

Original Article

Research on Social Aspects of Leprosy: A Comprehensive Analysis of 11 Year Publications of Indian Journal of Leprosy

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ABSTRACT

Research is an essential aspect of any problem, as research findings provide the knowledge and understating, further engage the people towards the solution. Research findings help to advocacy and mass movements, policy intervention and most importantly, provide future studies direction with more funding possibilities. In the case of leprosy, a highly stigmatised disease, it has a long and cruel history of human suffering, signify the importance of extensive research and a more comprehensive aim in solving the problem and making the lives of affected people less miserable. This study attempted to create a profile of research published (from 2010 to 2021) in the Indian Journal of Leprosy. It is one of the oldest journals of leprosy and a favourite stall of many eminent researchers and practitioners. The themes that emerged in the analysis are expected to provide a roadmap for future studies towards contemporary or left out social issues of Leprosy.

Keywords: Comprehensive analysis, Indian Journal of Leprosy, research, social aspects of leprosy.

INTRODUCTION

Leprosy, a disease believed to be as old as humankind and civilisation, is also known for tormenting humans throughout history and is a leading cause of human suffering. The way it affects the physical, mental, and social well-being of affected people, makes the disease unique and stands out from the list of other infectious diseases. Previously, a chain of infection-stigma, hiding illness, disability, debaillation, and ultimately becoming active spreader of infection was quite common. Other factors such as lack of treatment and understanding were the primary causes for fear among people, resulting in a larger number on the street with wounds and sanies on the body; because of lack of knowledge and research, the

disease was primarily considered as divine curse because of sins in current or previous life.

Hensen's scientific research finding in 1873 *Mycobacterium leprae*¹ has flipped the coin from orthodox belief to science. *M. lepromatosis* evident as the cause of disease and leads to more research towards the development of treatment, resulted in treatment, prevention, and surgical correction of disabilities. It was when leprosy jumped into the lap of the biomedical model backed by germ theory, from being a matter of morality, sins, and God's curse, the primary focus shifted on the development of treatment and diagnostic. Soon, the need was felt that leprosy requires a comprehensive approach; researchers started acknowledging and exploring the socio-cultural cause and implications of leprosy and possible intervention to change the behaviour and perception of people. Since then, a lot has been achieved. Thousands of articles and their findings speak in volume that we have already crossed the half-mile; remaining will soon be achieved by active engagement in practice and research on left out issues, both social and medical, of leprosy-affected people.

Research is essential, whether the intention is to understand or solve the problem. The need for research in leprosy requires no justification, Hansen's *M. Leprae* discovery was itself a research that opened the possibility for treatment and provided a more scientific understanding about the disease leprosy. Over the years, thousands of manuscripts have been produced, as leprosy has always been a prime subject of interest for researchers from many fields, medical and social scientists are to name here. In this regard, the Indian Journal of Leprosy (IJL) has played a vital role by helping researchers produce quality work, IJL being as a depository of both medical and social advancements in leprosy, not only in India but all over the world.

About IJL: IJL was started in the British India period, in July 1929. Over the years, it gained high popularity among researchers, and received high citations, and was renamed as Indian Journal of Leprosy in January 1984. Since then it is known as the Indian Journal of Leprosy, IJL for short. The journal is producing high-quality empirical/reviews, case studies, and editorial articles dealing with the fundamental and applied aspects of leprosy in primary and other mycobacterium diseases. By continuing efforts to ensure quality and publication ethics, the journal has become a voice of the Indian anti-leprosy movement and took a remarkable position in the global scientific community. It is considered one of the best publications on leprosy, published quarterly in four issues, English language, on psycho-social and biomedical aspects.

METHOD

This analysis was carried out with the aim to create a profile of the research studies on social aspects of leprosy published in the Indian Journal of Leprosy (IJL) from 2010 to 2021. During this period, numerous (both aspects biomedical and social) studies have been published by the eminent academicians, researchers, and policymakers. A complete list of papers published by the Journal is available on the website (www.ijl.org.in). Full articles were accessed and downloaded in the pdf. Out of complete publication, 54 were on the social aspects, fifty-three on leprosy and one on tuberculosis. Papers were thematically analysed to assess the trend, aspects covered, design, and methodology of the study, applied contemporary relevance, and research gap in leprosy research.

RESULTS AND DISCUSSION

Thematic analysis revealed that studies published in IJL had covered several social aspects related to leprosy and leprosy-affected people, but an absolute lack of some aspects is apparent. A large number of studies focused on the knowledge, attitude, and practice related to leprosy among patients, masses or health care practitioners. Studies were broadly classified in below discussed theme; however, many studies talked more than one aspect or theme.

Knowledge, attitude, and practice (KAP) : Out of all, 11 articles focused on the KAP and other associated or similar aspects. These studies covered many factors, such as Rajkumar et al² and Prakash Kumar et al³ studied knowledge and attitude of nursing and physiotherapy students towards leprosy^{2,3}, respectively. Rajkumar et al³ reported

that students who received training in leprosy hospitals showed higher knowledge than others.² Kanodia et al⁴ studied school student's KAP towards leprosy⁴; Leena and Priya⁵ in their study found that final year medical students have better knowledge and attitude than others.⁵ Annamma⁶ examined knowledge and attitude among non-formal healthcare providers. The study reported that more significant (80%) non-formal healthcare providers considered leprosy as a non-infectious illness, and only 20% were aware of MDT.⁶ Grewal et al⁷, Sharma et al⁸, and Govindharaj et al⁹ studied the KAP in community settings among ordinary people. Grewal et al⁷ reported from their slum based sample that only 33.3% were aware of the report and its causes. Sharma et al⁸ wrote that 17.1% of general people knew that leprosy is infectious, and 58.5% had knowledge about leprosy.⁸ Recently, Govindharaj et al⁹ reported that a significantly larger portion were not aware of the cause and mode of transmission; however, 84% believed to know that disease is curable. Two articles from the year 2014^{10,11} and one article from 2015¹² studied the KAP among patients and their family members. While Stephen et al¹⁰ concluded that the patients and their family members have average knowledge of leprosy, Saha et al¹² concluded that the place of residence and level of education attributed to better knowledge, and Seshadri et al¹¹ found that higher education is a positive predictor of knowledge and attitude.

Disability and its related social aspects: Eight studies focused on the disability and its associated social and psychological factors, out of these eight, two^{13,14} are from Brazil; four from India¹⁵⁻¹⁸, and two studies^{19,20} from Indonesia. Moura et al¹³ studied the physical impairments and psychological disorders and the value of rating scales in assessing disabilities. Based on the findings, they concluded that the screening of activity limitation and self awareness and Hamilton Scales are most efficient in measuring the change in the status of patients after completion of multi-drug therapy (MDT). Calixto et al¹⁴ concluded from their findings that pain is associated with difficulties in performing daily living activities; however, physical deformities do not seem to cause significant impediments in work or daily activities. Ishore et al¹⁵ found that utilisation of disability prevention services is poor. Disability was highest among cases aged 60 years or above; no disability was seen in cases less than 15 years of age; the overall proportion of disabilities among newly diagnosed patients was unacceptably high in the study sample. Moturu et al¹⁶ concluded from their findings that

delay is responsible for defaulting, deformity, and debilitation, while defaulting is responsible for deformity and debilitation; further deformity is responsible for the delay, defaulting, and debilitation, subsequently. They added that there is a need for a three-arm social multidrug therapy similar to the medical multidrug treatment, where there would be one arm for curing the medical problems of leprosy, a second arm focusing on empowering the people, and the third arm for advocacy and peoples' full participative involvement. Malviya¹⁷, in his article, based on the changing definitions and concept of deformities in other diseases, emphasizes the need for studies to understand and develop a better understanding; concerning the role of physical, social, cultural, and political environment and disability related to leprosy. Kumar et al¹⁸, based on the study findings concluded that the disability percentage in new cases declined steadily, and the absolute number indicates the better situation. Mahardita et al¹⁹ studied the disability and dropout from treatment and based on their findings concluded that social stigma and motivation for healing are associated with disability and dropout among leprosy-affected people; and indicate the need for a comprehensive care plan for leprosy-affected people. Utama et al²⁰ studied the degree of disability and quality of life, and based on findings they reported that the level of disability was found to be related to the quality of life of patient released from treatment, as disability leads to a negative response in their life, this affects the quality of life; they concluded that improvement programs are required with quality of life, especially for those with disabilities.

Women, children, and older people: Out of four studies, one study by Olivera et al²¹ studied distribution of leprosy in elderly patients in an endemic area.²¹ However, their study was mainly focused on describing the distribution; no social aspects were studied, it only focused on the elderly. Similarly, Solanki et al¹² study is unique, as it is the only study that explored leprosy among adolescents. However, their research focused on leprosy, deformities, reaction, and family history. Based on the facts and findings, they concluded that more studies are required on leprosy among adolescents to understand the aetiology psycho-social effects of the disease. Devi et al²³ studied childhood leprosy, and based on findings concluded that zero disability in all patients is possible because of early treatment seeking behaviour of the population in Kerala, leading to early diagnosis and treatment and prevention of deformities development. Verma et al²⁴ was the only study

that focused on women; however, they primarily analysed women's participation in National leprosy Eradication Programs and concluded that the rural Indian women are keen to play in leprosy eradication, and in a community-based approach with minimum support required from government and non-government agencies.

Interventional studies: Three articles, the most recent was Raju et al²⁵, conducted a community based participatory research in a rural setting of Uttar Pradesh; they aimed to experiment and mobilise community action against leprosy stigma. The authors concluded that community action is the ultimate means of achieving success in stigmatised diseases programme. Kumar et al²⁶ reported the effectiveness of SLAC (Sparsh Leprosy Awareness Campaign) and found a significant shift in the understanding of people about leprosy after SLAC inter-vention. Mishra and Sharma²⁷ reported findings of care and concern camps organised over three decades; the methodology of those camps was based on the cohesive action by patients, providers, and people; based on the findings, they concluded that these camps are highly effective in social, behavioural change, and can be adopted in other contagious illness such as HIV/AIDS.

Human rights violation: Two studies, Dwivedi²⁸ from India and Susanto²⁹ from Indonesia, studied and reported the human rights violation and protection of leprosy-affected people. Dwivedi reported that affected people are isolated and discriminated in their family and community, medical personnel also showed hesitancy in providing health care to them.²⁸ Susanto²⁹ concluded from their study that minimizing the impact of inequality in the protection of leprosy patients is highly desirable.

Economic aspects: Two studies attempted to analyse the economic aspect of leprosy, Majumdar³⁰ from India and Ganeza et al³¹ from Indonesia. Majumdar concluded that the overall socio-economic conditions of leprosy-affected people are deplorable and unsatisfactory. Ganeza et al³¹ figured that the family economic condition is directly associated with the occurrence of new cases in their sampled population. However, both study findings cannot be generalised to larger populations, but both provided more clarity to the situation.

Post-treatment follow-up studies: There were two studies, Vieira et al³² from Indonaesia, and Sharma et al³³ from India, Himachal Pradesh based sample. While Sharma et al³³ only focused on the post-treatment health complications. Vieira et al³² reported health complications

and social issues; they found 60.48 % of sample people had activity restriction; they concluded that decreased social participation was more evident among people who have economic limitations, visible physical deformities.

Stigma: Three publication by Silva et al³⁴ from Brazil, Sinha et al³⁵ and Rao³⁶ from India, studied and reported the issues of stigma; however other studies gave minimal attention on this issue. While Silva et al³⁴ based on their data concluded that patients are stigmatised, sometimes they hide from their relatives, friends, and neighbours, and they believe that their isolation is essential and justifiable. Sinha et al³⁵ concluded that participants' restriction was positively correlated with disease duration and negatively correlated with education.³⁵ Rao, in his article, compared leprosy stigma with the other stigmatised illness.³⁶

Participation restriction and debilitation: Two articles broadly covered these aspects, Bhat et al³⁷ studied the role of debilitation on the health of Leprosy patients in terms of anxiety and depression, and based on their findings, they concluded that social un-acceptance is the major and foremost reason which plays a crucial role in debilitation among leprosy patients other than the disease itself, and social dysfunctions are the primary cause behind the anxiety and depression among patients. David et al³⁸ studied the factors behind the participation restriction of leprosy patients, and based on the findings, they concluded that participation restrictions are highly influenced by education and type of occupation in most of the states of India, and other factors such as gender, age, locality and disability have a moderate role; more social factors such religion and caste were found to have no influence on participation restriction of leprosy patients. Raju³⁹ studied the factors associated with debilitation, through qualitative analysis, based on the findings, he concluded that the delay in diagnosis, economic and financial problems, default from treatment, the embarrassing look of dressing of ulcer, misinterpretation of leprosy as mental illness, and lack of immediate improvement after taking MDT are a few responsible factors for patients' debilitation.

Health and treatment seeking behavior: Three studies^{40,41,42} analysed the health-seeking behaviour of leprosy patients. Balegar et al⁴⁰ reported that one patient diagnosed with leprosy went to a faith healer and six to Homoeopathic and Ayurvedic clinics. Kumar et al⁴¹ concluded that urban patients seek a longer duration of help from Homoeopathic than rural patients before taking help from allopathic medicines. There is a considerable delay in

starting MDT after noticing the first symptom of leprosy. Samraj et al⁴² reported from their sample that the mean delay was 25.9 months, and the reason for the delay was ignorance and monitoring and hope those symptoms will disappear by themselves. Lack of vigilance among local medical practitioners in the lower levels of the health system was also a cause behind the delay in diagnostic and treatments.

Other themes: Eight studies focused on the different aspects, such as Verma et al⁴³ and Raju et al⁴⁴ studied the public awareness and medical social concerns of leprosy after integration of leprosy services in public health care, both studies suggested the requirement of people educating and bridging gap between leprosy communities and public health care system. In other themes, Sharma and Saxena⁴⁵ studied the health status of affected people staying in rehabilitation colonies; based on their data, they concluded that affected people's socio-economic and health status is inferior, primarily illiterate, disabled having commodities. Thilakavathi et al⁴⁶ reported the community views on acceptance with relevance to leprosy control. Based on findings, they concluded the need for person-centred social treatment and increased case detection rate to counter the case occurrence and address the issues. Sanyal et al⁴⁷ studied the physical and psychological determinants of social functioning in leprosy. Their findings concluded the need for psychosocial intervention strategies to improve social functioning in leprosy patients. Shyam Sunder et al⁴⁸ studied the impact of race on leprosy-affected person's experience in diagnosis and treatment in a Brazil based sample; they found that racism causes inequality and hinders patient access to treatment care. Palo et al⁴⁹ studied the role of reconstruction surgery and improvement in quality of life. They concluded that the awareness of the importance and acceptance of reconstructive surgery would help improve the quality of life of leprosy cases, especially with deformities. They also noted that the improvement in self-confidence and satisfaction level at social and vocational levels would also help reduce stigma and increase social acceptance. Pitchaimani et al⁵⁰ constructed and validated an instrument (LFSS Leprosy family support scale) for measuring family support among leprosy-affected people. They reported that their scale has acceptable validity and reliability; other researchers and government programs can use it.

DISCUSSION ON RESEARCH GAP

Many but not all aspects explored: Studies have evaluated a significant number of areas related to social

aspects of leprosy and leprosy affected people; however, lack is apparent on some very crucial aspects such as leprosy among adolescents and its consequences on their psycho-social development, acceptance in school, among peers, in family, kins, and relatives. Similar studies are required on women and the elderly population, their acceptance, participation, and dehabilitaion after being diagnosed with leprosy. Suppose these social issues are still in practice, where do these impoverished people stay after dehabilitaion and manage their food and other daily living activities. We also need to explore leprosy in tribale, schedule caste, and minorities population, and their issue and experiences living with leprosy in everyday life. There is an absolute lack of studies on sexual wellness and health among leprosy people. Empirical data and, most importantly, case studies are desirable before and after the diagnosis of leprosy and family economic crisis. Until each and every aspect is not covered with a proactive attitude to change data findings into practice, no research will do justice to those affected people living on the social and economic outcasts.

Research method and design used: Cross-sectional studies are in the majority, lack of longitudinal research is apparent, only three with intervention, even those used intervention did not use experimental methods such as RCT or quasi-experimental. Such as the study of Raju et al²⁵, if used an experimental design (RCT/Q-Experimental), the result would have been more valid and reliable, as the non-experimental design always left a space for doubt. Experimental studies not only eliminate the confounding variables but enhance the reliability and validity by reducing certain biasness. Similarly, if any of these studies used the retrospective or prospective longitudinal, produced results would have comprehensive aspects covered. Cross-sectional studies are convenient and undoubtedly valuable but fail to answer 'how it was yesterday' and 'what will be the result/outcome tomorrow'. Disease leprosy has both a long history to retrospect and a future to prospect.

The conclusions/suggestions made are not in practice: Sociological studies seems like failing in their ultimate aim to provide solutions and change the phenomena; as biomedical studies do, Hensen findings not only discovered the cause of leprosy, provided future studies with a road map towards new knowledge and discoveries, and ultimately benefited people affected with leprosy. Of course, social research does have that potential, but self vs mass interest, lack of will to engage in the community-

level practice, and tendency to research, conclude and end the process by notifying only, is not only taking a toll on people benefits from research, also hindering social investigations from reaching its capacity. Many of these studies cited and discussed above have made very noble conclusions and suggestions; if implemented and taken into practice, it would have changed the whole scenario.

Limitations: Only publication in IJL are used in the analysis; studies are classified organised based on their broad aim and themes; many studies have also given due respect to other similar issues in the text, but very superficially; hence, thematic analysis carried out considering only the broad aim of the studies that appear through the title and abstract of the study. The one question arises why only IJL when there are other journals, lepra review, to name. A close look at the authors, explicit that same or people with similar profiles, published in both journals; hence, analysing only one journal publication will not suffer injustice to the subject.

CONCLUSION

The themes that emerged and the research gap identified and discussed concluded that research on the social aspects of leprosy requires a more comprehensive approach. Researchers are required to choose the subject/issue of contemporary requirement and usefulness of findings in future research, intervention, policy, and practice for the real benefit of leprosy-affected people and more updated methodology and design, experimental research is highly desirable.

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