what has been studied on the effects of stigmatization in people's lives, as well as the interventions that can be put in place to minimize them and how to educate society on how to embrace these people. Research shows that the involvement of affected people in stigma-reduction interventions and their empowerment has achieved great results on both how society perceives them and how they perceive themselves. However, there is still a long way to go in terms of social equality for people affected or cured from the disease that involves the community population as a whole.

**Keywords:** Leprosy; Tendons; Stigma

### Introduction

Leprosy or Hansen's disease - named after Armauer Hansen who discovered *Mycobacterium leprae* - is one of the oldest diseases in the history of mankind and is presented with the growth of granulomas mainly in the nerves, skin and respiratory tract [1]. Its several manifestations include optical ulcers and loss of vision due to nerve damage; contractures in hands, feet, muscles, tendons and skin; wounds due to lack of sweat and sensitivity; and inflammation/ fibrosis of the extremities [2].

The World Health Organization (WHO) defends that the way of transmitting leprosy isn't fully understood. The theory of casual contact with affected people, which was widely defended until recent years, is gradually being replaced by theories of respiratory aerosols or insect bites still to be proven [3]. Yet, in the past, it was believed to be hereditary and, in the nineties, the contagion argument gained strength [4].

Due to this belief, people affected by leprosy were isolated to protect the remaining population and this measure, concomitantly with discrimination based on physical aspect, contributed to highly stigmatise people affected by this disease. Leprosy has been a curable disease for decades [5,6] but stigmatisation is still a current problem that affects aspects like the level of autonomy for the daily activities and the ability to marry, as well as to work and be financially independent [7].

This article intends to explore interventions already in practice to reduce leprosy related stigma and look at some recent new approaches that aim to assure the social equality.

### Discussion

Stigma has been described by Heijnders & Van der Meij [8] as a vector in a power struggle between society members who perceive themselves as superior for not carrying the condition. The authors talk about stigma as discrimination in a situation that society sees as in favour of those who are not affected by a condition dispraised by it. According to them, people with the disease are seen as different which leads to status loss. Also, as per ILEP [9], "when such a stereotype is attached to a label, people tend to no longer see the actual person, but only the stereotype".

Historically, the treatment of leprosy has been the engine for the drastic magnitude of stigma over the years. Silva et al. [10] report that in Brazil, in 1951, the isolation of leprosy patients was mandatory and they were persecuted and confined to leprosy colonies.

As Sato and Frantz [4] highlight in their research about leprosy isolation in Japan, a lot of people carrying Hansen's disease had no fixed abode, so either they were wanderers or created their own colonies. By 1897, as the first International Conference on Leprosy took place, Japanese believed that patient isolation was the only way to entirely stop leprosy spreading, and the national survey run on leprosy had the Law "The Act on Leprosy Prevention" as its outcome, under the belief that, although scientists had already proven the low probability of person-to-person contagion, it was necessary to take the homeless affected people in consideration. As a result, twelve years later, five public leprosy centres were established by the government.

Sato and Frantz [4] also studied the evolution of leprosy in the United States where the quarantine and isolation of leprosy patients was implemented and, after ample discussion on patient isolation, the need of legislation arose. By 1894, Louisiana, New York and California had all built legal facilities to receive and treat leprosy patients.

As Medicine advanced and drugs started being used to treat leprosy, there was a radical change of procedures regarding affected people. From 1940, many countries abolished patient isolation and aimed to re-insert people in their communities. This wasn't entirely successful due to a lot of obstacles in policy update, which resulted in prolonged institutionalization of patients who were stable health wise. "Leprosy

\*Corresponding author: Joana Margarida Costa Bastos Castro, London School of Hygiene and Tropical Medicine, London, UK, Tel: 00351918346700, 00447510865836; E-mail: [joanacastro02@hotmail.com](mailto:joanacastro02@hotmail.com)

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was thus dreaded, not because it killed, but because it left one alive with no hope" [4]. This excerpt clashes with the WHO definition of health, "a complete state of physical, mental and social well-being, and not merely the absence of disease or infirmity" [9-11] and highlights the need of eradicating the concept of isolating - physically and socially - people with leprosy. Casual contact contagion belief still affects the lives of hundreds of people who live in a misinformed society that deprives them from achieving the best health possible with the condition they carry. Therefore, stigma has been getting increasing attention in the healthcare field due to its impact in the affected person's life, both in the aspect of treatment/ disease follow up as it can cause "delay in presentation to the health services, prolonged risk of transmission, poor treatment adherence and increased risk of disability" [8], but also the social aspect thus when people are the subject of stigmatisation for a long time, they too start behaving according to what society expects of them, which is defined as self-stigmatisation.

In the specific case of leprosy, mainly due to the physical changes it can cause in the individual, such as hypopigmentation of the skin, plaques in the face, wrists, elbows and knees, foot drop, and inflammation of the fingers and toes ("sausage shape"), stigma usually comes from discriminating people who don't match the beauty standards of society. According to Rao et al. [12], "Even footwear developed for anaesthetic feet had to be changed due to the stigma attached", although cosmetic surgery has a good response in terms of social approval. In addition, the affected person who frequently is ashamed of his appearance, is prone to self-exclusion, which can be explained by two factors: the association of the disease with certain behaviours condemned by society and people's morals and beliefs. The fear of catching the disease has been studied as one of the main causes of stigmatisation as well, which can act both ways, giving that people affected can be discriminated but they can also self-exclude themselves due to the fear of being subject of stigmatisation once they reveal their condition, which is also one of the main causes for not seeking help. This also links to the lack of confidentiality, as people don't often seek help with the fear of their condition becoming public. It doesn't necessarily mean that the health professionals are being negligent with the management of confidential information, it might be unintentional in the form of a reminder letter or a visit by a health worker driving a car with the programme logo [9].

When we talk about the stigma around leprosy and wrong beliefs behind it, it seems safe to deduct that the key is to educate the population. Raising awareness of the spreading of the disease, incubation period and pathology is important, but should not be used as an intervention alone, more as a co-adjunct. Furthermore, education has to be thorough, an intervention over time, as few sessions have a low success rate. Children tend to be a good target in education based interventions, not only because they are more predisposed to change behaviours and beliefs, but they can pass the information on to their families too [13]. Equally, "Stigma arising out of fear or revulsion must be handled differently from stigma arising out of ingrained beliefs on the supernatural causes of leprosy" [12].

Social marketing has been proven by Brown [13] to be a very effective co-adjunct in reducing leprosy related stigma. Media campaigns, especially with celebrities, have been used to instigate people to seek help instead of health professionals seeking affected people, which can be expensive and time and resources consuming. In resource-poor areas, where television is not easily accessible, other type of communication tools can be used. Radio is a good alternative, but also theatre, street music, posters discussion groups and puppet shows seem to achieve similar results in these areas.

As discussed above, places built to treat only leprosy patients increase stigma and society exclusion for these people. WHO [5,6] has been trying to battle this with the integration of leprosy centres in general health services as part of the leprosy eradication programme but Brown [13] draws the attention to the fact that most of the times people prefer to travel longer distances seeking anonymity and, consequently, absence of stigma. Overcoming this is a complex process that can be fought with the education of health professionals as they are the ones who can monitor and stimulate adherence to treatment. Stigma can cause abandonment of treatment, especially if keeping the disease hidden is in jeopardy. In addition, "Monthly visits to a health post, leprosy medications, and increased pigmentation from Clofazimine may be difficult for patients to conceal". However, health professionals can use treatment in their favour, as medication prevents the deterioration of the patient carrying the disease and, therefore, the increase of the scale of stigmatisation [13]. People not seeking medical help becomes from various factors as explained above, including lack of knowledge, and health professionals have the power to battle this through the education of the community on how to recognise signs and symptoms, but Brown [13] suggests they will need natural healers on their side as they commonly forbid patients to contact with health services, particularly those people who live far away from the centre and have no education. These natural healers can also be a helpful source to change beliefs. Risky or censored behaviours are perceived in most poor resourced countries as a way of transmitting the disease, as well as the conviction that the affected person is being haunted or carrying a devil inside of him. In these cases, education needs to be culture specific, otherwise it will be fruitless [13]. Cross and Choudhury [14,15] explore a strategy called self-care, broadly used in Nepal to minimise the negative impact of a non accepting society that compromises individuals' development. This strategy comes as a cooperation between an outside promoter and the community, and the main idea of this concept is to empower the community and everyone as individuals. People who are marginalised, when incited to use their personal latent resources, can use that power to become "their own change agents" and later on use those skills to become community agents of change for people with the same needs [14]. As the authors showed in their study, self-care is based on how positively self esteem can impact change. What STEP (Stigma Elimination Programme) [14,15] has shown, is that this powerful self resource gains life when people are empowered "to focus their energy to effect positive developments, that enhance the lives of others". Moreover, STEP has been showing that they have been getting outstanding results. This strategy was studied by Cross and Choudhury [14,15] in ten villages in Nepal and they came to the conclusion that the people used as change agents had a major breakthrough. "Three years ago they were mostly illiterate, physically impaired, stigmatised and marginalised. Given their initial disadvantaged status, their achievements can be considered remarkable".

Laws also play an important role in stigmatisation. For instance, the creation of the leprosaria built by the government had a major impact in how the society perceived these patients. Consequently, there are some countries already moving towards a fairer and less discriminative society and the proof of that is the new document issued by the Government of India in April of this year [16].

In this document it is suggested a change in several laws that contribute to stigmatise people affected by leprosy. One of them is the marriage annulment law that grants rights to leprosy affected people spouses based on the argument of their protection [17-19]. The Government's proposal is backed with the scientific evidence of 99.9%

of efficacy killing the bacillus after the first dose of multidrug therapy and the argument that the majority of the population has immunity to leprosy [20-24]. Also, According to the India Government, the terms Leper or Persons with disability should be replaced by Persons Affected by Leprosy or Persons Affected by Leprosy undergoing treatment. Access to healthcare, adequate housing, equal opportunities of education and employment are also contemplated, as well as the ownership of properties in leprosy colonies, where a lot of leprosy affected people chose to live with their families but have no right over, making them at risk of eviction. Isolation is also mentioned as a measure that needs to be fully extinguished.

## Conclusion

Stigma in people suffering from leprosy has been one of the main focuses of healthcare professionals lately and a lot of interventions have been put in place aiming to reduce its impact in people's health and well being [25-29]. As shown throughout the article, people submitted to stigmatisation should be pro-active agents in the strategies implemented towards their empowerment. They should also have a word in setting the priorities of the interventions [8]. However, according to various authors, these people should not be expected to take full responsibility for programmes towards reducing stigma, which is a social problem and not an individual feature. It was also demonstrated via numerous authors that involving the community has a positive impact in decreasing stigma but educating them or increasing their tolerance is not enough; higher powers such as the government need to be involved in order to create major change.

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