

Disclosure of the Disease among People Affected by Leprosy

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Received : 03.05.2021

Accepted : 10.08.2021

Today, leprosy is completely curable with multidrug therapy. Unfortunately, the stigma attached to leprosy still persists. Fear of social exclusion prevents disclosure of the disease to the family and community. This study aimed to explore disease disclosure among people affected by leprosy reporting at a leprosy referral centre, Purulia, West Bengal, India. A cross-sectional study was conducted among 358 people affected by leprosy (PAL), of the age 18 years and above, married and who were reporting at the tertiary leprosy referral hospital, Purulia, West Bengal. A semi-structured questionnaire was prepared and used to collect the demographic profile, disease profile and disclosure of disease with their family and friends. Of the 358 respondents, 41% were female, 60% were aged between 18 to 45 years, 58% were literate, and 40% of the participants had a physical disability. In disease disclosure, 95% and 43% of them disclosed their disease to their families and friends, respectively. The respondents with disability grade '2' and disease duration above 5 years disclosed their disease status more to their friends than the respondents with grades '0' and grade '1'. People affected by leprosy had disclosed their disease more to their families than friends. At the same time, they felt that it was better not to disclose the disease to their friends. People who disclosed their disease to their family and friends mostly received good support after disease disclosure.

Keywords : Leprosy, Disclosure of Disease, Disability, India

Introduction

Leprosy is a chronic infectious disease caused by *M. leprae*, and it is curable with multidrug therapy (MDT). Unfortunately, the stigma attached to leprosy still persists (Scott 2000, Kaur & Ramesh 1994), and it affects the psychosocial well-being of the affected person (Singh 2012). Perception of stigma and experiences of discrimination cause people to feel ashamed, and may cause them to isolate themselves from society, thus perpetua-

ting the stereotype that leprosy is something shameful to be hidden away (Arole et al 2002). Some studies from India have reported that people had low knowledge about leprosy and negative attitudes towards persons affected by leprosy (van't Noordende et al 2019).

People have multiple feelings of fear, anxiety, and sorrow when first diagnosed with leprosy; they are also embarrassed and blame themselves for contracting the infection (Govindharaj et al 2018).

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Fear of social ostracism has been reported to prevent the disclosure of disease to the community (Kaur & Ramesh 1994). People often did not want to disclose their disease condition to avoid negative reactions or social exclusion (Barrett 2005, Adhikari et al 2014, Thilakavathi et al 2018, van't Noordende et al 2019). Purulia in West Bengal (India) continues to be endemic for leprosy despite good leprosy institutions serving the leprosy affected persons of the area for several decades. As information on this aspect is important from this area to find the reasons of this continuous challenge, therefore, this study was carried out to assess disease disclosure among the people affected by leprosy in a tertiary referral hospital, Purulia.

Methods

This cross-sectional descriptive study was carried out on 358 individuals affected with leprosy who attended a territory referral hospital (The Leprosy Mission Hospital, Purulia), Purulia, West Bengal, India, from April to June 2017. This study included all adult persons affected with leprosy who were above 18 years and diagnosed as leprosy at least for one year at the time of interview. Persons who were living in the leprosy colony were excluded. A semi-structured questionnaire was prepared to collect the demographic and disease profile along with disclosure of disease. The tool was evaluated by three health professionals who were experts in leprosy rehabilitation. In addition, we purposively recruited five respondents to test the tool. An informal discussion was held with the respondents about their view on the relevance and adequacy related to the concept of disclosure of the disease with the family and friends. Based on their suggestions, the investigator drafted the tool and established the validity of the scale.

Ethical consideration : Approval of this study was 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.

Procedure : First author of the study 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 the vernacular language 'Bengali'. The interview was conducted in strict privacy after building rapport with the participants, and precaution was taken to avoid participants' emotional distress. In case of any apparent emotional distress, the interview was terminated.

Data analysis : The data were entered and analysed by using SPSS. Descriptive statistics were used to describe the socio-economic, disease disclosure with family and friends. Association tests were done between the disease disclosure and the demographic (gender, age, education) and disease profiles (disability grade and disease duration).

Results

The participants' details - demographic profile, disability status, and disease duration are summarised in Table 1. Of the 358 participants, 41% were females, 60% were aged between 18-45 years, 58% were literate, and 55% were labourers or farmers. One hundred and sixty-seven (47%) were living in a medium-sized families and 75% of their monthly family income were below Rs. 5,000. More than half of them (58%) had physical impairment (grade 1; 18% and grade 2; 40%), and 60% of their disease duration was more than three years.

Table 1 : Demographic profile, disability status and disease duration 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
House wife	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

Table 2 : Disclosure of the disease with family (n=358)

Disclosure of disease with family	Frequency (n)	Percent (%)
After Disclosure		
Supportive	334	93.3
Not supportive	7	2.0
Not disclosed		
Feel better if disclosed	1	0.3
Not feel better if disclosed	16	4.4

Table 3 : Disclosure of the disease condition with friends (n=358)

Disclosure of disease with friends	Frequency (n)	Percent (%)
After Disclosure		
Supportive	153	42.7
Not supportive	2	0.6
Not disclosed		
Feel better if disclosed	27	7.5
Not feel better if disclosed	176	49.2

Table 4 : Statistical analysis of association between disclosure of disease condition with family and demographics, and disease profile

Status	Disclosure of disease condition with family				Total (n=358)	P value
	Yes (n=341)		No (n=17)			
	N	%	N	%		
Gender						
Male	196	92.5%	16	7.5%	212	.003**
Female	145	99.3%	1	0.7%	146	
Age						
20 to 30	66	95.7%	3	4.3%	69	.768
30 to 40	106	96.4%	4	3.6%	110	
40 to 50	69	95.8%	3	4.2%	72	
50 to 60	70	94.6%	4	5.4%	74	
60 to 70	30	90.9%	3	9.1%	33	
Education						
Illiterate	200	96.6%	7	3.4%	207	.154
Literate	141	93.4%	10	6.6%	151	
Disability Grade						
Grade '0'	142	94.7%	8	5.3%	150	.895
Grade '1'	61	95.3%	3	4.7%	64	
Grade '2'	138	95.8%	6	4.2%	144	
Disease Duration						
1 to 3 years	135	93.8%	9	6.3%	144	.545
3 to 5 years	108	96.4%	4	3.6%	112	
> 5 years	98	96.1%	4	3.9%	102	

Disclosure of the Disease with Family

In the disclosure of disease with family, 95% of the respondents disclosed their disease to their

families, and 93% received support. Only 5% of them did not disclose the disease condition to their families (Table 2).

Table 5 : Statistical analysis of association between disclosure of disease condition with friends and demographics and disease profile

Status	Disclosure of disease condition with friend				Total (n=358)	P value
	Yes (n=155)		No (n=203)			
	N	%	N	%		
Gender						
Male	95	44.8%	117	55.2%	212	.486
Female	60	41.1%	86	58.9%	146	
Age						
20 to 30	29	42.0%	40	58.0%	69	.983
30 to 40	46	41.8%	64	58.2%	110	
40 to 50	33	45.8%	39	54.2%	72	
50 to 60	33	44.6%	41	55.4%	74	
60 to 70	14	42.4%	19	57.6%	33	
Education						
Illiterate	92	44.4%	115	55.6%	207	.608
Literate	63	41.7%	88	58.3%	151	
Disability Grade						
Grade '0'	58	38.7%	92	61.3%	150	.001**
Grade '1'	19	29.7%	45	70.3%	64	
Grade '2'	78	54.2%	66	45.8%	144	
Disease Duration						
1 to 3 years	50	34.7%	94	65.3%	144	.001**
3 to 5 years	46	41.1%	66	58.9%	112	
>5 years	59	57.8%	43	42.2%	102	

Disclosure of the Disease with Friends

In the disclosure of disease with friends, 43% of the respondents disclosed their disease condition to their friends and received support. Forty-nine percentages of them felt that it was better not to disclose the disease condition to their friends (Table 3).

In the disclosure of disease condition with family, the significant association was found only with the gender (Table 4). The proportion of female respondents disclosing their disease status was higher to their family than the male respondents.

In the disclosure of disease conditions with friends, the significant association was found only among the disability grade and disease duration (Table 5). In disability grade, the respondents with disability grade '2' disclosed disease status more to their friends than the respondents with grades '0' and grade '1'. In disease duration, the respondents with duration of 5 years or more disclosed their disease status more to their friends than the respondents with disease duration of less than 5 years.

Discussion

It is well known that social stigma, discrimination, and fear of rejection influence the disclosure of leprosy disease by the diseased person. The present study has analysed the disclosure of the disease among people affected with leprosy who belong to Purulia and were patients of a tertiary care hospital of area.

Studies from India found that people affected by leprosy (PALs) had perceived fear after disclosing the disease (Barrett 2005, Thilakavathi et al 2018). In the study of Thilakavathi et al (2018) around 61% of the people had disclosed their disease to their spouse, family members, relatives or friends, and the rest of them had not disclosed due to fear of social rejection, stigma, isolation, or ill-treatment. Some of the people affected by leprosy did not disclose their causes of disabilities to their close ones, and it was a huge burden for them to keep this secret (Adhikari et al 2014). In this study, almost all the respondents disclosed their disease to their families and received support. Maybe the reason behind the positive attitudes towards the diseased person by the family members influenced their attitude. On the other hand only 43% of the respondents disclosed their disease to their friends and received support.

Regarding to the disclosure of disease with family, most of leprosy affected persons in our study disclosed their disease status to their family and received good support. The female proportion of respondents disclosing their disease status was slightly higher to their family than the male respondents. Besides, the factors of age, education, disability grade, and disease duration are not associated with the disclosure of disease to their family. It was pleasant experience to observe the findings that the family members had accepted the diseased person and were supportive of their lives.

Nagaraja et al (2011) observed that disabilities due to leprosy were associated with leprosy stigma. In the present study, the respondents who had grade '2' disability disclosed their disease status more to their friends than the respondents with grade '0' and grade '1' disability. The visible impairments or deformities might be the reason for disclosing the disease condition to their friends as they might have preferred to take chances of gaining acceptance by voluntary disclosure. As they received good support from their friends after disclosure of their disease, self stigma appears to be main issue. In addition, those who had not disclosed their disease to their friends felt that it was better not to disclose the disease. Because people still have false beliefs about the transmission, severity and myths attached to the disease (Adhikari et al 2014, Thilakavathi et al 2018).

Moreover, higher proportion of respondents with duration of more than 5 years disclosed their disease status to their friends than the respondents with below 5 years of disease duration. It is possible that people start to disclose the disease once they are completely get cured, and it may help to accept that leprosy disease is curable by the people. As these cut offs are arbitrary, in depth studies are required to understand the significance of such findings.

Our study was not without limitations. This is a cross-sectional study from a limited geographical region of adult PALs reporting to a tertiary care hospital during a limited period and diagnosed as leprosy at least for one year at the time of interview. However, the study was conducted with a good sample size. Cultural and environmental aspects may also play an important role. Further the findings of this study may not represent other areas. Therefore, further comparative work is needed to be undertaken on disease disclosure among people affected by leprosy in different settings.

Conclusion

People affected by leprosy disclosed their disease more to their families. In contrast, they felt that it was better not to disclose the disease to their friends. People who disclosed their disease to their family and friends mostly received good support after disease disclosure. The awareness about the disease should be enhanced in the community to address self stigma. It would develop a positive attitude among them and encourage affected people to disclose the disease condition with friends and the community to receive better timely support.

Acknowledgements

The authors express sincere thanks to Prof Dr. M. Thavamani, Formerly Head-Department of Sociology, Bharathidasan University, Tamil Nadu, Dr. Famkima Darlong, Head-Healthcare, The Leprosy Mission Trust India, New Delhi (Formerly, Superintendent, The Leprosy Mission Hospital, Purulia) and The Research domain, The Leprosy Mission Trust India, New Delhi for their guidance and encouragement. We thank Ms. Sneha Mahato, Mr. Subir Ketiar and Mr. Deepraj Mardy for their sincere involvement in data collection. We thank all the persons who participated in this study. We thank Mrs. Vidhya L, Senior Lecturer in English, Sri Ramachandra Institute of Higher Education and Research, for fine-tuning in language. We extend our sincere thanks to the staff of the Physiotherapy Department, Purulia Leprosy Mission Hospital, for their support.

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How to cite this article : Pitchaimani G, Srinivasan S, Darlong J (2021). Disclosure of the Disease among People Affected by Leprosy. *Indian J Lepr.* **93**: 361-367.