

Evolution of Social Wellbeing of Leprosy Affected People

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Leprosy is not new; it is one of the oldest diseases and perhaps among the most cited illnesses of human suffering. Leprosy not only affects the physical and mental state of a person but significantly limits the social well being; it affects an individual's ability to create good social relationships, social acceptance; it also causes the stigmatization and de-habilitation of patients. Leprosy-related social issues have resulted from perceptions made because of misunderstanding, unavailability of treatment, socio-economic conditions, and mainly because of disabilities arising in the absence of effective, timely diagnosis and treatment. Many of these factors are considered changeable. Over a long time scale, significant changes have become evident; therefore, the need to explore the situation through literature has been felt; hence, this study was carried out with a focus on the Indian scenario. Review indicates a significant change in leprosy-affected people's social well-being with shifts in eras from no treatment to monotherapy, MDT and later. While in no treatment era, the body of leprosy-affected people was not considered as pure to sacrifice to the Gods; in the current post-elimination era, leprosy patients are largely accepted by their families and community, being invited to participate in family and social functions; but the undeniable fact is, still many affected are forced to live as outcasts and stigma in various forms exists that demands more proactive evidence-based locally adapted approaches to address the issues. In addition, to strengthen the availability of timely medical and surgical management services, psychosocial & social interventions as per personal and local needs will be required in the times to come.

Keywords : Leprosy, Evolution, Social Wellbeing, Leprosy Affected People, India

Introduction

For thousands of years and continue, leprosy was considered a curse of the gods, a punishment for sin, or a hereditary condition. Such consideration resulted in heavy stigmatisation of disease and individuals; even the term leprosy itself heavily stigmatised that it has become synonymous with abandonment, social isolation, and condemnation to a lifetime at the margins of society (The Lancet 2019). Leprosy is the oldest disease known to man and tormented humans through-

out history (Dogra et al 2013, WHO 2021). Leprosy is also considered one of the leading causes of human suffering, as it affects physical well-being and significantly hampers or disturbs affected people's social lives. WHO (1948) defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. Considering the definition of health, leprosy affects all these aspects, impacts the physical and mental state of the affected person and significantly limits their social well-being.

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Social well-being is important because it demonstrates the circumstances and functioning of the individual in society (Keyes 1998, Salehi et al 2017). It consists of aspects essential for the cohesion between individuals and society. In leprosy, these aspects can be categorised as the ability to create good social relationships, social acceptance, freedom from stigma and management of de-habilitation/rehabilitation issues. Nevertheless, these social aspects and issues make the disease unique, unlike other infectious illnesses.

Leprosy-related social issues result from perception made because of misunderstanding, unavailability of treatment, socio-economic condition, and mainly because of disabilities arising in the absence of early diagnosis and effective treatments. Discriminatory laws were also based on such misconceptions (All India Leprosy Act 1898). Many of these issues, such as rejection, restriction (Sinha et al 2010b), and de-habilitation (Seshadri et al 2015, Kaur & van Brakel 2002a, Kaur & van Brakel 2002b), are considered changeable. Over time, significant changes have been evident. Development and availability of treatment; and other socio-cultural improvements have resulted in awareness, understanding and change in people's perception; therefore, exploring the situation through literature is essential.

Need of Study

Review studies have the robust potential to provide contextual understanding; identify gaps for future research and intervention more fruitfully. This work is an effort with the same motive to gather and concise the known facts and phenomena through the literature to provide a quick understanding of the evolution of the social well-being status of leprosy-affected people. Based on the history of leprosy treatment, the duration covered by the study is categorised in to four eras viz. no treatment, mono-therapy, multidrug

therapy, and post-elimination. Along with each era, there has been multiple effects on the epidemiology of leprosy, especially the availability of effective treatment impacted towards reduction of disabilities and disfigurement, which in turn were likely to have had effected on reduction of fears and prejudices of society and the resultant stigma, de-habilitation and social status of leprosy-affected people. However, no consolidated information is available on what changes have taken place in the four eras in terms of fear and prejudices of society and the resultant stigma, de-habilitation, and social status of leprosy-affected people have been impacted by changing disabilities and disfigurement. This review aims to understand this relationship so that future research and interventions are focused on according to needs.

This study was thus carried out with the question, what are the changes that might have happened in the social well-being of leprosy-affected people at par with the development and availability of effective treatment(s) impacting disfigurement and disabilities over the last major four eras.

Aims and Objectives

Aim of this study was to examine whether the process of evolution of the social well-being of leprosy-affected in the four eras coincides with that of medical and surgical treatment of leprosy. The specific objectives are to compare the changes during the four eras in the social well-being of leprosy-affected in the following broad areas viz. their abilities to create good social relationships, social acceptance and support, stigmatisation, and patients' de-habilitation through the review of available literature.

Material and Methods

Keywords such as 'leprosy in India', 'leprosy patients' ability to create social relationships', 'social acceptance of leprosy-affected people' social support of leprosy-affected people', 'stig-

matiation of leprosy and people affected, and 'de-habilitation of leprosy-affected people' were used to list and access the literature from PubMed and Google Scholar. The literature on leprosy and associated issues are extensive and vast; only those most relevant for social well being were gathered and analysed. Out of total 365 articles screened, 42 addressing the markers related to the social wellbeing and aspects relevant for discussion with a focus on the India scenario were short-listed for further consideration (Table 1).

These were thoroughly reviewed; four tables are prepared based on different eras pertaining to developments in leprosy treatment and these becoming available to the people. Findings are presented in the results & discussion section below, and the citation and inference method was used to prepare the manuscript.

Results and Discussion

De-habilitation, rejection, stigmatisation, failure to establish social contacts and poor social support of patients are not very rare in other contagious or chronic and disability causing diseases such as tuberculosis, human immuno-deficiency virus, epilepsy, syphilis, paralysis; but social issues associated with leprosy has been a prominent feature of the disease, even in those countries where leprosy is not, or no longer endemic. The fear of contracting leprosy and developing disabilities and associated socio-

religious beliefs lead to a shameful social situation that impacts the social well being of people affected with the disease.

In ancient India, those affected with leprosy were marginalised due to the disease's chronic and potentially disfigured nature, lack of effective therapy, linking disease with sin, and the fear of contagion (Jacob & Franco-Paredes 2008). Over the period country has witnessed tremendous change in the social status of leprosy patients, while in ancient times, the bodies of leprosy-affected people were not considered pure to sacrifice to the Gods (Bryant & Bryant 2001, Sinha et al 2010a). In contemporary times, they are largely accepted by their families and community; they are being invited to participate in social functions, despite their disease disclosure (Thilakavathi et al 2012).

The social well-being of leprosy patients in India has been analysed as per four major categories:-

No Treatment Era (Table 2): during this era, no specific treatment was available (Jacob & Franco-Paredes 2008); however, there is mention of the use of oil derived from plant leaves, not eating a particular food, and voiding some habits and sexual intercourse (Sinha et al 2010a) was considered as a cure, but these therapy or efforts were not consistently effective (Jacob & Franco-Paredes 2008). Leprosy was purely viewed as a result of sins, wrongdoing and unfaithful to God.

Table 1 : Number of relevant studies included in the era wise analysis

Aspect	No Treatment Era	Mono Therapy Era	MDT-Pre Elimination Era	Post Elimination Era
Ability to create a social relationship	0	1	1	3
Social acceptance	3	2	1	2
Stigmatization	1	1	1	3
Rejection and de-habilitation	1	5	2	4
Total	5	9	5	12

Table 2 : Social wellbeing of Leprosy Patients during “No Treatment” Era

Aspect	Study	Review inference
Ability to create a social relationship	No relevant study found	-
Social Acceptance	Sinha et al (2010a), Bryant & Bryant (2001), & Sinha et al (2010b);	In the ancient Vedic period, the body of leprosy-affected people was not considered as pure to accept and sacrifice to the Gods. It has been mentioned that it was customary to bury them alive. Ancient Muslim texts mention that 'Escape away from the leprous'.
Stigmatization	Jacob & Franco-Paredes (2008)	In ancient Indian times, those affected with leprosy were marginalized due to the chronic and potentially disfigured and nature of the disease, lack of effective therapy, linking this disease with sin, and the fear of contagion that led to a unique stigma towards leprosy.
Rejection and de-habilitation	Alam et al (1997)	From the earliest times, leprosy has been a disease set apart from all others; affected people were de-habilitated or left out from the family; even those who cared for them were rejected by society.

Those affected with leprosy were marginalised due to the chronic and potentially disfigured and nature of the disease, linking this disease with sin. The fear of contagion led to a unique stigma towards leprosy (Jacob & Franco-Paredes 2008). Even the dead body of leprosy-affected people was not considered as pure to accept and sacrifice to the Gods. It has been mentioned that it was customary to bury them alive (Sinha et al 2010a, Bryant & Bryant 2001); not only affected people were rejected and de-habilitated, but those used to care for them were also rejected from the family and social life (Alam et al 1997). This was possibly the harshest period for those affected with the disease leprosy.

Mono-Therapy Era (Table 3): Identification of *Mycobacterium leprae* by Armauer Hansen in 1873 was the major landmark; it was the first pathogen recognised as a cause of any infectious disease. However, in 1897, the first International

Leprosy Congress concluded that "Leprosy is incurable". The use of chaulmoogra oil, and later in 1941, the discovery of dapsone generated hope that leprosy is treatable (Dogra et al 2013). Still, the social well being of leprosy patients remained a serious issue, and affected people were de-habilitated from their families and living on the streets, not allowed to marry (Brody 1974), stigma against leprosy was prevalent (Kakar 1996). This led the British crown to send the leprosy commission; the commission submitted his report and concluded that leprosy is a disease *sui generis* caused by a bacillus having a striking resemblance to tuberculosis. It is not a hereditary disease and spread by contagious means, but the chances for that are minimal (National Leprosy Fund 1892, Jacob & Franco-Paredes 2008, All-India Leprosy Act 1898, Mushtaq 2009, Buckingham 2002). Hansen's discovery that leprosy is caused by a bacterium later named

Table 3 : Social wellbeing of Leprosy Patients during “Mono Treatment” Era

Aspect	Study	Review inference
Ability to create a social relationship	Brody (1974)	Leprosy affected people who were not allowed to marry and had to leave their families.
Social Acceptance	Hansen's Discovery (2008), Patil et al (2019)	In 1873, Hansen's identified leprosy causing bacteria <i>Mycobacterium leprae</i> ; this change leprosy from being a curse of God to a disease; resulted in perception change and slit acceptance for affected people. Patil et al reported the case of Ladha Maharaj, who was believed to be cured through Bilwa leaves oil, used to recite religious verses to Gandhi's father when Gandhi was only 13 years old. Such acceptance of cured patients in society indicates a positive attitude and acceptance.
Stigmatisation	Kakar (1996)	Stigma against leprosy was prevalent; however, some people used to care for affected people; out of religious beliefs.
Rejection and de-habilitation	National Leprosy fund (1892), Jacob & Franco-Paredes (2008), All-India Leprosy Act (1898), Mushtaq (2009) & Buckingham (2002)	Leprosy was a serious issue in the country people were affected people were de-habilitated from their families and living on the streets, this led the British crown to send the leprosy commission, the commission submitted his report and concluded that leprosy is a disease sui generis caused by a bacillus having a striking resemblance to tuberculosis. It is not a hereditary disease, there is spread by contagious means, but the chances for that are minimal. In 1898 and Leper Asylums were established in significant parts of the country, and forcible segregation of lepers was carried out.

Mycobacterium leprae led to the change from being a curse of God to an infectious disease; resulted in some perception change and some social acceptance for affected people. Patil et al (2019) reported the case of Ladha Maharaj, who was believed to be cured through Bilwa leaves oil, used to recite religious verses to Gandhi's father when Gandhi was only 13 years old. Such acceptance of cured patients in society indicates a positive attitude and acceptance (Hansen's Discovery 2008). Nevertheless, many people used

to voluntary care for the leprosy-affected people (Kakar 1996) out of religious beliefs. During this period, medical treatment to treat the disease and prayers to God for forgiveness for sins were part of thinking.

MDT-Pre Elimination Era (Table 4) : Development and launch of multidrug treatment (MDT) in 1981 (WHO - Leprosy Fact Sheet, Kar & Gupta 2015, Maymone et al 2020) can be considered as the most important innovation that created a significant change in the status of leprosy-

Table 4 : Social wellbeing of Leprosy Patients during “MDT-Pre Elimination” Era

Aspect	Study	Review inference
Ability to create a social relationship	van Brakel (2003)	Leprosy related stigma still impact the inter-personal relationship, marriage, employment, leisure activities, and attendance at social and religious functions
Social Acceptance	Kopparty (1995)	The extent of acceptance of deformed patients in their families varied significantly among those facing and not facing problems due to their deformity. The deformed patients without any handicap were accepted in a large majority of their families (82%) regardless of their caste, class or gender and status.
Stigmatisation	Ghosh et al (2001)	With the start of MDT in 1981, a significant change came in the status of leprosy-affected people. Still, stigma against leprosy was prevalent in the early MDT era.
Rejection and de-habilitation	Zodpey et al (2000), Kaur & van Brakel (2002b)	Leprosy patients were isolated and refrained from various activities in the family. The attitude of society towards those suffering from leprosy has given rise to many unfortunate incidents of insult, rejection and even murder of patients, and in some communities, these continue.

affected people (Ghosh et al 2001), as the proper and early treatment proved to be effective in short term management of disease and also prevention of deformities. MDT effects that leprosy case reduced from nearly 6 million in 1983 to only 2-3 lakhs in 2005 (National Leprosy Eradication Programme, Annual Report 2012-13). Such a more considerable decline was due to the proper management of care and prevention of disability in leprosy-affected people. Feared social image of disfigured persons begging in the streets and roads vanished from most parts of the country. However, some stigma against leprosy was still prevalent (Rao 2015) in the early post-treatment era, even after such considerable success in leprosy management and disability prevention through MDT. The life of leprosy-affected

persons; their interpersonal relationships, marriage, employment, leisure activities, and attendance at social and religious functions were affected as reported in some studies (van Brakel 2003). Leprosy patients were isolated and refrained from various activities in the family. The attitude of society towards those suffering from leprosy has given rise to many unfortunate incidents of insult, rejection and even murder of patients in some communities (Zodpey et al 2000, Kaur & van Brakel 2002a). Women and children have been easy victims due to their social and economic situation in the household. De-habilitation and rejection of women from social and family life were quite common in the early post-treatment era. The extent of acceptance of deformed patients in their families varied significantly

Table 5 : Social wellbeing of Leprosy Patients during “Post Elimination” Era

Aspect	Study	Review inference
Ability to create a social relationship	Thilakavathi et al (2012), Slim et al (2010), Sinha et al (2010b)	A sizeable proportion of affected people are being invited to social and cultural gatherings. Still, there are some who experience low participation and less opportunity to have a good social relationship with the people in the community.
Social Acceptance	Katoch et al (2017), Raju & Rao (2011)	Integrating leprosy services and public health care services and increased tracing and treatments of new cases has created a positive change among the people perception and attitude towards leprosy, resulting in acceptance of LAPs by society. Self-stigma remains a problem. There has not been much change in the socio-cultural situation of cured patients, especially those disabled.
Stigmatisation	Rao (2015), Raju et al (2008), Raju et al (2021)	Despite all the development, stigma against leprosy patients is still a reality. Leprosy affected people continued to be stigmatized, and many patients are living in leprosy colonies. Disability and ulcers associated with the disease are some of the primary causes of stigmatization; however, community engagement and actions found effective in reducing stigma.
Rejection and de-habilitation	Guthi & Sreedevi (2018), Seshadri et al (2015), Moturu & Pamidipani (2018), Raju (2019)	Delay, defaulting, deformities, de-habilitation prevalent and all four are positively associated with each other. Many leprosy patients are temporarily or permanent de-habilitated or living in leprosy colonies, especially those with visible deformities. There may be many causes of settling and remaining in leprosy colonies, such as the availability of free facilities in leprosy colonies.

among those facing and not facing problems due to their deformity. The deformed patients without any handicap were accepted in a large majority of their families (82%) regardless of their caste, class or gender and status (Kopparty 1995). During this period, Government agencies, missionaries, and non-government organisations were actively contributing to the betterment of leprosy patients' lives, rehabilitation to everyday social life, and minimising the stigma. Actively

pursued treatment, rehabilitation, and social awareness programs have made a difference; many such flagship programs and activities continue. It resulted from those welfare activities and programs that significantly changed the life and status of leprosy-affected people.

Post Elimination Era (Table 5) : With massive public health campaigns and with active participation of many non-governmental institutions in providing multi-drug treatment and recons-

tructive services, the numbers of leprosy cases in India were reduced to 1 per 10,000 populations in India by the end of 2005. This was the declaration as elimination as a public health problem. By now, some very positive changes were seen in the daily and the social life of leprosy patients as well. Integrating leprosy services and public health care services and increased tracing and treatment of new cases has created a positive change among the people's perception and attitude towards leprosy, resulting in acceptance of LAPs by society but self-stigma remaining as a lasting challenge (Katoch et al 2017). As a result, de-habilitation and rejection of leprosy patients has been reduced compared to mono and early MDT treatment Era. However, the chain of delay in starting the treatment, defaulting, deformity and de-habilitation continues in some cases (Moturu & Pamidipani 2018). Timely access to treatment should continue to receive due attention as it affects the ultimate social well being of leprosy affected people even after complete medical treatment if it does not prevent deformity.

A sizeable proportion of affected people are being invited to social and cultural gatherings, but few still experience low participation and less opportunity to have a good social relationship with the people in their community (Thilakavathi et al 2012, Slim et al 2010). After integration, there was not been much change in the socio-cultural situation of cured patients, especially those disabled (Raju & Rao 2011). Despite all the development, stigma against leprosy patients is still a reality. Though quantitatively and qualitatively, the situation is better, some of leprosy-affected people continued to be stigmatised; many leprosy patients were temporarily or permanently de-habilitated and continued living in leprosy colonies, especially those with visible deformities and disability and stigmatisation.

There may be many more causes of settling and remaining in leprosy colonies, such as availability of free facilities in leprosy colonies (Rao 2015, Raju et al 2008, Guthi & Sreedevi 2018, Seshadri et al 2015, Raju 2019). Despite a more favourable socially secure atmosphere to persons living in settlements, they cannot be considered happy (Bhat et al 2020, Sharma & Saxena 2019). Even though a significant change came in the status of leprosy-affected people in the post eliminations era, it is also an undeniable fact that leprosy is still being stigmatised and socially backwards. Marginalised segments of the community such as backward caste, elderly, women, and minorities are more like to stigma and face discrimination (Staples 2004). However, generalisations cannot be made, and emphasis should be on actual situation analysis.

This study is the first to specifically analyse the status of social wellbeing of leprosy-affected people coinciding with major therapeutic developments. All of us know that leprosy is an age-old disease, described in the literature of ancient civilizations. Throughout history, people afflicted have often been ostracized by their communities and families. WHO's strategy adopted by all member states has a vision of zero leprosy specially zero stigma (WHO 2021). While the social well being of leprosy-affected persons has visibly changed with the revolutionary and landmark changes in treatment modalities and their effectiveness, the persistence of social problems in some areas and groups indicate the need of community-based interventions operated by the society (Raju et al 2021).

Conclusions

The study concludes that positive changes in the social well-being of leprosy-affected have occurred eventually during each of the eras and are in progress with the development and availability of better treatments facilities.

During the no-treatment era, the concept of the ability to create social relationships by leprosy affected seem to not in the minds of the community or the researchers; the affected were heavily stigmatised, rejected and had no acceptance in the social system, which changed in monotherapy era to poor levels of acceptance, rejection, and de-habilitation.

Considerably greater acceptance and less rejection of affected people was apparent during the multidrug therapy era, but the impact on interpersonal relations, marriage, employment, insult, rejection, de-habilitation were still prevalent.

In comparison to the other eras, currently, during the post-elimination era higher proportion of leprosy-affected are not de-habilitated, are also being invited in cultural, social and religious activities with better acceptance by their family and communities. Self-stigma is still prevalent, reflecting on delay in diagnosis, treatment, deformities and patients' hiding of their illness etc. needs to be addressed through psycho-social research inputs.

Future perspective

The future of leprosy control and rehabilitation programs requires several interventions at the structural and cultural level to address the problems; continuous efforts are needed to educate the people for a more scientific approach towards contagious illnesses in general and disability associated diseases, leprosy in particular. To achieve them, we need to take up more of literature studies to find out the gaps and emphasize the research needs based on the existing information, which will widen the understanding of the context and improve the quality of the services.

Limitations

Due to the availability of limited studies or reports that have data to compare the situation in earlier

times, especially of no treatment era and monotherapy era, in the present study, only selected more relevant characteristics of social well being were included, which is one of the limitations of the present article. Some indicators such as economic status and sexual well-being have not been analysed in the present study. Lack of retrospective or evaluation studies that compared the social wellbeing at different times was another limitation. The inclusion of more aspects and literature might have widened the understanding of the context and improved the quality of the study.

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