

Disclosure of Leprosy by Health Care Providers in South-India: Patients' Perception and Relevance to Leprosy Control, Tamil Nadu

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Stigma, isolation and discrimination are typically associated with diagnosis of leprosy and its disclosure. Health care providers (HCPs) find it challenging to disclose the diagnosis of leprosy to patients and their family members. A qualitative study was done in a rural community near Chennai in Tamil Nadu, from August 2011 to March 2012, covering 155 out of 648 (23.9%) purposively selected leprosy patients from 53 out of 148 panchayats, representing 264 villages in the study area; Out of these 155 patients, 59% were males; 30% were illiterates; 70% were married; 56% were living in nuclear families; half the leprosy patients were either agricultural labourers or skilled workers (50%). Thirty two percent were multi bacillary (MB) cases and 68% were pauci bacillary (PB) cases; 77% were old patients and 23% were new patients; 22% had leprosy deformity; 12% had disfiguration; 23% had anaesthesia and 3% were with lagophthalmous. Of the 155 patients, 31 (20%) reported that they were not informed about diagnosis of their disease by the concerned HCPs. They were informed to be having a skin disease or a skin patch. Of these 31 patients, 22 (71%) were women; all, except one with PB leprosy. Seven patients (23%) had not yet started on treatment; 3 patients (10%) were given treatment when they were young and neither, them nor their parents were informed about this disease. Seven (33%) of the married patients who had the disease during their childhood or when they were young, were not informed of the diagnosis by the HCPs. Ten respondents (32%) were neither bothered nor concerned about non disclosure of the disease by HCPs. Now, after knowing the diagnosis of the disease 4 females (13%) mentioned that they were having some fear, worry or stigma. As non-disclosure of leprosy by HCPs may adversely affect acceptance and adherence to treatment by the patients, appropriate communication strategies should be developed and implemented.

Keywords : Leprosy, Non-disclosure of leprosy diagnosis, Health care providers

Introduction

Leprosy is still prevalent in certain parts of the world, particularly in India, South-east Asia and

South America (Briden and Maguire 2003). Social stigma and prejudices associated with leprosy still remain major obstacles for its eradication

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(Kar et al 2010). Leprosy has been associated with stigma and social exclusion throughout the history and in all countries (Jopling 1991) with some degree of variations in different communities (Opala and Boillot 1996). Despite effective leprosy treatment and massive efforts for public education to facilitate leprosy control through general health services, leprosy-related stigma remains a barrier to access adequate clinical services for diagnosis and treatment (Nicholls et al 2005). Most of the untreated leprosy patients develop severe deformity and disfigurements contributing to stigma (Navon 1998). Stigma, isolation and discrimination are typically associated with diagnosis of leprosy and its disclosure. Health care providers (HCPs) always find it challenging to disclose the diagnosis of leprosy to patients and their family members. Some health care workers never disclose the diagnosis of leprosy to patients and even avoid mentioning leprosy. This qualitative study in a rural community among the old and newly diagnosed leprosy patients was undertaken with an objective to understand the perceptions of patients on the disclosure of leprosy diagnosis by health care providers.

Materials and Methods

Study Setting and Participants

The study was conducted in a rural community covering 7 health sub-centres with a population of 2,00,000, near Chennai in Tamil Nadu. The study areas were Kancheepuram and Thiruvallur districts. Pauci-Bacillary (PB) and Multi-Bacillary (MB) cases detected from 1991 to 2011 comprising of 648 patients formed the study population. Since this was a qualitative study, selection of study participants was purposive. However care was taken to ensure representation of genders, type of leprosy (PB-MB) and age of the respondents.

Data Collection and Analysis

This study was conducted from August 2011 to March 2012. There were 155 study participants who were selected purposively from 53 out of 148 panchayats representing 264 villages in the study area. A trained investigator after obtaining written informed consent from each willing patient proceeded with in-depth interview. The interview was conducted using an interview guide covering domains on, knowledge of patients' on the patch/lesion, diagnosis of the patch as informed by the HCPs, patients' reactions on the patches, disclosure of having a patch/lesion to others/marital partners and reaction of patients after knowing about leprosy. The interview was in the local language - Tamil and since the subject of the study was sensitive, the venue of interview was selected by the respondents as per their place of convenience and privacy (in their houses or fields). There were few patients who opted for the interview in the vehicle parked little far-off from the house of the patient. Average time taken for each interview ranged between 45 and 60 minutes. Three respondents required two interview sittings for optimum data collection.

Since this was a qualitative study the data analyses were done thematically using different domains.

Ethics Approval

The proposal was approved by the Scientific Advisory Committee (SAC) for the technical part and Institutional Ethics Committee (IEC) for the ethical aspects.

Results

Profile of the Respondents

Out of the 155 patients, (91/155) 59% were males; (47/155) 30% were illiterates; (108/155) 70% were married; (87/155) 56% were living in nuclear families; half the leprosy patients were

either agricultural labourers or skilled workers (78/155) (50%).

As far as the cause of the disease was concerned, (81/155) 52% did not know anything; (25/155) 16% mentioned heredity as the cause; (19/155) 12% reported that because their parents had leprosy; (53/155) 34% mentioned that they have not disclosed to others; (25/155) 16% had reported that their marital relationship had been affected; (11/155) 7% informed that they had been separated from their respective spouses. (12/155) 8% mentioned that because of leprosy, they were living alone.

Disease related features

Thirty two percentage (50/155) were MB cases and (105/155) 68% were PB cases; (119/155) 77% were, old patients and (36/155) 23% were new patients; (34/155) 22% had leprosy deformity; (19/155) 12% had disfigurement; (36/155) 23% had anaesthesia and (5/155) 3% with Lagophthalmous.

Of the 155 patients, 31 (20%) reported that they were not informed about diagnosis of their disease by the concerned health care providers. Instead they were informed that they had a skin disease or a skin patch. Of these 31 patients who did not know the diagnosis of leprosy, 22 were females. Majority of these patients (n=30) were PB cases and only one patient had MB leprosy.

Not yet started the treatment

There were 23% patients (7/31; 2 male & 5 female) who informed that they had not initiated any treatment as it was informed by the concerned HCPs that they had only a skin patch or skin disease.

"I did not know it is leprosy; I was told that it is a skin patch; so I did not take it seriously; I was given tablets for one month; I have kept them safely, but I have not taken even a single dose". (F:27 PB)

"Since I was told by the lady who came in the jeep that I have only skin patches (thembal - in Tamil), I did not consider it serious and I have not taken any treatment" (F:33* PB)

"I am waiting for the person who came and identified that I have a skin problem to give me treatment for it: because of that I have not started on any treatment" (M:65* PB)

Leprosy not disclosed by HCPs: when the patients were young children: Ten percent of the patients (3/31; 2 male & 1 female) reported to have taken treatment when they were children or when they were young. But the HCPs had neither informed them about having leprosy patch nor to their parents. This could be inferred from the following statements:

"I was told 15 yrs back (when I was 8 yrs old) that I had skin patch ("padai" in Tamil) for which I was given treatment; but I don't know for how long... now, nobody knows anything about that..." (M:23* PB)

"I really do not know about this disease as I was not informed; all this happened when I was 7 years old. Since I don't have any problems, we have not discussed anything on this" (M:27* PB)

"When I was 10 yrs of age I took treatment for skin problem. I don't know much about the treatment; nobody from the hospital told my parents about this being a leprosy patch" (F:32* PB)

Inadequately informed patients chose not to disclose to their marital partners

Among the married patients, 33%; (7/21; 3 males and 4 females) who had the disease during their childhood or when they were young, were not informed of the diagnosis by the HCPs. Because they did not know specifically about the disease and its treatment, they had not informed to their spouse's families. These reporting could be found from,

"When I was 8 yrs old I was told that I had skin problem called "thembal" and now I am married and none of my husband's family know about my treatment history" (F:26* PB)

"Since the treatment was before my marriage, we never thought of informing my wife; so nobody knows; I myself do not know about the entire thing" (M:32* PB)

"As I had this problem before my marriage, I did not know anything about this patch; My wife and friends also do not know; Since everything is over now, I don't want to tell my wife and her family members on my earlier treatment" (M:32* PB)

Respondents were not bothered and were not serious about the disease: With respect to "not bothered" attitude, 32% (10/31; 1 male and 9 females) mentioned that they were not bothered about whatever disease they had, as it had subsided now and they were not bothered about the same any more (n=6) and also they were not very serious (n=4). This could be noted from the following statements:

"Since the patch has disappeared, I am not bothered" (F:20* PB)

"I will never get this sort of disease; I am alright now; I know it is only a skin patch... which was told like that... now you are telling that it is related to leprosy patch;... I am just not bothered as I am alright now...." (F:45* PB).

"It is only a skin patch; I am not bothered; my worry is, I am weak...that is all" (F:58* PB)

"We all know that it is only a 'thembal'; nobody knows it is related to leprosy; so, we are not serious about this" (F:25* MB).

Knowledge of the diagnosis, results in some fear, worry or stigma

However, 13% (4/31) of the females mentioned that being informed that they had leprosy patch

earlier, started developing some fear and worry due to the possibility of experiencing stigma. After knowing the actual diagnosis of leprosy, they started feeling disturbed. It could be seen from,

"In the hospital the staff told me it is "thembal" and all our relatives and friends knew only as thembal; now when I come to know about this disease (being leprosy), I am somewhat afraid" (F:13* PB).

"I did not know that it was leprosy; we were told by the nurse amma that it was only 'thembal' - now I am little worried: (self stigma)" (F:43* PB).

In all, 55% (17/31) of patients due to the non-disclosure of the disease by HCP either to the patients or to their guardians would have avoided the adverse impact like not starting the treatment or developing a stigma of not knowing exactly what was the disease.

Discussion

Stigma is one of the important social determinants likely to affect help-seeking and treatment adherence and eventually effectiveness of disease control (Weiss 2008). The present study reveals that because some patients were not informed of their precise diagnosis, a portion of them had not started the treatment as they did not consider it serious and, for child patients - the diagnosis was not informed even to their parents. In a study conducted in Maharashtra (Atre et al 2011), despite having been diagnosed and receiving treatment, only 48% of adult cases knew their condition as leprosy, reflecting their poor knowledge of the disease and lack of communication between providers and patients. The symptom 'patch on the skin' seems to have percolated in the community (Atre et al 2011). Case finding and management strategies suffer a setback when disease manifestations are not picked up in time by health-care providers

(Sachdeva et al 2011). Delay in diagnosis and start of effective treatment is very common and an important risk factor for disability in leprosy (Bekri et al 1998, Meima et al 1999, Nicholls et al 2003, Kumar et al 2004). A study (Kar et al 2010) conducted in Assam stressed the need to organize training programs at regular intervals to train new recruits, as well as reinforce and update the knowledge of those already trained HCPs. The attitudes of health care professionals can influence how patients and communities perceive leprosy; this needs to be addressed with more leprosy awareness training during initial education and as a part of ongoing professional development. If the HCP discloses the patient that he/she is having a leprosy patch, there could be a social problem in the patient or in the family leading to stigma, isolation, fear, worry, etc. But due to the seriousness of the disease and fear of getting deformity or disfigurement, they will start the treatment immediately and complete it. In the same way, if the HCP does not disclose the patch as leprosy, the seriousness of the disease and the intensity of treatment - taking will be lost and the patients will not understand true nature of that disease; instead they may consider it as, after - all a "skin patch." Anecdotal examples show that stigma may also encourage treatment and promote adherence, so that a motivated patient may become free of a condition that is more undesirable because of stigma.

Conclusion

From public health point of view, non-disclosure of leprosy by HCP is an issue because, a) the patients may not get alerted and cautioned about seriousness of the disease; this may adversely affect acceptance and adherence to treatment b) Inadequate or lack of treatment can lead to progression of disease and occurrence of deformity and c) In the context of general decline

in the burden of leprosy in India and lack of expertise in primary health care settings, HCPs need to be re-oriented on disclosure of leprosy to patients and not hiding the disease diagnosis from them in view of its implications on prevention and control.

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References

1. Atre SR, Rangan SG, Shetty VP et al (2011). Perceptions, health seeking behaviour and access to diagnosis and treatment initiation among previously undetected leprosy cases in rural Maharashtra, India. *Lepr Rev.* **82**: 222-234.
2. Bekri W, Gebre S, Mengiste A et al (1998). Delay in diagnosis of leprosy and start of treatment in leprosy patients: a case control study of disabled and non-disabled patients in three different settings in Ethiopia. *Int J Lepr Other Mycobact Dis.* **66**: 1-9.
3. Briden A and Maguire E (2003). An assessment of knowledge and attitudes towards leprosy/Hansen's disease amongst healthcare workers in Guyana. *Lepr Rev.* **74**: 154-162.
4. Jopling WHO (1991). Leprosy stigma. *Lepr Rev.* **62**: 1-12.
5. Kar S, Ahmad S, Pal R (2010). Current Knowledge, Attitudes, and Practices of Healthcare Providers about Leprosy in Assam, India. *J Glob Infect Dis.* **2**: 212-215.
6. Kumar A, Girdhar A and Girdhar BK (2004). Nerve thickening in leprosy patients and risk of paralytic deformities: a field based study in Agra, India. *Lepr Rev.* **75**: 135-142.

7. Meima A, Saunderson PR, Gebre S et al (1999). Factors associated with impairments in new leprosy patients: the AMFES cohort. *Lepr Rev.* **70**: 189-203.
8. Navon, L (1998). 'Beggars, metaphors and stigma'. *SocHist Med.* **11**: 89-105.
9. Nicholls PG, Croft RP, Richardus JH et al (2003). Delay in presentation, an indicator for nerve function status at registration and for treatment outcome-the experience of the Bangladesh Acute Nerve Damage Study cohort. *Lepr Rev.* **74**: 349-356.
10. Nicholls PG, Chhina N, Bro AK et al (2005). Factors contributing to delay in diagnosis and start of treatment of leprosy: analysis of help-seeking narratives in northern Bangladesh and in West Bengal, India. *Lepr Rev.* **76**: 35-47.
11. Opala J and Boillot F (1996). Leprosy among the Limba: illness and healing in the context of world view. *Soc Sci Med.* **42**: 3-19.
12. Sachdeva S, Khan Z, Ansari MA et al (2011). Leprosy: down but not out. *Trop Doct.* **41**: 28-30.
13. Weiss MG (2008). Stigma and the Social Burden of Neglected Tropical Diseases. *Plos Negl Trop Dis.* **2**: e237.

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