



Barriers Towards National TB Elimination Program (NTEP): Myths and Misconception about Tuberculosis: A Qualitative Study

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Abstract

Background: Development of need-based Information, Education and Communication (IEC) tool will serve for national control and preventive interventions. Understanding drivers of misconceptions is important, which is more prevalent in rural areas.

Methods: The study was conducted in Urban health training centre, Villupuram. It was a Qualitative study. In phase I, Focus Group Discussions (FGD) were conducted among paramedical students to explore their perceptions about Tuberculosis, followed by IEC material preparation based on the findings from FGD in the 2nd Phase, tailed by intervention in phase III. Six FGD, with total of 63 students, who were vocal and willing were purposively selected. Manual Thematic content analysis was done for qualitative data and IEC material was developed based PATH Guidelines.

Results: These findings from the study reflect that people are strongly adherent to misconceptions with regards to gravity of TB, prevailing in rural background. Understanding the knowledge gap this study ties with development on need-based health education material. Some of the surprising facts explored were participants believe that it is caused due to “previous sin”, “Evil eye”, “Black smoke”, “Cold air”, so on.

Conclusion: Implementation of need-based intensified IEC activity and sensitization programs plays a major role in achieving TB elimination.

Keywords: Tuberculosis, Myths, IEC, Flipbook, Qualitative

Introduction

Tuberculosis (TB) is a social problem has existed for millennia and remains a major global health problem.^{1,2} As we all know in spite of lot of awareness on TB, misconception has been in existence especially in rural areas and it might have an impact on their treatment seeking behavior. Hence addressing misbelief of community people is key issue in improving their treatment seeking behavior and reducing the missing cases.³⁻⁵ Perhaps Poor knowledge of TB, ignorance toward the modes of

spread of the disease, stigma and misbeliefs regarding TB contribute to poor health seeking behaviour leading to missing cases.^{6,7} Current National TB Elimination Programme (NTEP)^{8,9} have reinforced that developing need based context specific Health education tool and training of paramedical staffs is mandatory for community advocacy, stigma mitigation efforts which are often catalysts for change in attitudes and practices, connect people to health services. WHO - STOP TB strategy¹⁰, Engage TB strategy¹¹ have also

highlighted to enhance community awareness on TB and trained of paramedical staffs on TB. Hence KAP survey will serve as a base to identify the Knowledge Gaps on tuberculosis and to provide comprehensive intervention to bridge the Gap and serve the purpose. The focus on myths and misconceptions is borne out of the fact that they are potential threat to preventive efforts.

With this backdrop this study was taken up, we have targeted paramedical students and ANM coming from rural background. The rationale for targeting paramedical students is being a part of health care professionals they have role and responsibilities for counselling the patients on TB and they can empower the community by raising awareness on TB which pays way towards TB elimination. Objective of our study is to develop need-based, context specific health education material on Tuberculosis to fill the knowledge gap by providing comprehensive training

Material and Methods:

Study Setting And Participants: The present study was conducted for paramedical students in two Paramedical training institutes located in our field practice area of Urban Health Training Centre (UHTC) of Sri Manakula Vinayagar Medical College and Hospital in Villupuram, Tamilnadu district. Majority of the students studying in these institutes were from the rural area.

Study Design: It was a Qualitative study design which was conducted in three phases. Focus Group Discussions were conducted among paramedical students in the Phase 1 to explore their perceptions about TB, followed by IEC material preparation based on the findings from FGD in the 2nd Phase. Comprehensive training programme was provided by trained person in TB management for the study participants using the developed IEC tool (phase 3)

Sample Size And Sampling: Six Focus Group Discussions, three in each institute were conducted with around 10-12 participants in each group. Total of 63 students, who were vocal and willing were purposively selected for the study from the two paramedical institutes, hence Participants were selected based on Homogenous type of purposive sampling.

Table 1: sociodemographic profile of study participants

Sample size for data collection	
Paramedical students	N=63
ANM	14
Lab technician	49
Criteria for selection of study participants	
Locality	Rural background
Age	20-30 years
Work	Indulged in Diagnosis, counselling for TB care services, Providing community-based TB care services.
Sex	Male (42) and Female (21)
Others	
Venue	At Urban Health Training Centre (UHTC), Villupuram
FGD (Duration)	Duration (35 -45 minutes)

Data collection and Analysis:

Phase 1: After obtaining written informed consent, Focus Group Discussions were conducted among paramedical students to explore their beliefs and knowledge about Tuberculosis. FGDs were conducted by the female Principal investigator, who is trained qualitative research methods in the native Tamil language using a semi structured interview guide with broad, open-ended questions. The interviews were conducted in their own paramedical institutes at a time which is convenient for the participants. After obtaining consent from the participants, the interviews were audio-recorded and important points were noted down in the diary. Each interview lasted for around 40 min to 1 hour. To ensure participant validation debriefing was done before closing the interview and participants were asked if they wanted to add any extra information. The FGDs were conducted until data saturation was attained, i.e. no new information was derived from the discussions.¹²

Transcripts were prepared from the audio recordings in verbatim in English on the same day of the interview. Transcripts were proofread and edited before it was thoroughly read and manually analysed thematically by two trained qualitative researchers. Discrepancies arising between the two were solved by mutual consensus. Codes derived from the transcripts were merged to form broad categories. Statements in italic indicate direct statement from participants.

Phase 2: From the information obtained from the FGDs, health education material (Flipbook) was developed based PATH Guidelines. The steps followed in the development of Health Education material (Flip Book) is depicted in the Figure 1.

Phase 3: Interactive training^{12,20-22} for Allied health workers: Participants were divided into six groups with 7-8 participants in each group. Comprehensive health education session was improvised to emphasize their knowledge gap, flipbook was used which was more of pictorial representation with correct messages and their queries were also addressed in the end. In addition to it pamphlets which contained all the key message on TB was also distributed to the audience

Ethical issues:

The study was approved by the Institutional Research Committee and Ethics Committee of SMVMCH (IEC No:). Permission was obtained from the Heads of the Paramedical Institutes and Informed written consent was obtained from all participants. Respect for person, privacy and confidentiality was maintained throughout the study.

Reporting Guidelines:

“Consolidated Criteria for Reporting Qualitative Research (COREQ)” checklist was used for reporting the findings of the study.¹⁴

Results:

(Table1) Total of 63 participants were involved in the study, each group contained 10-12 participants, The mean age of the respondents was 18.4 ± 2.6 years of age. All of them were 1st year lab technician training students came to our UHTC centre for training. Among them 80% were female and 20% were Male. All the participants were from rural background. Majority of them were Hindus (91%).

None of them were married. No one had family history of TB.

Table 2: Myths evolved from FGDs from paramedical students

Category	Myths: statements emerged from students from their experience
About TB	<i>“TB is incurable it leads to death”</i>
	<i>“People who are pure in heart will not get TB”</i>
Cultural and social aspects	<i>“Mostly people who committed sin will acquire TB that’s why village people will neglect them.</i>
	<i>“One of the females in our village got TB when she was 17-18 years, she became very thin but after doing pooja and she took treatment she recovered, she got married at 20 she was not able to get pregnant at all for many years, my grandmother told her menstrual blood also became impure that’s why she has become infertile”</i>
	<i>“one of the females after getting married she got TB and she was rejected by her in-laws and husband as she brought bad name to the family and she also committed suicide”</i>
	<i>“TB people are cursed that’s why even if they eat well, they loose weight and become very bony and die”</i>
	<i>“Tuberculosis bacteria affect only people who are poor living in hut, not rich people</i>
Stigma	<i>TB is Hereditary: TB can be considered a ‘curse’ on a family, as the illness often affects multiple generations, in my village father got TB, then Mother and both their son on after another got TB, nobody are willing to marry him and next generation will get TB</i>
	<i>When i invited a family for my</i>

	<p>marriage my parents told me that family got affected with TB 4 years back and not to invite them, their presence will cause bad eye</p> <p>One of the male villager who got TB, drinks alcohol daily he stated that instead of drinking poison he is drinking alcohol so that I can die soon AS my own wife is neglecting me”</p>
Religious grounds	<p>“TB affect mostly Hindus than other religion because kali god will punish bad people”</p> <p>“Hindu people who get TB will commit pooja in temple to get rid of the sin so they will recover from TB”</p>
Risk groups and Mode of transmission	<p>TB is caused because of Bad Air hence farmer and people who are working in cotton industry will acquire the disease</p> <p>TB could be transferred from one person to another by sharing plates or clothes or shaking hands. Spread through water and Food handled by bad people</p> <p>Black smoke from vehicle will also cause TB, Hence Traffic police will get TB, some factory workers where black colour smoke is emitted acquire TB</p> <p>When people have sex with bad people, with the person who have already got TB will get TB, hence it is sexually transmitted.</p> <p>TB mother milk will lack energy especially vitamins, new-born baby will not grow well if it breastfed, so breastfeeding should not be done by TB infected mother recently or in the past it will kill the baby</p> <p>“We should not touch TB patients, because if we touch their sweat TB will spread easily”</p>

	<p>“TB people are cursed that why they also get HIV and die”</p> <p>“TB is caused by cold air”</p>
Symptoms	<p>People will have Cough for 1-month, loose stools, will not be able to sleep, their skin becomes dry, conjunctivitis, they will have tremors, skin on bone appearance etc</p> <p>They will not be able to walk,</p>
Childhood TB	<p>“TB will not affect children at all because BCG vaccine is given during birth”</p> <p>“Breast fed infants will not get TB”</p>
Extrapulmonary	<p>“TB will not affect other organs apart from lungs”</p> <p>“TB will affect blood”</p>

Knowledge and perception of TB: It was surprising various myths and misconception was still prevailing whereas few participants were aware of the correct concepts. Tuberculosis were commonly referred in local name “Nenjuri kinoi” , “Alkollinoi”. They mentioned “TB is incurable it leads to death” and “People who are pure in heart will not get TB”.

Following seven categories emerged from TB focusing on the myths. (Table 2)

Discussion:

Development of IEC material: This study ties with development of need-based context specific health education material understanding the knowledge gap as propounded by STOP – TB, Engage TB and NTEP guidelines. Deeper understanding of the community regarding TB is vital requirement in order to bring positive behavioural change in TB response. This study reflects there is strong adherent to lots of Myths with regards to gravity of TB especially on religious and cultural grounds. The stigma of TB as “a disease of the poor” still persists, more recently, HIV stigma affects TB patients, as shown in studies in Pakistan, Ethiopia, Thailand and south India^{3,15-17} Myths and superstitions about the treatment of TB, cure the disease, were also observed. Malhotra et al¹⁸ TB was

mentioned as being hereditary in study conducted in Canada, Aboriginal population.¹⁹ In the present study participants assumes that TB can be transmitted through sexual contact, sharing utensils, food, physical touch and through sweat etc. they are likely to be receptive to people infected with, and affected by TB. Some similar misconceptions such as drinking water and food as means of transmission and TB being an inherited disease were obtained in the study conducted in Croatia.²⁰ Therefore, it is suggested that IEC messages focus on removing such myths and superstitions and bringing about a paradigm shift in society's attitude toward TB.

Rationale for training paramedical professionals:

The major component NTEP programme emphasis training all health care workers in effective implementation of the framework and they are responsible for counselling the patients on TB and they can empower the community by raising awareness on TB which pays way towards TB elimination to community people break the barriers. To effectively impart such education this study has tried to address the existing gaps in knowledge, attitude and practices, well designed validated health education tool (Flipbook) can help to ascertain the same.²¹ Comprehensive training followed by FGD was done based on NTEP guidelines. IEC tools are useful in improving the overall knowledge of patients and their families about healthy lifestyle and their adherence to treatment Therefore, there is a need to intensify IEC activities in these subgroups of the population and also to emphasis on TB as being a curable disease. Intensified awareness on childhood TB and Extrapulmonary TB is needed. Limitation of the study is group interaction allows participants to agree and disagree thereby stimulating richer responses which aid in revealing the respondent's real perceptions on the subject of interest. Gathering ideas and cultural beliefs surrounding TB was possible through this method of data collection. Comparison of urban and rural perspective is needed.

Conclusion

The content and implementation of need based Intensified IEC activity and sensitization programs should be improved and more emphasis needs to be placed on (traditional) myths about TB aetiology. Consequences of stigma prevailed discrimination,

social exclusion, and isolation leading to a decreased quality of life and social status should be addressed. Whatever approach is taken it is vital to bring a critical analysis to enable a change process in the TB response; 'Vital' to avoid stagnation and for pushing the TB response to enhanced success and 'critical' because health systems alone cannot cope and need the skills, knowledge and work of communities to maximise the scope and effectiveness of national plans and a comprehensive TB response.

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