Patients’ perceptions on disclosure of Leprosy by health care providers in South India: Relevance to Leprosy Control

S. Thilakavathi
P. Manickam
SM. Mehendale
& The team

National Institute of Epidemiology,
Indian Council of Medical Research, Chennai - 77

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Introduction

• Stigma, isolation and discrimination are typically associated with diagnosis of leprosy and its disclosure. Health care providers (HCP) always find it challenging to disclose the diagnosis to patients and their family members. Some HCPs never disclose the diagnosis to Patients and avoid mentioning leprosy.

• We explored perceptions of leprosy patients in South-India regarding disclosure of leprosy disease status to them by HCPs.
Methods

This qualitative study had 2 components: 1. In-depth interviews with the leprosy patients and 2. Focus group discussions with people in the community.

- **Rural community**: Villages of Kancheepuram and Thiruvallur districts
- **Health facilities**: 7 peripheral health facilities
- **Panchayats and population**: 148 panchayats with a total population size of 2,00,000
- **Study population**: PB and MB cases detected in 1991-1999 & also newly detected in 2008 – 2011
A trained investigator obtained written informed consents from the willing respondents and collected the data through in-depth interviews.

The interview was in the local language (Tamil)

The interview guide covered inquiry about knowledge, attitude and social acceptance in the context of disclosure of leprosy
Results

- Interviewed 155 (purposively selected) leprosy patients of 1175 from 53 out of 148 panchayats having 264 villages in the study area.

- Of the 155 leprosy patients, 31 (20%) reported that they were not informed of their disease by HCP. They were informed of having skin disease or a skin patch.

- Of these 31 patients, 23 were women.

- Most of them were PB, except a single case of MB.

"Nursamma informed me that I have a thembal (skin patch) – I am alright now; I know thembal will go on its own”
(F:45 PB)

“I was informed that I have only skin disease and nothing else; why should I take any treatment? There was no need”
(M:18 PB)
Not yet started on treatment

(2 males and 5 females – all PB cases)

“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)

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

“Since I was told by the lady who came in the jeep that I have only skin patches (thembal – Tamil), I did not consider it serious & I have not taken any treatment”
(F:33 PB)
Not disclosed when they were children/ very young

Three patients took treatment when they were very young: HCPs had not informed of patient having a leprosy patch even to their parents

[ 2 male & 1 female]

“\textit{I was told 15 yrs back (when I was 8 yrs old) that I had skin patch (padai) 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 yrs 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 Rx; nobody from the hospital told us about this being a leprosy patch”
(F:32 PB)
Treatment during childhood and now married

3 males & 4 females said that they did not know about their problem earlier, which they have not mentioned to their spouse family

“Since the RX 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)

“When I was 8 yrs old I was told that I had skin problem called “thembal” and now I am married & none of my husband’s family know about my RX history”
(F:26 PB)

“I had this skin problem 13 years back which was before my marriage; since now I am alight & I don’t have any problem; I don’t think of it at all”
(M:31 PB)

“When I was 8 yrs old I was told that I had skin problem called “thembal” and now I am married & none of my husband’s family know about my RX history”
(M:32 PB)
**Not bothered**

There were 6 women who informed that, they did not bother about their skin patch as they were informed of having just a skin patch/skin disease & the same has almost disappeared.

“It is only a skin patch; I am not bothered; my worry is, I am week…”
(F:58 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)

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

“All my family members & my relatives know that I have some skin problems and nervous weakness... I do not have any other problem... I don’t bother as I was informed”
(F:33 PB)
Not being serious

“I myself do not know about the disease and others also think that I have only skin disease”  
(F:16 PB)

“We all know that it is only ‘thembal’; nobody knows it is related to leprosy”  
(F:25 MB)

“All of us know it is only ‘thembal; nothing like leprosy’”  
(F:50 PB)

“Every body know that I have one skin patch; that is all”  
(F:40 PB)

“Every body ie.myself, my family members, relatives and friends know it as “thembal””  
(F:50 PB)
Fear, worry & stigma!

“I don’t have any serious disease like leprosy; I am not facing any problem; But since now I understood that mine was leprosy, I have some fear.”
(M:40 PB)

“I did not know that it was leprosy; we were told by the nursamma that it was only ‘thembal’ – now I am little worried: (self stigma)”
(F:43 PB)

“In the hospital the staff told me it is ‘thembal’ & all our relatives and friends knew only as thembal; now when I come to know about this disease, I am really afraid”
(F:13 PB)

“I was told only as ‘thembal’; so everybody know only as thembal; since now I know, I won’t be telling others – because of stigma”
(F:52 PB)

“Health staff informed me it as ‘padai’; now you are telling it as leprosy....; I am afraid of deformity & infecting others.....”
(F:38 PB)
Main problem related to disclosure & non-disclosure

• If the HCP discloses......
  ❖ Social problems: stigma, fear, worry, discrimination, etc.
  ❖ But due to the above, and fear of getting deformity/disfigurement they will start and continue to have the treatment

• If HCP does not disclose....
  ❖ Other problems: They are not bothered; will not be serious about starting treatment;
  ❖ for self healing patches - it is OK; but for others, it may lead to various other problems
Conclusion

From public health point of view, non-disclosure of leprosy by HCP is an issue because,

1. The patients may not get alerted and cautioned about seriousness of the disease; this may adversely affect acceptance and adherence to treatment

2. Inadequate or lack of treatment can lead to progression of disease and occurrence of deformity

3. 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 & control.
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The biggest disease today is not leprosy or tuberculosis, but rather the feeling of being unwanted.

(Mother Teresa)