

A Rapid Assessment of GENDER AND TUBERCULOSIS in India (2018)

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Foreword

2018 has been a milestone year for the TB response in India. In March 2018, the Honourable Prime Minister reiterated India's commitment to eliminate TB by 2025. India's new National Strategic Plan for 2017-25 reflects this commitment and lays out an ambitious road-map for the country to implement a comprehensive response to TB.

I am pleased that India is one of the first countries to utilize the Communities, Rights and Gender Tools developed by the Stop TB Partnership. This is in keeping with our efforts to engage civil society and affected communities in the TB response through the creation of National, State and District TB Forums and involving TB Champions or Kshay Veers at various levels. An increased focus on the areas addressed by the CRG tools has the potential to not just increase case detection and treatment outcomes but also improve the overall quality of care.

We know that TB affects an estimated three million women every year and remains among the top five leading causes of death among adult women globally. Although more men are affected by TB, women experience the disease differently, and gender disparities play a significant role in how men and women access healthcare in the public and private sectors. Women also experience the impact of stigma disproportionately.

The Gender Assessment of TB in India reveals the many gendered aspects of the disease including the impact of gender on access to services, delays in diagnosis and treatment adherence. The report also highlights issues linked to TB and pregnancy as well as the gendered nature of nutrition in India.

On behalf of the Central TB Division, I congratulate REACH on the publication of this document and look forward to continuing our work with the TB community for a gender-sensitive response to TB.



Message from Stop TB Partnership

The tuberculosis (TB) response needs a paradigm shift – to become people and community centered, gender sensitive and human rights based. There is a need for country specific data and strategic information on key, vulnerable and marginalized populations. There is a need to facilitate an enabling environment to effective prevention, diagnosis, treatment and care – which requires legal and gender related barriers to be analyzed, articulated and alleviated.

The Stop TB Partnership CRG Assessments are the tool for National TB Programmes to better understand and reach their epidemics. With TB being the leading cause of infectious disease deaths globally, and with over 10 million people developing TB each year, this disease continues to be a public health threat and a real major problem in the world. The Stop TB Partnership's Global Plan to End TB and the World Health Organization (WHO) End TB Strategy link targets to the Sustainable Development Goals (SDGs) and serve as blueprints for countries to reduce the number of TB deaths by 95% by 2030 and cut new cases by 90% between 2015 and 2035 with a focus on reaching key and vulnerable populations. The Strategy and the Plan outline areas for meeting the targets in which addressing gender and human rights barriers and ensuring community and people centered approaches are central.

Ending the TB epidemic requires advocacy to achieve highly-committed leadership and well-coordinated and innovative collaborations between the government sector (inclusive of Community Health Worker programs), people affected by TB and civil society. Elevated commitment to ending TB begins with understanding human rights and gender-related barriers to accessing TB services, including TB-related stigma and discrimination. It has been widely proven that TB disproportionately affects the most economically disadvantaged communities. Equally, rights issues that affect TB prevention, treatment and care TB are deeply rooted in poverty. Poverty and low socioeconomic status as well as legal, structural and social barriers prevent universal access to quality TB prevention, diagnosis, treatment and care.

In order to advance a rights-based approach to TB prevention, care and support, the Stop TB Partnership developed tools to assess legal environments, gender and key population data, which have been rolled-out in thirteen countries. The findings and implications from these assessments will help governments make more effective TB responses and policy decisions as they gain new insights into their TB epidemic and draw out policy and program implications. This provides a strong basis for tailoring national TB responses carefully to the country's epidemic – the starting point for ending discriminatory practices and improving respect for fundamental human rights for all to access quality TB prevention, treatment, care and support services. The development of these tools could not be more timely, and the implementation of these tools must be a priority of all TB programmes.



RESOURCE GROUP FOR EDUCATION AND ADVOCACY FOR COMMUNITY HEALTH

Preface

The TB response is continually evolving. In the last few years, we've seen new diagnostic tools, new algorithms to reduce delays in diagnosis, breakthrough research on latent TB and TB infection, new social welfare schemes to support those affected by TB and even two new drugs to treat TB. We've also seen, for the first time, the language of rights and equity enter the TB discourse.

Today, I am delighted to see that globally and in India, we are talking about adopting a rights-based approach to TB. Since REACH's inception almost two decades ago, we have tried to adopt a patient-centric approach in our response to TB. Over the last 19 years, working closely with those affected by TB and their families, we have witnessed and tried to address the many vulnerabilities that impact their health. We have been part of nascent discussions on issues affecting treatment literacy and the rights of affected communities.

I am grateful that REACH has had the opportunity to be part of this important conversation in India, by undertaking the Communities, Rights and Gender Assessments. The CRG assessments has given us an opportunity to study these vulnerabilities through a more structured framework and to contribute to the discussions on data collection and measurement. It has been a steep learning curve for us and allowed us to reflect on our own work, challenge ourselves and push ourselves to do better. I am thankful to the Stop TB Partnership for giving us this opportunity and for the leadership at the Central TB Division and the Ministry of Health and Family Welfare for welcoming these conversations.

I hope that the TB community in India will find the findings of these assessments useful and interesting, and that we can work together to translate the recommendations into concrete actions that will strengthen the TB response in this country. We look forward to your feedback and continued partnership.

Nalini Krishnan

Dr. Nalini Krishnan

Director, REACH

Acknowledgements

Report authored by Amita Pitre

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Acknowledgements from the Author

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I would also like to acknowledge and thank the Stop TB Partnership for providing the Community Rights and Gender Tools which served as the guiding framework for the Rapid Assessment. I join REACH in thanking the Stop TB Partnership for financially supporting this study.

Thanks also to the REACH (Resource Group for Education and Advocacy for Community Health) team - especially Dr Ramya Ananthakrishnan, Executive Director, and Anupama Srinivasan, Deputy Project Director, TB Call to Action, REACH, who conceptualised the Rapid Assessment and facilitated the process at every step. They also organised the various interviews required and gave me a free hand in writing the report. I also received valuable feedback on the first draft of the report. Thank you to

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Glossary

ACF	Active Case Finding
ASHA	Accredited Social Health Activist
CB-NAAT	Cartridge Based Nucleic Acid Amplification Test
CDR	Case Detection Rate
DBT	Direct Benefit Transfer
DMC	Designated Microscopy Center
DOTS	Directly Observed Treatment Short Course
DTC	District Tuberculosis Center
DTO	District TB Officer
EPTB	Extra Pulmonary TB
FNAC	Fine Needle Aspiration Cytology
PWID/ PUD IDU	PWID People who inject drugs or PUD People who use drugs. Formerly referred to as Intravenous Drug Users
LTBI	Latent TB Infection
MDR	Multi-drug-resistant TB
MO	Medical Officer
NACP	National AIDS Control Programme
NFHS-2	National Family Health Survey – 2
NHM	National Health Mission
NSP	New Sputum Positive
NSN	New Sputum Negative
NEP	New Extra Pulmonary
OBC	Other Backward Classes
OTC	Over-the-counter
PAF	Population Attribution Fraction

PDS	Public Distribution System
PHC	Primary Health Center
PPM	Public-private Partnership Management
RNTCP	Revised National Tuberculosis Control Program
SC	Scheduled Castes
ST	Scheduled Tribes
STO	State TB Officer
STS	Senior Treatment Supervisors
TB	Tuberculosis
TISS	Tata Institute of Social Sciences
WHO	World Health Organization
XDR	Extremely drug-resistant TB

Communities, Rights and Gender Tools

The Communities, Rights and Gender (CRG) Tools were developed by the Stop TB Partnership in consultation with various partner and donor organisations. The CRG tools provide a guiding framework for undertaking rapid assessments of three different dimensions of our response to TB – gender; key and priority populations; and law and human rights. An increased focus on these aspects has the potential to not just increase case detection and improve treatment outcomes but also improve the overall quality of care available to those affected by TB.

The three tools that form part of the CRG initiative are:

1. Data for Action Framework for Key Populations, which focuses on measuring the burden of TB among key, vulnerable and priority populations in the country
2. Gender Assessment tool for national TB response, which applies a gender lens to TB in the country and assess ways in which gender affects and interacts with TB
3. Legal Environment Assessment Tool that looks to understand and examine the legal environment for TB through a rights-based framework

In 2017, the Stop TB Partnership hosted a workshop for partners from six countries including India, which would be the first to utilize the CRG tools.

India's National Strategic Plan (NSP) for 2017-25, recently formulated by the Ministry of Health and Family Welfare, Government of India, lays out an ambitious road-map for the country to achieve TB elimination by 2025. The new NSP is a sign of renewed political commitment to the fight against TB in India and this is therefore an opportune time to introduce the Communities, Rights and Gender Tools. Each of these three tools provide an opportunity to reflect on a person-centred and rights based approach to TB.

CRG Assessments Timeline in India

July 2017:	REACH Participation in CRG Workshop in Thailand
Sep – Oct 2017:	Preparatory discussions for rollout of CRG tools in India
October 2017:	Constitution of Expert Advisory Group
November 2017:	Consultative Meeting of Expert Advisory Group
December – March 2018:	Assessments underway
April – August 2018:	Feedback and revision of assessment reports
September 2018:	Final consultative meeting and publication of assessment reports

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Executive Summary

Women and girls account for over a million cases of Tuberculosis in India each year. In 2016, about 40% of the 2.79 million new cases of TB in India were among women. TB is also the fifth leading cause of death among women in the country, ahead of maternal deaths.

India is the highest contributor of new TB cases, TB deaths and Multi-Drug Resistant (MDR) TB cases to the global TB burden each year and the country has accorded top priority to eliminating TB. Evidence from elsewhere shows that gender is a significant influencer of the distribution and impact of TB in communities. A gendered approach to TB prevention and care in India's National Strategic Plan for TB Control (2017-2025) which may be implemented by the Revised National Tuberculosis Control Program (RNTCP) is a felt need. However, a gender analysis of the epidemic is yet to be incorporated into India's response to TB.

This first rapid assessment of gender and TB in India -- which includes an extensive review of literature primarily from India, as well as 70 interviews with various stakeholders of the RNTCP -- shows that TB affects different genders differently. Gender affects susceptibility to TB, its diagnosis, access to treatment, adherence to treatment, the availability of supportive care and treatment outcomes. The findings raise significant concerns and queries that merit further investigation and show that the application of a gender lens can lead strengthen strategies towards eliminating TB in India.

Key Findings

1. TB data collection

A clearer epidemiological picture of TB in India stratified by age and sex is needed and may be partly achieved by improving the notification of TB cases from the private sector. Age and sex-disaggregated TB data from public and private health sectors needs to be collected each year to obtain time-trends in TB epidemiology, and such data needs to continually inform program strategies for men, women and transgender people at the national, state and district levels.

2. TB diagnosis

There is a growing body of evidence that women may be diagnosed late or not diagnosed at all; that TB presents differently among women, making diagnosis among them more difficult; that there are various socio-cultural barriers which hamper women's access to diagnostic facilities; that

women may be at added risk of the disease in certain stages of their lives and on account of their role as caregivers in the family. The RNTCP has largely concentrated on identifying and treating the infectious form of TB namely sputum positive pulmonary TB and the diagnosis of Sputum negative and Extra-Pulmonary cases of TB (EPTB) is often missed. In recent times, more girls and women are being diagnosed with TB due to increased access to healthcare and the deployment of newer diagnostic technologies like CBNAAT. TB among children remains under-diagnosed again due to the different presentation of TB in this age group and the challenges in diagnosis. Detecting all forms of TB, particularly among women, is necessary to progress towards the targets of the End TB Strategy.

3.Risk factors for TB

Malnutrition substantially increases risk of TB disease in women and results in poorer outcomes mostly related to poorer adherence to treatment. Over half of all women in the country are anaemic and one in five are underweight. Recognizing that adherence can be improved by nutritional support, the National Health Mission has approved supplementary nutrition for those affected by TB.

Diabetes, a significant risk factor for developing TB disease affects about 6% of women in India. For most women, the first indication that they may develop diabetes in later life is when they are diagnosed with gestational diabetes. A window of opportunity exists in the national program to counsel and track such women.

About 40% of those with HIV in India are women and many of them go on to develop TB. Cross referrals between the National AIDS Control Program and the RNTCP need to be strengthened to ensure care for women who have both HIV and TB.

Men face a higher risk of developing TB disease than women due to risk factors such as smoking and intravenous drug use that are more common among males. Women are exposed to high levels of indoor pollution from wood-stoves and women who smoke, a good proportion of whom are in the North Eastern states, also require awareness and counselling. Alcohol dependence is a leading cause of non-adherence to TB treatment among men and is associated with poor treatment outcomes. The existing monitoring capacity of RNTCP needs to be strengthened to support and ensure treatment among TB patients – both men and women - who are alcohol or drug dependent.

4.Social determinants of TB

Women delay seeking care for ailments because of a high burden of household work combined with the deprivation of health literacy, mobility, access to resources and decision-making powers. We found a high level of stigma associated with a TB diagnosis among both unmarried and married women. Unmarried women were anxious that they might not get married if they had TB. Consequently, families hid the diagnosis, marrying off the women and later sending them to a relative's home to begin treatment. The women were forced to continue TB treatment clandestinely after marriage. For already married women, the fear of being divorced or being sent back to their natal family is an obstacle to accepting TB diagnosis and treatment. The constant struggle and priority for women and

their families is to get married and stay married rather than get diagnosed, start TB treatment and adhere to it until cured. These factors considerably influence TB case detection and adherence to treatment, and need to be addressed.

In contrast, men suffered less from TB related stigma and discrimination. Men diagnosed with TB are generally accepted and cared for by their families, especially their wives, even in the face of misconceptions linked to TB disease. Women, on the other hand, often face harassment at home, are begrudged nutritious food and may be sent to the natal home to recover from the illness and may, therefore, face worse treatment outcomes.

Men often delay taking time away from work to seek health care for fear of losing income. Some feel a sense of shame for not being able to fulfil the traditional role of the provider for the family when they are too sick to work. Men also face frequent disruptions in treatment because of having to migrate in search of work.

Overall, there is better adherence to TB treatment, better overall outcomes and lower incidence of MDR-TB among women. However, men face challenges in these domains. More research is required to understand both these phenomena.

5. Marginalized minorities

Transgender people and sex-workers are examples of stigmatized and marginalised minorities who need to be incorporated into the public health system. They are habitually viewed as stakeholders in HIV prevention and care, and TB among these communities is diagnosed and treated almost entirely in the narrow context of HIV-TB co-infection. Given that these groups face barriers in accessing health care generally, effort needs to be taken to ensure the timely detection and treatment of TB among them - and in a way that respects their right to dignity.

6. Tribal communities

Reaching health care facilities for TB diagnosis and treatment is challenging for tribal communities, particularly in hilly terrains, due to inadequate means of transportation. Some District Tuberculosis Centers (DTCs) are located far from the communities; free X-rays are sometimes unavailable at the sub-district level. Inadequate facilities to collect and transport sputum - partly due to the erratic availability of lab technicians - are specific concerns for the RNTCP in tribal areas. These barriers together with widespread malnutrition affect both women and men and have resulted in a high prevalence of TB combined with lower case detection rates in many tribal areas. Scheduled Tribe (ST) women are the worst affected.

7. Health systems

The lack of a patient-centric orientation, inadequate facilities and staff shortages pose stiff challenges to the functioning of the health system. Chief among these is the lack of women staff, evidenced by the huge number of unfilled positions of field supervisory staff (STS, DOTS and DOTS Plus supervisors)

who have substantial interactions with TB patients. The scarcity of women-friendly services also feeds the misconception that TB is a ‘man’s’ disease. ASHAs from the National Health Mission are increasingly taking on the role of treatment supporters providers, but there is also a need for male field-based staff and volunteers to provide DOTS. The National Health Mission supervisory staff are mostly male and the field staff, namely ASHAs mostly female, a model that does not bode well for progress towards gender-equal services.

Community members experience several barriers to accessing care. These include mandatory daily visits to the DTC for DOTS, their fears of being stigmatized by neighbours following home visits by RNTCP staff, lack of information about TB, inadequate or absent counselling, confidentiality and the poor attitudes of health staff. Some of these issues are attributable to the fact that the RNTCP has yet to recruit counsellors and the existing staff handle a very high workload. Community members also said that multiple visits were required before TB diagnosis was confirmed, that they faced difficulties in getting appropriate referrals and were rarely guided in negotiating care in medical college hospitals. These findings are complemented by literature showing that TB diagnosis is often delayed from 1 to 2 months. During this phase the patient continues to be symptomatic and might transmit TB. The RNTCP has a stated goal of integrating with the National Health Mission and much needs to be done in this direction to deliver significant results.

While the State Tuberculosis Officers (STOs), District Tuberculosis Officers (DTOs) and City Tuberculosis Officers (CTOs) are highly motivated thanks to high-level political commitment to the RNTCP, they remain poorly paid and shoulder multiple responsibilities in addition to administering TB services. A similar factor which cannot but affect services, is that almost all RNTCP staff other than STOs, DTOs and CTOs, are contract employees who are poorly paid compared to other health system employees.

The impact of existing gendered interventions

MDR-TB counsellors employed on a project basis by TISS (Tata Institute of Social Sciences) and MSF (Medecins Sans Frontieres) have helped women patients deal with adverse drug reactions and navigate personal problems of various kinds. Such counsellors are required in the RNTCP to support Drug-Susceptible Tuberculosis (DST) and DR-TB cases because both face complex challenges with adherence and side effects. Other examples of model projects suitable for scale-up are the provision of nutritional support to TB patients by REACH in Chennai, the deployment of X-ray equipped mobile vans in tribal areas and transit homes such as the Sahara Aalhad home in Pune for near-destitute TB and HIV-TB patients. Gender sensitive schemes outside the health sector such as Ujwala have helped reduce women’s risk of TB by reducing indoor pollution.

Recommendations for the RNTCP

We recommend that RNTCP develop and adopt a Gender and TB policy and inculcate a gendered approach to TB prevention and care which would include:

1. Developing a better understanding of the age and sex disaggregated epidemiological picture of TB in India
2. Developing a patient-centric and gender-sensitive approach to TB
3. Developing a gender-response Operations and Implementation Research Agenda for the RNTCP program as well as for those Private Health Services that provide TB care

1. **Develop a better understanding of the age and sex disaggregated epidemiological picture of TB in India:**

- Publish age and sex disaggregated RNTCP data at national, state and districts levels. This is achievable with NIKSHAY (a web based notification system for TB) data.
- Build a knowledge base of epidemiology, presentation and outcomes of TB among women and children, so that TB among them may be appropriately addressed. TB surveys may be gender-sensitively designed to gather such information.
- Encourage and incentivise research to cover sputum negative forms of pulmonary TB as well as extra-pulmonary TB, with the findings analysed by age and sex.
- Analyse historical age and sex disaggregated RNTCP data to understand the time-trends in epidemiology.
- Publish age and sex-disaggregated data for Active Case Finding (ACF) measures.
- Institute a 'TB in Pregnancy' register to document, monitor and track outcomes for TB and HIV-TB among pregnant and post-partum women.

2. **Develop a patient-centric and gender sensitive approach to TB**

Increase awareness about Tuberculosis

- Conduct awareness campaigns about pulmonary and extra-pulmonary TB, signs and symptoms, modes of transmission, curability and the importance of early diagnosis and complete treatment.
- Adopt Behaviour Change Communication strategies that specifically aim to correct misconceptions about TB and its transmission and curability to help remove the TB stigma and discrimination especially among women.
- Increase awareness of the high susceptibility to TB for smokers, drug and alcohol dependent persons, pregnant and post-partum women, and underweight and undernourished persons.

Improve responsiveness of health services

- Increase awareness about the gender dimensions of TB among medical professionals and the staff of the RNTCP.
- Build capacity (knowledge, attitudes and practices) of all RNTCP staff to provide respectful, patient friendly, gender sensitive and gender responsive services.
- Improve measures for confidentiality and privacy in the health system.
- Improve measures for building confidence of health staff and foster respect for all patients including transgender persons, sex workers, those dependent on drugs and alcohol and any other marginalized groups.
- Track the pathways of patients' access to diagnosis and treatment as part of regular monitoring. This would help curtail unnecessary visits and improve the efficiency of access to health services.
- Recognise smokers and persons dependent on alcohol and drugs, as key populations for TB and devise supportive measures to not only create awareness about the risks of TB within this group but also to enable them to access diagnoses, comply with treatment and undergo de-addiction.
- Recognise pregnant and post-partum women and undernourished persons as key population at risk of TB.
- Prioritise transgender persons and sex-workers as those at risk of TB beyond their risk for HIV-TB. Enlist the support of TB Champions and HIV-TB Champions from within the community, TB activists and NGOs to reach them.
- Consider supplementary nutrition and/or added supplies (ration) through the Public Distribution Services rather than through the RNTCP, not only for TB patients but also for their families.
- Advocate for compensation of the wages that TB patients lose while on leave during the intensive phase of treatment.

Increase support for TB patients closer to the community

- Build support groups for TB patients, particularly women with TB, and those dependent on alcohol or drugs with the help of NGOs and TB activists.
- Honour TB champions and TB activists at the community level and call for participatory meetings with TB survivors to understand how to make the program gender and patient sensitive to reduce TB stigma.
- Provide budgets for participation of voluntary organisations in outreach and support for TB patients. Voluntary organisations are adept at tailoring their services for the needs and rights of local communities as also for awareness generation.

Improve staffing of RNTCP to effectively respond to TB

- Recruit more women and transgender people to make the RNTCP an equal opportunities employer
- Engage male and transgender DOTS providers at the ground level in cities and villages, alongside women providers.
- Ensure provision for counsellors and psychosocial support for all TB patients including DS-TB.

Improve reach of the health system and facilities in the health system

- Employ active measures to reach primary health services to people and through these increase case detection of TB while ensuring the confidentiality and privacy of the suspected patients. Dedicate an adequate budget for the same.
- Review the current format of Active Case Finding (ACF). Also conduct regular health camps for general ailments close to communities, especially for communities with poor access- either financial or physical or social, as a mechanism to reach patients.
- Allocate a budget for involving NGOs and civil society to sustain awareness of TB in the community and to create TB champions in the community.
- Provide budgets for mobile medical clinics/vans and health camps in tribal areas including hard-to-reach rural areas of all districts.
- Provide free X-ray facilities (including mobile x-ray units in difficult areas) at Primary Health Centres, especially in tribal areas.
- Increase access to CBNAAT diagnostic machines.

3. Develop a patient-centric, gender sensitive operations and intervention research agenda to understand...

- Patient pathways to health services, access to diagnosis and care and delays in care by age and gender
- Quality of care and perceptions of quality of care given by the RNTCP program and the private sector
- Difficulties faced by patients in accessing care, continuity of care, and collect feedback on experiences with the health system
- Reasons for loss to follow up, discontinuation of treatment, relapse and poor outcomes
- Experiences of women, men, transgender persons, sex workers, drug users, migrants, smokers and those who are alcohol dependent with the health system

- Reasons to opt for public sector or private sector or AYUSH providers or informal care
- Research studies to understand the comparative impact of supplementary nutrition in various forms (eg food supplies, conditional cash transfers etc) on TB treatment and outcome

Recommendations for the Health System beyond the RNTCP

- Improve the integration of the RNTCP with the National Health Mission and Reproductive and Child Health programme, especially the Maternal Health Services.
- Increase health budgets and strengthen the health system overall, especially in tribal areas.
- Incentivise medical officers and staff to work in a sustained fashion in tribal and difficult-to-reach areas; recruit local persons as far as possible.
- Tackle under-nutrition at the population and family level.

Recommendations for Civil Society and Voluntary Organisations

- Generate awareness about TB, especially among the most marginalised communities.
- Undertake innovations in program strategies, for instance, to increase adherence to treatment and reduce TB related within the community. Such innovations may be undertaken in collaboration with the RNTCP and the successful innovations upscaled.
- Foster community based support groups for TB patients, especially women patients, those dependent on alcohol, drugs or tobacco, thus also nurturing TB champions in the community who may include TB survivors.
- Support transgenders, sex-workers and other gender and sexuality minorities in accessing care and help them become active advocates for their cause.
- Carry out studies on socio-cultural and gender aspects of Tuberculosis to understand how best TB can be addressed in the community. RNTCP would be able to take the learnings to improve programme delivery.

Recommendations for the ICMR and the ICSSR

- Institute guidelines for gender sensitive and gender responsive research studies which will ensure gender equality in research in following ways
 - o Choice of research topics needs to address existing gaps in knowledge also from a gender and socio-cultural perspective.
 - o Quantitative studies need to be designed to collect and analyse data in an age and sex disaggregated manner.

- o Adopt a policy of presumed inclusion of pregnant and post-partum women in clinical trials and document with reasons where exceptions are required. Also include them in epidemiological and operations research.
 - o Ensure the informed participation of women, men, transgender persons, sex workers and children and include their perspectives in research studies.
- Incentivise and encourage research where there are gaps in knowledge about epidemiology, presentation, access to health care and other aspects of illnesses especially for women, children, transgender persons, sexual minorities and others marginalised on the basis of their sexuality such as sex workers
- Ensure that constituencies such as pregnant and lactating women and women patients are included in all forms of research including clinical trials where no specific harm is expected on account of the research, so safety, tolerability and response to existing and new drugs is known, knowledge about side effects, difficulties with adherence and experiences with the health system are garnered.

I. Introduction

1.1 Background and Concepts

Women account for three million of the estimated seven million people affected by Tuberculosis (TB) every year¹. TB remains among the top five leading causes of death among adult women globally. Although more men are affected by TB, women experience the disease differently, and gender disparities play a significant role in how men and women access healthcare in the public and private sectors. Even so, little is known globally and in India about the different biological and social factors that affect the incidence, disease manifestation, progression and health seeking behavior of persons suffering from TB, their response to treatment and treatment outcomes.

In India, the incidence of TB in 2016 was 2.76 million, with women accounting for 40% of the new cases². The male to female ratio for TB stood between 1.07 to 2.25 in 2016. There is evidence of male to female ratios of persons suffering from TB varying between 30 to 40% from across the world³. This suggests that the differences in incidence of TB may be due to more than biological differences, and that significant social factors such as exposure to the infection and access to health care are at play too. The substantial gap in TB incidence between men and women could also be due to under-reporting of the disease among women. Qualitative studies and interactions with program managers and patient advocates brought up a range of issues including stigma, barriers to access health services and neglect of the disease among populations who do not conform to society's gender norms.

1.1 The Gender Assessment Tool by The Stop TB Partnership and UNAIDS

This assessment uses the guiding framework provided by UNAIDS and the Stop TB Partnership for a rapid gender assessment of the TB Epidemic and response in India⁴. The tool seeks to move the HIV and TB response along the continuum of gender-blind to gender-sensitive, and ultimately to gender transformative.

The Concept of Gender

Indian society, like most, is a deeply patriarchal society. Patriarchy literally means 'rule of the father'.

1 TB in India Annual Report 2017

2 TB in India Annual Report 2017

3 Weiss, Auer et al, 2006

4 "Gender_Assessment_Tool_TB_HIV_UNAIDS_FINAL_2016 ENG.Pdf"

It not only privileges men over women and other genders, but it institutes and institutionalizes a variety of hierarchies in society. Men, women and other genders are not homogenous groups, but divided across structures of class, caste, ethnicity, religion, sexuality and gender. Access to health care differs by rural and urban locations and this adds another layer to the hierarchy. Understanding the impact of gender on health and more specifically on TB calls for a nuanced understanding of gender as embedded in other social orders. Society harnesses the concept of gender as it does other rigid codes prescribed by caste and religion to maintain these hierarchies.

Gender and sex are two distinct concepts. Sex indicates a biological category (male, female or intersex) based on characteristics such as external and internal genitalia, the chromosomal makeup (22 XY-male and 22 XX-female) of the person and levels of male and female hormones in the body. Gender, on the other hand, is a social construct and defined as “a socially constructed set of norms, roles, behaviors, activities and attributes that a given society considers appropriate for women and men, with the inclusion of people who identify themselves as transgender...Gender based prejudice includes any kind of stigma, discrimination, or violence against somebody because of their gender, gender identity or their sexual orientation.”⁵

Whether babies are born as male, female or intersex, genderization shapes them to act in conventionally masculine or feminine ways. Patriarchal societies are organized along lines of gender, where society prescribes dress codes, roles and responsibilities, the division of labor and the value to be placed on the lives of boys and girls, men and women. Relations of power characterize gender relations in society where girls and women and their work are often valued less than that of men. Both men and women are entrapped into rigid gender roles that are acceptable to prevailing societal norms. For example, men are overwhelmingly viewed as breadwinners and a man is awarded respect or denied it based on the extent to which he is able to fulfill this role. Similarly, bearing children is considered a woman’s gendered obligation to family and society. Women are taunted and harassed for not bearing children.

The principal impact of gender power differentials in society has, thus far, been the creation and maintenance of hierarchical relationships that disproportionately favour men and adversely impact women and intersex people --who are then dubbed as the ‘weaker’ sexes. Overall, the prevailing gender power differentials are disadvantageous for women and intersex people and lead to the deprivation of nutrition, education, decision-making power, resources and mobility.

The problem with a rigid gender identity is that all those who do not conform to the binary gender identity prescribed by society are ridiculed, harassed and sometimes forced out of society. Transgender communities such as *Hijras*, for example, are forced to live as outcasts. They are largely deprived of education, decent housing, access to health care and dignity. Homosexuals and sex workers too suffer discrimination, including criminalization, as they do not conform to the expectations of society.

5 Gender Assessment tool by UNAIDS/Stop TB Partnership

Gendering does not operate in isolation; the process meshes with other axes of power such as ethnicity, class, caste and location to create differential access to resources and lead to differential outcomes in well-being. For example, one's gender affects susceptibility to TB as well as one's response related behaviours such as seeking health care.

Gender and sexuality-based discrimination is a barrier to TB detection and care. This rapid assessment includes an enquiry into how the gender and sexual identities of persons affect case finding and health care access to TB, and identifies practical recommendations and doable action for a more gender responsive service, as a step towards the ultimate goal of control and elimination of TB in India.

For purposes of this report the term 'Gender Assessment' is being used synonymously with the term 'Gender Analysis' in the context of health issues and programs. The concept of application of a gender lens to understand how gender interacts with any phenomenon such as a health problem was first conceptually developed in the form of a 'Gender Analysis'.

II. Objectives of the Gender Assessment

- To understand the gender dimensions of the TB burden and response in India, including the impact on men, women and transgender persons as also among sexual minorities.
- To undertake an analysis of available sex-disaggregated data on TB and propose steps to ensure future cross-cutting availability of sex-disaggregated data.
- To understand the gender responsiveness of the national TB programme, in terms of both policy and practice.
- To outline key recommendations for India to move towards a gender-sensitive response to TB.

III. Methodology

The Conceptual Framework of Gender Analysis of a Health Program

As per WHO (Gender Mainstreaming for Health Managers: A Practical Approach, 2011), a gender assessment/analysis in health identifies, assesses and informs actions to address inequality that stems from:

- Gender norms, roles and relations
- Unequal power relations between and among men and women
- Interaction of contextual factors with gender, such as location, ethnicity, education or employment status, sexual orientation

A gender assessment contributes to understanding health differences and disparities among and between women, men and other genders in the following areas:

- Risk factors and vulnerability.
- Patterns of disease, illness and mortality.
- Health effects of policies, legislations and programs (e.g. OPD care for TB is not covered under Health Insurance).
- Access to health care.
- Decision making processes.

A Gender Assessment can increase effectiveness of the program by...

- Ensuring the right to health of different groups of men and women;
- Recognizing and reducing the constraints women and girls face in protecting and promoting their health;
- Considering and addressing how male gender norms, roles and relations may harm the health of men and boys;
- Reducing inappropriate, ineffective services, programs or policies that ignore the realities of women's and men's health needs and living conditions;
- Identifying and reducing gender bias in the health system;
- Developing and implementing gender-responsive policies, laws and services (primary, secondary and tertiary) and programs; and
- Improving health information, documentation and use.

The following matrix presents various factors that influence health outcomes. Each gender related consideration may be assessed against each health-related consideration to identify the intersections between gender and health.

Table 1: Gender Analysis/Assessment Matrix for Health Programs

Factors that influence health outcomes: <i>Health-related considerations</i>	Factors that influence health outcomes: <i>Gender-related considerations</i>		
	Biological factors	Sociocultural factors	Access to and control over resources
Risk factors and vulnerability			
Access and use of health services			
Health-seeking behavior			
Treatment options			
Experiences in health care settings			
Health and social outcomes and consequences			

Source: WHO, 2011

A gender assessment of TB is the first step in moving country level TB programs from being gender-blind to gender-sensitive to gender-transformative. These concepts are captured in the table below.

Table 2: From Gender Blind to Gender Transformative Health Programs

Type of Intervention	Impact	Example
Gender-negative or gender-blind	Fails to acknowledge the different needs or realities of women and men and transgender people. Aggravates or reinforces existing gender inequalities and norms.	Lack of disaggregated TB data because of a failure to acknowledge that programs and policies have different effects on women, men and transgender people.
Gender-sensitive or gender-responsive	Recognizes the distinct roles and contributions of different people based on their gender; takes these differences into account and attempts to ensure that women, men and transgender people equitably benefit from the intervention.	DMC operational hours are changed to suit the convenience of working men and women.
Gender-transformative	Explicitly seeks to redefine and transform gender norms and relationships to redress existing inequalities.	Challenges and changes power norms in order to strengthen women’s ability to seek TB diagnosis and treatment without fear of stigma

Source: UNDP, 2014

Methodology for the current Gender Assessment

The methodology followed for the rapid assessment was a review of literature available from secondary sources and interviews with various stakeholders in the field of TB.

Literature Review

There is a wide range of literature that explores gender issues in TB, sex-wise epidemiology of TB, how TB affects women, socio-cultural aspects of TB, community responsiveness and gender responsiveness of TB programs, access to health care with a community and gender perspective and the impact of TB on the health of women and marginalized groups. We reviewed research, policy and program related reports from governmental and non-governmental sources, peer reviewed journals and UN publications, keeping the above-mentioned themes in focus and concentrated on those specifically pertaining to India. Some important papers studying global and South Asian evidence were also reviewed.

For this purpose, a key word search was undertaken using the key words 'tuberculosis' and 'gender' and 'India' starting from the year 1990 till date. The database covered was PubMed. 108 papers were downloaded and the abstracts studied using these criteria. At the same time other sources of reports and policy papers were researched mostly through papers suggested by TB and public health experts whom we interviewed, including a database generated by an Indo-Canadian research initiative on 'Gender and TB' by Prof. Bilkis Vissandjee of Montreal University and Prof. Lakshmi Lingam of Tata Institute of Social Sciences. A further short-listing of papers was done based on their specific substantial contributions made to the understanding of gender and TB and these papers have been analyzed to inform this report.

Interviews with Stakeholders

We interviewed the following stakeholders in three states, viz., Odisha, Maharashtra and Delhi:

- State TB Officers (STOs) and Central TB Division Officers (CTOs).
- District TB Officers and the program managers in their teams.
- Field-level functionaries namely Senior Treatment Supervisors (STs), DOTS (Directly Observed Treatment Short Course) Supervisors, DOTS Plus Supervisors, HIV-TB program coordinators and Public-Private Partnership Management (PPM) coordinators.
- Medical Officers who were present during the visits.
- WHO consultants who were present during the state visits.
- TB survivors and TB activists; most of the TB activists were themselves TB survivors.

We also talked to chest physicians, TB experts, public health specialists, social scientists and researchers to obtain a country perspective on gender and community issues in addition to gender concerns related to TB and to the RNTCP.

In each state, we visited at least 2 districts and 2-3 District Tuberculosis Centers (DTC). We also interviewed the STO (State TB Officer) and two or more DTOs (District TB Officer) and members of their respective teams. In Odisha we visited one tribal and one coastal district; in Maharashtra one urban center and one rural district; and in Delhi we visited the DTCs close to large slums, in order to observe the interplay of gender with rural-urban locations, class and ethnicity.

We interviewed a total of 70 people including 28 women, 1 transgender representative and 41 men. Among these were 7 senior health officials, 18 TB officials/managers, 7 TB survivors/activists, and 38 others from various categories. (Table 3) Details of the state-wise categories of interviews may be found in Annexure 1. The table below presents a brief version here for ready review.

Table 3: Details of Interview Respondents

Interviewee	Female	Male	Total
Clinician / Chest Physician/ TB Expert and Public Health Specialist	3	5	8
Field Functionary	3	11	14
Medical Officer	1		1
Civil Society Representative/NGO/ TB social project manager (including MDR TB)	3	1	4
Senior and other Health Officials/ Managers (STO, DTO etc)	6	19	25
Social Scientist /Researcher	5	2	7
TB/ MDR TB Counselor	1	1	2
TB Survivor / TB Activist and/or Touched by TB member	5	2	7
Transgender people’s representative (1 TG)			1
WHO Consultant to TB program	1		1
Grand Total	29 (1TG)	41	70

Challenges linked to the stakeholders reviewed: Lack of women staff in the RNTCP program

The overwhelming proportion of men employed in the RNTCP ensured that most of our interviews were with male staff. Only one STO, two CTOs and one DTO among the respondents were women, whereas 19 STO/DTOs and other health officials or managers interviewed were men. Even most of the field staff who are expected to have a interface with TB patients are men. Of the 11 field staff interviewed, all 8 belonging to RNTCP were men while the 3 women interviewees were ASHAs (Accredited Social Health Activists), who are part of the NHM. There are more women only in the categories of Social Scientists/Researchers and TB survivors/TB Activists where special effort was

made to ensure that women are represented. This is a telling observation on the sex-wise composition of the RNTCP program.

A senior TB expert and public health specialist who was interviewed for the rapid assessment commented that lack of women in the RNTCP is among one of its problems, one that prevented the health system from knowing the life experiences and perspectives of women. He stated that not more than 2 or 3 DTOs in any state are women and the others are all male. He observed that even an Indian Medical Association (IMA) meeting is attended only by men.

FINDINGS OF THE RAPID ASSESSMENT

IV. Gender and Epidemiology of TB in India

Gender bias in health has historically taken many forms. For example until recently women were being diagnosed with Angina and Myocardial Infarctions using diagnostic criteria developed for men. Recently, it was brought to light that heart attacks may present very differently and in a silent form among women. Many health research studies did not include female participants but their results were used to treat female patients. Not using sex-disaggregated data for the analysis of research studies is one of the many forms of gender biases in health.

4.1 Incidence of TB among women and girls

Globally more men are seen to be diagnosed with TB than women and the ratio is approximately 60:40 between men and women. More men die of TB globally, both as a proportion of total cases and in absolute numbers. This has given TB the image of being a 'men's disease'. Even so, in absolute numbers, the number of women with TB globally as well as in India is very high. Women and girls account for 1 million TB cases in India each year. TB is also the fifth leading cause of death among women in India. Therefore, in order to control and eventually eliminate the disease from India, it is important to pay attention to the sex and age wise profile of the disease. This is also important for the TB program to be able to tailor its strategies to the different presentations of TB in different age and sex groups.

The reasons why the incidence of TB appears less among women could be because -

- Fewer women suffer from TB
- Fewer women are diagnosed with TB
- Women are unable to access health services for TB
- A combination of the above

Further, it is possible that women suffer less from TB because they are less exposed to the infection or because they are in some way protected from the disease. Similarly, fewer women being diagnosed with TB could be due to providers not being able to diagnose TB among women on time or because women approach the health facility late. A host of gender and social barriers, such as access to finance and mobility is linked to women's inability to access health services. Most of these

factors are amenable to social, human behavioral and environmental change. This is another important reason to be alert to changes in age and sex-based incidence patterns of the disease, besides geographical patterns and patterns among key populations. Uplekar, Rangan and others cite studies which urge us to cross-check whether indeed incidence of TB among girls and women is as low as is currently widely presumed i.e. about 40% of the total⁶. When TB was a formidable disease in the industrialized world, higher levels were documented in young and early middle-aged women as compared to men⁷. They also point to socio-cultural barriers that prevented women from accessing services which were deemed unacceptable or which were expensive.

4.2 Epidemiological Picture of TB Based on Literature Review

Sex-disaggregated data regarding the incidence and prevalence of various forms of TB, as well as the monitoring indicators used in the RNTCP, which would have clarified the sex-specific epidemiology of TB in India, is available at the state and district level. However, it is not published for wider use and does not appear to be used in designing the local program. Sex-disaggregated data is also not available for cases found during active case finding (ACF). One senior health official told us, *“We do not think differently for men and women. For us they are all (a single) population.”* When we asked health officials about the age-sex linked trends in their states or districts, all of them told us that they would have to look at the details of the data before answering, indicating a lack of familiarity with age and sex-disaggregated data which they regularly collect.

Studies have documented that under the age of 20 years, the notification of TB among men and women, boys and girls is similar (Mukherjee et al. 2012). After this age, the diagnosis of TB among men steadily rises in comparison to women. On the other hand, in a four country study initiated by WHO, a lower number of female TB patients were identified in India and Bangladesh as seen by the case registries, but Malawi reported an equal number in both sexes and Columbia reported more cases among females. Therefore, the reasons behind the gap in diagnosis between men and women need to be further explored.

The RNTCP has historically focused on the sputum test to diagnose TB. The test is suited primarily to diagnose sputum positive pulmonary TB which is most commonly found among men. The next most commonly used criterion has been chest X-ray, which is again useful to diagnose pulmonary TB.

There is evidence to show that the presentation of TB among women may be substantially different from men, making it difficult to diagnose TB in women. Various studies on incidence of TB in India point to the higher incidence of sputum negative presentations of TB and extra-pulmonary TB (EPTB) among women. A study undertaken in Chennai found a larger proportion of men than women had sputum positive TB. The same study noted that a higher proportion of women than men suffered from EPTB (16% in women and 5% among men)⁸.

6 Uplekar et al. 2001

7 Holmes, Hausler, and Nunn 1998

8 Balasubramanian et al. 2004.

In a WHO study, the proportion of women was higher among new sputum negative (NSN) patients starting their treatment in India and Bangladesh, indicating a higher proportion of NSN TB cases among women (Weiss et al. 2006). The same study recorded that men in India more frequently reported signs such as blood in the sputum which is typically associated with TB by people as well as clinicians and formed the 'text-book picture' of TB. On the other hand women presented with non-specific findings such as fever, body ache, loss of appetite and fatigue. Greater delay in diagnosis by health providers were also linked to non-specific physical signs of illness.⁹

Another study based on the utilization of RNTCP services found that women had a lower proportion of sputum positive diagnosis compared to men¹⁰. Mukherjee and others also documented a higher proportion of NSP cases among men (40%), followed by New Sputum Negative (NSN) cases (38%) and New Extra Pulmonary (NEP) cases (8%), while for women the proportion was higher for NSN cases (42%), followed by NSP (35%) and NEP cases (13%) which were relatively higher¹¹. Women may also have more atypical forms of the disease, such as six times higher number of cases of calvarial Tuberculosis¹², a rare form of bone TB.

Interviews with senior health officials indicated that where better diagnostic facilities are available, such as in larger cities, the proportion of EPTB cases are on the rise.

Globally there is evidence that women in their early reproductive years may have faster progression from TB infection to disease and higher mortality rates¹³. Balasubramanian and others recorded a higher progression of infection to disease among men, but when smokers and alcoholics were removed from the data, the male:female ratio was 1.2 indicating the special vulnerability faced by smokers. When smokers were omitted from the analysis, men and women faced similar progression in TB disease.

4.3 Age and Sex-linked Incidence of TB from RNTCP Data

Age and sex disaggregated TB data are available at district and state levels and throw up interesting findings which have implications for care and prevention strategies. The following are findings from the analysis of state level data from Maharashtra from one quarter of 2016.

9 Weiss et al. 2006.

10 The proportion of sputum positive diagnosis among women was 10.8% [95% CI 10.5%-11.1%] as compared to men who had 17% [95% CI 16.7%-17.3%] (Dandona et al. 2004)

11 Mukherjee et al. 2012

12 Jadhav and Palande (1999)

13 Needham et al. 2001

Table 4: Maharashtra Data, 2016, Age and Sex wise New Sputum Positive (NSP) cases

Age Group	Maharashtra			% of Females	Mumbai			% of Females
	Male	Female	Total		Male	Female	Total	
0-14	234	576	810	71	43	130	173	75
15-24	5376	5075	10451	49	939	913	1852	49
25-34	6069	3924	9993	39	735	446	1181	38
35-44	5764	2471	8235	30	602	203	805	25
45-54	5106	1818	6924	26	475	165	640	26
55-64	3870	1517	5387	28	273	132	405	33
>65	3580	1361	4941	28	154	80	234	34
Total	29999	16742	46741	36	3221	2069	5290	39

The overall incidence of NSP cases among men (74%) is higher than women (36%) in Maharashtra and in Mumbai where the proportions were 71% among men and 39% among women. However, the age and sex-disaggregated data indicates that in the age group of 0 to 14 years, 71% of cases in Maharashtra and 75% in Mumbai are found in girls. Though the numbers are smaller, this reversal of the pattern is a consistent finding in the district records that we reviewed.

In the age group of 15-24 years, we found the number of NSP cases among males and females to be nearly equal. 49% of women and girls in Maharashtra and Mumbai each had NSP TB. The numbers in these categories are substantial. In fact, 15-24 year-olds account for the largest number of cases for women in any age group. This suggests that women are most susceptible to TB in the age group of 15 to 24 years and the numbers are comparable to men. This finding is also consistently seen across the districts.

The Mumbai district figures were selected for analysis because the overall TB numbers in Mumbai are high. In some TB districts in Mumbai, we found that females in the age group of 0 to 14 years as well as 15 to 24 years show a much higher incidence of TB compared with boys in the same age groups. Some districts of Maharashtra also show a much higher incidence of TB in girls compared to boys in this age group. On the other hand, some TB districts in Mumbai — Centenary, Govandi, Kurla and Vikhroli, have comparable numbers of TB cases among men and women when aggregated across age groups. (See Annexure 2)

New Sputum Negative and New Extra-Pulmonary Cases

Among New Sputum Negative cases (NSN), the total proportion of women affected in Maharashtra is 41%, and is higher in Mumbai at 46%. Some TB districts in Mumbai have higher overall number of NSN cases compared to men in the same age groups.

Women also have a higher incidence of NEP in both Maharashtra (52%) and Mumbai (58%). In some districts of Maharashtra and TB districts of Mumbai, women far outnumber men in the NEP category. Senior health officials said that the recently introduced diagnostic technologies such as CB-NAAT (Cartridge-Based Nucleic Acid Amplification Test) have made it easier to diagnose EPTB cases as also sputum negative cases. These cases would go have gone undetected earlier. More cases of EPTB are being diagnosed in cities like Delhi and Mumbai where the new diagnostic facilities are widely available. It is possible that TB among women is being better diagnosed now.

Table 5: TB cases in Maharashtra by category (2016)

TB Categories	Maharashtra			% of Females	Mumbai			% of Females
	Male	Female	Total		Male	Female	Total	
NSP	29999	16742	46741	36	3221	2069	5290	39
NSN	13742	9610	23352	41	2392	2053	4445	46
NEP	12144	13386	25530	52	2506	3480	5986	58

Doctor Level Delay in Diagnosis

A number of studies have pointed to patient level and doctor and health system level delays in TB diagnosis¹⁴. These delays may be linked to the epidemiological picture of the disease and may affect an early and accurate diagnosis of TB in women. There is a steady attrition of cases of presumptive female TB patients from the time they reach a public facility; fewer women submitted their sputum for testing and still fewer were found to be smear positive. Sputum negative TB and EPTB cannot be diagnosed on sputum microscopy. Newer technologies of CBNAAT have been very recently introduced and not available yet in many rural areas. Also our interviews with health officials indicated that x-ray facilities, another avenue to diagnose NSP cases, are not always available at the sub-district levels. The NHM is working with states to make these available. For example, an interview with a woman from a tribal village of Odisha revealed that she got diagnosed with TB after a year of repeatedly visiting public and private health facilities -- only when she became sputum positive. During this delay, she had lost substantial weight and her mother was also diagnosed with pulmonary tuberculosis, possibly due to close contact with her daughter.

4.4 TB during pregnancy and post-partum period

Prevalence of TB in pregnant women: In 2011, it was estimated that more than 200,000 pregnant women suffered from Tuberculosis globally, a majority of these in the WHO African region and WHO South East Asian region (67,500 cases). India ranked highest in the estimated number of pregnant women with TB, with more than 44,000 cases and 21% of the global burden. This is on account of high burden of TB in the country, a large population as well as relatively high crude birth rates¹⁵.

¹⁴ Dandona et al. 2004, Weiss et al. 2006

¹⁵ Sugarman et al. 2014

Another estimate of burden of TB among pregnant women was similar, i.e. 20,000 to 40,000 cases¹⁶. Other smaller studies provide prevalence figures ranging from 19% to 34% among HIV-negative women in India¹⁷.

Higher risk of TB in pregnancy and in the post-partum period: Mathad and Gupta (2012) draw upon a growing body of research to make the case that physiological changes in pregnancy have an impact on the epidemiology of TB. Pregnant women and women in post-partum period face a higher risk of TB. Women in the early post-partum period are twice as likely to develop TB as non-pregnant women¹⁸. Bates and others (2015) also highlight that immunological changes during pregnancy make new infections as well as activation of latent infection more common among this group. This research outweighs the earlier findings that pregnant women are only as much at risk of TB as the general population. National Programs have yet to collect and report data on number of pregnant women with TB and the lack of this data makes it difficult to get a clear national picture of this burden¹⁹. Gupta et al (2007) also note that women who are HIV +ve face an even greater risk of contracting TB in the post-partum period (incidence of about 5 cases per 100 person-years) as borne out by research on Indian women. Gupta et al (2016) also found that TB, generally diagnosed in the post-partum period, is also associated with increased mother-to-child transmission of HIV (30% vs 12%). They recommend that steps should be taken for prevention of TB and treatment of latent TB in HIV infected mothers, especially in communities where HIV/TB burden is high. However, scientists, researchers and practitioners note that despite substantial prevalence and mortality for TB among women in the reproductive years, there is very little research or understanding about the epidemiology and presentation of TB in pregnancy and post-partum period. On the other hand, a substantial proportion of these women may never get an early diagnosis of TB, which can markedly reduce health risks to mothers and new borns.

Difficulty in diagnosing TB in pregnancy: Several researchers record the difficulty of diagnosing TB in pregnancy. This is because TB in pregnant women may present with non-specific symptoms such as malaise, loss of appetite, breathlessness and sweating which may be mistaken for common symptoms in pregnancy and not with fever, haemoptysis and night sweats typically seen in men²⁰. Secondly, even when women have symptoms, doctors may be reluctant to ask for a chest X-ray in pregnant women due to the potential risk to the fetus. Besides, access to diagnostic facilities such as X-ray, FNAC (Fine Needle Aspiration Cytology), CBNAAT etc., is limited, especially in rural and tribal areas. Additional problems faced by HIV+ve women is that sputum tests are less sensitive and sputum culture requires considerable time to yield results, thus delaying diagnosis. Diagnosis of extra-pulmonary TB poses even greater challenges as the signs of TB may be masked. For example, weight loss of TB is masked due to weight gain of pregnancy. It may be far more difficult to undertake

16 Jana Narayan et al. 2012

17 Mathad and Gupta 2012.

18 Gupta et al 2016

19 Ibid

20 Long, Diwan, and Winkvist 2002.

a surgical or endoscopic biopsy or use other methods to get a sample in pregnant women due to obvious risks of the procedure itself or associated anesthesia, risk to the fetus and difficulty of accessing the affected tissue, for example, in abdominal TB. Diagnosis is therefore considerably delayed. Pregnant women who are diagnosed late or treated late for TB, especially in the third trimester, face poorer outcomes for themselves as well as their infants. On the other hand, Sugarman and others (2014) have estimated that nearly 53% and 55% of the estimated TB in pregnant women may be diagnosed with X-rays and CBNAAT technology respectively delivered through maternal care services.

Impact of TB and HIV-TB co-infection in pregnancy

Increased maternal mortality due to TB in Pregnancy and Post-Partum period: Tuberculosis is one of the leading non-obstetric causes of maternal mortality in low-income countries. Evidence suggests that untreated TB in pregnant women may result in 40% maternal mortality. Active tuberculosis disease in HIV positive women can increase the risk of maternal mortality by 300%²¹. In India, though evidence is sparse, one study based on causes of death found in post-mortem (autopsy) reviews of maternal deaths reported a more than 9% maternal mortality (26 among 227 deaths) on account of Tuberculosis²². Among these four women had tubercular meningitis and four had tubercular peritonitis. Co-infection with TB in HIV +ve women substantially increases maternal deaths by more than 2 times and infant deaths by about 3 and ½ times in this group²³. Better reporting of causes of maternal deaths and better implementation of maternal death reviews can build more robust evidence on the subject.

Most deaths in HIV-TB co-infected women were on account of TB and not due to obstetric complications. A study of pregnancy outcomes among TB-HIV co-infected and HIV infected women, found that of the 17 co-infected pregnant women only seven (41%) were alive and on ART; seven (41%) had died, and three (18%) were lost to follow-up. On the other hand women who only had HIV and were taking ART, showed better outcomes with 71% alive and on treatment²⁴.

Adverse impact on fetus and infants: Jana Narayan and others (2012) as well as Mathad and Gupta (2012) note that both TB and HIV-TB co-infection in mothers add to pregnancy related complications and also have an adverse impact on the fetus and infant. TB in pregnancy increases hospitalizations during pregnancy, increases incidence of pre-term births, miscarriage and causes other complications. Infants born to women with TB as well as HIV-TB co-infection face increased chances of fetal distress during delivery, generally weigh lower at birth, are small-for-date²⁵, may be born premature and experience increased mortality within the perinatal period as well as the first year. There is also the possibility of TB being passed on to the child both in the womb and through air-borne droplets in the

21 Zumla, Bates, and Mwaba 2014.

22 Panchabhai et al. 2009

23 Gupta et al 2007; Maternal deaths increases 2.2 fold; 95%CI 0.6–3.8 and infant deaths 3.4 fold; 95%CI 1.22–10.59.

24 Suresh et al. 2016

25 Weight less and are overall smaller than expected for gestational age. These babies are generally not pre-term but small for age.

immediate post-partum period. Again, diagnosis of TB in infants is challenging, thereby increasing the chances of a missed diagnosis in the infant. Increased and early diagnosis of TB among pregnant women can reduce many of these complications and improve outcomes for both mother and child.

TB in pregnancy rooted in social determinants: Other important findings from the study by Suresh and others were that TB-HIV co-infected pregnant women with poor delivery outcomes had significantly lower initial weights and lived greater distances from the nearest health facility, thus underlining the importance of factors such as nutrition and better access to health services²⁶. Jana Narayan et al (2012) also note that the TB in pregnancy is closely tied to poverty, under-nutrition, anemia, over-crowding and multiple births in women and not merely biological or immunological susceptibility. They also note that many women may be too unwell at times to attend either the ANC clinic or the DOTS centre, thus also increasing interrupted treatment and worsening the outcome. The toll on the family by way of expenses, lost wages, transportation and emotional toll is high.

Interactions of gender and TB in pregnancy gleaned from our field experiences: Two senior doctors having significant experience with TB told us that during pregnancy and the post-partum period the need for calories and proteins in the body increases, therefore it is not surprising that women become more vulnerable to TB in this period. One senior scientist mentioned that she had seen many pregnant and post-partum women with TB in maternity wards in tribal areas. At least two case studies narrated spontaneously to me were about women who contracted TB immediately after child-birth. The TB in both women was initially MDR-TB and subsequent diagnosis was of XDR-TB.

A senior physician who practices in tribal areas told us that newly married women who are on TB treatment and who are responding well, often feel the pressure to start a family. Counselling to delay pregnancy until the TB treatment is complete, is rarely considered. As soon as the family comes to know that the woman is pregnant, both she and her family do not want her to continue the treatment for fear of medicines affecting the unborn foetus. Relapses are common in this situation and some women come back with DR-TB. That Rifampicin, one of the primary drugs used in TB treatment also interferes with oral contraceptives, makes the task of the health care provider tougher.

Narayan and others reiterate that incomplete and irregular treatment is a common problem in pregnant women. To overcome this challenge, they recommend that impediments at three levels will need to be addressed namely, at the level of the health system, at social and family level and at personal levels²⁷.

Health System Issues linked to TB in pregnancy

Better integration of RNTCP with the RCH programme: The unique challenge of diagnosing TB in pregnancy and the inadequate availability of diagnostic tests pose a difficulty for the health system. In addition, pregnant women find it difficult to attend ANCs as well as the DOTS centres²⁸. The

26 Suresh et al. 2016

27 Jana Narayan et al. 2012

28 Jana Narayan et al. 2012

need is for the RNTCP to be better integrated with the Reproductive and Child Health program, especially maternity services. More needs to be done to screen pregnant women for TB and prevent transmission to the infant as compared to preventing the parent to child transmission of HIV.²⁹ Mathad and Gupta (2012) point out that there is inadequate evidence of the cost-efficacy of routine screening for TB among pregnant women. TB symptoms are generally commonly found --even in the absence of TB-- leading to unnecessary tests for TB. They recommend better research to generate cost-effective screening tools and protocols. However, active screening is recommended for TB among HIV positive pregnant women given the high incidence as well as poor outcomes in this condition.³⁰ Given the low access to health services observed among young women, especially in rural and tribal areas, maternal and reproductive health clinics present an important and sustained opportunity to integrate TB care and screening for women, especially pregnant and post-partum women as has also been advocated by WHO.³¹ Sugarman et al also highly recommend such integration noting that often the National TB programs are based at the district level and maternal services are accessed by women in primary health set-ups closer to the community, thus often creating a disconnect between the two. They estimate that more than 50% of TB in pregnancy could be diagnosed by making appropriate diagnostics available through maternal health programmes³². Even without universal screening, there is scope to improve the diagnosis of TB among pregnant and post-partum women by instituting better protocols to identify at-risk pregnant women such as undernourished pregnant women, training doctors on the varying symptomatology of TB, training ANMs and ASHAs to identify TB symptomatics at the field level, and creating ready access to diagnostics through maternal health clinics. Pregnant women are often unlikely to visit the clinics repeatedly and hence it is important to provide as many services to her as possible, in a single visit.

If the RNTCP begins to maintain separate records for pregnant women with TB, it would improve the monitoring of services and outcomes as well as provide epidemiological learning for the RNTCP program. In the absence of research studies, programme data can serve as a valuable source of information on the ground realities. Mathad and Gupta (2012) recommend a Tuberculosis Pregnancy register to note the safety and outcomes of pregnant women on ATT.

HIV-TB co-infection: Since 2006, both the NACP and RNTCP have instituted measures to ensure that all HIV patients be screened for TB and all TB patients be screened for HIV infection. Besides, all pregnant women are screened for HIV during ANC visits. Even so, due to the challenges in TB diagnosis already described, it is possible that HIV-TB coinfection is missed among HIV +ve pregnant patients. Though the NACP maintains records of pregnancy status and outcomes for all HIV patients, the RNTCP has yet to do so for pregnant women with TB. Doing so would help the monitoring of services from the RNTCP end and augment the learnings of the program with regard to HIV-TB co-infection.

29 Bates et al. 2015.

30 Gupta et al, 2007

31 WHO, Tuberculosis in Women, 2016

32 Sugarman et al. 2014

Inclusion of pregnant women in Tuberculosis drugs research: Leading researchers in the field of Tuberculosis in India and globally, note that women- especially pregnant and post-partum women- are excluded from epidemiological studies, operations research and research on clinical presentation of TB, though TB is an important cause of maternal deaths. Lack of such research has also delayed formulation of protocols and suitable algorithms keeping the specific challenges of TB diagnosis in mind. Despite the fact that pregnant and lactating women face added risks of TB disease and are being treated using the same TB drugs, they are not included in clinical trials, safety evaluations, tolerability and study of drug pharmacokinetics of existing or new drugs³³. Pregnant and lactating women thus rarely get the benefit of updated information on optimum dosage and pharmacokinetics of existing drugs, dosages for MDR TB drugs -- or receive new drugs. The prevailing TB treatment regimens during pregnancy and in the post-partum period need greater evidence to support them and led to inconsistencies in the national and international guidelines to treat TB. Treatment options for multi-drug resistant TB in pregnant women, for the same reasons, are extremely limited. Other challenges to TB treatment in pregnancy include difficulties in adhering to ARV and ATT as well as continue with ante-natal care, dealing with drug interactions between ARV and ATT regimens³⁴, potential damage to the liver due to hepatotoxic drugs, contraindications to anti-TB and anti-HIV drugs, and risks posed to the fetus due to the drugs³⁵. More research on these topics is needed, to develop better treatment options³⁶.

Gupta and others (2016) who were members of an international experts panel convened by the US National Institutes of Health on building a consensus on research in pregnant and post-partum women with respect to TB, have recommended that the policy should be one of presumed inclusion in research and clinical trials and exceptions be made for specific trials or research which could harm them. They note that HIV+ve women benefitted greatly from a policy of presumed inclusion, thus becoming early beneficiaries of the latest available drugs .

4.5 Infertility on account of Tuberculosis

Genital TB is another under-diagnosed and neglected form of TB among women. Genital TB generally affects the fallopian tubes, endometrium and ovaries and is recognized to be a leading cause of infertility among women³⁷. Figures from India indicate that 9% of all extra-pulmonary TB cases are genital TB³⁸. An ICMR paper has noted an increase in prevalence of female genital TB in women seeking treatment for infertility from 19% in 2011 to 30% in 2015³⁹. Globally nearly 24% of all cases of infertility are estimated to be on account of TB, as per a systematic review and meta-analysis of

33 Mathad and Gupta 2012; Jana Narayan et al. 2012;

34 Adhikari 2009

35 Bates et al. 2015

36 Gupta et al. 2016

37 WHO Factsheet, 2016

38 Shende et al. 2017

39 Quoted in Grace, Devaleenal, and Natrajan 2017

existing studies.⁴⁰ Genital TB is generally silent for a long time and is difficult to diagnose.⁴¹ Some women experience reduced menstruation, amenorrhoea or irregular menstrual cycles while some may experience vaginal discharge and abdominal pain. In most women, however, the problem is silent and most genital tuberculosis among women is discovered during the work-up to diagnose the causes of infertility. Though TB in such conditions is treatable, the fallopian tubes or endometrium may often be too severely damaged to regain fertility. There is also the increased possibility of ectopic pregnancies and miscarriages when conception occurs⁴².

In India, where getting married and bearing children is the norm, infertility causes significant emotional trauma to the woman and often invites harassment and discrimination. Within the orthodox patriarchal set-up of the family, a woman earns some measure of legitimacy and respect when she bears a child, especially a male child. Childless women, therefore, often live in perpetual insecurity of being deserted or of the husband taking a second wife. Infertile women are often not invited to religious ceremonies or may be excluded from some rituals in social events, making their sense of discrimination acute.

The public health system at the primary level has little to offer to poor women who are childless, though secondary and tertiary hospitals do provide diagnosis and treatment for infertility. Private infertility clinics and Assisted Reproductive Technology Centres are available mostly in cities and are exorbitantly expensive, putting them out of reach of common citizens. It is vital, therefore that genital TB is considered an important problem, is diagnosed early and appropriately treated. It is also critical that the public health system provides diagnosis and treatment for infertility emerging from TB right from the primary level with the help of trained doctors, nurses, ANMs and ASHAs.

Policy Implications for epidemiology of TB

The above findings suggest that we have yet to understand the full picture of the burden of TB disease in women and children, and that the subject needs further investigation. It appears that boys and men are presumed to be suffering from TB more than are girls and women and this may lead to missed diagnosis among girls and women. TB diagnosis among children needs improvement. We particularly need to understand the burden of TB as well as HIV-TB co-infection in pregnant and post-partum women. Finally, program managers at the state and national level need to analyze data at their levels and the analyses, needs to inform the RNTCP. The special needs of pregnant and post-partum women with TB and TB-HIV infection suggest that better research is required to understand the epidemiology of TB among them, and also indicate that RNTCP services must be fashioned to serve those needs.

40 Kefayat, et al. 2016

41 Grace, Devaleenal, and Natrajan 2017

42 Ibid

Recommendations for the RNTCP:

Maintenance and Analysis of RNTCP Data:

- Analyze RNTCP data disaggregated by age and sex and publish this data at national, state and districts levels. This is achievable with NIKSHAY, a web based solution for monitoring TB patients developed by National Informatics Center.
- Use age and sex-disaggregated data to inform program strategies, such as -
 - o Raising awareness of TB, and TB in pregnancy and in the post-partum period among women and in the community especially where TB diagnosis among women is low.
 - o Using health camps and other methods with the help of ASHAs and women field functionaries to reach women and children, both girls and boys.
 - o Increasing the availability of X-rays and CBNAATs at sub-district levels in sufficient numbers to improve diagnosis in NSP and EPTB cases.
- Publish ACF data in age-sex disaggregated format to understand which groups need help to reach diagnosis and treatment.
- Maintain a TB Pregnancy register to document and follow-up outcomes of pregnant women with TB. Analyse the data regularly to improve services for this group. The register could include pregnant women with TB-HIV irrespective of their documentation through the HIV programme.

Response of the RNTCP and Health System to women with TB

Pregnant and post-partum women with TB and TB-HIV Co-infection

- Better integrate reproductive and child health services in general, and maternity services in particular with the RNTCP through measures such as the following:
 - o Organize services in such a manner that the ANC clinic coincides with the visit of the chest physician where possible for eg., at district and sub-district levels.
 - o Improve linkages between the RNTCP and community level and primary level ANC services where frontline workers have an active relationship with pregnant and post-partum women
 - o Build capacity among doctors, ANMs and ASHAs to recognize TB in pregnant women
 - o Make fetal guards available during chest X-rays among pregnant women. Doctors need to have evidence at their disposal, showing that the risk of missing a diagnosis of TB in pregnancy outweighs the risk.
 - o Improve access to CBNAAT to improve the diagnosis of extra-pulmonary and sputum negative TB.

- Support young women of poor families to access ante-natal clinics, take DOTS, ARV treatment.
- Appoint counselors with the RNTCP beyond DR-TB who can actively provide psychosocial support and support pregnant women with TB/ TB-HIV to adhere to treatment.

Health Services for women seeking to conceive:

- Women seeking infertility services need to be able to access screening for TB and TB treatment following appropriate diagnosis at the primary care level. Build better linkages between the RNTCP and infertility services in public as well as private sector.

Recommendations for ICMR regarding research guidelines and priorities:

- Provide guidelines and best practices on the conduct of TB research, which would include age and sex disaggregated analysis of data and ethics built into the design of the research. Research studies need to include patients or presumptive patients with sputum negative and EPTB along with sputum positive TB. All population groups need to be covered in studies, especially those where no added harm may come to specific groups (eg., pregnant and lactating women in the context of operations research where drugs or potentially unsafe substances are not being administered). There is also a need for guidelines regarding good quality research in communicable and non-communicable diseases that cover these essential aspects.
- Design TB prevalence studies to collect age, sex disaggregated data on TB as well as information on key populations and sex distribution within key populations.
- Develop guidelines to ensure
 - o a policy of presumed inclusion of pregnant and post-partum women (including HIV +ve women) in all clinical trials where the drugs are likely to be used for treatment among them (existing as well as new) and provide specific reasons for exclusion.
 - o that pregnant and post-partum women, including HIV +ve pregnant and post-partum women are adequately included in all epidemiological and operations research.
- Focus on the high priority research areas identified by the international experts panel convened by the US National Institutes of Health and stated in their published paper ‘‘Toward Earlier Inclusion of Pregnant and Postpartum Women in Tuberculosis Drug Trials: Consensus Statements From an International Expert Panel’ (Gupta et al. 2016) are (among others):
 - o Prevent progression of latent tuberculosis infection, especially in women co-infected with HIV

- o Evaluate new agents/ regimens for treatment of multi-drug resistant tuberculosis
- o Evaluate safety, tolerability and pharmacokinetics of tuberculosis drugs already in use during pregnancy and postpartum period.
- Adopt the recommendations by Mathad and Gupta for further research on:
 - o Epidemiology of active tuberculosis and latent tuberculosis
 - o Immunology and pathogenesis of tuberculosis
 - o Cost-efficacy of screening methods for active tuberculosis and latent tuberculosis
 - o Epidemiology and management of active tuberculosis and latent tuberculosis in infants born to mothers with tuberculosis
 - o Development of low-cost assays that distinguish active tuberculosis from latent tuberculosis
- Prioritize research
 - o to understand the problems currently faced by pregnant and post-partum women in accessing and adhering to treatment.
 - o to ascertain usefulness of capacity building of health staff with and without screening methods for TB in ANC clinics and in post-natal care programs to understand the comparative advantages of each
- Use the results of such studies to improve the performance of the RNTCP.

V. Gender and Access to Health Care in TB

Several respondents told us about social barriers to accessing health care faced by both women and men. These barriers interact with or are influenced by gender, class, caste, religion and region to produce varying levels of exclusions in accessing care.

This section outlines the gender and social barriers mostly faced by women and the elderly. In tribal areas, physical barriers compound the financial and mobility related constraints. Physical barriers to access health care, such as those faced by tribal populations, can be conceptualized as a social and development barrier given that better roads and transport services including health care have not reached the tribal areas even 70 years after independence. In effect this amounts to a form of social inequity and discrimination. A review of literature also supports these reports.

Table 6: Conceptual Mapping of Gender Delays in Health Care Seeking

	Patient Level Delays	Health System Delays or Delays after Diagnosis
Males	<p>On account of fear of losing their job and income</p> <p>Difficulties in accessing health care e.g. for migrants, miners working illegally or in place of formal workers.</p> <p>Those dependent on drugs and/or alcohol may delay seeking care</p>	<p>Loss of income in making multiple visits to the health centers</p> <p>Difficulties in accessing health care e.g. for migrants, miners working illegally or in place of formal workers.</p>

	Patient Level Delays	Health System Delays or Delays after Diagnosis
Females	<p>Perceived lower risk of TB</p> <p><u>Unmarried girls:</u> On account of hiding the illness from neighbours; marriage may be preferred over diagnosis and treatment of TB.</p> <p>Treatment may be interrupted after marriage</p> <p><u>Married women:</u></p> <ul style="list-style-type: none"> • Overwhelming household responsibilities. • Neglect of a woman's illness until she is seriously ill or cannot do the housework. • Lack of financial resources. • Lack of mobility. • Need for permission from decision maker to seek care. • Need for an escort to go to the hospital • Fear of rejection, being sent back to natal home or husband getting remarried results in women delaying treatment or keeping it a secret. <p>Higher possibility of seeking care first with informal provider, pharmacist or private doctor.</p>	<p>Perceived lower risk of TB</p> <p>Lower index of suspicion for TB, including for TB among pregnant and post-partum women</p> <p>Historical emphasis more on Sputum Positive Pulmonary TB as a public health problem leading to lower diagnostic capabilities for Sputum Negative Pulmonary TB and EPTB</p> <p>Lower incidence of Sputum Positive Pulmonary TB and higher of Sputum Negative Pulmonary TB and EPTB making the diagnosis among women difficult.</p> <p>Lack of a gender perspective in TB.</p> <p>Lack of information transmission and counseling for bringing up the right quality sputum for testing.</p> <p>Cultural barriers to coughing in public.</p> <p>Lack of privacy and confidentiality in health system. Privacy and confidentiality are valued much more by women patients.</p> <p>Lack of women staff in RNTCP program.</p> <p>Lower diagnostic capabilities for pediatric TB and in the age group of <14 years, girls are more at risk of TB than boys in this age group leading to further lower diagnosis among girls.</p>

5.1 Physical and Health System Barriers to Access Care

The TB India report 2017 mentions that rural areas including tribal areas, are characterized by high prevalence and low incidence rates. One of the reasons for this phenomenon is the limited access to health care, leading to delayed case detection.

Health officials identify the following physical barriers as most commonly faced by people in tribal areas:

- A difficult terrain and limited transportation facilities that hamper access to health care.
- Inadequate facilities for transportation of sputum to diagnostic centers.
- Fewer diagnostic facilities. E.g. Availability of x-rays is still limited at sub-district levels. X-ray facilities are also not free of cost, and this adds another barrier. There are efforts now being taken through the NHM to make x-ray facilities for TB free of cost.
- Widely dispersed health facilities.
- Lack of adequate lab technicians to cater to the workload, sometimes for long periods.

Studies have shown a substantial delay of 30 to 60 days among patients in tribal areas from the time symptoms develop to reaching the Designated Microscopy Centre (DMC). Six percent of the cases came after two months and were found to be highly infectious with high grade sputum⁴³. A lower case detection rate (CDR) and lower cure rate for sputum positive pulmonary tuberculosis patients were recorded in some tribal and backward districts⁴⁴.

Tribal women are more affected by physical barriers to health care because they lacked money, needed an escort to accompany them and required multiple visits. A study based on National Family Health Survey-2 (NFHS-2) data found that women belonging to Scheduled Tribes (ST) reported the highest prevalence of tuberculosis (2.63%) among all groups including ST men (1.07%); the overall prevalence of TB in the survey being 0.6%⁴⁵.

The study based on NFHS-2 data complements what respondents told us in interviews. It shows a lower treatment-seeking behavior among ST men (77%) and women (73%) than overall treatment seeking (80%). It is also important to note that Das and Dwivedi did not undertake a sex-disaggregated analysis in their 'delays' study that might have shed light on how the different genders are affected differently.

Policy implications

Tribal populations are already recognized as a 'Key Population' by the RNTCP. Yet tribal women, especially ST women remain a neglected group. Steps need to be taken for better diagnosis and treatment for TB among tribal communities.

43 Dasarathi Das and Bhagirathi Dwivedi n.d.

44 Muniyandi et al. 2015

45 Kaulagekar and Radkar, 2006

Good Practice

A TB researcher from Odisha and a senior chest physician in Mumbai, both suggested that mobile clinics with mobile x-ray facilities would be very useful in tribal areas. The chest physician volunteers his time in a tribal village of Maharashtra and said that mobile vans for proved extremely useful for early diagnosis and commencement of treatment in Tansa. In Odisha we were told that tribal areas as compared to coastal areas, have better availability of Medical Officers due to the incentives provided by NHM.

Recommendations

- Make mobile medical clinics available in tribal areas, especially the more remote hamlets.
- Make X-ray facilities, including mobile x-ray units available at the Primary Health Center (PHC) levels.
- Make CBNAAT facilities widely available given the difficulty in sputum transportation.
- Institute better facilities for sputum transportation.
- Manage human resources better, to ensure that lab technicians and other resources are in place and do not compromise diagnosis.

5.2 Barriers Associated with Rigid Gender Roles

Studies show that a maze of barriers to care is linked to women's gendered lives. Among these are:

- The need to convince herself and the family that her illness requires help
- The need to find the money and time to seek care
- The need to get the necessary permissions to leave the house in search of health care.

Household chores and caring for their children are important priorities for married women. Rigid perceptions of these gender roles (both their own and those of their families) make these tasks more important than women's health. Families often neglect a woman's health unless she is unable to do any household chores -this indicates that the health of a woman is only given importance when it hinders her from performing her gender-accorded duties. Women's health is not an end goal but rather a means to keep her functional (Khan 2012).

A senior health official in Odisha told us that women often come to the health facility very late. Many times they are seriously ill, have haemoptysis (blood in the sputum) and high fever. The main reason, according to her, is that girls and women remain largely ignored as long as she can attend to the housework. Only when she is unable to work, is she taken to a doctor. Women themselves ignore their health. Women are not taken early to a qualified doctor. Very often they seek health advice from a quack or from the chemist and take over-the-counter (OTC) medicines. By the time they reach a TB facility, they may be seriously ill or have MDR-TB or may die. Such 'patient level delays' are common among women.

In urban slums, families live among familiar caste, community and ethnic groups. For example the *Meena, Kanjar or Chhura* communities in the Delhi slums follow their traditional customs, binding women to traditional gender roles. Much effort on the part of health workers is needed to educate them about health. The impact of caste on TB diagnosis and treatment has been adequately studied, although Dalits, particularly Dalit women are at the lowest end of the spectrum of health seekers.

A TB activist from Pune told us that many women took TB treatment and shelter at the Sahara Aalhad facility (a center for residential care and rehabilitation for underprivileged patients terminally ill with HIV and TB) in Pune. Most were from an extremely poor background. When Sahara tried to help them train for work, their families would not allow them to step outside their homes.

5.3 Delays in Diagnosis of TB and Neglect in Care faced by Women

Studies have documented delays of up to 65 days in starting treatment for TB, and this is an area of concern for the program⁴⁶. Both women and men face delays in diagnosis and care-seeking for health. As is seen generally in all matters related to gender, delay in diagnosis and treatment affects women and men differently. Women's 'patient level' delay in health care seeking is related closely to their gender roles such as subordinate status in the family.

In a study undertaken by Mistry et al in Mumbai, being a female was significantly associated with delayed diagnosis. Another study based on NFHS-2 data, points to a slightly lower access to treatment of married women (70%) as compared to never-married or divorced or separated women (80%).⁴⁷ Women above 60 years were also less likely to seek treatment (74%) as compared to the overall proportion who sought treatment (80%). Men above the age of 45 years had the highest proportion of seeking treatment (86%) but the statistical significance of these findings is not mentioned⁴⁸.

Women often access sources of health care other than the public health system, depending on what may be more accessible and acceptable to them. Many women prefer to access an informal provider, pharmacist or private doctor before they may be referred to a public facility. Weiss et al found that women actually sought help earlier than men, average delay among women being 48 days as compared to 57 days for men. But women took an additional 18 days to reach the PHC, while men reached there in 11 days. This actually reduced men's overall delay in seeking formal and useful help. In the final tally women took 24 days to reach the PHC and get a sputum examination while men took 13 days, thus significantly accelerating the speed of diagnosis for men⁴⁹. A more serious problem is that several women may not seek care at any kind of health facility at all.

46 Mistry et al. 2016 Dasarathi Das and Bhagirathi Dwivedi n.d. Weiss et al. 2006

47 Kaulagekar and Radkar, 2006

48 Ibid

49 Weiss et al. 2006.

Unfortunately, the health care system does not recognize any gender and social barriers to health care seeking by women, men and other genders. On the other hand, experiences of the TB field functionaries (mostly) and some health officials and medical officers told us, based on their ground level experiences, that women do face barriers to care. As mentioned above a senior health official from Odisha mentioned that women come to the health facility only when they are seriously ill.

Multiple respondents mentioned the neglect and abandonment of married women who had TB. The sister of a woman XDR (extensively drug-resistant TB) patient who is now deaf due to side-effects of TB medication, told us of her travails. She said,

“My sister was a school teacher. She contracted TB soon after childbirth. When her family came to know they were quite upset. Her husband threw away the sputum sample collected through bronchoscopy at the hospital. The sample was meant to check for MDR-TB. Hence her diagnosis as MDR was also delayed. Her in-laws too did not treat her well. They refused to follow up on her treatment and sent her back (natal home). They kept the matter hushed up in their locality. They would wear a mask on the rare occasion when they came to visit her. Shortly after being diagnosed of MDR, further tests showed that she had XDR TB. Now she is taking treatment for XDR TB and showing signs of recovering.”

A senior activist who runs a voluntary group for TB patients called ‘Voice of Patients’ in Odisha narrated cases of women who came to her. She has often witnessed complex stories of neglect interacting with other social problems.

She narrated the case of a girl who contracted MDR TB from her brother. She was working and earning an income but was still neglected by her family. She was not cared for as much as her brother. Then she had to stop working because of the illness. After that the family stopped looking after her completely. They only looked after the brother. When she was near completion of her treatment, the girl stopped taking her medicines and began working again. Now she has resumed treatment and is under observation.

Another TB activist also told us about several women suffering from TB and HIV-TB being abandoned by their families at the Sahara residential facility for HIV and TB patients in Pune.

She also narrated the tale of an 18-year old woman who was in love with a man to whom she got married. Owing to class differences, the husband’s family did not welcome her. She got pregnant immediately after marriage and after going to her natal home for the delivery continued to stay there. Her husband was not working and she began working in a nursery where she became infected with MDR TB from a co-worker. She began to run a fever. The activist from the Voice of Patients narrated the following:

“They were from a ‘good’ family, so they never suspected TB. Her husband took her to a private doctor. She also came in contact with government services but the government doctor was ‘Khadoos’ (mean). He did not treat them well. When she stopped treatment in-between, the doctor abused

her. She again sought care at a private doctor's who only had X-ray equipment for diagnosis. He diagnosed her with DST and started on Cat I medicines. So MDR was not diagnosed. Private clinics lack systems to track patients. No sensitivity test for drugs or counseling was carried out, and she did not get better. She was later referred to Capital Hospital by the private doctor and diagnosed with Pulmonary MDR-TB. She was constantly worried for her husband and baby, and interrupted treatment frequently. When tested again she was found to have XDR-TB. She was eventually admitted to the Vivekanand Hospital where she died. When she died her weight was only 22 Kilos."

Gender is deeply ingrained in the working of society, as witnessed in this narrative by the project manager of a TISS (Tata Institute of Social Sciences) run project in Mumbai, 'Saksham'. Saksham trains and places counselors to assist patients with MDR-TB in the various District Tuberculosis Centers (DTCs) of Mumbai. The project manager also provides training inputs on gender and the barriers it poses for health workers. She narrated how TB field functionaries persuaded a woman to continue her treatment. "They tell her, "If you die, what will happen to your kids? Who will take care of them?" The project manager said, "We tell them to value the woman for herself. What if she did not have children? Does she deserve to die?"

Active Case Finding in TB

A senior health official in Odisha told us that ACF has helped to identify women patients early. ACF in rural communities is mostly done with the help of ASHAs in the community and that was a good confidence building exercise that allowed them to reach women in the community. PPM initiatives undertaken by REACH have demonstrated that providing access to newer diagnostics like GeneXpert to private practitioners have increased identification of DR- TB. Private Practitioners were keen that their DR-TB patients received the best care and were most willing to refer them to Government Hospitals, As these were large set ups, patients need to be guided into the system by REACH field staff.

As a suggestion, there can be steps taken to provide feedback to the PPs and a coordinator who can guide them through the various steps within the hospital. All patients would like to see and listen to a friendly guide while coming forward for Drug Resistant -diagnosis and treatment. Counselling on TB and how to cope with TB-Drug sensitive or drug resistant is important to patient and the family members.

Good Practice

Several respondents mentioned conducting health camps close to the community where all common illnesses including suspected TB would be addressed and patients right to confidentiality and future course of treatment would be maintained, as a good practice. So was creating and strengthening support groups for men and women TB patients to increase hand-holding and adherence with TB medication as well as reducing the stigma associated with the disease. Cured TB patients, also referred to as TB survivors, have been encouraged by civil society organizations such as REACH to be TB champions and activists in the community. This creates a pool of TB related knowledge in the community and easier access to accurate information, diagnosis and treatment options. The active involvement of women in these forums together with creating separate support groups for women would help encourage them to be TB champions without any coercion.

Policy Implications

The RNTCP should take cognizance of ‘gender and social barriers to access TB services’ in the National Strategic Plan 2017-2025 and chalk out specific steps to reduce these barriers.

5.4 Stigma and Discrimination

Both the literature review and interviews conducted are replete with stories of stigma and discrimination associated with TB. The literature review includes a systematic review of qualitative studies which assessed gender differences in access to TB diagnostics and treatment⁵⁰. The domains in which women and men suffer TB stigma vary as does the impact. The options available to mitigate such impact also vary. Counselors, health care providers, field functionaries, civil society representatives as well as TB survivors all agreed that women face greater stigma with far reaching implications on their lives. Respondents spontaneously shared stories, predominantly about women, when asked about stigma associated with TB. For women the stigma is mostly associated with marriage and marriage related problems, harassment and differential treatment within the household; whereas men experience a sense of shame because they cannot work, income levels drop and other women members of the household are required to work.

Stigma Linked to Marriage and Rejection

Among women, fears of TB related stigma usually surface at the time of marriage. Families fear that a diagnosis of TB threatens the prospect of marriage of their daughters⁵¹ and marriages are sometimes broken when the wife is diagnosed with TB. Women tend to hide the illness, keep treatment secret and refuse home visits by DPTS providers⁵², fearful that they may be sent back to their natal homes. Women with TB also face harassment and discrimination within the family. In one case documented

50 Krishnan et al. 2014 Khan 2012 McArthur, Bali, and Khan 2016.

51 Weiss et al 2006

52 Khan 2012; McArthur, Bali, and Khan 2016

by Khan, a woman neglected her cough for a month till a free government clinic diagnosed her with TB. Her husband dispatched her from their urban home in a slum, to her parents' home in a village, where she had no access to TB treatment. She took medicines from a local healer for a month till her husband agreed to take her back, after much pleading by her parents. She enrolled for TB treatment without telling him and had nearly completed her treatment at the time of the interview. She was determined to save her marriage.

Weiss et al found that the TB related stigma common among South Asian families (from India and Bangladesh) was rooted in the misconceptions that TB was dangerously contagious and incurable. The stigma affected women disproportionately causing them immeasurable mental trauma. Women with TB not only face rejection from the joint families they are married into, but at times from their natal families. Weiss documented extreme cases where some women with TB were instigated to commit suicide by the husband and the in-laws and of others who feared they would be killed. TB related stigma was found to be more widespread in India than in Bangladesh and Malawi.

Our interviews with health care providers, TB survivors, civil society activists and TB experts complement the above findings. Women said that getting married mattered more to them than being cured of TB. This belief directs the choices that both women and their families make, although the women have no guarantee of finding happiness and acceptance within marriage. ASHAs interviewed in rural Maharashtra narrated stories about young girls reluctant to approach them for TB care due to the need to hide the illness. Respondents told us that it is quite common for young women to be sent to the house of a relative to complete TB treatment discreetly or to be married off without divulging their TB diagnosis.

In another case, a young unmarried girl sought confidential treatment from the private sector for TB. However, because she did not get any information or counseling about adherence to treatment, she stopped treatment on her own when she felt better. When she fell ill again, she repeated the experience. The third time, she was diagnosed with MDR TB in a private hospital, which she confirmed in a government hospital. She was later cured with appropriate treatment and follow-up.

A counselor working with MDR-TB patients in Mumbai came across a young woman, who on being diagnosed with MDR-TB disappeared without any forwarding address. She had been married off and her family refused to disclose her location. Another counselor from Odisha recalled the instance of a young woman who, on learning she had MDR-TB, called off her marriage with the man she loved.

In another case a young woman was diagnosed with MDR-TB a month before her wedding to a friend. While the parents on both sides did not want to proceed with the marriage, she was lost to follow up for four months although counseled to take treatment. She married her friend, negotiated to stay separately, away from her parents-in-law and was ready to take treatment.

An ASHA shared the story of a woman from a vegetarian family, who after being diagnosed with EPTB was asked to supplement her food with eggs. With her husband's help, she was able to get and

eat the eggs in secret, but the couple feared that she would be sent home to her parents, if her TB status became known to his parents.

TB related stigma pushes families to seek care for daughters in the private sector while the same families do not mind their sons being taken to the public hospital. For instance, a single mother of three young daughters with symptoms of TB, who was the sole earning member of the family, nevertheless sought care from a private pediatrician, who diagnosed all three children with TB and traced the source of infection to their grandfather, who had TB.

Stigma Faced by the Elderly

TB related stigma affects elderly women in different ways. In one case an elderly widow who had become frail due to weight loss due to being deprived of nutritious diet, was further deprived of nutrition and kept away from her grandchildren after she was diagnosed with TB. With help from the counselor, the woman improved her diet and health, but chose to undertake a religious month long fast and died soon after. A chest physician spoke of how the elderly are often powerless to resist being sent back to their villages once they are diagnosed with TB due to fear of contagion in the cramped living conditions of cities.

All of the above observations suggest the need for systematic research of the impact of TB related stigma on women.

Good Practice

While extreme gender inequality, including the dependence of women on highly patriarchal families need to be redressed through fundamental societal change, psychosocial support and counseling can help remove misconceptions about contagion. They can also help the women value themselves better and work with them to find options to address problems. For example, A TISS counselor worked on a young woman's prospective parents-in-law and persuaded them to proceed with the marriage, even making it possible for the bride to take her Bedaquiline on the day of the wedding. The NSP (2017-2025) has created the post of a counselor at the district level to make psychosocial support available to all TB patients.

Recommendations

- Measures to increase case detection among women:
 - o Undertake awareness drives about TB, its signs and symptoms, modes of transmission, curability and need for early diagnosis and treatment, among women and generally in the community to bridge the gap in health literacy for women.
 - o Increase awareness about gender dimensions of TB among RNTCP staff, NHM staff and ASHAs.
 - o Articulate a clear 'Gender and TB' policy to make the RNTCP more gender responsive.

- o Conduct awareness campaigns to dispel the 'stigma' attached to TB.
- o Dedicate a budget to engage TB survivors from among local women, transgender and sex-worker communities especially in tribal areas, in the promotion of early diagnosis among women.
- o Track socio-cultural and health system delays in diagnosis of TB among women and men and use it as an indicator for the reach of the program.
- Recruit women and other genders on staff to constitute at least 50% of the RNTCP staff.
- Build the capacities of the RNTCP staff towards making the program 'gender sensitive'.
- Provide nutritional supplements to the family of female patients and compensate the costs of conveyance to health facilities and lost wages to ease womens' access to health services.
- Improve measures for confidentiality and privacy in the health system to ensure that women feel confident about accessing public health services.
- Recruit enough women and transgender people to constitute at 50% of the counsellors in the RNTCP, to help women negotiate the various challenges they face in the process of getting diagnosed and treated.

VI. Gender Barriers in Accessing Health Care Faced by Men

Men's lives too are affected by gender, though they often have more options than women to meet gender related challenges. We found that the main gender barriers that men face are linked to four factors:

- Men's role as the breadwinner in the household
- Smoking
- Alcoholism
- Intravenous Drug Use

Gender, Men and Masculinity

Men are expected to earn an income and run the household and this derives directly from their gender roles. On the other hand, gender also inflicts a pressure on men to appear strong, be masculine, hide their feelings and be ready to take risks, when required. This often translates into markers of masculinity such as smoking, drinking and taking risks regarding their health to become more acceptable in society. Therefore, while alcoholism and smoking among women is poorly accepted, these behaviors may be condoned or even encouraged by the prevailing gender norms for men. Wives and family members would be loath to question men's behavior, due to the power that men enjoy in the household. At the same time this acceptance of alcohol and tobacco consumption makes men easy targets of promotional advertising for these products. Smoking and alcohol consumption, particularly, are gender-linked barriers to TB diagnosis and treatment.

Issues linked to migration are not gender issues per se. On the other hand, men form bulk of the migrant workers and feeling compelled to migrate and fulfill their role as bread-winners is a gender and masculinities issue for men. In this context both social and health system issues which result in inadequate health care access to migrants, also disproportionately affect men.

Migrant Workers

A major challenge faced by the RNTCP with regard to TB among migrant workers is failure to complete treatment. The program tries to establish a continuity of care for migrant workers through

a system of forwarding the addresses provided by migrant workers the particular state and district RNTCP units. In practice, the system works poorly both for both the patients and the health system. Migrant workers are often impoverished and with the issues of survival on a daily basis, and the continuity of TB care is rarely their priority. Many migrant patients discontinue treatment without giving a forwarding address. In all probability they do not have a forwarding address to give. Many fear that they may lose employment by openly declaring that they have TB and hesitate to share their employers' addresses with the program. Often, they lack any effective means of communication including stable cellphone numbers, making it difficult for the RNTCP to track patients who miss treatment. Lack of awareness about drug resistance forms an important barrier to the continuity of treatment to completion. A senior health official in Delhi pointed out that health systems both at the place of origin and the place of work both need to be sensitive to the needs of migrant workers to ensure quality care to completion of treatment.

Smoking

Several studies note the linkages between smoking and increased incidence of TB as well as TB related morbidity and mortality⁵³ Smoking increases the risk of TB and half of all TB deaths are associated with smoking. People who have ever smoked are three times as likely to report having had TB, as do non-smokers. Smokers in the age group of 25 to 69 years have a substantially higher mortality for TB. In an at-risk population, a higher proportion of smokers developed clinical TB due to poor adherence to treatment for Latent TB.

Alcohol consumption

A number of studies in Indian and international settings have shown that heavy alcohol consumption is associated with a higher incidence of TB, greater rate of default during treatment, higher treatment failure rates and higher mortality.⁵⁴

In Chennai, Dhanaraj and others found a significant association of alcohol dependence and the risk of contracting sputum positive and culture positive Pulmonary TB among undernourished men. A meta-analysis of alcohol consumption and TB risk, additionally found an increased risk of TB with increase in alcohol consumption. Alcohol intake was responsible for 22 incident cases and 2.35 deaths per 100,000 people globally in 2014. TB linked to alcohol consumption increased from 2000 to 2014 in all high prevalence countries. At the same time the mortality attributable to TB associated with alcohol decreased.⁵⁵

Kollappan and others found that male smokers who were alcohol dependent had a significantly higher mortality (approximately 11 times more than the general population) on account of TB. They recommend that along with monitoring standardized death rates, ACF should also be instituted among those with these risk factors and that the latter should be used to monitor the performance

of the RNTCP.

53 Gajalakshmi et al. 2003; Kolappan et al. 2006; Lavigne et al. 2006 ;Jain et al. 2014

54 Dhanaraj et al. 2015

55 *ibid*

Studies on MDR-TB show that adherence to treatment, treatment outcomes and mortality are higher for TB patients dependent on alcohol. Jain et al found both smoking and drinking independently associated with poor treatment outcomes in the DOTS-Plus regimen for MDR patients in the RNTCP⁵⁶. Cox et al found that prior history of heavy drinking among MDR-TB patients was significantly related to default in the treatments.⁵⁷ Prior history was used as a proxy indicator for alcohol addiction since alcohol consumption was strictly discouraged during the regimen and study period. A study by Kliiman and others found that alcohol consumption was significantly associated with poor treatment outcomes in MDR patients.

Several State TB Officers (STOs), District TB Officers (DTOs), Medical Officers (MOs) and TB experts told us that alcohol consumption is linked to the majority of treatment defaults. A senior TB expert told us that the RNTCP needs to focus more on supporting drop-outs to resume treatment.

People who use drugs (PUD) and People who inject drugs (PWID), (formerly referred to as Intravenous Drug Users (IDUs))

In a drive to test Intravenous Drug Users (IDUs) in Delhi, the STO of Delhi, told us that they identified a high proportion of IDUs with TB, and most of them were men. Similarly, other drug users such as street children from Delhi and Chennai who inhaled drugs, *chillum* smokers of *ganja* and *hashish* and *safi's* and urban rag-pickers known to use drugs may also be highly susceptible to TB. PUDs in general and PWIDs in particular, are generally excluded from mainstream society because of their addiction. Some PWIDs may also be suffering from HIV, which is an added risk to contract TB. Their addiction, the stigma attached to it and the discriminatory attitudes they face in the healthcare system keep them away from accessing health services. Among these groups, under-nutrition is a common risk factor. The NSP 2017-25 identifies these groups as key populations for TB. Supportive measures need to be instituted among these groups to diagnose TB, help them comply with treatment as well as undergo de-addiction with dignity.

Policy Implications

The NSP 2017-2025 includes initiatives to identify tobacco/alcohol users among those with TB symptoms who visit public health facilities and support them to quit tobacco/alcohol use as well as provide screening for TB. The RNTCP proposes to partner with the National Program for the Prevention and Control of Cancer, Diabetes, Cardiovascular disease and Stroke (NPCDCS) and the National Tobacco Control Program to screen for TB. Treatment counsellors are to be appointed at each health facility to support adherence to treatment.

Need for male DOTS providers

ASHAs have helped improve adherence to TB treatment compliance in rural areas by becoming the DOTS provider who is based in the village itself, thereby saving patients- both women and men – trips to a DTC. At the same time, ASHAs who are mainly women, face difficulties in counseling men

56 Jain et al. 2014

57 Cox et al.2007

who are alcohol dependent. There is a need for male field functionaries living in the villages who can support alcohol dependent TB patients to adhere to treatment.

Recommendations

- Create awareness among smokers and alcohol addicts about the risk of TB.
- Implement screening of TB patients to know whether they smoke or consume alcohol so that patients at risk of default of treatment are identified early on, as described in the NSP 2017-25
- Employ counselors and train RNTCP staff to provide support to smokers and alcohol addicts to adhere to treatment.
- Facilitate those who are alcohol or drug dependent to enroll in de-addiction programs.

VII. Gender and Nutrition in TB

High risk of TB on account of Undernutrition

Malnutrition is the most common, widely prevalent risk factor for TB in India and it is responsible for the highest proportion of TB cases in India among men, women and other genders compared to any other risk factor. Bhargav and colleagues (2014) used data on under-nutrition from the large and representative NFHS 3 survey (2005-06) together with Cegielski et al's relative risk of TB of 4.49⁵⁸ to show that the 'Population Attribution Fraction' (PAF) of under-nutrition as a causal risk factor for TB is more than 50% in India. The PAF of TB with respect to a particular risk factor and population is the proportion of TB cases which would have been reduced - if this risk factor was absent. To provide a comparative reference, an earlier estimation of PAF of under-nutrition in relation to TB in India was calculated to be 31.6% while the PAF of HIV was 5%, for diabetes it was 9% and for smoking it was 11%. This shows that the contribution of under-nutrition to incidence of TB is far greater than it is for HIV, smoking or diabetes⁵⁹.

Addressing under-nutrition is a crucial and neglected policy priority in India. While the acquired immune-deficiency following HIV has been recognized for many years, acquired immune deficiency on account of under-nutrition in India is much higher, has been there from much before the HIV epidemic and it's prevention and cure known for decades. Under-nutrition compromises cell mediated immunity and renders a person vulnerable to TB disease.

Health officials and managers of the TB program, medical officers, field functionaries, TB experts as well as TB survivors and activists all reiterated the crucial role played by nutrition in TB on the basis of their professional and personal experience. Daily, adequate and regular meals hasten the recovery from TB as well as increase the tolerance of TB medications. They stressed that a special diet is not required for TB but that homemade, regular meals containing a combination of items namely rice, wheat, other millets, vegetables, *dals*, dairy and/or non-vegetarian items are adequate nutrition for TB patients. They noted that treatment failures are often linked to lack of nutrition. Many respondents also told us that TB was more likely to become active when the nutrition levels decline.

58 Cegielski, Arab, and Cornoni-Huntley 2012

59 Lönnroth et al. 2010

The National Health Mission has cleared a Direct Benefit Transfer (DBT) scheme to transfer Rs 500/- to the bank accounts of all TB patients in order to help them buy better nutrition. It may be useful to undertake a comparative study of provision of direct nutrition to the TB patient's family vs. DBT to arrive at the ideal way to provide the best nutritional support to the patient. Nutrition support to families with a TB patient may be better than linking nutritional support to the individual patient, as mentioned by a TB expert. It is common to see more than one TB patient in a family, especially in the poorer sections of society and in tribal areas. This strengthens the analysis that family members share vulnerability to TB. The RNTCP rightly emphasizes contact tracing when TB diagnosis is confirmed, recognizing the risk to those in immediate contact with the patient. Similarly, recognizing that under-nutrition increases the risk of TB, nutrition support needs to be extended to the entire family.

Age, Sex and Social Group PAF of Under-nutrition

While it is imperative to address the issue of nutrition across genders, priority needs to be accorded to those whose risk of TB is further compounded by age, sex and social group. The risk is the highest in the age group of 15 to 19 years (PAF in boys is 67% and girls is 62%). The levels of under-nutrition and TB risk are higher for women as compared to men in the age groups of 20 to 39 years, a period associated with maximum reproduction⁶⁰.

The poorest and poorer classes fare the worst (PAF ranging from 59.7% to 64.3%) with women in both groups faring worse than men. Often there are multiple TB patients found in the same household indicating that under-nutrition is not an individual characteristic but rather a symptom of poverty and social marginalization.

Among social groups the PAF of under-nutrition to TB is highest among the Scheduled Tribes (ST), followed by the Scheduled Castes (SC), then the Other Backward Classes (OBC) and then the general category. Among these in each category women fare worse than men, the worst faring being ST women (PAF 62%) (Bhargava et al. 2014).

Traditional Social Norms further handicap Women

Besides the specific and higher risks of under-nutrition that women face, they are specifically handicapped by social norms that make their health and well-being a low priority. Respondents shared how it was normal practice for women in the household to eat last and eat leftover food. Women commonly forced to hide their TB disease from the family are further challenged to access nutrition. While men have mobility and finances to eat when they feel hungry, these options are often closed to women.

India has thus far implemented several discrete schemes to tackle malnutrition. In 2017, the country developed a National Nutrition Policy, with the aim of addressing the longstanding problem of nationwide malnutrition in a comprehensive fashion. While the government has initiated the disbursement

⁶⁰ Bhargava et al. 2014.

of a monthly sum to TB patients to help them buy nutritious foodstuff, a detailed policy to address undernutrition in particular relation to TB needs to be clearly articulated.

By and large, a woman's nutritional needs are most likely to be met when she is pregnant. The National Nutrition Policy mentions the following measures to improve maternal care and nutrition: (i) supplementary nutritional support during pregnancy and lactation, (ii) health and nutrition counselling, (iii) adequate consumption of iodised salt and screening of severe anaemia.

RNTCP's role in providing nutritional support

Without a collaborative arrangement with the National Nutrition Mission, the RNTCP would be hard pressed to ensure nutrition for TB patients. Earlier attempts to do so have put an enormous strain on RNTCP program personnel. For example, in Mumbai, the RNTCP has been asked to invite tenders to procure stocks of grains and food supplies and make arrangements to distribute these to TB patients. RNTCP state programs do not seem to have the staff, facilities or skillsets essential to undertake the kind of work usually carried out by the PDS.

Good Practice

Kerala has implemented a scheme to provide additional rations to TB patients and their families through the PDS in a confidential manner. This system can potentially become a model for other states.

The Sahara Aalhad center in Pune provides counseling to their TB patients, as well as provides dry rations and recipes of how to augment nutrition values of common foods. They realized that only medical treatment of TB was not sufficient nor was it found to be a long term solution, instead they found that nutrition was an important factor that helped patients recover faster. The NGO hired a nutritionist to give the patients fortified wheat flour, chickpeas and other such foods. They also increased the number of meals from 3 to 5 per day and noticed that people started recovering and their hemoglobin counts rose gradually. According to the nutritionist's recommendation, who felt that the health and nutrition of the entire family was important Sahara also started giving 15 day's worth of dry rations to the families of patients suffering from TB.

The Resource Group on Community Education and Health (REACH) began giving nutritional support to TB patients from 2008 onwards. Five 5 kg of rice and 1kg of lentils were provided to each patient per month and the initiative is now run through an online provider who directly delivers the dry food rations to the patient's house. Providing nutritional and adherence support to TB patients has acted as an "enabler" to successfully complete TB treatment. Supporting patients with nutrition, auxiliary drug support, cost of travel to doctor's clinic and for investigations, gives patients a feeling of comfort and has a positive impact psychologically to cope with TB. Providing support to patients was also seen to strengthen the " provider patient bond" which is crucial for successful outcomes.

Recommendations

- Carry out TB screening of undernourished people approaching the health system.
- Active case finding needs to be guided by the understanding that undernourished persons are more at risk of the disease.
- Provide all diagnosed TB patients and their families additional rations from the Public Distribution System. Merely providing for the patient is not enough.
- Compensate loss of wages during the intensive phase of the treatment. This support should extend for 18 to 24 months in case of MDR-TB patients.
- Provide counseling to all patients particularly women and girls.
- Undertake awareness campaigns on the importance of nutrition in TB care.

VIII Conclusion

- An urgent requirement is for RNTCP to make age and sex disaggregated data public for successive years which will also provide time-trends of the changes in TB epidemiology over the years.
- Alcohol addiction is one of the leading causes of non-compliance with TB treatment and poor outcomes in men. RNTCP has good monitoring systems, but mechanisms to support and ensure treatment adherence by TB patients, especially those afflicted by alcoholism and drug addiction, is needed.
- Scheduled Tribe (ST) women are the worst affected in TB detection and treatment. They face the combined effect of poorer access to health care due to physical, financial, transportation, gender linked barriers as well as severe undernutrition.
- Pregnant and post-partum women are at higher risks of contracting TB. Pregnant and post-partum women with TB and TB-HIV co-infection have poor maternal and infant health outcomes. They need to be recognised as key populations and urgent steps need to be taken for their early diagnosis and effective treatment.
- Transgenders and sex-workers, are examples of marginalised populations that need to be incorporated into the public health priorities for TB.
- Undernutrition is a major risk factor for TB in both men and women, and substantially increases risk of TB, results in poorer outcomes, poorer adherence with treatment as well as possibility of relapse. Given the huge proportion of the problem and its contribution to TB, undernutrition in India should be tackled at the population and family level. The Government of India will have to take cognisance of this and take appropriate steps.
- Gaps in the RNTCP which need to be bridged are:
 - The lack of women staff, including staff which have substantial interface with TB patients. This impedes women-friendly services and reinforces the belief that TB is a 'men's' disease.
 - There are no counsellors employed by the RNTCP (except for DR-TB) and the existing RNTCP staff has very high work load.

- Difficulties faced by women because of the need to attend the DTC daily for DOTS, the stigma attached to home visits, lack of information provision, counselling, consent, confidentiality and privacy and poor attitudes of health staff create difficulties to access care.
- The need for multiple visits before diagnosis is confirmed, difficulties in getting appropriate referrals and lack of guidance while negotiating care in medical college hospitals.
- The incomplete integration of the RNTCP with the National Health Mission.

Good Practices that may be adopted:

The following good practices serve as models for scaling up and continuation by the RNTCP.

- MDR counsellors employed on project basis by TISS (Tata Institute of Social Sciences), MSF (Medecins Sans Frontieres) and others are showing the way to support MDR patients to complete treatment. Such counsellors are equally required in the RNTCP to support Drug-susceptible Tuberculosis (DST) and DR-TB cases as well since both face similar complex issues with adherence and side effects.
- Use of X-ray equipped mobile vans in tribal areas
- Homes such as the Sahara Aalhad home in Pune for near-destitute TB and HIV-TB patients
- Nutrition supplementation and patient support programs by NGOs
- Support groups and TB champions in the community
- Health Camps in the locality of poor and marginalised communities to enable detection of TB along with other ailments, thus also ensuring confidentiality and privacy to TB patients

It is clear that the RNTCP needs to inculcate a comprehensive gender lens in its working to enable a better-informed response that may inspire new strategies and new research needed to end TB in India. An expert group may be set up to devise a Gender and TB policy and develop a gender mainstreaming strategy for the RNTCP. The recommendations provided in this report, if implemented, have the potential to help the RNTCP to accomplish its goals of equitable and better case detection and treatment of TB in India among men and women, in turn facilitating progress towards the attainment of the Sustainable Development Goal (SDG) linked to TB for India.

Annexure 1: State-wise distribution of interviewees

State/ Interviewee	Female	Male	Total
Delhi	9	13	22
Civil Society Representative	1	1	2
Clinician	1		1
Field Functionary		6	6
Health Official/Manager	2	3	5
Medical Officer	1		1
Social Scientist /Researcher	1		1
Senior Health Official/Manager		2	2
TB Survivor / TB Activist and/or Touched by TB member	2	1	3
WHO Consultant to TB program	1		1
Maharashtra	10	10	20
Chest Physician	1		1
TB Counselor		1	1
Field Functionary	3	3	6
Health Official/ Manager		5	5
MDR TB Counselor	1		1
NGO/Social Project Manager (MDR TB)	1		1
Senior Health Official/ Manager	2		2
Social Scientist	1		1
TB Survivor	1	1	2
Odisha	7	11	18
Field Functionary		2	2
Health Official/Manager	1	7	8
NGO/ TB project manager and TB activist	1		1
Scientist/ Researcher	1	1	2
Senior Health Manager	1		1
Social Scientist		1	1
TB Survivor and TB survivor's sister	2		2
Representative from the Transgender community	1		1
Others	3	7	10
Senior Health Officials/ Managers		2	2
Social Scientist/ Researcher	2		2
Clinician and Public Health Expert		1	1
Chest Physician/ TB Expert and Public Health Specialist	1	4	5
Grand Total	29 (1TG)	41	70

Annexure 2 District-wise New Sputum Positive Cases in Mumbai, 2016

	0-14		15-24		25-34		35-44		45-54		55-64		>65		Total	Total	% of fe- males	
	M	F	M	F	M	F	M	F	M	F	M	F	M	F				
Andheri East	1	8	44	51	41	24	35	8	26	12	13	5	15	5	175	113	288	39
Andheri West	1	10	49	37	28	26	37	13	26	12	13	9	10	6	164	113	277	41
Bandra East	3	8	62	37	32	23	33	7	23	4	10	3	4	2	167	84	251	33
Bandra West	1	3	19	23	11	7	14	6	12	5	6	2	4	1	67	47	114	41
Bail Bazar Road	2	5	47	41	25	25	22	7	19	5	9	3	8	6	132	92	224	41
Byculla	1	3	30	25	33	11	31	4	15	3	11	4	5	4	126	54	180	30
Borivali	0	4	23	11	21	16	12	3	19	4	8	5	10	4	93	47	140	34
Colaba	2	7	11	18	21	13	16	8	23	4	11	4	8	1	92	55	147	37
Chembur	3	16	56	41	44	18	27	8	20	6	11	9	2	1	163	99	262	38
Centenary	1	7	44	70	35	26	28	6	22	6	16	3	4	4	150	122	272	45
Dadar	1	6	40	41	38	15	30	15	23	2	14	5	4	5	150	89	239	37
Dahisar	0	1	35	25	23	12	15	5	10	6	4	6	6	1	93	56	149	38
Ghatkopar	1	6	44	43	35	15	21	11	15	3	6	7	0	2	122	87	209	42
Goregaon	0	1	44	28	27	17	18	5	28	7	13	4	4	1	134	63	197	32
Grant Road	1	0	18	6	13	9	13	2	20	3	3	3	3	2	71	25	96	26
Govandi	7	9	25	63	35	23	25	15	20	12	9	5	5	4	126	131	257	51
Kandivali	6	7	54	63	33	18	33	9	20	6	8	7	9	6	163	116	279	42
Kurla	2	4	20	24	10	10	8	5	4	3	6	3	4	1	54	50	104	48
Malad	3	8	109	106	77	45	45	22	31	18	31	11	15	6	311	216	527	41
Mulund	0	1	14	9	15	7	18	2	7	0	8	2	3	3	65	24	89	27
Prabhadevi	0	1	21	17	21	13	18	7	16	6	17	4	7	4	100	52	152	34
Parel	1	1	30	28	39	13	37	6	32	8	21	7	8	3	168	66	234	28
Sion	3	5	52	54	34	24	38	19	27	10	12	14	10	2	176	128	304	42
Vikhroli	3	9	48	52	44	36	28	10	17	20	13	7	6	6	159	140	299	47
Kalyan Dombivli MC	2	8	77	72	56	37	56	13	37	17	16	9	6	3	250	159	409	39
Navi Mumbai	8	18	133	129	98	85	82	25	50	13	37	19	12	8	420	297	717	41
Total	53	156	1149	1114	889	568	740	241	562	195	326	160	172	91	3891	2525	6416	39
% of females in total cases		75		49		39		25		26		33		35		39		

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The Gender Assessment Tool is one of three tools that forms part of the Communities, Rights and Gender Assessments. This report presents the findings of the rapid assessment of Gender and Tuberculosis (TB) conducted in India in 2017-18. The rapid assessment confirms that TB affects different genders differently, affecting vulnerability to TB, its diagnosis, access to treatment, adherence to treatment, the availability of supportive care and treatment outcomes. The report also highlights issues linked to TB and pregnancy as well as the gendered nature of nutrition in India.

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