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LEPROSY AND ITS SOCIAL STIGMA: A COMMUNITY PERSPECTIVE

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ABSTRACT:

INTRODUCTION: Leprosy was and is one of the major stigmatizing conditions affecting multiple facets of a patient's life. Much of this burden is owed to patients' own family, the community, health care workers and even themselves. The consequences of stigma are pervasive, affecting not just the physical health, mental well being and health seeking behavior, but also having significant impact on social interactions, marriages and employment. Thus this disease of antiquity has major economic implications even in the 21st century.

OBJECTIVE: To explore the prevalence of stigma against leprosy among community members in Hyderabad, Telangana, India.

MATERIALS & METHODS: Data was collected over a period of 12 months from April 2022 to March 2023. Demographic details were collected and participants were administered two standardized questionnaires - STIGMA – EMIC (community version) - Explanatory Model Interview Catalogue - and the Social Distance Scale. Results are expressed in numbers and percentages for each category.

RESULTS: Out of 108 participants 48% were female, 47% were male and 5% -identified as other. 56 participants were of the age group 26 to 35 years, 32 were of 36 to 50 years old and 120 of 51 to 65 years old. 52 of the participants held a professional degree. The others were illiterate, Primary School, Middle school, High School, Intermediate / Diploma holders and Graduates. Almost 60% of respondents said that a person with leprosy would hide their condition, it causes shame or embarrassment and people in their community would avoid them. 42 % thought less of a person with leprosy, 45% said having leprosy would cause difficulty for a person to find work and would refuse to visit their home. 60% of the participants said that they would dislike buying food from them, 73% said leprosy would be a problem for a person to get married, 62% said having leprosy could cause problems in an ongoing marriage, 41% said it could cause problems for the relatives of a leprosy patient to get married, 45% did not want their children to marry someone with Hansen's or introduce them to a prospective bride/groom. A few encouraging findings that we discovered were that more than 60% said that they would recommend someone with leprosy for a job and did not think less of themselves if any of their family members had leprosy. More than 50% did not mind renting out a room in their home to them, being their neighbor or co-worker.

DISCUSSION: Our participants belief that patients with Leprosy might conceal the disease, unwillingness to enter their home or buy food from them are all indicators that Hansen's is still very much a stigmatizing disease with wider implications such as hesitant health seeking behavior leading to delay in diagnosis, treatment and subsequent disability development. A leprosy affected person or their family member experience difficulties in finding a partner and thus marriage, even an ongoing one, as seen in our study. The degree of stigma experienced by a person with Hansen's are also be influenced by various factors such as socioeconomic status, education and especially gender, where we see more incidence of cancellation of marriage after knowing the leprosy status, difficulty finding partners, divorce, sexual abuse, and domestic violence among female patients. A few of the more encouraging findings from our study was that people are willing to recommend someone with leprosy for a job and did not think less of themselves if any of their family members had leprosy. Neither did they mind being their neighbor or co-worker. Thus we see that while people are more open to providing jobs and homes to those afflicted, they are certainly unwilling to welcome them into their own families.

INTRODUCTION

Many health conditions are associated with social stigma, including epilepsy, mental illness, disability, and infectious diseases such as HIV/AIDS, tuberculosis, leprosy, lymphatic filariasis, and Buruli ulcer. Stigma occurs when "labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them" [1]. Stigma is characterized by social exclusion or separation, rejection, blame, and loss of status of an individual or group [1,2].

For many stigmatized individuals, the psychosocial consequences of their health condition are harder to bear than the physical consequences [3,4]. Stigma is associated with poor psychosocial health outcomes such as reduced quality of life, low self-esteem, depression, and social exclusion [3,5]. This is also the case for persons affected by leprosy who experience stigma [6]. Leprosy is an infectious disease that primarily affects and damages the peripheral nerves and skin, which can result in disabilities [7,8]. Leprosy has had a very negative image for hundreds of years and is known for being a very stigmatized condition [9]. Leprosy and its stigma may affect different areas of a person's life such as mobility, social relationships, marriage, employment, and social participation [4].

Stigma and discrimination can lead to stress, anxiety, depression, suicide, isolation, and problems in the interpersonal relationships of persons affected [4]. Stigma in leprosy can also worsen already existing social inequalities due to age, gender, and social class or status [10]. Stigma, as well as a lack of knowledge about leprosy, are obstacles to case finding and adherence to treatment [11,12] and therefore reduce the effectiveness of leprosy care and control activities [4,13]. In an attempt to hide their disease and prevent discrimination, stigmatized individuals often delay seeking treatment until they develop permanent, visible disabilities [8].

When people delay seeking treatment, transmission of the disease is prolonged, which hinders the treatment and prevention of the disease. To improve strategies for early case detection it is essential to enhance the knowledge of leprosy and reduce stigma. Many factors contribute to the stigma of leprosy, including fear of transmission and contagion, the visible manifestations such as deformity and disability in persons affected religious and cultural beliefs regarding the causes and treatment of leprosy [12,13].

Knowledge about leprosy is crucial in stigma [14–18]. Local (mis)beliefs, such as the beliefs that all leprosy patients end up with disabilities, that leprosy is not curable, or results in death or that implies that the person affected has done wrong and brought the disease upon himself all contribute to stigma [13,14,18–23]. Research showed that personal characteristics such as gender [15,16,22,24], occupation [16,22,24–26], years of education [15–17,22,25], age [15,25,27,28] and living areas [15,24,27,29,30] are associated with community stigma against persons affected by leprosy.

Although knowledge, attitudes, and practices regarding leprosy have been studied extensively and different determinants of knowledge and community stigma have been identified, we lack consensus about determinants of stigma and insight into how we can change negative perceptions and stigmatizing local beliefs about leprosy. Insight into the dynamics, differences and commonalities in knowledge, attitudes, and practices between leprosy-endemic countries can help us to better target interventions to improve the knowledge and perception of leprosy, and thus reduce stigma. This study aims to examine the differences and commonalities in and determinants of knowledge, attitudes, practices, and fears regarding leprosy in leprosy endemicdistricts in India

MATERIALS & METHODS

Ethical approval for this study was obtained from the Institutional Ethics Committee of Osmania Medical College. All participants were fully informed about the nature, objectives, and procedures of the study, their rights, and of confidentiality of the data before data collection. Written consent for participation in the study was obtained from each participant.

Study design

The study used a cross-sectional research design with a mixed methods approach. Interviewer-administered questionnaires included demographic characteristics and knowledge and attitudes of people towards (persons affected by) leprosy. In-depth information was obtained using semi-structured interviews and focus group discussions.

Study population and sample

The study group which was included in the study was community members. We aimed to include a random sample of at least 100 persons for the interview-administered questionnaires. These participants were to be a subset of those in the quantitative sample.

Eligibility criteria

Participants needed to be inhabitants of one of the districts of Telangana. Persons below the age of 18 and persons unwilling or unable to give informed consent were excluded. Potential participants were also excluded if they were or had ever been diagnosed with leprosy.

Sampling methods

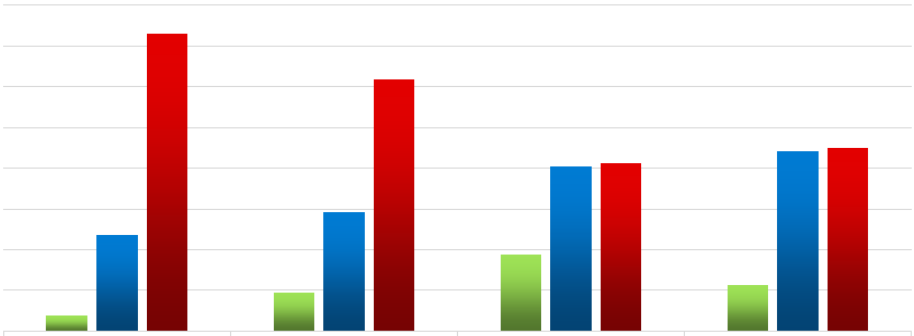
Participants for the interview-administered questionnaires were selected as follows. The persons affected were selected by stratified systematic sampling with a random start from a list of patients attending the regular Outpatient services at the department of Dermatology, Venerelogy and Leprosy. The participants for the qualitative interviews were a subset of those in the quantitative sample.

Data analysis

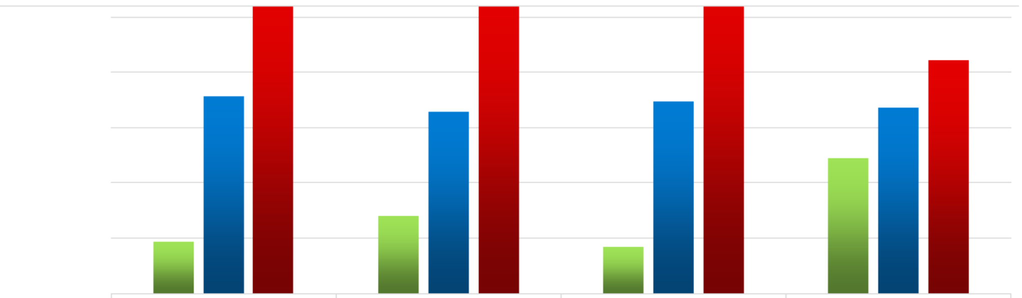
Quantitative data analyses were performed in SPSS version 24. Simple descriptive methods were used to generate a demographic profile of the study sample. Stepwise multivariate regression with backward elimination was done to investigate the contribution of potential determinants (age, gender, participant type, education, occupation, knowing someone affected by leprosy, and district) to the outcomes of interest (knowledge, stigma, and social distance). Qualitative data analyses were performed in Nvivo version 12, Microsoft Word, and Microsoft Excel. All records were anonymized before analysis.

RESULTS

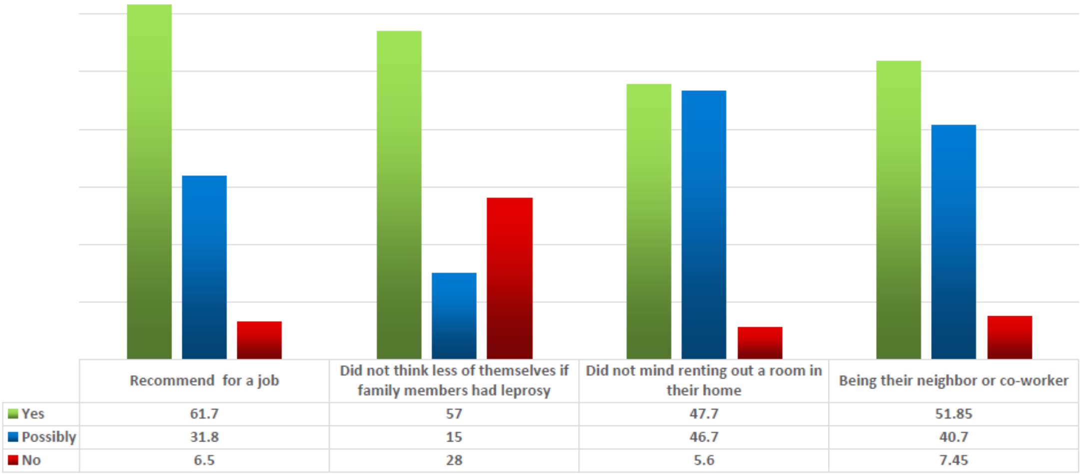
Out of 108 participants 48% were female, 47% were male and 5% identified as other. 56 participants were of the age group 26 to 35 years, 32 were of 36 to 50 years old and 120 of 51 to 65 years old. 52 of the participants held a professional degree. The others were illiterate, Primary School, Middle school, High School, Intermediate / Diploma holders and Graduates. Almost 60% of respondents said that a person with leprosy would hide their condition, it causes shame or embarrassment and people in their community would avoid them. 42 % thought less of a person with leprosy, 45% said having leprosy would cause difficulty for a person to find work and would refuse to visit their home. 60% of the participants said that they would dislike buying food from them, 73% said leprosy would be a problem for a person to get married, 62% said having leprosy could cause problems in an ongoing marriage, 41% said it could cause problems for the relatives of a leprosy patient to get married, 45% did not want their children to marry someone with Hansen’s or introduce them to a prospective bride/groom. A few encouraging findings that we discovered were that more than 60% said that they would recommend someone with leprosy for a job and did not think less of themselves if any of their family members had leprosy. More than 50% did not mind renting out a room in their home to them, being their neighbor or co-worker.



	Problem for a person to get married	Problems in an ongoing marriage	Problems for the relatives of a leprosy patient to get married	Did not want their children to marry someone with Hansen’s
🟩 No	3.7	9.3	18.7	11.2
🟦 Possibly	23.4	29	40.2	43.9
🟥 Yes	72.9	61.7	41.1	44.9



	Hide their condition	Causes shame or embarrassment	People in the community would avoid them	Thought less of a person with leprosy
🟩 No	9.3	14	8.4	24.3
🟦 Possibly	35.5	32.7	34.6	33.6
🟥 Yes	55.1	53.3	57	42.1



	Recommend for a job	Did not think less of themselves if family members had leprosy	Did not mind renting out a room in their home	Being their neighbor or co-worker
🟩 Yes	61.7	57	47.7	51.85
🟦 Possibly	31.8	15	46.7	40.7
🟥 No	6.5	28	5.6	7.45

DISCUSSION

Our findings identified three main drivers of stigma: (1) poor knowledge and misconceptions about leprosy, (2) local beliefs, and (3) fear of contagion.

Poor knowledge and misconceptions

Lower levels of knowledge of leprosy were associated with higher levels of social distance, a proxy for fear and stigma in the community. Lacking knowledge about leprosy is more often found to be associated with negative attitudes towards persons affected by leprosy [14–18]. Misconceptions such as that leprosy is transmitted by touch, a prominent belief among participants from India in the present study, increase stigma. These misconceptions are often linked to fear of the disease and fear of transmission [13,20,38,39]. To reduce stigma these misconceptions need to be addressed and challenged and knowledge needs to be increased. This is also crucial to improve strategies for early case detection since a lack of knowledge of leprosy is a major contributing factor to late diagnosis [7].

Local beliefs

Interestingly, even though the questions related to knowledge were answered correctly the local beliefs, especially considering the cause and mode of transmission, varied by area of residence. This confirms findings from other studies that showed that (socio)cultural beliefs about leprosy can increase stigma [13,14,18–23]. We found several local beliefs that can be addressed, such as the belief that leprosy has been in the family for seven generations, that a cause of leprosy is that a woman conceives while having sexual intercourse during her period that leprosy has a supernatural cause and that persons affected by leprosy are untouchable .

Some studies have suggested that these beliefs are influenced by religious beliefs and religious teachings about leprosy [13,19,20,40]. We hypothesize that the local beliefs in the present study have to some extent also been influenced by religion and religious practices.

Fear of contagion

A third important driver of stigma found in the present study was that people were afraid of getting infected with the disease. This is something found in other studies also [13,20,38,39] and something that should receive specific attention when designing leprosy campaigns. The present study found that community members had the highest stigma levels This may be explained by their poor knowledge about leprosy, something that has been associated with higher levels of stigma towards persons affected by leprosy in other studies also [14–17]. The image that community members have of persons affected by leprosy is likely not based on knowledge from personal contact, but on incorrect information and negative beliefs. The present study reported mean stigma scores (EMIC-CSS) ranging from 11.8 (contacts) to 17.4 (community members), which is above the cut-off score for perceived stigmatization of 8, as proposed by

Sermrittirong and colleagues [45]. This confirms findings in Indonesia, Brazil, Thailand, Nepal, Nigeria, and New Zealand (mean or median EMIC-CSS scores ranging from 12 to 18) [14,16,22,25,28,45–48].

Desired social distance towards persons affected by leprosy, how close one is willing to be towards an affected community stigma (EMIC-CSS) score, their mean social distance (SDS) score was about the same as that of community members. We expect that the difference between stigma and social distance scores of close contacts can be explained by the way the questions are asked. In the EMIC-CSS respondents are asked how 'others' feel or behave, while in the SDS respondents are asked how they would feel relating to the person portrayed in a vignette.
Thus, the SDS assesses personal attitudes and fears and the EMIC-CSS perceives attitudes and behavior of others.

Several determinants of stigma have been identified in other studies, including knowledge of leprosy [14–18], (cultural) beliefs [13,14,18–23], female gender [15,16,22,24], occupation [16,22,24–26], fewer years of education [15–17,22,25], older age [15,25,27,28], knowing a person affected [28], religious beliefs [13,19,20,40], and living areas [15,24,27,29,30]. We included almost all of these determinants, except for living area and religion, and found that together they explained very little of the variability in the level of stigma (7% on the EMIC-CSS and 10% on the SDS). We expect that 'local beliefs' and local explanations play an important role in knowledge and stigma and that these explanations vary by area of residence. Furthermore, some studies have found additional determinants of stigma, such as having seen a leprosy patient [21],

Interventions to improve the knowledge and perception of leprosy

Our findings indicate the need for effective interventions to positively influence the perception of leprosy and improve knowledge of leprosy. We believe our findings of local differences in knowledge gaps, misconceptions, beliefs, and fears indicate that interventions should be culture--specific and contextualized [54,55]. This is expected to be much more effective in increasing positive attitudes and acceptance of persons affected by leprosy than generic messages [40]. We believe our knowledge findings indicate that certain topics should be prioritized in health education in our countries: cause, mode of transmission, early symptoms, and contagiousness of leprosy. These findings also show that some messages may be important as such, but do not have to be prioritized at the moment: knowledge about the treatability of leprosy was good . This is likely a reflection of the messages in past government education campaigns. While knowledge gaps can be addressed by information, attitudes, beliefs, and fears require an additional approach. Changing knowledge and perceptions is best done as a combination of health education and behavioral change interventions [56,57].

CONCLUSION

Our study revealed poor knowledge regarding leprosy, especially regarding its cause, mode of transmission, early symptoms, and contagiousness of leprosy. Knowledge about treatment and treatability was good. Stigma levels were high in both countries and were driven by poor knowledge and misconceptions about leprosy, local beliefs, and fear of contagion. These findings show the importance of investigating the perceptions regarding leprosy in the communities targeted for educational interventions. Local misconceptions and beliefs, especially around the cause and mode of transmission of leprosy. Contextualized health education and behavior change interventions are required to improve knowledge, reduce misconceptions, and positively influence the perception of leprosy. Interventions should address specific knowledge gaps, beliefs, and fears. Despite the advancements and availability of treatment, the various preventive and rehabilitative measures undertaken by the government, the burden of stigma was found to be still substantial. Hence, more rigorous awareness programmes and educational activities need to be undertaken at all levels of health-care to provide an inclusive environment for those with Hansen's to lead a fulfilling life.

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