

Strategies for Reducing Leprosy Stigma

Claudia Marcela Castro^{1*}, Lina Erazo² and Maria Luz Gunturiz¹

¹Project Bank Team, Department of Public Health Research, National Institute of Health, Bogotá, Colombia

²Group of Mycobacteria, Department of Public Health Networks, National Institute of Health, Bogotá, Colombia

*Corresponding author: Claudia Marcela Castro, Project Bank Team, Department of Public Health Research, National Health Institute, Bogota, Colombia, Tel.: 572207700 Ext.1629; Email: ccastro@ins.gov.co

Received date: January 17, 2018, Accepted date: January 29, 2018, Published date: February 02, 2018

Copyright: © 2018 Castro CM, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Abstract

Leprosy is an infectious, chronic, long-lasting disease caused by *Mycobacterium leprae* and *Mycobacterium lepromatosis* that leads to multiple clinical symptoms including skin manifestations, disfigurement, deformity, stigma and disability. The World Health Organization considers leprosy a complex disease that has a great impact on health in addition to causing social, economic and psychological burdens in affected populations.

With this review, we intend to demonstrate how the stigmatization of leprosy induces negative behaviors towards patients, impairing their attention and access to diagnosis and treatment and leads to a deterioration in their quality of life.

Keywords: Leprosy; Hansen; Stigma; *Mycobacterium leprae*; Disability

Introduction

Hansen's disease or leprosy is an infection caused by *Mycobacterium leprae* and *Mycobacterium lepromatosis* [1]. Patients with leprosy have symptoms related to the skin symptoms include spots, papules, plaques, nodules, and ulcers and peripheral nervous system that present characteristic progressive neural alterations and have hypochromic, anhydrous and anesthetic lesions. The neuronal alterations occur in the form of tingling, numbness, electrical sensations, tenderness or spontaneous pain in a nervous trunk and the thickening of nerves. Finally, disability, disfigurement and social rejection lead the patient to behavior of introversion and depression, which increases their health problems in the absence of assistance to health services.

The main mode of transmission of *Mycobacterium leprae* is direct and prolonged contact with untreated cases; however, 30 to 60% of new cases have not been in contact with people with leprosy, indicating the existence of an environmental source such as water and soil close to center with endemic leprosy [2,3]. The key aspect in the environment human transmission appears to be the intensity of exposure to contaminated soil and water. The extensive land area of endemic countries, endemicity in the bordering countries, diversity of biomes and the lack of urban infrastructure are possible factors that could influence disease [4]. De Macedo Arres and collaborators found viable *M. leprae* in 76.7% of water samples conducted one of the most recent studies [5]. On the other hand, has been documented the zoonotic transmission. Studies conducted by researchers from South American countries and the United States have reported the presence of *M. leprae* in wild armadillos [6-8] Truman and collaborators demonstrated that unrelated leprosy cases in the southern United States are associated with the same strain of wild armadillos [8].

The incubation period ranges from 6 months to 20 years. Although most people's immune system can fight the disease, which results in spontaneous resolution, leprosy patients have a susceptible immune system and genetic predisposition such that there is a greater probability of developing the disease [3].

Clinical manifestations presented by the patient constitute the traditional methodology used to diagnose the disease, supported by a histopathological examination. Bacteriological, immunological and molecular biology studies had been use to establish and control treatment identify subclinical infection and perform epidemiological surveillance [9].

Elimination of Leprosy

The World Health Organization (WHO) considers leprosy a complex disease that has a great impact at the health level as well as at social, economic and psychological levels. The disease is a public health problem due to its characteristics and symptoms, among which are duration, disability, permanent physical deformities and social rejection, which can lead to economic and psychological problems [9,10].

In 1991, a global commitment was initiated in order to eliminate leprosy by the year 2000. The goal was achieve a prevalence of less than one case per 10,000 inhabitants [11], which was achieved worldwide, with the exception of some countries that have populations of less than 1 million inhabitants; this target prevalence has been maintained [12].

For many years, leprosy has been primarily controlled using passive detection methods, with occasional active detection. These practices have translated into a decrease in prevalence but with little evidence of decreased incidence in some areas [13]. The new post-elimination era requires novel approaches and strategies to eradicate the disease: the timely and adequate supply of multidrug therapy (dapsone, rifampicin and clofazimine); the exploration of zoonotic or environmental sources of infection; the establishment of chemotherapy to patient contacts and

the creation of a new vaccine that increases the spectrum of protection of the current bacillus Calmette-Guérin (BCG) vaccine [14].

Actually, MIP vaccine, developed by Gursharan Pran Talwar, has been effective in improving the treatment of leprosy with high bacillary load, it has shown a good therapeutic response. The vaccine is based on an atypical Mycobacteria, the *Mycobacterium indicus pranii* a cultivable mycobacteria; it is an ancestor of both *M. leprae* and *M. tuberculosis* [15,16]. Introduction of the vaccine began in Gujarat and Bihar states of India with the goal to break the chain of transmission to give it to close relatives and other contacts of leprosy patients [17].

During the last five years, there has been a moderate decrease in the detection of new cases of leprosy. Of the 213,899 new cases in 2014, 81% were reported from India, Brazil and Indonesia. Countries considered overpopulated and report more than 10,000 new cases annually. Of the new cases, 14,110 were diagnosed with grade 2 disability, indicating a delay in detection [18]. Stigma is one of the primary causes of late diagnosis, which increases the transmission among families and communities as well as patient disabilities [19].

The stigma of leprosy

Leprosy has been framed by discrimination and stigmatization of the patients who suffer from it, either in endemic or non-endemic countries, of a lack of health education, policies focused on service providers, and an absence of community support. The stigmatization of patients is a phenomenon that occurs worldwide, engendering shame and fear of rejection from society, which is perpetuated by the fear of contagion [10]. Stigma is the primary barrier that hinders the early consultation of patients for diagnosis and timely treatment [3], contributing to the transmission of the disease and the disability of patients.

Leprosy confers a profoundly discrediting stigma perpetuated historically. Patients often experience the isolation and the confinement and fear rejection by society, family and their social network. Often, families will stigmatize and reject patients and check them into care centers, where, over time, they are forgotten [19,20].

In addition to the impact on health, social damage can result in the diminishment of the patient as a person because rejection by the community can lead to divorce, unemployment, displacement from the area of residence, psychiatric disorders, and even suicide [21].

In general, patients' responses tend to deny the existence of rejection attitudes from their closest relatives. As a manifestation of rejection, they state that they separate their clothing and belongings for personal use. At the couple level, patients do not perceive that they have been discriminated their partners. At the level of community, patients whose neighbors are aware of their condition mention having been subjected to social stigma, not because the manifestations of the disease are visible but because of the idea of leprosy. In work environments, the perception of those with leprosy is rejection (including dismissals) and a lack of solidarity or companionship in their work space. Leprosy patients are physically characterized as weak, with spots and deformities. This definition of their physical appearance further increases behavioral traits such as introversion and depression. From a socioeconomic perspective, associated characteristics include poverty, rural origin and lack of education. Additionally, patients with leprosy develop self-hatred and disgust, expressed as diminished self-esteem, lack of socialization, seclusion and isolation [21,22].

Strategies for disease management and stigma reduction

Sermrittirong and collaborators, found in their systematic review, five categories have been developed to reduce stigma and discrimination [21]:

1. Integration of leprosy services in health care
2. Information, education and communication (IEC) programs
3. Socio-economic rehabilitation (SER) programs
4. Change the name of the disease
5. Counseling

Integration of leprosy services in health care

The integration of leprosy services in general health care consists of providing care to leprosy patients close to their homes and reducing discrimination against leprosy patients from other patients. The aim of integration of leprosy care services into general health services is to reduce the feeling of difference in patients, and gradually decrease society's negative perception, making an integration between leprosy patients and patients with other disease [23,24].

Implementation of integration varies within and between countries; the key is to identify the most appropriate institutions to provide diagnosis and multi-drugs treatment based on easy access, client's acceptability and service providers' willingness. The integration should be guided to improve knowledge and change the attitude of health personnel towards patients [25].

Information, education and communication programs

IEC programs were developed for community awareness to deter discrimination and to detect leprosy when characteristic symptoms were identified [21], in addition to training medical and nursing staff. An example of the effectiveness of this type of intervention is a study conducted in Sri Lanka in 1990, in which there were campaigns to identify cases, educate the community, and train health center staff to detect and diagnose the disease. Surveys of perception and knowledge in the community were designed to convey that leprosy is a treatable disease and that disability can be prevented with early treatment. These education and communication campaigns increased the number of new cases by 150%, half of which were reported through the patients' initiative [26].

Public health models based on group communication are used to prevent health problems and promote changes in behavior [27]. Some programs have increased public awareness, provided opportunities, and allowed people to exercise their rights and help their peers [27-29].

Socio-economic rehabilitation strategies

Socio-economic rehabilitation (SER) strategies are primarily focused on patients with disability who must reintegrate into society with autonomy and self-sufficiency [21]. In Nepal in 2002, Cross and collaborators developed a project for the conformation of self-care groups (Stigma Elimination Program, STEP) between cured patients and current patients, with the aim of mitigating disability. Over time, STEP included support for earning credits and microenterprise training, eventually incorporating other marginalized populations [30].

Within SER programs, a different type of intervention was designed, called "Community-based rehabilitation." This program enlists actors, including cured 24 patients, families, organizations, communities, health institutions, non-governmental health organizations, educators, social workers and other service providers, so that patients have access to basic needs including food, housing, education, health care, and equal opportunities. This strategy aims to eliminate barriers between patients and society with the active participation of patients, focusing on their abilities and empowering them in making decisions. This program encourages equal opportunities and support for the disabled by providing sustainable aid, protection, and effective partnerships with organizations that contribute to activities that benefit patients with leprosy [31]. In Thailand, a two-phase project was developed in which patients who had suffered discrimination by their family or friends had their disability and socio-economic status evaluated. Based on those data, rehabilitation and fundraising activities were proposed [32].

Change the name of the disease

Changing the name of the disease have implemented by some countries, but has not been demonstrated its effectiveness. For example, in Japan since the word 'leprosy' evoked negative impressions and had led to social stigma and discrimination, the National Leprosy Patients' Association "Zen-Ryo-Kyo" began as early as 1952 to promote the term 'Hansen's disease; in Brazil, 'leprosy' was rejected and replaced with hanseniasis in 1970, the change has helped solidify MDT treatment and establish it as a dermatological disease separate from biblical leprosy [33-35].

Counseling

Counseling is one of the most recommended strategies in the world and consists of meetings with 5 to 7 patients who have had psychological evaluations and exhibit low self-esteem or have experienced rejection by their family but have not been clinically diagnosed with depression. Counseling creates trust that allows patients to share painful experiences, receive comfort, learn from others' experiences and prepare for the possibility of future rejection [36].

In the same way, the WHO established the "Guidelines to strengthen the participation of persons affected by leprosy in health centers" as well as the new "Global Leprosy Strategy 2016-2020" for the early detection and timely treatment of leprosy. These guidelines are meant to prevent the disability, reduce transmission in the community, and raise awareness of care services. Community participation and disease management are promoted as well as participation by cured patients to support and develop strategies to reduce stigma and discrimination [31,37]. However, communities often lack knowledge on dissemination, promotion and prevention, increasing the need for implementing strategies specifically aimed at demystification, adoption of positive attitudes and non-discrimination of patients and families. This action is so important that one of the primary strategies involves the elimination of discrimination and the promotion of inclusion.

Conclusion

In order to achieve the objectives of stigma reduction in leprosy, it is necessary to implement strategies that involve the communities. National leprosy programmes in endemic countries should implement these strategies, these efforts include early detection and control of the

disease, as well as in countries with low incidence, where can be performed an active search. Ultimately, we hope to see the eradication of the disease.

Additionally, it is necessary to identify the methodology and procedures used by health service providers, understand attitudes towards patients, and obtain information that will allow search solutions adjusted to the contexts and needs of each country inclusive of each region given the cultural differences and that will reduce the stigma of leprosy. This will be possible through the inclusion of cured patients, the promotion of self-care, and the empowerment of communities to encourage the welfare of individuals [24].

Acknowledgements

The authors thank the National Institute of Health for their support in the publication of this article.

References

1. Han XY, Seo YH, Sizer KC, Schoberle T, May GS, et al. (2008) A new Mycobacterium species causing diffuse lepromatous leprosy. *Am J Clin Pathol* 130: 856-864.
2. Franco-Paredes C, Rodriguez-Morales AJ (2016) Unsolved matters in leprosy: A descriptive review and call for further research. *Ann Clin Microbiol Antimicrob* 15: 33.
3. Klatser PR (2000) Strategies for pro-active case-finding in leprosy control. *Lepr Rev* 71: 30-32.
4. de Souza EM, Carrijo FM, Ignotti E (2015) Prevalence of Mycobacterium leprae in the environment: A review. *Afr J Microbiol Res* 9: 2103-2110.
5. Arraes MLBM, Holanda MV, Lima LNGC, Sabadia JAB, Duarte CR, et al. (2017) Natural environmental water sources in endemic regions of northeastern Brazil are potential reservoirs of viable Mycobacterium leprae. *Mem Inst Oswaldo Cruz* 112: 805-811.
6. Cardona-Castro N, Beltrán JC, Ortiz-Bernal A, Vissa V (2009) Detection of Mycobacterium leprae DNA in nine-banded armadillos (*Dasypus novemcinctus*) from the Andean region of Colombia. *Lepr Rev* 80: 424-431.
7. Daps PD, Alves BL, Gripp CG, Aragao RL, Guedes B, et al. (2008) Contact with armadillos increases the risk of leprosy in Brazil: A case control study. *Indian J Dermatol Venereol Leprol* 74: 38-342.
8. Truman RW, Singh P, Sharma R, Busso P, Rougemont J, et al. (2011). Probable Zoonotic Leprosy in the Southern United States. *N Engl J Med* 364: 1626-1633.
9. National Institute of Health (2014) Directorate of surveillance and risk analysis in public health. Leprosy event report until epidemiological period XIII, Colombia.
10. Ministry of social protection (2012) Comprehensive leprosy care guide. Bogotá, Ministry of social protection.
11. WHO. World Health Assembly (1991) Elimination of leprosy: resolution of the 44th World Health Assembly. Geneva: World Health Organization. Resolution No. WHA 44.
12. Nsagha DS, Bamgboye EA, Assob JC, Njunda AL, Kamga HL, et al. (2011) Elimination of leprosy as a public health problem by 2000 AD: An epidemiological perspective. *Pan Afr Med J* 9: 4.
13. Ministry of Health and Social Protection of Colombia (2009) Colombia's strategic plan for alleviating the burden of illness and sustaining leprosy control activities 2010-2015, Bogota, Colombia.
14. Steinmann P, Reed S, Mirza F, Hollingsworth T, Richardus J (2017) Innovative tools and approaches to end the transmission of Mycobacterium leprae. *Lancet Infect Dis* 17: 298-305.
15. Talwar GP, Gupta JC, Mustafa AS, Kar HK, Katoch K, et al. (2016) Development of a potent invigorator of immune responses endowed with both preventive and therapeutic properties. *Biologics: Targ and Ther* 11: 55-63.

16. Kamal R, Pathak V, Kumari A, Natrajan M, Katoch K (2017) Addition of *Mycobacterium indicus pranii* vaccine as an immunotherapeutic to standard chemotherapy in borderline leprosy: A double-blind study to assess clinical improvement (preliminary report). *Br J Dermatol* 176: 1388-1389.
17. Kumar S (2017) India resurrects forgotten leprosy vaccine. *Science* 356: 999.
18. World Health Organization (2015) Global leprosy update, 2014: need for early case detection. *Weekly Epidemiological Record* 36: 461-476.
19. Salazar AR (2001) La lepra: Invisibilidad y estigma. *Opcion* 35: 11-42.
20. Adhikari B, Kaehler N, Raut S, Marahatta SB, Gyanwali K, et al. (2013) Risk factors of stigma related to leprosy - A systematic review. *J Manmohan Mem Inst Health Sci* 1: 3-11.
21. Sermrittirong S, Van Brakel WH, Bunbers-Aelen JF (2014) How to reduce stigma in leprosy-A systematic literature review. *Lepr Rev* 85: 149-157.
22. Romero-Salazar A, Parra MC, Moya-Hernández C, Rujano R, Salas J. (1995) The stigma in the social representation of leprosy. *Cad Saude Publica* 11: 535-542.
23. Cardona-Castro N (2013) Leprosy in Colombia: post elimination stage? *Lepr Rev* 84: 238-247.
24. Lanza FM, Vieira NF, de Oliveira MM, Lana FC (2014) Instrument for evaluating the actions of leprosy control in Primary care. *Rev Bras Enferm* 67: 339-346.
25. Wijesinghe TS, Wijesinghe PR (2013) Integration of leprosy services into the General Health Service in Sri Lanka: overcoming challenges to implementation in a remote district. *WHO South East Asia J Public Health* 2: 63-68.
26. Williams PG, Dewapura D, Gunawardene P, Settinayake S (1998) Social marketing to eliminate leprosy in Sri Lanka. *Soc Mar Q* 4: 27-31.
27. Organización panamericana de la salud (1995) Manual de técnicas para una estrategia de comunicación en salud. OPS, Washington.
28. Marco de comunicaciones sobre el VIH/SIDA (1999) ONUSIDA, Ginebra.
29. Larrauri RC (2005) Comunicación y educación para la promoción de la salud. Lima-Peru.
30. Cross H, Choudhary R (2005) STEP: An intervention to address the issue of stigma related to leprosy in Southern Nepal. *Lepr Rev* 76: 316-324.
31. Guidelines for strengthening participation of persons affected by leprosy in leprosy services (2011) New Delhi, WHO. Regional office for south-east Asia.
32. Finkenflügel H, Rule S (2008) Integrating community-based rehabilitation and leprosy rehabilitation services into an inclusive development approach. *Lepr Rev* 79: 83-91.
33. Hosoda M (2010) Hansen's disease recoverers as agents of change: A case study in Japan. *Lepr Rev* 81: 5-16.
34. Couto Dal Secco RG, França K, Castillo D, AHarbi M, Lotti T, et al. (2017) A sinopsis of the history of Hansesn's disease. *Wien Med* 167: 27-30.
35. Sillo S, Lomax C, de Wildt G, Da Silva Fonseca M, de Almeida Galan NG, et al. (2016) A temporal and sociocultural exploration of the stigma experiences of leprosy patients in Brazil. *Lepr Rev* 87: 378-395.
36. Richard MF, Gurung S (2000) Stigma reduction through group counselling of persons affected by leprosy: A pilot study. *Lepr Rev* 71: 499-504.
37. Global Leprosy Strategy 2016-2020: Accelerating towards a leprosy-free world. Sub-regional New Delhi. WHO.