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Factors affecting psychosocial adjustments to illness of active tuberculosis patients

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Abstract

Tuberculosis is still a major public health problem all over the world. Psychosocial adjustment to illness of tuberculosis patients is important for successful treatment. This study was conducted to determine factors affecting psychosocial adjustment to illness of active tuberculosis patients. This cross-sectional and descriptive study was performed on 48 active tuberculosis cases in Kayseri Province. A sociodemographic questionnaire and Psychosocial Adjustment to Illness Scale–Self-Report (PAIS–SR) were used for data collection. Pearson's chi square test, Fisher's exact test, Mann Whitney U test and Kruskal Wallis H test were used for statistical analyses. It was determined that, 56.5% of the patients were female, 69.6% married, 41.3% primary school graduates, and 21.7% current smokers. Mean age was 46.0±16.2 years, and mean duration of disease was 3.6±2.2 months. Mean of total PAIS-SR scores was 62.5±23.6 and psychosocial adjustment for 73.9% of the patients was evaluated as poor. The most negatively affected domains were domestic environment and social environment. Psychosocial adjustment to illness of tuberculosis patients is poor in general and the patients who are female, low educated, housewife and unemployed have higher risk for poor adjustment to illness. Tuberculosis patients should be supported psychosocially to improve their psychosocial adjustments to illness.

Keywords: Tuberculosis; psychosocial adjustment, social environment, household

Introduction

Tuberculosis (TB) is a chronic, necrotizing infectious disease caused by Mycobacterium tuberculosis, which has very different clinical features. The disease affects not only the lungs but also the organs and systems such as bones, joints, brain, kidneys, digestive system, spine [1-3]. Although TB can be treated effectively, it is still a major public health problem all over the world [4].

About one third of the world's population is infected with tuberculosis. Approximately 5–10% of infected people get ill at some time in their lives. According to 'Global Tuberculosis–2015 Report' of World Health Organization (WHO), TB incidence, prevalence and mortality rates are decreasing worldwide. However, the global TB burden is still very high [1].

In Turkey, a total of 13,378 TB patients entered the TB dispensaries in 2014. Of the TB patients, 92% (12253 people) are new cases and 8% (1.125 people) are already treated. Of the total 13,378 patients, 58% were male and 42% were female and 65% have pulmonary tuberculosis [1].

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World Health Organization (WHO) recommends Directly Observed Treatment Strategy (DOTS) for effective and successful TB treatment [1].DOTS is taking each dose of medication of the patient under the supervision of an officer or responsible person and its being recorded during the treatment. With DOTS, treatment success increases, incidence of disease, recurrence rates and drug resistance rates decrease [2,3].

Drug therapy alone cannot be sufficient because TB is an illness that affects the individual not only physically but also spiritually and socially, as in all chronic illness. The long duration of treatment, the difficulties in drug use, the socio-cultural level and self-esteem of the patient, and the stigmatization that the patient applies to himself and the community to the patient are the most important factors affecting the treatment success [4]. Due to the fact that tuberculosis is a stigmatizing disease, patients cannot easily express their illness and avoid social relations [5-7]. Because TB is a long-standing disease, it can cause socioeconomic and psychological problems and negatively affect the quality of life [8]. TB treatment is beneficial for both patient and community health. For this reason, it is important to maintain both mental and social cohesion of the patient in the treatment of tuberculosis in terms of the continuation and effectiveness of the treatment. This study was conducted to determine the psychosocial adjustments to illness of the patients diagnosed as active tuberculosis and the factors affecting this adjustment.

Material and Methods

This research is a cross-sectional and descriptive study. The research was conducted in March-April 2016. Ethical approval from Erciyes University Ethics Committee for Clinical Investigations and permission from the Public Health Directorate of Kayseri were obtained for the research. No sampling has been done since it is planned to include all of the 48 patients above 18 years of age who have been diagnosed as active tuberculosis and who are registered with the Tuberculosis Unit of Kayseri Public Health Directorate. From these patients, 46 persons who didn't have communication disabilities and who agreed to participate in the study were included. Patients included in the study were interviewed at the Tuberculosis Unit of Kayseri Public Health Directorate. After giving information about the purpose of the study, verbal approval was taken. Socio-demographic questionnaire and PAIS-SR were applied to the patients who accepted to participate in the study by face to face interviewing method.

Data collection tools

"Socio-demographic questionnaire" and " Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR)" were used as data collection tools.

The questionnaire consists of 17 questions to determine the socio-demographic characteristics of the patients (age, gender, education, marital status, income status, residence type, etc.) and their situations related to smoking and alcohol use.

Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR) was developed by Derogatis [9] in 1986 and adapted to Turkish by Adaylar [10]. The scale consists of 46 items measuring the reciprocal interaction of individuals with other individuals and institutions forming the socio-cultural domain. Each item is scored between 0–3. The questionnaire included seven sub-dimensions which are about health care orientation (8 questions), vocational environment (6 questions), domestic environment (8 questions), sexual relationships (6 questions), extended family relationships (5 questions), social environment (6 questions), and psychological distress (7 questions). The sum of all dimensions gives the total scale score. The total score that can be obtained from the scale is between 0–138. High scores in all dimensions indicate worse psychosocial adjustment. For the total score; 35 and below points are considered as "good", 35–51 as "fair", 52 and above as "poor" psychosocial adjustment [9, 10]. Reliability coefficients for health care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress domains of PAIS-SR were 0.87, 0.85, 0.80, 0.95, 0.89, 0.93, 0.83, and 0.94 for the whole scale [10].

Statistical analysis

The data were evaluated using SPSS 15.0, and the answers to the PAIS-SR were evaluated according to the guideline of the scale. The fitness to normal distribution of the scale scores was tested by the Shapiro Wilk test. Mann Whitney U and Kruskal Wallis tests were used to compare the groups, assuming that the data did not fit the normal distribution. Pearson Chi-square test and Fisher's exact test were used for statistical analysis of categorical data. Sperman's rank correlation coefficient was calculated to evaluate the relation between the variables. Values of $p<0.05$ were considered significant in all analyzes.

Results

It was determined that, 56.5% of the patients were female, 69.6% were married and 41.3% were primary school graduates. The mean age was 46.0 ± 16.2 years and the mean duration of illness was 3.6±2.2 months. Of the patients, 21.7% were current smokers. Approximately two thirds of the patients evaluated the economic situation as poor. When the distribution of the patients according to the location of disease was examined, it was determined that 67.5% had pulmonary and meditational lymph node involvement. All of the patients participating in the study were receiving directly observed treatment (DOT).

Table 2 summarizes the PAIS-SR total and subscale scores of the subjects. The arithmetic mean of the PAIS-SR total scores was 62.5±23.6 and the median score was 65.5 (min–max: 19.0–110.0), and 73.9% of the patients were evaluated as having poor psychosocial adjustment.

Table 1. Distribution of Socio-demographic and Patient Related Characteristics of the Study Group.

Variables n=46)	Groups	Number	%
Gender	Male	20	43.5
	Female	26	56.5
	Married	32	69.6
Marital status	Married	32	69.6
	Single	14	30.4
	Undergraduate-primary school	16	34.8
Educational background	Primary – Secondary school	19	41.3
	High school and higher	11	23.9
Personal income	Has	29	63.0
	Doesn't have	17	37.0
Evaluation of income	Well	5	10.9
	Moderate	10	21.7
	Worse	31	67.4
Occupation	Housewife	20	43.5
	Retired	9	19.6
	Student	3	6.5
	Unemployed	7	15.2
	Other	7	15.2
Residence type (n:46)	Apartment flat	26	56.5
	Separate house	12	26.1
	Slum	8	17.4
Smoking status	Still smoking	10	21.7
	Quit smoking	10	21.7
	Never smoked	26	56.6
Age (years) (mean±SD)		46.0±16.2	
Duration o the disease (months) (mean ±SD)		3.6±2.2	
Family size (mean ±SD)		4.8±2.2	

Table 3 shows the PAIS-SR scores according to various characteristics of the patients. As seen in the table, the PAIS-SR total score and subscale scores tend to be higher in general, among the patients who are female, under 50 years of age, housewife and unemployed. Domestic environment and social environment domains scores were significantly higher in females than males;

and PAIS-SR total score and social environment domain scores were significantly higher in housewives compared to the other groups. For the other scores, the differences between the groups were not statistically significant. There was no significant effect of the patients' educational level on their PAIS-SR scores also.

As shown in Table 4, 73.9% of the patients in the study group had poor psychosocial adjustment to the disease. The patients who are female, under the age of 40, unmarried, poorly educated, housewife and unemployed have higher percentage of poor psychosocial adjustment, but the differences between the groups are not statistically significant. As shown in Table 5, there were generally negative correlations between the duration of illness and PAIS-SR scores of the patients in the study group. Correlation coefficients between vocational domain, family domain and total PAIS-SR scores and duration of illness were found statistically significant ($p<0.05$). Table 1

Table 2. Distribution of Total Scores and Sub-Dimension Scores of Psychosocial Adjustment to Illness Self-Report Scale.

Dimensions (n=46)	Probable Score Range	Mean±SD	Median (Min–Max)
Health care orientation	0 – 24	9.6±6.2	8.0 (2.0 – 24.0)
Vocational environment	0 – 18	9.5±4.6	12.0 (2.0 – 18.0)
Domestic environment	0 – 24	11.5±5.1	12.5 (2.0 – 24.0)
Sexual relationships	0 – 18	7.6±5.6	6.0 (0.0 – 18.0)
Extended family relationships	0 – 15	6.9±3.7	9.0 (0.0 – 15.0)
Social environment	0 – 18	10.8±4.5	12.0 (6.0 – 18.0)
Psychological distress	0 – 21	8.1±4.1	7.5 (4.0 – 16.0)
PAIS-SR Total	0 – 138	62.5±23.6	65.5 (19 – 110.0)

Table 4. Psychosocial Adjustment Status of the Patients in the Study Group According to Various Characteristics

Characteristics	Groups	n	Psychosocial Adjustment to the Illness			
			Good–Moderate		Poor	
			Number	%	Number	%
Gender	Male	20	7	350	13	65.0
	Female	26	5	20.0	21	80.0
X2 (p)				1.458 (0.227)		
	18 - 49	26	6	23.1	20	76.9
Age Groups	50 and above	20	6	30.0	14	70.0
X2 (p)				0.281 (0.596)		
Marital Status	Married	32	7	21.9	25	78.1
	Single	14	5	35.7	9	64.3
X2 (p)				Fisher's Exact tTst (0.467)		
Educational Level	Undergraduate-Primary School	16	2	12.5	14	87.5
	Primary-Secondary School	19	5	26.3	14	73.7
	High School and above	11	5	45.5	6	54.5
X2 (p)				3.672 (0.159)		
Occupation	Housewife	20	2	10.0	18	90.0
	Unemployed	7	2	28.6	5	71.4
	Other*	19	8	42.1	11	57.9
X2 (p)				5.235 (0.073)		
Total			12	26.1	34	73.9

*: Employed, retired, student

Table 5. Correlation Coefficients between' Duration of the Illness and PAIS-SR Scores in the Study Group

PAIS–SR Dimensions	Correlation Coefficient (Rho)	P
Health care orientation	-0.157	0.297
Vocational environment	-0.355	0.016
Domestic environment	-0.445	0.002
Sexual relationships	0.122	0.491
Extended family relationships	-0.200	0.182
Social environment	-0.237	0.113
Psychological distress	-0.273	0.066
PAIS-SR Total	-0.315	**0.033**

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Table 3. Distribution of Adjustment to the Illness Scores of the Patients in the Study Group According to their Various Characteristics*

Characteristics	Groups	n	Health care orientation	Vocational environment	Domestic environment	Sexual Relationships	Extended family relationships	Social environment	Psychologic distress	PAIS-SR Total
Gender	Male	26	7.0 (3 – 23)	8.5 (2 – 15)	9.0 (4 – 24)[a]	6.0 (0 – 18)	5.5 (0 – 11)	9.0 (0 – 18)[a]	6.0 (3 – 14)	57.0 (28 – 84)
	Female	20	7.0 (0 – 24	12.0 (2 – 18)	13.0 (0 – 24)[b]	6.0 (0 – 18)	6..5 (0 – 15)	12.0 (0 – 18)[b]	9.5 (2 – 16)	61.5 (6 – 110)
Z			0.300	1.723	2.007	0.214	0.866	2.679	1.162	1.541
P			0.764	0.085	**0.045**	0.831	0.386	**0.007**	0.245	0.123
Age Groups	19 – 49	20	16.0 (2 – 24)	12.0 (2 – 18)	13.5 (2 – 24)	6.0 (0 – 18)	9.0 (0 – 15)	12.0 (6 – 16)	12.0 (4 – 16)	81.0 (19 – 109)
	50 and above	26	6.5 (3 – 16)	9.0 (2 – 16)	12.0 (4 – 24)	6.0 (0 – 18)	5.5 (3 – 12)	11.0 (6 – 18)	6.0 (4 – 14)	58.0 (32 – 110)
Z			1.491	0.022	0.424	0.072	1.058	0.681	1.609	1.364
P			0.136	0.982	0.672	0.942	0.290	0.496	0.108	0.173
Marital Status	Married	32	7.0 (2 – 23)	10.0 (2 – 16)	12.0 (2 – 24)	6.0 (0 – 18)[a]	9.0 (0 – 12)	12.0 (6 – 18)	7.0 (4 – 14)	64.0 (19 – 110)
	Single	14	16.0 (5 – 24)	15.0 (8 – 18)	14.0 (12 – 16)	0.0 (0 – 0)[b]	9.0 (5 – 15)	15.0 (7 – 16)	14.0 (10 – 16)	83.0 (47 – 99)
Z			1.427	0.084	0.120	3.397	1.127	0.342	0.277	1.254
P			0.154	0.933	0.904	**0.001**	0.260	0.732	0.782	0.210
Educational Level	Undergraduate-Primary School	16	7.5 (6 – 18)	11.0 (6 – 16)	14.0 (8 – 22)	7.0 (0 – 18)	9.5 (5 – 12)	12.0 (6 – 18)	7.5 (5 – 14)	67.5 (42 – 110)
	Primary-Secondary School	19	14.0 (2 – 23)	12.0 (2 – 18)	11.0 (2 – 24)	6.0 (0 – 18)	9.0 (1 – 15)	12.0 (6 – 15)	7.0 (4 – 14)	80.0 (19 – 100)
	High School and above	11	7.0 (4 – 24)	8.0 (2 – 12)	12.0 (8 – 16)	6.0 (0 – 12)	6.0 (0 – 15)	7.0 (6 – 18)	10.0 (4 – 16)	58.0 (44 – 99)
KW			2.055	2.977	1.942	3.126	0.993	3.122	2.001	3.401
P			0.358	0.226	0.379	0.210	0.609	0.210	0.368	0.183
Occupation	Housewife	20	16.0 (2 – 23)	12.0 (2 – 16)	14.0 (2 – 24)	6.0 (0 – 18)	10.0 (1 – 12)	12.0 (6 – 18)[a]	12.0 (4 – 14)	83.0 (19 – 110)[a]
	Unemployed	7	14.0 (7 – 18)	12.0 (6 – 13)	12.0 (8 – 24)	7.0 (6 – 12)	7.0 (5 – 10)	9.5 (6 – 15)[b]	9.0 (5 – 14)	76.5 (49 – 84)[a,b]
	Other*	19	6.0 (3 – 24)	6.0 (2 – 18)	12.0 (4 – 16)	6.0 (0 – 18)	5.0 (0 – 15)	10.0 (6 – 18)[b]	6.0 (4 – 16)	56.0 (32 – 99)[b]
KW			5.709	3.011	2.691	2.859	3.674	7.874	4.384	7.892
P			0.058	0.222	0.260	0.239	0.159	**0.020**	0.112	**0.019**

*: The values in the table are median (min–max)

a, b: The difference between groups that do not have the same letter for each variable is statistically significant ($p<0.05$).

Discussion

PAIS-SR scores of the patients were quite high (Table 2), and psychosocial adjustment was assessed as poor in approximately four-thirds of the study group. Although there were some studies which identified the social effects of tuberculosis, we couldn't found any study to determine the psychosocial adjustment to illness of active tuberculosis patients in the literature [4,5,11-14]. Negative behaviours as stigmatization, isolation, etc. are known to be shown to the patients with tuberculosis [5]. Many studies have reported that the most stigmatized patients after HIV–AIDS are tuberculosis patients, and a large proportion of patients with tuberculosis conceal their illnesses with the thought of being excluded by society [15-16]. For this reason, it is becoming difficult for patients to adapt to social life and patients are removing themselves from society. The negative effects of this detachment are seen in many areas such as domestic, social and vocational environments.

In our study, the median scores in domestic, social and vocational environment domains were found to be higher than 50% of the maximum score. These data indicate that the areas where psychosocial adjustment is most deteriorated in TB patients are domestic, social, and vocational domains (Table 2). In a study, which had been conducted on the patients with heart failure by Akın and Durna [17], it was found that the domains of vocational and social environments were significantly impaired, which is similar to our study.

When the effects of various sociodemographic characteristics of the patients on psychosocial adjustment to illness are evaluated; the overall score of PAIS-SR and all subscale scores tend to be higher among the patients who are female, under 50 years of age, housewife and unemployed (Table 3). When total PAIS-SR scores are grouped; the percentage of those with poor psychosocial adjustment was found to be higher in female, under 50 year old, low-educated, housewife and unemployed patients, but the differences between the groups were not statistically significant (Table 4). The fact that the differences between the groups are not statistically significant may depend on the small number of patients included in the study.

In our study, it was specified that the psychosocial adjustment scores of the female patients were higher than the males and the differences between the groups in the social environment and domestic environment domains were statistically significant (Table 3). In Turkey, Celik et al. [18] found that women who were diagnosed with type 1 diabetes and who were in the 18-45 age groups had more problems with their compliance with health care. In addition to being an individual in society, women have very difficult tasks that require responsibility such as being a mother, a wife, and a housewife at home [19]. We think that the result of the poor psychosocial adjustment of the women in our study is due to their difficulty in taking care of their own health issues because of their difficult responsibilities.

It has been reported that there is a relation between educational level and adjustment to illness and that higher educational level affects psychosocial adjustment positively [17,20]. In our study, when we examined the relationship between educational level and psychosocial adjustment to illness, the level of psychosocial adjustment scores and poor psychosocial adjustment were found to be higher in patients with low educational level, but the differences between the groups were not statistically significant (Table 4). It has been reported that the educational level is related to adjustment to illness and the level of education increases the adjustment level [17,20]. We think that as individuals become more educated, it is easier to adapt to the disease because they can be more conscious about their illness and what to do about it.

The total PAIS-SR scores for the housewives and unemployed patients in the study group were found to be significantly higher than employees, retirees and students. Housewives have many responsibilities, such as home cooking, dishwashing, housework such as washing clothes, and child care at the same time [19]. Therefore, this result in our study suggests that housewives may neglect what they need to do about their illness.

In Akın and Durna's study, it was determined that psychosocial adjustment decreased as the level of family income decreased [17]. Unemployment causes individuals to experience economic problems [21]. We think that it is even more difficult for the individuals to cope with their economic problems together with illness, and psychosocial adjustment is affected negatively in this situation.

In the study of Çelik et al. [18], no significant relation was found between the duration of disease and the psychosocial adjustment to illness. On the other hand, the duration of treatment in tuberculosis is defined as a risk factor for adjustment to treatment [22]. There are some studies indicating that, patient's treatment compliance may decline as duration of treatment is prolonged [23, 24].

Table 5 shows the correlation coefficients between the duration of illness and PAIS-SR scores. As seen in the table, there is a negative correlation between duration of illness and PAIS-SR scores in general, and the correlation coefficients were found statistically significant for vocational environment and domestic environment domains and total PAIS-SR scores. This data shows that as the duration of the illness of TB patients is prolonged, their psychosocial adjustment to illness is improved. The stronger relationships, especially for domestic environment and vocational environment domains, suggest that family members and colleagues of patients have accepted their illness in the time.

The limitations of this research are that the study was conducted on the patients in only one province who were registered in a tuberculosis unit and received DOT treatment and that the number of the patients was limited.

The data show that the vast majority of TB patients have poor psychosocial adjustment to illness and that, female, young, low educated; housewife and the unemployed patients are under higher risk in terms of psychosocial adjustment to illness. TB patients should be evaluated in the domestic, social and vocation environments and they should be supported in terms of psychosocial adjustment as well as medical treatment.

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