

## Factors Influencing Leprosy-Affected People for Migration, Distant Registration and their Effect on Leprosy Services in Bangladesh

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The research investigated factors affecting migration, distant registration and their expected effects on leprosy service in Bangladesh. This qualitative study was conducted from April 2018 to September 2019. 130 leprosy-affected people (LAP) were selected for in-depth interview (IDI) and 23 professionals for Key informant's interview. A Semi-structured interview guide was used for data collection. Different factors were identified by key informants (KIs) and IDI participants (IDIPs) both for migration and for distant registration. Main factors for migration of LAP, mentioned by both groups, were fear of social exclusion. Lack of treatment facilities under the treatment category, job transfer under financial category and marriage under the personal category are the other main influencing factors for migration. Reasons for leprosy cases registering in distant places are similar to reasons for migration: lack of expert professionals under treatment category, relatives' influence under the personal category and job transfer under the financial category. It is concluded that migration and distant registration should be considered in studying the geographical distribution of leprosy. Interpretations proposed by key informants may not reflect the actual field situation. The opinions of those directly affected by leprosy should be sought and heeded in designing and evaluating leprosy programmes.

**Keywords :** Leprosy Control, Leprosy-Affected People, Registration, Migration, Geographical Distribution

### Introduction

Despite being known as an ancient disease, leprosy is still a problem in the modern world that can lead to physical deformities and disabilities

that cause stigmatisation. Leprosy, which is known as one of the Neglected Tropical Diseases (NTD), occurs in more than 120 countries with an exceeding 200,000 new cases every year. Globally,

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207,624 and 202,185 new cases were detected in 2010 and 2019, respectively that representing a global decrease of 5,439 cases in ten years and the similar trend was observed in Bangladesh that 3,848 new cases diagnosed in 2010 and 3,638 new cases in 2019 was a decrease of only 210 cases (WHO 2020).

Almost constant new case detection rates over the past 15 years suggests that undetected cases are still infecting other people before they are diagnosed and treated. The number of new cases detected per year reflects trends in incidence rates, provided that no significant changes occur in case of detection efforts, self-reporting behaviour, or diagnostic procedures or criteria (Beyene et al 2003).

Over 120 upazilas (sub-districts) in Bangladesh are endemic for leprosy (National Leprosy Program 2019); several districts, as well as Dhaka and Chattogram cities, still exist where registered prevalence is more than the lower limit of 1/10,000 population. Furthermore, new cases are also being detected from places where the prevalence is less than 2/100,000. In districts with low registered prevalence rates, provision of leprosy services is not a priority, and new cases occurring there may go elsewhere to obtain leprosy treatment (distant registration). From the underdeveloped rural districts in the North-western of the country, which have the largest proportion of leprosy cases, the movement of people into the cities further south is a major social trend (Marshall & Rahman 2013). It is likely that amongst the rural to urban migrants moving into lower prevalence districts, there are many undiagnosed leprosy cases who will present for treatment in the new district (internal migrant cases), but this has not yet been investigated.

Studies of migration have looked at “Push and Pull factors”, at the age/ gender distribution of migrants, at employment and housing issues

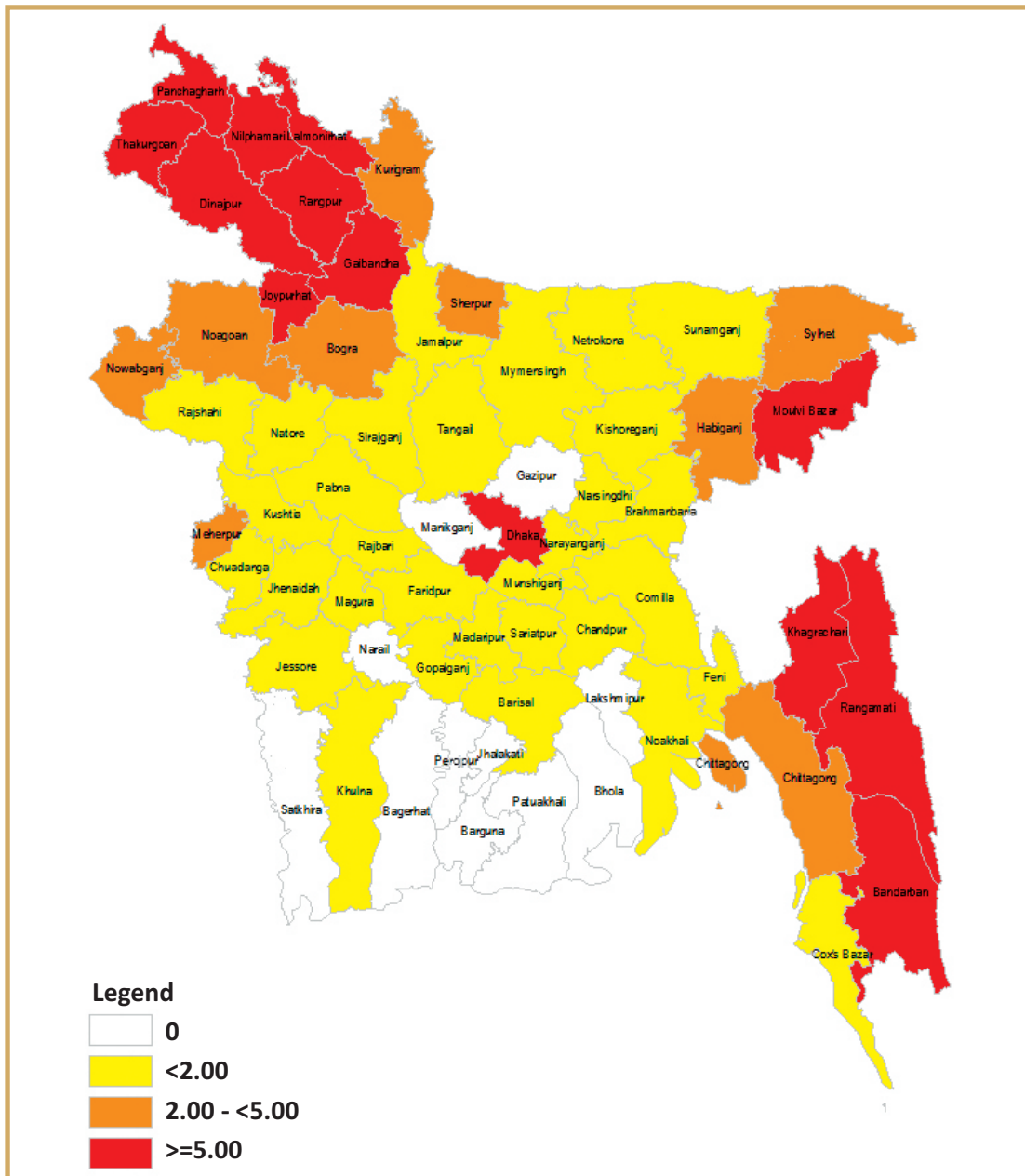
(Afsar 2003, Uddin & Firoj 2013) but less attention has been paid to the health needs of the migrants or health-related reasons for migration. Farhana (2015) has shown a variety of reasons of which economic factors appear dominant for internal migration but both physical and social factors also influence the process in Bangladesh.

In Bangladesh, information on the geographical distribution of leprosy is obtained from the numbers of registrations in each district, but this may not truly reflect current geographical patterns of transmission.

Diagnosis and treatment of leprosy in internal migrants (people who move to live in another region / district of the same country), and duplicate registrations in different districts, and patient selection of reporting places other than their home district, were issues raised in a recent discussion with national program managers. Although there are a few publications relating to cause and effect of migration in leprosy transmission and disease control for other countries, there is little evidence regarding factors influencing migration/relocation of leprosy patients, complications in disease control relating to migration, and factors influencing distant registration. Clarifying the reasons why leprosy-affected people feel compelled to move or to avoid registration in their birthplaces will help the national program managers to plan services to meet their needs. Thus the research aims to identify reasons for migration immediately prior to and soon after diagnosis of leprosy, and the factors influencing distant registration, and to consider their likely impact on district-wise registered prevalence rates in Bangladesh.

## **Materials and Methods**

This is a qualitative study with some quantitative analysis using data collected from April 2018 to the end of September 2019. Hospital/ clinic registers were scrutinised to identify cases who



**Stratification criteria**

- Stratum-1 [Red]:** 12 districts plus Dhaka City Corporation ( $\geq 5$  cases/100,000 Population)
- Stratum-2 [Orange]:** 8 districts plus Chittogram City Corporation (2- <5 cases/100,000 Population)
- Stratum-3 [Yellow]:** 33 districts plus Khulna City Corporation (<2 cases/100,000 Population)
- Stratum-4 [White]:** 11 districts have "zero" reported cases.

**Fig. 1 : Stratification of leprosy burden in Bangladesh**

registered after 2015 with a home address outside the district of registration.

As study sites, 3 city corporations, 5 districts and 4 sub-districts (upazilas) following stratum-based criteria were selected randomly in proportion to population size from high, medium and low endemic areas of the country. Fig. 1 (Map) shows the stratification of Leprosy burden prepared by the Government of Bangladesh (GoB) in 2016, based on registered prevalence rates then current.

### **Study Population**

#### **In-depth interview of participants**

Any cases newly detected/ on treatment in the selected districts and, in addition, any foreign-born or foreign-returned cases. Key informants interview participants: People who have knowledge on leprosy and migration of the selected district and national level.

A total of 130 in-depth interviews (IDI) were conducted with leprosy-affected people (LAP) chosen proportionately from 3 strata. 72 LAP (55%) from stratum-1 (higher prevalence), 24 LAP (19%) from stratum-2, and 34 LAP (26%) from stratum-3 (lowest prevalence) were interviewed. From stratum-1, LAPs were collected from 6-medical colleges and hospitals in Dhaka City Corporation, one district sadar hospital and one upazila health complex; from stratum-2, LAPs were collected from one hospital in Chattogram City Corporation, two district sadar hospital and one upazila health complex; from stratum-3, LAPs were from a mission hospital in Khulna City Corporation, one district chest disease centre, one district sadar hospital and two upazila health complex. In the same areas where LAPs were interviewed, local government health staff and staff of NGOs working in leprosy were approached for suggestions for suitable people for KI interviews. Total 23 people knowledgeable on leprosy and migration were selected and inter-

viewed as key informants (KI). Data was collected from In-depth interviews and key informant interview using Semi-structured pre-tested in-depth interview guides. A convenience sample was taken at each site. Any of the eligible study population who were available at the time of the survey and willing to participate were included. Child cases were included if they were old enough to agree and in the presence of their parents or guardian.

All subjects were informed verbally in their own language (Bengali) about the study, its objectives and benefits and given the freedom to withdraw from the study at any time and without showing any reason. All participants were requested to sign to confirm informed consent, and the study investigator also signed. For children, parents or guardians signed the consent letter.

All field data were recorded on paper initially, then transcripts were prepared for analysis and then entered into a database. These data were sent to the Khulna University, protecting the individuals' confidentiality by use of unique identifying numbers instead of names. Quality checks on all aspects of the data collection and entry were completed regularly, and feedback on the results was given to the field staff and the data entry operator. Transcripts had been prepared from every single interview, then edited and coded appropriately. Coded data were tabulated in Microsoft Excel sheet and categorised it according to the aim of the study. Different graphs, tables, and multiple correspondence analysis (MCA) output were generated to visualise the results. The justification for using MCA was that it is a data analysis technique suitable for nominal categorical data that allows studying the association between two or more qualitative variables to give a general understanding of how categorical variables are related.

**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).

**Table 1 : Distribution of respondents according to socio-demographic variables**

Variable	Characteristics	Frequency	Percent (%)
<b>Gender (n=130)</b>	Female	46	35
	Male	84	65
<b>Age (years) (n=130)</b>	≤15	4	3
	16-30	32	25
	31-40	27	21
	41-50	30	23
	≥51	37	28
<b>Residence (n=130)</b>	Rural	62	48
	Sub-urban	21	16
	Urban	47	36
<b>Education (n=130)</b>	Illiterate	29	22
	Can sign only	46	35
	Primary	16	12
	Secondary	31	24
	College	6	5
	University	2	2
<b>Occupation (n=130)</b>	Day labourer	45	35
	Van/ rickshaw puller	9	7
	Driver	3	2
	Farming	9	7
	Service holder	7	5
	Small business	4	3
	Shopkeeper	3	2
	Housewife	39	30
	Student	11	9
<b>Unemployment increase (n=14)</b>	At diagnosis	43	33
	At interview	57	43
<b>Monthly income in BDT (n=66)</b>	4,500-6,500	6	9
	7,000-8,500	18	27
	9,000-10,500	18	27
	11,500-13,000	13	20
	13,500-15,000	4	6
	>15,500	7	11

## Results

### Characteristics of IDI Participants

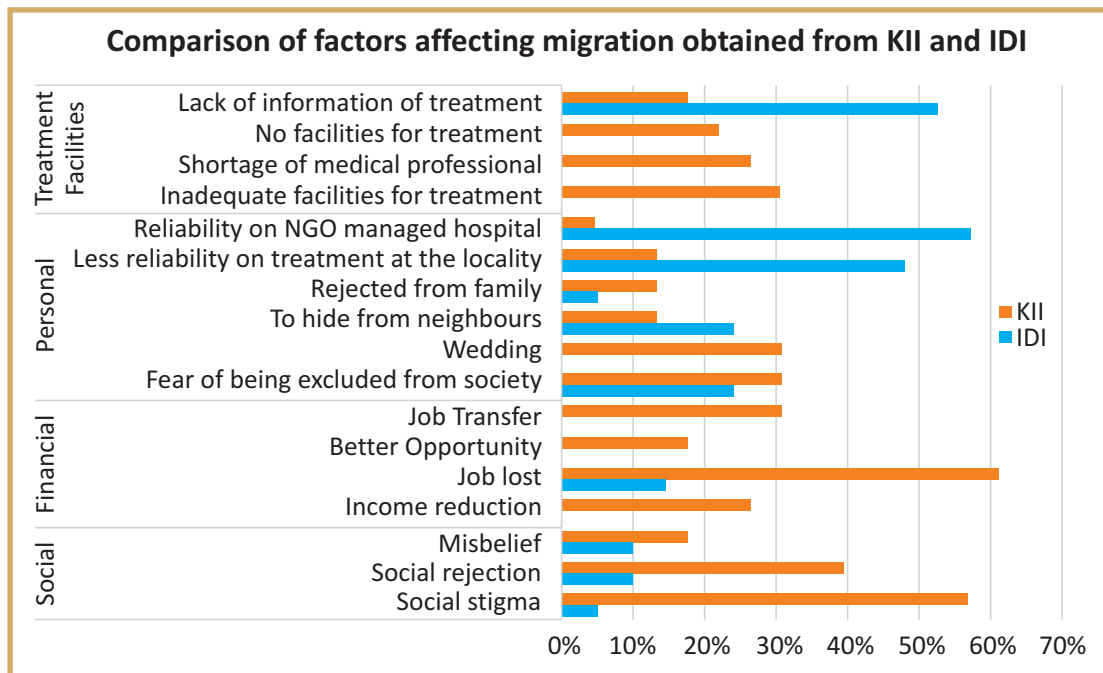
Socio-economic, clinical characteristics, and migration and distant registration-related conditions of leprosy-affected IDIPs are described here. Table 1 shows the socio-demographic characteristics of IDIPs: out of 130 IDI participants (IDIP) involved in this study, 46 (35%) were female, and 84 (65%) were male. One-fourth of the participants were from 16-30 years of age, 21% were from 31-40 years, and 23% were 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%). More than half of the participants (57%) were either illiterate (22%) or can sign only (35%). Among women, most of them were housewives, and amongst the males, the largest group of the patients were day labourers. Of the total participants, 33% reported that they had been unemployed at registration of leprosy, but 43% were unemployed when interviewed. Among those who were earning, more than half (54%) had a monthly income between BDT 7,000-10,500 (US\$ 85-125).

As seen in Table 2, of the total, 88% (114 patients) were newly diagnosed cases, 5% (7 patients) were returnees after default, 5% (7 patients) were

**Table 2 : Distribution of respondents according to their clinical characteristics and history of migration and distant registration**

Variable	Characteristics	Frequency	Percent (%)	
Type of patient (n=130)	New case	114	88	
	Transfer in	2	2	
	Returned/ defaulter	7	5	
	Reaction/ relapse	7	5	
Type of leprosy (n=130)	PB	36	28	
	MB	94	72	
Disability grade at diagnosis (n=130)	Grade -0	91	70	
	Grade -1	12	9	
	Grade -2	27	21	
Migration (n=109)	Circular movement (n=76)	76		
	Relocation (n=109)	Rural to Rural (66)	61	
		Rural to Urban (97)	89	
		Urban to Rural (10)	9	
		Urban to Urban (6)	6	
	Internal migration (n=7)	7		
	International migration (n=14)	The Kingdom of Saudi Arabia (3)	21	
Sultanate of Oman (1)		7		
The Republic of India (10)		72		
Distant registration (n=60)		60		



**Fig. 2 : Comparison of factors for migration identified by IDI participants and KIs**

with reaction/relapse, and the remaining 2% (2 patients) were transferred to other categories. 72% (94) of the patients were multibacillary (MB) leprosy cases, and the rest 28% (36 patients) were paucibacillary (PB). Over two-thirds (70%) of the participants had no disability, 12 (9%) had grade-1 disability, while 27 (21%) of the leprosy patients had a grade-2 disability (Table 2).

Table 2 shows that out of 130 IDIP, 109 had more or less migration or relocation history; amongst them 76 respondents have had daily/ weekly/ monthly or yearly commuting movement only within their own district: in the local market, tea stall, prayer centre, gossiping area, agricultural field. 109 respondents became relocated of more than two days up to 15 days for meeting their relatives or engaging in agricultural activities outside from their own sub-district. The relocation was highest between rural to urban (97) and then rural to rural (66), urban to rural (10) and the

lowest of urban to urban (6). A few respondents (8) reported internal migration for seeking a job and/or hiding from neighbours on account of stigma. Among the total respondents, around fifty percent (60 IDIPs) were distant registration cases. Most of the distant registration cases were attracted to a leprosy specialist hospital.

#### **Factors Associated with Migration**

The factors for migration of leprosy-affected people have been categorized into social, financial, personal, and treatment facilities, which are briefly discussed below. The comparison of factors identified by both KIs and IDIPs are shown in Fig. 2. The social factors are perceived social stigma, social rejection, and misbelief. The financial factors are income reduction, job loss, better opportunities and job transfer. The personal factors are rejection by or fear of being excluded from the family, marriage, hiding from neighbours, less trust in treatment at the



locality and reliance on NGO managed hospitals; the treatment factors are inadequate or no facilities for leprosy treatment, shortage of medical professional for leprosy care, and lack of information.

### **1. Social Factors**

Social stigma is a social, mental effect, and it causes discrimination. 57% of the KIs believed it was a cause of migration, but only 5% of the IDIPs who had experience of migration claimed that their moving was due to social stigma. Social stigma is observed more in the low prevalent area compared to high prevalent areas. Similarly, more than one-third of the KIs (39%) give social rejection as a reason, while only 10% of the IDIPs have this opinion. According to 17% KIs and 10% IDIPs have mentioned misbelief as a reason for the migration of LAP.

### **2. Financial Factors**

Four factors were proposed which may have influenced migration. The first was Job lost (identified by 61% KIs and 14% IDIPs), and the other three were identified only by KIs and not by IDIPs: reduction in income (25% KIs and 0% IDIP), better opportunity (17% KIs and 0% IDIP), and Job transfer (30% KIs and 0% IDIP). Income reduction happens for various reasons, such as change of job nature, and reduction in working hours due to sickness. Although no IDI participant mentioned it, the interviewer noticed that at least 5 LAPs had income reduction due to their reduced physical ability. They could not cope with a full-time job due to sickness. According to the key informants, job transfer could happen in either of two ways: the employer transfers the patient after recognising the disease or the patient deliberately initiates a transfer to hide the disease from colleagues and neighbours.

### **3. Personal Factors**

It appears that many patients lack faith in local services, and 57% IDIPs migrated to avail themselves of treatment at one of the NGO hospitals which specialise in leprosy care.

Similarly, less trust on treatment is a reported reason (48% IDIPs and 13% KIs). It was seen from the field that healthcare professionals at the locality had less knowledge on leprosy. They treat leprosy as a skin disease and usually take a longer time to diagnose it correctly. As a result, the disease condition becomes worse, and sometimes disability arises. In this regard leprosy-affected people need to move from there to somewhere specialised leprosy care is available.

Thirty percent KIs and 24% IDIPs identified that LAP migrate from the fear of being excluded from the social activities if their diagnosis is disclosed. The fear of leprosy leads to stigma and discrimination which is due to a lack of understanding and knowledge about leprosy in society. This factor is closely related to the tendency of the LAP to hide their diagnosis from their neighbours, relatives and even the family members (13% KIs and 24% IDIPs).

A minority of IDIPs and KIs felt that, due to the burden on family member and their negative views, sometimes the affected people are rejected from the family (5% IDIPs and 13% KIs) and then the LAP migrates. About one-third of the KIs mention marriage as a factor for the migration of leprosy-affected people, but—perhaps surprisingly—IDIPs did not mention it.

### **4. Treatment Related Factors**

KIs expressed it differently from IDIPs, but they also imply that there is justification for the tendency to seek treatment at distant NGO hospitals rather than locally. KIs identified a few factors for which LAP migrates, which have not been mentioned by IDIPs during the survey, like inadequate facilities



for leprosy treatment (30% KIs) at their localities; no facilities for treatment (22% KIs); shortage of medical professionals (26% KIs). IDIPs mentioned lack of information on local availability of treatment as the main treatment-related factor for migration. Some 17% KIs recognised this factor also, and the research team themselves observed Health professionals who had deficient knowledge of leprosy.

**Problems Likely to be Caused by Migration of LAP**

The problems identified by KIs have been categorized into three areas: problems related to disease spreading, treatment, and national statistics and planning.

**1. Problems Related to Disease Spreading**

Disease spreading includes increased risk of spreading, hinder contact survey, an increase of MB patients, and presence of many undetected cases (Fig. 3). 80% of the KIs acknowledged that migration increases the risk of spreading into other areas when an untreated MB patient migrates. Delay in diagnosis may increase the proportion of new cases who are MB and potentially infectious. One-fourth of the key informants think that cases remain undetected for longer due to migration. One-fourth of the KIs opined that the proportion of MB patients increases with the migration of patients and one-fifth KIs mentioned that migration

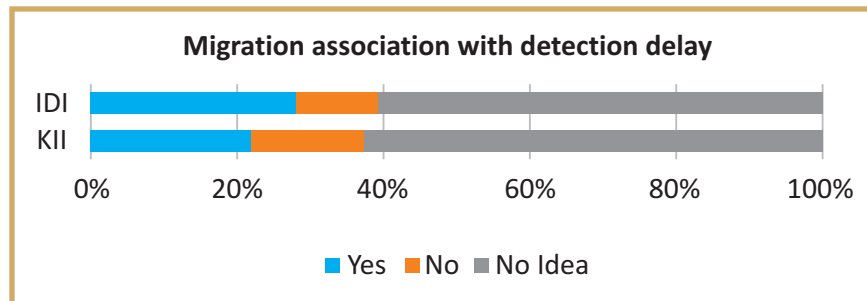


Fig. 3 : Comparison of migration as a factor for detection delay identified by IDI participants and KIs

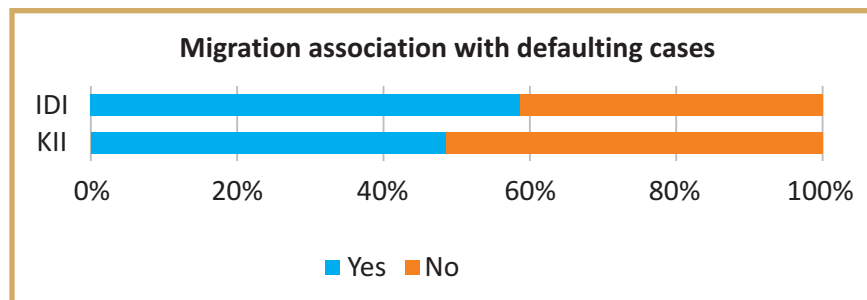


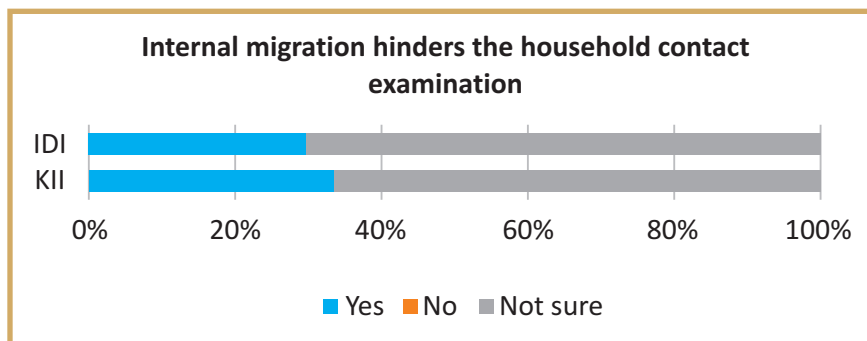
Fig. 4 : Comparison of migration as a factor for defaulting identified by IDI participants and KIs

hampers the household contact check-up of affected people's family as this process is the key method to find out new leprosy cases early.

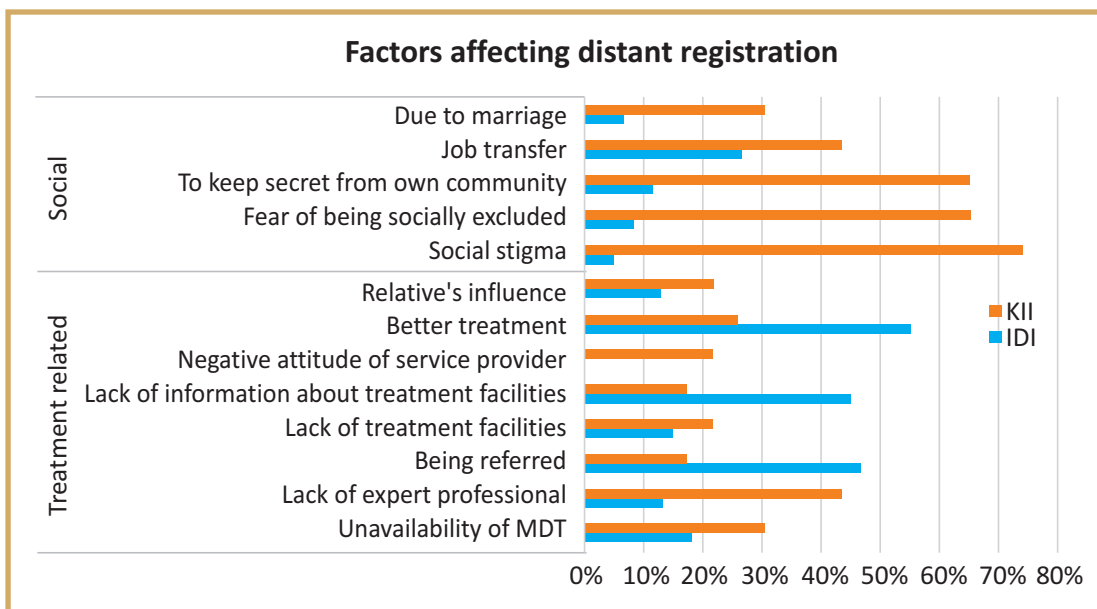
**2. Problems Related to Treatment Compliance**

When a patient moves to a new area, the treatment related problems are difficulties

in regular treatment, increased disability grade, problems of following up, more reaction occurs, increased drug resistance, and increased defaulting. Two-thirds of the KIs opined that if a patient moves to new areas from the place of registration, this creates difficulties in regular treatment and



**Fig. 5 : Comparison of factors that hinder the household contact examination identified by IDI participants and KIs**



**Fig. 6 : Comparison of factors of leprosy cases to be registered in distant place identified by IDI participants and KIs**

chance to increase the disability grade. Two-fifth of the KIs opined that follow up problems arise and drug resistance may occur if a case migrates to new areas. Again, one-fourth of the KIs opined that default cases may occur due to migration (Fig. 4).

**3. Problems on National Statistics and Planning**

One-fourth of the KIs opined that migration may have an effect on national statistics, either by double registration or because the case is not registered where he was infected. It may increase/ decrease the prevalence and incidence rate of new cases of a geographical location. Similarly, it affects national level resource planning. One-third of the KIs opined that migration of LAP has an effect on national resource planning. If data are inaccurate, resource allocation will also be inappropriate and inefficient (Fig. 5).

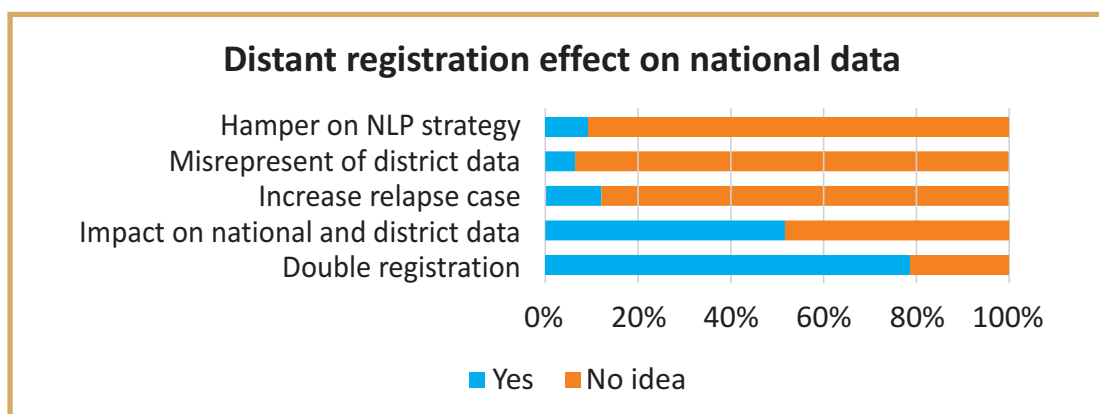
*“In my experience while working with leprosy patients, I have found a lot of case diagnosed at late stage due to migration to other district. They come to clinic for treatment to the new areas after worsening the situation, wasting much time”* commented by a KI.

**Reasons of Leprosy Cases to be Registered in Distant Place**

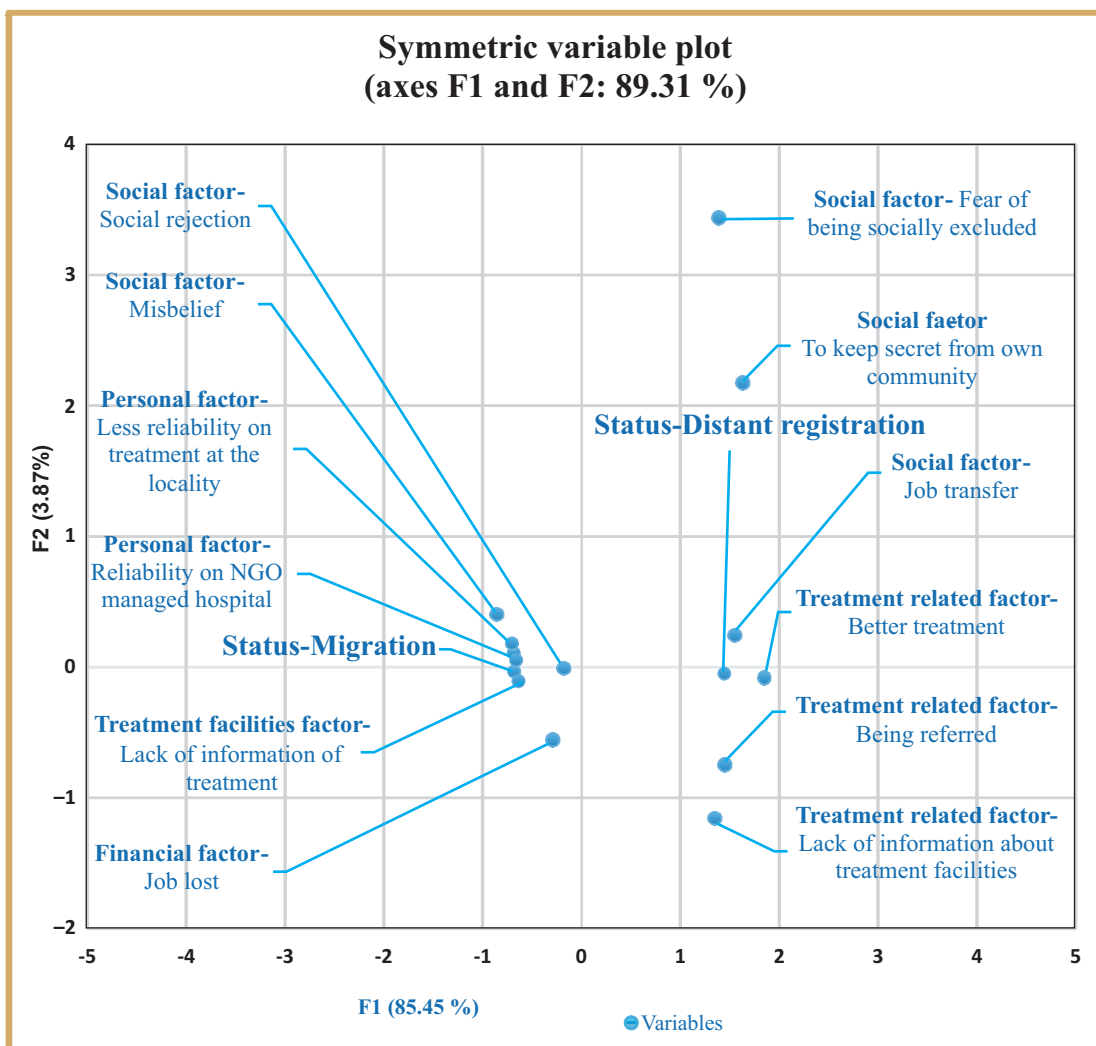
The reasons of leprosy cases to be registered in distant place are very similar to the factors affecting migration (Fig. 6).

**1. Social Reasons**

The factors are social stigma, fear of being excluded from the family, to hide from society, job transfer, weddings, and relatives' influence. Three-fourth of the key informants opined that leprosy-affected people go for distant registration due to social stigma but only 5% of the IDI participants agreed with the statement. Similarly, two-thirds of the KIs, but less than one-tenth of IDIPs, opined that leprosy-affected people go for distant registration due to fear of being excluded and to keep the disease secret from the family, community, or society. Three-fourth of the KIs and 27% IDIPs believe that marginal leprosy-affected people are driven from their locality for job opportunities, and then register in place of working. Sometimes LAPs migrate due to marriage and do register in a distant place (30% KIs and 7% IDIPs). Only



**Fig. 7 : Perception of leprosy affected people and key informants of distant registration effect on national data**



**Fig. 8 : MCA represent the influencing factors opined by IDI participant for migration and distant registration**

22% of the key informants and 13% of the IDI participants recognised that relatives have an influence for distant registration; however, the relatives' influence may be either positive or negative.

## 2. Treatment Related Reasons

Many KIs (and to a lesser extent IDIPs) apparently believe that local facilities are

not adequate or are not used because they are not known to be available. The factors mentioned are discussed below:

Unavailability of MDT (30% KIs and 18% IDIPs), lack of expert professionals at the local area (43% KIs and 13% IDIPs), lack of treatment facility at the locality (22% KIs and 15% IDIPs), lack of information about local

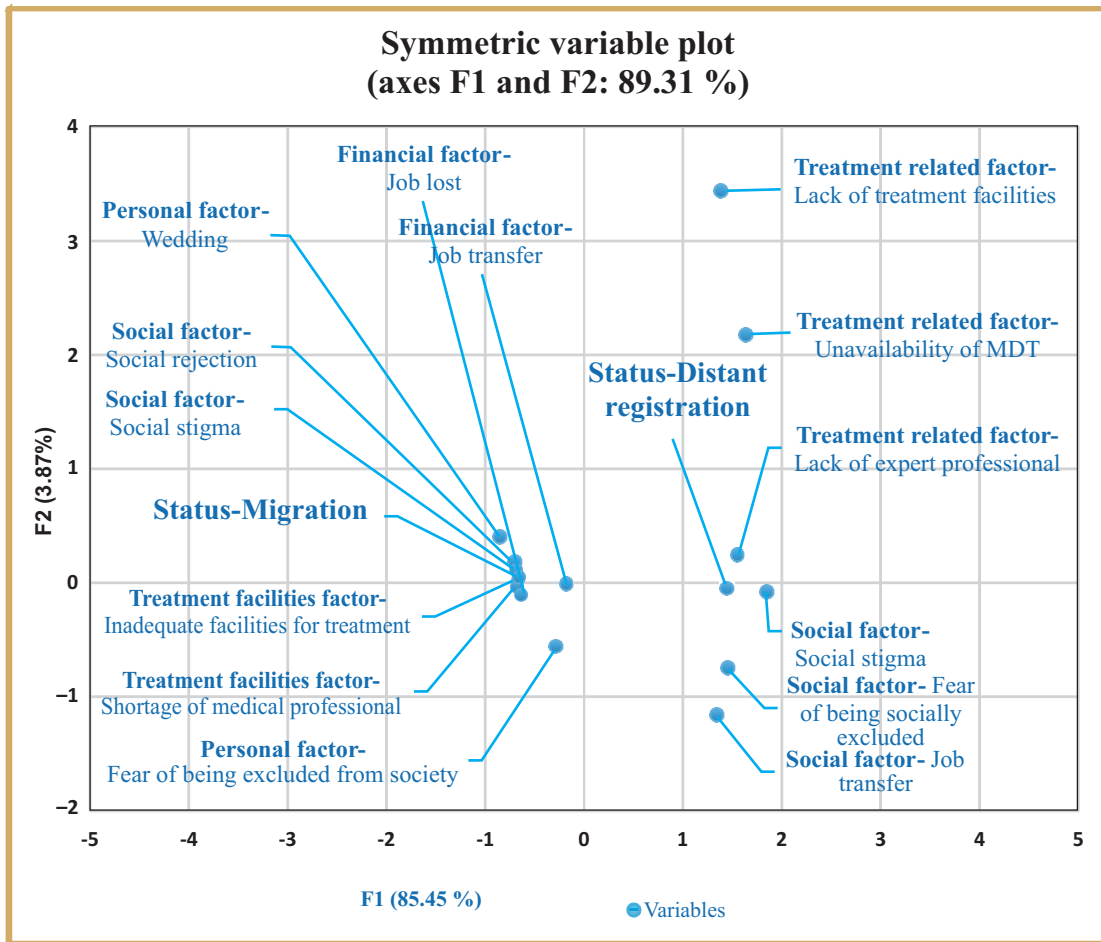


Fig. 9 : MCA represent the influencing factors opined by KI for migration and distant registration

treatment facility (17% KIs and 45% IDIPs) are the treatment-related factors that impel LAPs to do distant registration. Similarly, few key informants (17%) and around half (47%) of the IDI participants opined that leprosy-affected people do distant registration after being referred by local staff to a distant specialized leprosy care hospital for better treatment. Only one-fifth of the KIs opined that LAPs sometimes do registration in distant place specifically because of the negative attitude of service providers. LAPs in

some survey areas have the mindset that treatment facilities are not satisfactory in their local hospital/ clinic. One-fourth of the key informants and more than half of the IDI participants opined that LAPs do distant registration to get better treatment.

**Problems Caused by Distant Registration of LAP**

A few of the key informants have opined that distant registration may increase relapse cases, misrepresent district data, and hamper proper strategy on the National Leprosy Program (NLP): it causes the high registered prevalence rates in

city areas i.e. Dhaka, Chattogram; some districts show registration rates that do not reflect the true new case detection rates amongst their population, either too low or zero and in some areas too high; and it also affects the NLP strategy because NLP makes their activity plan according to registered prevalence (Fig. 7).

- **Multiple Correspondence Analysis of IDIP**

Multiple correspondence analysis (MCA) supported the IDI participants' opinion. Fig. 8 shows factors associated with migration and distant registration by MCA and 85.45% of the variability can be explained by the factors. MCA supported the IDI participants' opinion that social rejection and disbelief under the social category, job loss under financial category, reliability on NGO managed hospitals under the personal category, and lack of information of treatment under the treatment facilities category are the main influencing factors for migration. Similarly, better treatment under treatment-related category and job transfer under the social category are the main influencing factors for distant registration.

- **Multiple Correspondence Analysis of KI**

Multiple correspondence analysis (MCA) supported the key informants' opinion. Fig. 9 shows factors associated with migration and distant registration by MCA, and 85.45% of the variability can be explained by the factors. MCA supported to the key informant's (KI's) opinion that social stigma under the social category, inadequate facilities for treatment under the treatment facilities category, job lost under financial category and wedding under personal category are the main influencing factors for migration. Similarly, lack of expert professionals under treatment-related category and social stigma under the social category are the main influencing factors for distant registration.

## Discussion

In this study, the IDI guide was different from that used for KI, but some questions asked were similar. In those cases, the responses have been carefully compared to understand the actual situation and reasons for the gap. We have found differences in responses in several areas and the possible reasons for differences are that the responses of KIs were mostly theoretical (whereas IDIPs responded from recent lived-experience). In some cases, we found that the KIs had responded from their previous professional experience, and most were not directly involved in the leprosy program at the time of the survey. On the other hand, the IDI participants were infected and suffered within last 5 years (2015-2019). They moved hospitals, experienced treatment systems, and had up-to-date knowledge regarding leprosy.

Moreover, leprosy services are mostly available in Stratum -1 where leprosy cases are more prevalent compared to the other two strata. Government organizations and NGOs are actively working in those areas to reduce the burden of leprosy. Due to NGO and government's activities in most of the prevalent areas, the IDI participants had suffered lower social stigma and prejudice regarding leprosy and leprosy patients. But the KIs, in some cases, had preconceptions and responded accordingly.

In this findings, 72 (55%) IDI participants were from the Stratum -1 where leprosy prevalence is higher than in other strata. As a result of above-mentioned reasons, the participants from the stratum -1, almost all have overcome the social stigma, and resultant social rejection, as well as exclusion from the society. The rest 45% IDI participants from the Stratum -2 and Stratum -3 had some social stigma as well as fear of being excluded from society and a tendency to hide their diagnosis. Factors proposed by KIs may be

devoid of current ideas and experiences as it was different from the feelings of the IDI participants of Stratum -1. If programs are designed purely based on key informants' views, they may not work for improving the Stratum-based leprosy-affected people's situation.

#### **Factors Influencing Migration**

Key informants' belief that mainly financial and social factors influence migration of leprosy-affected people does not match with IDI participants' views. IDI participants have mainly recognised treatment-related factors for migration.

61% key informants recognised job loss and social stigma by 57% of them as the main influencing factor for migration, while only small number (14% and 5%, respectively) of the IDI participants recognised those factors. Social rejection was also identified by two-fifth of the key informants compared to small number of IDI participants.

These social factors may have been reasons of migration during previous years, but nowadays, they have less impact. Although some of the key informants are currently in service, some are now retired and have responded from their old knowledge acquired when working.

Key informants do also recognise some treatment-related factors like inadequate facilities for treatment, shortage of medical professionals and inadequate facilities for treatment for migration which were not recognised by any of the IDI participants.

IDI participants mainly recognized lack of information for treatment, reliability on NGO managed hospitals and less reliability on treatment at the locality for migration which were not prioritised by key informants.

Joint TB/Leprosy clinics are available in most of the sub-districts, but are generally known specifically as "TB clinics". People usually do not

rely on those peripheral clinics but go, if possible, to specialized leprosy hospital. Initiatives need to be taken at local hospitals to be recognized as offering a leprosy clinic (the message that 'leprosy treatment is available here' etc. can be displayed in front of all sub-district government health complexes on large signboards, billboards and conspicuously placed). Besides this, service is to be improved, and related information is to be disseminated to increase the utilisation of local services

Fear of being excluded from society and hiding from neighbours are the two factors recognised by both key informants and IDI participants. This means that social stigma is still perceived as prevalent in society and negatively impacting on leprosy-affected people's lives, even if it has not been recognised as factor for migration.

Drought related migratory movements may be involved in the introduction of leprosy in Rio Grande do Norte State—Brazil (Nobre et al 2015); treatment of the leprosy disease, migration for job, settling down with their grown-up children, and marriage for women are related to migration in Tamil Nadu, India (Samuel et al 2012); and stress as a result of separation from family and friends, and difficulty to reaching the healthcare facility related to migration of LAP (Murto et al 2013).

#### **Factors Influencing Distant Registration**

The factors for distant registration are very similar to those for migration: KIs tend to attribute it to perceived social stigma, whereas IDIPs attribute it to unavailability of good treatment. Most of the key informants have recognized social stigma, fear of being excluded and keeping diagnosis secret from the society are the three factors for distant registration, but very small number of IDI participants recognised these as influencing factors. Most of the IDI participants recognized better treatment, lack of information about the



treatment facility and being referred by the physicians are the three main factors for distant registration, which were recognised by small number of key informants. This difference may occur for the same reasons as mentioned at the migration section.

Both key informants and IDI participants recognised some factors like relatives' influence and lack of treatment facilities.

One-third of the key informants think leprosy-affected people registered in distant places due to marriage, while only 7% of respondents agreed to this factor. 43% of the key informants and 27% IDI participants supposed job transfers cause leprosy-affected people to register in distant places.

Since resources for health care services are allocated partly on the basis of the reported geographical distribution of disease, naturally, the low registered-prevalence districts may have a lesser quality of leprosy services compared with higher registered-prevalence districts where specialist leprosy hospitals are also more likely to be situated. Hence it is understandable that people from lower prevalence districts tend to go to higher prevalence districts in search of care, but in the long run, this is counterproductive as it disguises the real need in their home districts.

#### **Limitations**

The small number of people affected by leprosy interviewed is a limitation to this study. There were, unfortunately not enough respondents to do meaningful subgroup analyses. Respondents were contacted by NGO workers of their respective district/ sub-district simply on the basis of availability and willingness. The perception of representatives and significant actors are offered here to enhance understanding of factors that contributed to the migration or relocation of the leprosy-affected people knowingly or un-

knowingly about their disease. We did not enrol for interview members of the general public, as the intention was not to compare the LAPs with other migrating population groups but rather to understand the experiences of LAPs and to look for any matching of their reality with the opinions of KIs. The very large difference between the outcomes of two groups of interviews was a potential limitation on the interpretation of MCA.

#### **Conclusions**

Leprosy-affected people move about regularly within their districts, going from their homes for regular activities to the local market, tea stalls, prayer centre, agricultural field. Sometimes they move to other districts for longer periods driven by multiple factors (financial, social, personal and treatment-related) identified by KIs and IDIPs. If the patient is untreated and MB in the category, it increases the chance of spreading the disease. Further research should be conducted to understand the size of the problem and the relative impact of different factors identified by the study participants.

The factors identified by key informants seem very theoretical and may be based on their own ideas or some outdated experience which may not represent the current field situation. If programmes are designed based on key informants' views, they may not work for improving the leprosy-affected people's situation. In this regard, consultations with LAP are recommended for inclusion during program design and implementation. For any situation, if LAP migrates or registers in distant places, this may affect district disease prevalence statistics. As a result, national planning regarding disease control can be inappropriate. Migration and distant registration should be considered at the national level in interpreting registration data as an indicator for the geographical distribution of leprosy.

Both key informants and IDI participants recognised that LAP migrate or do distant registration as they lack information regarding treatment, feel stigmatised and are afraid of rejection. Information on the availability of leprosy treatment should be disseminated so that people can recognise the health facilities. Activities should be undertaken to reduce social and personal stigma and fear. To avoid the fear of being excluded, an electronic registration and service system can be developed so that people can be registered and get service easily.

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