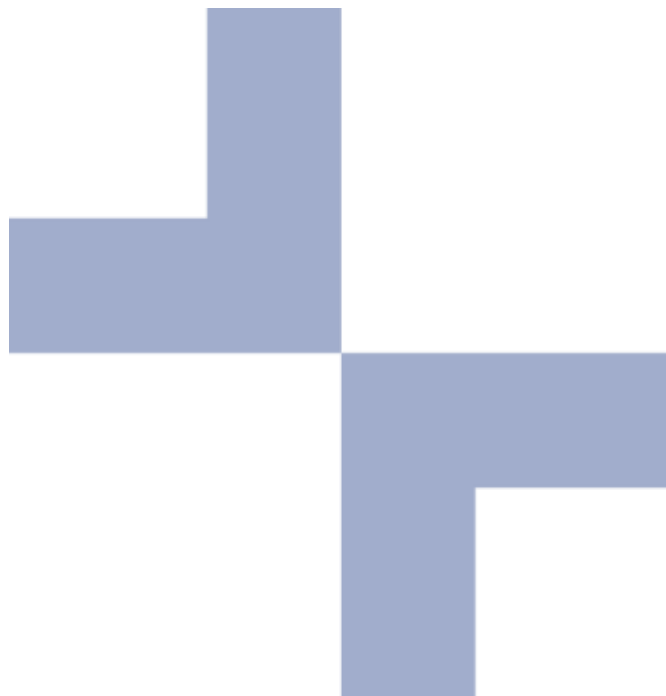

Understanding Stigma and Discrimination Associated with Tuberculosis

Unraveling a Silent Barrier to TB Care in India



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About SHOPS Plus: Sustaining Health Outcomes through the Private Sector (SHOPS) Plus is USAID's flagship initiative in private sector health. The project seeks to harness the full potential of the private sector and catalyze public-private engagement to improve health outcomes in family planning, HIV/AIDS, maternal and child health, and other health areas. SHOPS Plus supports the achievement of US government priorities, including preventing child and maternal deaths, an AIDS-free generation, and supporting the goals of FP2020. The project improves the equity and quality of the total health system, accelerating progress toward universal health coverage.

About SHOPS Plus India: The Sustaining Health Outcomes through the Private Sector (SHOPS) Plus project in India is an initiative to increase the use of family planning, maternal, neonatal and child health, and tuberculosis (TB) treatment products and services among the urban poor by harnessing the potential of the private sector and catalyzing public-private engagement. The project's TB activities focus on improving TB control and care through social and behavior change communication (SBCC) support to the Central TB Division and through leveraging the National Urban Health Mission's (NUHM) platform.

The SHOPS Plus India project builds on past successes and lessons learned from investments made by the United States Agency of International Development (USAID) in private sector solutions. These include the Private Sector Partnerships (PSP)-One, Market-Based Partnerships for Health (MBPH), and Strengthening Health Outcomes through the Private Sector (SHOPS) projects implemented by Abt Associates in India.

These projects have demonstrated the effectiveness of SBCC in increasing uptake of health products and services, harnessing innovations and resources of the private sector for improving health outcomes, demonstrating effective public-private engagement approaches, and implementing market-based approaches to reach underserved populations with health products and information in a sustainable way.



Abt Associates Inc.
6130 Executive Boulevard
Rockville, MD 20852 USA
Tel: +1.301.347.5000
abtassociates.com

American College of Nurse-Midwives | Avenir Health
Broad Branch Associates | Banyan Global | Insight Health Advisors
Iris Group | Population Services International | William Davidson Institute at the
University of Michigan

Understanding Stigma and Discrimination Associated with Tuberculosis

Unraveling a Silent Barrier to TB Care in India

Disclaimer: The author's views expressed in this publication do not necessarily reflect the views of the United States Agency for International Development or the United States government.

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Acronyms

ACSM	Advocacy, Communication, and Social Mobilization
ALERT INDIA	Association for Leprosy Education, Rehabilitation and Treatment-India
CB-NAAT	Cartridge-Based Nucleic Acid Amplification Test
DOTS	Directly Observed Treatment, Short-course
FGD	Focus Group Discussions
GOI	Government of India
HIV/AIDS	Human Immunodeficiency Virus infection and Acquired Immune Deficiency Syndrome
IDI	In-Depth Interviews
IEC	Information, Education and Communication
ISMH	Indian Systems of Medicine and Homeopathy
KHPT	Karnataka Health Promotion Trust
LGBT	Lesbian, Gay, Bisexual, and Transgender
LTBI	Latent TB Infection
LTFQ	Less-Than-Fully-Qualified
MBPH	Market-Based Partnerships for Health
<i>M. tb.</i>	<i>Mycobacterium tuberculosis</i>
NSP	National Strategic Plan for Tuberculosis Elimination 2017–2025
POMM	Practitioners of Modern Medicine
PSP	Private Sector Partnerships
REACH	Resource Group for Education and Advocacy for Community Health
RNTCP	Revised National Tuberculosis Control Program

SBCC	Social and Behavior Change Communication
SHOPS	Sustaining Health Outcomes through the Private Sector
TB	Tuberculosis
USAID	United States Agency of International Development
WHO	World Health Organization

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Finally, the project would like to express deep gratitude to the participants of the focus group discussion and in-depth interviews, as well to as the public health experts who shared their knowledge and experience, including those interviewed for the gender analysis.

Executive Summary

This report on understanding stigma and discrimination associated with tuberculosis (TB) captures insights from a rapid qualitative assessment. There are three strategic reasons to invest in reducing TB-related stigma and discrimination, both to halt the process that results in stigma and discrimination, and to mitigate their adverse consequences:

1. Better and faster realization of India's goal of TB elimination.
2. Reduced catastrophic costs and better resource utilization.
3. Higher acceptance and utilization of program services.

Addressing stigma and discrimination with a **vision of 'stigma-free TB care'** is a critical step toward achieving India's aim of a TB-free India with zero deaths, disease, and poverty due to TB, by 2025.

The World Health Organization estimated that the global incidence of TB in 2017 was 10 million, with 1.57 million people dying of this preventable and treatable disease. Partly because of its huge population, India carries over a fourth of this burden.

The Government of India (GOI) developed, and is rolling out, the National Strategic Plan for Tuberculosis Elimination 2017–2025 (NSP). The NSP is supported by the GOI at the highest political and administrative levels.

TB is an airborne disease. It is curable, and its transmission diminishes rapidly once effective treatment is initiated (Schwartzman and Menzies 2000). In India, basic awareness of TB ('heard of TB') is high at 87 percent. However, knowledge of TB transmission, and of its diagnosis and treatment, remain low.

Though anyone can get TB, the urban poor are particularly vulnerable due to overcrowding, poor ventilation, undernutrition, social deprivation, and migration. This rapid assessment and the recommendations of this report are therefore focused on lower-income sub-populations living in Indian cities.

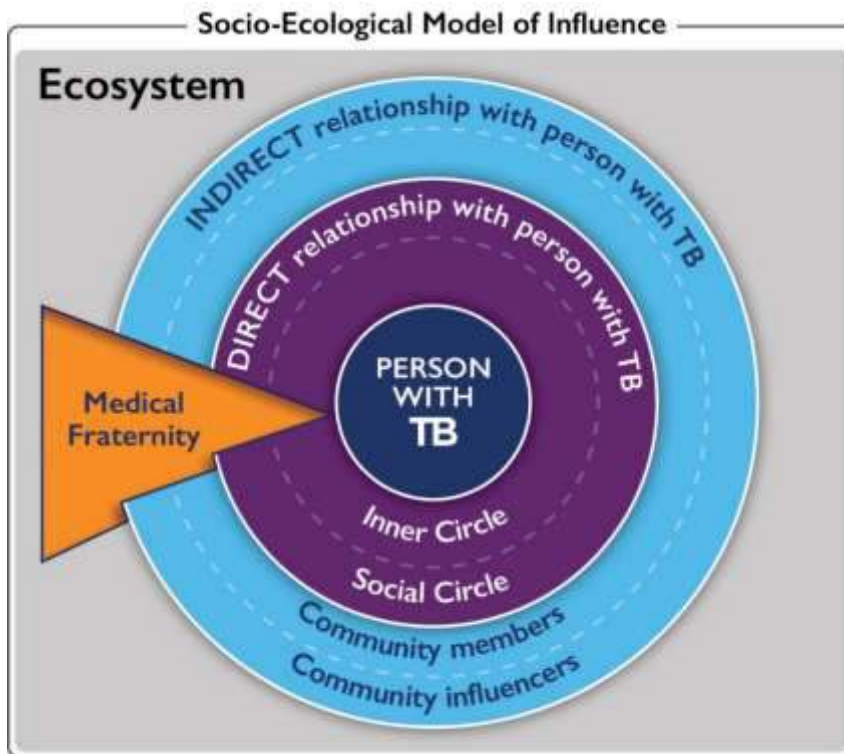
The Sustaining Health Outcomes through the Private Sector (SHOPS) Plus project used and carried out a multi-fold methodology to understand stigma and discrimination linked to TB. This was conducted in collaboration with partner organizations supporting the Revised National Tuberculosis Control Program (RNTCP). The methodology included: (a) desk research on the existing information about stigma and discrimination associated with TB and a review of anti-stigma advertising campaigns related to various health areas in India; (b) focus group discussions with the urban poor, persons with TB, their caregivers, and frontline health workers involved in TB care; (c) in-depth interviews with health care providers; (d) technical discussions with key stakeholders, including on gender; and (e) individual and organizational in-field experiences of individuals and partners.

Stigma is a "...phenomenon whereby an individual with an attribute which is deeply discredited by his/her society is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoils normal identity."

Erving Goffman, 1963

Stigma is described as a phenomenon whereby an individual with an attribute that is deeply discredited by her/his society is rejected as a result of that attribute. Erving Goffman, a noted sociologist, in his book 'Stigma: Notes on the Management of Spoiled Identity' (first published in 1963) saw stigma as a process by which the reaction of others spoils normal identity. Stigma disqualifies the individual from full social acceptance. There are various types of stigma: social or public stigma, self-stigma, perceived stigma, anticipated stigma, health care provider stigma, and also structural or institutional stigma.

Figure 1: The socio-ecological model of influence



TB has for centuries been treated as a fatal illness resulting in prejudice, discrimination, and isolation. It has been showcased through a lens of foreboding and stereotypes, even in Indian cinema. Stigma around TB tends to be latent and manifests when someone is known to have the disease. Stigmatizing attitudes are present in 73 percent of the population, and discriminatory attitudes toward the person with TB in 98 percent (Sagili, Satyanarayana, and Chadha 2016).

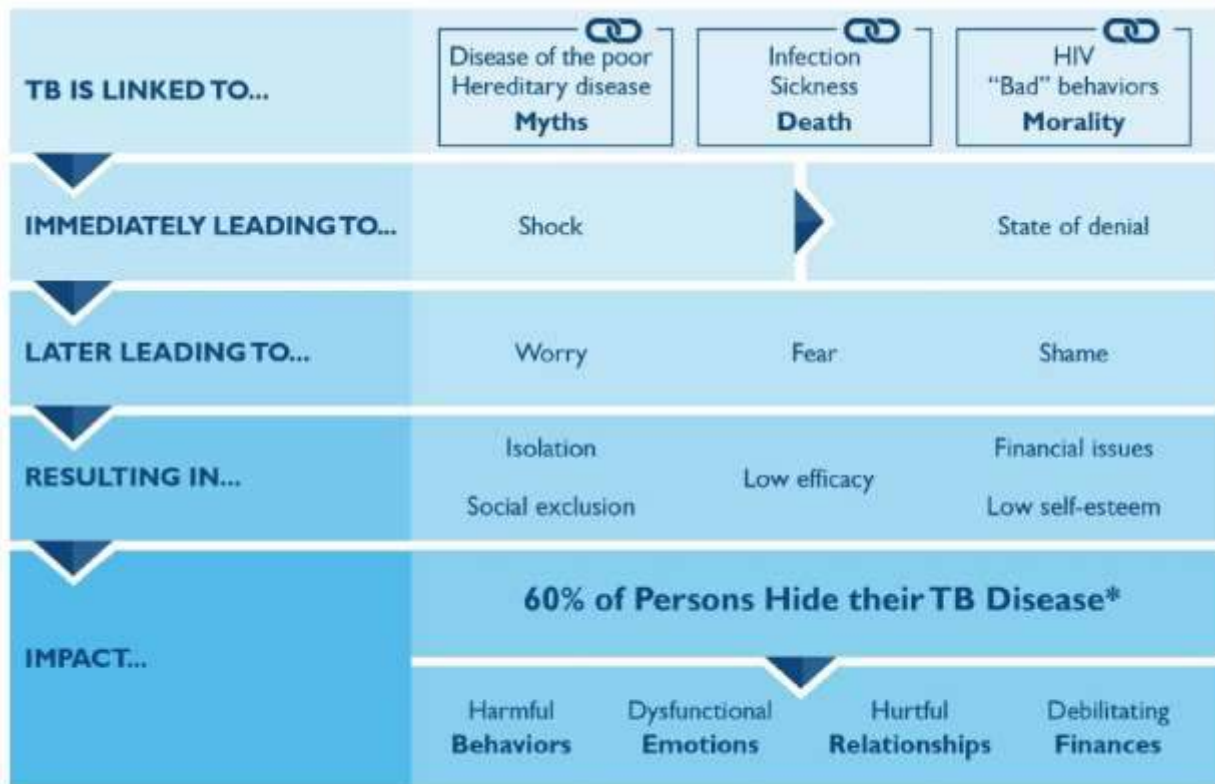
This report uses the socio-ecological model (Centers for Disease Control and Prevention 2019) to

understand how stigma influences people who are directly or indirectly connected to persons with TB disease. It details how stigma and discrimination are perceived or felt by people affected by TB (including persons with TB disease, their families and friends, and those who are emotionally invested in such persons) and how it influences others who are not emotionally connected, but who, out of fear or prejudice, behave in ways that adversely impact those affected by TB.

The main reasons for stigma are (a) the fear of TB infection—the sub-text being the belief that TB will never be cured, that the treatment is long and drawn out, and the perception that it eventually leads to death; (b) the fear that TB leads to economic disaster; (c) prejudice about the person with TB and believing that the disease afflicts those who do 'bad things'; and (d) a belief that it is the societal norm: doing what others, who stigmatize and discriminate against persons with TB, do.

Stigma has consequences on the mental, social, personal, physical, and financial health of persons with, and affected by, TB. These consequences influence each other, leading to an overall adverse domino effect. The consequences of stigma and discrimination affect men and women differently.

Figure 2: Impact of stigma and discrimination in TB, and factors leading to them



*Dhingra, V.K., & Khan, S. (2010). A sociological study on stigma among TB patients in Delhi.

A study has shown that due to stigma, 60 percent of persons with TB hide the disease from friends and neighbors, and that it harms their behaviors, emotions, relationships, and finances (Dhingra and Khan 2010). These consequences delay TB diagnosis and affect treatment outcomes, and have an impact on the health of individuals and their families.

Studies have shown that stigmatizing behavior is not inversely related to knowledge. A U.S. Surgeon General's Report in 1999 concluded that while stigma was expected to abate with increased knowledge, what occurred was just the opposite: stigma intensified, even though understanding improved (Martin, Lang and Olafsdottir 2008). The essence of this conclusion is reflected in a more recent TB-related study published in 2016, which concludes that stigmatizing and discriminatory attitudes toward TB patients remain high among the general population in India and that these attitudes are independent of the knowledge regarding TB. It adds that the knowledge disseminated about TB is mainly medical, and may not adequately address the factors that lead to stigma and discrimination toward persons with TB (Sagili, Satyanarayana, and Chadha 2016).

Increasing knowledge alone will not change the prejudiced attitudes, stigmatizing and discriminating behavior of the people represented through the socio-ecological model of influence. There is need to show behaviors that are positively deviant.

A change, with collaborative effort, is required for reduction in stigma and discrimination. Within the entire socio-ecological model of influence, there is a need to build a solid voice of reason by addressing reasons for stigmatization and discrimination and to create and leverage stakeholders who exhibit positive deviance and influence people in the socio-ecological model of influence.

For an effective disease control program, the management of TB needs to be social as well as medical, with each complementing the other. Standards for TB care need to be enabled, simultaneously with efforts to reduce stigma and discrimination. A paper by Ogden et al. suggested a paradigm shift in TB control and concluded that TB control programs must address the social dimensions of TB, and adhere to the principles of good TB care with the same commitment that is devoted to ensuring that people with TB follow treatment guidelines (Ogden et al. 1999).

Reduction of stigma and discrimination, addressed through a gender lens and administered differently among men and women, will help make TB care services equitable and empower persons with TB, particularly women, to manage the serious socioeconomic consequences of the disease.

It is vital to invest in the reduction of TB-related stigma and discrimination, in order to halt the stigmatization process and mitigate discrimination.

Addressing stigma and discrimination, with a **vision of stigma-free TB care** is a critical step toward better and faster realization of India's goal of TB elimination, reduced catastrophic costs, and higher acceptance and utilization of RNTCP services and resources.

Overview of this Report

The reduction of stigma and discrimination associated with tuberculosis (TB) will complement other ongoing efforts to end TB in India. Including this social element to TB management can contribute substantially toward TB elimination. Along with improving health outcomes, the reduction of stigma in TB will also help in the mental, emotional, social, and financial well-being of the persons with TB. Stigma reduction, addressed through a gender lens and administered differently among men and women, will help make TB care services equitable, and empower the person with TB, particularly women, to manage the serious socioeconomic consequences.

This report will help readers understand:

1. TB as a disease, and in brief, its burden on the country.
2. Stigma and discrimination and its manifestations in health.
3. The people who matter to persons with TB, identified using the socio-ecological model of influence.
4. Factors and stereotypes influencing people's behaviors, and their impact on TB-affected persons.
5. The need for a complementary approach of social and medical management, and collaborative change from all in the socio-ecological model of influence, to halt stigmatization and discrimination, and to mitigate their adverse consequences.
6. The need to invest in the reduction of stigma and discrimination to help achieve the vision of ending TB in India by 2025.

This report is relevant to organizations and persons wanting to end TB in India.

TB Care in India

About TB

Tuberculosis (TB) is an ancient infectious disease caused by a bacteria called *Mycobacterium tuberculosis* (*M. tb.*). It nearly always spreads from one person to another through the air. When a person with pulmonary TB coughs, sneezes, spits, shouts or sings, invisible droplets carry the bacteria into the air. Transmission occurs when infected droplets are inhaled by another person and reach inside the lungs. TB is not spread by touching or hugging, sharing food or drink, handling bed linens or toilet seats, or kissing (Centers for Disease Control and Prevention 2016).

As we all breathe the same air, anyone exposed can get TB. How the infection manifests after entering another person, however, depends on several factors, but most importantly, on the new host's ability to resist and fight the bacteria. The urban poor, in particular, are highly vulnerable to TB due to overcrowding, poor ventilation, undernutrition, (World Health Organization South-East Asia 2019).

Not everyone who inhales the bacteria becomes sick with TB disease. In most cases, the body's defenses kill or repress the majority of inhaled bacteria over a period of two to eight weeks. The bacteria may, however, remain viable, a condition called latent TB infection (LTBI), resulting in reactivation and disease at a later time. People with LTBI do not suffer symptoms of TB and cannot transmit the infection to others. An estimated 30-50 percent of Indians have LTBI (Chadha 2005).

Several conditions predispose an individual to TB disease. These include being in close proximity with someone who has TB, and factors or conditions in which the body's immune system is weak. People recently infected with TB bacteria are also at higher risk of developing TB disease. Some develop the disease within weeks after becoming infected with *M. tb.* Others may become ill years later when their immune system weakens.

The modern era for TB management began with the discovery of suitable antibiotics, starting with streptomycin in 1944 (Schatz, Bugle, and Waksman 1944). Along with the use of antibiotics came knowledge and experience of antibiotic resistance, especially when the numbers and dosages of drugs, and the durations for which they were administered, were suboptimal.

TB is curable and TB transmission diminishes rapidly once effective treatment is initiated (Schwartzman and Menzies 2000). In spite of it being curable among individuals, TB as a public health problem is difficult to eliminate when health systems, social norms, and behaviors block access to quality treatment and care, cause delayed detection and treatment initiation, and impact treatment adherence. To end TB, countries need to invest adequately in effective public health programs, adopt use of modern diagnostic and treatment protocols, build capacity to enable provision of standard TB care services, foster treatment completion, and ensure that persons affected by TB have access to acceptable, equitable, and quality care. To do so effectively, countries need to invest in engaging individuals and communities affected by TB so as to improve utilization of services, and reduce harmful social norms and behaviors that are barriers to TB care, and hence to disease elimination.

The World Health Organization (WHO) estimated that India had 2.74 million new cases of TB in 2017; more than a fourth of the global TB burden. The WHO further reported that about a seventh of all incident cases of TB in India died (an estimated 421,000 deaths, including from

TB-HIV) (World Health Organization 2018). There is a higher proportion of estimated deaths among persons with TB who are not notified to the Revised National Tuberculosis Control Program (RNTCP), and therefore not supported for treatment adherence.

TB control programs need to address the challenges, and actively break down the barriers to disclosure, and therefore to TB notification. Such challenges and barriers may lie with affected individuals and communities, and also with the providers of TB service.

Key principles for TB care

The broad principles along the continuum of TB care for people with TB disease are:

Early health seeking, where persons with TB symptoms recognize them early, know where to go for screening, and expect a standard microbiological diagnostic test to be carried out.

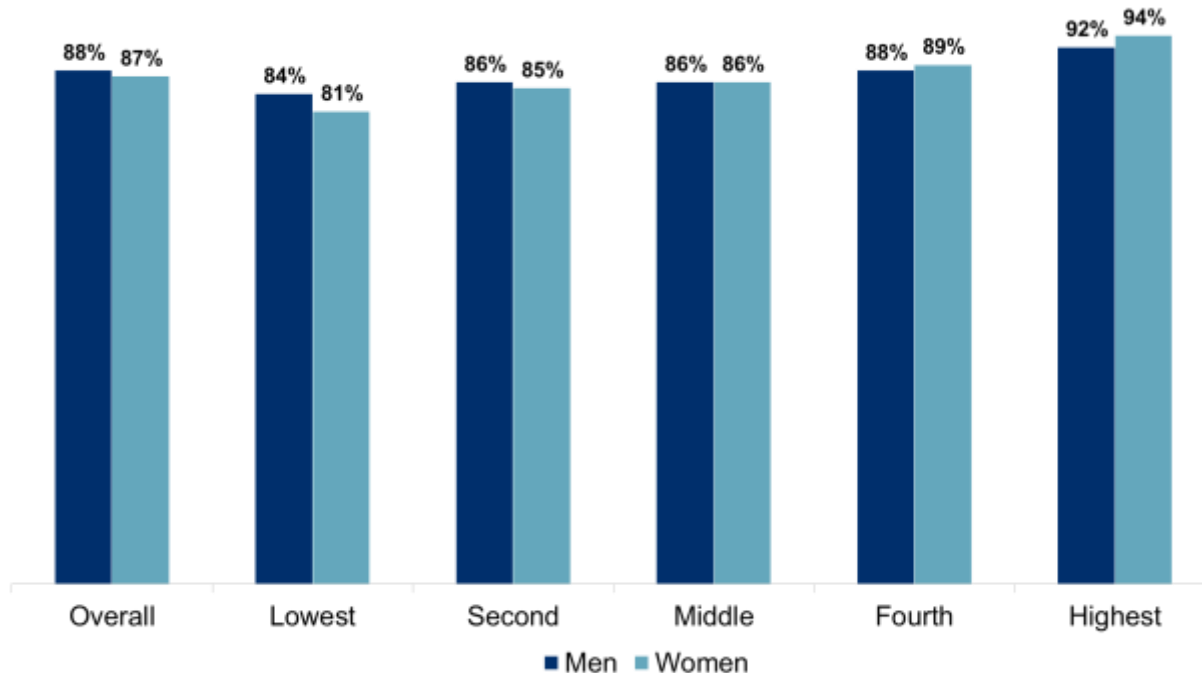
Adoption of standards for TB care by all health care providers, primarily involving:

- **Evidence-based diagnosis**, where all people with TB symptoms are effectively screened, and undergo the best available microbiological tests to establish definitive diagnosis, including for drug susceptibility, and where these tests are conducted at certified, quality-assured laboratories.
- **Good-quality treatment**, where standard anti-TB regimens are used to treat persons with TB who are sensitive to first-line drugs, and where persons with known drug-resistant TB, after drug sensitivity testing, are initiated on tailored treatment regimens.
- **TB notification**, where all persons with TB who are diagnosed and initiated on treatment by clinical providers, and all persons confirmed to be microbiologically positive for TB at laboratories, are notified to public health information systems.
- **Treatment follow-through**, where all persons with TB are initiated on treatment, and are counselled and closely monitored and supported for treatment adherence, and for prevention of spread of the disease.

Basic awareness of TB in India

The basic awareness of TB ('heard of TB') is high in India at 87 percent, both among men (88 percent) and women (87 percent). The awareness is slightly lower in the lowest and second wealth quintiles, as seen in Figure 3 (IIPS and ICF. 2017).

Figure 3: Proportion of people who have heard of TB: Overall, and by wealth quintile



Knowledge of TB transmission and its treatment

Overall, many people are aware that TB spreads through coughing or sneezing (72 percent in men and 69 percent in women) and that TB is related to the lungs or chest. In spite of the high level of reported awareness, there remains low knowledge and a higher degree of confusion about the causes of TB and its management (IIPS and ICF. 2017). For instance, a study showed that 40 percent of people think TB is hereditary (Thakur and Murhekar 2013). Many people think TB is caused by their smoking, use of tobacco, alcohol, other 'bad habits,' malnutrition, their occupations or an increase in stress. They do not know that TB is caused by a germ transmitted from person to person, and that some of these factors, such as smoking and undernutrition, and others like HIV and diabetes, make them more susceptible to the disease.

Some factors influencing care seeking and treatment adherence

A study has shown that more men than women postpone care seeking (Paramasivam et al. 2016). On the other hand, women are more likely to drop out of treatment due to the triple burden of housework, child care, and employment, which together allow them little time to access health care (Rajeswari et al. 1999). Studies have also shown that social and economic factors influence both care seeking and treatment adherence under directly observed treatment, short-course (DOTS). People belonging to 'lower' social orders (castes) delay care seeking. Similarly, treatment compliance under DOTS is poorer among 'lower' social orders and among people living below the poverty line (Chakrabarty et al. 2015).

The RNTCP and National Strategic Plan for TB Elimination 2017-2025

The Government of India (GOI) developed, and rolled out, a framework for TB elimination in the National Strategic Plan for Tuberculosis Elimination 2017–2025 (NSP). The NSP recognizes the huge burden of TB in India, builds on past learning and is in line with other global strategies, such as the National Health Policy 2015, the WHO’s End TB Strategy, and the Sustainable Development Goals of the United Nations.

The Central TB Division of the GOI Ministry of Health and Family Welfare stewards the RNTCP, and it is supported by the WHO and other partners, including multilateral and bilateral donors, Indian and foreign philanthropies, public and private industry, professional associations, non-governmental and civil society organizations, and a myriad of smaller actors and individuals. All of these entities work to decrease the burden of TB. The NSP for TB elimination is rolled out under the RNTCP and is led by the ministries of health of the central and state governments. The NSP provides an action plan to detect and treat TB, and covers partnerships and engagements that are intended to reinforce the efforts of RNTCP to eliminate TB by 2025. It also provides financial and in-kind support to persons with TB, treatment supporters, and service providers.

The **vision** of the NSP is a “**TB free India with zero deaths, disease and poverty due to TB.**” Its goal is to achieve a rapid decline in the burden of TB mortality and morbidity, while working toward the elimination of TB in India by 2025. In March 2018, Prime Minister Narendra Modi announced that India set a target for complete elimination of TB by 2025, five years ahead of the global target of 2030.

“... I urge every person, every government, every institution, and every representative from the civil society to take up this resolution of playing an active role in building a TB-Free India and reaching out to that last person affected by TB.”

Prime Minister, Shri Narendra Modi; excerpts from his speech on March 13, 2018

Advocacy, Communication and Social Mobilization under RNTCP

Advocacy, Communications and Social Mobilization (ACSM)¹ has been an important and integral component of RNTCP since its inception. ACSM initiatives are meant to generate demand leading to early diagnosis, and to promote correct and complete treatment. Effective ACSM ensures long-term and sustained impact through improved knowledge, better understanding, and behavior change.

¹ This report uses the terms ACSM and social and behavior change communication (SBCC) interchangeably. The RNTCP and other government-led programs use these and still other terms, including behavior change communication (BCC), and information, education and communication (IEC), to describe the field.

ACSM in the NSP focuses on improving awareness of symptoms of TB and community referrals to aid in early case detection. ACSM also supports treatment adherence through combating stigma and discrimination, and by empowering people. ACSM can mobilize political commitments and build capacity for demand and supply of quality services and products.

What the NSP says about addressing stigma

“ACSM is a cross cutting, supportive strategy that focuses on all aspects of TB care for ensuring quality in diagnosis and treatment interventions, strengthening social support systems for TB care and **community interventions to reduce stigma**. ACSM will focus on... **combating stigma and discrimination...**” (*Introduction to ACSM; NSP*)

“High visibility, high decibel communication for demand generation **and stigma reduction**” (*Strategic Interventions; ACSM; NSP*)

“Sensitize media and program staff about language so as to **avoid stigmatizing**” (*Activity 2 [Media Advocacy]; ACSM; NSP*)

“Design a campaign to **combat stigma/myths**” (*Activity 3 [Communications]; ACSM; NSP*)

Methodology Used to Harness Insights

The methodology used to harness insights on stigma and discrimination associated with TB for this report focused on the urban poor, who are particularly vulnerable to acquiring TB infections and also progressing to TB disease. A multi-fold study methodology was followed (Figure 4).

Figure 4: Multi-fold report methodology



Desk research

As a first step, the project conducted intensive desk research to understand existing information about stigma and discrimination associated with TB in India. The Sustaining Health Outcomes through the Private Sector (SHOPS) Plus project conducted a historical landscaping of TB-SBCC interventions in India to look at the evolution of TB-related SBCC alongside TB control programs from the beginning of the twentieth century. The project also reviewed the RNTCP's plans to address stigma and discrimination in TB. The desk research reviewed evidence available in literature around stigma associated with TB to identify barriers and challenges along the continuum of TB care, and of solutions to inform stigma reduction.

The literature review gave particular focus to factors such as gender, social norms, demography, economic status, and geography. The number of reports and publications that the desk research reviewed are shown in Table 1:

Table 1. Documents researched to glean information on stigma in TB

Reports and Plans		Scientific Publications	Grey Publications	MBPH, SHOPS Publications
Global	National			
8	9	32	1	3

Note: MBPH=Market-Based Partnerships for Health

SHOPS Plus, through its creative agency partner, also conducted a review of anti-stigma advertising campaigns in India. This included conducting analyses of advertising campaigns in areas such as mental health, menstruation, cancer, HIV/AIDS, and lesbian, gay, bisexual, and transgender (LGBT) issues, etc.

The project mapped and analyzed reports and publications on the impact of stigma and discrimination on TB. The Health Stigma and Discrimination Framework, a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas, was used as a guiding principle for the information collated and analyzed (Stangl et al. 2019).

Formative study

The critical inputs from the desk research formed the basis to finalize the objectives, formulate the hypotheses, and draw up the research design for a formative study that included focus group discussions (FGD) and in-depth interviews (IDI) among key stakeholder groups.

SHOPS Plus conducted the formative study in six large Indian cities supported by seven TB partner organizations. The project trained moderators from partner organizations, who in turn carried out the FGD and IDI in their respective cities. This provided an opportunity for partners to share resources and expertise, build capacity, and take a step forward in working together to support RNTCP. The geographies and partners involved are tabulated in Table 2.

Table 2. Collaborating partners and geographies covered for FGD and IDI

Partner	City, State	FGD	IDI
ALERT INDIA, PATH	Mumbai, Maharashtra	Yes	
Karnataka Health Promotion Trust (KHPT)	Bengaluru, Karnataka	Yes	Yes
Mylan, supported by TB Alert India	Delhi, Delhi	Yes	
Resource Group for Education and Advocacy for Community Health (REACH)	Chennai, Tamil Nadu	Yes	Yes
TB Alert India (TBAI)	Hyderabad, Telangana	Yes	Yes
World Health Partners (WHP)	Kolkata, West Bengal	Yes	Yes

Focus group discussions

The purposes of the FGD were to understand stigma and discrimination associated with TB, from affected persons and communities, and to inform the potential solutions to reduce stigma and discrimination.

The objectives of the FGD were to understand:

- Feelings, perceptions, and opinions of the urban poor, and of persons with TB and their caregivers, and the impact of these on care seeking, service delivery, and treatment adherence.
- Barriers to desired behaviors along the continuum of TB care. This includes barriers to health seeking among persons with TB symptoms, and those around treatment adherence among persons with TB disease who had been initiated on treatment.
- Facilitators that improve:
 - Confidence of a person with symptoms to access or seek appropriate health care,
 - Desire, intent, and action by a person with TB to adhere to prescribed TB treatment.

The target audience, comprised of adult men and women, and the sample size are outlined below:

- Urban poor populations (people living in urban slums) in the six metro cities of India.
- Persons with TB and who are on treatment, or who had recently completed treatment.
- Caregivers of persons with TB, including family members and close friends.
- Frontline public and non-government community health workers.

Thirty-one FGD were conducted and each group consisted of six to eight respondents. The sample distributions are shown in Table 3.

Table 3. Number of FGD conducted

Stakeholder (sex)	Bengaluru	Chennai	Delhi	Hyderabad	Kolkata	Mumbai	Total
Urban poor (male)	1	0	1	1	0	0	3
Urban poor (female)	1	1	1	1	0	0	4
Persons with TB (male)	1	1	1	0	1	0	4
Persons with TB (female)	1	1	1	1	1	0	5
Caregivers (male & female)	2	1	0	1	2	1	7
Frontline workers (male & female)	2	1	1	2	1	1	8
Total	8	5	5	6	5	2	31

The FGD facilitators used projective techniques to tap into the deep feelings, motivations, beliefs, attitudes, and values of the target audiences and recognized that behavior, especially around stigma and discrimination, can be emotional in nature. Following training, partners conducted field work, shared summaries of their insights and learnings, and, where possible, translated and transcribed recordings of these sessions. SHOPS Plus compiled the findings and led the data analysis.

In-depth interviews

The purposes of the IDI were to understand stigma and discrimination associated with TB, and the potential solutions that may be addressed, from the perspective of health care providers. They included qualified and informal clinicians managing persons with TB. As noted above, learnings from the desk research were taken into consideration when formulating the IDI objectives.

The objectives of the IDIs were to understand, from the perspective of health care providers, the following:

- Feelings, perceptions, and opinions of the urban poor, and of persons with TB and their caregivers, and the impact of these on care seeking, service delivery, and treatment adherence.
- Barriers to desired behaviors along the continuum of TB care. This includes barriers to health seeking among persons with TB symptoms, and those around treatment adherence among persons with TB disease who had been initiated on treatment.
- Facilitators that improve:
 - Confidence of a person with symptoms to access or seek appropriate health care,
 - Desire, intent, and action by a person with TB to adhere to prescribed treatment.
- Triggers that will improve adoption of standards for TB care by health care providers.

The target audience and sample size for this study included:

- Practitioners of modern medicine (POMM).
- Practitioners of Indian systems of medicine and homeopathy (ISMH), and less-than-fully-qualified (LTFQ) medical practitioners.

Eight IDI were conducted; the sample size is shown in Table 4.

Table 4. Number of IDI conducted

Stakeholder	Bengaluru	Chennai	Delhi	Hyderabad	Kolkata	Mumbai	Total
Health care providers (POMM)	2	2	0	1	0	0	5
Health care providers (ISMH/LTFQ)	2	0	0	0	1	0	3
Total	4	2	0	1	1	0	8

The IDI interviewers used projective techniques to tap into the deep feelings, motivations, beliefs, attitudes, and values of the health care providers. As with FGD, collaborating partners were trained to conduct the IDI, and they shared summaries of insights and learnings, and where possible, translated and transcribed recordings of the IDI.

Technical discussions

SHOPS Plus held one-on-one technical discussions with several key stakeholders, including persons with TB, family members and close friends of persons with TB, frontline workers, and TB partner personnel. The discussions focused on the knowledge and experience of these stakeholders, and their expertise on stigma and discrimination as well as barriers and triggers for TB care. Their observations, thoughts, and opinions on stigma in TB were incorporated into this report.

SHOPS Plus conducted a gender assessment that included an analysis informed by stakeholder interviews and a desk review and culminated in a workshop to vet the findings. The assessment comprised 13 interviews with various stakeholder groups, including TB-affected community representatives, public health experts, officials from donor agencies, managers of TB partner organizations, and researchers. The findings added value to this report from a gender perspective.

Field experience

The individual and organizational field experiences of TB partners, including Abt Associates, across various TB projects and regions of India also informed this report. They shared their in-depth experience across a decade of work conducted on TB and knowledge in project planning, designing, on-ground implementation, and SBCC on TB through mass media, mid-media, and interpersonal communications.

SHOPS Plus, via its communications agency partner, held further one-on-one meetings with individuals in the cities of Delhi-NCR, Mumbai, and Kolkata to enrich this report. They included TB survivors, caregivers, community members, and health care providers.

Limitations of this report

A key objective of this report was to gain a better understanding of stigma and discrimination related to TB. Qualitative research was used to understand the feelings, perceptions, opinions, motivators and barriers of a limited population (persons with TB, their caregivers, urban poor and service providers) in the six metro cities of India. The findings from this report cannot be generalized to the large segment of rural dwellers, or to the general population living in urban areas. Furthermore, qualitative methods used for gathering data are better suited for in-depth analysis of softer variables like beliefs, perceptions, and experiences than for generalizable variables such as prevalence.

This report does not deal specifically with stigma and discrimination faced by persons with drug-resistant TB. With its more prolonged treatment, numerous and serious drug effects, frequent recurrence, and poorer treatment outcomes, the stigma and discrimination associated with it is likely to be more complex and debilitating for the persons with this form of the disease.

Understanding Stigma and its Manifestations in Health

Understanding stigma

Erving Goffman, a noted sociologist, wrote in his book 'Stigma: Notes on the Management of Spoiled Identity' that the Greeks, who were strong on visual aids, originated the term stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the ones who bore the signs. The signs were cut or burned into the body and advertised that the bearer was a slave, criminal, or traitor—a blemished person, ritually polluted, to be avoided, especially in public places (Goffman 1963).

Stigma now is described as a phenomenon whereby an individual, with an attribute that is deeply discredited by her/his society, is rejected as a result of that attribute. Goffman saw stigma as 'a process by which the reaction of others spoils normal identity (Goffman 1963).

Stigma occurs when an individual is identified as deviant, linked with negative stereotypes. It leads to 'othering,' a process of treating people from another group as essentially 'different' from and generally inferior to the group one belongs to. Stigma generates prejudice and leads to discrimination. It disqualifies the individual from full social acceptance; society often excludes and devalues stigmatized people.

The various consequences of stigma are shown in Figure 5.

Figure 5: Consequences of stigma



Social stigma is commonly related to culture, gender, race and health. Stigmatized and discriminated individuals are disadvantaged in various aspects and face inequities in income, education, mental well-being, housing, status, health, and medical treatment. Stigmas are time- and context-related. What is considered a stigma in one time and place may not be considered so in another.

Stigma in health

Individuals are stigmatized due to various physical or mental health conditions: HIV/AIDS, obesity, TB, venereal disease, leprosy, skin conditions like psoriasis and vitiligo, depression and other mental health illnesses, and many others.

Figure 6 shows six types of stigma associated with health conditions in general, and TB in particular. The various types were gleaned from literature related to stigma and health.

Figure 6: Types of health-related stigma

<p>Social/Public stigma</p> <ul style="list-style-type: none"> When a person faces negative stereotyping, prejudice and discrimination, <u>endorsed by the general population</u>.
<p>Health care professionals' stigma</p> <ul style="list-style-type: none"> When a HCP allows stereotypes and prejudices of the illness to <u>negatively affect a patient's care</u>.
<p>Self-stigma</p> <ul style="list-style-type: none"> When a person <u>internalizes</u> negative stereotypes, prejudice and discrimination, this <u>causes low self-esteem and shame</u>.
<p>Perceived stigma</p> <ul style="list-style-type: none"> When a person <u>thinks/believes that others</u> have negative stereotypes and prejudice, and discriminate against her/him.
<p>Anticipated stigma</p> <ul style="list-style-type: none"> When a person <u>expects</u> negative stereotypes, prejudice and discrimination against her/him <u>from others</u>.
<p>Structural/institutional stigma</p> <ul style="list-style-type: none"> When the person <u>faces decreased opportunities</u> due to institutional policies or societal system.

A person can perceive different types of stigma at different times over the course of illness. The person may anticipate stigma when symptoms first appear or soon after diagnosis, often before community members learn about the illness. Self-stigma also can start at this point. Anticipated and perceived stigmas can weaken a person's willingness to seek help or health care. Social stigma can begin when others can see physical manifestations of the disease or see the person seeking treatment. Overlying structural, institutional, or health provider stigma is largely based on societal negative stereotyping. Illnesses that produce visible change—for example, a cough, weight loss, and fatigue of TB, the physical sequelae of leprosy, the loss of skin pigment from vitiligo, and even some benign tumors—can produce overt stigmatizing and discriminatory behaviors in other people.

Stigma and discrimination can exacerbate the challenges that disease or disability brings to a person by having negative implications for health seeking, treatment, and recovery.

Stigma and TB

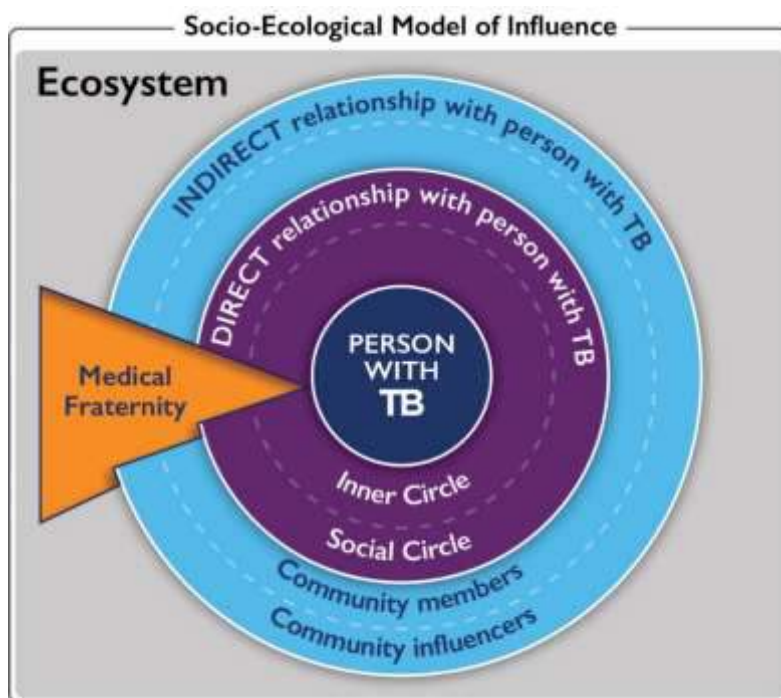
All six types of stigma identified and listed above apply to TB. For several reasons, and possibly because a person with TB may not 'show' the external signs associated with the disease, such as being emaciated and sick looking, stigma in TB tends to be latent or silent, appearing only when the notion surfaces that a person has, or may have, TB disease. Subsequent chapters of this report describe stigma associated with TB in greater detail.

Stigma and Discrimination in TB: The Socio-Ecological Model of Influence

The socio-ecological model is a theory-based framework for understanding the multiple levels of a social system, and interactions between individuals and the environment within this system. This model is used to bridge the gap between behavioral and anthropological theories. It helps in identifying factors that can be leveraged at all levels of the model for health-related activities.

The socio-ecological model of influence adapted for the understanding stigma and discrimination in TB is shown below in Figure 7 (Centers for Disease Control and Prevention 2019):

Figure 7: The socio-ecological model of influence



Person with TB

In the context of stigma, persons with TB are those with TB disease: they include persons with pulmonary or lung TB, and those with extra-pulmonary TB, where the site of the disease is outside the lung. The term does not differentiate between persons with drug-sensitive disease and those with drug-resistant TB. However, the term does not include persons with LTBI.

Anyone can contract TB; medically, it does not differentiate hosts based on social or economic class. However, the urban poor are particularly vulnerable due to overcrowding, poor ventilation, undernutrition, social deprivation, and migration.

A person with TB may be unemployed and financially dependent on someone else, or be employed,² and responsible for the well-being of others. Dependencies are associated with age, such as for children and some elderly persons, or are due to physical, emotional, social, or mental disabilities. This status, combined with the specific socio-financial circumstances of the

² In large cities, the urban poor may be daily wage laborers, or work as rickshaw pullers, painters, carpenters, drivers, guards, vendors, textile mill workers, static or mobile sales or delivery persons, police, or sanitation workers. They may work in offices, printing shops, homes of the more affluent, or in city or nearby factories, quarries, and mines. They may also be exposed to various degrees and types of indoor or outdoor pollution.

person with TB and of the nature of dependencies involved, has considerable relevance from the point of view of stigma and discrimination.

TB and gender

In most settings, TB incidence rates are higher for males at all ages except in childhood. The reasons for the higher male prevalence and incidence are poorly understood. Differences in TB notification rates between men and women may reflect biological differences (differences due to sex) in the epidemiology of TB, differences in the societal roles of men and women (differences due to gender) that influence risk of exposure, and/or gender differences in access to care. Examining the gender dimensions of TB is more than ascertaining which sex has a higher prevalence rate or a higher case fatality rate. It includes looking at issues such as differences in risk of exposure to infection, health-seeking behavior and health systems response, economic consequences, and social stigma associated with being known as a 'TB patient' (World Health Organization 2002).

Individuals with a direct relationship with the person with TB

Individuals who have a direct relationship with the person with TB are divided into two groups: those in the **Inner Circle** and those in the **Social Circle**.

Inner Circle

The Inner Circle includes people who are close to the person with TB (e.g. family, friends, and health workers). This group spends a lot of time with the person with TB and hence shares a deep emotional bond with her/him and is often mentally and financially invested in the person.

From an urban poor context, the Inner Circle lives in slums, government community buildings, and low-income societies. Their accommodation could be a house or shanty; it is usually a small room, where four to six persons, and sometimes even more, live together.

Inner Circle members may or may not share a household with the person with TB. Immediate family members often do, with the older members of the family at home, and the younger children going to school. Unrelated members who share the household could be friends or co-workers, or migrant men or women working in cities. They may share their bedding, clothes, and even towels; eat together, sharing their food and utensils; clean and wash their clothes and utensils together; and so forth. They often share toilets and bathrooms as well.

Social Circle

The Social Circle comprises of people who frequently interact with the person with TB, and with this person's Inner Circle, but may fewer emotional ties to them. The Social Circle includes people in the neighborhood, workplace colleagues, and extended family members. In an urban poor context, they live in the same type of households as those in the Inner Circle, have similar occupations, and come from similar socioeconomic backgrounds.

People in the Social Circle may have resided in the same complex as the person with TB for years. They meet frequently in corridors, doorways, lanes, shops, and water collection points; they may leave together for work; their spouses spend time in the afternoon chatting; and their children play indoors and outdoors with each other. They celebrate traditional festivals together

and visit each other's houses on special occasions, borrow appliances or food, or chat informally.

As workplace colleagues, they may have been working with the person with TB for years. They meet for tea breaks, and have and share their lunch. At these break times, they sit together and chat about work, and about their personal lives. They are extended family members, who occasionally visit each other's houses for special occasions.

Individuals with an indirect relationship with the person with TB

Other groups have an indirect relationship with the person with TB, and/or their affected inner circle. They include **community members** and **community influencers**.

Community members

This group includes people who are from the same community as the person with TB, and they can also share common interests based on age, language, religion, caste, class, ethnicity, culture, values, socioeconomic status, occupation, hobbies, and so forth. Their interactions with persons with TB are infrequent.

Community influencers

Community influencers are prominent figures within the communities or sub-communities with which the person with TB identifies. They may also be from other influential communities, for example, a global community of activists. Community influencers are generally trusted and their opinions valued by community members, including by persons with TB, and often, by their Inner Circle.

Medical fraternity

In the context of the TB-adapted socio-ecological model of influence on stigma, health providers and institutions are segregated into a cross-cutting group called the medical fraternity.

The medical fraternity comprises of people from a wide spectrum of health-related services, facilities, industry, and institutions. They include formal and informal health care service providers—doctors, nurses, personal clinic assistants, allied medical service providers such as pharmacists/chemists and laboratory staff, and frontline health care workers. The fraternity also refers to medical institutions, health professional associations, manufacturers and marketers of drugs and ancillary medical devices, pharmacies and medical retailers, health planners, and health experts. They belong to government and private sectors. The level of influence of members of the medical fraternity, especially clinicians, on persons with or affected by TB is high, but varies by provider type and reputation.

Ecosystem

The environment is the overarching ecosystem. It includes the country's laws, policies, guidelines, and norms that have a direct or indirect effect on the person with TB. It also includes political and administrative governance, and the government's commitment level to TB control and elimination, including its investment in TB care. These are determined at local, state,

national, and global levels. The environment also includes the overall impact of formal or informal media networks on information and education.

There are various non-health institutions, organizations, and associations that are also part of the ecosystem. These can be government and non-government, and can be in the fields of management, education, finance, industry, religion, and others. These may be public agencies, civil society organizations, donors, implementing partners, community and faith-based organizations, and educational institutions.

Factors Driving Positive Stigma and Discrimination-Related Behaviors in TB, Using the Socio-Ecological Model of Influence

Historical background

TB has a long history of association with stigma. It has been called ‘phthisis’ (from the Greek, ‘to waste away’), the ‘white plague,’ and then ‘consumption’ (Weisse 1995). TB for centuries has been treated as a fatal illness, and this belief persists even today. TB has been showcased through a lens of foreboding, echoed in stereotypes in popular media, including in Indian cinema across the decades.³

Underlying reasons for this stigma and discrimination

Sagili, Satyanarayana, and Chadha (2016) found that 73 percent of the population feels TB carries stigmatizing attitudes toward TB, while 98 percent have a discriminatory attitude toward the person with TB.

The main reasons for stigmatizing and discriminatory attitudes are:

1. Fear of contracting TB disease
2. Fear of TB leading to financial ruin
3. Judgment toward a person with TB
4. Societal stereotyping; following the prevalent social norms

Figure 8 shows what some people stated in regard to these points.

³ Examples of Indian cinema showcasing TB as a deadly and/or impoverishing disease include: In Hindi cinema, Aah (1953), Amar Akbar Anthony (1977), and Lootera (2013); in Bengali cinema, Meghe Dhaka Tara (1960), and Deya Neyya (1963); in Telugu cinema, Varasudochhadu (1988) and Puttilinla Mettinilla (1994); in Tamil cinema, Kudumbam Oru Kadhambam (1981).

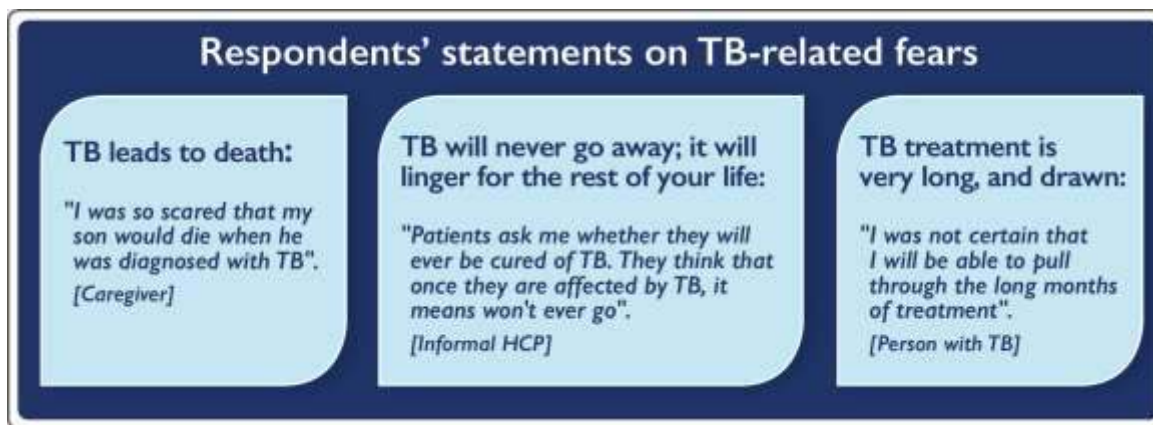
Figure 8: What people say about TB-related stigma and discrimination



Fear of TB as a disease

TB is considered to be dangerous, and people's beliefs at varied levels drive the fear of catching the disease. Figure 9 shows three kinds of fear related to TB infection:

Figure 9: Respondents' statements on TB-related fears



There is also the fear in anticipation of being stigmatized if one catches the disease. These fears result in a core need to protect oneself and one's family from this 'deadly disease.' The fear of stigma and discrimination may be overpowering for persons with TB, and for people in their Inner Circle. This can lead to an unwillingness to disclose their disease status to others, which has adverse consequences along the continuum of TB care. *"I will not tell my mother regarding my disease as I am not willing to 'give tension to her'"* [a person with TB, during a FGD]. *"Stigma is still there so they don't want to share the disease status...they may not be asking their family members to seek a TB test"* [a community health worker, during a FGD].

Fear of economic ruin

From places within their own neighborhood to the wider world of cinema and other media, people see and hear stories of how TB can result in severe financial hardship for people with the disease and their families. This happens because of the costs they incur from care seeking, treatment and related costs, as well as the loss of livelihood; sometimes resulting in serious debt and destitution. People fear that if they catch this disease, they too will face economic catastrophe. *"I have seen family members in my neighborhood whose lives were shattered due to the husband getting TB. They had no money, and even the children were taken out of school. I definitely do not want this to happen to my family. I am completely staying away from the affected family, so that I do not get TB"* [a community member, during a FGD].

Being judgmental about the person with TB

Some people believe that TB disease is a consequence of bad behavior or lower socioeconomic status. They have seen that people who get TB are those who drink, use tobacco products, or have HIV/AIDS, another stigmatized disease in many societies. *"The patients think that this is an immoral man's disease"* [a community health worker, during a FGD]. Believing that the affected person brought the disease upon her/himself justifies their shunning the person. Associating TB with low castes and classes could play an important role in stigmatization or discrimination (Sagili, Satyanarayana, and Chadha 2016).

Follow the societal norm

Many people, especially those in the Social Circle and in the wider community, see others around them stigmatizing and discriminating against the person with TB. They therefore do the same. At times, community members see the people in the Inner Circle isolate the person with TB at home, and feel this justifies their own stigmatizing and discriminatory behaviors. *"I have seen how my neighbor, a young boy of 26 years, was kept away by his family, with everything separate"* [a community member, during a FGD].

Interplay of positive and stigmatizing behaviors between the person with TB, Inner Circle, and Social Circle

Persons with TB

A person with TB disease needs to deal with stigma and discrimination, in addition to the physical, emotional, and financial difficulties that she/he faces over the course of dealing with the disease. This may begin at any time during the period of illness. Stigma and discrimination may persist after the person becomes well, and even after she/he is completely cured. People suffering from TB face all the different types of stigma (see Figure 6). Persons with TB

belonging to middle and upper-middle (economic) classes, and women overall, felt greater stigma and discrimination as compared with people in the lower-middle and lower classes (Dhingra and Khan 2010). While higher- and middle-income groups have more stigmatizing and discriminatory attitudes (Sagili, Satyanarayana, and Chadha 2016), the burden of TB-related stigma and discrimination is felt more strongly by people from lower social and economic classes, those of a higher age (Saad and Tirkey 2013), and women (Rajeswari et al. 1999).

When a person is informed about her/his TB diagnosis, the immediate response is that of shock and lack of understanding of what has happened to her/him. *“I wondered, God! Why did I get this...it is better for me to die, than to live with this illness”* [a person with TB, during a FGD]. Health care providers echo this sentiment and say that their patients think that TB is dangerous and that they think they may die.

Immediately after the shock, many people go into a state of denial about having TB. Denial can stem from the lack of clarity on the possible causes of TB disease; they cannot or do not accept their TB diagnosis because there is no family history of TB, they do not smoke or drink alcohol, and they lead a ‘normal routine life’ and were perfectly healthy until about a fortnight ago. This state of mind can persist for a long time.

A person in denial of having TB tends to consult other doctors for a second opinion; this has been reported to have happened even after the diagnosis is microbiologically confirmed. Many people conduct an Internet search, both before and after the diagnosis. *“Convincing the patient about their (TB) status is a major challenge, as many times, patients are not ready to accept (that) they have TB; they are not even ready to believe the test results”* [a qualified doctor, during an IDI]. Some doctors feel that their less-educated patients accept TB diagnosis and treatment more readily than those who are better educated. An example comes from a qualified doctor: his patient, an IT software employee, refused to accept that he had TB, even after confirmation from a Cartridge Based Nucleic Acid Amplification Test (CB-NAAT); it took the doctor more than a month to convince this patient. *“The IT employee thought that TB is a disease which affects those of a lower social class and those who don’t follow hygiene. In spite of one’s education, when certain things do happen to us, we defy our own intelligence because of our ego and social status”* [a qualified doctor, during an IDI].

As the person with TB comes to terms with the diagnosis, she/he starts thinking of how to protect the immediate family from infection, and how to reduce their fears and worries. The person fears transmitting the TB to others, and therefore keeps a distance until the treatment is completed. *“I have got this illness, but no one else should get it from me”* [a person with TB, during a FGD]. One person isolated all his belongings, such as plates and water can, so that he would not spread TB to the children at home. Many people are not aware that TB is not spread by touching, sharing food or drink, handling bed linens or toilet seats, or kissing (Centers for Disease Control and Prevention 2016).

Persons with TB are most worried about their disease status being disclosed to others (Rajeswari et al. 2005). A study done in Bihar states that 53 percent of people with TB want to hide their status from the community due to discrimination (Vishal, Rai, and Sharma 2014). A smaller proportion of women, compared to men, disclose their disease to colleagues, employers, or friends, and/or share information about the disease with the family (Dhingra and Khan 2010).

The person with TB has a feeling of dependency and helplessness, which often leads to anticipated stigma. A study reveals that men and women report the same emotional and social symptoms but women often feel more distressed, especially around arranging marriages, social isolation, and inability to care for their children and family (Atre et al. 2004). The fear and

thought of isolation is high in their minds, and they feel as if their lives have been cursed, now and in the future.

The thought of the economic burden that she/he will have to face and the potential loss of a job also burdens a person with TB. *“If I tell my manager, he will throw me away from my job”* [a person with TB, during a FGD].

The shame and fear surrounding TB remains after a person completes treatment.

Jaggarajamma et al. mentions a woman who was not allowed to do household work, even after recovery from TB (Jaggarajamma et al. 2008).

Emotional and social symptoms were frequently reported for both men and women, but often considered most distressing for women, especially around arranging marriages, social isolation, and inability to care for children and family.

Inner Circle

The Inner Circle, immediate family and close friends, of the TB-affected person tries to deal with mental, economic and physical challenges that require decision making. They consider:

- Who will carry out everyday care tasks like meals, nutrition, medication, and hygiene?
- How will I deal with aggressive behavior, depression, missed medicine doses, loss of appetite and weight, weakness, and drug side effects?
- Who will manage household finances, especially when the person has been the only source of income for the family?
- How can I deal with my depression and anxiety?

The Inner Circle faces emotional difficulties when everyday routines shift to revolve around the person with TB, and this takes a toll on them, especially on the principal caregivers.

The Inner Circle usually lacks knowledge of the disease; they have not seen or know anyone with TB—or at least are not aware that they have. They have no idea about how to deal with the situation, and they worry, trying to understand and grapple with the disease, and its ramifications on their lives.

On one hand, the Inner Circle has a positive attitude and desire to correctly care for and support the person with TB. *“The more you share love with a TB-affected person, the faster he will recover”* [brother of a person with TB, in a FGD]. Friends are understanding and genuinely concerned. *“We are 4-5 bachelors staying together in one room. One of our friends got TB. We took turns to take him to the doctor and supported him throughout his treatment course”* [a friend who was a caregiver, during a FGD].

On the other hand, the Inner Circle is confused and scared about what to do, or not do. They receive solicited or unsolicited advice, some of it incorrect and conflicting, from others in the circle, and from people outside it, and this can lead to harmful choices. This often happens during the early weeks of the disease and its treatment, a time when it is important to establish the correct medical and dietary habits that will maximize the ill person’s chances of a full recovery.

Some in the Inner Circle seclude the person with TB during the initial stages of TB treatment. They consider this temporary and necessary to avoid disease transmission, and do not see it as

discriminatory behavior. However, the person with TB may perceive this as stigmatizing if she/he does not understand, or accept, the rationale for the temporary seclusion.

Though there is care and concern, the Inner Circle may display other stigmatizing behaviors, knowingly or unwittingly, because they wish to protect themselves and other household members, especially vulnerable younger children. These behaviors include keeping bedding, utensils, and other personal items of the person with TB separate, isolating her/him in the house, maintaining a distance, and not letting a mother breastfeed her baby or interact with her older children (Yadav, Mathur, and Dixit 2006). A spouse may desert a partner with TB, a husband may send his wife back to her parents' house, or he and his family subject her to emotional, physical, and/or mental abuse. The earning members of a household may be kept away from a person with TB for fear of catching the disease and thereby losing their ability to generate an income.

While the Inner Circle takes care of the person with TB, they may also want this person to take on some responsibilities: *"I am taking care of my son, but he should also remember to take his medicines"* [a mother who was a caregiver, during a FGD].

Like the person with TB, the Inner Circle may face stigma and discrimination—again, social, perceived, anticipated, and self-stigma—from the Social Circle and community. Their house is referred to as the 'house with TB' and the community may keep its distance from the entire household. This distancing might continue even after the person is completely cured of the disease.

Social Circle

The Social Circle of persons with TB include people who frequently interact with a person with TB, and their Inner Circle, but have few emotional ties to any of them. There are anecdotal accounts of the Social Circle members supporting persons with TB and her/his family, and interacting positively with them. They continue to engage socially with TB-affected persons, refer them to doctors known to be good at managing TB, and sometimes help them to access medical care by accompanying them to health facilities.

More often, however, their lack of strong emotional ties and fear of catching 'this dreadful disease' outweigh the need to interact with the person with TB and her/his Inner Circle. Many believe that being afflicted by TB is the downfall of the affected family. They understand that TB is a difficult disease to live with, but the Social Circle wants their own lives to go on. Also, if the Social Circle witnesses stigmatizing and discriminating behavior of the Inner Circle, this justifies their own similar behavior.

Stigmatizing and discriminatory behavior of the Social Circle can be short or long-term:

Short-term stigmatizing and discriminatory behaviors of the Social Circle include not visiting the house of the person with TB and forbidding family members to visit, covering their face with a handkerchief when passing a TB-affected house, not maintaining eye contact with and turning their heads away from a person with TB, not sharing lunches at school or the workplace, and encouraging others to stay away. *"Our neighbors stopped coming to our room. They would ask me from outside how my husband is"* [an Inner Circle caregiver, during a FGD].

A person with TB can anticipate, perceive, and experience a high degree of stigma and discrimination at the workplace, from both colleagues and employers. A study showed that 65.5 percent experienced negative behaviors by colleagues (Anand et al. 2014). Co-workers are afraid to mingle with a person with TB; they do not eat lunch or stand or sit next to the affected

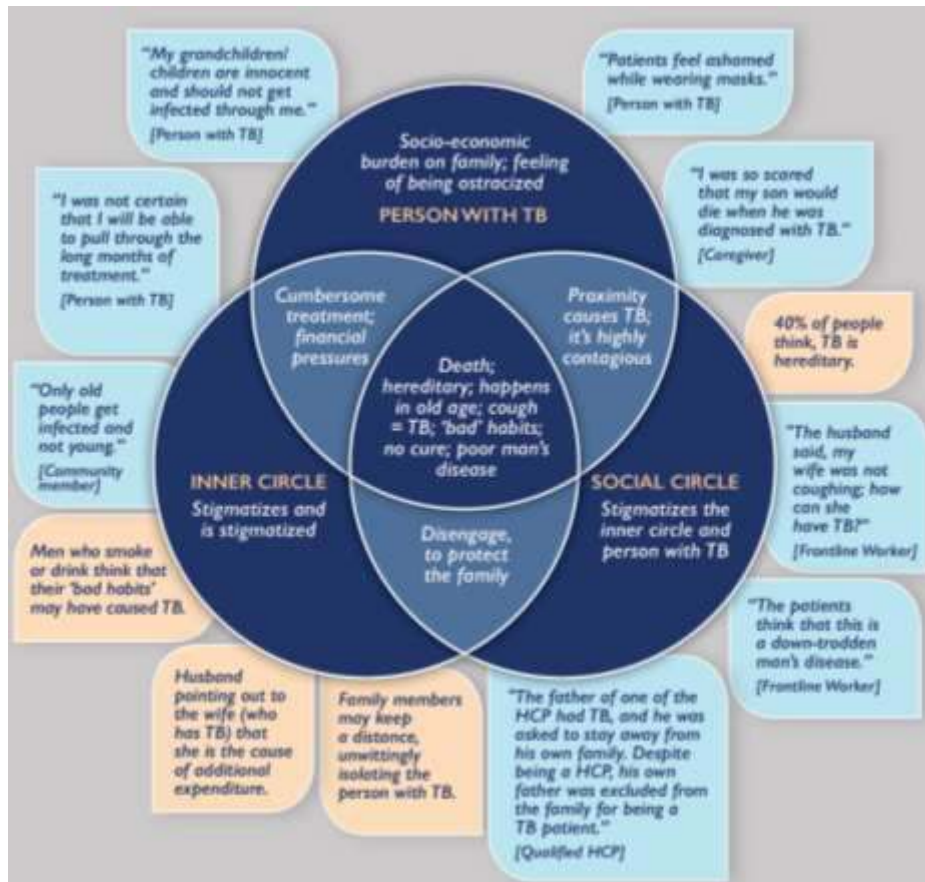
individual. *“Others working with me will not talk to me or interact with me”* [a person with TB, during a FGD]. Many employers fire employees with TB disease. *“Employers will not allow us to wear a face mask and come to work”* [a person with TB, during a FGD]. And there are gender differences as well: a study reveals that a smaller percentage of women than men continue with the same job after the disclosing they have TB disease (Dhingra and Khan 2010).

Long-term stigma is prejudiced behavior even after the person with TB is completely cured. The Social Circle will not resume social connections and will not marry into the family of a person who had TB (Atre et al. 2004). Young girls in the affected family are quickly married off without telling the in-laws know about the family’s TB history. Employers do not hire people who they know have had TB. Long-term stigma and discrimination involves mentally branding an individual, and her/his family, as one with TB.

Figure 10 summarizes the interplay of stigma and discrimination between the person with TB, the Inner Circle, and the Social Circle.

Figure 10: Interplay of stigma and discrimination among persons affected by TB

People in the Inner Circle stigmatize and discriminate against a person with TB, and are stigmatized by people in their Social Circle and community. This stigma exacerbates self-stigma, and accelerates anticipated stigma among persons with TB and those in the Inner Circle.



Positive and stigmatizing behaviors of persons who have an indirect relationship with the person with TB

Community members

As with the Social Circle, there are reports of community members accepting persons with TB, showing positive behaviors, and helping people affected by TB. *“Some people in the community now have better knowledge of TB, and they do not treat persons with TB differently”* [a community member, during a FGD].

Yet overall, people in the community avoid interaction with persons with TB, or with their families; they tend to ignore them. A study showed that more people in the 18–24 age group consider TB to be a socially stigmatized disease, than people in the 65–75 age group (Saad and Tirkey 2013). Studies have also shown that lack of knowledge about TB leads to misconceptions and negative attitudes in the community (Jangid et al. 2016).

Members of a community often have a negative attitude about a person with TB, sometimes even a feeling of hatred. This is largely due to the fear of the disease spreading to them. TB-affected persons are often isolated, and sometimes barred from accessing certain community amenities and gatherings. The community may see TB almost as a disease of the ‘untouchables,’ where contact with the affected person would ‘defile’ others. A study showed that 71.0 percent were of the opinion that people with TB should be isolated from family; 74.1 percent felt that food should not be shared with people with TB; 33.0 percent believed that

people with TB should quit their jobs; 27.6 percent claimed that people with TB should not marry, and 18.0 percent were of the opinion that people with TB should be prevented from attending social functions (Singh et al. 2002).

Discrimination continues even after a person is completely cured of TB. People often continue to treat persons who had TB in the past with fear and distance themselves from them. A study reports that 90 percent of people would not visit the house of a person with TB because of fear of getting the disease (Jangid et al 2016). People don't not want their sons to marry a woman with a history of TB so that the disease does not get passed on in the family.

Community influencers and institutions

Community influencers tend to reflect the feelings, attitudes, and behaviors of the Social Circle and of people in the community, and representatives of non-health institutions behave as community influencers. There have been instances where they have shown positive attitudes toward persons with TB and people in their Inner Circles, and urged the community to be supportive. This has a huge positive impact on the behaviors of others.

Community influencers may have personal prejudices, which result in stigma and discrimination enhancing or amplifying action. This, in turn, has an adverse impact on a person with TB and her/his Inner Circle, and reflects in the behaviors of people in the Social Circle and the community at large.

Impact of behaviors of the medical fraternity on a person with TB

Positive behaviors of the medical fraternity

Health care providers—clinicians, allied health personnel, and community frontline health workers—are mostly helpful and supportive of persons with TB. They understand and are sensitive to the adverse impact of TB in the lives of their patients. *“TB has tremendous effect economically and there are emotional repercussions; it does not just affect physical health”* [a qualified doctor, during an IDI].

Doctors want to be sure that they are giving the right diagnosis and treatment. *“I want to ensure the best is being given to the patient irrespective of their economic background”* [a qualified doctor, during an IDI]. *“A doctor wants to be sure of making the right diagnosis and giving the right treatment. As a medical professional, they are keen to do their best for their patients and wanted nothing left out”* [a qualified doctor, during an IDI].

Doctors are also of the opinion that persons with presumptive TB should be tested, and quickly started on treatment if found to have TB disease. By doing so, they stop transmitting TB to others in their household, or to their friends and colleagues. Many doctors also support testing of family members for TB, including children, to make sure that infection within the household does not go unnoticed.

Community frontline workers tend to show care and compassion toward those living with TB and do their best to ease the lives of people affected by TB. They counsel affected persons on cough hygiene, on nutrition, on screening of close contacts, and on Isoniazid Preventive Therapy (IPT) for young children. Frontline workers understand the lives and situations of persons with TB under their care, and act accordingly to get them to adhere to and complete treatment. They also support family members of the person with TB, through education and

counselling on dealing with the situation. Due to their frequent visits, and over time, a relationship based on trust develops between frontline workers and affected families, who begin to take the workers' advice seriously. Frontline workers feel a great sense of achievement when they are able to ensure a cure or treatment completion among persons with TB under their care. *"I am in this profession not just for money; it is my passion that motivates me to work for the community. I get satisfaction when a person gets cured of the disease"* [a frontline worker, during a FGD].

Stigmatization and discrimination by medical fraternity

Qualified, high-volume, doctors with a robust clinical practice, including chest specialists, do not consciously stigmatize or discriminate against their patients. However, some doctors inadvertently hide the reality of TB behind euphemisms such as 'Koch's disease,' giving the persons affected the impression that 'TB' or 'tuberculosis' are terms to be avoided. Some do not name the disease at all, or give the person with TB incomplete information about it. *"I fear telling the patient that she/he may have TB, in case she/he goes into a panic. Non-acceptance from patients due to fear is a barrier to effective TB management"* [a qualified doctor, during an IDI].

Some doctors exhibit other stigmatizing behaviors. *"If a doctor himself hesitates to touch and treat a patient, it would influence family members to do the same. They may also neglect the patient on seeing the doctor's behavior, assuming that if a doctor hesitates to touch the patient, then it must be some 'big disease'"* [a qualified doctor, during an IDI]. Nursing staff have been known to keep a distance from a person with TB, and some private hospitals do not admit TB patients.

Many informal providers have little knowledge about TB transmission, treatment, and care, and this affects their behavior and the advice they give patients. *"My colleague (an informal provider) thinks that TB will lead to death. She feels that TB is a non-curable disease"* [an informal health provider, during an IDI]. Some informal providers suggest that the person with TB should not talk directly with others.

Some stigmatizing and discriminatory behaviors exhibited by health care providers are often inadvertent and ingrained—they reflect the norms followed by the society in which they live and practice. And, like the general public, many providers fear TB. A study has shown that 51 percent of resident doctors reported feeling of fear, lack of compassion, and a tendency to avoid people with TB (Pardeshi et al. 2017).

Negative or apparently discriminatory behaviors by members of the medical profession, including support staff and frontline workers, are usually not limited to persons with TB—this also happens with patients who have other illnesses. However, affected persons who are already sensitive to such behaviors perceive them as TB-related.

The protocols of the DOTS strategy are at times seen as conducive to promoting structural stigma. In one study, 47 percent of respondents said that taking their DOTS treatment had a negative impact on them with respect to social discrimination within the community (Vishal, Rai, and Sharma 2014). For such reasons, some TB-affected families do not want government frontline workers to visit their homes.

Most health care providers limit conversations with their TB patients to diagnosis- and treatment-related information; a small number proactively discuss important other medical aspects of TB management, such as nutrition, co-morbidities, contact tracing, barriers to treatment adherence, and adverse drug reactions. Few, however, address the social aspects of TB. It is uncommon for a doctor or their support staff to talk to their patients about disclosing

their TB disease status to family members and friends who can support them through the period of treatment, or on how to prevent or deal with stigmatizing and discriminating behaviors or 'othering.' It is the rare doctor who considers her/his patient to be a part of a family, or of the larger community, and deals with the person's Inner Circle holistically. The medical fraternity, especially those directly engaging persons affected by TB, have tremendous influence beyond medical care, and on how those affected respond to the social turbulence caused by TB.

Consequences of Stigma and Discrimination in TB

Stigma associated with TB, and the resulting discrimination, has consequences on the person with TB and on this person's Inner Circle. They face adverse consequences on their finances, social interactions, personal life, and health (Figure 11). These issues cannot be separated—one influences the other, leading to an overall negative domino effect.

Consequences on self

Due to stigma and discrimination, persons with TB and members of their Inner Circle hide the disease from their Social Circle and community (e.g. friends, neighbors). A study in Delhi showed that 60 percent of persons with TB hide the disease (Dhingra and Khan 2010).

Stigma and discrimination undermines the confidence of persons with TB, and of people in their Inner Circle. They start to doubt themselves, and that increases self-stigma. During the period of the ailment, affected persons, and even their families, are isolated by their Social Circle and by members of the community who are not willing to interact with them. This isolation leads to feelings of loneliness and sadness, and to low self-esteem. If this is not prevented or addressed in a timely and effective way, it can lead to depression or suicidal thoughts in the person with TB. This has a negative effect on the person's health and social behavior, and has financial implications as well.

When stigma and discrimination by the Social Circle and community are widespread, the person with TB starts believing these behaviors are 'normal.' *"I felt that the different treatment that I received as a TB patient was okay, and it was normal for others to treat me that way"* [a woman with TB, in a FGD]. This woman's rationale was that the community was *"just being concerned about not catching the infection."* She justified her isolation as 'normal' under the circumstances.

In the long-term, a cure does not necessarily bring an end to self-stigma: persons with TB often do not believe that they will get cured, even when they do get well. They continue to feel guilty and ashamed, still instinctively cover their mouth or face, even years after completing treatment and being declared completely cured.

Social consequences

Figure 11: Consequences due to stigma and discrimination in TB



Many people with TB and their Inner Circle do not want to accept or talk about the disease due to stigma. The person with TB feels uncomfortable answering questions and hence avoids meeting people. *“People will ask why you are looking so lean and sick”* [a person with TB, in a FGD].

People on treatment find it difficult to socialize with colleagues or friends, for example, since they have to carry their medicines with them and take them at the workplace, school, or other places outside of their homes. This has an adverse impact on treatment adherence. *“People ask me questions (regarding) why I keep taking medicines in the day, and what is wrong with me; hence I fear taking medicines, that other will see it”* [a person with TB, in a FGD]. They hide their disease and limit their interactions, which leads to isolation, depression, and increased self-stigma.

Men in particular are concerned about being laid off from work, and finding a new position if their TB status is known to employers. This also impacts them financially.

Social stigma adversely affects more women than men, primarily because of their sensitivity to social interaction (Saad and Tirkey 2013). Women are more vulnerable to depression when they are isolated from their spouse, and unable to care for their children and family. Small children are often separated from a mother with TB. TB can affect a young girl’s marriage prospects, and in turn her aspirations and life.

Women feel they are responsible for taking care of a husband with TB, and they are not sure that, if the situation were reversed, they would get the care they need from their husbands or in-laws. A woman may hide her TB status even from her husband and mother-in-law, for fear of harassment, separation, and creating problems in the lives and marriages of her children (Jaggarajamma 2008). When a married woman with TB is sent back to her parent’s house, it impacts her current and long-term relationship with her husband; at times it leads to divorce and the husband marrying someone else. It also causes emotional and financial stress to the woman’s parents, who are expected to care for her.

Financial consequences

The financial implications of TB can be severe or catastrophic. The onset of TB is related to increased medical costs, but also loss of productivity and even of a job, and an increase in debt (Rajeswari et al. 1999).

Even when the person’s work performance is not affected, employers and supervisors may demote or discharge the person with TB, and finding a suitable new job can be difficult or impossible. Especially when this person is the sole family breadwinner, this has an impact on all the members of the family. Such loss of employment when due to stigma and discrimination, rather than to any physical limitations of the disease, demonstrates a need to address the social ramifications of TB.

Coupled with the decrease in income is the increase in family expenditures due to the cost of medical care, including consultations, tests, and medicines, and of procuring good nutrition for the person suffering from TB. *“How will the poor be able to sustain themselves?”* [a person with TB, in a FGD].

A person’s inability to provide for her/his family or to be financially dependent on someone else may exacerbate the difficulty of living with TB. The person with TB may feel helpless and guilty, and treatment seeking and adherence, or even accepting care and support, may take a back seat to this financial stress—with consequences for treatment outcomes.

These problems affect both earning and non-earning household members. A study indicated that job loss and reduced income were most troubling for males (Atre et al. 2004). On the other hand, husbands have been known to tell their wives that their illness is very expensive and a financial drain on the family. Since she is not an earning member, she feels guilty, and her confidence drops. She may become unable to take care of her children and family. Whichever sex, the person with TB is regularly reminded that the drop in the family's resources is due to her/him. Such regular comments may lead to emotional trauma and self-stigma, putting further mental strain on the person dealing with TB, a disease that needs a lot of care and support, in addition to good medicines.

The stress of losing financial independence may ironically have a positive impact on some persons. It pressures the person to seek and adhere to treatment and to get well sooner. *"I have to get well as quickly as possible. My family is dependent on me. I have to take care of them!"* [a person with TB, in a FGD]. A study reveals that daily wage labourers and self-employed people are more proactive in seeking early sputum examination (Chakrabarty et al. 2015).

Health consequences

Stigma, including anticipated stigma, leads people to hide their TB symptoms or disease status from others, including from other members of the Inner Circle. When anticipated stigma happens before a person with TB symptoms is screened, tested, or diagnosed, it can lead to delayed health seeking—one study found that delay in diagnosis is significantly associated with stigma (Chakrabarty et al. 2015). Another found that 21 percent of people with TB reported delaying health seeking due to stigma (Anand 2014). And the report on yet another study stated that people with TB who considered TB as socially stigmatizing had a longer 'patient delay' in seeking care for TB symptoms than those that did not (Saad and Tirkey 2013). Other people with TB can seek treatment from the wrong type of health provider, which can end in incorrect treatment. Both delay and incorrect treatment worsen the disease and increase complications, costs, and adverse outcomes.

After treatment begins, stigma, including self and anticipated stigma, leads to low acceptance of care and support. This affects treatment adherence, possibly resulting in transmission of TB to others, drug resistance and even death.

Stigma and discrimination affect access to TB care and discourage TB testing, resulting in additional delays, and impacting treatment outcomes. This creates emotional, mental, physical and economic imbalances in the person with TB, and that of the household. Stigma also impacts TB detection. A study found that if the person with TB is an unmarried woman, she would not be notified to RNTCP when issues related to confidentiality, and to discrimination or stigma, came up (Philip et al. 2015).

Stigma leads to delays in health care providers reporting to a hospital and consequently increases mortality from the disease. People with TB who considered TB as a socially stigmatizing disease had a longer 'patient delay' in seeking care for TB symptoms than those that did not (Saad and Tirkey 2013).

Adherence to treatment is a big challenge due to fear of stigma and discrimination. A study conducted among the urban poor showed that women tend to hide their disease and drop out of treatment due to pressures at home and the strain of hiding the disease from others. This was particularly the case when family members routinely questioned the reasons for their movements outside the home when they attempted to seek treatment (Nair, George, and Chacko 1997). Another study showed that persons with TB who refused treatment under the

RNTCP attributed the refusal to not wanting to disclose the disease due to social stigma (Haque, Kumar, and Vyas 2014). To avoid being identified with TB, some persons seek treatment at health facilities that are far from their homes; this has implications for treatment adherence, cost, and outcomes.

Family support, especially from a spouse or from adult children, drives treatment initiation and completion. Married men and single women experienced a greater level of family support for TB treatment initiation and completion (Nair, George, and Chacko 1997).

Adversities in these four areas) influence one another, leading to an overall negative domino effect.

Overall consequences

The consequences of stigma and discrimination affect men and women differently. While differences in TB notification rates between men and women may reflect biological differences (differences due to sex) in the epidemiology of TB, differences in the societal roles of men and women (differences due to gender) that influence risk of exposure, and/or to access to care need to be specially examined and addressed. Examining gender dimensions includes looking at issues such as differences in risk of exposure to infection, in health-seeking behaviors, health system responses, economic consequences, and stigma linked to having TB.

The overall consequences of stigma and discrimination on TB control are summarized in Figure 12.

Figure 12: Impact of stigma and discrimination in TB, and factors leading to them



*Dhingra, V.K., & Khan, S. (2010). A sociological study on stigma among TB patients in Delhi.

From the perspective of a TB control program, these consequences impact the health of the individuals affected, delay TB diagnosis, and affect treatment outcomes.

Conclusions

Stigma is a well-documented barrier to health seeking behavior, engagement in care and adherence to treatment across a range of health conditions globally, and this applies to TB in particular. Considered for centuries as a fatal illness, TB results in prejudices, discrimination, and isolation. Stigma associated with TB is latent; it is always present and manifests when someone is known to have the disease. To address stigma and discrimination, SHOPS Plus recommends the TB community focus on collaborative change, complementary approaches of social and medical management, and increased investment in stigma and discrimination reduction in TB.

Collaborative change required for stigma and discrimination reduction

A person with TB and people in her/his Inner Circle are stigmatized and discriminated against according to the socio-ecological model of influence. The adverse emotional, social, financial, and health consequences of TB disrupt their lives; facing stigmatizing and discriminating behavior can accentuate their trauma. To successfully deal with the disease and return to 'normal,' there is a need for behavior showing positive deviance from everyone in the socio-ecological system of influence; the change must be collaborative.

A U.S. Surgeon General's Report in 1999 concluded that while stigma was expected to abate with increased knowledge, just the opposite occurred: stigma intensified, even though understanding improved (Martin, Lang, and Olafsdottir 2008). A more recent study in India on 'knowledge regarding TB associated with stigmatizing and discriminating attitudes of the general population toward TB patients' reiterates this finding. It concludes that stigmatizing and discriminatory attitudes toward persons with TB remain high among the general Indian population independent of knowledge about TB. It adds that current information disseminated about TB is mainly from a medical perspective, and the factors that lead to stigma and discrimination toward persons with TB may not be adequately addressed. The study recommends reviewing the messages about TB and the dissemination strategies currently used (Sagili, Satyanarayana, and Chadha 2016). Increasing knowledge alone will not change the prejudiced attitudes and stigmatizing and discriminating behavior of the people represented in the socio-ecological model of influence.

There is a need to review the messages and strategies currently used for disseminating knowledge regarding TB, which not only informs people about medical aspects of TB disease, but also removes stigma and discrimination

(Sagili, Satyanarayana, and Chadha 2016)

The TB community must build a solid voice of reason among people within the socio-ecological model of influence by addressing reasons for stigmatization and discrimination. It also needs to create and leverage stakeholders who exhibit positive deviance and influence people in the model. Positive deviants⁴ in all the different layers of the ecosystem need to influence others to dispel myths and misconceptions about TB and change social norms and behaviors toward

⁴ Positive deviants are the few individuals in a group who find unique ways to look at, and overcome, seemingly insoluble difficulties, by seeing solutions where others don't; positive deviants drive change.

persons with the disease and their Inner Circle, which will help the person with TB and their Inner Circle reclaim their lives.

Complementary approach of social and medical management

In 1999, Ogden et al. suggested a paradigm shift in TB control, away from a focus on diseased patients and toward enabling health in the community. *“Effective tuberculosis control cannot be achieved so long as the disease is considered in isolation from the social processes that maintain it, create the conditions facilitating its spread and act as barriers to care.”* They conclude that failure of treatment should not be seen as the failure of the person with TB. Instead, TB control programs must address the social dimensions of TB, and adhere to the principles of good TB care, with the same commitment that is devoted to ensuring that people with TB follow treatment guidelines (Ogden et al. 1999).

As part of the TB control program approach, it is important that social and medical management complement each other. The program needs to ensure that service delivery follows established standards for TB care, and that stigma and discrimination are reduced simultaneously.

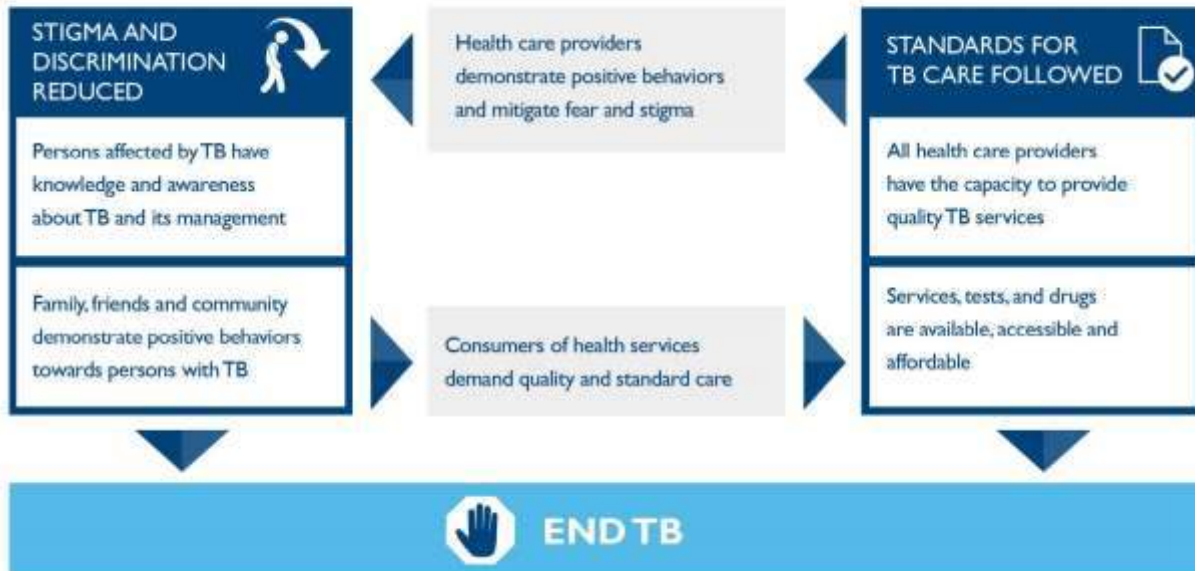
For standards for TB care to be followed appropriately, all health care providers must have the capacity to provide quality TB services. Services, tests, and drugs must be available, accessible, and affordable, and consumers of health services must demand quality and standard care.

For stigma and discrimination to be reduced, the person with TB and the Inner Circle must have knowledge and awareness about TB and its management, but it is equally critical that the Inner and Social Circles and community members and influencers display positive behaviors toward the person with TB. Health care providers must also demonstrate positive behaviors and mitigate stigma and discrimination.

The overall evidence will steer law, policy, guidelines, and protocols of social and medical management of TB. Figure 13 summarizes how social and medical management complement each other.

Figure 13: Complementary approach of social and medical management

Evidence steers law, policy, guidelines, and protocols



Reasons for investing in stigma and discrimination reduction in TB

Three strategic reasons for investing in stigma and discrimination reduction are:

1. Better and faster realization of India's goal of TB elimination.
2. Reduced catastrophic costs and better resource utilization.
3. Higher acceptance and utilization of program services.

To mitigate TB-related stigma and discrimination as well as their adverse consequences, investment in stigma reduction is vital to support early diagnosis, initiation of TB treatment, and improved treatment outcomes. It will also help in the mental and emotional well-being of the persons with TB. It encompasses improving cough hygiene and screening contacts of persons with TB, thus reducing TB transmission and may also improve the impact of efforts to identify and manage latent TB infection.

Addressing stigma and discrimination, with a vision of 'stigma free TB care' is a critical step toward achieving India's aim of ending TB.

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