ORIGINAL ARTICLE

Knowledge, Satisfaction and Social Acceptance of Tuberculosis patients of District Sargodha-Pakistan

IBADULLAH SAJID[1], SYEDA NUSHEEN FATIMA[2], UZMA ASHIQ[3]
[1]Social Welfare Officer, Social Welfare & Bait-ul-Mall, Rawalpindi.
[2]Department of Social work, University of Lahore, (Sargodha Campus)
[3]Lecturer, Department of Social Work, University of Sargodha, Sargodha
Correspondence to Ibadullah Sajid, Email: ibad_sajid@yahoo.com Cell No. 092 300 6020694

ABSTRACT

Aim: To assess the knowledge and satisfaction of the tuberculosis patients as well as their social acceptance within the community.
Methodology: In this quantitative descriptive cross-sectional study, multi stage sampling technique i.e. Stratified-Purposive was used to select the sample. Sample size for this study was taken as 200 TB patients out of total 668 registered patients. A semi-structured Interview schedule was used to collect the data while frequency analysis method was used to analyze the data.
Results: 80% patients were aware that TB is an infectious disease while 75% know that it is preventable. However, 70% respondents considered TB is a non-curable disease whereas 73% think that it is a fatal. 85% respondents reported that the attitude of the family members towards them was very much discouraging (25%) or discouraging (60%). 89% respondents were neglected by the family either to great extent (20%) or to some extent (69%). Merely 10% TB patients faced positive attitude from their community. 12% TB patients started treatment from government hospital and 8.5% from TB hospital/ Center from day first.
Conclusion: Sufficient knowledge and awareness regarding TB as a disease and health seeking behavior was deficient among the respondents. Lack of social acceptance by the family and community for the TB patients may be a big reason for high dissatisfaction of patients regarding health and current life situation..
Keywords: Tuberculosis, patients, knowledge, satisfaction, social acceptance, Pakistan.

INTRODUCTION

Tuberculosis (TB) is a contagious, infectious disease caused by bacteria named *Mycobacterium tuberculosis* (MT), which generally lasts throughout the life span and determines the formation of tubercles in different body parts.[1] TB has always been associated with a high mortality rate over the centuries, and also nowadays, it is estimated to be responsible for 1.4 million TB deaths, among infectious diseases after Human Immunodeficiency Virus (HIV).[2] In 2017, 6.4 million new TB cases were reported. Thirty countries were identified with the highest burden of the disease which added 87% new cases every year to the already existent lot of TB patients. Eight countries were identified which account for 66.6% (2/3rd) of the total cases and India was on top among these eight countries. The other seven countries where the problem is concentrated include, China, Indonesia, Philippine, Pakistan, Nigeria, Bangladesh and South Africa respectively[3]. In year 2018, a total of 1.5 million reported deaths have been caused by TB alone. The report further indicated that among the ten top causes of deaths the world over, TB is one of them[4]. Amongst the high TB burden countries in the world, Pakistan ranks 5th as reported by the National TB Control Program of the country. The prevalence, incidence and mortality per 100,000 population per year from TB in Pakistan are 340, 265 and 27 respectively[5]. Pakistan loses about 70,000 humans annually as a result of infection due to TB and about 4,30,000 people annually contract TB including 15,000 children[6].

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Creating maximum awareness among general public regarding TB as disease, its symptoms, diagnosis and treatment is considered an effective tool to control the disease. TB awareness, especially among the vulnerable population of slums and poor communities, is important and can be considered the initial step towards taking safety measures, thereby providing a more positive attitude and response during treatment programmes.[7] In Pakistan, review of different studies reflects poor awareness of and low compliance to the World Health Organization or National Tuberculosis Programme's guidelines[8]. Along with the many socio-economic problems, social acceptance and stigmatization is a major issue for TB patients. Friends, family members and community people often do not accept and avoid being close to the patient. The patients have to face social boycott by the community people. People avoid visiting the patient or greeting physically if faced.[9] Nevertheless, it is said that the social integration and support by the family and community have positive impact on health of a diseased person.

A patient especially with TB has numerous medical and non medical needs and their fulfillment can accelerate the pace of healing. But when a patient is ignored and disregarded by the family and community, it may lead to non-cooperation towards treatment and; non-cooperation to TB therapy or medical treatment can resulted towards lingering the disease and ultimately to death[9]. The current study aimed at investigating the knowledge and satisfaction of the TB patients regarding disease and treatment as well as their social acceptance in the family and community as a TB patient.

METHODOLOGY

This quantitative descriptive cross-sectional study has been conducted in the year 2020 in District Sargodha, Pakistan. A list of registered patients was obtained from the District TB Control Office and District Headquarters Hospital comprising the data of about 668 patients. Multi stage sampling technique i.e. Stratified-Purposive was used to select the sample. Stratification was made on the basis of sex. The Purposive sampling means here that who so ever was available in the TB center of the hospital as a TB patient, and those willing to be interviewed and those who could afford the lengthy interview time of about 30-50 minutes, were sampled out. The sample size for this study was taken as 200 TB patients (100 male, 100 female) from the entire district by using Yamani (2005) formula as given hereunder:

$n_{Yamane} = N / (1 + Ne^2)$, where n is sample size, N denotes the population and e is error level.

$= 668 / (1 + 668(.05)^2$
$= 668 / (1 + 668(0.0025)$
$= 668 / 1 + 16.74$
$= 668 / 17.74$
$= 200$

A semi-structured Interview schedule was used to collect the data. Before analysis, the raw data was transferred on SPSS spread sheet for tabulation purpose. Frequency analysis method was used to analyze the data.

RESULTS

Data shows that average age of a TB patient was calculated as 38.7 years, a young workable population. Data indicated an interesting upward trend of TB incidence with an increase in age. The youngest a person is, TB probability will be less while greater the age of a person is, more is the probability of TB among them. Gender wise marital status shows that nearly equal numbers of male and female were married i.e. 61/100 and 60/100 having a very marginal difference. The number of unmarried males was a bit more than females as the cultural practice of early marriages of girls is in vogue. Majority of TB patients (70%) were from rural background while only 30% were from urban areas. These figures fairly coincide with the national figures of rural-urban background. The average monthly income per family was about 24,434 rupees, about $5 a day for an average 6 person's family.

Table-1 depicted the knowledge of the patients regarding tuberculosis as a disease. 160(80%) patients were aware that TB is an infectious disease while 150(75%) patients know that it is preventable. However, a majority of patients 140(70%) considered TB is a non-curable disease whereas 147(73%) think that it is a fatal disease.

This table indicated the social problems of the TB patients faced in the family, community and hospital. On the question about the attitude of the family members, the patients opened their hearts and one fourth of the respondents 50(25%) complained that the attitude of the family members towards them was very much discouraging while 120(60%) stated that family attitude was discouraging. Merely 30(15%) were happy with the very encouraging and encouraging attitude of the family members. Results showed that 40(20%) respondents were neglected by the family to great extent, 137(69%) were neglected to some extent while only 23(11%) were not neglected by the family at all. The community attitude was positive towards only 20(10%) TB patients while 61(30%) negative and 119(60%) faced neutral attitude by the community as a TB patient. The attitude of staff of hospital was harsh as 170(85%) respondents complained for it.

Table-3 indicated the general health seeking behavior of the respondents as well as their first treatment for TB. Results showed that maximum respondents 103(51%) visit government hospital, [n=45] to nearby street clinic and 17(8.5%) visited the private hospital to consult the doctor for general health issues. However the role of traditional healers/ Hakeems and faith healer looked very crucial in this regard. About 20(10%) respondents contact spiritual persons while 15(7.5%) go to the traditional healer for seeking treatment/ getting rid of health issues. Majority of patients 139(69%) started to get treatment of TB from their nearby street clinic. 23(11%) respondents were seeking treatment of TB from traditional healers while 9(4.5%) visited faith healer for sooth saying to get rid of TB. Only 25(12%) started treatment from government hospital and 17(8.5%) from hospital or clinics specifically meant for TB from day first.

One of the major causes of spread of TB is the unauthentic and irrelevant treatment common in Pakistan both in rural and urban areas. The so-called traditional *Hakeems* and the so-called practitioners/ quacks who practice because one of their fore fathers was a doctor or healer and the profession passed from generation to generation in the family. As they are cheap in terms of fees and other costs of medicines, the treatment is cheapo as well in terms of quality and relevance. Similar is the case with homeopathic practitioners who treat this high grade infectious disease. When the patient become serious and the disease affect the vital organs of the body, then the patients resort to proper treatment.

Another trend commonly observed is that people prescribe medicine to others if they have similar symptoms without knowing the disease. For example, if someone has a fever of unknown origin, another person who had temperature will advise analgesics and antipyretics. In case of TB, these medicines can lower the temperature but for a while and; it will continue. Knowing the actual cause takes a long time even in ordinary simple sickness.

Table-4 shows the satisfaction of the TB patients with the health state and current life situation after being hit by the disease. 41% [n=83] respondents said that they were satisfied but not totally or to the maximum. Some expressed themselves by saying at least they are alive and have a family and social life. Only 25% [n=30] respondents showed a greater satisfaction with their health and life situation. 43% [n=87] respondents reported a total dissatisfaction and dismay with their health state and current life situation. However, a majority of the patients i.e. 140(70%) were satisfied with the medication and treatment being provided.

Table-1: Percentage distribution of knowledge among TB patients about disease (n=200)

Is it an infectious disease	Freq.	Is it preventable?		Perception about disease			Is TB fatal?			Total
		Yes	No	Curable	Non curable	Don't know	Yes	No	Don't Know	
Yes	80.0	58.5	21.5	9.5	60.0	10.5	60.5	13.0	6.5	80.0
No	20.0	16.5	3.5	5.5	10.0	4.5	13.0	4.5	2.5	20.0
Total	100.0	75.0	25.0	15.0	70.0	15.0	73.5	17.5	9.0	100.0

Table-2: Percentage distribution of social acceptance of TB Patients (n=200)

Family attitude	Freq.	Neglected by family members?			Community attitude			Attitude of hospital staff			Total
		To great extent	To some extent	No	+Ve	-Ve	Neutral	Friendly	Harsh	Neutral	
Very Discouraging	25.0	5.0	16.0	4.0	1.0	7.0	17.0	2.5	21.0	1.5	25.0
Discouraging	60.0	11.5	44.0	4.5	4.0	14.0	42.0	3.5	54.5	2.0	60.0
Encouraging	5.0	1.0	3.0	1.0	2.0	3.0	0	1.5	3.5	0	5.0
Very Encouraging	10.0	2.5	5.5	2.0	3.0	6.5	0.5	2.5	6.0	1.5	10.0
Total	100.0	20.0	68.5	11.5	10.0	30.5	59.5	10.0	85.0	5.0	100.0

Table-3: Percentage distribution of health seeking behavior of the TB patients (n=200)

General health seeking behavior	Freq.	First treatment of TB from						Total
		Govt. Hospital	Private Hospital	Traditional healer/ Hakeem	Nearby street clinic	Faith healer	TB hospital	
Govt. Hospital	51.5	8.0	1.0	3.5	32.5	4.0	3.5	51.5
Private Hospital	8.5	1.0	0.5	2.5	5.0	0	0	8.5
Traditional healer/ Hakeem	7.5	1.5	0	1.5	3.0	0	0.5	7.5
Nearby Street clinic	22.5	0.5	0.5	2.5	13.5	0	2.5	22.5
Faith healer (sooth saying)	10.0	2.0	0	1.5	9.0	0.5	2.0	10.0
Total	100.0	13.0	2.0	11.5	63.0	4.5	8.5	100.0

Table-4: Percentage distribution of satisfaction of TB patients (n=200)

Satisfaction regarding health and life situation	Freq.	Satisfaction regarding treatment/ medicines		Total
		Satisfied	Not satisfied	
Satisfied to great extent	15.0	10.0	5.0	15.0
Satisfied to some extent	41.5	32.0	9.5	41.5
Not satisfied	43.5	28.0	15.5	43.5
Total	100.0	70.0	30.0	100.0

DISCUSSION

It is widely perceived that Tuberculosis is the disease of poor and Poverty[10]. This means poor, under nourished, slums residents, congested families who are poor, having someone already infected with TB are easy prey to the disease. The results of the study in hand somehow confirmed the notion as the family income of the respondents of the study was less than the required amount needed for maintenance and sustenance of a person having a decent living or not falling below the poverty level. The average income was 24,435 rupees a month per house hold or 4073 rupees per capita per month, or 136 per day per capita or a little over one US dollar a day, for the average family size of 6 persons.

The results of the study indicated the respondents were aware that Tuberculosis is an infectious and preventable disease. However majority of respondents considered that it is non-curable (70%) and a fatal disease (73%). The results of the study are in line with the findings of another study conducted in Pakistan which reported that about 67% respondents believed that tuberculosis is a fatal disease[11].

Personal and social problems resulted from TB disease were there for the patients. Among these problems, problems pertaining to the family attitude were the most felt. These problems were not from relatives but from the very intimate relations like mother, father, wife, and in-laws living in the same house. One fourth of the respondents (25%) complained that the attitude of the family members towards them was "very much discouraging" while three fifth (60%) stated that family attitude was "discouraging". Merely 15% were happy with the "very encouraging" and "encouraging" attitude of the family members Findings of many other studies supported these results. A study conducted in Pakistan confirmed that TB patients experienced an overall low level of care and social support from their families, friends and communities.[9] Another study reported that a majority of patients and their relatives feel that the dishes of TB patients should be kept separate from rest of the family members thus isolating them further from their families.[12]

Results of the study showed that the public attitude towards TB patients varied from avoidance of the patient to his social boycott by some segments in the community. The community attitude was positive towards only 10% TB patients while 30% faced negative and 60% respondents faced neutral attitude by the community as a TB patient. This is really hard hitting and hurting for a person expecting sympathies and encouragement and support from someone. Another study undertaken in Pakistan reported that about half of the respondents believed that TB patients

were stigmatized. About 32% respondents thought people were friendly but avoided TB patients. Only 20% believed that society was supportive of TB patients.[11]

Health seeking behaviour is considered fundamental to determine the health state of any individual, group or community.[13] The results of the study portrayed that maximum respondents visit government hospitals to seek medical treatment for their general health issues. A big ratio n=45 were approaching nearby street clinic which may be a health practitioner, homeopathy doctor or a quack which is easily available on economical fee. Role of traditional healer or herbal doctors/ Hakeems and Faith healers (sooth saying) are also not ignorable in the health system of Pakistan. About 10% respondents approached to faith healers while 7.5% went to the traditional healers for seeking treatment. Another study confirmed the findings regarding health seeking behavior in Pakistan with the results that about three fifth (61%) people approach medical doctor, 11% herbal doctor or Hakeems while a few (3%) consult faith healers to seek treatment of general diseases[13].

With reference to rural Pakistan in particular, the mode of treatment of even very dangerous diseases are taken easy and differently. There are many ways of treatment including the local herbal doctors known as Hakeems and traditional healers who are either illiterate or if literate, did not study medicines or herbal pharmacopeia, but the art of treatment and prescribing medicines, even in cases of cancer and TB, is that which they learnt from their fore fathers and the profession continues from generation to generation in the family. They prescribe a mix of herbal and modern medicines or homeopathic medicines rich in steroids without realizing the consequences and when a patient gets worsen, refers to a hospital or other doctor. As this method of treatment is cheaper and easily available, people are tended avail it first. This was told by 11.5% TB patients who initially visited the Hakeems or quacks etc for getting treatment of TB but latterly came to hospital. 70% told that they visited nearby street clinic, 12% government hospital and 8.5% TB hospital/ Centre. 5% respondents contacted faith healers to get the disease treated. A study conducted in Pakistan validated the findings that 27% TB patients visited traditional practitioners (herbalist, spiritual healer, etc.) while 29% visited government hospitals.[14] Another study conducted in Ethiopia regarding tuberculosis reported that majority of pastoralists patients sought help for their illness from traditional healers[15]. Lack of awareness about the cause and treatment of TB has been long associated with the poor health care seeking behavior and delayed diagnosis and treatment because of the first consultation of non-health professionals[15].

With regard to the satisfaction of the TB patients with the health state and current life, after being hit by the disease, 41% respondents were satisfied but not totally or to the maximum. Only one fourth of the respondents showed a greater satisfaction with their health and life current situation. 43% reported a total dissatisfaction and dismay with their health state and current life situation. Another study conducted in Kashmir confirmed that 92% TB patients were satisfied with their current life situation while 8% were dissatisfied in this regard.[16] A majority of the patients (70%) was satisfied with the medication and treatment being provided. The findings were closely associated with the results of another study conducted in Pakistan which reported that overall 82% of the patients were satisfied with TB care services.[14]

CONCLUSION AND RECOMMENDATION

Sufficient knowledge and awareness regarding TB as a disease and health seeking behavior was deficient among the respondents. The researchers are of the opinion that concerted efforts are much needed to create maximum awareness among general public especially vulnerable population of slums and poor communities as well as to tackle the social barriers within the communities so as to combat TB. For the purpose, community based awareness strategies should be designed, information and education on TB must be disseminated out. Observance of TB weeks, advocacy seminars and awareness walks should be arranged to spread the message that TB is preventable and treatable.

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