

## PSYCHO-SOCIAL DYSFUNCTION: PERCEIVED AND ENACTED STIGMA AMONG TUBERCULOSIS PATIENTS REGISTERED UNDER REVISED NATIONAL TUBERCULOSIS CONTROL PROGRAMME

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### Summary

**Objective:** To examine the perceived and enacted stigma experienced by TB patients and the community.

**Methods:** We interviewed 276 TB patients registered for treatment during January-March 2004 in government health facilities of two Tuberculosis Units of south India. Data on perceived and enacted stigma were collected after two months of starting treatment, using a semi-structured interview schedule. In addition, four Focus Group Discussions were conducted among Directly Observed Treatment (DOT) providers and community members. Narrative summaries were also taken down to collect additional qualitative information.

**Results:** Of the 276 patients, 190 (69%) were males. There was no significant difference between the genders in relation to social stigma. Perceived stigma was higher than enacted stigma in both genders and significantly higher among males (Low self esteem  $p < 0.05$ ), change of behavior of community ( $p < 0.05$ ), ashamed to cough in front of others ( $p < 0.05$ ).

**Conclusion:** Considering the social and emotional impact of the disease, it is essential to adopt support strategies to enhance acceptance and for a successful health programme. [Indian J Tuberc 2008; 55:179-187]

**Key words:** Tuberculosis, Perceived stigma, Enacted stigma, Psycho- social dysfunction

### INTRODUCTION

Illness and chronic disease create multiple burdens for patients, including the necessity to deal with pain, suffering, reduced quality of life, premature mortality, financial costs and familial emotional trauma. Ultimately, society must bear the negative impact of the social consequences created by the combined effects of the disease on patients and their families.<sup>1</sup>

Tuberculosis (TB) is a classic example of a disease with both medical and social dimensions, characterised by its close relation to poor socio-economic conditions. Previous studies indicate that the stigma associated with TB adds to the burden of disease for both men and women particularly if they are of marriageable age.<sup>2</sup> A survey carried out in India in 1997, before implementation of Directly Observed Treatment Short-course (DOTS) strategy, estimated that 100,000 women were rejected by their families each year because of their TB disease.<sup>3</sup>

DOTS, the accepted, standard comprehensive strategy for the diagnosis, treatment and monitoring of TB world-wide, known as the Revised National Tuberculosis Control Programme (RNTCP) in India, was pilot-tested in 1993, and after rapid expansion since 1998, the entire country was covered by March 2006.<sup>4</sup> India's RNTCP is the second largest programme in the world based on population coverage and the large number of patients initiated on treatment.<sup>5</sup> The millennium development goal for TB is to reduce its incidence and mortality to 50% by 2015. However, one of the recognised barriers to TB treatment is the stigma associated with the disease. In the year 2004, a study done at our centre reported that both men and women TB patients aged <45 years registered under RNTCP felt equally inhibited discussing their treatment with friends and family.<sup>6</sup> Another study on "Perceptions of tuberculosis patients about their physical, mental and social well-being" reported that stigma remained unchanged even after completion of treatment.<sup>7</sup> In order to gain further insight into

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the issue of stigma related to TB, the present study was undertaken to examine the perceived and enacted stigma (actual discrimination) experienced by TB patients and the community perceptions on stigma related to TB.

## MATERIAL AND METHODS

### Settings

India's Revised National Tuberculosis Control Programme (RNTCP), an adoption of the internationally recommended Directly Observed Treatment Short course (DOTS) strategy, focuses on providing free quality sputum smear microscopy for diagnosis as well as quality drugs for treatment

free of cost. This strategy also provides decentralized treatment services close to patients' residence under direct observation with the help of government health workers and community volunteers. The primary objective of RNTCP was to achieve 85% cure rate and to detect 70% of new sputum smear positive cases (Central TB Division, 2006). Treatment is administered under direct observation (DOT) on a thrice-weekly schedule in two phases: an initial intensive phase (IP) for 2-3 months, followed by a continuation phase (CP) of 4-5 months. The DOTS takes into account the patient's convenience and the responsibility of ensuring completion of the treatment by DOT provider. TB control programme is a felt-need oriented programme as more than 80% of persons

**Table 1:** Demographic, socio-economic characteristics of TB patients enrolled in the study (n = 276)

	Female (86)		Male (190)		Total (276)		p-value
	number	percentage	number	percentage	number	percentage	
<b>Age(years)</b>							
≤35	65	76	76	40	141	51	≤0.01
>35	21	24	114	60	135	49	
<b>Marital Status</b>							
Married	56	65	141	74	197	71	NS
Unmarried	30	35	49	26	79	29	
<b>Literacy</b>							
Illiterate	26	30	36	19	62	22	≤0.05
Literate	60	70	154	81	214	78	
<b>Occupation</b>							
Unemployed	73	85	33	17	106	38	≤0.01
Employed	13	15	157	83	170	62	
<b>Income</b>							
Nil	73	85	28	15	101	37	≤0.01
≤1000	7	8	57	30	64	23	
>1000-3000	6	7	105	55	111	40	

with chest symptoms have been reported to seek relief of symptoms on their own. TB awareness was not up to expectations due to poor literacy rate or lack of availability of effective communication channels resulting in improper health seeking behaviour and the treatment compliance.

#### Study area

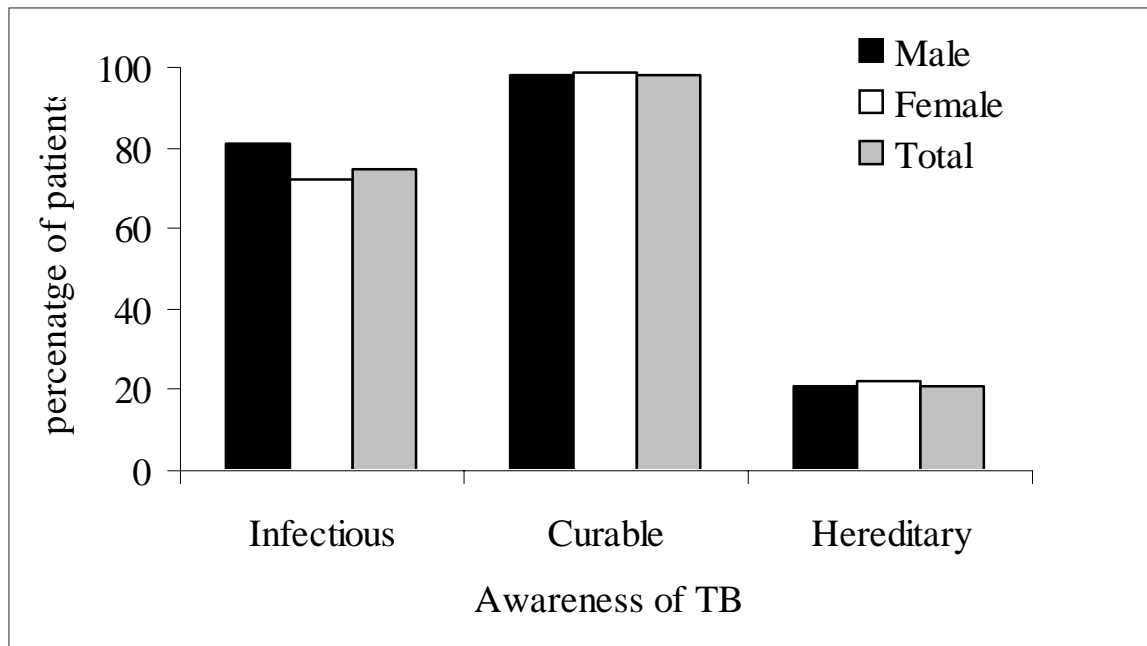
This study was carried out in two Tuberculosis Units (TUs), Kancheepuram (rural) and Chennai (urban), covering a population of 1.1 million in the state of Tamil Nadu.

**Table 2:** Stigma related problems after disclosing the disease

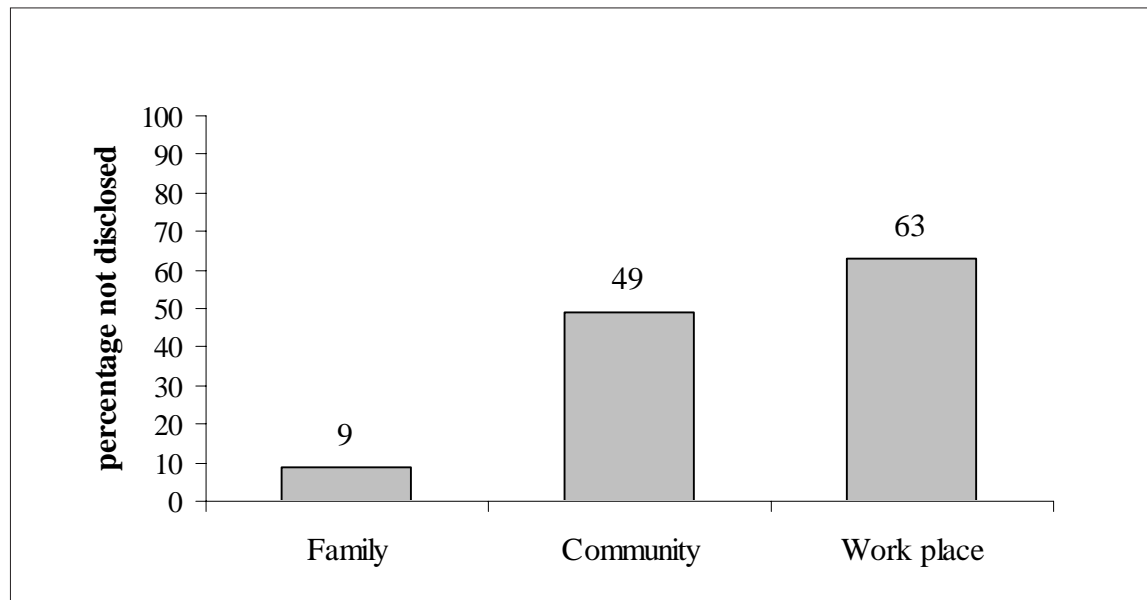
Factor		Percentage	
		Yes	No
<b>Family</b> (n = 252)	Looked down	24	76
	Change of attitude	11	89
	Keeping separate	10	90
<b>Community</b> (n = 140)	Looked down	54	46
	Problems faced from them	9	91
	Change of behaviour	47	53
<b>Work place</b> (n = 170)	Staff behaviour changed	7	93
	Discontinued job	26	74
	Job changed	9	91

**Table 3:** Perceived stigma among TB patients enrolled in the study

	No	%
<b>The disease not revealed to</b>		
Family	24	9
Friends/relatives/neighbours	136	49
Work-place	44	63
Reluctant to attend social function	74	27
Felt friends/relatives/neighbours avoiding	18	9
Feeling ashamed to cough	107	43
Felt others looked down upon	85	32
<b>Among Unmarried</b>		
Problems expected	19	63



**Figure 1:** Awareness of disease among Tuberculosis patients



**Figure 2:** Proportion of TB patients who have not disclosed their illness to family, community and fellow workers

### Study population

Three-hundred and fifty TB patients attending government health facilities during the first quarter (January-March) of 2004 formed the study population. Seventy-four patients could not be contacted due to the following reasons: transferred to other TUs (10), unwillingness for interviews (4) and the remaining 60 patients had defaulted from the treatment during IP. In all, 276 (79%) patients were interviewed at the clinics of the two TUs.

### Tool for data collection

A semi-structured, pre-coded, pre-tested patient interview schedule was prepared on the basis of Explanatory Model Interview catalogue (EMIC).<sup>8</sup> The EMIC is not a fixed scale, but rather a frame

work for flexible interviews and an instrument for studying illness related experience, its' meaning and related behaviour. This was used to obtain information from TB patients' problems faced in their houses, attitude of neighbors, friends and co-workers. Interview schedule included data on socio-economic and demographic characteristics, awareness of TB and the nature of their disclosure of their disease to family members, relatives, neighbours, friends and employers. The information was also elicited regarding behavioural changes such as maintaining appropriate personal distance and avoiding close contact activities with family members, neighbours, friends and employers. Data was collected by Medical Social Workers (MSWs) after obtaining informed written consent. All the interviews were conducted two months after initiation of Anti-TB Treatment (ATT).

#### ***Box 1. Narrative summaries from patients***

- *I did not reveal my disease to my family members since I will be separated from others*
- *I am scared to tell my disease to my husband and mother-in-law because of fear of rejection*
- *Myself keeping away from others to avoid spread of infection*
- *I want my children to be married without any problems. My disease may create problems.*
- *I feel ashamed of coughing in front of others since they may look down upon me.*
- *My employer does not know about my disease. If he knows, I will be sacked, also my colleagues will avoid me*
- *After knowing my disease, my husband left me with three children and started living with another woman*
- *After my diagnosis as TB, my mother-in-law sent me to my parents house*
- *Even after cure, I was not allowed to do household work*

In addition, Focus Group Discussions (FGDS) were conducted among DOT providers and community members. The FGDs examined community contexts, perceptions and explanation of TB with particular consideration of stigma related problems anticipated and actually faced at home, community, and at work-place. The group discussions were conducted in the local language by a moderator and were recorded by an observer. Six FGDs were conducted among men and women in both rural and urban areas. Each group comprised eight to ten members with men and women aged 15-60 years. The discussions were based on a semi-structured topic guide covering the research questioner on TB stigma. Discussions were recorded verbatim and transcribed.

### Definitions used

**Stigma** A powerful and discrediting social label that radically changes the way individuals view themselves and are viewed by others (National Institute of Health, 2000)

**Enacted stigma** Refers to actual discrimination or un-acceptability.<sup>9</sup>

**Felt or perceived stigma** Refers to the fear of discrimination or acceptability.<sup>9</sup>

### Data management

The statistician scrutinized the data for completeness and consistency. Data was entered and analysed using SPSS and Epi-Info (version 6.04d Centers for Disease Control, Atlanta, GA, 2001). Univariate analysis was used to compare perceived and enacted stigma among males and females and the Chi-square test was used to test the difference in the proportions of responses. The level of statistical significance was defined as  $p < 0.05$ .

## RESULTS

### Demographic and socio-economic profile of study population

Of 276 TB patients interviewed, 190 (69%) were males. The demographic and socio-economic

characteristics of these patients were as follows: 51% were  $\leq 35$  years of age, 78% literates, 62% employed, 71% married and 40% were getting monthly income of  $> \text{Rs.}1000$  (1\$=Rs 45). The following characteristics were significantly different between male and female genders: aged  $\leq 35$  (40% vs 76%;  $p < 0.01$ ), literates (81% vs 70%;  $p < 0.05$ ), employed (83% vs 15%;  $p < 0.01$ ) and personal monthly income  $> \text{Rs.}1000$  (55% vs 7%;  $p < 0.001$ ) Table-1.

Of these, majority of TB patients (62%) had a history of TB in their family but only about a quarter of them were aware of other TB patients in their village (21%).

### Awareness of tuberculosis among patients

Seventy-five per cent of both male and female patients knew that TB is infectious in nature (male 81%; female 72%), curable (male 98%; female 99%) and equal proportion of both sexes reported that TB is hereditary (male 21%; female 22%) Figure-1.

### Perceived stigma

Since the data on perceived and enacted stigma in males and females were similar, it was combined and presented in Table-2 and Table-3.

Table-2 describes perceived stigma in terms of person, family, community and work place in both genders. One third of the patients were reluctant to attend social functions and they felt that others looked down on them. Forty-three per cent of the patients felt ashamed to cough in front of others, it was significantly higher among males (76% vs 24%;  $p < 0.05$ ). About 9% felt that friends/relatives/neighbors avoided them.

The disease status was not revealed by patients to family members by 9%, to the community by 49% and to their work spot colleagues by 63%. Among unmarried patients, anticipated problems in terms of getting married due to their disease was reported in 63% (Table-2).

### Enacted stigma

Table-3 describes enacted stigma in the context of family, community, and work place in both genders. Of the patients who disclosed their disease to the family, 24% felt they were looked down upon, 21% were not allowed to do house hold activities, 10% were kept isolated, 8% found change in the behaviour of family members and 23% did not receive additional care.

Among married patients, 18% were reluctant to discuss their disease with their spouses, 28% faced problems in sexual life and 8% were (male 7%, female 12%) rejected and separated from the spouse. It was also observed that among these patients, 57 (69%) male and 26 (31%) female received family support from their parents-in-law.

Among the patients who had disclosed their disease to the community, 54% felt they were valued 'less', 47% experienced change in behaviour towards them and 9% faced rejection due to their disease. Of the total 170 employed patients, 37% disclosed their disease at work place and among them about one fifth experienced change in the behaviour of their colleague and more than two thirds had to discontinue their job.

From FGDs among the community members and DOT providers, it was observed that blood in sputum and persistent cough were considered as symptoms for TB. They said that there was stigma attached to the disease. Many of them said that most of the patients disliked to be called as TB patients. It was noted that unmarried patients especially females experienced difficulties in getting married. They also informed that some of the patients do not want to reveal their disease to their employers/ co-workers since they felt that they will be sent out of jobs/rejected by the community. In all, the FGDs, perceived stigma was expressed more by the members than enacted stigma.

Narrative summaries were also taken down to collect additional qualitative information (Box 1).

### DISCUSSION

The main finding of this study was that perceived stigma was more than enacted stigma in the context of personal, family, community and work place interactions among both male and female TB patients enrolled under RNTCP.

In the present study, one third of the TB patients were reluctant to attend social functions due to their illness. Similar findings were observed in an earlier study from our centre, where before, during and at the end of treatment, 38%, 30% and 24% of TB patients were reluctant to attend social gatherings. This study highlighted the fact that perceived stigma remained unchanged even after completing treatment.<sup>7</sup> More than one third of the present study population felt that others looked down upon them and they were ashamed to cough in front of others. This is corroborated with study done at Centre of Health Research and Development (CHRD), Maharashtra<sup>10</sup> where 43% of male and 60% females think less of self, reflecting a low self esteem. Studies from other parts of India reported that stigma and ostracism have been associated with chronic illnesses like leprosy, mental illness and TB.<sup>10</sup> A study on HIV positive individuals from Chennai brings out the finding that actual (enacted) stigma experienced among those infected with HIV is much less (26%) as compared to the fear of being stigmatised or perceived stigma (97%).<sup>11</sup> The programme managers should recognize this social issue and adopt appropriate strategies to reduce the stigma attached to TB.

In our study, 10-25% of the patients experienced negative reactions from the family members. However, in observations reported by a study conducted prior to implementation of RNTCP, 60% of the patients reported negative reactions.<sup>12</sup> Similarly a study from New Delhi reported severe psycho-social dysfunction in personal, familial, vocational, social and cognitive areas among patients with TB.<sup>13</sup> Patients, who revealed their disease to the community, faced negative reactions such as being looked down upon by the community and change of behaviour and rejection by community members. Under DOTS strategy there is scope to



motivate the patient's family to provide family support and involvement of community DOT providers. These factors might have contributed for the reduction in negative reactions.

Not in conformity with the popular belief that perceived stigma is associated with poor awareness of TB among patients and community, the present study showed awareness on TB diagnosis and treatment to be good among TB patients (75% knew that TB is of infectious nature and 98% were aware that TB is curable). With the idea that better understanding of the disease may result in more social support and reduction of perceived stigma, Leprosy control and HIV/AIDS programmes have been successful in reducing stigma using the direct and indirect approach through qualitative research and awareness programmes.<sup>14,15</sup> Also WHO has initiated a global programme for lymphatic filariasis to improve knowledge and attitudes of Egyptian school children, which included messages on Mass Drug Administration (MDA) and stigma reduction through a comic book. A well-accepted comic book for children is a proven way to reduce stigma and increased knowledge about disease prevention and treatment.<sup>16</sup> So, the authors feel that in the area of tuberculosis, more studies are needed to explore the relationship between awareness and stigma reduction.

In the present study, employed patients faced problems such as loss/discontinuation of the job. The participants of the FGDs among the community members and DOT providers corroborated these findings. Hence there is a need to sensitize the community and the employers on TB and control programme.

We found that both male and female patients faced rejection by spouse due to their illness. Similar findings were reported by the earlier studies from our centre, 15% of married women were rejected by their families on account of tuberculosis,<sup>3</sup> 2% of male and 4% female facing rejection due to their illness.<sup>6</sup> Married women from western India had expressed fear of rejection from husbands and harassment by in-laws.<sup>17-19</sup> This is in agreement with the estimates made in India that every year 1,00,000

women are rejected by their family members on account of their illness.<sup>4</sup>

Problems related to marriage prospects were expressed by 63% of unmarried patients from this study. Uplekar et al., from Maharashtra report that parents of young women do not want to reveal their daughter's illness or do not want to send them for Directly Observed Treatment (DOT) due to difficulties that may arise in marrying them off.<sup>2</sup>

## CONCLUSION

**This present report highlights psychosocial dysfunctions faced by TB patients registered under RNTCP in south India. Understanding of these issues will help the providers in planning more comprehensive efforts to educate the community on TB and thereby reduce the social sufferings faced by the people with tuberculosis. Currently the entire country is covered by RNTCP and every year more than one million patients are being initiated on treatment. The findings of this study bring out the need to provide adequate psychosocial support to patients enrolled in the programme, which will help in enhancing their compliance.**

## Limitations of the study

This study has been done on tuberculosis patients attending TB clinics of Tamil Nadu for DOT treatment and therefore may not be representative of TB in its wider context. A major limitation of this study is that we used a cross-sectional design, which is based on a one time interview. Another limitation was that we could interview only 79% of the patients enrolled in the identified cohort.

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## REFERENCES

1. Thomas A Hodgson. The state of the art of cost-of-illness estimates. *Advances in health economics and health services research*, 1983; 4: 129-164. Jai Press. England, London (edited by Richard M. Scoffer, Louis F Rossiter)
2. Uplekar MW, Rangan S, Weiss MG, Ogden J, Borgdorff M, Hudelson P. Attention to gender issues in tuberculosis control. *Int J Tuberc Lung Dis* 2001; **5(3)**: 220-224.
3. Rajeswari R, R Balasubramanian, Muniyandi M, Geetharamani S, Thresa X, Venkatesan P. Socio-economic impact of tuberculosis on patients and family in India. *Int J Tuberc Lung Dis* 1999; **3(10)**: 869-77.
4. Central TB Division. TB India 2006: RNTCP Status Report. Directorate of General Health Services Ministry of Health and Family Welfare, Nirman Bhavan, New Delhi <http://www.tbcindia.org> (Accessed on June 2006)
5. Agarwal SP, Chauhan LS. Tuberculosis Control In India. Central TB Division. Directorate of General Health Services Ministry of Health and Family Welfare, Nirman Bhavan, New Delhi, 2005.
6. Balasubramanian R, Garg R, Santha T, et al. Gender disparities in tuberculosis: report from a rural DOTS programme in south India. *Int J Tuberc Lung Dis* 2004; **8(3)**: 323-32.
7. Rajeswari R, Muniyandi M, Balasubramanian R, Narayanan PR. Perceptions of tuberculosis patients about their physical, mental and social well-being: a field report from south India. *Soc Sci Med* 2005; **60(8)**: 1845-53.
8. Weiss MG. Cultural epidemiology: an introduction and over view. *Anthropology and medicine* 2001; **8(1)**: 5-29.
9. Scambler G Stigma and Disease: Changing paradigm. *Lancet* 1998, **352**: 1054-1055.
10. Sudhakar Morankar, Deepali Desmuckh. Social stigma and tuberculosis: Soicetal response. Centre for Research and Development (CHRD) Maharashtra Association of Anthropological sciences (MAAS), Maharashtra, India, 2001.
11. Thomas BE, Rehman F, Suryanarayanan D, Josephine K, Dilip M, Dorairaj VS, Swaminathan S. How stigmatizing is stigma in the life of people living with HIV: a study on HIV positive individuals from Chennai, South India. *AIDS Care* 2005; **17(7)**: 795-801.
12. Arora VK, Amit Johri, Ramesh Varma, Palani. Post-treatment adjustment problems and coping mechanisms in pulmonary tuberculosis patients. *Indian J Tuberc* 1992; **39**: 181-184.
13. Bhatia MS, Bhasin SK, Dubey KK. Psychosocial dysfunction in tuberculosis patients. *Indian J Med Sci* 2000; **54(5)**: 171-3.
14. Paz C Medina I, Ventura E. A multidicipilinary study of stigma in relation to Hansen's disease among the Tausug in the Philippines. Social and Economic Research Project reports. No 7. Geneva, Switzerland: WHO, 1990.
15. Blinkoff P, Bukanga E, Syamalewe B, Williams G Under the Mupundu tree: volunteers in home care for people with HIV/AIDS and tuberculosis in Zambian copperbelt. Strategies for Hope. No.14. London UK: Actionaid, 1999.
16. el-Setouhy, M. A. and F. Rio. Stigma reduction and improved knowledge and attitudes towards filariasis using a comic book for children. *J Egypt Soc Parasitol* 2003; **33(1)**: 55-65.
17. Uplekar M, Regan S. Tackling TB: The search for solutions. Bombay, India: The Foundation for Research and Community Health, 1996.
18. Gershon W, GR Srinivasan. German Leprosy Relief Association Rehabilitation Fund and Services. *Lepr India* 1982; **54(3)**: 536-9.
19. Nair D, George A, ChackoK T. Tuberculosis in Bombay: new insights from poor urban patients. *Health Pol Plan* 1997; **12**: 77-85.