

Factors that Influenced and Delayed Self-reporting and Registration of Leprosy Affected People in Different Prevalence Areas of Bangladesh

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This research aims to investigate factors favouring and those hindering self-reporting. Qualitative study was conducted from April 2018 to September 2019. Total 130 leprosy-affected people (LAP) were selected for in-depth interview (IDI) proportionately from 3 strata based on prevalence of leprosy and 23 professionals for key informant's interview (KII). A semi-structured in-depth interview guide was used to collect the data and recoded for analysis. 35% of the IDI respondents were female, and 65% were male. Around half of the respondents were from rural areas, 85% were married, and three-fourths (76%) were Muslim. Amongst them, 8% had self-reported to the leprosy hospital/ clinic for the diagnosis of Leprosy. Others had visited several different places for advice before receiving a diagnosis of Leprosy. Overall, 68% had detection delay >24months. The psychosocial factors that negatively influenced self-reporting are fear of being excluded from family, relatives, neighbours and society, and fear of being separated and divorced from spouse. The other reasons for not self-reporting are non-cooperation from family members, less knowledge on leprosy, lack of information and awareness on leprosy and treatment, lack of proper motivation, and problems relating to counselling and accessibility of the health centre. If LAP delay reporting for leprosy treatment for 2-years after first symptom, the patient's condition may deteriorate with onset of disability which could have been prevented. So, public awareness about leprosy and willingness to initiate a consultation for leprosy diagnosis may reduce the burden of disability.

Keywords: Self-reporting, Detection Delay, Registration, Referral, Social Stigma, Leprosy, Bangladesh

Introduction

From ancient Vedic (1400 BC), Leprosy was known in India as "Kushtha" derived from "Kushanti", which means eating away (Thangaraj & Yawalkar 1988). Leprosy is a chronic infectious disease, caused by a slow multiplying bacillus (*Mycobacterium leprae*), characterised by

symptoms of pale and reddish skin, numbness of hands or feet or loss of feeling in a patch of skin, leading to disability (Thangaraj 1983). Self-reporting indicates the self-motivated and/ or self-initiated visits to the leprosy service provider for diagnosis and/or treatment. The time between the onset of the first lesion and

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diagnosis, is defined as detection delay (Deps et al 2006). The incubation period can be up to 20 years (Kiely 2019). The disease mainly affects the skin, peripheral nerves, mucosa of the upper respiratory tract, and the eyes; if left untreated, causing permanent damage to organs and limbs (Basel et al 2014). Leprosy is a curable disease and disability due to leprosy can be averted by early diagnosis and treatment (Britton & Lockwood 2004) but in some states of India, most of the patients ignore early leprosy symptoms due to early signs being inconspicuous, painless and of a non-troublesome, quiescent nature; they seek help only with the onset of visible or bothersome complaints (Samraj et al 2012).

In 2019 a total of 3,638 people in Bangladesh were brought under treatment as they were found as affected by leprosy while 898 people were found affected by leprosy in the first six months of 2020. About 4,000 fresh leprosy cases were being detected every year in Bangladesh and almost 8% people suffer from leprosy-related disability (LTCC 2021). Leprosy affected disabilities among detected cases were 7-11% from 2011-2017 (Sasakawa 2019) in Bangladesh, and the accumulated prevalence of leprosy-related disability amongst adults in the northwest of the country was 45.35/100,000 population (Butlin et al 2016). This indicates that many people are being diagnosed late when they already have developed a disability, shortage of expertise at all levels, inadequate human resources and financial support, delay in case detection, and no policy and non-availability of quality-assured MDT at the local level (WHO 2019). Wandering of the patient from one healer to another healer delays the start of MDT. It has long been recognized that the delay in getting medical treatment for Leprosy causes permanent physical deformities in the patient and may result in an unfavourable appearance causing other people to look at the leprosy patient with hatred (Thomas 1983). In one

study of population from rural districts of UP, Bihar and Madhya Pradesh of India, adopting native/traditional forms of therapy was a common first action. Application of neem leaf oils, bandages, mineral oils and other modes of home remedies and alternative medicine (homoeopathy, Ayurveda) were used many patients (Samraj et al 2012). Many patients take ineffective treatment for their leprosy symptoms from various types of medical/ non-medical agencies such as self-care (home remedies), medico-religious treatment, indigenous drugs, unqualified doctors, traditional healer/ quacks, qualified doctors, government hospitals, dispensaries (pharmacy/ grade-3 pharmacist) before coming to leprosy hospital/clinics. The reasons for the diagnosis delay can be categorized under medical (painless and insidious initial symptoms), cognitive (ignorance, lack of awareness, inadequate knowledge about treatment availability, lack of motivation), socio-economic (work constraints, reluctance to lose daily wages due to hospital visits, gender bias in health seeking), psychological (stigma and denial) and also time spent in pursuit of ineffective forms of treatment or doctor shopping. Worth highlighting is the finding that local medical practitioners tend to maintain a low index of suspicion for leprosy even in endemic regions (Samraj et al 2012).

Bangladesh is making efforts to achieve the leprosy elimination target at the sub-national level in some districts. But in a few districts, and Dhaka and Chattogram cities- prevalence is still above the threshold level. Furthermore, new cases are being detected from places where the prevalence is less than 2/100,000. This research has been undertaken to understand more about detection delay before reporting for diagnosis and treatment by LAP.

Materials and Methods

This is a qualitative study using quantitative analysis. In selected districts, secondary analyses

were conducted of past year's case detection data. Hospital/ clinic register books were scrutinised to identify cases with a home address outside the registration district. The duration of the study was 18 months, from April 2018 to September 2019.

Sample Size Distribution and Study Population

Total 130 leprosy-affected people (LAP) who had been diagnosed within the past five years (2015-2019) were selected proportionately by judgement method from 3 strata for interview from the study population. 72 (55%) LAP from stratum -1 were interviewed. Primary information of those patients was collected from 6-medical colleges and hospitals in Dhaka City Corporation, one district sadar hospital and one Upazila Health Complex (UHC). 24 (19%) LAP from stratum -2 were interviewed, and similarly, primary information was collected from one hospital in Chattogram City Corporation, two district sadar hospitals and one Upazila health complex. 34 (26%) LAP from stratum -3 (because stratum-4 had not found any IDI) were interviewed at a missionary hospital in Khulna City Corporation, one district chest disease centre, one district sadar hospital and two upazila health complex. All cases newly detected / on treatment in the selected districts throughout the study were reviewed (from hospital/ clinic registers), and in addition, any foreign-born or foreign returned cases identified or those known to be internal migrants were interviewed.

A total of 23 people, of them one-fourth from Government of Bangladesh (GoB) and another three-fourth from NGOs comprising of national-level experts with practical knowledge on an average 20 years of leprosy were selected by snowball method and interviewed as key informants.

Study Site

Data were collected from 3 city corporations, five districts and four sub-districts (Upazilas) following

stratum-based criteria, which were selected randomly in proportion to population size from high, medium, and low endemic areas of the country. This is according to the leprosy burden stratification prepared by the Government of Bangladesh in 2016 (Fig. 1).

Data Collection Tools and Methods

A semi-structured interviewer-administered pre-tested in-depth interview guide was used to collect the data from the affected people, and a pre-tested interview guide was used with key informants. In-depth interviews (IDI) and key informant interviews (KII) were applied for data collection. A convenience sample of cases was selected from each stratum for an in-depth interview, attempting to include a representative selection covering those registered in the home district, those registered elsewhere, and those who have lived abroad. It was considered to keep a balance between female, male and different age groups and WHO disability grading (DG) and MB and PB classification, typical of the whole patient population.

Data Entry and Analysis

A transcript was prepared from every single interview. After that, the transcripts were edited and coded appropriately. Coded data were tabulated in the Microsoft Excel sheet and categorised according to research question and objectives. Different graphs and tables were created to visualise the results, and multiple correspondence analysis (MCA) was done for explaining the variability of factors.

Inclusion Criteria

Any of the study population who are available at the time of survey and willing to participate was included. Child case was included if they were below 15 years, and agreed to participate in presence of their parents or guardian.

Exclusion Criteria

LAP who were not willing to participate in the study were excluded.

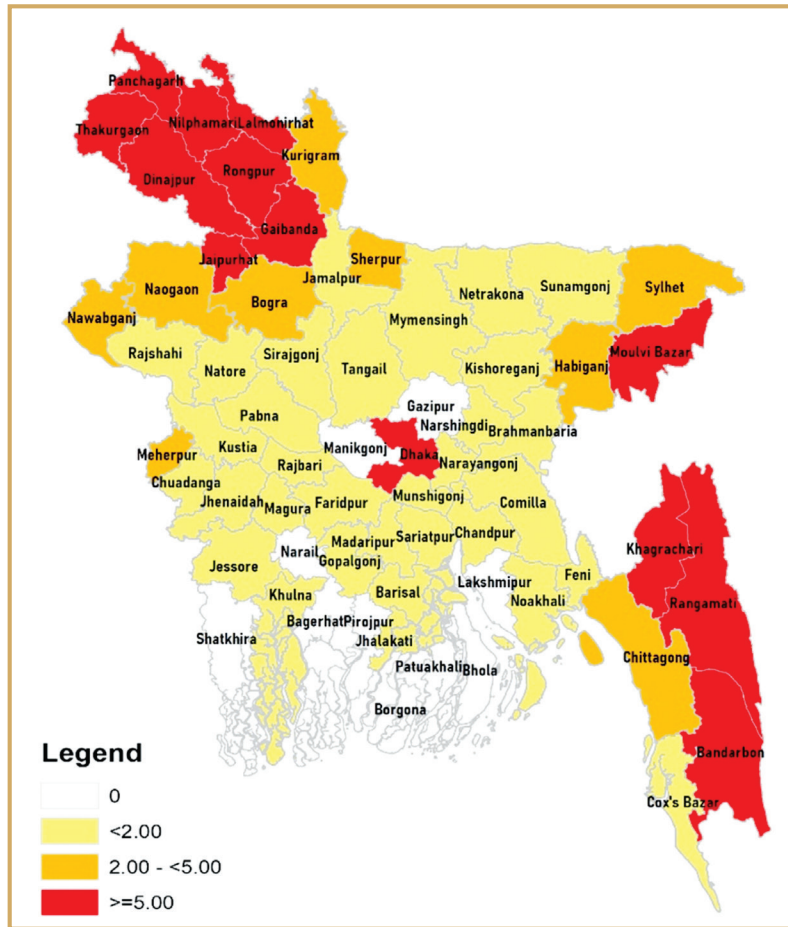


Fig. (Map) 1 : Stratification of Leprosy Burden in Bangladesh, 2016.

Stratum-1 [Red]: 12 districts plus Dhaka City Corporation (≥ 5 cases/100,000 population);
 Stratum-2 [Orange]: 8 districts plus Chattogram City Corporation (2- <5 case/100,000 population);
 Stratum-3 [Yellow]: 33 districts plus Khulna City Corporation (<2 case/100,000 population).

Ethics Statement

The National Research Ethics Committee (NREC) of the Bangladesh Medical Research Council (BMRC) in Dhaka provided clearance for this study (ref. no. BMRC/NREC/ 20016–2019/797; Dated: 14.08.2018).

Results

A total of 130 respondents have been interviewed for data collection from 17 hospitals/clin-

ics under four divisions of Bangladesh, namely Dhaka, Chattogram, Rajshahi and Khulna (72 LAP from stratum-1, 24 from stratum-2, and 34 from stratum-3).

Socio-demographic Characteristics

Table 1 shows that out of the respondents (130) involved in this study 44(34%) were adult female and 82 (63%) were adult male. One-fourth of the participants were from 16-30 years of age,

Table 1 : Distribution of respondents according to socio-demographic variables (SR: Self-reported).

Variable	Category	Frequency (SR)* Frequency: Total (SR)	Percent* (SR%) Percentage: Total (SR)
Sex (n=130; SR=11)	Female child ≤15	2	2
	Female adult ≥16	44 (5)	34(45)
	Male child ≤15	2	2
	Male adult ≥16	82 (6)	63 (55)
Age (Years) (n=130; SR=11)	≤15	4	3
	16-30	32 (2)	25 (18)
	31-40	27 (5)	21(45)
	41-50	30 (2)	23(18)
	≥51	37 (2)	28 (18)
Residence (n=130; SR=11)	Rural	62	48
	Sub-urban	21 (3)	16 (27)
	Urban	47 (8)	36 (73)
Marital Status (n=130; SR=11)	Unmarried	13 (1)	10 (9)
	Married	111 (9)	85 (81)
	Divorced/ Separated	2 (1)	2 (9)
	Widow	4	3
Education (n=130; SR=11)	Illiterate	29 (5)	22 (45)
	Can sign only	46 (3)	35 (27)
	Primary	16	12
	Secondary	31 (2)	24 (18)
	College	6	5
	University	2 (1)	2 (9)
Religion (n=130; SR=11)	Muslim	99 (8)	76 (73)
	Hindu	26 (2)	20 (18)
	Christian	5 (1)	4 (9)
Occupation (n=130; SR=11)	Day labourer	45	35
	Van/ rickshaw puller	9	7
	Driver	3	2
	Farming	9 (3)	7 (27)
	Service holder	7 (2)	5 (18)
	Small business	4 (3)	3 (27)
	Shopkeeper	3	2
	Housewife	39 (2)	30 (18)
Student	11 (1)	9 (9)	

Monthly income in Bangladeshi taka (BDT) (n=66; SR=08)	4,500-6,500	6	9
	7,000-8,500	18 (5)	27 (45)
	9,000-10,500	18	27
	11,500-13,000	13	20
	13,500-15,000	4 (2)	6 (18)
	>15,500	7 (1)	11(9)
Employment	At registration	87	
	At present	73	
Earning	Increase	02	
	Decrease	05	

*In column -3, the frequency of the total respondents of 130 within them is shown, self-reported respondents were only 11-persons that put in the appropriate rows (criteria-wise only) of the Table in parenthesis. Another column -4, represents percentage of total no of respondents (130) but within parenthesis percentage of self-reported 11-person are shown. That is, relation established in column 3 & 4 of without parenthesis of total respondents 130 and within parenthesis of self-reported 11-person –frequency & its percentage.

21% were from 31-40 years, and 23% are of 41-50 years. Four of the patients were aged less than or equal to 15 years. Around half of the respondents (48%) were from rural areas, followed by urban (36%) and sub-urban (16%). The majority of the patients (85%) were married, followed by unmarried (10%), widow (3%), and divorced/separated (2%). More than half of the IDI participants (57%) were either illiterate (22%) or can sign only (35%). Only a few of the patients had tertiary levels of education (college, 5% and university, 2%).

Three fourth of the patients (76%) were Muslim; the rest, one-fourths were Hindu (20%) and Christian (4%). Among women, most of them were housewives (30%), and of the male, most of the patients were day labourers (35%). Other occupations were rickshaw/van puller and farming of 7% each, service holder (5%), small business (3%), shop keeper and driver of 2% each. Rest 9% of the respondents were school-going students. Of the total respondents, 87 were employed at registration of Leprosy, which

decreased to 73 when interviewed. Among those who were earning, more than half (54%) of the participants monthly income were between BDT 7,000-10,500. Only 11% of the participant's monthly income were more than BDT 15,000.

Clinical Characteristics

As summarised in Table 2, 88% (114/130 patients) were newly diagnosed cases; returnees after default and relapse cases were 5% (7 patients) each and the remaining 2% (2 patients), were transferred in from other clinics. 72% (94 patients) of the IDI participants were multibacillary (MB) leprosy cases, and the rest 28% (36 patients) were paucibacillary (PB). Out of those involved in this study, passively detected cases were only 20%, of these 8% (11) were self-reported and the rest 12% were referrals having been identified as Leprosy suspect by Leprosy affected family member 7 (5%), other old patients 4 (3%), neighbour 3 (2%), and relatives 2 (2%). On the other hand, actively detected cases comprised 80%, where NGO and CRP were 40%, and Government doctors were the rest 40%. Over two-third (70%) of the IDI

Table 2 : Clinical characteristics and detection delay of IDI participants (SR: Self-reported).

Variable	Category	Frequency (SR) Frequency: Total (SR)	Percent (SR%) Percentage: Total (SR)
Type of patient (n=130; SR=11)	New case	114 (11)	88 (100)
	Transfer in	2	2
	Returned/ Defaulter	7	5
	Relapse	7	5
Leprosy group (n=130; SR=11)	< 6 Patches	PB	36 (5)
	≥ 6 Patches	MB	94 (6)
Mode of detection (n=130; SR=11)	Passive (Self-reported)	Own/ Self	11
	Passive (Referral)	Relative	2
		Neighbour	3
		Leprosy affected family member	5
		Other old patient	4
	Active (Contact examination)	By NGO worker	51
		Community resource person (CRP)	2
	Active (Diagnosis)	Government hospital doctor/ Health provider	52
Disability grade at diagnosis (n=130; SR=11)	Grade -0	Skin lesion	91 (8)
	Grade -1	Numbness	12 (2)
	Grade -2	Visible damage	27 (1)
Year of registration (n=130; SR=11)	2019	Stratum -2=2	12 (2)
	2018	Stratum -1=5; Stratum -2=1	70 (6)
	2017		19
	2016	Stratum -2=1; Stratum -3=1	25 (2)
	2015	Stratum -1=1	4 (1)
Number of providers consulted (n=130; SR=11)	Maximum		10 Services
	Minimum		1 Service
	Average		4 Services

	1-2 Services	32 (5)	25 (45)
	3-4 Services	60 (5)	46 (45)
	5-6 Services	22 (1)	17 (10)
	>7 Services	16	12
Place where First sought treatment (n=130; SR=11)	Self-care	2	2
	Magico religious practice	3	2
	“Village doctor” (Unqualified practitioner)	22 (1)	17 (9)
	Homeopathic doctor	2 (1)	2 (9)
	Traditional healer	4 (1)	3 (9)
	Pharmacy shop keeper	33 (3)	25 (27)
	Allopathic medicine doctor	28 (4)	22 (36)
	Dermatologist	4	3
	Leprosy NGO worker	1	1
	Private clinic	8 (1)	6 (9)
	Private hospital	7	5
	Leprosy hospital/ Clinic	11	8
	Government hospital	5	4
	The duration of symptom before detection (n=130; SR=11)	Maximum period	144 Months
Minimum period		6 Months	
Average period		60 Months	
6-12 Months		11 (2)	8 (18)
13-24 Months		31 (4)	24 (36)
25-48 Months		34 (3)	30 (27)
>48 Months		54 (2)	38 (18)

respondents had disability grade -0 where only skin lesions were found. 12 (9%) cases had grade -1 disability (numbness) while 27 (21%) of the leprosy patients were with grade -2 disability (visible damage). Hospital/ clinic record card data were reviewed. Among the total IDI participants, four patients had registered to the hospital/ clinic in 2015 of them one was self-reported, 25 patients in 2016 of the 2 were self-reported, 19 patients in 2017, 70 patients in 2018 of them 6 were self-reported, and 12 patients in 2019 of them 2 were self-reported. Stratum wise self-

reported cases were registered for treatment in 2019 of stratum-2 (2), in 2018 of stratum-1 (5) and of stratum-2 (1), in 2016 of stratum-2 (1) and of stratum-3 (1), and in 2015 of stratum-1 (1).

Detection Delay

The leprosy diagnosis and treatment provided by the service provider in every upazila health complex of Bangladesh were still hardly known to the community. About fifty per cent (SR: 5) of people attended appropriate health centres only after having taken 3-4 wrong treatments elsewhere. About one-sixth (SR: 1) leprosy-

affected person met with 5-6 different service providers sequentially for treatment before the correct diagnosis of their leprosy symptoms. One fourth (SR: 5) affected persons visited one or two service providers. Most of the people (33; SR: 3) at first sought treatment with medicine selling shop (pharmacy) followed by a doctor of medicine (28; SR: 4) or unqualified “village doctor” (22; SR: 1), private clinic (8; SR: 1), traditional healer (4; SR: 1) and homoeopathic doctor (2; SR: 1). In this way, about two-thirds of the patients (68%) suffered from inappropriate treatment for more than 2 years, while the average was 5 years (Table 2).

Sample stories from the 11 self-reported IDI respondents (Table 3) are given below:

From stratum -1, 4-IDI’s from the capital city for better treatment self-initiated the consultation with Dermatology Department at the renowned Government hospital and became diagnosed as Leprosy. On the other hand, 2-IDI’s from the Panchbibi sub-district of Joypurhat district came to know about the sign and symptoms of Leprosy from male NGO workers (Integrated Leprosy Service through Strengthening Health System (ILSH)) campaign. They went directly to Upazila Health Complex and were finally given correct diagnosis and treatment.

From Stratum -2: Three IDI’s from Meherpur came to know about the sign and symptoms in the leaflet about Leprosy, distributed by a local female NGO worker of Church Mission (CBSDP). Noticing similarity to their symptoms they went directly to Upazila Health Complex for diagnosis and treatment. But the other IDI saw a big signboard along the road showing clearly visible the sign similar to one on her own face and went to Upazila Health Complex with the help of NGO worker.

From Stratum -3: The one IDI respondent, a married female, aged 47 years, resides in Mirpur sub-district of Kushtia district. She was illiterate, an agricultural field worker, with a Patch in her body (PB case) visible during 2016. She went directly to the Upazila Health Complex (UHC) for diagnosis and treatment with eight (8) months delay because she knew about leprosy cases from her family members.

The Factors Negatively Influenced Self-reporting of People with Leprosy

Some psychosocial, familial, knowledge and motivation, and health-related categories negatively influence leprosy-affected people’s self-reporting (Fig. 2).

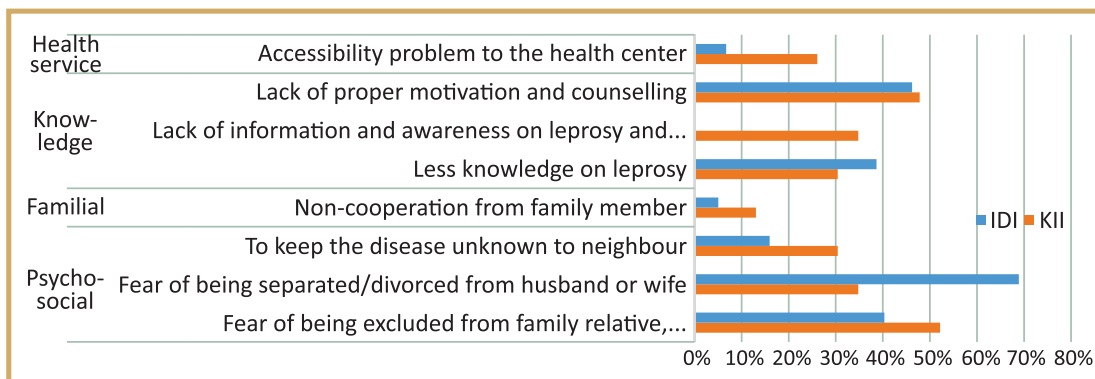


Fig. 2 : Comparison of factors identified by IDI participants and KIs on influencing not doing self-reporting.

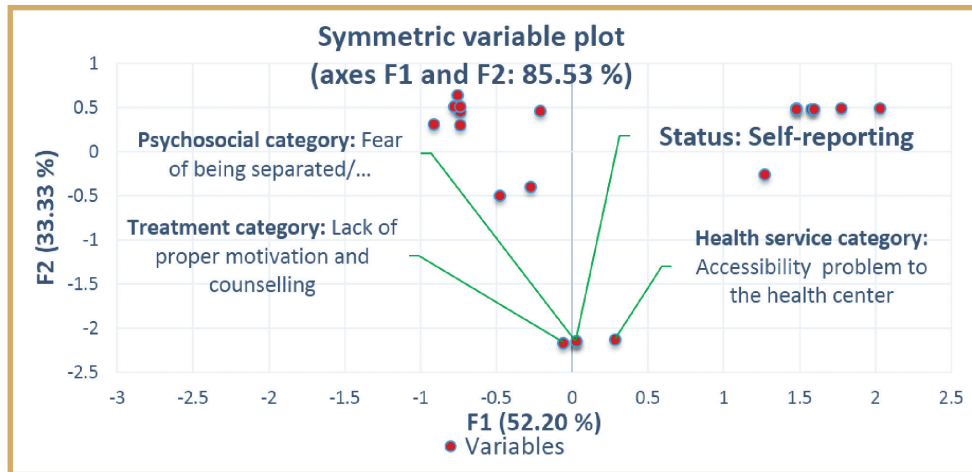


Fig. 3 : Influencing factors for not to do the self-reporting by MCA.

1. Psychosocial Category

The psychosocial categories are fear of being excluded from family, relative, neighbour, society; fear of being separated/ divorced from husband or wife; and keeping the disease secret from the neighbours. Nearly half of the key informants and two-fifth of the IDI respondents have opined that leprosy affected people delay self-reporting because of fear of being excluded from family, relatives, neighbours, society. One-third of the key informants and two-third of the IDI respondents have discussed that leprosy affected people defer self-reporting from the fear of being separated/ divorced from husband or wife. Again, one-third of the key informants and one-sixth of the IDI respondents have stated that people avoid self-reporting to keep the disease unknown to neighbours (Fig. 2).

2. Familial Category

The reasons for not self-reporting identified by both key informants (one eighth) and the IDI respondents (one-twentieth) are that people delay self-reporting due to lack of support from the family members (Fig. 2).

3. Knowledge and Motivation Category

The other factors for not self-reporting identified by key informants and IDI respondents are in the knowledge and motivation category. In this category, around fifty per cent of IDI respondents and one-third of the KIs have suggested a lack of information and awareness on Leprosy and treatment. Both IDI and KIs of around fifty per cent stated lack of proper motivation and counselling was the reason (Fig. 2).

4. Health Service-Related Category

The health service-related category includes accessibility problems at the health centre hindering self-reporting: identified by one-fourth key informants and one-sixteenth of IDI respondents (Fig. 2).

Patients instinctively hide their disease from family, relatives, neighbours, and society as they are afraid of being excluded. They live with the disease without treatment. After a while, the conditions become worse. For example, one respondent having signs of Leprosy was working in a restaurant as a cook. He was advised to visit leprosy hospital for confirmation, because of his

Table 3 : Stratrum based data of self-reported IDI respondents.

Sl. no. & strata	Socio-demographic variables					Clinical details				Prior health seeking/delay		
	Age in year, sex	Residence	Marital status/Religion	Educ Ation	Occu- pation	Earn- ings, BDT/m	Group	DG	Year of registra- tion		Prior serv ices	Site of first contact
Stratum 1												
1	27, M	Urban	Married/ Muslim	2 ^o School	Small business	14,000	MB	2	2018	5	Allo med Doctor	51m
2	38, M	Urban	Married/ Muslim	Uni- versity holder	Service holder	18,000	MB	0	2015	4	Allo med Doctor	34m
3	36, M	Urban	Married/ Muslim	Illiterate	Service holder	8,500	MB	1	2018	3	Homeo doctor	29m
4	39, M	Urban	Married/ Muslim	Can Sign only	Small business	14,000	PB	0	2018	2	Allo med Doctor	10m
5	50, M	Subur- ban	Married/ Hindu	Can Sign only	Farming	8,500	MB	1	2018	2	Allo med Doctor	16m
6	66, M	Subur- ban	Married/ Muslim	Illiterate	Farming	8,000	MB	0	2018	5	Pharma- cy shop	53m
Stratum 2												
7	40, F	Urban	Married/ Muslim	Illiterate	House wife	----	PB	0	2016	3	Pharma- cy shop	33m
8	60, F	Urban	Married/ Chris- tian	Illiterate	House wife	----	MB	0	2018	1	Pharma- cy shop	15m
9	37, F	Urban	Divorced/ Mus- lim	Can Sign only	Small business	7,000	PB	0	2019	1	Unqual. doctor	17m
10	17, F	Urban	Single/ Muslim	2 ^o School	Student	----	PB	0	2019	3	Allo med Doctor	13m
Stratum 3												
11	47, F	Subur- ban	Married/ Hindu	Illiterate	Farming	7,500	PB	0	2016	1	Allo med Doctor	8m

fear of being excluded if he was diagnosed with leprosy cases the cook did not go there.

Multiple Correspondence Analysis (MCA)

Fig. 3 shows factors associated with self-reporting by multiple correspondence analysis (MCA). The factors can explain 85.53% of the variability. Fear of being separated/ divorced from husband or wife under psychosocial category and lack of motivation and counselling under treatment related category are responsible for not doing self-reporting. Also, accessibility problems at the health centre in the health service category were identified by both IDI and KIs, major cause for negatively influenced self-reporting.

Discussion

Around half of the IDI respondents were from rural areas, followed by urban and sub-urban. Among women, most of them were housewives, and of the male, most of the patients were day labourers. More than half of the IDI respondents were either illiterate or can sign only. Among those who were earning, more than half of the participant's monthly income was marginal level. Urban residence, jobless or hand to mouth condition, lack of education and low level of earning may negatively influence the self-reporting, only one-twelfth.

It was found that 70% IDI respondents reported a patch as the first symptom, where in Uttar Pradesh, India, it is 54% (Samraj et al 2012). Other study populations had noticed numbness only 9%. The numbness preceding the patch may be regarded as an early symptom of Leprosy (Zhang et al 2009). Percentage of disability grade -2 was 21% in this study, which is the same as in the Uttar Pradesh, India (Samraj et al 2012). Harju et al (2006) have reported that both implicit and explicit attitudes play a key role in deciding when and where to seek medical care. Leprosy continues to be associated with significant stigma among communities, translating into a delay in seeking appropriate treatment and adversely

affecting their care-seeking habits (Nicholls et al 2003a). In the present study, all the patients were diagnosed with more than 6-months detection delay period but in Brazil, 65% of patients were diagnosed after a delay of 6 months (Deps et al 2006). Delay longer than six months is detrimental to the clinical outcome (WHO 1998, Nicholls et al 2003b). The mean detection delay observed was 60 months in the present study, in Uttar Pradesh, India was found to be 26 months (Samraj et al 2012), in a tertiary hospital in South India was 13 months, in Purulia, West Bengal was 18 months, and in Nilphamari, Bangladesh was 20 months (Nicholls et al 2003a, Renita et al 2010). Reasons for delay varied from ignorance about the symptoms and signs of the disease, monitoring of symptoms in the hope that they would disappear by themselves and lack of vigilance among local medical practitioners in the lower levels of the health system (Samraj et al 2012).

Most patients in Uttar Pradesh, India, ignore early leprosy symptoms due to their painless, quiescent nature and seek help only with the onset of visible or bothersome complaints (Samraj et al 2012). About one-sixth Leprosy affected people met with 5-6 different service providers sequentially for their treatment. Only one-fourth of the affected person visited between one or two service providers. In study population from rural districts of UP, Bihar and Madhya Pradesh; adopting native/traditional forms of therapy was a typical first action. Application of neem leaf oils, bandages, mineral oils and other modes of home remedies and alternative medicine (homoeopathy, ayurveda) were tried by some patients (Samraj et al 2012). Most of the study population first sought treatment with drug selling shop (pharmacy) followed by qualified medicine doctor and unqualified "village doctor". The first contact with the health service was usually a local medical professional (quacks,

PHC medical officers, private GP/dermatologist) (Samraj et al 2012). In this study, symptoms of Leprosy triggered about fifty per cent of people to attend inappropriate health centres, with 3-4 wrong treatments being received before the diagnosis of Leprosy was made. The considerable number of misdiagnoses/ delays in suspecting Leprosy among the local medical practitioners proved to be a determining factor in keeping the patient from the start of effective treatment and have been referred to leprosy hospital only on developing ulcers or visible physical deformities (Samraj et al 2012). In this way, two-thirds of the patient suffered with wrong treatment for more than two years. Ultimately, three-fourth of patients were multibacillary (MB) leprosy cases in the present study. Bacillary index and disability grade at presentation are objective indicators of delay (van Brakel et al 2004).

In case of self-reporting, stratum wise IDI respondents ratio is Stratum -1 (higher prevalence) =6/72 : Stratum -2 (moderate prevalence) =4/24 : Stratum -3 (lower prevalence) =1/34 which indicate who was aware of the sign and symptom of Leprosy and also the correct decision was taken to select the appropriate physician, they became diagnosed and escape from disability grade -2 (except one). In Stratum -2, female NGO workers had played a vital role in being aware of the Meherpur district population to show the sign and symptoms of Leprosy by leaflet distribution among the community. The potential role of Anganwadi workers and ASHAs for diagnosis of leprosy among women, which may otherwise go unreported or unnoticed because of their low social status and limited mobility, is noteworthy in India (Samraj et al 2012).

Both key informants and IDI respondents have recognised fear of being excluded from society or family or being separated/ divorced from husband or wife among the causes of delayed

self-reporting. This shows the existence of stigma to the person, family, neighbour, and society. One-third of the key informants think fear of being separated, divorced from a husband or wife plays a vital role not to self-register, and more than two-thirds of the IDI respondents think so. The reasons for detection delay are socio-economic (work constraints, reluctance to lose daily wages due to hospital visits, gender bias in health-seeking), and psychological (stigma and denial) (Samraj et al 2012). More than half of the key informants have identified fear of being excluded from family, relatives, neighbours and own community is responsible to not to be self-reported at the early time but 40% respondents showed similar thinking for this factor. The almost same percentage of the key informants and respondents think lack of proper motivation and counselling can influence leprosy cases, not to self-report. Reasons for delay varied from ignorance about the symptoms and signs of the disease, monitoring of symptoms in the hope that they would disappear by themselves and lack of vigilance among local medical practitioners in the lower levels of the health system (Samraj et al 2012). One third of the key informants, but more than one-third of respondents consider lack of knowledge on leprosy can be an important factor in failing to self-report at an early stage for leprosy cases. More than one-third of the key informants think lack of information and awareness on Leprosy and treatment is one of the factors for not self-reporting, but no IDI respondents believe so for the leprosy cases. With the advent of mass information, education and communication (IEC) strategies and easy accessibility of free multidrug therapy (MDT), delay in treatment is more dependent on patient's initiative and subsequent health seeking habits (Samraj et al 2012). One-third of the key informants and one-sixth IDI respondents recognised that leprosy affected people are reluctant to self-report being

influenced to keep secret their disease from the neighbour. Inversely Samraj et al (2012) reported that a significant portion of the study population presented at the referral hospital only when advised by neighbours/ relatives, a fact which emphasises the role of word-of-mouth as a means of mass communication. A few key informants and IDI respondents think that non-cooperation from leprosy affected families can be a factor for not willingly reporting for leprosy treatment.

Conclusions

Leprosy affected people defer self-reporting from the fear of being separated/ divorced from husband or wife. To avoid anxiety, both clinic staff and contact examiner should keep them discrete during diagnosis and the result in veil.

Many of the people consulted inappropriate health service providers before having proper treatments. In many cases, they go to a medicine-selling shop and ask for treatment whereas the TB/ leprosy clinic is available in most of the sub-districts of Bangladesh; thinking it is for TB only, often the public do not recognise it for the Leprosy treatment.

Self-reporting of affected person is to be encouraged, and delay in detection and treatment has to be reduced for eliminating leprosy. For this, the government and non-government organisations will have to work to improve leprosy clinics' services, organise motivational campaigns through mass media, billboards, etc. to reduce stigma, and promote self-reliance.

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