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Original Article

Disease Disruption among People Affected by Leprosy

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Stigma-associated psychosocial problems are common in leprosy. Therefore, this study aimed at assessing the disease disruption among people affected by leprosy (PAL). A cross-sectional study was conducted among 358 people affected by leprosy above the age of 18, married and who were reporting at the tertiary leprosy referral hospital, Purulia, West Bengal. A semi-structured questionnaire was prepared and validated to collect the demographic and disease profile. The 11 points numerical rating scale was used to measure the disease disruption in family, social and work life. The results showed that 42%, 57% and 82% of the respondents felt that their disease conditions did not disrupt their work life, social life, and family life respectively. Association test showed that the male respondents experienced more disruption in their social life whereas female respondents experienced more in their family life. People with disability due to leprosy disease and disease duration above three years experienced more disruption in their work, social and family life due to disease than the people without disability and disease duration less than three years. The study emphasizes that awareness about leprosy should be improved among the family and community to enhance positive attitudes towards the disease.

Keywords : Leprosy, Disability, Stigma, Disease Disruption, Purulia, India

Introduction

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* and it is primarily affects the skin and peripheral nerves (WHO 2010). It is a leading cause of permanent disability in the world and predominantly affects the poor marginalized people (Chatterjee et al 2001, Singh et al 2009, Seshadri et al 2015, WHO 2016). Chronic illness may encounter basic functions such as financial, housing and employment in their daily life and social problems such as marriage prosperous and childbirth (Singh 2012, Chandler et al 2015, van't Noordene et al 2016).

Fear of infection has been identified as most important cause of stigma in different countries including Nepal (Adhikari et al 2014), China (Chen et al 2005), and India (Nagaraj et al 2011, Govindharaj et al 2018a). People fear mainly due to consequences of disease, deformity and social exclusion. Lack of knowledge and information, age-old beliefs, perceived fear of infection and shame all resulted in stigma towards the people

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affected by leprosy (Nagaraj et al 2011, Govindharaj et al 2018a), also, it leads to irrational behaviour towards them. Community attitudes are part of a cultural belief and value system and form a powerful determinant of stigma (Heijnders & Meij 2006).

Social factors are more possible to determine people's health conditions. According to World Health Organization, the social determinants of health are "the conditions in which people are born, grow, work, live, age and the set of forces and systems shaping the conditions of daily life" (WHO 2011). Moreover, the factors of family, social and work life possibly will determine the health of the people affected by leprosy. Therefore, this study aimed to assess the disease disruption among people affected by leprosy.

Material and Methods

A cross-sectional descriptive study was conducted with 358 individuals affected by leprosy who attended the outpatient department in a territory referral hospital Purulia, West Bengal, India, from April to June 2017. The Purulia district is endemic for leprosy (NLEP 2015).

Eligibility of respondents/participants: The people affected by leprosy who were above 18 years and diagnosed as leprosy at least for a year at the time of interview were included in this study. People who were living in the leprosy colony were excluded.

Semi-structured questionnaire: A semi-structured questionnaire was prepared to collect the demographic, and disease profile along with disease disruption of the people affected by leprosy.

Disease disruption: The 11-point numerical rating scale (Horizontal Rating Scale) was used to measure the disease disruption in family, social and work life (De Vaus 2013). The score ranges from '0' to '10' and it is categorized as no disruption (score-'0'), minimal disruption (score-'1' to '3'), moderate disruption (score-'4' to '6') and severe disruption (score-'7' to '10').

Validity: To determine the content 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 on the relevance and adequacy related to the concept of disease disruption in the family, social and work life. Based on their suggestions the investigator drafted the tool and established the validity of the tool.

Procedure: The first author was assigned to recruit respondents, 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 respondents and precaution was taken to avoid emotional distress of respondents. In case of any emotional distress, the interview was terminated.

Ethical approval: Study approval was obtained from the Doctoral Research Committee members, Department of Sociology, Bharathidasan University and Research Ethics Committee of The Leprosy Mission Trust India, New Delhi. Respondents were voluntary and information was collected anonymously after obtaining written consent from each respondent by assuring confidentiality throughout the data collection period.

Data analysis: The data were entered and analysed by using SPSS. Descriptive statistics were used to describe the demographic and disease profiles of the respondents. Chi-square test was used in assessing the significance of associations between disease disruption and gender, disability grade and disease duration.

The p-values less than 0.05 were regarded as statistically significant.

Results

The respondents' details of demographic profile, disability status and disease duration were described in Table 1. Of the 358 respondents, 41% of them were female, 60% were aged between 18-45 years, 58% were literate and 55% of them were doing occupations as labourers or farmers. Nearly half of the respondents were living in a medium-sized families and the majority of their

Table 1 : Demographic profile and disease profile of the participants (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 : Disruption in work, social life and family life of the participants (n=358)

Disease disruption		Frequency	Percent
1.	**Work life**		
	No disruption	150	42%
	Minimal disruption	51	14%
	Moderate disruption	45	13%
	Severe disruption	112	31%
2.	**Social life**		
	No disruption	205	57%
	Minimal disruption	36	10%
	Moderate disruption	48	14%
	Severe disruption	69	19%
3.	**Family life**		
	No disruption	294	82%
	Minimal disruption	29	8%
	Moderate disruption	18	5%
	Severe disruption	17	5%

Table 3 : Disease disruption in work life of the participants (n=358)

Variables	Disease Disruption in Work life								Total	P-value
	No		Minimal		Moderate		Severe			
Gender										
Male	85	40%	26	12%	29	14%	72	34%	212	.32
Female	65	45%	25	17%	16	11%	40	27%	146	
Total	**150**	**42%**	**51**	**14%**	**45**	**13%**	**112**	**31%**	**358**	
Disability Grade										
Grade '0'	92	61%	22	15%	18	12%	18	12%	150	<0.01
Grade '1'	31	48%	8	13%	9	14%	16	25%	64	
Grade '2'	27	19%	21	15%	18	13%	78	54%	144	
Total	**150**	**42%**	**51**	**14%**	**45**	**13%**	**112**	**31%**	**358**	
Disease Duration										
1 to 3 years	78	54%	21	15%	12	8%	33	23%	144	<0.01
3 to 5 years	35	31%	18	16%	17	15%	42	38%	112	
Above 5 years	37	36%	12	12%	16	16%	37	36%	102	
Total	**150**	**42%**	**51**	**14%**	**45**	**13%**	**112**	**31%**	**358**	

monthly family income was below Rs. 5,000 INR in Indian currency. More than half 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 describes the disease disruption in work,

Table 4 : Disease disruption in social life of the participants (n=358)

Variables	Disease Disruption in Work life								Total	P-value
	No		Minimal		Moderate		Severe			
Gender										
Male	110	52%	28	13%	30	14%	44	21%	212	<0.05
Female	95	65%	8	5%	18	12%	25	17%	146	
Total	**205**	**57%**	**36**	**10%**	**48**	**13%**	**69**	**19%**	**358**	
Disability Grade										
Grade ‘0’	111	74%	12	8%	15	10%	12	8%	150	<0.01
Grade ‘1’	40	63%	9	14%	7	11%	8	13%	64	
Grade ‘2’	54	38%	15	10%	26	18%	49	34%	144	
Total	**205**	**57%**	**36**	**10%**	**48**	**13%**	**69**	**19%**	**358**	
Disease Duration										
1 to 3 years	102	71%	10	7%	16	11%	16	11%	144	<0.01
3 to 5 years	51	46%	15	13%	18	16%	28	25%	112	
Above 5 years	52	51%	11	11%	14	14%	25	25%	102	
Total	**205**	**57%**	**36**	**10%**	**48**	**13%**	**69**	**19%**	**358**	

Table 5 : Disease disruption in the family life of the participants (n=358)

Variables	Disease Disruption in Work life								Total	P-value
	No		Minimal		Moderate		Severe			
Gender										
Male	183	86%	14	7%	11	5%	4	2%	212	<0.05
Female	111	76%	15	10%	7	5%	13	9%	146	
Total	**294**	**82%**	**29**	**8%**	**18**	**5%**	**17**	**5%**	**358**	
Disability Grade										
Grade ‘0’	136	91%	7	5%	6	4%	1	1%	150	<0.01
Grade ‘1’	54	84%	4	6%	4	6%	2	3%	64	
Grade ‘2’	104	72%	18	13%	8	6%	14	10%	144	
Total	**294**	**82%**	**29**	**8%**	**18**	**5%**	**17**	**5%**	**358**	
Disease Duration										
1 to 3 years	129	90%	7	5%	7	5%	1	1%	144	<0.05
3 to 5 years	84	75%	14	13%	7	6%	7	6%	112	
Above 5 years	81	79%	8	8%	4	4%	9	9%	102	
Total	**294**	**82%**	**29**	**8%**	**18**	**5%**	**17**	**5%**	**358**	

social and family life by respondents. Of the 358 respondents, 112 (31%) and 69 (19%) had a severe disruption in their work and social life due to disease respectively. Whereas two hundred and ninety-four (82%) of the respondents had no disruption in their family life due to disease.

A significant association was present among gender (male and female), disability grade (grade '1', grade '2' and grade '3') and disease duration (1 to 3 years, 3 to 5 years and above 5 years) in disease disruption in work (Table 3), social life (Table 4), and family life (Table 5).

It was found that there is a significant association of respondents' disability grade and disease duration in their work life, social life, and family life. The people, who had disabilities, experienced more disruption in their work life, social life, and family life due to disease than the people without disability. The people who had disease duration 1 to 3 years, experienced less disruption in their work life, social life, and family life due to disease than the people with more than 3 years duration of disease. In gender, the signi-ficant association was found only in social life and family life. Due to disease, the male respondents experienced more disruption in their social life and female respondents experienced more disruption in their family life.

Discussion

Leprosy gives rise to many other problems, besides the medical ones. With reference to the analysis of disruption due to disease, 82% of the respondents felt that their disease conditions did not disrupt their family life and 57% felt that their disease conditions did not disrupt their social life. However, 31% opined that they faced severe disruption in their workplace, due to the disease.

Predominantly, Indian family systems are patriarchal in nature (Kapadia 1982), and it was observed in this study. The female respondents reported more significant disruption in their family life due to leprosy disease than males. On the contrary, the male respondents reported more significant disruption in their social life due to leprosy disease than females. However, both the male and female respondents had a similar disruption in their work-life due to leprosy disease.

Our findings corroborate the observations reported by others which show that disabilities due to leprosy cause problems in the lives of affected people (van Brakel et al 2012, Reis et al 2014, Govindraj et al 2018b). The respondents who had grade 2 disability reported more significant disruption in their work life and social life due to leprosy disease than respondents with grade 0 and grade 1 disability. While in the family life, respondents with grade 2 disability had less disruption due to leprosy disease when compared to their social and work life. A study from Brazil, found a higher prevalence of psychological distress in people affected by leprosy, with higher disability levels and further affected people to suffer the lowest quality of life (Reis et al 2014).

Early diagnosis of the disease and appropriate and timely treatment will reduce the complications and improve the quality of life of people affected with leprosy (Govindharaj et al 2018b). In this study, the respondents with a disease duration of above three years had a more significant disruption in their work and social life due to leprosy disease than respondents who had disease duration below three years. While in the family life, respondents who had a duration of disease above three years had less disruption when compared to their social and work life.

Accordingly, World Health Organization physical, mental, and social factors are determining the health of individuals (WHO 1946). Besides, the family, social and work life will determine the quality of life of people affected by leprosy. Since, the psychosocial consequence was due to disease extended beyond the affected persons, it affects their families as well (Kaur & van Brakel 2002, Singh 2012). The World Health Organization had included in Global Leprosy Strategy 2016-2020, as one of the main strategies the comprehensive education of the patients, healthcare workers, and the public on leprosy-related issues (WHO

2016). Studies showed that patient education and counselling for leprosy results in increased knowledge, change of behaviour and a reduction of stigma (Takor & Murthy 2004, Raju et al 2008, Sermrittirong et al 2014, Lusli et al 2016, Komalaningsih et al 2017). Hence, awareness about the disease must be provided to the people affected by leprosy and it has to be extended to the family and community as well.

Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self - actualization. Since the respondents who had grade 2 disability reported more significant disruption in their work life. The socio-economic rehabilitation would be reduced the disruption in work life and trigger the reduction of stigma through the mechanism of protecting people against the loss of social value by facilitating their continuous engagement in daily social roles and participation in financial exchange in the community (Nuri et al 2012).

The study was conducted with a large sample size and assessed the disease disruption among people affected by leprosy. Due to resource and time limitations, the study was conducted as a cross-sectional study in a tertiary leprosy referral centre. Therefore, further comparative and intervention studies are needed to be undertaken on disease disruption among people affected by leprosy.

Conclusion

The study observed that the disease caused more disruption to male respondents in social life, while female respondents suffered in family life. The counselling of patients and families may possibly reduce the disruption in family life. The disability and disease duration were caused more disruption in their social life and work-life due to leprosy disease than their family life. Awareness about the disease must be provided to the people affected by leprosy and it has to be increased to the family and community to enhance positive attitudes towards the disease.

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