Perception toward the Disease of the People Affected by Leprosy

Pitchaimani Govindharaj¹, Sampathkumar Srinivasan², Joydeepa Darlong³
¹Department of Sociology, Bharathidasan University, Trichirappalli, ²Department of Sociology and Population Studies, Bharathiar University, Coimbatore, Tamil Nadu, ³Knowledge and Management, The Leprosy Mission Trust India, New Delhi, India

Abstract

Background: This study aimed to explore the disease severity perceived by people affected with leprosy reporting at leprosy referral center, Purulia, West Bengal, India. Methods: A cross-sectional study was conducted among 358 persons affected by leprosy above the age of 18 and married who were reporting at tertiary leprosy referral hospital, Purulia, West Bengal, India. A semistructured questionnaire was prepared to collect the demographic profile, disease profile, and perceived severity of the disease. Results: Among the participants, 41% were female, 60% were aged between 18 and 45 years, 58% were literate, and 40% of the participants had physical disability. The participants had multiple feelings of fear, anxiety, and sorrow when first diagnosed as leprosy affected. Majority (69%) of the participants had fear of the disease. A significant association was present among males and females feeling fear of leprosy and the female feared more than male. Conclusion: The present study emphasizes the need for continuous counseling and health education for persons affected with leprosy to avoid or minimize the psychological problems. Periodical screening and counseling will improve their psychosocial well-being and quality of life.

Keywords: Disability, disease severity, leprosy, purulia

Introduction

Leprosy is a chronic infectious disease caused by Mycobacterium leprae and remains a major public health problem in India.¹ India accounts for the highest number of persons affected by leprosy with about 135,485 new cases detected in 2017¹ and accounts for over 63% of the global leprosy burden.² Still, it is a stigmatized disease mainly because of its potential to cause disability in a small proportion of those affected and is a cause for social stigma and discrimination.³ Physical disabilities caused by the disease resulted in enormous psychological consequence and more possibility to get the worst quality of life.⁴⁻⁶ Perceived severity refers to the degree people deem a particular disease or condition is serious. Perceived severity includes how people perceive the deleterious consequences of a serious health event or outcome, such as a diagnosis of leprosy. Witte defines perceived severity as a person’s beliefs about the significance or magnitude of a health threat.⁷ The perceived severity of consequences may relate to an anticipated event that may occur in the future, or to an operant state such as a preexisting health problem. Hence, this study attempts to explore the disease severity perceived by leprosy-affected people reporting at leprosy referral center, Purulia, West Bengal, India.

Methods

A cross-sectional descriptive study was conducted with 358 individuals affected with leprosy who attended the hospital outpatient department from April to June 2017.

Study settings

The present study took place in a territory referral hospital, Purulia, West Bengal, India. The purulia district is endemic for leprosy.⁸

Participant eligibility

All adult persons affected with leprosy who were 18 years and above and diagnosed with leprosy at least for 1 year at the time

Address for correspondence: Mr. Pitchaimani Govindharaj, Department of Sociology, Bharathidasan University, Trichirappalli - 620 024, Tamil Nadu, India. E-mail: pitchu_mani83@yahoo.com

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of interview. A person who was living in leprosy colony were excluded from the study.

Semistructured questionnaire
A semistructured questionnaire was prepared to collect the demographic and disease profile along with the severity of the disease.

Procedure
A first author was assigned to recruit participants, describe the study to them, obtain informed consent, and perform the interview with assistants of trained field investigators. All interviews were conducted in vernacular language “Bengali.” The interview was conducted in strict privacy after building rapport with the participants, and precaution was taken to avoid the emotional distress of participants. In case of any emotional distress, the interview was terminated.

Approval of this study obtained from the Doctoral Research Committee members, Department of Sociology, Bharathidasan University and Research Committee of the Leprosy Mission Trust India, New Delhi. Participation was voluntary, and information was collected anonymously after obtaining written consent from each participant by assuring confidentiality throughout the data collection period. Data were entered and analyzed using SPSS version 23.0 (IBM, NY, USA).

Results
The participant’s details of demographic profile, disability status, and disease duration are described in Table 1. Of the 358 participants, 41% of them were female, 60% were aged between 18 and 45 years, 58% were literate, and 55% of them were laborers or farmers. Nearly half of them were living in a medium family size, and majority of their monthly family income was below Rs.5000. More than half of them had physical impairment (Grade 1; 18% and Grade 2; 40%), and 60% of their disease duration was more than 3 years.

Disease severity
The participants had multiple feelings when first diagnosed with leprosy. Two hundred and eighty-one (78.5%) of them felt fear; in addition, 58% had anxiety, 46% had sorrow, and 22% had embarrassment and also guilt (8%) and denial (2%) [Table 2]. Of the 358 participants, 69% had fear of the disease. Among the diseases listed, 56% had fear of leprosy and 25% for cancer [Table 3]. Reasons for fear are described in Table 4.

Figure 1 describes the disease severity perceived by the participants. Among the diseases such as AIDS, tuberculosis, cancer, diabetes mellitus, stroke, heart disease, and leprosy, cancer was perceived as the most severe followed by leprosy and AIDS. Less than one-fourth considered tuberculosis, malaria, heart disease, and stroke as severe.

A significant association was present among males and females afraid of leprosy, and the females were more afraid than male [Table 5].

| Status | Frequency (%) |
|--------|---------------|
| Age (years) |  |
| 18-30 | 69 (19.3) |
| 31-45 | 145 (40.5) |
| 46-60 | 111 (31.0) |
| Above 60 | 33 (9.2) |
| Gender | |
| Male | 212 (59.2) |
| Female | 146 (40.8) |
| Education | |
| Illiterate | 207 (57.8) |
| Literate | 151 (42.2) |
| Occupation | |
| Labor | 99 (27.7) |
| Farmer | 96 (26.8) |
| Housewife | 135 (37.7) |
| Others | 28 (7.8) |
| Family income | |
| Below Rs. 5000 | 270 (75.4) |
| Above Rs. 5000 | 88 (24.6) |
| Disability grade | |
| Grade 0 | 150 (41.9) |
| Grade 1 | 64 (17.9) |
| Grade 2 | 144 (40.2) |
| Disease duration (years) | |
| 1-3 | 144 (40.2) |
| 3-5 | 112 (31.3) |
| Above 5 | 102 (28.5) |

| Status | Frequency (%) |
|--------|---------------|
| Fear | 281 (78.5) |
| Anxiety | 207 (57.8) |
| Sorrow | 163 (45.5) |
| Embarrassment | 77 (21.5) |
| Blame | 28 (7.8) |
| Denial | 7 (2.0) |

Discussion
Today, leprosy is curable with multidrug therapy (MDT), and persons affected with leprosy are free from leprosy once they have regularly completed the course of MDT. However, unfortunately, the stigma attached to leprosy still persists due to visible deformities. Fear and worry about illness are closely linked to the concept of severity. According to tipping and Segall, the manner in which people perceive their disease and its treatment determines their health-seeking behavior. Perceived severity of leprosy depends mainly on the health consequences of disease and deformity, and consequences of psychosocial problems may lead to stigma and discrimination. As a result of stigma and discrimination, people affected with leprosy often experience
a loss of self-esteem and dignity and feel fear, shame, hopelessness, and guilt.[13] Studies have shown that these effects are greater in female than male patients.[14,15] Mankar et al. found that the persons affected with leprosy are aware more about the infectious nature of the disease, symptoms, transmission, and curability than the community members. However, a negative attitude was seen toward the persons affected with leprosy in the society.[16]

In this study, the patients had multiple feelings of fear, anxiety, and sorrow when first diagnosed with leprosy. Further, few were embarrassed and blamed themselves for contracting the infection. The females had more feared than males. Among the diseases such as AIDS, cancer, tuberculosis, heart disease, diabetes mellitus, and leprosy, half of them perceived leprosy disease as the most dangerous disease. Because they felt that the leprosy disease leads to deformity and difficulty to achieve a cure. However, half of them had an opinion that cancer is the most dangerous disease and it mostly leads to death.

Stigma can be categorized from the perspective of the affected person into internalized, perceived and experienced stigma.[17,18] Higher perceived disease severity may lead to internalized or perceived stigma among persons affected with leprosy. As a result of perceived stigma, people may adopt a first choice strategy of nondisclosure and concealment. This had been a deterrent in the early diagnosis, prompt treatment, and cure of leprosy in the earlier days.

Diagnosis at an early stage is absolutely essential for earlier treatment to prevent the leprosy-related disabilities and its benefit for termination or control of infection transmission. Stephen et al. observed that majority of the family members understood that leprosy was curable and the deformities can be prevented by early and regular treatment.[19]

**Conclusion**

The present study emphasizes the need for continuous counseling and health education to avoid or minimize the psychological problems for people affected with leprosy. Periodical screening and counseling will improve their psychosocial well-being and the quality of life.

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Conflicts of interest
There are no conflicts of interest.

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