SOCIAL ASPECTS OF PATIENTS WITH PULMONARY TUBERCULOSIS IN INDONESIA

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Abstract. Tuberculosis (TB) patients have not only medical but also social problems related to their illness, which may influence their motivation for the completion of treatment. This study investigated the social aspects of patients with TB in an urban area of Jakarta, Indonesia. Most TB patients had poor nutritional status and lived in crowded environments. They faced joblessness and negative attitudes from their neighbors and relatives. A few of the patients were afraid that they would not find a partner; others said that their diseases impaired their marriages. We found that patients with a subnormal body mass index restricted their social contact with their family more than patients with a normal body mass index. In general, patients were supported by their families, both financially and socially. Our findings suggest that priority should be given to developing programs aimed at strengthening the family support of TB patients.

INTRODUCTION

Tuberculosis (TB) kills more adolescents and adults than any other infectious disease. In 1993, WHO declared TB a 'global health emergency' (WHO, 1993). Eighty percent of TB cases occur in persons aged 15 to 59 years. Each person with open pulmonary TB will infect on average between 10 and 15 people each year and about 5-10% of people who are infected become sick during their lifetime (WHO, 1991).

TB is still one of the most important public health problems in Indonesia, where the prevalence is the third highest of all the countries of Asia. Based on the Household Health Survey 1995, TB is the third most common cause of death in Indonesia (Ministry of Health, Republic of Indonesia, 1995). In the TB prevalence survey carried out in 15 Indonesian provinces during 1979-1982, the average prevalence was 0.29% (Aditama, 1991).

Factors influencing the spread of TB are not only medical. Non-medical factors including urbanization, overcrowding, and economic constraints, have put millions at risk of contracting the disease. Standard anti-TB drugs are about 95% effective when prescribed and taken correctly for several months (WHO, 1996). However, owing to the side-effects of the drugs and their high cost, patients do not always complete the full course of treatment; in addition, patients often forget to take their medication, or discontinue their treatment once they start feeling better. Patients who fail to take the full course of treatment may encourage the spread of the disease and promote the development of resistance to one or more drugs (WHO, 1996).

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Although incidence rates of TB have declined steadily in rural areas, they have not done so in urban areas, as reported from a study of a large urban area of British Columbia, Canada (Enarson *et al*, 1989). Factors that contributed to the high incidence of TB in urban areas included malnutrition, anemia, poor sanitation, and poverty (Khan, 1995). A study among pulmonary TB patients in urban Jakarta showed that 59% were anemic, 33% suffered from marginal plasma retinol (vitamin A) concentrations (< 0.70 μmol/l), and 21% had plasma zinc concentration < 10.7 μmol/l (Karyadi *et al*, 2000).

TB patients living in urban areas of low socio-economic status often have severe financial problems because of their losing employment, their loss of other earnings, and the need to defray transport costs while attending a clinic for treatment. Absence from work due to sickness has not only financial but also social consequences. The social burden of a diagnosis of TB may be sufficient to preclude marriage and provoke the negative attitudes of relatives (Cornwall, 1997). When patients with TB are too sick to work, they and their families become impoverished; moreover, family members must care for the sick person, so the family loses other income opportunities. The problem also extends to the economy of the whole community because people who are sick with TB, and those caring for them, stop earning money that would, in normal circumstances, be spent (WHO, 1996).

The present study investigated the socio-economic factors and consequences related to nutritional status in Indonesian patients with pulmonary TB; the aim of the study was to determine the social conditions endured by patients with pulmonary TB and to consider the consequences of the disease.

MATERIALS AND METHODS

This study was part of a research project to investigate the effect of micronutrient supplementation on the efficacy of TB treatment among Indonesian TB patients; in the course of this research, data regarding patients' social conditions were also collected.

Study area and subjects

Untreated out-patients (n = 90) with active pulmonary TB attending pulmonology clinics in public hospitals and health centers in Central Jakarta were enrolled from December 1997 until December 1998. Inclusion criteria were: previously untreated active pulmonary TB based on clinical symptoms and signs; three sputum specimens positive for acid-fast bacilli; radiographic abnormalities consistent with pulmonary TB; age 15 to 55 years; not pregnant and not lactating. Only those who signed an informed consent form were included in the study.

Data collection

A structured pretested questionnaire was used to collect data: the first data were demographic and socio-economic and included age, gender, marital status, number of family members, ethnicity, religion, educational level, current and previous occupations, and the patient's and family's monthly income. Total household income was divided by the number of family members to give an indication of income per head; the second data were about the risk of acquiring TB and included living and housing condition, family members with TB or a history of TB, and smoking habits. Crowding was defined as the number of people per room; (irrespective of age) overcrowding was ≥ 2.5 people per bedroom (Schoeman *et al*, 1991); the third data were factors considered to be social aspects of the disease, including the reasons for unemployment, the impact of TB on occupation, the role of family members in supporting treatment, socialization with friends and family, heterosexual relationships, opportunities for marriage, and the capacity for childcare.

A Karnofsky performance score was awarded on the basis of personal interview and clinical examination by experienced physicians; the score ranged from 0 (dead) to 100 (nor-

mal). Weight and height were measured using standardized methods (Gibson, 1990); body mass index (BMI) was calculated by dividing body weight by height squared (kg/m^2).

Statistical analysis

An independent *t*-test was used to test the differences of nutritional status among groups based on social consequences of disease. Analysis of variance (ANOVA) was used to assess the difference of nutritional status among patients with no occupation. Further comparison of groups was made with the least significant difference test. The SPSS software package (Windows version 7.5.2, SPSS Inc, Chicago, IL) was used for all statistical analysis. $p < 0.05$ was considered significant.

RESULTS

Demographic and socio-economic variables

Data were obtained from 56 males and 34 females (Table 1) with a mean age of 25 years (range 15-55 years). The largest group (43%) was Javanese and the majority (91%) was Moslem. More than half of the patients (57%) had completed at least 11 years of formal school education, while 5% had less than 3 years formal schooling. As shown in Table 2, 63% of respondents had no occupation; the main reason for unemployment was illness (72%). Of those with no job at the time of data collection, 40% had been daily-paid workers.

The median monthly income of employed patients (n = 25) was Rupiah 200,000 (approximately US$ 30; range $9 - 75. The mid-1998 exchange rate was Rupiah 7,000 per US$); the other patients (n = 65), including housewives (n = 8), had no income. The median monthly income of family members who worked (n = 85) amounted to Rupiah 250,000 (US$ 35); the median monthly family income of all patients (including the income of patients and family members) was Rupiah 300,000 (US$ 43; range $4 - 500). The median monthly income for each member of a patient's family was Rupiah 60,000 (US$ 9; range $1 - 100), which is below the 1998 poverty line of Rupiah 96,959 (US$ 14) for an Indonesian urban area (Sutanto, 1999). Therefore 64 patients (71%) were in families with a median monthly income per head that was below the poverty line.

Living conditions, TB contacts, and smoking habits

Most respondents (82%) belonged to families with more than 4 persons, which reflects the average family size of 5-6 in Java. Houses with just one room were rare (2%); 21% of the houses had two rooms, including one bedroom; 43% of houses had three rooms, including 2 bedrooms; 34% of houses had more than 3 rooms. Overcrowding (≥ 2.5 people per bedroom) was found in 55% of households. Of the 34 families with a former TB patient, four families had two former TB patients, and two families had three former TB patients. In the families with former TB patients, the contact was generally of longer than one year (85%). According to the current patients, 35% of former TB patients in their family had received no treatment. Only 9% of the respondents admitted to smoking at present, although 36% said that they had smoked before suffering from TB, which is higher than estimates of the national proportion of smokers (23%) published in the latest survey (Department of Health, Republic of Indonesia, 1995).

Social consequences due to TB

Extra expenses due to cost of treatment were reported by 57% of patients (Table 3). Six respondents (12%) felt that TB would have an adverse effect on the chances of getting married. Five of 40 married patients said that TB had impaired their relationships with their partners. Of the patients with children, 12 had one child, 9 had two children, and 13 had three or more children. In the majority of cases (23/34), the patient's mother looked after the children; 11 patients said that their children were cared for by other family members (Table 4). The delegation of childcare was primarily be-

Table 1
Demographic characteristics of patients with pulmonary TB (n = 90).

Variables	n	Proportion, %
Age (years)		
15-20	20	22
21-30	41	46
31-40	17	19
41-55	12	13
Number of patients (males/females)	56/34	62/38
Marital status		
Married (with children)	40 (34)	44 (38)
Single	50	56
Ethnic group		
Javanese	39	43
Sundanese	18	20
Betawi	23	27
Others	10	10
Religion		
Moslem	82	91
Christian	7	8
Buddha	1	1
Formal education (years)		
< 3	5	5
3-6	27	30
7-11	51	57
> 11	7	8

Table 2
Occupation of patients with pulmonary TB (n = 90).

Occupation	n	Proportion (%)[a]
Currently employed (33/90; 37%)		
Student	8	24
Industrial worker	10	31
Traders	5	15
Daily-paid worker	5	15
Others[b]	5	15
Currently unemployed (57/90; 63%)		
Too ill to work	41	72
Laid off due to monetary crisis	8	14
Housewife/unemployed	8	14
Previous employment		
Student	4	7
Industrial worker	8	14
Traders	5	9
Daily paid worker	23	40
Housewife	8	14
Others[c]	6	11
No answer	3	5

[a]Proportion of those currently employed or unemployed respectively.
[b]Teacher and driver; [c]Salesman and driver.

Table 3
Social consequences of patients with pulmonary TB (n = 90).

Social consequences	n	Proportion (%)
More expenditure due to the illness	51	57
Illness regarded as having negative impact on activities/ occupation	64	71
Restriction of social contacts with other family members	6	7
Restriction of social contacts with friends	11	12
Fear of being unable to find a partner and missing the chance of marriage	6	12[a]
Illness regarded as impairing marriage	5	13[b]
Illness regarded as provoking negative attitudes from relatives	28	31
Less time for childcare	9	27[c]

[a]Proportion of those who were not married (n = 50); [b]Proportion of those who married (n = 40); [c]Proportion of those with children (n = 34).

Table 4
Supportives Roles of family members.

Role of family member (s)	n	Proportion,%
Supporting the cost of treatment	60	67
Being involved in monitoring drug compliance	69	77
Contributing to family income	85	94
Taking care of patients' children	11	32[a]

[a]Proportion of those with children (n = 34).

Table 5
Reasons for unemployment among patients with TB by nutritional status (n = 57).

Reasons	n	Body mass index (kg/m^2)[a]
Too ill to work	41	17.8 ± 2.2[b]
Laid off by company due to monetary crisis	8	16.8 ± 2.4[b]
Housewife/unemployed	8	20.9 ± 5.5[c]

[a]Mean ± SD.
[b,c]Significantly different from one another using least significant differences multiple comparison test ($p < 0.05$, ANOVA test).

cause of the fear of transmission, although 9 patients said that they had less time for taking care of their children because they had to go to the hospital for regular treatment.

Role of family of TB patients

Most patients (94%) mentioned that other family members earned money to support the family income (Table 4). Those responsible for contributing family income were parents (39%), husbands (18%), wives (4%), children (7%), and others such as grandparents, uncles, aunts, and cousins (36%). They also supported the cost of treatment (67%) and were involved in monitoring treatment compliance (77%) (Table 4).

Karnofsky score and nutritional status

One patient had a Karnofsky score of 60, which meant that he required occasional as-

sistance but was able to care for most of his needs; two patients had a score of 70 and could care for themselves but were unable to carry out normal activities or do active work; most patients (74/90) had a score of 80, meaning that they were able to perform normal activities with effort. Thirteen patients had a score of 90: they were able to carry out normal activities with only minor signs or symptoms of disease. Almost two-thirds (57/90) had chronic energy deficiency (BMI < 18.5 kg/m^2).

Association between social consequences of the disease and nutritional status

Patients belonging to families with members currently or previously suffering from TB had a significantly lower BMI (17.0 ± 2.2 kg/m^2) than those who had no such contact (18.3 ± 2.9 kg/m^2) ($p = 0.039$). Patients with BMI > 18.5 kg/m^2 had more contact with other family members than patients with BMI < 18.5 kg/m^2 ($p = 0.049$). Many ($n = 41$) of those who were unemployed ($n = 57$) did not work because of their sickness, while 8 patients had been laid off because of the financial crisis in the country. Housewives had a higher body mass index than other unemployed patients ($p < 0.05$) (Table 5).

DISCUSSION

This study found that socio-economic constraints and social implications were serious problems for TB patients. We found an unemployment rate of 57% in our patients, who were in the most productive years of their lives. This rate was very high compared with the national unemployment rate of 5.5% among those of 15 years of age or older that was shown by the national labor force survey in 1998 (CBS, 1999). In contrast to our findings, in a Canadian study TB patients were mostly employed (Emerson *et al*, 1989). Most patients felt a negative impact of the disease on their daily activities. As a consequence, the extended family often not only bears the financial burden of treatment but also steps into the patient's role of earner. The extended family also made an effort to seek treatment for the patient and monitor treatment compliance. Studies in Puerto Rico and Kenya (Ndeti, 1972; Hunter and Arbona, 1985) showed that patients often felt social rejection from their relatives and neighbors. However, we found that most families were very supportive. Parents, wives, children, and other family members supported the family income: this finding is in agreement with a study in Tamil Nadu, India (Ramachandran *et al*, 1997), in which the vast majority of men (85%) and women (68%) in an urban area reported that their families had accepted the burden of their disease.

We found that one-third of patients had lived with at least one family member who suffered from TB: a clear risk factor for the transmission of TB. In addition, we found that the families of former TB patients had a lower median income per head than families without former TB patients. This may be explained by the socio-economic barriers to the seeking of TB treatment and the provision of adequate household food. Patients who had lived with a family member with TB had a poorer nutritional status than those who had not lived with a family member with TB.

We found that 55% of patients lived in overcrowded conditions. Most patients were aware that TB spreads from person to person. However, patients had lived for years in poor living conditions and it was difficult for these patients to change their living conditions because of economic constraints. Since TB transmission occurs almost exclusively in closed environments, improvements in housing (better ventilation and the reduction of over crowding) are likely to have an important impact (Smith and Moss, 1994). Our finding was not in agreement with a South African study which found that the majority of TB patients did not live in overcrowded environments (Coetzee *et al*, 1988).

Three single female and three single male patients (7%) expressed the fear that they would be unable to find a partner and would not have the opportunity of getting married because of their illness. Five of forty married patients

(13%) complained that the illness impaired their relationships with their partners, although neither divorce nor separation had come about. Studies in Pakistan and India found that divorce and broken engagements were often due to TB and that unmarried girls with TB found it difficult or impossible to get married (Khanna *et al*, 1977; Liefooghe *et al*, 1995).

Some female patients who had children complained about the limited time available for childcare because of the illness; we found that their families were willing to assume the responsibility of childcare. When a woman becomes sick with tuberculosis, her household suffers from both the loss of her earnings and the reduction in her routine household activities such as childcare. In addition, women worried that close contact could infect their children; this fear is not unfounded - mothers may infect their children with TB before dying of the disease themselves (WHO, 1996).

We found that patients with a better nutritional status retained good contact with their friends; on the other hand, patients with poor nutritional status restricted their social contact with other family members. Patients with poor nutritional status tended to limit their social contacts in order to keep their disease secret from friends, neighbors and family members; these patients did not expect their neighbors or friends to be supportive and understanding. Such concerns were voiced by 69% of women in rural India who felt that they could not discuss their disease with their neighbors (Ramachandran *et al*, 1997).

We also found that patients who were housewives had a better nutritional status than the patients who were unemployed due to illness or laid off by their companies. Poorly nourished people are more likely to develop active disease (WHO, 1996). Housewives do not have the responsibility of earning money and may take more care to improve their health compared with TB patients who are responsible for supporting a family. This is in agreement with the studies from Benin, Malawi, Nicaragua, and Senegal, which showed that women with TB were examined more frequently than men (WHO, 2000); in Nepal, however, men were more likely to seek treatment than women (Cassles *et al*, 1982).

In conclusion, we found that TB patients had a poor nutritional status and lived in crowded environments. They faced joblessness and negative attitudes from their neighbors and relatives. A few patients were afraid that they would not find a partner; others said that their diseases impaired their marriages. This study also showed that the families of patients were very supportive, both financially and socially. Priority should be given to developing programs aimed at strengthening family support, including the supervision of anti-TB medication: this may reduce the work of health workers, who are at present largely responsible for the Direct Observed Treatment Short-course (DOTS) program in Indonesia.

ACKNOWLEDGEMENTS

This study was funded by the Gesellschaft für Technische Zusammenarbeit (GTZ) GmbH, Eschborn, Germany and Neys-van Hoogstraten Foundation. Especial thanks PT Indo Farma, Indonesia, who provided standard anti-tuberculosis drugs for our TB patients.

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