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Health Seeking Behaviour among Past and Current Tuberculosis Patients in a Low-Income Country

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Abstract

In Nepal, the estimated incident cases are 0.07 million, of them, 0.03 million people are diagnosed and enrolled in the treatment annually, and numbers of undiagnosed people living with tuberculosis (TB) might be a threat to achieving END TB strategy targets. Understanding health-seeking behaviour and care pathways is crucial to reducing missed cases and decreasing TB transmission. The objective of the study was to identify the health-seeking behavior of TB patients and understand the reasons behind TB diagnostic and treatment delays in Nepal. This was a cross-sectional, population-based survey carried out in 99 clusters of 55 districts (total of 77) of Nepal. Primary Sampling Units were Village Development Committees or Municipalities and wards selected using systematic proportional to population size method. Of the total 54,200 people who attended in the survey, 1,825 had a history of TB and asked their health-seeking practice. 62% and 72% of the TB patients utilised the government health facilities for diagnosis and treatment. 18% of the TB patients said that they received diagnosis services, and 16% of patients took their treatment from outside of the country, especially India, due to fear of stigma and easy access to the services. The majority of the TB patients utilised government health facilities to receive diagnosis and treatment services. Some of the participants sought TB services from private health care providers, and a significant proportion of participants received them from India due to difficulty in accessing local services and fear of stigma and discrimination.

Keywords: *Community Based Directly Observed Treatment, Health Seeking Behaviour, Prevalence Survey, Tuberculosis.*

Introduction

Tuberculosis (TB) is the leading infectious diseases killer and a significant public health challenge worldwide. Globally, an estimated 10 million people developed TB disease in 2019, of whom approximately 3 million were not diagnosed, treated, or notified to national tuberculosis programs (NTPs). Of the remaining 7 million, many experienced substantial delays in accessing and receiving appropriate diagnosis and care. This unacceptable situation leads to unnecessary disability and loss of life and impedes tuberculosis control because of the onward transmission of TB at both household and community levels. To rectify these shortcomings and eliminate tuberculosis, new strategies are urgently required to find the missing cases, enhance tuberculosis case notification rates, and support people with TB to access quality care and become cured [1].

Tuberculosis (TB) remains a public health threat in Nepal and is responsible for the ill-health of thousands of people annually. In 2019, the estimated TB prevalence of Nepal was 215 TB cases per 100,000 population and incidence

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of 151/100,000. These estimations are based on calculations by the World Health Organisation (WHO), which are informed by expert opinions, tuberculin skin test surveys, and trends in TB case notification imply that rates of TB have been static in Nepal since 2015. TB also ranks as the leading cause of death (20/100,000 population) in the country in 2019 as well.

There were 32,043 TB cases (all forms of TB) registered with the National TB Program of Nepal (NTP) in 2018/19, which includes 31,397 were incident TB cases (new and relapse). Among the NTP-registered cases at NTP, 37% were female and 63% male. The national case notification rate (all forms of TB) was 109 / 100,000 population in 2019 [2].

There are multiple interlinked risk factors associated with TB exposure, infection, and progression to TB disease, which may explain the reasons behind this trend. First, exposure to TB (e.g., the number of viable TB bacilli to which an individual is exposed) and transmission rates are influenced by proximity to and duration of exposure to asymptomatic individuals with pulmonary TB and the amount of TB that individual is producing. Thus, transmission can be affected by the extent of pulmonary TB disease, duration, and frequency of cough, poor cough hygiene or self-isolation measures, overcrowded living circumstances (e.g., due to poverty, incarceration, shared accommodation), occupation (e.g., high-risk jobs such as mining and healthcare), or belonging to an underserved group (e.g., indigenous or homeless populations). Second, many other individual-level risk factors influence the likelihood of acquiring TB infection and the development of TB disease. Such risk factors include human immunodeficiency virus (HIV), poverty, malnutrition, chronic renal impairment, and diabetes, extremes of age, excess alcohol consumption, and smoking, and indoor air pollution. Barriers to accessing TB diagnostic and care services can influence TB rates by leading to more severe clinical disease, which in turn increases the likelihood of onward transmission of TB disease in the community [3]. Moreover, stigma and discrimination related to TB illness, especially in areas with high HIV and/or poverty prevalence, can lead to a reluctance to disclose TB status and seek TB diagnosis and care [4]. Without understanding and addressing these individual, household, and health systems-level risk factors for TB disease, TB control strategies, whether at a national or international level it will be difficult to eliminate TB.

The objective of the study was to identify the health-seeking behavior of TB patients to better understand the reasons behind TB diagnostic and treatment delay in Nepal and thereby inform national policy and contribute to the National Strategic Plan to eliminate TB in Nepal. It is expected that outputs from the study will include the development of a plan to reduce diagnosis and treatment delays through improved access to care, education to the patients, engagement of informal care providers (like traditional healers), strengthening private health care providers in TB program, and potentially contributing to design of socio-economic interventions to address the biosocial aspects of TB.

Methods and Material

National Tuberculosis Programme adopted the Tuberculosis Prevalence Survey-A handbook published by WHO to design the survey in Nepal [5]. This was a cross-sectional, population-based survey carried out in 99 clusters of 55 districts (total of 77) of Nepal. Primary Sampling Units (PSUs) were village development committees (VDC) or municipalities and wards (smallest administrative unit of the country) selected using the systematic PPS (proportional to population size) method, and within the wards, a social map was drawn of all block and households in the study sites, and 200 households were selected randomly and ensured in average 600 family members above the age 15 years in each cluster. Before organising the TB screening camps, the

census was done at the selected households. There were 93,085 people enumerated, of whom 58,956 (63%) were eligible, and they were invited to participate in the survey. Out of them, 54,200 (92%) took part in the survey. Of them, 53,622 (onsite) participants were screened by both Xray and symptom screening questionnaire and 578 off-site participants were screened by only symptom screening questionnaire; out of them, 15,212 (28%) screened participants had symptoms and radiological abnormalities and were recommended for sputum examination, of them, 1,934 (13%) had cough 2 weeks or more, 414 (3%) had hemoptysis, and 2,882 (19%) had less than two weeks cough reported symptoms and 9,780 (65%) had radiological abnormalities compatible with TB. Out of eligible participants for the sputum test, 15,011 participants submitted their sputum samples for Xpert MTB/RIF and smear testing through fluorescence microscope, and half of them submitted one more morning sample for molecular testing (Culture). Selected socio-economic and demographic characteristics were examined using multiple logistic regression analysis because all the four outcome measures were dichotomous, and other relevant indicators were analyzed in frequency and percentage distribution.

Results

Out of the total participants who attended the survey, 1,825 (3%) people had a history of tuberculosis. Table 1 gives a detailed overview of the prevalent TB disease seen in all the age groups, sex, terrain, ethnicity, education level, occupation, and wealth groups, indicating that tuberculosis is all over the country and any social dimensions. Age category wise, the participant's age over 65 years and above had a TB 6 times higher than the age group of 15-24 years, followed by nearly 3 times higher among the male participants, 4% in Kathmandu valley, 4% in Muslim around 5%, education-wise, participants who had no education, suffered from the disease more, followed by unskilled manual workers and 3.5% reach people got tuberculosis. The likelihood test results also show that TB is likely to be common in every social characteristic and all over the country.

Table 1. Socio-demographic Characteristics of the Participants, Percentage of Disease Presented, and the Likelihood of TB History and Adjusted Odd Ratio (aOR) of the People Living with the Disease

Variable	**Tuberculosis**		**% Of Yes**	**Logistic Regression**	
	No	**Yes**		**OR**	**95% CI**
Age (N=54,200)					
15-24	14147	172	1.2		
25-34	10795	220	2.0	1.597	(1.265 - 2.015)
35-44	9132	321	3.4	2.594	(2.068 - 3.252)
45-54	7360	339	4.4	3.247	(2.582 - 4.084)
55-64	5567	355	6.0	4.601	(3.645 - 5.807)
65+	5381	411	7.1	5.466	(4.312 - 6.928)
Gender (N=54,200)					
Male	21851	1126	4.9		
Female	30536	687	2.2	0.517	(0.453 - 0.590)
Terrain (N=54,200)					
Mountain	4605	108	2.3		
Hill	17309	499	2.8	1.317	(1.065 - 1.628)
Terai	25250	997	3.8	1.864	(1.512 - 2.298)
Kathmandu Valley	5209	223	4.1	2.190	(1.708 - 2.809)
Ethnicity (N=54,200)					

Dalit	7444	246	3.2		
Janjati	16734	625	3.6	1.056	(0.906 - 1.232)
Madhesi	7682	295	3.7	0.953	(0.796 - 1.140)
Muslim	2531	114	4.3	1.256	(0.993 - 1.588)
Brahmin/Kshetri	17087	510	2.9	0.863	(0.735 - 1.013)
Other	897	35	3.8	1.285	(0.891 - 1.853)
Education (N=54,200)					
No education	16451	757	4.4		
Incomplete primary	12710	488	3.7	1.043	(0.920 - 1.184)
Completed primary	5922	164	2.7	0.975	(0.808 - 1.177)
Incomplete secondary	7918	195	2.4	0.975	(0.808 - 1.177)
Completed secondary	4506	111	2.4	0.931	(0.739 - 1.172)
Above secondary	4868	110	2.2	0.799	(0.617 - 1.034)
Occupation (N=54,200)					
Professional/technical/managerial	1513	50	3.2		
Clerical	1207	37	3.0	0.900	(0.579 - 1.398)
Sales and services	2747	123	4.3	1.164	(0.817 - 1.659)
Skilled manual	2328	112	4.6	1.282	(0.887 - 1.851)
Unskilled manual	1423	70	4.7	1.294	(0.867 - 1.932)
Agriculture	14107	680	4.6	1.121	(0.805 - 1.562)
Student	6851	76	1.1	0.862	(0.569 - 1.305)
Housewife	16802	396	2.3	0.993	(0.701 - 1.407)
Other/no occupation	5400	278	4.9	1.068	(0.759 - 1.501)
Wealth Index (N=54,200)					
Rich	21782	790	3.5		
Middle	10382	343	3.2	0.923	(0.803 - 1.061)
Poor	20213	690	3.3	0.981	(0.866 - 1.113)

Data source: Nepal National Tuberculosis Prevalence Survey- 2018/19, Note: Variables that showed significant association during bivariate analysis at ***p<0.001, **p<0.01, and *p<0.05 (OR=Odds Ratio, CI=Confidence Interval).

Diagnostic Practice by Current and Past TB Patients

Figure 1 gives an overview of the health-seeking practices of current and past TB patients for diagnosis. 1064/1767 (66%) of the current and 38/58 (60%) of the past tuberculosis patients visited government health facilities for the diagnosis. Similarly, 273/1767 (22%) of the current and 13/58 (16%) of the past TB patients were diagnosed by the private health facilities, 330/1767 (19%) of the past and 6/58 (10%) of the current TB patients had taken diagnostic services from abroad. The below- outlined graph presents health-seeking practices by current and past tuberculosis patients.

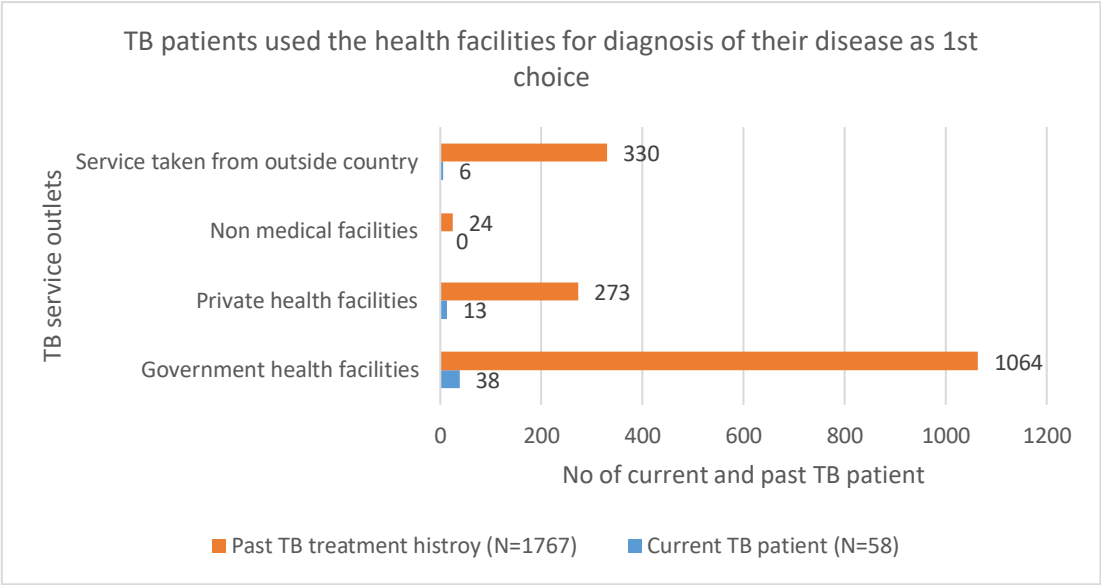

Figure 1. TB Patients used the Health Facilities for Diagnosis of their Disease as 1st Choice

Note: Government health facilities: Own and run by the government, private health facilities: own and run by the private sector supervised by the government, non-medical facilities: pharmacy, self-medication, and traditional healers, service is taken from outside country: patients who took medicine from India.

Figure 2 describes the current and past TB patient's first choice of place for TB treatment. 48/58 (83%) of the current and 1237/ 1767 (70%) of the past people living with tuberculosis took the treatment services from government health facilities. Similarly, some proportion (5/58 (9%), 187/1767 (11%) of the patients (current, past) received the services from the private health facilities, very few patients (36 persons) took their treatment from the non-medical facility (pharmacy) and 5/58 (9%) of the past and 307/1767 (7%) of the current patients were took anti TB treatment services from the abroad (majority from the India).

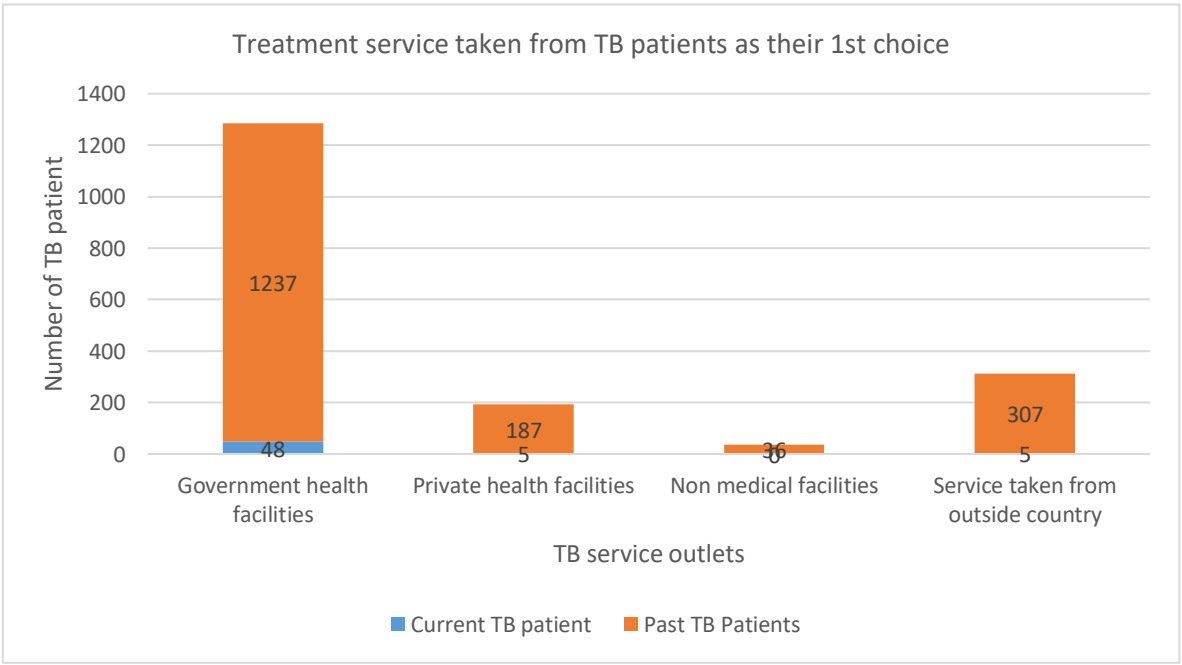

Figure 2. Treatment Service taken from TB Patients as their 1st Choice

Note: Government health facilities: Own and run by the government, private health facilities: own and run by the private sector supervised by the government, non-medical facilities: pharmacy, self-medication, and traditional healers, service is taken from outside country: patients who took medicine from India.

Globally, there are two types of TB treatment commonly in practice which include health facility-based and community-based medication for the patients. The same therapy is practiced in Nepal. The graph outline below (Figure 3) provides the scenario of the current medication practices of the patients. 62% of the current people living with TB and 56% of the past TB patients had their medication at home and 28% and 26% current and past TB patients took treatment services from the government health facility. Similarly, 7% and 9% of the current and past TB patients managed their treatment without any observation. None of the patients reported community-based TB program, which is very crucial for the TB services to be people friendly. Figure3 provides the picture of utilisation practice of treatment services.

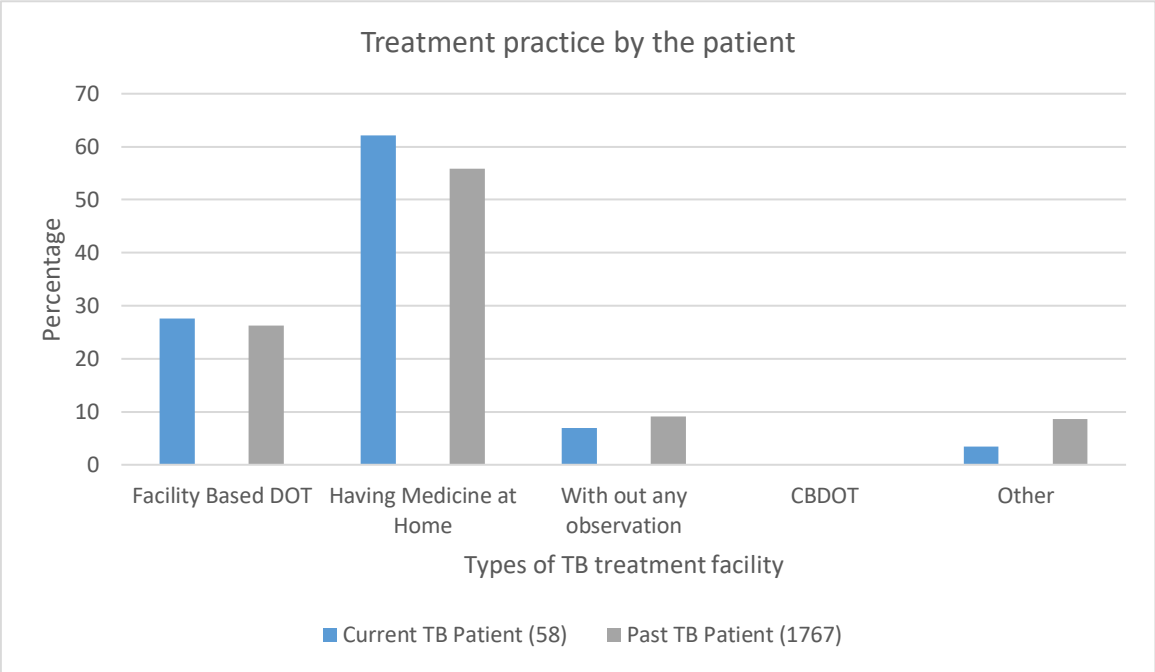

Figure 3. TB Treatment Practice by Current and Past TB Patients

Note: Facility-based DOT- patient visits at the health facility having medication, Having Medicine at Home: patient take medicine from the treatment center for a week or more and having medicine at home with the supervision of the family members, without any observation: patient take medicine from the treatment centre for a week or more and having medicine at home without the supervision of the family members, CBDOT: community-based DOT-trained volunteer provides the medicine to the TB patients in the community, and Other: Participants who had a history of TB, they were taken anti-TB medicine from outside of the country (majority from India).

Discussion

Tuberculosis is common and prevails in all age groups, sex, terrain, ethnicity, education status, occupation, and wealth index groups. The majority of cases are seen in the age of 65 and above, in the male population (survey participants from the Kathmandu valley), Muslim caste are mostly affected by tuberculosis compared to ethnic groups, uneducated person, engaged in unskilled profession participants and people from reach groups.

According to Anderson's health care utilization model, there are predisposing factors, enabling factors, and need issues. Those aspects determine the utilization of the health care system [6]. The majority of the respondents who had a history of tuberculosis choose government health facilities as their first choice for diagnosis. Likewise, some proportion of the respondents reported that they visited private health facilities to take the diagnosis services as 1st choice for identifying their disease and substantial numbers of participants visited outside of the country (majority in India) to diagnose their tuberculosis disease.

The choice of health facilities for TB treatment also demonstrates a similar portion of health service utilization for diagnosis. The majority of participants selected government facilities similar to the finding in the same survey of the Philippines [7], and almost 82% of TB patients sought tuberculosis treatment from the public health system in Gambia [8]. The reason for selecting government health facilities as the first choice could be due to free TB diagnosis and treatment services, accessibility and reliability, and faith on government services. An interesting fact is that some of the past TB patients and current TB patients also received the treatment from the outside of the country (most of them in India) due to fear of stigma and discrimination, lack of patient-friendly services, inaccessibility of the TB services and time limitation could be potential reasons. A similar study carried out in Indonesia demonstrates that most of the TB patients initially visited a nonformal health service providers (HSP) to seek the solution for their symptoms [9], but the majority of the TB patients from Gabon used combined treatment at the hospital with (herbal) self-medication and traditional/spiritual healing [10]. The study carried out in Kerala, India, highlighted the illiterate and people living in below the poverty line preferred to visit a public health facility to receive the diagnosis and treatment services [11]. The study done in Myanmar showed that the general practitioners were the first point of contact to address all kinds of tuberculosis issues [12].

The increasing private health providers that provide TB care and treatment are considerable facts in South East Asia [13], who provide easy access. On the other hand, the monitoring of diagnosis and treatment quality has become more challenging. The systematic review and meta-analysis in factors associated with the patient and diagnostic delays in Chinese TB patients indicated crucial reasons: availability of resources to perform prompt diagnosis and treatment, lack of trained health human resources, and geographical barriers [14]. The prevalence survey in Indonesia, as well as patient pathway analysis, found an important proportion of TB patients treated in private sectors [15, 16]. The TB prevalence survey in Ghana demonstrates that two-third of the TB symptomatic person less preferred to visit a public health facility to test their sputum and treatment due to long-distance, lack of training on guidelines, and fear of infection, leading to low motivation among health staff for TB work [17]. The research related to engaging Informal Private Health Care Providers for TB Case Detection done in India, demonstrates that engaging informal health care providers is feasible and possible a large number of Person with Presumptive TB and TB patients can be identified through this effort [18]. The study done in Nigeria described that more robust engagement of pharmacy in TB programme with clear terms of reference (ToR) through effective orientation, provision of pay for performance are recommended as a policy approach to improve linkage of the client to TB diagnosis and treatment centres [19]. The assessment done in improving pathways to care through interventions co-created with communities in Malawi showed that clear pathways to care involve interventions that need to consider in contextual concerns by resolving personal level of socio-economic aspects and also boarder level of structural factors of gendered social dynamics and health system environment [20], the socio-

economic and traditional factors are also substantial 'bottleneck' to hastening the uptake and utilisation of diagnostic and treatment tools for TB services [21], and adequate knowledge and positive health behaviour supports the TB patients in taking timely help from appropriate diagnosis and treatment health care outlets [22]. A quarter of the TB patients preferred for seeking care from the private health care service providers in Uganda [23]. However, more than seventy percent of people in Nepal still use and intend to visit the government health facilities to take TB diagnosis and treatment services.

The majority of men who participated in the survey shared their experience regarding the treatment they received from outside the country, and most of them were from the productive age categories. These findings, in some way, supported the prediction that a high proportion of migrant workers with TB treatment history took the health services. As many young populations migrant abroad as seasonal and regular workers, TB might have been identified and treated while they were there. Few papers mentioned the high prevalence of TB among migrants from Nepal. For example, in Western Sydney, among people born in Nepal, TB incidence was as high as 223 per 100 000 [24].

More than half of the participants with TB treatment history explained that the treatment was taken at home without supervision, but the patient themselves or their family members visited the health facility to collect the medicine once a week or more. More than a quarter of TB patients visited the treatment centre to have their medication under the direct supervision of health workers. Few numbers of patients took treatment themselves without observation. Nearly a quarter of TB patients did not take Directly Observed Treatment (DOT) of from the designated treatment centre in Nepal [25]. None of the patients received their medication from the Community DOT providers, which is a crucial and interesting finding from this study. This indicated that the quality of the DOT approach should be scrutinized for the future, and quality could be another issue for the patients.

Conclusion

The prevalence of TB is common in Nepali society. The majority of the participants explained that they wanted to receive the diagnosis and treatment services from the government health facilities. Some participants said that they received services from both private health institutions and outside of the country due to easy access, convenient times, and fear of stigma and discrimination.

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Conflict of Interest

The authors declare that there is no conflict of interest.

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