Original Article

PERCEPTIONS OF GENDER AND TUBERCULOSIS IN A SOUTH INDIAN URBAN COMMUNITY

Sudha Ganapathy[1], Beena E Thomas[1], M.S. Jawahar[1], K. Josephine Arockia Selvi[1], Sivasubramaniam[2] and Mitchell Weiss[3]

(Original article received on 23.3.2007. Revised on 10.7.2007. Accepted on 11.9.2007)

Summary

Background: The Revised National Tuberculosis Control Programme (RNTCP) in India advocating Directly Observed Treatment-Short course (DOTS) detects nearly three times more male than female TB patients. The reasons for this difference are unclear. An understanding of the community's health beliefs, perceptions on the disease and behaviour towards TB patients may throw some light on this issue.

***Material and Methods*:** A qualitative study using focus group discussions was conducted among men and women of younger and older age groups from lower income neighbourhoods. The information obtained was grouped into themes which included, understanding of TB, vulnerability, access to health care and social responses. Gender differences in community perceptions on TB seem to be critical in issues related to marriage.

Results: The stigma of TB is more visible in women than men when it comes to marriage. Men and children were perceived to get preferential attention by their families during illness. While the younger age group, irrespective of gender, accessed care from private providers, the older group preferred a government facility. Awareness of TB was acceptable but it seemed more associated as a respiratory disease and the common symptom associated with TB was cough.

Conclusion: This study highlights the need for gender specific intervention strategies to enhance better access of TB services. **[*Indian J Tuberc 2008; 55:*9-14]**

***Key words*:** Gender, Community, Tuberculosis

INTRODUCTION

The social and economic impact of Tuberculosis (TB) which claims lives of more than 4, 00,000 people every year is devastating, especially as it affects the economically most productive age group[1]. Furthermore, in virtually all countries, fewer female than male tuberculosis cases are notified[2]. In India, it has been found that more men report with chest symptoms than women and the Revised National Tuberculosis Programme (RNTCP) advocating Directly Observed Treatment-Short course (DOTS) detects nearly three times more male than female TB patients[3]. Higher tuberculosis notification rates in men may partly reflect epidemiological differences, exposure to risk of infection and progression from infection to disease[4]. However, this may not be the only factor influencing this disparity. It has also been generally observed that women in developing countries confront more barriers than men in accessing health care services due to a variety of socio-cultural factors[5,6].

The Revised National TB Control Programme is based on passive case finding which aims to diagnose and treat persons with TB symptoms reporting at various health facilities. The perceptions of TB prevailing in the community would influence the health seeking behaviour of people in accessing health care facilities for their symptoms. While there is information on the care seeking behaviour of chest symptomatic there is dearth of information on community perceptions on TB[7,8]. This study was carried out as part of a WHO/TDR collaborative multi-country project titled "Gender Differentials in Tuberculosis

1. Clinic Division* 2. Department of Statistics (Retd.)* 3. Department of Public Health and Epidemiology**
* Tuberculosis Research Centre, Indian Council of Medical Research (ICMR), Chennai.
** Swiss Tropical Institute, Basel, Switzerland
***Correspondence*:** Ms. Sudha Ganapathy, Tuberculosis Research Centre, Indian Council of Medical Research (ICMR), Mayor V.R. Ramanathan Road, Chetpet, Chennai, Tamilnadu, India – 600 031; Email: esgee70@yahoo.com; beenaelli@hotmail.com; Telephone: 91 44 28369527/9513; Fax: 91 44 28362528/2525

Control". The objective of this qualitative community based study is to find out gender differences in understanding of TB with reference (1) to symptoms, causes, spread and cure (2) perceptions about vulnerability to TB (3) gender differentials in care seeking, type of providers consulted, reasons for choice and perceptions about TB services (4) implications of TB on marriage, pregnancy and lactation.

METHODOLOGY

This is a qualitative study using focus group discussions (FGDs) to obtain information on the community's perception on TB with special reference to gender. We used this method as it has been proved a useful tool to collate information on the community's beliefs, values and understanding of health problems[9, 10].

A topic guide developed at the project development workshop on gender differentials in TB control in December 2000 was used to guide the FGDs. The topic guide included questions about awareness of TB, vulnerability to TB, care seeking behaviour and implications of TB on marriage and breast feeding. The topic guide was pilot tested for men and women separately and found to be culture specific and adaptable among men and women.

Study participants

Participants in the study were members of the community from Chennai city, belonging to the lower socio-economic strata. They were grouped into four different groups based on age and gender and were categorized as "old male" and "old female" (>40years) "young male" and "young female" (<40years). The help of a community leader of the area was used to identify eligible participants. They were first assessed for their willingness to be a part of the study and spare the time required for a discussion. If willing, the details of the study were briefly explained and their written consent obtained. Ineligible participants were below 18 years and above 80 years, as well as those persons who were too ill and hard of hearing. Each FGD lasted for one hour to 90 minutes. The team, which conducted the discussion, comprised trained medical social workers. One was a moderator responsible for leading the discussion and her role was purely as a catalyst. The other was responsible for recording the information, making detailed notes in addition to tape recording, noting down expressions and seeing to it that everyone in the group had an opportunity to participate. The moderator closed the FGD session when the saturation point was reached and no new information was obtained. Each discussion had 8-10 participants and was conducted in Tamil.

Study sites

The FGDs were conducted in places that were familiar to participants and at a time convenient to them. Community halls, residences of grass root level workers of the Non-Governmental Organizations (NGOs) and school premises were some of the venues used for the FGDs. A total of sixteen FGDs were conducted.

Statistical Analysis

The information collected was transcribed the same day and data entry completed within a week. The qualitative analysis was done using the MAXQDA software. Data was analyzed according to the different themes based on which the data was collected.

RESULTS

Understanding of TB (pertaining to symptoms, cause and spread)

Tuberculosis disease was familiar to both men and women in all the groups and considered as a respiratory disease. The main symptom that was associated with TB by all the groups, both among the men and women was "cough". Some of the participants mentioned continuous, severe cough with a whooping sound and expectoration and a few expressed cough with a yellow coloured sticky sputum as a symptom

of TB. Some of the men mentioned blood in the sputum, fever, breathlessness and many women expressed weight loss and loss of appetite as other symptoms of TB.

An often repeated response regarding the cause of the disease was "stamping on sputum". To illustrate from an often repeated response

"Since many people walk without slippers, they may get infected if they stamp on the sputum".

More males and a few females attributed smoking as a cause for TB. Drinking as a cause for TB among men was expressed more by the women. The women felt that eating stale food and breathing polluted air could be reasons for getting TB. Some women were also of the view that women being primary care givers were more prone to being infected, especially if there was a TB patient in the family. Some of the other responses among women were that contact with other TB patients, sharing of utensils, clothes and food with TB patients lead to the spread of disease.

Vulnerability to TB

Most of the respondents in all the groups were of the opinion that men were vulnerable to TB as they smoked, consumed alcohol and frequented dirty and polluted surroundings. In some of the groups, both male and female, it was felt that men were more vulnerable to TB since they had extra marital relationships.

Responses from women

"Men are likely to get TB more as they smoke, consume illicit liquor and take ganja."

"Men have extra-marital contacts and chances of getting TB are more".

Another interesting response among some of the females was that women were vulnerable to get TB since they cook using firewood and therefore, were exposed to smoke. Among older male groups, some of them said that TB was associated with age and elderly people are likely to get the disease.

Care seeking and perceptions about TB services

In all the groups, the general opinion was that children and men get priority in receiving care and attention from the family during any illness. Many of the women were of the opinion that men received more care being breadwinners, had to get well soon and return to work. Some of the women said that due to domestic responsibilities, women did not express their health problems or seek care till they were unable to bear their symptoms and other home remedies failed. A few women expressed the view that men generally sought care from good private doctors and got costly medicines as compared to women.

Among both men and women, the initial providers they approached when they had any health problems, were private doctors. This was mentioned more than once in the male groups. However, for serious illnesses requiring hospitalization and prolonged treatment, governmental health facilities were preferred by both men and women. It was also found that among older men and women groups, preference for a government facility was expressed. The reason attributed was that they were financially dependant on their children and hence could not afford to spend for their treatment.

With regard to care giving, both men and women were of the view that women were more concerned and were better at taking care of their family members when anyone in the family was ill. This point was stressed repeatedly by the women. The women justified this saying that men were busy with work and had 'no time' to look after women when they fell sick. Most women accepted the fact that the men had no patience in looking after the sick people.

With regard to treatment, most of the men and women said that treatment is available for TB and it is curable. However, a few of the males, both in the young and older age groups, and few females in the older age group felt that TB was incurable.

A female from the older group said "*Some may die of TB. Only one out of 100 gets cured*".

Most of the participants said that they were aware that treatment for TB is available in public health facilities. However, many of the males said that TB treatment was available only in specialized government hospitals dealing with TB treatment and not at all public health facilities. The duration of treatment for TB perceived by the groups ranged between three to 36 months. Longer duration of treatment was mentioned by females and to quote a remark from a female "Treatment for TB has to be taken till death".

With regard to regularity for treatment, most of the females, both young and old, were of the view that women would be more regular in taking treatment as they had the responsibility of taking care of the family, especially children. Many of the women and some of the men were of the opinion that men would be irregular for treatment due to pressure of work and dependence on alcohol.

Social responses (Implications of TB on marriage, pregnancy and lactation)

Men were of the opinion that it will be easier for males who are infected with TB or treated for TB to get married than females. Some of the males said that it would be easy for males to hide the fact that they had TB and get married as compared to women who were not expected to hide their TB diagnosis. A few of the men also felt that it would be difficult for women to hide their history of TB as relatives and neighbours would gossip about it and chances of her marriage would get affected. Another opinion among the males was that women treated for TB will have to pay a higher dowry. A few of the women said that TB would result in death and so it was better to avoid marriage.

Men and women said that a person with TB could get married but only after completion of treatment. Some of the younger males were of the opinion that those who have been treated for TB could be married but should have regular medical check-ups after marriage, even if cured. Among women, there was a strong opinion that the history of TB should not be disclosed to the prospective grooms and in-laws.

A response from a female.

"For the men it is not a big thing to get married after the treatment, but for women it would be a problem. The neighbours and relatives of the infected women would talk ill of her"

Response from a male

"It will be a problem for women to get married since beauty is needed for a woman and not for a man. If a woman is infected by TB she will become like a skeleton and her beauty will be spoilt".

All the groups emphatically said that women infected with TB should not conceive. Many of the males were of the opinion that the child will also be infected. Most of the females said that the tablets taken for TB will affect the child and hence they should not get pregnant. A few of the women, however, felt that women can conceive after consulting their doctor. Most of men and women said that TB infected women should not breast feed as the illness will pass on to the children through lactation.

Responses from older females

"A woman's blood is converted into breast milk. So a woman with TB cannot breast feed".

"A woman infected with TB should not breast feed as she will be passing on the infection to the infant".

Few of the older females and older males felt that TB infected women could breast-feed after consulting their doctor.

DISCUSSION

Gender differences in community perceptions on TB seem to be critical in issues

related to marriage. The stigma of TB is more visible in women than in men when it comes to marriage. It was generally felt among both men and women that it was easier for men infected or treated with TB to get married as compared to women. These views are in line with a qualitative research report from Pakistan where most participants of FGDs expressed the view that TB can have an adverse effect on the chances to get married more often in females than in males[11]. Another study from Mumbai also brought out that married women were concerned and anxious about rejection by husbands, harassment by in-laws and unmarried women worried about chances of marriage[12]. There were also concerns expressed by men and women with regard to conception and breast-feeding by women with TB.

There seemed to be more awareness about TB as a respiratory disease in line with qualitative research reports from Kenya and Viet Nam which have reported TB as a disease affecting lungs, chest or air passage[13,14]. Moreover, TB is more associated with cough and other cardinal symptoms do not seem to be known, especially among women. The cause of TB was attributed more to smoking, alcohol, stamping of sputum and airborne transmission did not seem to be expressed.

Another interesting view expressed was that men were more vulnerable to get TB as compared to women. This vulnerability was because of their social contacts, exposure to dust, smoking and consumption of alcohol. This was similar to a study from Viet-nam which also brought out that men have wider social contacts as compared to women and was more likely to get TB than women[14].

Finally, it is important to note perceptions in the community with regard to accessing health care with men availing proper and prompt care both from providers and family. On the contrary, women do not heed to health care till their symptoms aggravate and bear it no longer. This is in keeping with qualitative data from the Foundation for Research in Community Health (FRCH), among women in Pune, India, which has shown that a very important reason, particularly among women, for seeking help was a worsening of their symptoms[15]. Quantitative data from the EMIC interviews, which was part of the same WHO/ TDR study from Chennai, has also shown that the delay from the onset of symptoms to seeking first help was more among women than men. (Not published)

The study emphasizes the need for gender specific advocacy and intervention on TB and health care in the community which is crucial to enhancing proper and prompt care seeking behaviour.

ACKNOWLEDGEMENTS

The authors would like to acknowledge UNDP/World Bank/WHO Special Programme for Tropical Disease Research (TDR) for funding this study.

The authors are thankful to the staff of Mariyalaya, Montford Community Development Society (MCDS) and Madras Christian Council of Social Service (MCCSS), the Non Governmental organizations. We thank Ms. G. Sangeetha and Mr. S. Alwin, Project staff for their contribution. We are grateful to Dr. P.R Narayanan, Director, TRC, Chennai for his constant support and guidance. This study would not have been possible without the active participation and co-operation of the members of the community. We are thankful to them.

REFERENCES

1. TB India. 2004. RNTCP status report.
2. WHO Global TB Control: Surveillance, Planning, Financing WHO report. 2002. WHO/CDS/ TB2002.295.Geneva, Switzerland: WHO, 2002.
3. Khatri GR and Frieden TR. The status and prospectus of Tuberculosis Control in India. *Int J Tuberc Lung Dis* 2000; **4**: 193-200.
4. Howson CP, Harrison PF, Hotra D Lawn. *In her lifetime: female morbidity and mortality in sub Saharan Africa*. Washington DC: National Academy Press., 1996.
5. Uplekar MW, Rangan S, Weiss MG, Ogden J, Borgdorff MW, Hudelson P. Attention to gender issues in tuberculosis control. *Int J Tuberc Lung Dis* 2001; **5(3):** 220-224.
6. Hudelson P. Gender differentials in tuberculosis: the role of socio-economic and cultural factors. *Tubercle Lung Dis*, 1996; **77**: 391-400.
7. Thilakavathy Subramanian. Sample survey of awareness

of symptoms and utilization of health facilities by chest symptomatics. *Indian J Tuberc* 1990; **37**: 69-71.

8. Sudha G, Nirupa C, Rajasakthivel M, Sundaram V, Bhatt S, Renu G, Subramaniam K, Thiruvalluvan E, Mathew R, Santha T. Factors influencing the care-seeking behaviour of chest symptomatics: a community-based study involving rural and urban population in Tamil Nadu, South India. *Tropical Medicine and International Health* 2003; Vol **8(4):** pp 336-341.
9. Aubd J and Masour M. Qualitative community health research – A Tunisian example. *Health Policy and Planning* 1989; **4 (3):** 244-256.
10. Forrest KA, Austin DM, Valdes MJ, Fuentes EG and Wilson SR. Exploring norms and beliefs related to AIDS Prevention among California Hispanic men. *Family Planning, Perspect* 1993; **25**: 111.
11. Liefooghe R, Michiels N, Habib S, Moran MB and A. De Muynck. Perception and Social Consequences of Tuberculosis: A focus group study of Tuberculosis patients in Sialkot, Pakisthan. *Social Science and Medicine* 1995; Vol 41, No **12**: 1689-1692.
12. Dinesh MN, George A, Chacko KT. Tuberculosis in Bombay, New reasons for concern. 1995. Unpublished document.
13. Liefooghe R, Baliddawa JB, Kipruto EM, Vermeire C and De Munynck, A.O. From their own perspective. A Kenyan community's perception of tuberculosis. *Tropical Medicine and International Health* 1997; Vol **2 (8):** pp 809-811.
14. Long NH, Eva Johansson, Vinod K, Diwan, Anna Winkviot. Different Tuberculosis in men and women: beliefs from focus group in Vietnam. *Social Science and Medicine* 1999; **49**: 815-822.
15. Sudhakar Morankar and Mitchell G Weiss. Impact of gender on illness experience and behaviour: Implication for TB control in rural Maharashtra. *Health Administrator* 2003; Vol XV No **1-2**: 149-155.

The Editor-in-Chief and the members of the Editorial Board of *Indian Journal of Tuberculosis* wish you all a Very Happy and Prosperous New Year 2008.