Journal of the Postgraduate Institute of Medicine 2020; 7(2): E112 1-9

http://doi.org/10.4038/jpgim.8269

Original Article

Prevalence of stigma among patients with pulmonary tuberculosis

RMUK Rathnayake[1], TL Rathnayake[2], US Narasinghe[1], RTS Ranmuthuge[2], JU Kumari[3], RMJB Rathnayake[4]

[1]Chest Clinic, Matara, [2]District General Hospital, Matara, [3]Teaching Hospital, Karapitiya, [4]University of Ruhuna, Sri Lanka

Key words: external stigma, internalized stigma, anticipated stigma, courtesy stigma, disclose, DOTS, close contacts, isolation, depression

Abstract

Background

Tuberculosis (TB) has long been associated with negative attitudes among people as a contagious, incurable and emaciating disorder. This study aimed to assess the prevalence of stigma towards tuberculosis, among patients with pulmonary tuberculosis.

Methods

A descriptive cross-sectional study was carried out at the Chest Clinic, Matara among 116 smear positive pulmonary tuberculosis patients. Self-administered questionnaire and in-depth interviews were carried out to collect data and multiple variables were analyzed.

Results

Of the 116 patients 62(53%) were male and 54(47%) were female. Sixty (52%) were employed. Mean age was 47.84 years and age range 12 – 89 years. Analysis of education level indicated that 2(1.7%) had pre-primary, 49(42.2%) primary, 48(41.4%) lower secondary level, 15(12.9%) upper secondary and two (1.8%) post-secondary education. The four categories of stigma; external stigma, internalized stigma, anticipated stigma and courtesy stigma were assessed. With regard to external stigma, 68 (58.6%) were reluctant to investigate close contacts, 10(16%) lost their jobs and in two (16%), partners refused to marry. With regard to internalized stigma, 82 (70.7%) were reluctant to obtain direct observer treatment from a person in the village and 74(64%) had had a mental setback. In anticipated stigma, 94(81%) maintained a distance when talking to others and 89 (76.7%) were reluctant to disclose their status to persons other than close family members.

Conclusion

This study shows stigmatization towards the disease in many aspects. Findings could be utilized to implement multidimensional stigma mitigation interventions including advocacy programs, social mobilization and individual behavioural therapy.

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Corresponding Author: R M U K Rathnayake, E-mail: < urathke@gmail.com> https://orcid.org/0000-0003-4237-9568

Received: Feb 2020, Accepted Aug 2020, Published: Oct 2020

Competing Interests: Authors have declared that no competing interests exist

Introduction

In 2015, there was an estimated 10.4 million new cases of tuberculosis (TB) worldwide, of which 5.9 million (56%) were among men, 3.5 million (34%) among women and 1.0 million (10%) among children. Six countries accounted for 60% of the new cases: India, Indonesia, China,

Nigeria, Pakistan and South Africa. People living with HIV accounted for 1.2 million (11%) of all new TB cases [2]. Worldwide, the rate of decline in TB incidence remained at only 1.5% from 2014 to 2015. According to the World Health Organization, this needs to accelerate to a 4–5% annual decline by 2020 to reach the first milestones of the "End TB Strategy". Although the number of TB deaths fell by 22% between 2000 and 2015, TB remained one of the top 10 causes of deaths worldwide in 2015[2].

The incidence of tuberculosis in Sri Lanka in the year 2016 was 8664 cases [3]. The annual incidence in the Matara District was around 220-230 for the last decade [4]. In 2014, 70% were smear positive, 20% smear negative and the remaining had extrapulmonary tuberculosis. The incidence of TB is expected to increase in the future due to an increased prevalence of diabetes, HIV and rapid urbanization. During 2016, a total of 249 human immunodeficiency virus (HIV) cases were newly reported in Sri Lanka giving a prevalence of 0.03% [5]. However, there were only 25 cases of HIV patients with tuberculosis [3]. HIV/TB co-infection could affect TB control activities adversely in the future.

Tuberculosis (TB) has long been accompanied by negative attitudes among people as a contagious, incurable and emaciating disorder. Because of this, it is associated with stigma. Stigma refers to the process of devaluing or discrediting individuals in the eyes of the others. Even though we live in an era where tuberculosis is fully curable with antibiotics, social stigma related to the disease has not changed. However, the spectrum of the stigma may have changed with time. Evaluation of stigmatization among tuberculosis patients is valuable to identify gaps in human behavior towards tuberculosis that may impact the economic burden of patients and affect compliance with treatment. Research publications on stigmatization in TB are limited in Sri Lanka and need to be updated from time to time because of advances in medical management and changing patterns of social values.

Objective

To assess the prevalence of stigma towards tuberculosis among patients with pulmonary tuberculosis

Methodology

This was a descriptive cross-sectional study carried out at the Chest Clinic, Matara. The Matara District is situated in the southern part of the country and has a population of 804,000[6]. The study was conducted over one year from 20.08.2016 with convenient sampling. Smear positive pulmonary tuberculosis patients were recruited and a self-administered questionnaire and in-depth interviews were carried out to collect data. Smear negative pulmonary tuberculosis patients and extra pulmonary tuberculosis patients were excluded.

Sample size was calculated according to the following formula for prevalence studies. A pilot study conducted at the chest clinic by the authors showed some kind of stigmatization among 90% of the sample. $N= (Z_{1-\alpha})^2(p\ (1-p)/D^2$ $N=1.96^2$ X (0.9(1-0.9)/0.05^2) =3.84x,09/.0025 = 138). (N= sample size, Confidence interval=$Z_{1-\alpha}$=95%, = 0.95 =1.96, Prevalence =90% = p= 0.9, If absolute precision required for prevalence =D = 5%= 0.05). Therefore, the required sample size was 138 patients. A total of 223 patients were recruited but due to missing data 116 cases were selected for the analysis.

A self-administered questionnaire of close ended questions was used to collect data from patients. The questionnaire was translated to Sinhala from a validated questionnaire used in a study conducted in Thailand [7].

Four categories of stigma were assessed using multiple questions [8], namely: 1) external stigma (attitude or action of others to create insult, avoidance, rejection and discrimination towards the affected person), 2) internalized stigma (negative thoughts and negative behaviour originating among the affected people), 3) anticipated stigma (expectation of being treated differently or poorly due to stigmatized identity) and 4) courtesy stigma (stigmatization due to association with stigmatized people). Ethics clearance was obtained from the Ethics Review Committee of the Faculty of Medicine, University of Ruhuna.

Results

A total of 116 patients were included in the study with 62(53%) males and 54(47%) females. Sixty (52%) patients were employed. Mean age was 47.84 years (standard deviation ± 17.69) with a range of 12 – 89 years (Table 1).

Table 1: Age distribution

Age group (years)	**Frequency N(%)**
10-20	7(6)
21-30	18(15)
31-40	14(12)
41-50	23(20)
51-60	23(20)
61-70	18(15)
71-80	11(10)
more than 81	2(2)
Total	**116(100)**

Analysis of education level according to the international standard classification of education indicated that 2(1.7%) participants had pre-primary education, 49(42.2%) had primary education, 48(41.4%) had lower secondary level education, 15 (12.9%) had upper secondary level education, one (0.9%) had post-secondary non tertiary level education, none had first stage tertiary education and only one (0.9%) had second stage tertiary level education.

The results of the questionnaire comprising subcomponents of external, internalized, anticipated and courtesy stigma are shown in Tables 2-5.

Table 2: External stigma

Subcomponent	Description of stigmatization	Response N(%)			
		Yes	No	Don't know	Not applicable
Insult	Do you think that it is necessary to investigate close contacts at the clinic? N=116	39(33.6)	68(58.6)	9(7.8)	
	Were you hurt due to the others' attitudes because of the illness? N=116	49(42.2)	67(57.8)		
	Do you think that home visits by health workers for investigative purpose is appropriate? N=116	95(81.9)	21(18.1)		
Rejection	Do your friends keep away from you due to the illness? N=115	32(28)	83(72%)		
	Are you keeping away from sexual life due to the illness N=116	31(27)	57(49)		28(24)
Avoidance	Are the people reluctant to talk to you because of the illness? N=116	16(13.8)	81(69.8)	19(16.4)	
	Are the relatives and friends reluctant to have a meal with you? N=116	16(13.8)	72(62.1)	28(24.1)	
Discrimination	Did you lose the job due to the illness? N=115	10(8.7)	49(42.6)		56(48.7)
	Did your partner refuse to marry due to illness? N= 12	2(16.7)	8(66.6)	2(16.7)	

Table 3: Internalized stigma

Subcomponent	Description of stigmatization	Response N (%)			
		Yes	No	Don't know	Not applicable
Negative thoughts	Do you like to obtain DOTS from a person in the village? N=116	34(29.3)	82(70.7)		
	Have you had a mental setback due to the illness? N=116	74(63.8)	42(36.2)		
	Did you have a fear of seen by a known person when you were attending the clinic? N=116	48(41.4)	68(58.6)		
	Do you believe that contracting the disease is an obstacle to your future achievement of your family? N116	40(34.5)	76(65.5)		

	Do you feel that you have been isolated form your family and society due to illness? N=110	38(34.5)	72(65.5)		
	Do you feel that you will be marginalized even after completion of the treatment? N116	14(12.1)	92(79.3)	10(8.6)	
	Are you satisfied about the maintenance of the confidentiality by the clinic staff? N=116	111(95.7)	5(4.3)		
Negative behaviour	Have you informed your co-workers that you are suffering from TB? N= 60	26(43.3)	34(56.7)		
	Are you reluctant to tell your family that you are suffering from TB? N=116	27(23.3)	89(76.7)		
	Do you want to postpone close contact investigation? N=116	20(17)	90(78)	6(5)	

Table 4: Anticipated stigma

Factors	**Description of the stigmatization**	**Response N(%)**			
		Yes	**No**	**Don't know**	**Not applicable**
Anticipated stigma	Do you keep a distance when talking to another person? N=116	94(81)	22(19)		
	Do you like to disclose about the disease to a person other than your family member? N=116	27(23.3)	89(76.7)		
	Do you think that you have contracted AIDS with TB? N=116	8(6.9)	77(66.4)	31(26.7)	

Table 5: Courtesy stigma

Factors	**Description of the stigmatization**	**Response N(%)**			
		Yes	**No**	**Don't know**	**Not applicable**
Courtesy stigma	Do the others refuse to work or play with the family members due your illness? N=116	8(6.9)	97(83.6)	11(9.5)	
	Were your friends or family members physically harmed due to association with yourself? N=116		116(100)		

Table 6 shows the association of selected patient factors with stigma

Table 6: Stigmatization and association with patient factors

Characteristics	Response		Chi-square value	p-value
	Yes	No		
1. Do you believe that contracting the disease is an obstacle to your future achievement of your family? N=116				
<40 years of age	8	31	5.075	
>40 years of age	32	45		0.024*
2. Do you like to disclose about the disease to a person other than your family member? N=84				
Employed	8	52	6.8	
Unemployed	19	5		0.009*
3. Did you have a fear of seen by a known person when you were attending the clinic? N=116				
<40 years of age	21	18	3.7	
>40 years of age	27	50		0.05
4. Did you lose the job due to the illness? N=60				
Male	7	34	0.015	
Female	3	16		0.9
5. Do you feel that you will be marginalized even after completion of the treatment? N=106				
Male	4	49	8.85	
Female	10	43		0.12
6. Do you like to disclose about the disease to a person other than your family member? N=116				
Male	15	47	0.063	
Female	12	42		0.0802

*Statistically significant

Discussion

Regarding the 116 patients in this study, male to female ratio was 1:1, maximum number of patients were between 41 to 60 years of age and the majority was employed.

Two characters of anticipated stigma showed a high prevalence in this study. Keeping a distance when talking could be a precaution to avoid transmission and to avoid any blame from others. Similarly, an Indian study revealed that people keep an appropriate distance and take other precautionary measures to avoid contact with patients. It further stated that health care personnel also keep a distance when they treat such patients [9]. Reluctance to disclose infection to persons other than family members was a common problem among tuberculosis patients in this study. It was significantly associated with employment but there was no gender

difference A study conducted in Vietnam showed that males were more worried about the economic effects while females were more worried about social consequences of infection [10]. Similar findings were observed among females in an Indian study which identified gender-specific problems like arranging marriage, isolation and caring for children [11].

Two factors classified as negative thoughts under internalized stigma showed a high prevalence among this study group. Many were reluctant to obtain DOTS from a person in the village. Even though the reasons were not analyzed here, a Thailand study has revealed that females considered DOTS to be undesirable due to stigmatization [12]. Similar reasons could have influenced people in this study as well. Most of the patients experienced a mental setback when they heard that they had been affected by this chronic illness. Some studies have shown that TB patients showed a rate of depression 34% higher than the control group [13]. Further, it has been shown that mental setback is associated with poor adherence to the treatment [14]. This could lead to increased risk of relapse, reduce quality of life and increase public health costs.

Reluctance to have close contacts investigated for infection at the clinic scored a high stigma level. Contact investigation is recommended by the World Health Organization and is defined as the systematic evaluation for TB disease and/or latent TB infection of people who have had close contact with a TB "index" case [15]. Household contact investigations are more prominent in Sri Lanka than non-household contact investigations despite the risk of TB transmission in both settings. A study has indicated that, to promote contact investigations in congregate settings, interventions to overcome TB stigma and improve public knowledge about TB transmission are required [16]. Home visits by health workers for investigation purposes were not welcomed by a small proportion of the patients in this study and a similar small proportion wanted to postpone contact investigations. An Indian study has observed a similar situation and recommended conducting community awareness campaigns to address stigma at the community level. Training of health workers to help them understand what stigma is and how it affects the patients was also recommended [17]. A study conducted in Italy which is a low incidence country, has shown that TB related stigma leads to incomplete contact investigation [18].

Several subcomponents were identified as indicating moderate stigmatization in this population. Feeling of hurt due to others' attitudes was found as an external stigmatization. However, most of the moderate stigmatization was under the category negative thoughts in internalized stigma. Fear of being seen by a known person when attending the clinic, belief that contracting the disease was an obstacle to the future achievements of the family, feeling of burden to their families due to illness and feeling of isolation were among them.

These attitudes should not be ignored during the course of treatment. Further analysis showed that patients above 41 years were more likely to believe that the disease was an obstacle to them than younger patients. Elderly may have concerns over their extended families or grandchildren's future. Furthermore, these negative thoughts may indicate the degree of depression they suffered after contracting the disease. In a Chinese study, patients with depressive symptoms showed a higher likelihood of low adherence to TB medication than those with low stigma or without depressive symptoms [19]. In this study, early social and psychological interventions were recommended to combat stigmatization and depression in

TB patients and to improve medication adherence. It is possible that certain basic advice such as using separate utensils, burning used sputum cups, hand washing and living in separate rooms during the early part of the treatment, aimed at avoiding disease transmission, could have misled the patients and their relatives. This may have contributed to self-isolation and to a feeling of marginalization even after treatment. Therefore, care should be taken when preparing health education materials regarding infection control precautions.

Rejection by others was a problem faced by some patients. Fortunately, avoidance by friends was seen in only a minority and even fewer avoided sex.

There was a low level of stigmatization regarding home visits by health workers for investigation and with regard to postponing investigation of close contacts. Although the rates were low, they could have affected preventive activities. Such attitudes could be due to feelings of guilt and shame [20]. Loss of job scored a low level of stigma. In the Sri Lankan government sector, there is a low risk of losing one's job due to contracting tuberculosis but this may not be true for the private sector. In a study in Myanmar, they have shown that more effective communication strategies are needed to increase factory workers' knowledge about transmission and reduce stigma. Employers should be sensitized to protect employees with TB and invest in preventive activities [21].

There were only a few cases of refusal to marry due to infection in this study, similar to a study conducted in Ghana [22]. Avoidance was a problem faced by a few patients. Friends and relatives were reluctant to have meals with the patient and people were reluctant to talk to patients. This is a challenging situation for health workers as it is difficult to change the attitudes of the relatives [20].

However, it is notable that there was no physical harm to the patient or patient's friends and family members by others or refusal to play or work with family members due to the disease. This is in contrast to African countries, where co-infection with HIV is common [8].

A minority felt that they would experience marginalization even after completing the course of treatment. Females thought they were more likely to be marginalized than males and this may be due to the social, economic and cultural influences in Sri Lanka. However, it is difficult to assess the effect of the minimizing or denying strategies of the patients.

There were limitations to the study, such as inadequate ~~different~~ ethnic group representation so we were unable to evaluate the cultural influence on stigmatization. HIV-TB co-infected patients were not included due to low prevalence. The study ~~was~~ focused on clinic patients and community presentation was not included. Small sample size and convenience sampling were also limitations. Depressed patients may not be attending the clinic and may have been underrepresented.

These findings could be utilized to implement multidimensional stigma mitigation interventions including advocacy programs, social mobilization and individual behavioural therapy in patients with smear positive tuberculosis.

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