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Case Report

Awareness, social acceptance and community views on leprosy and its relevance for leprosy control, Tamil Nadu

S Thilakavathi[1], P Manickam[1], SM Mehendale[1]

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As the leprosy burden has declined considerably, we need to understand the current social status of the disease and patients. A qualitative study was conducted in a rural community near Chennai in Tamil Nadu, between March and October 2011. In-depth interviews with 72 leprosy patients from 25 villages and 3 focus group discussions (FGDs) with 26 women from 3 villages were conducted using a guide. The qualitative data were grouped into different domains and analysed. Most of them did not have basic knowledge on leprosy; instead there were misconceptions on cause and spread of leprosy. Nearly one third of the patients had not disclosed about the disease to their spouse, family members, relatives or friends for fear of social rejection, discrimination and ill treatment. In all, more than half of them had self-stigma and, most of them who had deformity faced actual stigma by way of disowning, isolation and social rejection. Many patients, particularly PB cases had the behavior of "denial". FGD women reported of self and actual stigma, particularly towards deformity and disfigurement, for fear of getting infected. Stigma among patients with deformity, and denial of the disease among PB cases, were highlighted. Importance of awareness programmes to remove misconceptions related to cause and spread of the disease was stressed. Need for person-centered social treatment was suggested for increased case detection.

Key words : Awareness, social acceptance, leprosy control

Introduction

Globally leprosy burden has declined substantially. India achieved the elimination (defined as <1 case per 10,000 population) by 2005. Considering the reduced burden of leprosy, since 2005, leprosy services have been integrated with the general health care services. Socially, the disease leprosy was resulting in social death of the patients since a very long time. A study done in Nepal showed that leprosy patients still experienced negative behaviour and 95% of the persons affected by leprosy recognized by the community, have visible wounds, swellings and deformity of the feet and hands (de Stigter et al 2000).

In Uttar Pradesh, (Barkataki et al 2006) it was reported that 50% to 60% of the study participants mentioned about social discrimi-

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[1] S Thilakavathi, PhD, D Litt, Scientist-E, Deputy Director
[1] P Manickam, BSM&S, MSc, PhD, Scientist-C
[1] SM Mehendale, MD, MPH, Scientist-G and Director
[1] National Institute of Epidemiology, ICMR, 2nd Main Road, TNHB, Ayapakkam, Chennai-600 077
Correspondence to : S Thilakavathi email : thilakavathi_s@rediffmail.com

nation of leprosy patients. The proportion of families having patients with deformities faced problems ten times higher (57%) than those without deformity (6%) (Kopparty et al 1995). People have left their families, and even their spouses and children, fearing the repercussions of the fact that they had leprosy (Kaur and Van Brakel 2002). Considering all these, and the reduced number of leprosy cases, it is of utmost importance to understand how the disease leprosy and the leprosy patients are accepted currently by the patients themselves, their families and the community. Based on this, a study was conducted in rural Tamil Nadu to understand the social status of leprosy and the leprosy patients and its relevance in leprosy control.

Materials and Methods

Study setting and participants

The study area was in a rural community covering 7 health sub-centres with a population of 2,00,000, near Chennai in Tamil Nadu. The study population had 2,706 leprosy patients (listed in 1994) covering both PB and MB patients from four (Thirumazhisai, Somangalam, Madhuramangalam and Sunguvar Chathram) health sub-centres with 25 villages. Since this was a qualitative study and wanted to collect in-depth details, selection of study participants was purposive. However care was taken to ensure representation of both genders, type of leprosy [PB-MB], deformity status [deformed/ not-deformed] and different age groups of patients.

Data collection and analysis

Data was collected between March to October 2011, from (Tamil language speaking - local vernacular) patients through in-depth interviews using an interview guide, covering areas for queries from the respondents on their understanding of leprosy, disclosure of the disease, acceptance on day-to-day affairs, involvement in family and social functions, impact of the disease on various areas and the presence of stigma.

Since the study involved sensitive data collection from leprosy patients, enough privacy for each interview was arranged. The choice of interview place (patient’s house, field, nearby place or work-spot) was decided by the respondents, without any disturbance or interference from others. Each participant recruited for in-depth interview was explained the purpose, procedure, risk and benefits, privacy and confidentiality of being involved in the study and only after obtaining the written informed consent from the willing participants, data was collected. Each interview took an average time of 50 minutes. The study investigator conducted the in-depth interviews.

Three focus group discussions (FGDs) were held among the community women (n=26) from 3 villages, to understand their, knowledge on leprosy and social acceptance of leprosy and the patients, using a guide. FGD was conducted in each village, in a neutral place, convenient to the respondents. All preparatory arrangements prior to the conduct of FGD were made in the villages and after obtaining written informed consent from all the group participants, FGD was conducted by the study investigator being the moderator and additionally having a recorder. All the qualitative data were grouped into six general thematic areas, namely (1) knowledge and awareness (2) disclosure of the disease (3) social participation (4) stigma (5) impact of the disease and (6) social acceptance, among community women (Table 1).

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.

Table 1 : Themes explored in the qualitative study of leprosy patients and community members about leprosy, Tamil Nadu

Themes	Areas explored
1. Knowledge and awareness of leprosy	* Knowledge of the current problem (Cause, investigations, treatment, spread & prevention) * Knowledge of leprosy (Cause, investigations, treatment, spread & prevention)
2. Disclosure of the disease	* Disclosure of the diagnosis (leprosy) to spouse/parents, children, siblings, other family members, relatives, friends and others.
3. Social participation	* Others inviting the patients for family and social ceremonies and functions
4. Stigma	* Self stigma * Actual stigma
5. Impact of the disease	* On day-to-day activities * In sharing toiletries, utensils, clothings and beddings * If married, marital relationship * If school/college going on studies * If not married future marriage * On the general health * Social interactions among family members, relatives, friends and society. * At the treatment centre
6. Social acceptance in community	* Understanding of leprosy women * Social acceptance of the disease and the patients

Results

Socio-demographic characteristics of patients

There were totally 72 respondents covered by in-depth interviews in which, 44 were males; 19 of them were between 19 and 40 years of age. In all, 16 persons were illiterates (more were females) and 29 had studied up to 5th standard; 34 persons were working as agricultural coolies or farmers; 15 persons each, were getting a monthly income of more than Rs. 3,000 up to Rs. 5,000 and Rs. 1000 to Rs. 3,000. Forty eight respondents were married, 13 were unmarried, 9 were widowed and 2, divorced; 34 respondents were living in kutcha houses and 31 respondents were from nuclear families. There were 44 PB patients and 28 MB patients; among them 21, had deformity; 60, were old patients and 12 were new ones.

Knowledge and awareness of leprosy

With respect to cause for getting leprosy, more than half of them said that they did not know the cause and some, mentioned that leprosy is hereditary; quiet a number of them reported of having a history of leprosy patients in their families. As regards to investigations to be done, many of them were aware of sensory or skin smear examinations. With respect to the spread of the disease, most of them were unaware of the same. However, 9 of them reported multi-partner sexual relationships as one of the modes of transmission.

"…. How will I know, how I got the disease? I do not know….nobody in my family had the disease for generations……so I am unable to tell you how I got the disease…" (52 year old male PB patient).

"… I know this is an infectious – hereditary disease; since my paternal aunt had this disease, I must have got it from her only…." (68 year old male deformed patient).

" they will check whether I have any sensation in the patch and then they will take blood from my ear for testing…" (55 year old male MB patient).

Misconception on cause and spread

There were number of misconceptions related to the cause and spread of the disease.

" Before my marriage I used to visit number of girls including female sex workers; because of my illegal sexual contacts with many females I got this disease…" (65 year old male MB patient).

"……If we sit next to an infected person, touch him, or even take bath in the same tank in which an infected person had taken bath, we will surely get the disease"…… (45 year old male with multiple patches).

Disclosure of the disease

Around 41 to 44 patients had disclosed about their disease to their spouse, family members, relatives or friends and 28 to 31 persons informed that they had not disclosed to them for the reasons of fear of social rejection, stigma, isolation, or ill-treatment. Fear of social rejection in a married female is reflected as follows :

"My husband and my 2 married daughters know that I have skin disease; more than that I have not disclosed anything about the disease nor they have asked me further. I feel there is no need to mention about the name of the disease; but I know this is leprosy". (48 years, MB patient with multiple patches).

"….. though I was informed that this is a leprosy patch by Dr. X… I have not gone further for treatment….. I have not told my son and daughter-in-law about this.. I am afraid whether I may be rejected (sent out of my house)…… but I am also feeling bad whether I will infect my grand children or get deformity in my later years". (52 year widower, with single patch)

Social participation

In all, 66 and 62 persons informed that they were invited to participate in family and social functions, respectively; in this 31 have not disclosed about their disease to others. So when we explored whether they were invited for the functions, many of them said that since they did not know anything about the disease, there was no change in getting invited; however, number of them told that many who knew about their disease did not want them to attend. Few informed that though they were invited, they would not attend, mainly because of fear of stigma/ill-treatment.

"Nowadays I have stopped going to others' functions or for any invitations; if I visit them, I have to remove my chappals when I go inside…if I remove my chappals, my deformity in my feet will be seen and I will be identified as a leprosy person; then I will feel bad; for this reason nowadays I send my wife and son and I avoid going to their places….". (68 year old, deformed male patient)

"…… since I have my right hand fingers deformed, when I go to functions, I have to eat with a spoon as I cannot eat with my hand; when I eat with a spoon I would be identified as a leprosy deformed person; so nowadays I avoid going to any functions… though I would be invited……….". (68 year old, right hand clawed male patient)

Stigma

Self-stigma

Of the 72 respondents, 55 reported of having self-stigma. Of these, 20 patients knew that they were having leprosy, but did not want to disclose about the disease for fear of stigma, rejection, social isolation and so on.

"I have told my family (wife and children) about my problem as skin disease, as I have only one patch; if I tell about the disease, there may be unnecessary problem among us… so I have not told them about the disease………..". (42 year old male with single lesion).

"….all my family members, relatives and friends every body know about my disease. They will mock at my deformity; many may talk behind me about my disease; since I have the disease they talk….. what is the point in feeling bad……I am also worried about my grand daughter's future marriage… as my daughter is also deformed……" (self & actual stigma) (73 year old male, with deformity in both hands and feet)

"…….. I have kept my soap and plate separately as I am afraid whether I will infect my wife and children.." (77 year old male with deformity in both hands and feet)

Actual or enacted stigma

Actual stigma was reported more by the patients who had visible patches, deformity or disfigurement. This was found more among aged persons.

"since I have my right hand fingers deformed, my neighbours will address me as "nondi" ('handicapped'); though I don't show my feelings in front of them, I will really feel sad inside. That disturbs me too much…" (68 year old male with clawed right hand)

"…………….. If I go to the public tap, for taking drinking water, the neighboring women will fight with me telling that I am infecting the drinking water also. And the women during the fight will call me as "nondi" ('handicapped'), "Noi Pudchichav" ('infected female') (40 year old widowed female with clawed hands and feet)

"…… my wife and sons have beaten and sent me out of the house…. She used to tell me that if I continue to stay there, our son will not get married …. She was my second wife.. she will not be bothered about whether I eat or not…..; after I was sent out of our house, and when I was staying in this hut alone.. one day my son came and asked me "what father? Are you still alive? We thought you would have died by now?" (patient was crying) … I have been humiliated and tortured by my own family because I have this disease (deformity)…. here also sometimes people who help me by providing water and food, do that from distance……. (feeling sad). (A 70-year old male with deformity in hands and feet).

Denial

Many leprosy patients (particularly PB) had the behaviour of "denial". In this there were three distinct groups. First category of people are those who knew that it was leprosy; not want to accept; informed the family members and others that it was a skin disease, lesions reportedly due to insect bite or pricking of a special type of thorn (from a plant called, *Velikathan,* P*rosopis juliflora)* and nothing about leprosy; however, they completed the treatment. The second category of persons, knew that it was a leprosy patch; did not want to accept, and did not want to go for treatment for fear of stigma. The last category of people were those who said that they were informed that it was only a skin patch or a *thembal* (in Tamil) and nothing about leprosy (by health personnel: to avoid fear and stigma for the patients). Among these categories of people, few did not realise the seriousness of the disease, neither went for treatment at all nor had regular and continuous treatment.

"…. I was told that I have only "thembal" (a skin patch); now after I took treatment it has gone… I know it is not related to leprosy…." (24- year old female with a single patch)

"…. we really do not know that it is leprosy related patch…. We were not told anything like that… we were told only as a skin problem; am I to take my daughter periodically for check-up?; do you think she needs to continue with some more treatment? … please advice… I do not want my daughter to know that it is related to leprosy patch" (mother was crying) (12 year old female, with single patch, school going student's mother).

".... this skin problem…… I got long back due to insect bite; it was treated and now I am alright…… I know it is not leprosy; I have told my family members and others that this skin problem is only because of insect bite and I have not even told my husband and son further. Nobody has asked me anything more on this". (denial) (35 year old married female with 2 patches).

"…. I know that I have some deficiency in my skin or body, which is shown as a patch; but I am sure it is not leprosy…" (35 year old married male with a single patch).

Impact of the disease

Among the married (n=48) two patients (one male and one female) mentioned of divorce due to the disease. Few mentioned that they did not sleep together as couples. Out of the 13 unmarried, 2 were worried about their marriage prospects. With respect to impact of the disease on the general health condition, number of them informed that if they ventured during sunshine they felt burning sensation of the skin. Hence, they preferred not going out during Sunshine. Some of them mentioned about inability to walk long distances and inability to do certain jobs due to deformity and worsening of vision .

Social acceptance of leprosy among community women

Three FGDs) were conducted in 3 different villages among 26 women. The women were between 23 to 60 years of age; their literacy ranged from illiteracy to 12th standard passed; most of them were house wives and few were wage earners, engaged mainly in agricultural work.

Most of the participants did not know the actual cause of the disease; they had number of misconceptions. For most of them leprosy means deformity and disfigurement; only very few mentioned of skin patches. "….they will have their fingers and toes shortened; they will look very awkward; some of them will have cloth bandage on their hands and legs….". Few said "……….in some part of the skin they won't have any sensation; it will be like "thembal" (rashes)". (FGD participants, village 2 and 3).

As regards to the cause and spread of the disease, "……this is mainly because somebody in their family would have had this…and, it passes through generations…."; "when some people have sex outside, with many people they also get this disease" "…this disease could spread through using their soaps, food, clothes and utensils; even between husband and wife also it could come; so it is better when the husband gets the disease, wife should avoid sleeping together…". (FGD participants, village 1, 2 and 3)

As regards to social acceptance and interactions, some of them informed, "when these deformed people are there in the house, we will always be afraid, whether we will get the disease; if the children go to them, again fear of whether they will get infected;……… because people don't want to get infected with this dreaded disease…all these happen"……..''When they have children at marriageable age they won't like to have these deformed people in the house; they would think the alliance may go off, if they come to know; so they would like to keep them out of the house"……''……as regards to persons having patch/patches, which are not that much visible others may not know from outside………. so there is no problem in acceptance and interactions but patients who are showing visible deformity and ulcer, they want to keep them away, ……..don't want to invite them for any functions; sometimes even family functions they won't call them" (FGD participants, Villages 1 and 3)….

The patients on the other hand had lots of reservations and fear (self stigma) for many of their social interactions; they would be afraid whether they would be scolded, discriminated, disrespected, humiliated, rejected and so on.. so they themselves would be withdrawn or refused to participate in any of the functions.

Discussion

We conducted a qualitative study on people's understanding and behaviour towards leprosy and patients. Most of the respondents, both leprosy patients and the community women in the present study did not have proper knowledge on cause, mode of spread and prevention of leprosy. Instead they had misconceptions about cause and spread. Infact, a study conducted in Uttar Pradesh (Barkataki et al 2006) reported that less than 10% of illiterates and about 40% of literates cited infection as the cause of leprosy; even literates had poor knowledge on the symptoms as well as the causation of leprosy. A study in Vellore (Renita et al 2010) stated that improved awareness is required to reduce patient-related delays and, sustained training need to be in place to tackle the problem of health care system-related delays.

A qualitative study (Barrett 2005) conducted in Northern India showed, strategies of concealment further the progression and spread of leprosy through late detection and under treatment and also, the internalization of stigma can lead to bodily dissociation and injury through self-neglect. In the present study, number of patients particularly PB cases who were having single patch or few patches, expressed behaviour of "denial", a sign of self-stigma. This included two of them reportedly avoiding treatment. This was shown in another study (Bekri et al 1998) that often, to prevent discrimination, patients try to hide their diseases by not immediately seeking medical help on finding signs of leprosy; later they may have significant disabilities and deformities (Meima et al 1999). Similarly, in a study at Pakistan "Denial" was found to be an understandable coping mechanism in view of the severe stigma associated with leprosy (Mull et al 1989). So if the community shows negative attitude towards the leprosy patients, then it would force the patients to conceal the disease as long as possible. Concealment of the disease obviously poses threat to early diagnosis and treatment of the disease. When the disease can no longer be hidden, it would perhaps be too late to prevent deformities, though cure is assured.

Number of patients in this study who had deformity reported of experiencing actual stigma which ranged from hatred to disowning from their social environment. This sort of reactions due to stigma was reported earlier (Ulrich et al 1993) which seems to be continuing now also. Fear of getting deformity at a later stage was there in some of our study participants. Research in Myanmar found that there was a belief that all leprosy patients would inevitably end up with some deformity (Myint et al 1992).

Considering lack of proper knowledge on leprosy with misconceptions, it is likely that following integration of the leprosy programme in the general health care, emphasis on health education got diluted. So there is an urgent need for improving strategies for health education and behavioral change communication as essential components of prevention and control of leprosy by achieving better awareness, improved case detection, early treatment and reduction in complications and deformities.

One of the key limitations of the study is about generalizability of the findings. This qualitative study included mostly older patients and therefore the views of the study participants cannot be generalized to the younger ones.

Conclusions

From the above study it is clearly seen that basic awareness on leprosy is very much needed for the patients and the community people. The awareness programmes on leprosy should be a need-based and focused. It should also address "stigma" related features. Providing knowledge and awareness on leprosy should continue by sensitizing the community about social problems related to the disease and the patients in their day to day affairs for better social acceptance. The importance of taking regular and complete treatment should be emphasised by making people to understand the seriousness of the disease. Each problem of each patient should be tackled uniquely for the success of social treatment of the disease and the leprosy patients. Psycho-social impact like denial, various forms of stigma, emotional disturbance, depression and others, should be addressed individually and effectively, and the patients should be socially accepted as a normal human being. Unless the visual impact of the disease, that is - visible patches and deformity, is removed, it is not that easy to remove the self and actual stigma. For this, we need to focus on early case detection and regular and complete treatment.

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