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Exploratory Qualitative Study for Community Management and Control of Tuberculosis in India

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Abstract

Tuberculosis (TB) is a major public health problem in India which accounts for nearly one-fifth of the global TB burden. Though India has been gaining success in eliminating TB, the disease still kills 1,000 people daily. It is of prime importance to control the TB situation in India. Motivated by the need to explore factors influencing TB, a qualitative study was conducted with 14 doctors and key TB informants in India over a period of one month involving face-to-face interviews. The interviewees came from diverse backgrounds and vocations, thus providing a rich data on varied issues in controlling the spread of TB in India for enhanced patient care. The data was coded and analyzed. The findings suggest the need to address mental and social well-being of the TB patients through three main themes, namely, Alerts, Care and Education, in order to control the TB situation in India.

Keywords: TB; India; Alerts; Care; Education; Qualitative methods

1. Introduction

Tuberculosis (TB) is a major global public health problem. In 2010, there were 5.7 million notifications of new and recurrent cases of TB, with India and China accounting for 40% of the world's reported cases of TB in 2010 (WHO, 2011). India alone accounted for an estimated one quarter (26%) of all TB cases worldwide. India has the highest burden of TB in the world with over two million TB cases amounting to more than one fifth of the global burden. Approximately 500,000 people die of this deadly disease (Agarwal, 2000) there. Although India's Revised National TB Control Programme (RNTCP) has made significant progress in TB control over the last decade through countrywide DOTS implementation (Udwadia et al., 2010), India is among the 22 TB high burden countries that constitute 80% of the global incidence of TB cases (WHO, 2011).

The nationwide TB control programmes have traditionally focused on case-finding and treatment of infectious patients. From a public health perspective, this approach is undoubtedly of top priority. However, to reduce the TB disease burden in the country and improve clinical care at an individual level, there is a need to identify TB control factors which can be complemented with the case-identification and treatment. Public health researchers need to identify different management strategies which can help control the TB situation in India.

Beyond the current efforts to prevent, detect and cure TB, new tools and technologies are needed to control the spread of TB and effectively manage the threat of drug-resistant strains such as MDR-TB and XDR-TB. These proposed new technologies are a process to prepare health systems at the country and global level to uptake new tools and technologies in the prevention and cure of TB. Realizing the fact that India is among the top five countries with the largest number of incident cases in 2010 (2.0 million-2.5 million) (WHO, 2011) and motivated by the need to identify key TB control and manage factors, the objective of this study was to identify key areas that can be implemented using current technologies through help fight TB in India.. The study can be extended and applied to other countries coping with a TB problem.

2. Materials and Methods

2.1 Design and Setting

This was a multi-site study involving several TB hospitals and TB centers in Mumbai. The study was conducted in urban metropolitan Mumbai, India where its burgeoning population and high incidence of TB is suspected to be a focus for multidrug-resistant-TB (MDR-TB) (D'souza et al., 2009). Several new cases of MDR-TB are reported each year, including extensively drug-resistant (XDR) TB. These are associated with high mortality rate. Qualitative method of data collection was employed which involved in-depth interviews with key TB informants in India.

Ethics approval was obtained from Nanyang Technological University (NTU, Singapore) Social and Behavioural Research International Review Board. Each subject was briefed about the intent of the study before they agreed to participate in the interview.

2.2 Subjects

Subjects actively involved in TB treatment and control were eligible for participating in the interview. The interviewees were chosen from diverse backgrounds and included both medical and non-medical professionals, thus providing rich information on varied issues in controlling and managing the spread of TB in India for enhanced patient care. Face-to-face individual interviews were conducted with the participants in their workplace or hospitals.

The study involved multiple interviews with the following: Head of Infection-Control-Committee from a major private hospital in India, World Health Organization (WHO) Consultant, Professors and Head of Chest Medicine Department from a major public hospital, Commissioner and Health Officers of Municipal Corporation, TB news correspondent, Non-government Organizations (NGOs) working actively to control TB in India. We also interviewed one TB survivor to understand the key areas to improve the TB situation in India from a patient's perspective. We restricted our interview to only one TB survivor because after interviewing him we realized that his opinions matched exactly with the medical/non-medical TB professionals. As our study was on controlling the TB situation and the spread of TB, it was more apt to include the professionals working in the area of TB rather than TB

survivors alone, We were keen to understand how the health policies need to be designed and how the doctors can manage the current TB situation in India.

Table 1 presents the profiles of the interviewees.

Table 1

Profiles of Interview Respondents

Id	Profession	Gender	Affiliation	Role
Medical (M)				
M1	Doctor	Female	Inter aide Development India	TB doctor at an NGO administering DOTS.
M2	Medical consultant	Male	WHO RNTCP	TB specialist
M3	Doctor	Female	Hinduja Hospital	TB specialist in private hospital.
M4	Executive Director	Female	PUKAR	NGO to spread awareness of TB.
M5	Doctor	Male	The Maharashtra State Anti-TB Association	Private practitioner for TB.
M6	Executive Health Officer	Male	Brihanmumbai Mahanagarpalika (BMC)	Municipal corporation trying to curb the spread of TB.
M7	Joint Executive Health officer	Male	BMC	Municipal corporation trying to curb the spread of TB.
M8	Doctor	Male	KEM Hospital,	Public hospital dealing with TB cases and treating by administering DOTS.
M9	Doctor	Male	KEM Hospital	Public hospital dealing with TB cases and treating by administering DOTS.
M10	Doctor	Female	KEM Hospital	Public hospital dealing with TB cases and treating by administering DOTS.
M11	Doctor	Male	NGO	NGO treating TB patients.
Non-Medical (NM)				
NM1	News Correspondent	Female	DNA News	Media writing on TB news
NM2	Civic administrator	Female	BMC	Municipal corporation trying to curb the spread of TB.
NM3	IT specialist	Male	IIT- B	TB survivor

2.3 Procedures

Initial contact was made by our research team in Mumbai at individual clinics and hospitals in March 2012. Our research team searched for major TB hospitals in Mumbai (both public and private) through Internet and newspapers. The list of medical and non-medical professionals actively involved in the treatment of TB was created by searching through online articles and journal papers on TB. In addition, our Mumbai research team had a chance to interview around 10 TB patients/survivors/caretakers. The medical professionals suggested by those TB victims were included in the list. We searched for their email ids and phone numbers and requested them for individual interviews. Our sampling criterion was that the participants must be actively involved in controlling and managing the spread of TB in India.

Fourteen face-to-face individual interview sessions were conducted over a period of one week in April 2012. The interviews were conducted by our research team of six members in combination, when necessary, with an interpreter fluent in Hindi. Specifically, in each interview-setting, the lead interviewer began the session with an open-ended standard question that began at all sessions with key TB informants. Some of the questions asked were “What are the early symptoms of TB?”, “Do doctors here follow WHO guidelines for TB treatment regimes?”, “What are the challenges faced by healthcare system in treating TB patients?”, “Should doctors be more involved in the emotional and mental care of their patients?”, “How do caregivers play a role in helping a patient recover?”, and “Are people aware about TB in this society?”. Using open-ended, probing questions, the TB informants and survivor were asked to share their challenges and experiences in fighting with this deadly disease. The participants discussed the problems in adhering to their TB medicine regimes, medicine side-effects, lack of knowledge about

TB and much more. At the end of each session, the interviewer summarized salient points emerging from the discussion and invited further comment and discussion around these points and confirmed agreement.

2.4 Data Collection and Analysis

For all interviews, data obtained were audio-recorded, transcribed verbatim and analyzed. There were 12 hours in total for the interviews ranging from 30 minutes to 2 hours per interview. For comments made in Hindi, field notes were kept by the researchers fluent in the language. A total of 262 textual responses were obtained from interviewers' qualitative responses using constant comparative analysis (Mays and Pope, 2000). These textual responses were then content analyzed to identify patterns and themes. Several strategies were used to monitor the validity and reliability of the data Classification was performed by two independent coders who were not briefed on study or expected study findings. This helped us control for any potential bias due to the any theoretical knowledge about the study (Bhattacharjee and Premkumar, 2004). The coders were provided with the coding scheme along with the formal definitions and illustrative examples which emerged from the constant comparative analysis. Then they were asked to code into one or more categories. This coding scheme was derived based on the problems identified with the researchers while interviewing the key informants as well as by extensive literature review about TB (e.g. Bolton, 2009, Courtwright and Turner, 2010). This helped monitor the validity and reliability of the data. Sample qualitative response and their classification are presented in Table 2 for illustration purposes.

Table 2

Sample Qualitative Response Classification

Responses	Initial Coding		Consensus Coding
	Coder 1	Coder 2	
1. One generic insight which I feel, in terms of medication, medical in India, is that people take it very lightly. Everything, like from diabetes, to TB, to everything. Very lightly.	MTH	MTH	MTH
2. I'm not sure you came across these ads for TB on radio. What they force on, is, don't stop your treatment in between.	ALT	AWS	AWS
3. Secondly, because they are taking this thinking that okay, already gone, so we need not continue the medication.	MTH	EDU	EDU
4. I was coughing severely and then I realized that the colour of my cough was a little bit darker than usual. So I told the doctor this.	ADH	CAR	CAR
5. Doctor didn't tell me the type of TB. He just said you're positive with TB.	CAR	CAR	CAR

Coding Scheme: ADH: Adherence, EOA: Ease of Administration, SE: Side-effects, HCF: Healthcare Facilities, EMI: Emotional Impact, SOS: Social Support, MTH: Myths, STG: Stigma, AWS: Awareness, CLT: Civic-literacy, ALT: Alert, CAR: Care, EDU: Education.

The categories were then collapsed and analyzed for emergent themes. The next step was to test the reliability of the responses obtained by various coders to demonstrate agreement among the coders. For this research, we used percent agreement and Cohen's kappa (k) as a reliability coefficient to measure the agreement between the coders. The two coders agreed on more than 90% of the classifications and the measured Cohen's Kappa (k) value was acceptable at 0.95, indicating strong agreement. Most discrepancies occurred when the user responses fell in more than one pre-defined codes. Upon completion of the coding responses, the two coders collectively revisited each response, debating and resolving any discrepancy, until they were satisfied with one single consensus code.

3. Results

Extensive qualitative interviews with key TB informants in India highlighted three significant problems.

- Patients may skip their medication regimens by forgetting or purposely avoiding taking medications on time, especially elderly people. The main cited reason for doing so was to avoid the the immediate side-effects of the medication at the expense or ignorance of the seriousness and detrimental impact of skipping medication which is TB patients defaulting on their treatment develop resistance to TB drugs.

- Inadequate perceptions on the need for treatment and lack of proper knowledge of the disease. For example, in a country like India, uneducated and lower-income group of people might prioritize earning their living for the day rather than going to the hospital for DOTS. This situation is quite likely in the middle of the treatment when the patients start feeling better than before. In addition, some patients get depressed and need words that provide hope, care, concern and encouragement from other patients, recovered patients and doctors for their mental and social well-being.
- Health authorities face challenges in curbing the spread of TB to caregivers (families, friends, neighbours). There is minimal outreach in educating the general public on TB civic literacy. These challenges are largely focussed on civic literacy and the social responsibility of the patients suffering from TB. It is of prime importance to educate the dos and don'ts to the TB patients as well as to the general public so that the growing problem of TB can be controlled efficiently.

These issues and careful analysis of the interviews with the interview respondents suggested the emergence of several themes which are illustrated with their number and percentage in Table 3. **Table 3**

Number and Percentage of Textual Responses

Codes	Code names	Number of Responses	Percentage textual responses
ALT	Alert	19	7.25
ADH	Adherence	40	15.26
EOA	Ease of Administration	67	25.57
SE	Side-Effects	27	10.3
TOTAL % of Alerts theme and its sub-themes			58.38
CAR	Care	73	27.86
HCF	Healthcare Facilities	75	28.62
EMI	Emotional Impact	34	12.97
SOS	Social Support	64	24.42
TOTAL % of Care theme and its sub-themes			93.87
EDU	Education	24	9.16
MTH	Myths	57	21.75
STG	Stigma	30	11.45
AWS	Awareness	56	21.37
CLT	Civic Literacy	20	7.6
TOTAL % of Education theme and its sub-themes			71.33

Note: Total number of textual responses for analysis was 262 textual responses

3.1 Adherence

Poor medication adherence refers to not taking medication on time, in the proper doses, or not taking any medication at all. Lack of medication adherence is the major source of unnecessary disease progression, disease complications, reduced functional abilities, a lower quality of life, and even death. Several patient-related factors have been cited for poor medication adherence by patients such as poor knowledge of the disease, inadequate perceptions of the need for treatment and forgetfulness. A report by New England Healthcare Institute (NEHI) revealed that on a worldwide basis, patients are not taking medications as prescribed thus leading to poorer health, more frequent hospitalization, a higher risk of death and as much as US\$290 billion annual increase in medical costs (Dolan, 2009). Adherence is important in the case of TB management as those patients who cannot or do not adhere to the treatment remain infectious longer and are more likely to relapse and die. They would also be vulnerable to developing multidrug-resistant TB, a strain resistant to two or more first-line drugs, or extensively

drug-resistant TB, a strain resistant to three or more second-line drugs. Highlighting the significance of adherence, for TB patients, one of the public sector doctors commented: *“By 1997 there is a new programme started by government of India with support from WHO called **DOT strategy**. As for that DOT strategy, the patients take treatment under someone’s **direct supervision**”* (M10).

3.2 Ease of Administration

Ease of Administration emerged as an important sub-theme describing Alerts and refers to the medication, medication schedule, the size and form of the medicines and the number of pills that the patients need to take. Alerts refer to the constant reminders to the TB patients or caregivers from the health authorities to complete their medication on time. As part of the DOT strategy, a health worker or a TB treatment supporter watches the patient take their antibiotics every day. Patients also receive counselling and support to ensure they do not stray from their treatment course. The doctors did mention the innovative strategies that the government is adopting to facilitate administration of drugs. For example, one of the respondents who is a TB specialist in a private hospital in Mumbai mentioned, *“But here they have very innovative things. Like in the DOTS-PLUS, they would ask, say they would have the “paans” man as a DOTS provider and he will remind you to take your medicine. The **patient comes every day to “paans man”** to have his tobacco. They make him a DOTS provider”* (M3). This whole set up reinforces a need for Alerts for the patients.

3.3 Side-effects

The treatment for TB is a combination of strong antibiotics that must be taken daily for at least 6 months. But side-effects, such as nausea and heartburn, dissuade some patients from sticking with the treatment. Other patients endure the side-effects only to drop the medication once they feel better. The ‘Stop TB Partnership’ reports that on average 5% of TB patients abandon treatment, although the figure is as high as 20% in some countries (WHO, 2011). Commenting on this issue of side-effect, one doctor said: *“Nowadays the patients are active, patients want to know everything, and we know because of the **side effects of many TB medications**, the patients are defaulting, that was one of the main causes of this Multi Drug-resistance”* (M11). In order to help the patients adhere to their medication regime, it is important to tell them about the side-effects of the TB medicines along with reminders for the medicine. This knowledge about side-effects will prepare them to fight against the disease and thus the medicine alerts would be more effective. Commenting in this context, one doctor working for a NGO in Mumbai stated: *“We need to tell them the **side effects**”* (M11).

3.4 Healthcare Facilities

Several interview respondents discussed on the need for improved healthcare facilities for enhanced patient care. Nearly 29% responses discussed the issue of healthcare facilities. The doctors as well as the TB survivor expressed their frustration about the healthcare system during diagnosis and treatment. The doctors highlighted the problems with the DOTS program initiated by the government. A public hospital doctor describing the lack of healthcare facilities in public hospitals mentioned: *Unfortunately, we have a very poor diagnosis system for MDR diagnosis. The biggest hospital in Mumbai, Sewri hospital, in TB, lacks all the facilities* (M9). Some of the doctors expressed their concern about the healthcare facilities in public hospitals due to which many patients still prefer private hospitals. One of the private doctors commented: *“Why do patients prefer **private practitioners**? Because it is **fast**. Every minute is money. He goes to the DOTS center, spending the whole day, he can’t afford it”* (M5).

Table 4

Selected Illustrative Quotes for Sub-themes of Adherence, Ease of Administration and Side-effects

Sub-Themes	Comments
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<i>Adherence</i>	With the existing weak medicines and diagnostics, whatever we have, it has been a challenge to actually control TB because long term duration affecting low social economic status. It's a long duration. So adhering to the treatment is difficult . The adherence is difficult just because of long duration.
<i>Ease of Administration</i>	Until ten years back we have this system at the district TB office. People used to come there, take the prescription like for a month or two months and take the drugs. And there was like... national TB programme in the country until 1995. So by 1997 there is a new programme started by government of India with support from WHO called DOT strategy.
<i>Side-effects</i>	Initially people felt the side effects of the medication. And that is why they went away to private practices again. Nowadays the patients are active, patients want to know everything, and we know because of the side effects of many TB medications, the patients are defaulting, that was one of the main causes of this MDR.

3.5 Emotional Impact

Emotional impact emerged as a significant sub-theme of care. Almost 15% of the quotes pertained to emotions experienced and expressed by the TB patients. The emotions common among TB patients are depression, shock and worry. On discussing depression, the TB survivor respondent commented: *"I was totally, super **depressed**. I felt that everything is gone"* (NM3). A doctor in an NGO commented on the issue of shock: *"If you say that a person has contracted malaria, and I talk to the patient and I diagnose a particular disease, the patient does not get a big shock. But when I say that it is TB, the patient does **get a shock**, the relatives get a shock, for two minutes they go blank"*(M11).

Thus, emotional impact emerged as an important sub-theme which needs to be tackled to provide enhanced patient-care and control the TB situation worldwide.

3.6 Social Support

This sub theme described the need for support from the family, friends, doctors and other recovered TB patients for enhanced patient care and recovery of the TB patients. Social support emerged an important factor to control the problem of TB with nearly 25% responses. The TB survivor discussed on the need for social support: *"Depression slowly went because of **support** from my professor, and support from a lot of my friends"* (NM3). This shows that social support is important to deal with emotional turmoil which the TB patients undergo. Commenting on the need for social support, the TB survivor said: *"The **support from my family and girlfriend motivated me to continue the treatment**"* (NM3).

TB being a stigmatized disease causes TB patients to hide their diagnosis and isolate themselves from family and friends not only because of the fear of infecting others but also because of the fear of discrimination and gossip where people tend to shun away from them. Consequently, TB patients are left lonely and so the social support is important for their mental and social well-being and for their speedy recovery. In this context, a medical consultant from WHO commented: *"...more important thing is to have **patient to patient support group**"* (M2) Existing solutions for social support includes TB clubs for social support and Information, Education and Communication (IEC) materials such as sharing information through mediums such as television, newspapers, banners, posters, public announcements, wall paintings, door-to-door campaigns and propaganda by movie actors (Sharma et al., 2009). Health organizations also put up informational leaflets to correct people's assumptions about TB (see Respiratory Health Association of Metropolitan Chicago, 2012).

Table 5

Selected Illustrative Quotes for Sub-themes of Healthcare facilities, Emotional impact and Social support

Sub-Themes	Comments
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<i>Health care facilities</i>	50% of the staff who treat TB patients have suffered TB and have died . Including doctors, staff, paramedical staff, everything. Because of the lack of facilities, nowadays they are changing, the change will take some time.
<i>Emotional Impact</i>	There are still a few cases that go on that they don't want even the families to know they have TB .
<i>Social Support</i>	Depression slowly went because of support from my professor, and support from a lot of my friends .
	Actually I don't really see any active patient group, TB patient group operation at the country right now. There are efforts being made sporadically here and there. Maybe some NGOs might be trying for it.

3.7 Myths and TB Stigma

TB myths and stigma attached to the disease appeared to be a burgeoning problem. Almost 33% of respondents raised their concern about TB myths and stigma. Myths refer to the misconceptions people have about this disease. These myths eventually contribute to the stigmatization of TB patients. Stigma is the social stigma experienced by the TB patients and occurs when an individual possesses an undesirable attribute or is part of a despised group that reduces and taints the individual's status in society (Macq et al., 2008). This leads to discrimination and unfair treatment towards these groups (Baral et al., 2007).

Admitting the fear of being stigmatized, the recovered TB patient commented: *"I told only one friend and told him don't tell anybody that I'm diagnosed with TB"* (NM3). Another respondent, who is a leading doctor in a public hospital, commented: *"I feel one thing the stigma needs to be taken off the TB"* (M8). Stigmatized TB patients feel a sense of low self-worth and develop an inferiority complex which could hinder their treatment process. Educating the general public and TB patients should be effectively strategized for TB treatment and control.

3.8 TB Awareness

The interview respondents highlighted their concern about the lack of TB awareness among the general public. The significance of the sub-theme of TB Awareness can be inferred from the fact that nearly 22% of the textual responses discussed about lack of awareness about TB among the general public. This is shown in Table 6. One of the leading doctors in a private hospital in Mumbai commented: *"First thing that you need to do is if you want to really help TB is to create awareness for public programme"* (M3). Another TB specialist from Mumbai commented: *"The awareness of TB among the general public, especially the higher and the upper-middle class is not that much"* (M5). This comment from the interviewee shows that separate measures need to be taken to increase TB awareness among the general public as even the educated class of people lack awareness of TB. Thus, it is not only the lower class of uneducated people but educated class of people as well who need awareness on TB. Similar comments from TB specialists and doctors indicate the need to create TB awareness among general public to win in the fight against TB.

3.9 General Civic Literacy

Civic literacy is when people are aware of public issues and are involved in the decision-making process (Zarcadoolas et al., 2005). The categories within civic literacy include media literacy skills, knowledge of civic and governmental processes, and awareness that individual health decisions can impact public health. The Indian health authorities find the lack of civic literacy as a major barrier in controlling the TB situation in India. One of the leading TB specialists in the private hospital expressed her concern commenting: *"Because the numbers are too big, who knows. They are going out coughing to patients"* (M3). One of the senior officials from the municipal corporation also expressed their concern on the lack of civic literacy and highlighted the steps taken by government in curbing the spread of TB by spreading civic literacy among the general masses: *"Auto-taxis have*

these slogans ‘*Spitting spreads TB*’ (NM2). These comments indicate the need to educate the general public to improve their civic literacy so that they can live lives of responsible citizens and curb the spread of infection.

Table 6

Selected Illustrative Quotes for the Sub-themes of Myths and TB stigma, TB awareness and General civic literacy

Sub-Themes	Comments
<i>Myths and TB Stigma</i>	...what exactly happens with the social stigma is that the infectious nature [of TB] itself makes everyone go away from the patient, whether they are really infectious or not.
<i>TB Awareness</i>	Most successful campaigns are community based, street plays or door to door.
<i>General Civic Literacy</i>	They wouldn’t be taking care. Nobody, at that level, if somebody is at that level, that person will not have this much conscience that he thinks, like I should not give it to anybody else .

4. Discussion

The three broad themes emerging from grouping the sub-themes are discussed in the following three sections.

4.1 Theme 1: Alert

The three sub-themes Adherence, Ease of Administration and Side-effects indicated the need for Alert to manage and control the TB situation in India and the world. Low adherence to prescribed medical regimens is a ubiquitous problem. Lack of patient adherence to prescribed medications poses a serious challenge to the global healthcare community. ALERT will help monitor TB patients to complete their drug treatment regime through medication reminders. It describes issues related to the adherence of medication regimes for TB patients.

TB treatment approaches fall into two categories. One is self-administered treatment (SAT) where the patient takes responsibility in adhering to the TB treatment, and the other is directly observed treatment (DOT) where a responsible person (health professional or lay person) is in charge of making sure the patient adheres to the full treatment course on time (Story & Cocksedge, 2012). DOT ensures that patients are taking their medication faithfully, which will lead to a better chance of a higher percentage cure rate and reduce any drug resistance that may happen. Although DOT (implemented by governments and endorsed by the World Health Organization) has helped to dramatically improve TB control around the world, it is insufficient or inaccessible for thousands of patients. Some respondents commented that many patients seek treatment in private hospitals which do not follow DOTS. Further, the doctor expressing her concern over TB treatment in India noted “*the issue is that in Mumbai the private clinics work without **close monitoring from their doctor***” (M3). As seen in Table 3, 58% of the quotes pertained to the need for Alert and its sub-themes of Adherence, Ease of Administration and Side-effects. A few respondents also highlighted the improper protocol by private doctors (M3, M8, M9). All the respondents felt the need for timely alerts and reminders for a disease like TB. One of the interview respondents commented “*If we can pick two to three challenges, what are the challenges in controlling TB? So one challenge is that long duration, **patients default**, they don’t get cured rather developed resistance*” (M2).

Hence, Alert emerged as an important theme in tackling with the TB situation in India and the world. Alert system with constant reminders to take medication on time can help patients adhere to the medication regime. In addition, the alert system can suggest innovative ways for TB patients who need to complete their DOTS medication without travelling from their villages to the DOTS centre in the cities. This would facilitate medication administration by the health authorities. In addition, Alert system can alert the patients on the side-effects of the

TB medication and encourage them to complete their treatment without defaulting. Thus Alert system encompasses three sub-themes of 'Adherence', 'Ease of Administration' and 'Side-effects'.

4.2 Theme 2: Care

Healthcare facilities, emotional impact and social support were grouped into Care as a critical factor in controlling and managing the TB situation in India and the world. Care system will help patients to go through treatment with a positive outlook by connecting them with support groups and recovered patients and also supports active monitoring of possible exposure of TB to families, friends, or neighbours. In addition, it will allow messages from personal doctors and healthcare authorities to encourage patients to complete their treatment regimes. Several patient-related factors have been cited for poor medication adherence by patients such as poor knowledge of the disease, inadequate perceptions of the need for treatment and forgetfulness (WHO, 2003). Improving adherence to long-term regimens requires care and social support from family and friends. It is common that some patients get depressed and need words of hope and encouragement from other people for their mental and social well-being. Thus, taking care of healthcare facilities and providing emotional and social support to distressed patients can help patients adhere to the medication regimes and thus control and manage the spread of this deadly disease.

Past studies have reported cynical and uncaring attitudes of the healthcare providers as a major barrier for effective medication adherence (Khan et al., 2005). Thus, non-adherence in patients is not only due to personal factors like forgetfulness and inadequate knowledge of disease but also due to social factors like lack of effective support networks for patients (Capegemini, 2011). When people have more social contact and support, they are mentally happier and healthier (Cohen & Wills, 1985). Almost 28% responses centered on the need for care in medical systems. The TB survivor commented on the issue of care: *"Doctors didn't actually play much role in dealing with my depression. They can say that 'Don't worry, it'll go away with time'"* (NM3). Another respondent who is a private doctor in Mumbai stated: *"Doctors were interested in their own timings and payments; they did not really have a **human approach** to the patients"* (M11). Thus, care emerged as an important factor in winning against this deadly disease of TB.

4.3 Theme 3: Education

TB myths and stigma, awareness and civic literacy were all related to the lack of education amongst the general public. Though members of the general public were not interviewed for this study, however, our interviewees are medical and non-medical professionals who deal with TB patients and general public on a regular basis. Their comments and opinions were critical as they highlighted the key shortcomings which they face in controlling and managing the spread of TB. The need for educating the general public emerged as a key factor in controlling the TB situation in India and other countries. Hence, the three sub-themes were grouped under the main theme of Education. EDUCATION will inculcate civic literacy in general public. If a TB Education system is developed, it will help disseminate timely information about TB-prone areas and outbreaks to general public, hospitals and relevant health authorities. And also reduce myths and stigma associated with TB.

4.4 Recommendations

As described above, the identified sub-themes were then grouped under three broad themes as illustrated in Figure 1 to understand the key factors in controlling and managing TB in India.

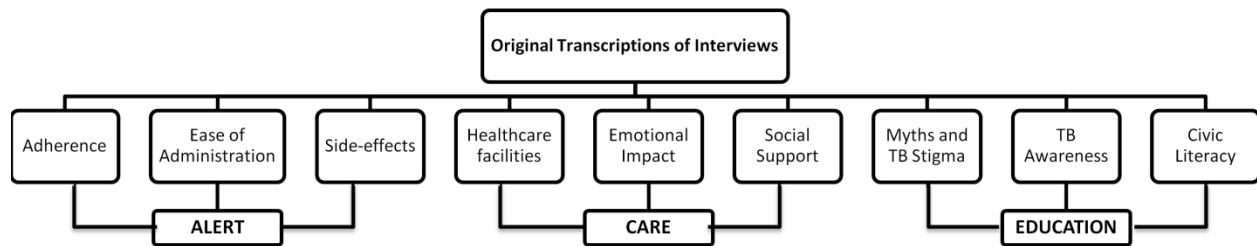


Figure 1

Main Themes and sub-themes identified through Interviews to control TB situation in India

An improvement in the care of TB patients requires not only new technologies and tools that will address the current TB challenges of controlling and managing its spread but also an expansion of existing tools concurrently. We hope that new technologies will be able to detect and manage more number of cases and thus control the spread of TB. Our study distilled three key factors to manage and control the spread of TB as Alert, Care and Education. We propose the development of technologies which can effectively provide Alert, Care and Education to TB community and general public and thus preventing the spread of this deadly disease.

Discussing ALERT as the first key factor, healthcare providers have been experimenting with several technologies that can help people overcome patient-related factors such as forgetfulness and follow their medicine regime effectively. A few such clinical innovations include iPhone apps for medication adherence such as The Pill Phone, myPillBox and even secure text messaging (Dolan, 2009). However, these technologies deal with alleviating the patient-related causes of non-adherence of medication regime.

In addition to alleviating the patient-related causes of forgetfulness and lack of knowledge for medication adherence, it is of prime importance to offer social support and care to the patients through their social networks of family and friends for effective treatment and drug compliance. This shows the significance of the second key factor 'Care' emerging from the study. Along with the sharing of information through the Internet and the growth of social media there are key trends that should be tapped upon for the treatment of patients and enhanced 'patient-care'. Social media is defined as digital content and network-based interactions developed and maintained by and between people (Cohen 2011). We believe that social media is expected to dramatically impact the patient behaviours to adhere to the medication regimes due to its ability to offer social support networks and CARE to the patients (Capegemini, 2011).

Furthermore, due to the strong reach of social media to the general public, it is expected to improve the awareness of the general public and educate them about TB. Thus, social media could be harnessed help control TB situation through the third key factor identified in the study as EDUCATION as well. Social media has revolutionized the manner in which information is shared and accessed and is expected to help patients achieve mental and social well-being due to the social support it offers. Thus, social media provide opportunities for large-scale information-gathering from people to successfully control TB, it is important to ensure that all cases with TB are diagnosed early and the patients undergo complete treatment until fully cured so as to curb community transmission at the earliest opportunity.

4.5 Implications

The implications of this study are four-fold. First, this study explores the major concerns of the TB community from the people actively involved in management and control of the disease, hence their opinions on Alert, Care

and Education are relevant to the country-level and health-level health policies to effectively manage and control this disease.

Second, our study proposes the use of technologies and social media to tackle the TB situation in India and other countries. The social media technologies reach the general public and thus help control the TB situation in an inexpensive manner.

Third, our study stresses on the need for care of the mental and social well-being of the TB patients. There have been technologies which have tried to create reminder systems for the patients to help them adhere to their medication regime. However, we believe, that by the way of implementing the Care component in the system which would give messages of hope and encouragement to the patients, in addition to reminder system, the patients can complete their medication regime successfully.

Fourth, the dramatic insurgence of social media seems to be a promising tool to create awareness and educate the general public as well as TB community on how to manage and control the TB situation.

4.6 Limitations

One major limitation of this study was that there were more medical representatives in the sample than non-medical persons. Therefore the issues and themes discussed might have been skewed more towards the opinions and concerns of the medical profession than the public community. However, we believe that since the doctors and other medical professionals are actively involved with the TB patients and interact with the TB patients and caregivers, their opinions can benefit the TB community the most.

Also, due to this study's qualitative and probing nature. Occasionally the interviewees would become overly-passionate about what they are saying and tend to go off-tangent often. Sticking to the interview questions became difficult and thus there were many parts of the transcripts that were unusable.

5. Conclusion

Our study indicates that despite the ability to cure TB through medication, there still remains a huge challenge for the TB community to control this burgeoning global problem. Since most of the current treatment therapy involves physical well-being through case-management and preventive or curative mechanisms like drugs, the impact of mental and social well-being has been ignored in past research. This research identifies factors significant for the mental and social well-being of the patients which may help improve the TB situation in India and the world.

On-going research involves the investigation of social media technologies which can build these non-medication aspects of TB management for effective TB treatment. With high ownership of mobile phones in India and insurgence of social media applications, we propose the development of social media technologies specific to various Indian communities that foster and empower peoples' civic health literacy and the ability to make decisions with increased awareness of how a personal decision may contribute to a whole. As TB is a social disease where socioeconomic factors are very much involved in its transmission and treatment (Paluzzi, 2004), intelligent systems with the ability to gather information from the public, sense and reach out to the social networks of TB contacts (patients; caregivers; and health workers) would help public health authorities in their policy-making and health action decisions. On-going research investigates integrating factors of civic health literacy into the development of sustainable healthcare technologies for the treatment of TB in education.

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