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Abstract - Groupe n°38 (Inde 2)

# Rural and urban Tuberculosis in South India: Patient's knowledge and impact of stigmatization, on work and family's life.

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*Problematic*
**I**ndia has the highest prevalence of tuberculosis in the world (20%). Tuberculosis is a real health community problem leading also to psychologic and social suffering in India. Directly Observed Therapy Short course (DOTS) is a control program of Tuberculosis in India.
Our research question focused on : « Among urban versus rural dwelling patients with tuberculosis, what are the burden of tuberculosis and the patients' perceptions of the disease ? »

*Objectives*
To identify the impact (stigma, work and family) for patients dwelling of tuberculosis. To identify the knowledge of the patient dwelling of tuberculosis.

*Methodology*
We completed a literature review reading literature about tuberculosis in India and we used local tools in Father Muller Charitable Institution (FMCI). Then we selected thirty articles, reports and books about impact and knowledge of Tuberculosis.
We proceeded to data collection with semi-structured interviews guided by translators of the community department of Nursing of FMCI. A team in the FMCI selected our patient's sample: 7 patients who live in rural area and 7 patients in urban area integrated in the Indian national TB program and 5 health care providers (physicians, laboratory worker, social health worker).

*Results*
**Knowledge:** Patients in urban area were more knowledgeable than rural patients. According to 2 doctors working for the DOTS program: " this is because of lower education in rural area". Our results are matching with specialist's account however we noticed that rural patients were more informed that TB is a communicable airborne disease than urban patients. This main difference, which came out of our study.
**Impact:** Moreover it transpired from our research many results regarding the impact of Tuberculosis such as marriage, isolation, use of separated utensils, impact on working and wearing a mask are similar in urban and rural areas. Patient didn't relate them specifically to stigmatization but they are part of it as mentioned by the literature and health care providers. Doctors told us that they observed that stigma was more present in rural areas especially for young people in their most productive years and in the age of getting married.

*Conclusion*
There are minors differences between rural and urban areas. Through educational and individual surveillance, DOTS has a positive impact on TB perceptions and burdens. Stigmatization seems to be decreasing in India among Tuberculosis.

*Keys words*
Tuberculosis ; India ; Perception ; Burden ; Patient ; Rural and urban.

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# Rural and urban Tuberculosis in South India: Patient's knowledge of the disease and impact of stigmatization, on work and family's life

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## PROBLEMATIC AND RESEARCH QUESTION

India has the highest prevalance of tuberculosis in the world (20%), which represents two deaths within three minutes. Tuberculosis is a real community and public health problem leading also to psychological and social suffering in India.

Directly Observed Therapy Short course (DOTS) is a control program of Tuberculosis in India. Our research question focused on : « Among urban and rural dwelling patients with tuberculosis, what are the impact of tuberculosis and the patients' knowledge of the disease ? ».

## OBJECTIVES

- To identify the impact (stigma, work and family) for patients dwelling of tuberculosis.
- To identify the knowledge of the patient dwelling of tuberculosis.

**« BEING SICK WAS A FRUSTRATION HOWEVER I HAD GOOD SUPPORT AND ADVICES… »**

## METHODOLOGY

- Literature review.
- Community-based participatory qualitative research with semi-structured interviews guided by translators of the community health care department of Nursing/Medicine of Father Muller Charitable Institution.
- Development of two questionnaries (patient and health care providers) composed of two parts: a preliminary one (age, religion, children…) and a main one (knowledge, impact, life experience, etc. )
- Research population patients: n= 7 rural patients and n= 7 urban patients (with definites cases TB with or without HIV)
  Research population health workers: n= 5 health care providers.

## PARTICIPANTS

| | RURAL | URBAN |
|---|---|---|
| Gender | F= 2<br>M= 5 | F= 3<br>M= 4 |
| Age | M= 38 | M= 44 |
| Civil status | Single : 3<br>Married : 4 | Single : 0<br>Married : 7 |
| Number of children | M= 1.9 | M= 2 |
| People living in the house | M= 7.2 | M= 6.3 |
| Economic status (CHF) | < 80 : 2 161-250 : 1<br>81- 160 : 4 > 251 : 0 | < 80 : 2 161-250 : 0<br>81-160 : 4 > 251 : 1 |

**WHAT IS TB: « IT'S A PAINFUL EXPERIENCE. »**

## RESULTS

### SIMILARITIES

**BETWEEN RURAL AND URBAN AREAS:**

- TB is known has an airborne communicable disease (4 patients). Most patient were defining TB by symptoms experienced.
- Risk factors: lack of nutrition, low immunity, cold, smoke, drink and heredity.
- How patients protect their surroundings : limiting the sputum spreading by covering mouth when coughing, maintaining distance and keeping apart their ustensils.
- The evolution of the knowledge similarly increasing.
- They had not faced any barriers to the cure.
- 50% of the patients stopped working.

**« I HAVE STRONG FEELINGS WITH THE MEDICATION I CAN BE CURED. »**

### DIFFERENCES

**BETWEEN RURAL AND URBAN AREAS:**

- In urban areas almost ¾ haven't told their neighborhood and friends about their disease. In contrast, in rural areas almost ¾ of the patients have told to their friends and to neighborhood.
- In rural areas two young patients were afraid of the consequences of TB which could affect their future (marriage, work).
- Urban patients had more expressed their feelings about TB than rural patients.
- Patients in urban areas focused their care experience on treatments, especially the organizational and the temporal dimensions and in rural areas on healthcare providers and their help.

## DISCUSSION

Knowledge:

- Patients in urban areas are more knowledgeable than rural patients.
- Rural patients were more informed that TB is a communicable airborne disease than urban patients. But do rural patients talk more freely about TB in their neighborhood and could it be the reason of a better knowledge on TB treatment?

Impact:

- Many results regarding impact on marriage, isolation, using separated utensils, working and wearing a mask are similar in urban and rural areas.
- Patient didn't related them specifically to stigmatization, more present in rural areas according to Doctors, but they are part of it as mentioned by the literature and health care providers.
- Stigma could hinder the control of TB. These finding corroborates with the finding of Anand *et al.* (2013) "Lack of understanding of the community perspectives towards TB may be a possible reason for TB remaining as a major public health problem".

**« EVEN THOUGH I'M CURED, I'LL KEEP MY DISEASE SECRET »**

## CONCLUSION

- Minors differences between rural and urban areas.
- Through educational and individual surveillance, DOTS has a positive impact on TB.
- Stigmatization seems to be decreasing in India among TB.

## LIMITS

- Barrier of the language (misunderstanding and translation) and culture (feeling and socio-cultural norms).
- Context of interviews: confidentiality, location, number of interviewers, intimidation.

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CHUV Institut universitaire de formation et recherche en soins

UNIL | Université de Lausanne

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