

The Attitude of People Affected with Leprosy towards Fellow People Affected with Leprosy in an Endemic District, West Bengal, India

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Stigma-associated psychosocial problems are common in leprosy. Hence, this study aimed to measure the attitudes of people affected by leprosy towards fellow people affected by leprosy in an endemic district in West Bengal, India. A cross-sectional study was conducted among 358 people affected by leprosy above 18 years and married who reported at a tertiary referral hospital in Purulia, West Bengal. A structured questionnaire was prepared to collect the demographic profile, disease profile and attitudes towards the disease. The results revealed that 132 (37%) of the respondents allowed their children to play with a child affected by leprosy, and 279 (79%) of them would not allow their son/daughter to marry a bride/groom with leprosy. Two hundred and thirty-nine (67%) recorded that people affected by leprosy should not have a child, and 203 (57%) were unwilling to work with someone concerned with leprosy. Two hundred and five (57%) said they would not employ someone with leprosy. Further, the female respondents had adopted a more positive attitude towards having a child of their own by people affected with leprosy, willing to work with them and employ them. While gender, age and duration of disease had relationship with attitude, no such association was observed with disabilities. This study indicates the potential usefulness of improving the knowledge about disease through proper education and awareness and develop positive attitudes towards affected people.

Keywords : Attitude, Leprosy, Purulia, Stigma

Introduction

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* (Bratschi et al 2015). Leprosy is still a stigmatised disease and a public health concern mainly because of its potential to cause disability in a small proportion of those affected and is a cause for social stigma and discrimination (ILEP 2007). Leprosy results in not only physical problems but also mental, social and economic consequences (Scott 2000).

Fear is a major driving force of stigma, and

people fear mainly due to the negative social consequences of deformity and discrimination (Govindharaj et al 2018). In addition to the fear of infection, lack of knowledge and information, false beliefs about leprosy, ignorance about the disease, and feelings of shame and lower socioeconomic status are related to the stigma of leprosy (Nagaraj et al 2011; Govindharaj et al 2018). People still believe that leprosy is a divine punishment for past sins and immoral behaviour (Mishra & Gupta 2010). It leads to irrational

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behaviour towards the persons affected by leprosy (DeStigter et al 2000).

Despite being curable each year globally, over 2,00,000 new cases of leprosy are detected, and India accounts for more than 60% of the new leprosy cases globally (WHO 2019). Attitude is a learned predisposition to respond in a consistently favourable or unfavourable manner concerning disease (Fishbein & Ajzen, 1975). Attitudes help us to understand how people perceive leprosy, the disease, and diseased persons. Studies from India found that people had low levels of knowledge about leprosy and negative attitudes towards persons affected by leprosy (Gopalakrishnan et al 2021, John & Rao 2009, Seshadri et al 2014, Stephen et al 2014, Barkataki et al 2006, Grewal et al 2013, Danturty et al 2016). To our knowledge, very few studies merely have measured the attitudes towards leprosy among the persons affected with leprosy. Therefore, this study aimed to measure the attitudes of people affected by leprosy towards fellow people affected by leprosy in an endemic district of West Bengal, India.

Material and Methods

A cross-sectional descriptive study was conducted with 358 individuals affected by leprosy who attended the outpatient department in a tertiary referral hospital for leprosy, Purulia, West

Bengal, India, from April to June 2017. This study included all adult people affected by leprosy aged above 18 years and diagnosed as having leprosy at least for an year at the time of the interview. People who were living in a leprosy colony were excluded.

Structured questionnaire

A structured questionnaire was developed to collect the attitudes towards people affected by leprosy, along with the demographic and disease profile. The respondents' attitudes were measured by asking them questions, and it consisted of five questions (Table 1). It covered primarily; children affected by leprosy, marriage prosperous, childbirth, willingness to work with people affected by leprosy and employment opportunities. The response was recorded as binary data; 0= No, and 1= Yes.

Validity

The developed tool was evaluated by three health professionals who were experts in leprosy rehabilitation. Further, we purposively recruited five respondents to test the tool. An informal discussion was held with the respondents about their perceptions of the relevance and adequacy related to the concept of attitude towards people affected by leprosy. Based on their suggestions, the investigator drafted the tool and established the scale's validity.

Table 1 : Questionnaire to measure attitudes towards people affected with leprosy (n=358)

| Questionnaire to measure attitudes towards people affected with leprosy | | | |
|--|--|-------------------------------|------------------------------|
| 1 | If you had children, do you allow your child to play with a child affected by leprosy? | <input type="checkbox"/> -Yes | <input type="checkbox"/> -No |
| 2 | If you had children, do you allow your children to marry anyone affected by leprosy? | <input type="checkbox"/> -Yes | <input type="checkbox"/> -No |
| 3 | Do you think that person affected by leprosy can have children? | <input type="checkbox"/> -Yes | <input type="checkbox"/> -No |
| 4 | Are you ready to work with a person affected by leprosy? | <input type="checkbox"/> -Yes | <input type="checkbox"/> -No |
| 5 | If you are an employer, do you give a job to someone affected by leprosy? | <input type="checkbox"/> -Yes | <input type="checkbox"/> -No |

Procedure

The first author was assigned to recruit the respondents, describe the study to them, obtain informed consent and perform the interview

with the assistants of trained field investigators. All interviews were conducted in the vernacular language 'Bengali'. The interview was conducted in strict privacy after building rapport with the

Table 2 : Demographic profile and disease profile of the respondents (n=358)

| Status | Frequency | Percent |
|-------------------------|-----------|---------|
| Age | | |
| 18-30 years | 69 | 19.3% |
| 31-45 years | 145 | 40.5% |
| 46-60 years | 111 | 31.0% |
| Above 60 years | 33 | 9.2% |
| Gender | | |
| Male | 212 | 59.2% |
| Female | 146 | 40.8% |
| Education | | |
| Illiterate | 207 | 57.8% |
| Literate | 151 | 42.2% |
| Occupation | | |
| Labour | 99 | 27.7% |
| Farmer | 96 | 26.8% |
| Housewife | 135 | 37.7% |
| Others | 28 | 7.8% |
| Family Size | | |
| Small Family | 128 | 35.8% |
| Medium Family | 167 | 46.6% |
| Large Family | 63 | 17.6% |
| Family Income | | |
| Below Rs.5,000 | 270 | 75.4% |
| Above Rs.5,000 | 88 | 24.6% |
| Disability Grade | | |
| Grade '0' | 150 | 41.9% |
| Grade '1' | 64 | 17.9% |
| Grade '2' | 144 | 40.2% |
| Disease duration | | |
| 1 to 3 years | 144 | 40.2% |
| 3 to 5 years | 112 | 31.3% |
| Above 5 years | 102 | 28.5% |

respondents, and precaution was taken to avoid the respondents' emotional distress. In case of any emotional distress, the interview was terminated.

Ethical considerations

Approval from the Doctoral Research Committee members of the Department of Sociology, Bharathidasan University and the Ethics Committee of The Leprosy Mission Trust India, New Delhi, was obtained to conduct the study.

Data Analysis

The data were entered into the Microsoft Excel database and analysed using SPSS. The descriptive statistics were done for the demographic profiles, disease profiles and attitudes questionnaire. A Chi-square test was done to compare the attitudes with the variables of demographic and disease profiles. P-values less than 0.05 were regarded as statistically significant.

Results

Of the 358 respondents, 59% were male, and 41% were female. Sixty percent were aged between 18 and 45 years, 42% were literate, and 55% worked as labour and farmer. Nearly half of them were living in a medium-sized families, and 75% of their monthly family income was below Rs. 5,000 in Indian currency. Two hundred and eight (58%) of the respondents had physical impairment (grade 1; 18% and grade 2; 40%), and 60% of their disease duration was more than three years (Table 2).

Attitudes towards People Affected by Leprosy

Table 3 shows the respondents' attitudes towards people affected by leprosy. Among the 358 respondents, 132(37%) of them expressed that they would allow their children to play with a child affected by leprosy, and 279(79%) of them said that they would not allow their son/daughter to marry a bride/groom affected by leprosy. Two

Table 3 : Attitudes towards the people affected by leprosy (n=358)

| Attitude | Frequency (n) | Percent |
|--|----------------------|----------------|
| 1 Allowing children to play with a child affected by leprosy | | |
| Allowed | 132 | 36.9% |
| Not allowed | 226 | 63.1% |
| 2 Get son/daughter to marry bride/groom affected by leprosy | | |
| Marry | 79 | 21.1% |
| Not marry | 279 | 78.9% |
| 3 Having a child of their own | | |
| Have | 119 | 33.2% |
| Not to have | 239 | 66.8% |
| 4 Willingness to work with a person affected by leprosy | | |
| Willing | 155 | 43.3% |
| Not willing | 203 | 56.7% |
| 5 Employ a person affected by leprosy | | |
| Employ | 153 | 42.7% |
| Not employ | 205 | 57.3% |

hundred and thirty-nine (67%) recorded that people affected by leprosy should not have a child of their own, and 203(57%) expressed that they do not want to work with another person affected by leprosy. Further, 205(57%) of them expressed that they would not employ a person affected by leprosy.

Association between Attitudes and Demographic Factors

Gender: The results showed a significant association between gender and attitude toward having a child, willingness to work and employing a person affected by leprosy (Table 4).

Age: The results showed a significant association between age and attitude of having a child of their own and willingness to work with a person affected by leprosy (Table 5).

Education: The results showed a significant association between education and the attitude of willingness to work and employ a person affected by leprosy (Table 6).

Association between Attitudes and Disease Factors

Disability: The results showed a non-significant association between disability grade and attitude towards the persons affected by the leprosy of the respondents (Table 7).

Table 4 : Association test between attitudes towards the people affected by leprosy and gender

| Gender | Yes | No | Total | P-value |
|--|-----------|-----------|-------|---------|
| 1. Allowing children to play with a child affected by leprosy | | | | |
| Male | 70 (33%) | 142 (67%) | 212 | 0.07 |
| Female | 62 (43%) | 84 (57%) | 146 | |
| Total | 132 (37%) | 226 (63%) | 358 | |
| 2. Get son/daughter to marry bride/groom affected by leprosy | | | | |
| Male | 47 (22%) | 165 (78%) | 212 | 0.96 |
| Female | 32 (22%) | 114 (78%) | 146 | |
| Total | 79 (22%) | 279 (78%) | 358 | |
| 3. Having a child of their own | | | | |
| Male | 59 (27%) | 153 (72%) | 212 | 0.01* |
| Female | 60 (41%) | 86 (59%) | 146 | |
| Total | 119 (33%) | 239 (67%) | 358 | |
| 4. Willingness to work with a person affected by leprosy | | | | |
| Male | 80 (38%) | 132 (62%) | 212 | 0.01* |
| Female | 75 (52%) | 71 (48%) | 146 | |
| 5. Employing a person affected by leprosy | | | | |
| Male | 79 (37%) | 133 (63%) | 212 | 0.01* |
| Female | 74 (51%) | 72 (49%) | 146 | |
| Total | 153 (43%) | 205 (57%) | 358 | |

Note. Numbers in parentheses indicate row percentages.

*.P<0.05

Table 5 : Association test between attitudes towards the people affected by leprosy and age

| Gender | Yes | No | Total | P-value |
|--|-----------|-----------|-------|---------|
| 1. Allowing children to play with a child affected by leprosy | | | | |
| 18-30 years | 30 (43%) | 39 (57%) | 69 | 0.37 |
| 31-45 years | 50 (34%) | 95 (66%) | 145 | |
| 46-60 years | 43 (39%) | 68 (61%) | 111 | |
| Above 60 years | 9 (27%) | 24 (73%) | 33 | |
| Total | 132 (37%) | 226 (63%) | 358 | |
| 2. Get son/daughter to marry bride/groom affected by leprosy | | | | |
| 18-30 years | 17 (25%) | 52 (75%) | 69 | 0.06 |
| 31-45 years | 23 (16%) | 122 (84%) | 145 | |
| 46-60 years | 33 (30%) | 78 (70%) | 111 | |
| Above 60 years | 6 (18%) | 27 (82%) | 33 | |
| Total | 79 (22%) | 279 (78%) | 358 | |
| 3. Having child of their own | | | | |
| 18-30 years | 33 (48%) | 36 (52%) | 69 | 0.01* |
| 31-45 years | 37 (26%) | 108 (74%) | 145 | |
| 46-60 years | 40 (36%) | 71 (64%) | 111 | |
| Above 60 years | 9 (27%) | 24 (73%) | 33 | |
| Total | 119 (33%) | 239 (67%) | 358 | |
| 4. Willingness to work with a person affected by leprosy | | | | |
| 18-30 years | 37 (54%) | 32 (46%) | 69 | 0.03* |
| 31-45 years | 54 (37%) | 91 (63%) | 145 | |
| 46-60 years | 54 (49%) | 57 (51%) | 111 | |
| Above 60 years | 10 (30%) | 23 (70%) | 33 | |
| Total | 155 (43%) | 203 (57%) | 358 | |
| 5. Employ person affected by leprosy | | | | |
| 18-30 years | 35 (51%) | 34 (49%) | 69 | 0.06 |
| 31-45 years | 54 (37%) | 91 (63%) | 145 | |
| 46-60 years | 54 (49%) | 57 (51%) | 111 | |
| Above 60 years | 10 (30%) | 23 (70%) | 33 | |
| Total | 153 (43%) | 205 (57%) | 358 | |

Note. Numbers in parentheses indicate row percentages.

*.P<0.05

Table 6 : Association test between attitudes towards the people affected by leprosy and education

| Gender | Yes | No | Total | P-value |
|--|-----------|-----------|-------|---------|
| 1. Allowing children to play with a child affected by leprosy | | | | |
| Illiterate | 82 (40%) | 125 (60%) | 207 | 0.22 |
| Literate | 50 (33%) | 101 (67%) | 151 | |
| Total | 132 (37%) | 226 (63%) | 358 | |
| 2. Get son/daughter to marry bride/groom affected by leprosy | | | | |
| Illiterate | 48 (23%) | 159 (77%) | 207 | 0.61 |
| Literate | 31 (21%) | 120 (79%) | 151 | |
| Total | 79 (22%) | 279 (78%) | 358 | |
| 3. Having a child of their own | | | | |
| Illiterate | 72 (35%) | 135 (65%) | 207 | 0.50 |
| Literate | 47 (31%) | 104 (69%) | 151 | |
| Total | 119 (33%) | 239 (67%) | 358 | |
| 4. Willingness to work with a person affected by leprosy | | | | |
| Illiterate | 105 (51%) | 102 (49%) | 207 | 0.00** |
| Literate | 50 (33%) | 101 (67%) | 151 | |
| Total | 155 (43%) | 203 (57%) | 358 | |
| 5. Employ a person affected by leprosy | | | | |
| Illiterate | 103 (50%) | 104 (50%) | 207 | 0.00** |
| Literate | 50 (33%) | 101 (67%) | 151 | |
| Total | 153 (43%) | 205 (57%) | 358 | |

Note. Numbers in parentheses indicate row percentages.

*, $P < 0.05$, **, $P < 0.01$

Disease duration: The results showed a significant association between disease duration and attitudes toward allowing children to play with a child affected by leprosy, having a child of their own and permitting a son/daughter to marry a bride/groom affected by leprosy (Table 8).

Discussion

Attitudes consist of a person's beliefs, perceptions and stereotypes about the disease. They may be positively or negatively directed towards the diseased person. This study reported the

attitudes of people affected by leprosy towards fellow people affected with leprosy and factors associated with attitudes.

The study's outcome reveals that one-third of the respondents allowed their children to play with a child affected by leprosy, and the majority of them would not allow their son/daughter to marry the bride/groom affected by leprosy. Nearly two-thirds said that people affected by leprosy should not have a child and were unwilling to work with another person affected by it. Furthermore, half

Table 7 : Association test between attitude towards the people affected by leprosy and disability grade

| Gender | Yes | No | Total | P-value |
|--|-----------|-----------|-------|---------|
| 1. Allowing children to play with a child affected by leprosy | | | | |
| Grade '0' | 57 (38%) | 93 (62%) | 150 | 0.88 |
| Grade '1' | 22 (34%) | 42 (66%) | 64 | |
| Grade '2' | 53 (37%) | 91 (63%) | 144 | |
| Total | 132 (37%) | 226 (63%) | 358 | |
| 2. Get son/daughter to marry bride/groom affected by leprosy | | | | |
| Grade '0' | 32 (21%) | 118 (79%) | 150 | 0.94 |
| Grade '1' | 15 (23%) | 49 (77%) | 64 | |
| Grade '2' | 32 (22%) | 112 (78%) | 144 | |
| Total | 79 (22%) | 279 (78%) | 358 | |
| 3. Having child of their own | | | | |
| Grade '0' | 55 (37%) | 95 (63%) | 150 | 0.35 |
| Grade '1' | 17 (27%) | 47 (73%) | 64 | |
| Grade '2' | 47 (33%) | 97 (67%) | 144 | |
| Total | 119 (33%) | 239 (67%) | 358 | |
| 4. Willingness to work with a person affected by leprosy | | | | |
| Grade '0' | 63 (42%) | 87 (58%) | 150 | 0.85 |
| Grade '1' | 27 (42%) | 37 (58%) | 64 | |
| Grade '2' | 65 (45%) | 79 (55%) | 144 | |
| Total | 155 (43%) | 203 (57%) | 358 | |
| 5. Employ a person affected by leprosy | | | | |
| Grade '0' | 62 (41%) | 88 (59%) | 150 | 0.90 |
| Grade '1' | 28 (44%) | 36 (56%) | 64 | |
| Grade '2' | 63 (44%) | 81 (56%) | 144 | |
| Total | 153 (43%) | 205 (57%) | 358 | |

Note. Numbers in parentheses indicate row percentages.

of the respondents would not employ a person affected by leprosy. Similarly, a study from Tamil Nadu, India, found that the people affected by leprosy and their family members had an adequate average level of knowledge about leprosy. Still, their attitudes towards the disease and practices were not favourable. Community

members also entertained negative attitudes towards people affected by leprosy (Stephen et al 2014).

Studies from India (Grewal et al 2013), Nepal (Adhikari et al 2013) and Ethiopia (Tesema & Beriso 2015) reported that the community members showed negative attitudes towards

Table 8 : Association test between attitude towards the people affected by leprosy and disease duration

| Gender | Yes | No | Total | P-value |
|--|-----------|-----------|-------|---------|
| 1. Allowing children to play with a child affected by leprosy | | | | |
| 1 to 3 years | 48 (33%) | 96 (67%) | 144 | 0.02* |
| 3 to 5 years | 35 (31%) | 77 (69%) | 112 | |
| Above 5 years | 49 (48%) | 53 (52%) | 102 | |
| Total | 132 (37%) | 226 (63%) | 358 | |
| 2. Get son/daughter to marry bride/groom affected by leprosy | | | | |
| 1 to 3 years | 30 (21%) | 114 (79%) | 144 | 0.02* |
| 3 to 5 years | 17 (15%) | 95 (85%) | 112 | |
| Above 5 years | 32 (31%) | 70 (69%) | 102 | |
| Total | 79 (22%) | 279 (78%) | 358 | |
| 3. Having a child of their own | | | | |
| 1 to 3 years | 46 (32%) | 98 (68%) | 144 | 0.01* |
| 3 to 5 years | 27 (24%) | 85 (76%) | 112 | |
| Above 5 years | 46 (45%) | 56 (55%) | 102 | |
| Total | 119 (33%) | 239 (67%) | 358 | |
| 4. Willingness to work with a person affected by leprosy | | | | |
| 1 to 3 years | 64 (44%) | 80 (56%) | 144 | 0.18 |
| 3 to 5 years | 41 (37%) | 71 (63%) | 112 | |
| Above 5 years | 50 (49%) | 52 (51%) | 102 | |
| Total | 155 (43%) | 203 (57%) | 358 | |
| 5. Employ a person affected by leprosy | | | | |
| 1 to 3 years | 62 (43%) | 82 (57%) | 144 | 0.11 |
| 3 to 5 years | 40 (36%) | 72 (64%) | 112 | |
| Above 5 years | 51 (50%) | 51 (50%) | 102 | |
| Total | 153 (43%) | 205 (57%) | 358 | |

Note. Numbers in parentheses indicate row percentages.

*.P<0.05

leprosy, particularly among people affected by leprosy. However, this study indicates that the person affected by leprosy also had negative attitudes towards people affected by leprosy.

This study found that both male and female respondents adopted a similar attitude in allowing

children to play with a child affected by leprosy and permitting a son/daughter to marry a bride/groom affected by leprosy. In India, motherhood is highly valued, and childlessness has significant psychological and social implications for couples, especially women. The stigma level is also

relatively high in women affected with leprosy compared to men (Mankar et al 2011). Social and psychological complications persist even after the completion of treatment due to the consequences of leprosy stigma. This study found that the female respondents entertained more positive attitudes toward having a child of their own and working with the man employed by them than the male respondents. The younger respondents also entertained more positive attitudes toward having a child of their own and working with a person affected by leprosy than the aged people.

Concerning education, both the literate and illiterate respondents adopted a similar attitude in allowing children to play with a child affected by leprosy, permitting a son/daughter to marry a bride/groom affected by leprosy and having a child of their own. However, literate people had more negative attitudes toward working with a person affected by leprosy and employing them than illiterate people.

Surprisingly, this study shows that both the persons with or without disabilities entertained similar attitudes towards the people affected by leprosy. However, the disease duration showed a significant difference in attitudes, and it also showed a slightly more positive attitude in people who were affected with leprosy for more than five years in allowing their children to play with a child affected with leprosy, having a child of their own and permit son/daughter to marry bride/groom affected by leprosy than the people who were below five years disease duration. This shows that the higher duration of the disease would bring a great change with good awareness and entertain positive attitudes towards people affected by leprosy.

This study has a few limitations. Due to resource and time limitations, the study was conducted as a cross-sectional study in a tertiary leprosy

referral centre. Cultural and environmental aspects may play an essential role in the attitudes of people affected with leprosy, and this study's findings may not represent other areas. Therefore, further comparative work is needed on the attitude of people affected by leprosy towards the disease and fellow people affected by leprosy. There is also a need to investigate it as an interventional study.

Conclusion

This study concludes that awareness about leprosy should be augmented among the people affected by leprosy to improve positive attitudes towards the disease and diseased person. Moreover, awareness about leprosy should be continued among family members and the community. Continuous health education would improve their knowledge about the disease and develop positive attitudes towards illness and diseased persons.

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