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Original Article

Perceived Stigma, Social Support and Quality of Life in Patients of Tuberculosis

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ABSTRACT

Stigma associated with tuberculosis impairs the quality of life in the patients of this disease by causing delay in seeking treatment whereas the social support improves their quality of life. **Objective:** To find out the role of perceived stigma, and social support in predicting the quality of life among patients of tuberculosis. A correlational research design using a survey method was used in this research. The study was conducted in hospitals of Lahore during 2019-2020. **Methods:** The sample consisted of 200 patients with tuberculosis (99 men, 101 women). Urdu versions of the Perceived Stigma Scale, Multidimensional Scale of Perceived Social Support, and World Health Quality of Life were employed to collect data. **Results:** Pearson correlation analysis indicated that patients who perceived more social stigma had a significantly poor quality of life whereas those patients who perceived greater social support had a better quality of life. Furthermore, regression analysis indicated that social support appeared to be the strongest positive predictor for quality of life followed by stigma which appeared to be a negative predictor for quality of life in patients of tuberculosis. **Conclusion:** The findings of this study have important implications for mental health professionals, health psychologists, and medical practitioners.

INTRODUCTION

Tuberculosis (TB) is a stigmatized disease in many third world countries and stigma is the most common problem which hinders the compliance to treatment of this disease [1]. Stigma related to TB tends to cause delay in diagnosis of TB [2]. It has also been observed that stigma related to tuberculosis had negative correlation with social support and quality of life in patients of tuberculosis [3]. Similarly it was also indicated in a research finding that social support and perceived stigma among patients were negatively correlated with each other [4]. Patients who had high social support experienced low stigma related to their disease. Furthermore, it was also suggested that when a patient has an ample support from family members, friends and care givers, they are less likely to experience stigma related to their illness [5, 6]. Disease related stigma had strong inverse correlation with quality of life. For instance, researchers reported that stigma among patients adversely affects the quality of life. Several research findings indicated that patients of TB who experienced lower levels of stigma had good health related quality of life whereas, the patients who were highly stigmatized individuals started devaluing them and developed negative emotions in the form of guilt, shame and disgust [7]. Researchers also developed negative attitudes that include social isolation, impaired interpersonal relationships and engagement in risky behaviors [8, 9]. Similar findings were revealed in India where social stigma persisted in Indian patients suffering from tuberculosis even after successful treatment of disease. Moreover, their emotional quality of life remained poor even after they were

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cured [10]. Another research explored gender differences in perceptions about tuberculosis in Gambia. Findings indicated that large majority of patients especially female patients reported stigma attached to the disease. Consequently they tried to keep their disease confidential and took treatment from pharmacies and spiritual healers. The study highlighted the need to provide health education about this disease [11]. In Pakistan, patients of TB suffer from various psychosocial problems. A study examined the social consequences faced by patients of TB. Findings revealed that female patients experienced more severe psychosocial problems than males. In female patients, diagnosis of TB lead to divorce, broken engagements and poor chances of marriage for young ones. The underlying idea was increased risk of relapse of TB. Some females could not pursue their treatment of TB because they were pregnant and most of them were financially dependent upon their husbands for treatment expenditure. On the other hand, male patients faced financial crisis as they could not carry on their jobs due to illness [12]. Another Pakistani study depicted psychological and social constraints faced by patients of TB. The participants of the study consisted of thirty six patients of TB and qualitative data were collected by conducting in depth interviews with them. Results indicated that patients tend to hide their disease because of social stigma attached to this disease. They also experienced social isolation, hatred and others feelings of disgust. Due to lack of awareness, they also believed that it is an incurable disease [13]. Keeping in view the existing literature, the present research used quantitative research approach to examine the role of stigma and social support in determining quality of life.

METHODS

It was a correlational research which aimed to investigate the relationship of social stigma, social support and quality of life in patients of tuberculosis. Initially permission was taken from concerned authorities of all scales used i.e. Perceived Stigma, Multidimensional Perceived Social Support and World Health Organization Quality of Life Scales. Prior to the data collection permission from concerned authorities of three hospitals were taken to ensure their willingness. Later participants were approached in their beds and required to fill the consent form. Researcher explained the objectives of the study to them. They were assured that their personal identity will not be disclosed and their responses will be used for research purpose only. Afterwards, Urdu version of scales was administered to them. The meanings of difficult items were explained to the patients and the items of scale were read out for illiterate participants. The sample of the study consisted of 200 TB patients (99 males and 101 females) from public and private hospitals. Purposive sampling technique was used to draw sample. Furthermore, the sample size was calculated through G-Power analysis in accordance with variable to partcipants ratio. Inclusion criteria for the sample was that they should be diagnosed and seeking treating from reputable hospitals and TB centers of Lahore. Exclusion criteria for this sample were those patients of TB who were also not seeking treatments from hospitals as outpatients. Patients of two age groups were selected which were young and middle-aged adults with an age range of 21-35 and 36-55 years respectively. Three questionnaires were used in the study. Perceived Stigma Scale for tuberculosis was used to measure stigma attached to tuberculosis [14]. The scale consists of 23 statements and responses were obtained on four-point Likert scale i.e., strongly disagree = 0, disagree = 1, agree = 2 and strongly agree = 3. The scale had two subscales i.e., Community Perspective and Patient Perspective. These subscales were related to how community and patients perceive stigma towards tuberculosis. The subscale of community perspective contained 11 items and patient perspective has 12 items. The scale had a good internal reliability for both of the subscales i.e. .88 for community perspective and .82 for patient perspective towards tuberculosis. For current study, the reliability of stigma scale was .94 and for subscales i.e., community perspective and patient perspective it was .94 and .86 respectively. The Multidimensional Scale of Perceived Social Support is a brief research instrument intended to inquire perceptions of support from 3 sources: Family, Friends, and a Significant Other [15]. The scale comprised of 12 items, with 4 items for each subscale. The response choices ranged from 1 = very strongly disagree to 7 = very strongly agree. The internal reliability of estimates of MSPSS was .93 for complete scale and .91, .89, and .91 for the Family, Friends, and Significant Others subscales. For current research, the internal consistency estimate is .91.The WHOQOL-BREF for Quality of life included 26 questions and responses were obtained on five-point Likert scale [16]. It has four subscales i.e., physical health, psychological, social relationship and environment. Physical health includes 7 items, psychological domain has 5 items, social relationships include 3 items and environment domain includes 8 items. Alpha coefficient ranging from .71 to .86 had been found for the four subscales. For current study, the reliability of stigma scale was .91. Gender, age, profession, no. of sibling, no. of children, total number of family members, birth order, education, marital status, family income, type of TB, duration of illness of patient, family history of TB and residence were included in demographic form.

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RESULTS

Table 1 shows that the sample consisted of both young as well as middle aged patients of TB. It has almost equal representation of both male and female patients. Majority of the patients had TB of lungs. Moreover most of the patients were less educated, married and belonged to low income group in rural areas. Nearly half of them also had the family history of TB.

Variables	Categories	f (%)	Mean ± SD
Age	Young Adult	115 (57.5)	30.43 ± 4.54
	Middle Aged Adult	85 (42.5)	49.06 ± 9.17
Gender	Male	99 (49.5)	
	Female	101 (50.5)	
Type of TB	Lungs	183 (91.5)	
	Bones	8 (4)	
	Spinal	1 (.5)	
	Abdomen	5 (2.5)	
	Blood	1 (.5)	
	Glands	1 (.5)	
	Heart membrane	1 (.5)	
Duration of TB	>1 year	86 (43.0)	
	≤ 1 year	114 (57.0)	
Family Size	Medium (≥ 5)	92 (46.0)	
	Large (More than 5)	108 (54.0)	
Education	Under-matriculation	113 (56.5)	
	Undergraduates	87 (43.5)	
Marital Status	Married	146 (74.5)	
	Unmarried	51 (25.5)	
Family Income	0-10,000	36 (18.0)	
	11,000-20,000	142 (71.0)	
	21,000-30,000	16 (8.0)	
	More than 30,000	6 (3.0)	
Area	Urban	52 (26.0)	
	Rural	148 (74.0)	
Family History of Tuberculosis	Yes	98 (49.2)	
	No	101 (50.8)	

Table 1: Descriptive Characteristics of the Sample

Table 2 shows that perceived stigma of patients is significantly negatively correlated with quality of life (r = -.62, p<.001) and also with its subscales i.e. physical health (r = -.55, p < .001), psychological (r = -.54, p < .001), social relationship (r = -.45, p < .001) and environment (r = -.43, p < .001). There is a significant positive correlation between social support and quality of life of patients with tuberculosis (r = .63, p < .001), and its subscales i.e., physical health (r = .43, p < .001), psychological (r = .61, p < .001), social relationships (r = .52, p < .001) and environment (r = .46, p < .001).

	Variables	1	2	3	4	5	6	7	8	9	10	11	12
1.	Perceived Stigma	-	.93*	.92*	-.58*	-.43*	-.49*	-.47*	-.62*	-.55*	-.54*	-.45*	-.43*
2.	Community Perspective		-	.71*	-.59*	-.43*	-.52*	-.46*	-.60*	-.53*	-.53*	-.46*	-.39*
3.	Patient Perspective			-	-.48*	-.37*	-.38*	-.41*	-.54*	-.48*	-.47*	-.37*	-.40*
4.	Social Support				-	.81*	.82*	.75*	.63*	.43*	.61*	.52*	.46*
5.	Significant Other					-	.56*	.32*	.43*	.33*	.44*	.35*	.29*
6.	Family Support						-	.45*	.59*	.41*	.59*	.40*	.48*
7.	Friends							-	.49*	.30*	.43*	.49*	.34*
8.	Quality of Life								-	.82*	.87*	.67*	.87*
9.	Physical Health									-	.63*	.44*	.58*
10.	Psychological										-	.44*	.69*
11.	Social Relationship											-	.49*
12.	Environment												-

Table 2: Correlation Matrix of Study Variables (N=200)
*p<.001.

The result of hierarchical regression analysis shows that in step 1, social support is the positive predictor of quality of life among TB patients (β= .63, p<.001) and it explains 39% of variance in quality of life of patients with tuberculosis, F (1, 199) = 130.35, p <.001. Step 2 indicates that perceived stigma added 10% increase in variance in predicting quality of life, F (2, 199) = 95.15, p <.001. At step 2, the model suggests 49% of variance in quality of life is accounted for by social support and perceived stigma collectively. Social support is the strong predictor of quality of life among patients with tuberculosis (β= .41, p < .001) followed by perceived stigma which negatively predict quality of life of TB patients (β= -.37, p < .001).

Predictors	ΔR2	β
Step 1	.39	
Social Support		.63*
Step 2	.49	
Social Support		.41*
Perceived Stigma		-.37*

Table 3: Predicting Quality of life from Perceived Stigma and Social Support (N=200)
*p<.001.

DISCUSSION

The results of correlation analysis indicated that perceived stigma and quality of life of patients with tuberculosis were negatively correlated; the patients who perceived more stigma had low quality of life. These findings are in line with the previous literature, which reported that lower stigma among TB patient is associated with better health related quality of life. The results also indicated the positive correlation between social support and quality of life of tuberculosis patients. These findings are also consistent with another study by Long *et al.*, which reported that patients have better quality of life when they have adequate social support from your family. The results of this study supported the hypothesis and indicated that social support is a strong positive predictor of quality of life among TB

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patients. When family members, and other key relatives provide financial assistance to poor patients of TB, they feel less stigmatized and show more compliance to treatment [17]. Moreover, when friends of TB patients visit them and boost up their morale to fight against the disease, they perceive socially and emotionally connected to them. They also get an opportunity to have catharsis with them which adds to their quality of life. This finding is in line with previous literature by Kaulagekar-Nagarkar *et al.*, and Holt-Lunstad *et al.*, which suggested that social support is a strong predictor of quality of life and it had a significant effect on health-related quality of life [18, 19]. Similar findings were reported in other study by Chang *et al.*, indicating that quality of life in TB patients increases when they have proper social support in their surroundings. Social support may come up in the form of financial and emotional support which may enhance their quality of life [20, 21]. The results of also suggested that perceived stigma is a negative predictor of quality of life among tuberculosis patients. It was reported that lower stigma among TB patient is associated with better health related quality of life. The possible explanation for this finding could be the phenomena that stigmatization associated with tuberculosis may lead to denial from presence of disease in patients. In an attempt to hide their disease, patients don't visit the doctors and give the impression to others that they have ordinary seasonal infection. When their disease becomes adverse, then they start taking treatment. Consequently, their physical, social and emotional quality of life gets impaired [22].

CONCLUSIONS

It can be concluded from the findings of the study that the stigma associated with tuberculosis decreases the physical, psychological, and social quality of life in the patients of TB. However the patients who received high social support from their families and friends experienced better quality of life.

Conflicts of Interest

The authors declare no conflict of interest

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