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DOTS PROVIDERS PERCEPTIONS OF BARRIERS TO TUBERCULOSIS CARE IN CHANDIGARH, NORTH INDIA

Dr. Sandeep Singh Sarpal*[1], Dr. Naveen Krishan Goel[2], Dr. Dinesh Kumar[3], Dr. A. K. Janmeja[4], Dr. Abhiruchi Galhotra[5] and Dr. Sonia Puri[6]

[1]Demonstrator, MBBS, MD, Department of Community Medicine, Govt Medical College and Hospital Sec 32 Chandigarh
[2]MD, Professor and Head, Department of Community Medicine, Govt.Medical College and Hospital Sector-32 Chandigarh.
[3]Associate Professor-cum-Statistician, Department of Community Medicine, Govt.Medical College and Hospital Sector-32 Chandigarh.
[4]Professor and Head, Department of Pulmonary Medicine, Govt.Medical College and Hospital Sector-32 Chandigarh.
[5]Additional Professor, Department of Community and Family Medicine, AIIMS, Raipur.
[6]Associate Professor, Department of Community Medicine, Govt.Medical College and Hospital, Sector-32 Chandigarh.

***Corresponding Author: Dr. Sandeep Singh Sarpal**
Demonstrator, MBBS, MD, Department of Community Medicine, Govt Medical College and Hospital Sec 32 Chandigarh.

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ABSTRACT
India is the second-most populous country in the world; one fourth of the global incident TB cases occur in India annually. Health care worker's knowledge, attitudes and perceptions about Tuberculosis play an important role in their ability to diagnose and care for individuals with Tuberculosis. The present study reports findings from a descriptive qualitative study seeking to explore barriers to effective health care provision of TB services in Chandigarh from the point of view of providers. **Materials and Methods**: A descriptive qualitative study was conducted from March 2012 up to September 2012. The principal research questions asked were: from a provider's perspective, what are the barriers to care for people suffering from TB? This was done using a pre designed, pre-tested questionnaire which was used to collect the relevant information from all the DOT providers. Besides this focused group discussions (FGD) were held with DOTS workers. A total of 115 DOTS workers were interviewed. **Results**: Out of 115 DOTS providers 60(52.2%) were females and 55(47.8%) were males. All of the DOT providers were aware that pulmonary tuberculosis is a communicable disease. All DOT providers knew that TB spread by droplets. 67(58.3%) said drowsiness was the most common side effect complained by patients after initiation of therapy. 111(96.5%) DOTS providers believed there is need to spread more information regarding DOTS. 100(87%) perceived alcohol as a reason for default. TB was perceived by the majority of respondents as a 'social disease' requiring multi-sector collaboration. **Conclusions**: This study has elicited the perceptions of DOTS providers on the multiple barriers to diagnosis and treatment of TB in Chandigarh.

KEY WORDS: FGD, DOTS, TB.

INTRODUCTION
Though India is the second-most populous country in the world one fourth of the global incident TB cases occur in India annually. In 2012, out of the estimated global annual incidence of 8.6 million TB cases, 2.3 million were estimated to have occurred in India.[1] 'RETREATMENT' for tuberculosis has long been a neglected area in global tuberculosis control. India, however, disproportionately accounts for nearly half of the retreatment TB cases notified globally.[2] Default among the re-treatment group is a serious public health problem.[1]

Multi Drug Resistant (MDR)-TB is defined as resistance to both the first-line TB drugs, Isoniazid and Rifampicin. Since the early 1990's MDR-TB has been on the rise and now threatens TB control programs in many parts of the world. It can be primary, in a patient who has not been treated before, reflecting overall poor TB control in the community, or acquired, reflecting either poor adherence or an inadequately conducted individual program. MDR-TB makes management even more difficult because of the need for longer courses of less potent, more toxic and more expensive second line drugs.[3] Proposed explanations for the rise in MDR-TB include HIV, physician mismanagement, substance abuse and failure

to complete therapy due to incomplete or inadequate therapy. [4]

DOTS is the strategy and heart of the program, so DOT providers have an equal importance.[5] DOT provider is an observer (health worker or a trained community volunteer who is not a family member) who watches and supports the patients taking drugs. It is this DOT provider who ensures that the patient takes right drugs in right doses at right interval for right duration. DOT providers should be accessible, acceptable and accountable.[1]

Health care worker's knowledge, attitudes and perceptions about Tuberculosis play an important role in their ability to diagnose and care for individuals with Tuberculosis. A variety of factors, such as training, cultural and ethnic background, practice settings, preferred sources of information and learning styles influence them. The successful completion of TB treatment is influenced greatly by 'how' care is delivered to individuals. It is paramount that Health care worker supporting clients with TB have positive attitudes.[6, 7]

Whilst most studies on access to care for TB to date have drawn on the perspective of users and analysis of systems, it may also be important to explore the views of providers as powerful stakeholders in the reform process. The present study reports findings from a descriptive qualitative study seeking to explore barriers to effective health care provision of TB services in Chandigarh from the point of view of providers. The present study was conducted to explore opinions of health care providers regarding barriers for effective health care delivery for TB patients in Chandigarh.

MATERIALS AND METHODS

Chandigarh, a Union Territory (UT) is also the capital of Punjab and Haryana situated in the northern part of the country. RNTCP was launched in Chandigarh on 25th January 2002.RNTCP is implemented in the UT through District Tuberculosis Centre (DTC) located in Sector 34. There are three Tuberculosis units (TU**).**

A qualitative study was conducted from March 2012 up to September 2012. The principal research questions asked were: from a provider's perspective, what are the barriers to care for people suffering from TB? This was done using a pre designed questionnaire which was used to collect the relevant information from all the DOT providers. The questionnaire consisted of questions regarding their knowledge and attitude about Tuberculosis, RNTCP and DOTS. Their beliefs and perceptions regarding TB were also asked. The response to certain items on the questionnaire was rated in a 4-point Likert scale as "strongly agree," "agree, "disagree," and "strongly disagree."

Besides this focused group discussions (FGD) were held with DOTS workers-. A focus group conversation invites discussion through participation and often results in groups dynamic which generates data that is rich in viewpoints as the lively collective interaction, can provoke more spontaneous expressive emotional opinions than an individual interview.[8] The interview-questions were developed based on searching the relevant literature and experience and were piloted for linguistic understanding prior to conducting FGD. The focus group discussions were held for 40–60 minutes at the DOTS centers and the findings were recorded. The sessions were moderated and the data from the interviews of providers was transcribed verbatim and transcribed into English. Codes and themes were developed concurrently with data collection. Direct quotes that illustrated important themes were extracted and are presented in this manuscript.

A total of 115 DOTS workers were interviewed. The opinions of the DOTS providers were explored using qualitative interview technique by convenient sampling. The sample was stratified to represent all the three TU of Chandigarh. Stratification was done on the basis of areas allocated to Tuberculosis Unit located in different parts of Chandigarh. Within selected TU as first stage units, DOTS center was allocated as second stage units. Within selected DOTS centres, a sample of health care providers was selected for qualitative survey. Only those respondents who gave consent to take part in qualitative survey were included, resulting in sample of 115 health care providers in the present study.

Informed consent was taken from the respondents and ethical guidelines under Declaration of Helsinki were followed. The institutional Ethical Committee also approved the study. The present study is a part of research undertaken to study the reasons for default among the tuberculosis patients in Chandigarh.

RESULTS

Out of 115 DOTS providers 60(52.2%) were females and 55(47.8%) were males. 55(47.8%) of the DOTS provider were in age group of 35-44 years, 49(42.6%) were in the age group of 25-34 years. 68(59.1%) of the DOTS provider were graduate, 32(27.8%) of the providers were secondary school, 9(7.8%) were educated at high school level. (Table 1).

All of the DOT providers were aware that pulmonary tuberculosis is a communicable disease. All the DOT providers knew that TB spread by droplets. All the DOT providers knew that cough with expectoration is the symptom of tuberculosis. Majority of the DOT providers (96%) said that tuberculosis is suspected if the patient had any of the symptoms like evening rise of temperature, blood in sputum, pain chest, weight loss or family history of tuberculosis. All the DOT providers believed that tuberculosis is more common in the lower socio-economic status.

67(58.3%) said drowsiness was the most common side effect complained by patients after initiation of therapy followed by 50(43.4%) who said itching was the most common side effect complained by the patients after the initiation of therapy.41 (35.7%) said GI upset was common side effect complained by the patients after initiation of therapy. (Table 2).

56(48.7%) of the provider spent 5-10 minutes on patients followed by 50(43.5%) who spent 1-5 minutes on DOTS provider. 109(94.8%) said they had faith on the DOTS therapy while 6(5.2%) said they did not have faith on the DOTS therapy. 111(96.5%) DOTS providers believed there is a need to spread more information regarding DOTS. 101(87.8%) believed that good nutrition plays important role in recovery of the patients, while 13(11.3%) did not know whether nutrition played a role in the recovery of patients.

111(96.5%) of the DOTS provider were satisfied with treatment compliance, followed by 3(2.6%) who were partially satisfied.108 (93.9%) were highly satisfied with treatment outcome.90(78.2%) were partially satisfied with IEC awareness in the community followed by 15(13%) were highly satisfied with IEC awareness in the community.98(85.2%) were partially satisfied with involvement in the community followed by 15(13%) who were highly satisfied with the involvement in the community.103(89.6%) were partially satisfied with the defaulters.(Table 3).

100(87%) perceived alcohol as a reason for default followed by 99(86.1%) who believed drug addiction followed by 80(69.6%) who believed migration as a main reason for default.55 (47.8%) believed long duration of treatment as reason for default. Only 8(7%) believed poor cure rate as a reason for default. (Table 4).

FGD analysis: TB was perceived by the majority of respondents as a 'social disease' requiring multi-sector collaboration. Poverty, poor housing and living conditions, malnutrition, drug and alcohol use, and unemployment were perceived as underlying causes of TB as well as obstructing access to TB care. Concerns regarding diet and provisions being made by the government were also raised by providers.

"TB affects whole of the family of the patient. It is a social as well as a medical problem".

"Even though the treatment is free, the side effects of the drugs are many and treatment is long".

"Free treatment does not include free diet. A person who loses a job due to TB say a labourer how can he cured by only taking drugs"

"Vegetarian diet is not sufficient to cure TB".

"Some dietary supplement should be given as patients are very weak and cannot afford good diet"

Themes of social stigma and discrimination as barriers to completing treatment also emerged during interviews with providers. Patients did not want health workers to visit their home for adherence counseling and did not want to attend their local treatment centre due to a potential disclosure of their disease. In particular, addressing issues of social stigma for unmarried women infected with TB was challenging for providers.

"Patients with MDR face a social stigma, family members are afraid they might catch TB"

"Younger patients and females in particular because of their fear of not being able to get married, may default because of the stigma associated with the disease".

"Patients don't like us visiting their homes due to fear that neighbors will start avoiding them"

In tracing and monitoring defaulters/interrupters the main problems include migrants, change of address, and perceptions of danger from aggressive and often 'asocial' patients towards the visiting staff.Alcohol abuse and addiction resulted in missed TB treatment doses, other scheduled appointments, and also in patients being unreceptive to counselling and treatment adherence messages by providers. Because alcohol abuse was intertwined with treatment non-adherence, providers suggested that relationships be developed with alcohol control programs. Patients who lacked strong networks of family and social support were more prone for default. "Often we are insulted by the patients who do not want to continue therapy".

"Defaulters become aggressive and are very uncooperative towards us".

"Defaulters are often addicts who live alone or are abandoned by family. They are very uncooperative"

"Government should charge some amount for the treatment so that patients do not default and remain serious about treatment"

Due to contractual nature of job of most DOTS workers there were perceptions regarding as government should also care for the health of the staff involved in TB care. Development of health insurance or cover by the government for the providers was stressed by most providers.

"If I catch TB government does not offer me insurance". "Considering our nature of work at least we should be regularized".

Table 1: Sociodemographic profile of the DOTS providers

Age of the provider (in years)	Number	Percentage
18-25	3	2.6
25-34	49	42.6
35-44	55	47.8
>44	8	7.0
Education of the Provider		
Graduate	68	59.1
Secondary School	32	27.8
High School	9	7.8
Doctor	4	3.5
Primary	2	1.8
Sex of the Provider		
Female	60	52.2
Male	55	47.8

Table 2: Side Effects of Drugs Complained To Providers by The Patients After Initiation Of Therapy

SIDE EFFECTS	Number	Percentage
Drowsiness	67	58.3
Itching	50	43.4
GI upset	41	35.7
Burning in hand and feet	35	30.4
Joint Pains	15	13
Dizziness and loss of balance	11	9.6
Ringing in ear	9	7.8
Fatigue	7	6.1
Loss of Hearing	6	5.2
Jaundice	3	2.6
Impaired vision	2	1.7

Table 3: Extent of Satisfaction of Dots Providers Regards To Their Performance

Variable	Highly Satisfied	Partially Satisfied	Satisfied to little extent	Not satisfied
	Number (%)	Number (%)	Number (%)	Number (%)
Treatment compliance	111(96.5)	3(2.6)	1(0.9)	-
Treatment Outcome	108 (93.9)	7(6.1)	-	-
Patient satisfaction	74(64.3%)	40(34.8%)	-	1(0.9)
IEC Awareness in community	15(13)	90(78.2)	10(8.8)	-
Involvement in the community	15(13)	98(85.2)	2(1.7)	-
Satisfaction with Defaulters	9(7.8)	103(89.6)	2(1.7)	1(0.9)

Table 4: Reasons for Default As Perceived By the Dots Providers

Reasons for default as perceived by the Providers	Number	Percentage
Alcoholics	100	87.0
Drug Addicts	99	86.1
Migrant Population	80	69.6
Long Duration of t/t	55	47.8
Lack of Information	21	18.3
Side effect of drugs	19	16.5
Lack of faith on DOTS	16	13.9
Social stigma	15	13.0
Prefer Private T/t	10	8.7
Poor Cure Rate	8	7.0

DISCUSSION

The present study comprised 115 DOTS providers. All of the DOT providers were aware that pulmonary tuberculosis is a communicable disease. All the DOT providers knew that tuberculosis is a curable disease.

Similar results have been shown by studies from other parts of India.[9,10]

96.5% providers believed that there is need to spread more information regarding the disease. This is quite significant and requires more efforts towards IEC activities of the patients and would further help in reducing the default. Similar findings have been shown by study in Nepal.[11]

58.3% providers said that drowsiness was the most common side effect complained by patients after initiation of therapy followed by (43.4%) itching followed by (35.7%) GI upset. However in a study by Kaur et al nausea (78%), vomiting (78%) followed by itching were the most common side effects reported by the providers.[9]

87% perceived alcohol as a reason for default followed by 86.1% who believed drug addiction as main reason for default. In a South Indian study 25% of patients almost two third of the defaulters were alcoholic.[12] Similar findings have been shown by a study in Nepal.[11] Long duration of treatment was responsible for default according to 55(47.8%) of the DOTS providers. Default occurring due to the long duration of treatment calls for the introduction of drugs that may further shorten the duration of chemotherapy.[13]

Around 5 %(6) of the providers did not have faith on DOTS therapy. Long duration of treatment and associated side-effects of therapy, ill health, social stigma and financial losses can lead to a situation where patients lose faith on the therapy even though the treatment is provided free of cost by the government has been shown by earlier studies.[13] However Health personnel should be sensitive to this issue and evolve suitable motivation strategies. And it further emphasizes the need of reorientation trainings and motivation of the workers for the success of RNTCP.

96.5% DOTS providers in the present study believed that is need to spread more information regarding tuberculosis in the community. Public attitudes and stigma appear to be important deterrents from seeking timely care, the consequences of which are not only damaging to the personal well-being of TB patients, but also likely undermine effective TB control and promote disease transmission. Efforts need to be made to improve the pre-treatment counseling, increase the proportion of patients treated by community based DOTS providers, repeated health education to the patients emphasizing the need to continue treatment.[13] In TB patients who are unable to accept the treatment due to a specific reason like inconvenient center-timing mingling with job, study and household work, unavailability of nearby DOTS center, social stigma or physical disability ,Family members specially the 'mother' could serve as a DOTS provider just like the other community members with training and supervision.[14,15]

This study has elicited the perceptions of DOTS providers on the multiple barriers to diagnosis and treatment of TB in Chandigarh. Reorientation courses should be organized periodically to update the knowledge of DOT providers regarding the TB disease, its diagnosis, treatment and follow up of patients. Knowledge about new and retreatment cases should be given to them. Home visits by DOTS workers should be encouraged.

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