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Stigma Related to Tuberculosis in Patients Taking DOTS Treatment from DOTS Center of Palpa District Hospital, Tansen, Palpa, Nepal

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Abstract

Background: Tuberculosis (TB) is infectious, communicable disease caused by *Mycobacterium tuberculosis*. It is one of the leading causes of death worldwide causing 1.5 million deaths globally and in context of Nepal, TB ranks as the sixth leading cause of death among top 20 death causes. Various studies has been conducted worldwide and found out that people suffering from TB are still receiving unfair treatment within their society.

Objective: The objective of this study was to find stigma experienced by tuberculosis patients taking DOTS treatment.

Methods: A descriptive cross sectional study was conducted with a sample of 89 TB patients taking DOTS treatment in Palpa District Hospital of Tansen, Palpa and were selected by Non-probability purposive sampling technique. The participants were asked semi structured questionnaire for socio demographic information and structured questionnaire for testing knowledge. Likewise for determining the level of stigma, data was collected using predesigned standard questionnaires from Explanatory Model Interview Catalogue (EMIC) developed by World Health Organization. Data was checked for completeness and accuracy and collected data was entered in SPSS Software version 20.Descriptive statistics such as number and percentage were used to describe demographic data and for analysis of the level of knowledge and stigma related to Tuberculosis inferential statistics were used.

Results/ Findings: The study found out that majority (88.8%) of the people had good knowledge on Tuberculosis. The stigma of tuberculosis in rural setting was also revealed by this study. The study revealed that 64% of people were stigmatized due to Tuberculosis. There was found to be significant association between the age of the participants and the stigma. Thus, the study concluded that people are still stigmatized due to tuberculosis although TB is included in the strategic plan of Government of Nepal.

Conclusion: The study concluded that despite good knowledge (88.8%), still stigma with tuberculosis was found high in study population. Inspite of various awareness programs, campaigns carried out each year along with National TB day celebration, yet people are afraid to talk about it openly with friends and society. This study highlighted that a lot is still to be done to reduce the stigma experienced by the people. It also suggested that interventions should also integrate anti-stigma strategies led by the community members themselves.

Keywords: Stigma; Tuberculosis

List of abbreviations: BPKIHS: B.P. Koirala Institute of Health Science; TB: Tuberculosis; WHO: World Health organization; EMIC: Explanatory Model Interview Catalogue; NTC: National Tuberculosis Center; FCHV: Female Community Health Volunteer

Introduction

Tuberculosis (TB) is infectious, communicable disease caused by *Mycobacterium* tuberculosis. It is one of the leading cause of death worldwide causing 1.5 million deaths globally. About one third on the world population has been found to be infected with tuberculosis along with 1% of new cases every year [1].

In Nepal, 45% of total population are infected with tuberculosis among which 40,000 people get TB every year 20,000 new sputum positive cases every year 5000-7000 people die each year from TB [2].

In Nepal, TB ranks as the sixth leading cause of death among top 20 death causes. The most of the TB deaths occurred in male whereas the deaths in female seem to be relatively lower. The mortality rate is still high due to TB although TB is one of the preventable and curable disease [3].

Many communicable diseases like Tuberculosis, HIV/AIDS and leprosy is still associated with stigma. Tuberculosis has been and is still considered as a 'dirty disease', 'a death penalty' or as affecting 'guilty people' in some cultures [4]. It is also associated with

witchcraft and curse in the family simply because it is a communicable airborne disease and can easily infect the family members if one of the members has the infection [5].

Nepal being a multi-linguistic developing country, there are various cultures, cast, religion and ethnicity and all of them have their own beliefs. The stigma is based not only in terms of beliefs but also due to lack of awareness of TB. There are still various stigma and discrimination related to TB and people are still experiencing discrimination based on such stigmas. The various stigma eventually effects the social status, employment status, isolation from family and society.

Palpa is one the rural districts with high incidence rate of TB. There was 300-450 TB patients were registered in this district annually [6].Tuberculosis is one of the diseases that Government of Nepal (GoN) has made strategic plans to meet the millennium development goals (MDG). Nepal implemented DOTS strategy since 1995 and 75 DOTS Centers all over the country since April, 2001. DOTS Center of Palpa is also a DOTS Center among them. National Tuberculosis Center (NTC) of Nepal is established for planning, implementing and evaluating various strategies to stop TB. There are 554 diagnostic centers, 4,258 treatment and sub centers and 84 Drug Resistant (DR) centers and sub centers offering diagnosis and treatment services free of cost all over the country. All DOTs Centers in the Nepal are using NTP Treatment regimen in which **Category I** has 2(HRZE)/4(HR)treatment regimen, here, Category I type of patients are such patients who are new sputum smear-positive, sputum smear-negative and extra-pulmonary TB cases, similarly, **Category II** has 2S(HRZE)/1(HRZE)/5(HRE) treatment regimen, here category II type of patents are those who are retreatment TB cases including failures, relapse and return after default [6,7].

In 2014, 6.7 million US$ was spent annually in TB program in Nepal. NTC has been working with various NGOs and INGOs, giving trainings, conducting workshop, campaigns, raising awareness through mass and media in order to meet the target of 2050 to eliminate TB as a public health problem. Every year 24 March is celebrated as World TB day making public aware about TB. More lately, DOTS services has been expanded up to community level i.e. involving the FCHV (Female Community Health Volunteer) in giving medicine to the diagnosed people in order to minimize the defaulter case [3]. In spite of all these strategies, various studies revealed that people are still stigmatized due to TB. Thus this study helps to find out the perception regarding TB and find out stigma if there is any in this district particularly.

Methodology

A descriptive cross sectional study was conducted with a sample of 89 TB patients selected by Non-probability purposive sampling technique who were taking DOTS treatment from Palpa District Hospital, Tansen, Palpa from August 2015 to January 2016.

Sample Size Technique:

According to the formula,

$n=z^2pq/d^2$

Where z=1.96(constant)
n=sample size
d=10%
p=63% (Prevalence rate of Stigma in Nepal) [8]
q=100-p= 37
n=89

Data was collected using predesigned standard questionnaires from Explanatory Model Interview Catalogue (EMIC) developed by World Health Organization as well as semi-structure questionnaire, after translation in local context in Nepali language. The interview schedule, which was consist of socio-demographic questionnaire, review of hospital records to determine the category of treatment patient is receiving, knowledge related questionnaire, and stigma related questionnaire. The stigma related questionnaire consisted of 18 items. Responses were coded on a 0-3 ordinal scale (0 = no, 1 = uncertain, 2 = possibly and 3 = yes). Items were scored on 4 point scale (3-0 with 3 = yes, 2 = possibly, 1 = uncertain and 0 = no). Maximum obtainable score was 54 and minimum score was 0.

Validity/Reliability: Validity and reliability was maintained by reviewing literature and consulting experts as well as advisor. The questionnaires regarding stigma was taken from Explanatory Model Interview Catalogue (EMIC) by WHO/TDR and socio demographic and knowledge questionnaires were then translated in Nepali version consulting Nepali and English languages experts and was pretested in 10% of the total sample size in different participants in similar setting and no modification was required, thus it was used in study population.

Formal approval letter was taken from concerned authority of research committee of Norvic Institute of Nursing Education and from the concerned authority of Palpa District Hospital, then ethical approval was taken from Nepal Health Research Council (NHRC). lastly,The informed written consent was taken from each participant.

Collected data was checked for completeness and accuracy and entered in SPSS Software version 20. Descriptive statistics such as number and percentage were used to describe demographic data and for analysis of the level of knowledge and stigma related to Tuberculosis inferential statistics were used. Descriptive data was presented in tabular form while summary statistics was used to find out the association between the variables using chi square test.

Findings

Demographic Patterns

The demographic pattern of 89 diagnosed Tuberculosis patients taking DOTS treatment. Tuberculosis was commonly found in age group above 30 years (61.2%). The incidence of Tuberculosis was higher in (62.9%) male than in (37.1%) female. The majority of the participants were literate (87.6%) and the minority (12.4%) were illiterate. The majority of the participants were Hindu (91.2%) and the minority (2.2%) were Christians. The majority of the participants were married (70.8%) and the minority (1.1%) were divorced. The majority (46.1%) of the participants had income 5,000-10,000 and the minority (14.6%) had income below 5,000.

Components	Frequency	Percent
Causes of tuberculosis		
Bacteria	38	42.7
Unhygienic food	7	7.9
Lack of personal hygiene	3	3.4
Smoking/alcohol	41	46.1
Symptoms of tuberculosis		
Persistent cough more than 2 weeks, fever	78	87.6
Headache	6	6.7
Stomach ache	5	5.6
Cure of tuberculosis		
Yes	89	100.0
Mode of transmission of Tuberculosis		
Air droplet	76	85.4
Water borne	3	3.4
From food	10	11.2
Prevention of Tuberculosis		
B.C.G vaccine	62	69.7
Not talk with TB patients	17	19.1
Eat hygienic food	8	9.0
Hand washing	2	2.2

n=89
Table 1: Knowledge regarding Tuberculosis

Table 1 shows knowledge about Tuberculosis. Only 42.7% knew about the cause of Tuberculosis, and majority (46.1%) said it was due to smoking or drinking alcohol. About 87.6% knew about the symptoms of TB which is persistent cough for 2 weeks and fever. When asked whether TB is curable or not, 100% knew that it is curable. Approximately 85.4% knew the mode of transmission of tuberculosis and 69.7% knew how it can be prevented.

Components	Frequency	Percent
Category		
Cat-I	78	87.6
Cat-II	11	11.2
Type of Tuberculosis		
Pulmonary	69	77.5
Extra pulmonary	20	22.5

n=89
Table 2: Clinical Profile

Table 2 shows that the incidence of pulmonary TB (77.5%) was higher than the extra pulmonary (22.5%). Extra pulmonary TB like instestinal, glandular, throat, endometrium and head. About the treatment taken by the participants, majority (87.6%) of the participants were taking Category I treatment and the minority (11.2%) were taking Category II treatment.

Items	No (%)	Uncertain (%)	Possibly (%)	Yes (%)
Desire to keep others from knowing	51.7	7.9	3.4	37.1
Did not disclose to confident	52.8	9.0	1.1	37.1
Think less of yourself	70.8	7.9	0.0	21.3
Shamed or Embarrassed	58.4	9.0	1.1	31.5
Others would think less of you	47.2	20.2	1.1	31.5
Adverse effect on others	25.8	10.1	1.1	62.9
Others have avoided you	56.2	16.9	1.1	25.8
Others refuse to visit	86.5	4.5	1.1	7.9
Others would think less of your family	82.0	5.6	2.2	10.1
Problems for your children	86.5	5.6	3.4	4.5
Problem for getting married despite cure	37.1	13.5	3.4	46.1
No support from spouse	88.8	0.0	5.6	5.6
Other problem in marriage	94.4	0.0	4.5	1.1
Problem for the relative to marry	88.8	4.5	4.5	2.8
Asked to stay away from work	91.0	0.0	3.4	5.6
Decided to stay away from work	84.3	0.0	2.2	13.5
Presumed other health problems	77.5	6.7	3.4	12.4
No Social Support	7.9	0.0	1.1	91.0

Table 3: Distribution of stigma score

Table 3 shows stigma score of TB participants. Likewise regarding stigma, 37.1% of the patients desired to keep people from knowing about their disease. Only 21.3% thought less about themselves because of the disease. Sixty two decimal nine percent (62.9%) believed that their disease will cause adverse effect on others. Thirty one decimal five percent (31.5%) of the participants felt shamed and embarrassed and 25.8% thought that they were avoided because of the disease. A total of 46.1% had an opinion of anticipating difficulty during their marriage. About 91% participants felt that they didn't have social support as expected in terms of being the talk of the village just because they have the disease which would also effect getting married later. And also some people preferred to go to hospital and take medicine themselves instead of getting it from local FCHV since it would not let the society people know that they have disease.

Stigma	Frequency	Percent
Not experienced	32	36.0
Experienced	57	64.0

Table 4: Distribution of stigma score

Table 4 concludes that 64% are still stigmatized just because they have Tuberculosis.

Sociodemographic items	Stigma experienced	Stigma not experienced	Chi² value	'p' value
Age				
>30	33.7	28.08	5.642	0.018*
≤30	30.33	7.8		
Sex				
Male	38.20	38.20	0.728	0.394
Female	25.84	25.84		
Education				
Illiterate	7.86	4.49	0.001	0.976
Literate	56.17	31.46		
Marital status				
Married	41.57	29.21	5.318	0.070
Unmarried	22.40	5.61		
Divorced	0	1.12		
Monthly Income				
<5,000	11.23	3.370	1.719	0.423
5,000-10,000	30.33	15.7		

Sociodemographic items	Stigma experienced	Stigma not experienced	Chi² value	'p' value
Monthly Income				
>10,000	22.47	16.85		
Category				
Cat-I	56.17	32.58	0.173	0.677
Cat-II	7.8	3.37		
Type of tuberculosis				
Pulmonary	50.56	26.96	0.183	0.669
Extra Pulmonary	13.48	8.9		

*p value<0.05

Table 5: Association of stigma with sociodemographic pattern and clinical profile

Table 5 shows the association between stigma and various sociodemographic factors. It was found out that only age had significant association with stigma with (p value =0.018) done by using Chi square test.

Discussion

This findings shows that people are still stigmatized due to Tuberculosis. The first objective of this study was to assess stigma experienced by TB patients. Results showed that 64% of the TB patients had experienced stigma, similar to a study conducted in Dharan by Aryal S, which shows that 63.3% stigma is present on patients and is associated with various sociodemographic factors [9,10].

The result showed that male (62.9%) were more infected due to Tuberculosis which is similar to the study conducted by Bhatt CP on knowledge of TB in Kathmandu where 64% were male and also study conducted in Dharan by Aryal S where 39 participants were male out of 60 participants [10-12].

Regarding knowledge on Tuberculosis, 88.8% participants had knowledge on TB which is contrast to the prospective study that was conducted in Thailand where participants had only 23% knowledge on TB. But the knowledge difference could be possible because of the sampling bias as it was asked to the TB patients and not the society people in contrast to the study done in Thailand [13].

About the stigma, almost half (48.2%) of the participants did not want to disclose the diagnosis with others like friends, neighbors or society people which is almost similar to the study conducted by Atre SR, *et al.* and by Aryal S in Dharan [4,10]. Most of the participants (62.9%) thought that their disease had adverse effect on others and 46.1% thought that people will have problems getting married despite cure. Participants said that once they are infected with TB, they will always be thought to be diseased thus there might be problems getting married. The study TB stigma in Indian perspective supports this [14-17].

The study also showed that there was association between age and the stigma where it was found that people under 30 years of age were more stigmatized which is contrast to the study done in Dharan by Aryal S where people over 30 years of age were more stigmatized [10]. Participants said that they haven't let anyone know that they have the disease and were afraid that their friends or neighbors might find out.

Although the participants were found to be stigmatized, it also showed that they had full support from their spouse and family members. They were willing to help the participants get the treatment and respected their choice of keeping it confidential.

Conclusion

➢ The findings from this study identified that people (64%) are still stigmatized due to TB and not only that age has significant association with the Stigma.

➢ People had good knowledge (88%) on TB but it cannot be concluded that in spite of the knowledge people are yet stigmatized.

➢ Various strategies has been carried out to reduce TB prevalence but yet a lot can be done to reduce the Stigma. Public are afraid of it because it is communicable disease and can be transmitted easily, thus efforts should be made by the health workers to educate about the treatment regimen and its benefits along with information on the duration of infectiousness after the start of treatment.

➢ The study was limited to Palpa district only.

➢ The error is put 10% in sample calculation method, thus the findings cannot be generalized.

➢ Support to patients from community members, recovered patients and others may also facilitate de-Stigmatization

Acknowledgement

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