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Psychosocial consequences of leprosy and the related deformity in Bangladesh

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ABSTRACT

Objective: To explore the psychosocial condition and consequences of the people affected by leprosy and the related deformity in some selected areas of Bangladesh.

Methods: A cross-sectional study was conducted from July to December 2015 among 92 leprosy-affected people. A pretested semi-structure questionnaire was used for collecting data by face to face interview from both the low prevalent areas of Khulna and the high prevalent area of Rangpur Division in Bangladesh.

Results: Nearly two-fifth of respondents were observed having deformity. Among them, around four-fifth was from Khulna region, about half were above 50 years of age and more than half had monthly family income lower than 5000 BDT. The development of deformity is found having highly significant association with region ($P < 0.001$), residence ($P < 0.004$), and family income ($P < 0.004$). Differences in consequences between 'with deformity' and 'without deformity' were found very high. About 65% of the respondents with deformity 'think less' of himself, and nearly 60% felt ashamed or embarrassed, 53% had to change job, and 47% was used to think having less respect in the society where the percentage was much lower in all cases to 'without deformity' group.

Conclusions: Early diagnosis and start multidrug therapy at the earliest stages have chanced to reduce the leprosy-resulted deformity, disfigurement and disability. For those who already have had some nerve damages, health education is highly important to prevent further injury and hence psychosocial consequences.

1. Introduction

Leprosy or Hansen's disease has long been known as a stigmatizing disease and it remains the same till today[1,2]. It is a chronic infectious disease with acute and sometimes severe clinical presentations[3] and is a challenge to public health, and social and rehabilitation services in endemic countries[4].

Persons affected by leprosy and resulted deformities face

forms of stigma that have an impact on persons' life, including intimate relationships[2,5]. Stigma is generated by the families and communities[5]. The social stigma connected to the patients makes this disease completely different from others[6]. Perceived stigma towards leprosy was the highest among participants with age of 61 years or older and lower duration of education[7].

Despite significant improvements in leprosy treatment since the introduction of multidrug therapy (MDT) 3 decades ago, the global incidence remains high, and patients often have long-term complications[8]. In Bangladesh, it is an eliminated disease[9] with a prevalence rate of 0.24/10 000 population in 2012[10]. Among 219075 new cases detected in 2011, the 3 countries contributed 83%, with India 58%, Brazil 16% and Indonesia 9%. In absolute number 3970 new cases were detected in Bangladesh at that time[11].

Because of the stigma associated with the disease, patients

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The study protocol was performed according to the Helsinki declaration and approved by the MS Thesis Evaluation Committee of Environmental Science Discipline, Khulna University along with Khulna University Medical Centre. Informed written consent was obtained from each of the survey participants.

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sometimes delay seeking proper care, which causes disabilities[12,13]. A study showed that the affected people first visited a doctor, due to their symptoms worsening (48.4%) or persisting (20.5%)[14]. Leprosy-resulted disability is more than a mere physical dysfunction. It includes activity limitations, stigma, discrimination, and social participation restrictions[4,13]. Reactions or neuritis may also lead to nerve damages and disabilities[15] can affect people for many years after MDT is complete[8]. The global rate of new cases with visible (grade-2) deformities per 100 000 population was 0.23. A total of 12225 new cases with visible disabilities were detected globally during 2011, a slight reduction as compared with 2010[11].

Participants with disfigurement or deformities, ulcers and odorous ulcers had higher perceived stigma score[16]. Patients face social rejection due to the prevalent beliefs regarding its hereditary contagious nature. The negative attitude has been found to be stronger, particularly in regards to marriage association, sharing of accommodation, and any other physical contact with the affected people[17]. Even nowadays people affected by leprosy have to leave their village and are socially isolated[6]. Data shows that people with disability are more disadvantaged in accessing health, education and employment opportunities compared to people without a disability[18]. The study was designed to explore the psychosocial condition and consequences of the people affected by leprosy and the related deformity in some selected areas of Bangladesh.

2. Materials and methods

A cross sectional study was conducted among the leprosy-affected people. The study was conducted in two divisions of Bangladesh during July to December 2015. One was Khulna (Southwest part) where both the prevalence of leprosy and activity of non-governmental organization (NGO) were low and the other was Rangpur (Northwest part) where both the prevalence and NGO activity on leprosy services were high in affected districts.

The subjects were hardly available in Khulna Division. So, all available 46 affected people who were willing to participate were included in the survey. The data collectors visited both government and NGO managed leprosy clinics several times and collected information from 35 affected people who came for treatment from different districts. The respondents were 23, 5, 2, 1, 1 and 3 respectively from Khulna, Bagerhat, Satkhira, Narail, Magura and Chuadanga. Data were also collected from another 11 respondents visiting their household in Kushtia (2) and Meherpur (9) districts.

The researcher decided to survey on 46 respondents from the high prevalent areas in Gaibandha District of Rangpur Division. The respondents were selected randomly from a list of affected people (sub-district wise list of Gaibandha District) provided by The Leprosy Mission International-Bangladesh. The affected people

participated to the survey were proportionally allocated from 3 sub-districts, including Gaibandha sadar (19), Shadullapur (20), and Fulchori (7). Finally, the sample consisted of 92 affected people from two divisions irrespective of age, gender, and deformity.

Semi-structured questionnaire was used at the field for data collection which was pretested in Khulna. The respondents were requested to provide relevant information and fill up the questionnaire in front of them through face to face interview. Informed written consent was taken from each of the survey participants before commencement of data collection describing the purpose clearly. The topics which could create discomfort to the respondents were avoided carefully.

The study protocol was approved by the MS Thesis Evaluation Committee of Environmental Science Discipline, Khulna University along with Khulna University Medical Centre.

Microsoft Excel and SPSS (version 16.0) were used to analyze data and the results are presented through tables and graphs. *Chi-square* test and relative risk (RR) were also calculated to interpret obtained results. For the statistical tests, $P \leq 0.05$ was considered statistically significant.

3. Results

3.1. Socio-economic information

The respondents were distributed by region, age, gender, education, residence, marital status, and types of family, and also by occupation, family income and the person who generated income (Tables 1 and 2). Among the 92 leprosy-affected respondents, 38 were found with deformity caused by leprosy. Among the respondents with deformity, nearly four-fifth (79%) was from Khulna where both the prevalence and NGO activity were lower compared to Rangpur. Affected people living in Khulna were almost 4 times (RR = 3.75) more likely to have deformity than affected people living in Rangpur. Half of the respondents having deformity were above 50 years of age in which no one was below 20 years.

Table 1 shows that 61% and 39% of the respondents were male and female respectively in the survey. 74% and 52% were male among the respondents with deformity ($n = 38$) and without deformity ($n = 54$), respectively. Males among the affected people were about 2 times (RR = 1.8) as likely to have deformity as females. Overall 43% of the respondents were illiterate, even cannot sign. Among the people with deformity, 53% were illiterate which was much lower (37%) in other groups.

Overall 63% and 37% of the respondents were living in urban and rural areas, respectively. Affected people living in rural areas were almost 2 times (RR = 2.1) more likely to have deformity than people living in urban areas. Overall 12% of the respondents (11% and 13%

people with deformity and without deformity, respectively) were unmarried. Nearly one-fourth (26%) of the subjects with deformity were living in joint family which was lower than the overall situation (34%).

Table 1

Social condition of the affected people [n (%)].

Social condition	Category	With deformity	Without deformity	Total
Region	Khulna	30 (79)	16 (30)	46 (50)
	Rangpur	8 (21)	38 (70)	46 (50)
Age	< 20	0 (0)	7 (13)	7 (8)
	20–30	4 (11)	10 (19)	14 (15)
	30–40	7 (18)	11 (20)	18 (20)
	40–50	8 (21)	10 (19)	18 (20)
	50–60	10 (26)	10 (19)	20 (22)
	60–70	7 (18)	6 (11)	13 (14)
	> 70	2 (5)	0 (0)	2 (2)
Gender	Male	28 (74)	28 (52)	56 (61)
	Female	10 (26)	26 (48)	36 (39)
Education	Illiterate	20 (53)	20 (37)	40 (43)
	Literate	18 (47)	34 (63)	52 (57)
Residence	Urban	17 (45)	41 (76)	58 (63)
	Rural	21 (55)	13 (24)	34 (37)
Marital status	Unmarried	4 (11)	7 (13)	11 (12)
	Married	34 (89)	46 (85)	80 (87)
	Separated	0 (0)	1 (2)	1 (1)
Type of family	Joint	10 (26)	21 (39)	31 (34)
	Nuclear	28 (74)	33 (61)	61 (66)

Table 2 shows that the respondents were mainly housewives (overall 29%; people with deformity 18%, without deformity 37%), followed by agricultural farmers (overall 16%; people with deformity 11%, without deformity 20%) and day labourers (overall 15%; people with deformity 24%, without deformity 9%); and 16% of the affected people with deformity were unemployed at the time of survey.

Table 2

Distribution of respondents by occupation and income [n (%)].

Category	With deformity	Without deformity	Total	
Occupation	Agriculture	4 (11)	11 (20)	15 (16)
	Day labourer	9 (24)	5 (9)	14 (15)
	Business	3 (8)	6 (11)	9 (10)
	Housewife	7 (18)	20 (37)	27 (29)
	Student	0 (0)	6 (11)	6 (7)
	Unemployed	6 (16)	2 (4)	8 (9)
	Others	9 (24)	4 (7)	13 (14)
	Family income	< 5000	20 (53)	9 (17)
5000–10000		11 (29)	33 (61)	44 (48)
10000–15000		2 (5)	7 (13)	9 (10)
15000–20000		2 (5)	3 (6)	5 (5)
> 20000		3 (8)	2 (4)	5 (5)
Generates income	Self	23 (61)	24 (44)	47 (51)
	Other members	15 (39)	30 (56)	45 (49)

Overall 80% of the respondents had monthly family income lower than 10000 BDT (78 BDT = 1 US dollar approx.). More than half (53%) of the affected people with deformity had monthly income lower than 5000 BDT. About half (51%) of the affected people were earning money for their family. The proportion is higher (61%) in the groups 'with deformity' compared to the groups 'without deformity' (44%).

3.2. Identification, treatment and possible source of being affected

Overall 68% of the affected people were identified by NGO workers. The remaining 14%, 10%, 6% and 2% respondents were recognized by government hospital workers, old leprosy-affected people, neighbours, and village doctors, respectively. Affected people identified by others were almost 2 times (RR = 2.1, odd ratio = 4.4) as likely to have deformity as affected people identified by NGO workers. Overall 90% of the respondents visited doctors/hospitals willingly and taken MDT. And 26% of the affected people with deformity had affected family member(s), 13% had affected relatives and 16% had affected neighbours (Table 3).

All 38 respondents with deformity were asked some specific questions to know the condition of deformity and disability which was also shown in Table 3. In response to the questions related to the development of first deformity, 76% said that it was developed after treatment in the health centre, 21% said during the treatment and the remaining 3% had deformity before the first visit to the centre. Deformity was observed mainly in hands (82%), eyes (76%) and some cases on feet (18%) which were visible to others (87%). Nearly three-fourth respondents (74%) with deformity couldn't walk or work normally.

Table 3

Distribution of subjects by identification, treatment, possible source and condition [n (%)].

Category	With deformity	Without deformity	Total	
Who noticed first	Others	19 (50)	10 (19)	29 (32)
	NGO workers	19 (50)	44 (81)	63 (68)
Go to doctor/hospital willingly	Yes	36 (95)	47 (87)	83 (90)
	No	2 (5)	7 (13)	9 (10)
Taken MDT	Yes	35 (92)	48 (89)	83 (90)
	No	3 (8)	6 (11)	9 (10)
Family member(s) affected	Yes	10 (26)	15 (28)	25 (27)
	No	28 (74)	39 (72)	67 (73)
Relative(s) affected	Yes	5 (13)	8 (15)	13 (14)
	No	33 (87)	44 (83)	78 (85)
	Don't know	0 (0)	1 (2)	1 (1)
Neighbour(s) affected	Yes	6 (16)	21 (39)	27 (29)
	No	29 (76)	25 (46)	54 (59)
	Don't know	3 (8)	8 (15)	11 (12)
Time to develop first deformities	Before first visit to hospital	1 (3)	-	-
	During treatment	8 (21)	-	-
	After treatment	29 (76)	-	-
Place of deformity	Hand	31 (82)	-	-
	Feet	7 (18)	-	-
	Eye	29 (76)	-	-
Visibility of deformity to others	Yes	33 (87)	-	-
	No	5 (13)	-	-
Can walk or work normally	Can	10 (26)	-	-
	Can't	28 (74)	-	-

Developing deformity was highly significantly associated with region ($P < 0.001$), residence ($P < 0.004$), family income ($P < 0.004$), and who noticed first ($P < 0.003$), and also significantly associated with age ($P < 0.042$), gender ($P < 0.049$) and neighbour

affected ($P < 0.015$). Education level ($P = 0.471$), types of family ($P = 0.265$), go to doctor/hospital willingly ($P = 0.221$), taken MDT ($P = 0.609$) and having affected family members ($P = 0.877$) or relatives ($P = 0.677$) had no significant association with developing deformity. Go to doctor/hospital willingly ($P < 0.002$), taken MDT ($P < 0.003$) and having affected neighbour ($P < 0.001$) were highly significantly associated with the region.

3.3. Psychosocial consequences of leprosy and deformity

Overall 78% of the respondents ($n = 92$) discussed that they were affected by leprosy by the closest one. About 42% of them used to think less, 28% feel ashamed or embarrassed, 24% think having less respect, 20% think that other people avoid them and refused to visit their house (23%). Around 22% of the respondents used to think that it caused social problems, 10% were asked to stay away, 16% decided themselves to stay away and also 25% had to change their job due to leprosy (Figure 1).

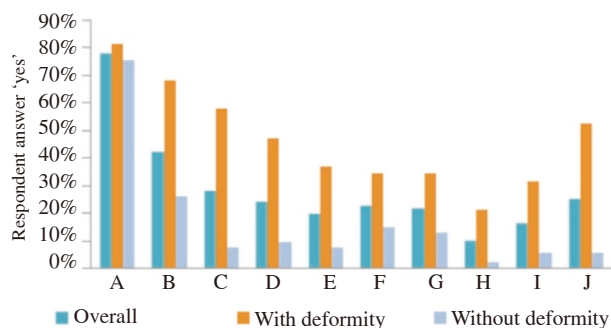


Figure 1. Differences in psychosocial consequences among the groups.

A: Discussed to the closest one; B: Think less; C: Feel ashamed or embarrassed; D: Think having less respect; E: People avoiding you; F: People refusing to visit home; G: Cause social problems; H: Asked to stay away; I: Decided to stay away; J: Had to change job.

The differences between 'with deformity' and 'without deformity' were very high in most of the cases except 'discussed to the closest one'. More than 65% of the respondents with deformity 'think less' of oneself, whereas the number was much lower (25%) in the other group. Nearly 60% of the respondents having deformity felt ashamed or embarrassed which was much higher as compared to subjects without deformity (7%). Around half (47%) of the respondents with deformity was used to think having less respect where only 9% of the respondents without deformity had same feeling. Almost similar differences were observed between the two groups to other cases like people avoid them, refused to visit home and cause social problems. The respondents with deformity were asked to stay away (21%) and decided to stay away (32%) where the number was very low in without deformity group (2% and 6%), respectively. More than half (53%) of the respondents with deformity had to change their job where only 6% from the other group were compelled to do.

4. Discussion

Scanty research work has shown about the consequences of leprosy-related deformity in Bangladesh. A study in Ethiopia showed that overall prevalence of disability was 65.9% from all categories of patients (40.2% Grade I and 25.7% Grade II)[13], which was very high compared to the present study (41%) and also distribution of subjects by disability grade were observed dissimilarly (5% Grade I and 36% Grade II). A study with 1358 persons with leprosy-related disability showed that 77% of the leprosy-related disability had physical impairments[4]. Another study in Sindh, Pakistan showed that 55 (55%) patients had deformity out of 100 observed cases of leprosy[19], which was also higher than the present study.

Plantar ulcer was the commonest deformity (51.5%), while lagophthalmos (9.2%) was the least common deformity in the patient group. Also, 30.7% claw hand deformities and 6.9% ulnar nerve abscesses were found[20]. Most of the cited articles showed that hands, feet and eyes are the 3 main body parts affected by leprosy. The proportion is observed very different in different studies. Studies in Pakistan showed that the body parts affected in the cases were hands (21%), feet (20%) and eyes (14%)[19], and the impairments were found mostly in hands and feet (83%)[21]. Deformities observed in eyes (41%), hands (68%) and feet (82%) [21] are much different compared to the present study [eyes (76%), hands (82%), and feet (18%)].

On an average, 30% of the leprosy-affected patients' work life was lost due to disability[22] and everyone with or without disability had to face challenges in finding a job[5]. Non-deformity subject showed a significant sign in income while deformity lost income. The reduced income in leprosy patients with deformity was related both to a change in employment status and reduction in wages[23]. Similar situation has been reflected through the present study.

Studies showed that leprosy and disability created a negative impact on their lives, limiting and restricting their social participation, and they also complained about experiencing rejection, felt ashamed and became isolated, faced problems related to marriage and employment[4,5], which was very similar to the present study.

A case study in south India showed that multiple deformities due to leprosy turned a middle-aged lady to beggar from housewife after rejection from the society[17]. The present study found that 53% of the subjects having visible deformity had to change their job.

The most important thing that can be done to prevent deformities is to diagnose and treat the affected people at the very earliest stages of the disease. As an eliminated disease, it is no more on the priority list and it has already lost attention of the sector workers in Bangladesh. Only few NGOs are working on primary detection

of new cases around the country, especially to the high prevalent areas. The capacity of NGOs in terms of budget and manpower is too low. For those who already have had some nerve damages, health education in the care of hands, feet, and eyes is highly important to prevent further injury. Awareness level on leprosy and consequences needs to be increased to inspire self-reporting. But in reality, misconceptions are available even to the highly educated society. If the false impression on the disease is not changed, it will certainly be difficult to reduce the social burden and will continue as a public health problem.

Conflict of interest statement

We declare that we have no conflict of interest.

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