

Social, Cultural and Psychological Perspective of Leprosy (Hansen's Diseases)

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Abstract

Even after the attainment of elimination goal of leprosy, there are still new cases arising in endemic countries. There is still a great gap in our understanding the biology, mode of transmission and epidemiology of leprosy. There lies great gap need to be filled through biomedical research in future. Further, Intensive work on social, cultural and psychological aspects of leprosy should try to improve delay treatment and complication. This paper reviews, English-literature with a social and cultural context of leprosy were used in order to clarify the gaps which will help in the future. The history of leprosy: crucial sources of perception and reaction towards the disease. These will give us an understanding on how to tackle the main aggravating factors for new case detection rate in endemic countries. There lies the need of a more integrated approach to fill biomedical gaps, sociocultural aspects and psychological impact of leprosy.

Keywords: Leprosy; Hansen's Diseases

Introduction

Leprosy is one of the aged diseases since the time of the Dark Age. Even though, there is an available effective treatment for it. There are still new cases detected in leprosy endemic countries. Countries such as India, Brazil, Bangladesh, Democratic republic of Congo, Indonesia, Myanmar report a large number of leprosy [1,2]. According to WHO report, in 2013 of total 215,656 new leprosy case detected worldwide [3]. It is one of the few diseases to have been known in ancient and medieval times, and it was one of the first diseases to be linked to a specific infectious agent, *Mycobacterium leprae* (*M. leprae*), in 1873 [4]. But until this day there is still a gap in the knowledge about leprosy. Yet even now, the organism cannot be cultured *in vitro* and important gaps persist in our understanding of its biology and epidemiology [5]. Even though leprosy diagnosis and treatment service are free to charge at all health care. Even after the attainment of the goal of the leprosy eliminate on as public health problem in 2005. The number of new cases continues to increase within endemic countries [6]. The Research studied documented that delay in presentation to health facility supposedly on account of socio-cultural belief about illness and causation contribute to delay in initiating leprosy treatment [7]. In some patients, the disease is challenging to diagnose since there is no gold-standard method to differentiate between infection and disease. Leprosy is also a neglected disease, being endemic in developing countries, where detection rates show only a slight trend toward a decrease in disease (or a number of cases) in spite of good treatment and the efforts of the World Health Organization (WHO) to improve the quality of leprosy control programs [8]. We should try to evaluate after so many years of definitive treatment what are the constraints of eliminating leprosy in endemic countries. The history of leprosy being intertwined in cultural, social and religious views makes it difficult to tackle. Most researchers state the different reason for new cases of leprosy in endemic countries. However, the steady number of new cases of leprosy in endemic countries is thought to result from the perpetuating reservoir of *M. leprae*-infected contacts and/or from the difficulties of early clinical diagnosis [9]. It is mandatory to further work on the social, psychological and cultural perspective of leprosy in order to decrease the new cases in

endemic countries. A Sociocultural aspect of leprosy is very important because they can result in a delay in diagnosis and treatment and also can influence the effectiveness of public health program and illness outcomes [10].

Aim of the Study

The aim of this this review article is to describe the history of leprosy and to review on existing social science scholars on leprosy. Furthermore, to state the main focus of most researchers in leprosy as; Cultural attitudes towards leprosy, Social practices towards leprosy i.e. specifically discuss on stigma and gender and Psychological impacts of leprosy.

We need to see the longer years that leprosy has existed but it is still an issue especially in endemic countries. We need to work on decreasing new case detection rate, decreasing disability and decreasing delay for treatment. These all intervention will be effective if we see leprosy as a wicked problem because the disease is interlinked to cultural attitudes, social practices, and psychological impact. We should know that the availability of definitive treatment alone doesn't help us to eliminate the disease. Hence, it is important to work on the social, cultural and psychological views in leprosy.

History of leprosy

When we see the history of leprosy it is attached with human suffering and misunderstanding. Researchers claim that leprosy appears in an Egyptian Papyrus document written around 1550 B.C. There is also evidence on Indian writings around 600 B.C. about a disease that resembles leprosy. In Europe, leprosy first appeared in the records of ancient Greece after the army of Alexander the Great came back from India and then in Rome in 62 B.C. coinciding with the return of Pompeii's troops from Asia Minor [11].

Throughout its history, the cause of leprosy has been misunderstood. For a long time leprosy was thought to be a hereditary disease, a curse, or a punishment from God. Even after the discovery of its biological cause, leprosy patients were stigmatized and rejected. For instance, in Europe during the middle Ages, leprosy sufferers had to wear special clothing, ring bells to warn others that they were close, and even walk on a particular side of the road, depending on the direction of the wind. Even in modern times, leprosy treatments has often occurred in separate hospitals and live in colonies called leprosarium's because of the stigma of the disease [11].

The history and belief towards leprosy say a lot on how it is influenced the reaction and attitude of leprosy.

In modern history, In 1873, Dr. Gerhard Henrik Armauer Hansen was the first person to identify the germ that causes leprosy under a microscope. Hansen proved that leprosy was caused by *Mycobacterium leprae* but was not hereditary, from a curse, or from a sin [11]. These starts the era of medicalization of leprosy. The discovery of the biological cause of the disease, *Mycobacterium leprae*. Because of change of researchers' point of view towards leprosy, they were trying to find medical treatment. In early 20th century, until 1940s doctors over the world used oil injection from chaulmoogra nut to treat patients with leprosy. The treatment was painful, and its long-term efficacy was questionable. In 1921, U.S. Public Health Service established the Gillis W. Long Hansen's Disease Center in Carville, Louisiana, which became known as "Carville." It became a center of research and testing to find a cure for leprosy and a live-in treatment center for leprosy patients. Later in 1941, Promin successfully treated leprosy but unfortunately, treatment with Promin required many painful injections. The 1950s, Dapsone pills, pioneered by Dr. R.G. Cochrane at Carville. Dapsone worked wonderfully at first, but unfortunately, *M. leprae* eventually began developing dapsone resistance. 1970, the first successful multi-drug treatment (MDT) regimen for leprosy was developed through drug trials on the island of Malta. Now, Researchers are working on developing a vaccine, understand the mechanism of transmission and ways to detect leprosy sooner in order to start treatment earlier [12].

We can see how medicalization has shaped the view towards leprosy. Despite the discovery of the biological cause of leprosy and successful multi-drug treatment, there are still large number new cases of leprosy endemic areas. The goal of the WHO by the end of 2015 is to reduce the rate of new cases with grade-2 disabilities worldwide by at least 35%. This will be carried out by enforcing activities to decrease the delay in diagnosing the disease and on time treatment with multidrug therapy. This will also have the impact of reducing transmission of the disease in the community [13]. Even though much work has been done in many countries to eliminate leprosy. There is some success seen from the work but still this day there are cultural, social and psychological constraints' that need to be worked on. It is a great concern to eliminate leprosy and long-term activity. Chemotherapy alone isn't sufficient to solve all treatment issue so we need to work in broader perspective on cultural, social and psychological impact in endemic areas.

Methods

The included articles were searched for English –language articles about leprosy using PubMed, Medline and Google scholar. Keyword used in the search was leprosy, sociocultural context, and research. There was no limit to the search to a specific time period. Inclusion limited to social and cultural aspects research of leprosy. Excluded literature which didn't have social and cultural aspects of leprosy i.e. Genetic and clinical aspects. The articles were selected which are read thoroughly and most were qualitative data but some had the combination. Furthermore, the remaining articles were read on pertinent issues related to the topic.

Cultural attitudes towards leprosy

In almost all **cultures** throughout history, leprosy has aroused apprehension and hatred about the prospect of incurable **disease** and a lifetime of progressive disfigurement. Many types of researches ascertain that every culture has their own interpretation of leprosy. Since ancient times, there has been a link between leprosy and sin. In Jewish tradition and in the regions of ancient Mesopotamia, there is an association between chronic skin disease and ceremonial uncleanness requiring ritual purification and quarantine. Shintoism in Japan uses the same word for both leprosy and sin [14]. Other studies show that, China linked the concept of personal guilt to the presence of repulsive skin diseases. Leprosy as the embodiment of evil forces also comes from the theory of *Feng Shui*, which held that individuals with leprosy needed to be buried alive to prevent the spread of the disease to other members of the family and community [15]. In ancient Benin, the darkest forces of nature were considered the source of the disease that was given to its victims as a punishment [16]. And Hindu belief was that the disease was contracted as a form of divine punishment [17]. Although much evidence today suggests that Hansen's disease, or true leprosy, is not the condition of concern in Leviticus and other biblical passages, the connection of the word lepra to leprosy was a major influence in Western attitudes about the victims of the disease being unclean and the subsequent rejection and isolation of the victims from the rest of society in a leprosarium [15]. In medieval times, leper masses were held in which diseased people were declared officially dead as far as the church and society were concerned and were banished and forced to wear distinctive clothing and announce their presence with bells or clappers [18]. All these cultural attitudes have greatly contributed to the stigma, alienation, and violence which continues to exist until these days. Feeny gives a number of examples of persecution within the past century. In the U.S., a man was left alone to die of exposure and starvation in a cattle truck; In China in 1937, 80 victims of leprosy, including women and children were shot and thrown into a lime pit; and in Korea in 1957, a mob beat 10 patients from a leprosarium to death [15]. There is evidence how cultural attitudes has been inculcated in society to result in structural violence towards citizens. Stigmatizing attitudes being included in modern laws which were used to violate human rights. As demonstrated in India where the Motor Vehicles Act of 1939 forbade the granting of drivers' licenses to leprosy sufferers and, until recently, the Indian Christian, Muslim, and Hindu marriage acts included leprosy as grounds for divorce [17]. We can see that there are critical influences of traditional, culture and supernatural beliefs towards leprosy which can make them seek help from traditional sectors. These can contribute to delay in diagnosis and treatment. In a study of leprosy patients in rural Maharashtra found that traditional belief was still prevalent among patients which in turn influence their health seeking behavior [19].

Social practices

Leprosy as a wicked social disease has been a major public health problem because of the social stigma and gender difference attached to it. This has a great effect on delaying seeking health care, early diagnosis, and treatment.

Stigma

Stigma is a Greek word that in its origins referred to a kind of tattoo mark that was cut or burned into the skin of criminals, slaves or traitors, to visibly identify them as blemished or morally polluted people [20]. These individuals were to be avoided, particularly in public places. The word was later applied to other personal attributes that are considered shameful or discrediting. In relation to health, stigma was defined by Erving Goffman as an attribute that signifies that an individual is different from 'normal' people and, further, that the person is 'of a less desirable kind-in the extreme, a person who is bad, or dangerous or weak [21]. People reaction towards disease or illness is strongly related to social and cultural background.

Until this day there are many people who have leprosy or those who are cured who are a victim of stigma and revulsion. It is known leprosy infection is curable with the multiple drug treatment available till this day. Patients on treatment will be noninfectious in 30 days after initiation of treatment. They will be cured after completion of treatment 6 to 9 months. But yet for many people, social stigma can persist a lifetime. A Study done by James Spradely in India, no one had gone so far as permanent reunite with their original households. Because of fear discrimination, most people who try to go far place in order to conceal their condition. Some also seeking traditional healer [22]. These have resulted in delay between initial symptoms and diagnosis and adherence to medication. Fear of being found to have Hansen's disease and possible consequence of the fear may even lead to discontinuation of treatment [23]. Stigma is one of the most important factors that can result in complications of Hansen disease. Hansen disease complication can cause gross deformities of face and limbs of an infected individual as well as crippling disability involving sight, touch and manual dexterity [24]. Stigma by itself can result in a delay in health seeking behavior which in turn aggravates complication. Most patients delayed seeking help for over a year. This resulted in complication which could have definitely been prevented. This deformity and disabilities led to deterioration in their functional capacities and their psychological state of mind. In a study done by Calcraft stigma of Hansen disease showed a negative impact on income generation because of the physical effect of the disease [25]. Even though, a breakthrough in elimination of Hansen disease is achieved in most of the world. Hansen's disease still remains a human problem. Stigma may affect many aspects of national leprosy eradication program and government policies [26].

Gender

Gender refers to the socially constructed characteristics of women and men such as norms, roles, and relationships of and between groups of women and men [27]. There appear to be differences in the gender ratio of leprosy patient being diagnosed. Helman observed such gender difference in awareness of the disease in many culture [28]. There are evidences showing that reporting of women lags behind that of men in many parts of the world.

Research done Netherlands leprosy relief stated three factors that influence gender difference i.e. biological, sociocultural and service factors. Biological factors describe there were more men than women registered as having leprosy. There is a strong relation with tradition, low status of women, their limited mobility, illiteracy and poor knowledge of leprosy appeared to be an important sociocultural explanation why women were under-reporting. Many researches done signify that male registered patients have higher rates of leprosy and grade 2 deformity than females [29-33].

It is known that women notice bodily problem quickly than men. Despite this gift because of a sociocultural status of male and female patients in every society is different. In particularly, with respect to freedom to make a choice and having access to material/resources. In a study done Nigeria shows that man were more seriously affected by leprosy than women [34]. This evidence shows that a sociocultural and economic factor has made the limitation even though women were more quickly aware of the health problem. Women couldn't be able to go to health care even if they want to because of the sociocultural constraints. Men on the other hand, traveled further in search of high quality of treatment and to ensure secrecy from their communities because of the available social and economic power for men. Researches done on four countries illustrates that men are both mobile and financially better off than women. This didn't mean that men got better care. This indeed shows that some men had been visiting traditional healer or leprosy referral center and private doctors. These have resulted in delayed treatment and unnecessary costs [34]. In Nepal, It was observed similar behavior: Not only were men in search for what they conceived as high quality care but also for secrecy which seemed better guaranteed if sought care far from their community [35].

There are varying degree of stigma occurred in every society towards leprosy. Men were mostly afraid of losing economic and social status in community while for women the fear concerned with domestic group and their spouse and in laws [34]. Researches evidences done in four countries ascertains that with exception of being as long as sick spouses could still perform economic domestic duties their health improved most married couple stayed with each other except until deformity appeared [34]. The other constraints seen in many studies are towards gender, staff to patient relation towards opposite sex is another problem and availability of privacy during diagnosis in leprosy clinic. Researchers showed that both male and female encountered difficulties in approaching and thorough investigation of a patient of opposite sex [34].

So, it is important to see how the gender difference arises starting from its roots. These main causes are the one changing the distribution of disease. We should still try to value the role of sociocultural and economic factors contributing towards influencing the health seeking behavior, delay in treatment and complication. So, we should try to work on further epidemiologic distribution of sex in every leprosy clinic which can enable us to see how the social, cultural and economic aspects of the society can affect public health policy implementation. We need to make the health facility to upgrade the ways to treat sensitive patients and issues. These all go down on how to tackle the sociocultural aspects of leprosy.

Psychological impacts

There are many social beliefs and attitudes towards leprosy that can affect mental health. Social stigma associated with leprosy makes it so different from other illness. Even though leprosy is a curable disease, till these day people affected by leprosy have to leave their villages and are exerted to social isolation. As a result of this rejection by family and community people with leprosy have a high risk for developing a psychiatric disorder. A Study done in a specialized hospital of Ethiopia 52.4% [26] of patients with leprosy was having a psychiatric disease. Another important finding is that long duration of illness and physical handicaps raise a risk of psychiatric disorder [36]. Most predominant psychiatric illness are anxiety disorder (27.8%) and mixed i.e. anxiety and depressive disorder (13%) [37].

These evidences show that we need to tackle leprosy from every aspect in order to minimize the emotional burden of leprosy. There are many policies adopted for leprosy elimination campaign but till this day the means of psychosocial support towards patients with leprosy and its complication need to be further worked on in an institutional case of Hansen's disease. Psychiatric treatment isn't being practiced in institutional case of Hansen's disease [38]. Integrated health care measures involving dermatologist, leprologist and mental health care professional is mandatory. Health education is important to measure in tackling leprosy [39]. There is a crucial need for compressive psychiatric care of patients with leprosy.

Conclusion

The concepts of stigma, gender, historical background and psychological impact of leprosy have been discussed. It is known that elimination goal has been achieved in most countries. However, there is different trend in different parts of the world. This has created great concern towards new cases of leprosy in endemic countries. The cultural concept of illness causation has associated impact on health-seeking behavior. There are evidences showing that reporting of women lags behind that of men in many parts of the world. Furthermore, fear of stigma also may lead to concealing leprosy which may delay the treatment and increase the spread of the disease. This can also result in dropping out from treatment. In addition, there are many social beliefs and attitudes towards leprosy that can affect mental health. Because of these; there is great need of psychiatric care to patients with leprosy.

To sum up, despite how ancient the disease is, there is still a gap in biological, mode of transmission and epidemiological knowledge that need further research. The other is that, social attitudes, cultural aspects and psychological impacts contribute great deal towards increase new case detection rate in endemic countries. We need to work on decreasing new case detection rate, decreasing disability and decreasing delay for treatment. There lays the need for coordinated and integrated work on the limitations of biomedical, social attitudes, cultural aspects and psychological impacts of leprosy.

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