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Case 3 : The Missing Four Million: Working to Increase the Case Finding Rate for People with TB

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CASE 3

The Missing Four Million: Working to Increase the Case Finding Rate for People With TB

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> *"We knew no one who had survived TB or maybe no one spoke about it." "My doctors had told me not to mention TB to anyone. I realised that there is a silence around TB as if it were my fault."*
>
> — Nandita Venkatesan, TB Survivor

> *"It can be a terrible stigma for your neighbors to know that you have tuberculosis or HIV, so our workers must be savvy enough to know what to look for, and to read between the lines in conversations."*
>
> — Unknown Author, Operation ASHA

Paru Hari lives in Bihar, one of the poorest states in India. As an Accredited Social Health Activist (ASHA), she is involved in daily outreach within her community to conduct home visits, facilitate community member access to health care facilities, administer medications, treat minor ailments, and generate health awareness. The majority of her work involves antenatal checkups, immunizations, and mild sickness treatments. However, with Bihar reporting approximately 70,000 new cases of tuberculosis (TB) annually, and with many cases going unreported and undiagnosed (Fathima, Varadharajan, Krishnamurthy, Ananthkumar & Mony, 2015; RESULTS Canada, 2018a), Paru decided to take action. She proposed that ASHAs act as TB educators and household screeners for patients who have TB because she was tired of watching people in her community suffer and die from a treatable disease.

As a health activist and advocate, Paru not only wanted to gain a better understanding of TB, but she also wanted to understand the barriers and challenges faced by patients who have the disease and what these patients required from ASHA workers. Paru decided to visit Dr. Tisha Guru, Bihar state's ASHA Program Director, to share her concerns about how to best integrate TB educational activities and household screening programs into her daily routine. For Paru to gain a clear understanding of what she needed to know to identify patients with TB and what they require during diagnosis and treatment, Dr. Guru suggested that she accompany patients from the initial stages of their diagnosis to the completion of their treatment (Exhibit 1).

In the spring of 2014, Dr. Guru introduced Paru to Nadine Vanita, a 23-year-old woman who had twice been a patient of the Bihar Regional ASHA Program. Being young women living in Bihar, the two had things in common. Nadine described her painful battle with TB and its overwhelming and burdensome treatment (Exhibit 1). Listening to the struggles that Nadine had faced throughout her TB journey upset Paru, especially the side effects from the TB medications, the difficulties in her diagnosis and treatment, and the mental and psychological impacts (Exhibit 1).

Sadly, Nadine's story was not uncommon. Dr. Guru informed Paru that there were many more women living in the rural region of Bihar who had similar experiences. The long distances patients had to travel to access health care facilities only added to their physical, mental, and psychological stress.

Although she did not have an extensive medical background, Paru knew that the ASHA program required a great deal of funding to ensure that it was sustainable and had the necessary resources to allow TB testing and care integration into their daily work. She knew that action needed to be taken, not only to continue the ASHA program but, more importantly, to help people being overlooked by the current health care system. Paru worked with Dr. Guru to identify the key stakeholders who could effectively communicate the critical need for improved TB surveillance and the inclusion of TB educational activities and household screening programs into the services ASHAs provide.

BACKGROUND

Global Burden of Tuberculosis

Tuberculosis is a curable and preventable disease that affects approximately 10 million people annually (World Health Organization [WHO], 2018a). One of the top 10 overall causes of death globally, it is the leading cause of death by an infectious agent (WHO, 2018a). Tuberculosis "is an infectious bacterial disease caused by *Mycobacterium tuberculosis* and is transmitted from person to person via droplets from the throat and lungs of people with the active respiratory disease" (WHO, 2018b). The disease claimed 1.7 million lives in 2016 alone, which is more deaths than those from HIV/AIDS, Malaria, and Ebola combined (RESULTS Canada, 2018b; WHO, 2018a). Despite global efforts to eradicate the disease, TB continues to be a major public health concern, largely in South-East Asia and in some African countries (Singh et al., 2017). In 2016, an estimated 45% of TB cases occurred in South-East Asia, followed by 25% in Africa, 17% in the Western Pacific Region, 7% in the Eastern Mediterranean Region, 3% in Europe, and 3% in the Americas (WHO, 2018a). What is even more alarming is that TB is currently the number one infectious killer worldwide, with an estimated 10.4 million people falling ill annually (Global TB Caucus, 2017). Of this total, 4 million people are undiagnosed, untreated, and/or missed by the health care system entirely, leaving TB more likely to spread and contribute to the 1.7 million deaths attributed to the disease each year (Global TB Caucus, 2017; WHO, 2018a). It is projected that this disease burden will cost the global economy approximately 1 trillion US dollars by 2030 if action is not taken to reduce its spread (United Nations, 2018).

The United Nations Sustainable Development Goals and the End TB Strategy

The Sustainable Development Goals include 17 goals that follow the Millennium Development Goals and offer a "universal call to action to end poverty, protect the planet, and ensure that all people enjoy peace and prosperity" (United Nations Development Programme, 2018). The third Sustainable Development Goal aims to "ensure healthy lives and promote well-being for all at all ages," which includes putting an end to the TB epidemic by 2030 (WHO, 2018a). In addition, the 2014 World Health Assembly introduced the WHO End TB Strategy and called on governments to help with the goal to end the global TB epidemic (WHO, 2018a). Global targets set for the year 2020 aim for a 35% reduction in TB deaths and a 20% reduction in the TB incidence rate (Exhibit 2, WHO, 2018a). Although the annual global TB mortality rates and TB incidence rates are declining each year by approximately 3% and 2%, respectively, these rates need to decline by 4% and 5%, respectively, and the TB case mortality rates need to drop from 16% to 10% by 2020, to successfully reach the first milestones (WHO, 2018a). If the actions outlined in the strategy are not taken, it has been predicted that it will take more than 150 years to end the TB epidemic and achieve the 2030 targets (RESULTS Canada, 2018).

Tuberculosis in India—A Focus on Bihar

India is considered by the WHO to be a 'high burden' country for TB, with two people dying from tuberculosis every three minutes, approximately 1 million people not receiving care for the disease each year, and a further 10 million people spending years suffering from the disease as a result of this lack of care (RESULTS Canada, 2018b; WHO, 2018a). Of the 29 states in India, Bihar alone reports approximately 70,000 new cases of TB annually, with many people affected by TB missed by the health care system (Fathima et al., 2015); Global TB Caucus, 2017; Know India, n.d.; RESULTS Canada, 2018b). Bihar is the third most densely populated state in India, has one of the highest population growths in the country, and has more than 325 people/km^2 (Noble, Dayal, & Dutt 2018; World Health Partners, n.d.). The state is predominantly rural, with 85% of the population residing in compact or clustered villages, and it continually falls below other Indian states in per capita income, with more than half the residents living in poverty (Noble et. al., 2018; RESULTS Canada, 2018b; World Health Partners, n.d.).

Health Care, Equity, and Equality in India

As a result of health care expenditures, approximately 39 million Indian citizens fall into poverty each year, and this number is steadily increasing (Balarajan et al., 2011). This number illustrates India's challenges in responding to the needs of its most disadvantaged and marginalized populations, and emphasizes the 'inverse care law', which states that "those with the greatest need for health care have the greatest difficulty in accessing health services and are least likely to have their health needs met" (Balarajan et. al., 2011, page 3). Many of the health inequities experienced by India's population result from social, economic, and political factors such as variations in gender, caste (social divisions in which each social group has privileges and limitations passed down through familial generations), wealth, education, income, resource allocation, and physical access (Balarajan et. al., 2011). These inequities are further compounded by rural–urban inequalities in the provision of health care services. In rural India, which accounts for 67% of the overall population, access to health care services is significantly more limited than it is in urban centers (Sing-Cheema, 2017). This has led to 67% of the population facing significant barriers to care (Singh-Cheema, 2017). People living in rural communities are often forced to travel long distances to reach health care facilities, which can lead to lost wages, unemployment, and difficulties in finding childcare (Singh-Cheema, 2017).

India's public health care system is further plagued by a shortage of health care professionals. In 2016, the country reported a shortage of 500,000 doctors, which primarily affected India's poorest states of Bihar, Uttar Pradesh, Madhya Pradesh, and Rajasthan (Singh-Cheema, 2017). Despite the effort of nongovernmental organizations to introduce initiatives aimed at combatting India's inequitable health care system and increasing access to health care for its rural populations, additional funding is required to create sustainable programs that include more training, equipment, and medications (Singh-Cheema, 2017).

A Sign of Hope—ASHAs

Bihar has 82,000 ASHAs for a population of 100 million people (Das et al., 2016). The acronym ASHA also means 'hope' in Hindi, and is a title given to formally educated, incentive-based female health workers who are 25 to 45 years of age (Das et al., 2016). Often referred to as "the backbone of primary health care in India's 600,000 villages", ASHAs are responsible for overseeing a village of approximately 1000 residents. They are selected by the community, reside in the community, and are trained, deployed, and supported to function in their own villages (Das et al., 2016; Akella, 2017). Accredited under the National Rural Health Mission of the Indian government, an ASHA's job responsibilities can be broken down into the following three key components (Akella, 2017; Fathima et. al. 2015):

- link worker (facilitating access and accompanying women and children to health care facilities);
- community health worker (distributing medicines and treating minor ailments); and
- health activist (creating health awareness and a desire for community change).

Essentially, ASHAs act as liaisons between villagers and the public health system (Das et al., 2016). Despite promoting critical health practices such as immunization programs, referrals for maternal, pediatric, sexual, and reproductive health care, and referrals for other critical health care-related activities, ASHAs only receive small incentives (Das et al., 2016).

WORKING TO INCREASE THE CASE-FINDING RATE FOR PEOPLE WHO HAVE TUBERCULOSIS

Paru and Dr. Guru agreed that there was a need for health care workers to be more proactive in TB diagnosis and detection. They believe that this approach to health care delivery would be most effective at improving the TB case detection rate and increasing care access at the community level. Dr. Guru and Paru also believe that this is when the government and civil society must work together to introduce, implement, and advocate for "innovative and ground-breaking techniques, interventions, approaches, and activities that result in detecting the undetected TB cases, leading to a reduced rate of transmissions and preventing the emergence of drug-resistant forms of TB" (Stop TB Partnership, 2018). Dr. Guru knew that if more residents of Bihar could be reached through improvements to the current health care system, then the case-finding rates for people who have TB would increase, which would positively affect the lives of people in Bihar and across India.

THE CHALLENGES—BARRIERS IN BIHAR

As per findings from Li et al. (2017), Dr. Guru and Paru discussed the high TB burden and regional inequities in accessing health care. They knew that the TB case-finding strategies were not sufficient and that the health facilities that ASHAs must link patients with are often under-resourced and badly equipped (Saprii, Richards, Kokho, & Theobald, 2015). Unfortunately, this was often because the residents of Bihar faced complex barriers pertaining to money, power, and resources at global, national, and local levels (Viner et. al., 2012). Paru knew that incorporating TB educational activities and household screenings into her daily work would not be easy. As a female resident of Bihar herself, Paru was familiar with many of the social determinants of health that made it challenging for the people of Bihar to access care.

Social Determinants of Tuberculosis

India has many of the adverse structural and social determinants that contribute to tuberculosis epidemiology (Exhibit 3), which include social, economic, and political inequalities such as variations in gender, caste, wealth, education, income, resource allocation, and physical accessibility, as well as high levels of mobility, rapid urbanization, and population growth (Balarajan et. al., 2011; Hargreaves et. al., 2011).

Paru knew that Bihar in particular had many social determinants of health that presented challenges for patients who have TB. These determinants include poverty, poor ventilation, overcrowding, power imbalances, gender discrimination, food insecurity, malnutrition, lack of health care workers and health care services, low health literacy, lack of education, low socioeconomic status, and poor sanitation, as well as financial, geographic, and cultural barriers to access (Exhibit 3; Hargreaves et. al., 2011; RESULTS Canada, 2018a). Women face additional challenges in accessing care, particularly in terms of travel, with trips to health care facilities often taking hours to days. These long distances put further strain on their already

compromised immune systems and add to the other stresses they endure, which include finding child care, missing work, losing employment, being harassed, and facing gender-based violence (Hargreaves et. al., 2011; RESULTS Canada, 2018a; Singh-Cheema, 2017).

Deficiency of Human Resources

As a doctor herself, Dr. Guru was keenly aware of the shortage of doctors and warned Paru that patient demands far exceed doctor supply. Dr. Guru and Paru knew this deficit was most prominent in India's poorest states, one of which was Bihar (Singh-Cheema, 2017). Further compounding the doctor shortage was the severe shortage of other health workers such as dentists, nurses, and midwives, among others (Exhibit 4; Hazarika, 2013). Ultimately, human resource shortages are negatively impacting the scale-up and expansion of health services, leading to overburdened health care systems and underserviced communities (Hazarika, 2013).

THE ACTION PLAN—WHO IS INVOLVED?

Community Level Engagement

Dr. Guru decided to accompany Paru on her daily home visits in an effort to best engage the community members and better understand their needs. As an ASHA worker and a member of the community, Paru had already established trusting and meaningful relationships with her patients; because she addressed the needs of these rural and marginalized populations, the community valued her opinions and trusted her judgement.

Regional Stakeholder Engagement

Dr. Guru and Paru requested a meeting with the National Rural Health Mission, the governing body that oversees management of the ASHA program within the Ministry of Health and Family Welfare. During the winter of 2014, they were invited to the Health Mission's annual meeting to discuss their concerns with national-level stakeholders involved in rural health issues. They communicated the critical need to improve TB screening and expand the role of ASHAs to include TB educational activities and household TB screening in their duties. Attendance at this annual meeting was crucial because it is where policy decisions, program plans, and budget approvals are made at the national level for state-level issues, including challenges pertaining to ASHA training, supervision, performance monitoring, and resources (K4Health, n.d.).

National and Global Partners

Dr. Guru and Paru then looked to TB REACH, a multilateral funding partnership that uses a 'Transition to Scale Up' grants framework to guide and support grantees who are providing innovative approaches and techniques to support, care, treat, and prevent TB among the world's hardest-to-reach populations (RESULTS Canada, 2018b; Stop TB Partnership, 2018). Paru was particularly excited that, if this initiative were successful, the program would be scaled-up and move beyond TB REACH to support National TB Programs and other external agencies (Stop TB Partnership, 2018). Through the TB REACH program, funding would go toward training, assisting, and providing resources to integrate TB testing and care into the daily community health work undertaken by ASHAs (RESULTS Canada, 2018b).

Dr. Guru also introduced Paru to Sherry Graham, TB Officer for RESULTS India. RESULTS India is a civil society organization that advocates for political support in ending extreme poverty through vaccination and immunization, HIV/AIDS, TB and malaria, water and sanitation, and maternal, newborn, and child health campaigns (RESULTS Canada, 2014). RESULTS India and its citizen advocates are known for their strong and successful history of campaigning for TB REACH India (RESULTS Canada, 2018a). Dr. Guru believed that working with RESULTS India would allow Paru to increase the TB REACH program in the Bihar area.

After discussing this with Sherry further, Paru discovered that, in 2016, the Government of Canada had announced a funding commitment of $85 million dollars to support another five years of international TB innovation grants (RESULTS Canada, 2018a). This was a small portion of Canada's Official Development Assistance budget, but Paru and Sherry knew that it could have a huge impact in helping organizations "understand and improve the community impact of their projects and how they might work to reach more people missing out on TB care and cure" (RESULTS Canada, 2018a).

THE IMPACT OF ASHAs—ASHAs TO THE RESCUE

Paru and Dr. Guru decided to research and reflect on the impact ASHAs have had on population health outcomes so far. From their own experiences, Paru and Dr. Guru knew that ASHAs had been successful in improving maternal, newborn, and child health through their active involvement in the reduction of infant polio, malnutrition, and mortality rates in Indian villages (Akella, 2017).

After interacting with community members, civil society organizations, and advocates, Paru and Dr. Guru knew that ASHAs have had a positive impact on the health outcomes of the people of Bihar. When working with rural Indian women diagnosed with AIDS, ASHAs have helped reduce stigma and isolation by promoting active coping techniques and dialogue (Nyamathi et. al., 2013). This has been important in reducing the incidence and prevalence of psychological distress and in increasing the number of people actively seeking access to health care services and adhering to treatments (Nyamathi et. al., 2013). Paru and Dr. Guru wondered whether ASHAs would have the same success in reducing the stigma and stress associated with TB.

After researching Operation ASHA, a not-for-profit organization serving two states in Cambodia and eight states in India (but not Bihar), Paru and Dr. Guru were pleased to learn that ASHAs had successfully reached 6.1 million people who have TB in more than 3,000 slums, villages, and other disadvantaged, hard-to-reach communities (Operation ASHA, 2013). ASHA intervention increased TB detection rates from 50% to 400% over 6 to 18 months, increased job retention via employer counselling, and increased mental health treatment and physician referrals for people who have comorbidities, such as diabetes (Operation ASHA, 2013). This intervention also led to a treatment success rate of 87% (Operation ASHA, 2013). Paru and Dr. Guru were thrilled about these successes because they had learned that, if left untreated, patients who have TB can infect up to 12 people before they die (The Wharton School of Business, 2018). Furthermore, the economic benefits of intervention were vast, with the treatment of one person who has TB having the potential to save the community up to US$12,000 in medical costs, simply by preventing the spread of the disease (The Wharton School of Business, 2018).

They also learned that not only are ASHA programs proven to be high impact, low-cost, and scalable, but ASHAs are considered to be fundamental at a grass-roots level in providing services to people at their doorsteps (The Wharton School of Business, 2018; Sateesh & Kumar, 2017). As they had suspected, ASHAs were viewed as a sustainable resource that can have a vast impact on vulnerable, marginalized, and hard-to-reach populations (Nyamathi et. al., 2013). They read about other patient encounters with ASHAs and were pleased to learn that patients who have TB noted significant benefits from working with ASHAs. ASHAs ensured that patients who have TB took their daily medications and felt less stigmatized and isolated, and they had an overall positive impact on their patients' mental and physical health (Centers for Disease Control and Prevention, 2013). This was encouraging news for Dr. Guru and Paru; however, they knew that to effectively reach their target population, ASHAs would require

appropriate training and their services would have to be developed properly (Sateesh & Kumar, 2017).

MAKING A DECISION—TO TRAIN OR NOT TO TRAIN?

Dr. Guru now felt it was critical to introduce an ASHA training program in Bihar to help patients who have TB get diagnosed and treated early. She decided to meet with each ASHA worker in her region to conduct interviews, solicit feedback, and collect patient data. An ASHA worker's only option for monitoring and surveillance was via handwritten medical records because community Internet access was very limited. Dr. Guru and Paru listened to the ASHAs' concerns and brainstormed ideas for increasing TB training that would enable ASHAs to deliver improved health care services to the people of Bihar. Their preference was to develop online training modules, mobile apps, and interactive websites; however, limited electricity, impoverished conditions, and poor infrastructure made it too difficult for most people to have a reliable Internet connection. Consequently, their only option was to create and distribute hard copy resources, although they knew that this introduced further challenges. Dr. Guru and Paru would need to:

- create a comprehensive and culturally appropriate training manual that could benefit all ASHAs working in the various villages of Bihar,
- ensure sufficient monitoring and surveillance of the manual,
- consider appropriate methods that could be used to assess the effectiveness of the training,
- determine how to cover the costs needed for program development and implementation, and
- consider which stakeholders they needed to engage to ensure that the training is effective and implemented at the community level.

CONCLUSION—MOVING FORWARD

Paru and Dr. Guru were unsure how it would all come together but they believed that they could meet their goals. They had passion, persistence, determination, and a strong group of advocates on their side.

EXHIBIT 1
Paru's Story— Battling Tuberculosis as a Public Health Professional

With a better understanding of the interconnectedness of structural and social determinants of health faced by the residents of Bihar, Paru and Dr. Guru decided that Paru should accompany Nadine through the treatment process step-by-step. This would be the best way for them to make the greatest impact in increasing the number of people who receive TB treatment and in understanding the complex journey faced by patients who have the disease.

Nadine warned Paru that it is harder for Indian women to survive TB than it is for Indian men because of the significant stigma society places on women who have the disease. When women acquire TB, they are blamed for contracting the disease, shamed, isolated, and silenced because many people believe that the women become sick after engaging in "risky behaviour" (Nyamathi et. al., 2013; Survivors Against TB, 2018). This is especially true for Indian women. Because they have low literacy rates, education levels, and employment opportunities, they often lack autonomy, decision-making capacity, and awareness about TB and its negative health implications (Nyamathi et. al., 2013). Nadine continued to share her story, noting that women and girls are often forbidden to disclose their diagnosis. There is a strongly held fear that they will be seen as 'damaged', which threatens their hopes of getting married and having children (Nyamathi et. al., 2013; Survivors Against TB, 2018).

Nadine was an 18-year-old college student when she was first diagnosed with an unknown viral infection that she contracted during the rainy season. When the rains ended and her cough persisted, she returned to the doctor to undergo a series of tests. As a consequence of ill-equipped hospital staff and the attitudes of many health care professionals who still stigmatized the disease, Nadine was left to diagnose her own illness. Her condition worsened until she began coughing up blood. Having heard stories of others who had similar symptoms, Nadine suggested that the staff conduct a computed tomography scan to check for TB (Survivors Against TB, 2018).

Not surprisingly, Nadine's concerns came true. During her first year of college exams, Nadine was diagnosed with TB and had to take a daily combination of 15 medications (Survivors Against TB, 2018). She struggled to understand what she was facing and lacked any counselling regarding what to expect, how to adhere to the daily drug regimen, and how to cope with the stigma she experienced from her doctors and her community about her TB diagnosis (Survivors Against TB, 2018). In fact, her doctors repeatedly told Nadine not to discuss her diagnosis with anyone, forcing her to hide her struggle from everyone around her (Survivors Against TB, 2018). As stigma often does, the isolation and fear of judgement for speaking out caused Nadine to suffer further mental health issues and depression (Survivors Against TB, 2018). However, after two long and difficult years battling the disease, Nadine became a survivor—no more medications, no more daily battles—she was free (Survivors Against TB, 2018).

After hearing Nadine's story, Paru realized the magnitude of the silence around TB. She wondered how people suffering from the illness would be able to speak out if Nadine's own doctors refused to listen to her. She assumed this silence was contributing to large numbers of TB cases in Bihar going undiagnosed and unreported each year.

At the age of 23, Nadine found herself in the same situation again, although this time she had Paru by her side. Nadine told Paru how she felt and reported the similar coughing and painful symptoms she had experienced years earlier (Survivors Against TB, 2018). Under Paru's

supervision, the two women travelled to the nearest health care facility, which was a full day trip of walking and taking public transit. They registered Nadine at a costly private health care facility where she was prescribed antiviral medications. Again, these medications failed and her pain worsened. They returned to the doctor after another long day of travel and Nadine underwent another series of tests. After weeks of waiting for a diagnosis, Nadine was told that her worst fear had come true. She was diagnosed with a TB reinfection, but this time it was a drug-resistant form of the disease. Nadine was told she needed to undergo surgery to remove part of her lung, and that this required a lengthy hospital stay and a trial-and-error drug regimen to find a combination of medications that would work with her daily anti-tuberculosis injections.

Paru accompanied Nadine to her family's home, a small shelter with poor ventilation that housed ten family members. Nadine was forced to leave her already low-paying job and had to inform her family about her high medication costs, the length of her upcoming hospital care and drug treatment, and her lack of access to individualized testing for drug susceptibility. This type of testing specifically determines the drug susceptibility of the TB bacteria a patient is infected with to help determine an optimized treatment plan (WHO, 2010). Paru listened as Nadine's family struggled to find ways to pay for their ailing daughter's treatment while still paying for food and housing costs and caring for elderly family members who had health complications from malnutrition.

Nadine was sent back to the hospital for several months this time because drug-resistant TB is much more difficult to treat, and patients are often quarantined for fear that the dangerous strain of the bacteria will continue to spread. Paru visited Nadine as often as possible during her stay in the hospital to reassure her that she would get through this as she had done once before.

However, nothing could have prepared Paru for her third visit, which was two days after Nadine's 24th birthday. Upon her arrival, Paru was notified that Nadine had permanently lost her hearing, leaving her feeling lost and confused. This was a side effect of one of the many medications Nadine had been taking that had not been disclosed by any health care professional.

Paru knew that she needed to help others before they too had to experience what Nadine and her family had faced. Paru took Nadine's story back to Dr. Guru and pleaded for her to help increase TB training for ASHAs.

EXHIBIT 2
The End TB Strategy at a Glance

BOX 2.3

The End TB Strategy at a glance

VISION	**A WORLD FREE OF TB** — zero deaths, disease and suffering due to TB			
GOAL	END THE GLOBAL TB EPIDEMIC			
INDICATORS	MILESTONES		TARGETS	
	2020	2025	SDG 2030[a]	END TB 2035
Percentage reduction in the absolute number of TB deaths (compared with 2015 baseline)	35%	75%	90%	95%
Percentage reduction in the TB incidence rate (compared with 2015 baseline)	20%	50%	80%	90%
Percentage of TB-affected households experiencing catastrophic costs due to TB (level in 2015 unknown)	0%	0%	0%	0%

PRINCIPLES

1. Government stewardship and accountability, with monitoring and evaluation
2. Strong coalition with civil society organizations and communities
3. Protection and promotion of human rights, ethics and equity
4. Adaptation of the strategy and targets at country level, with global collaboration

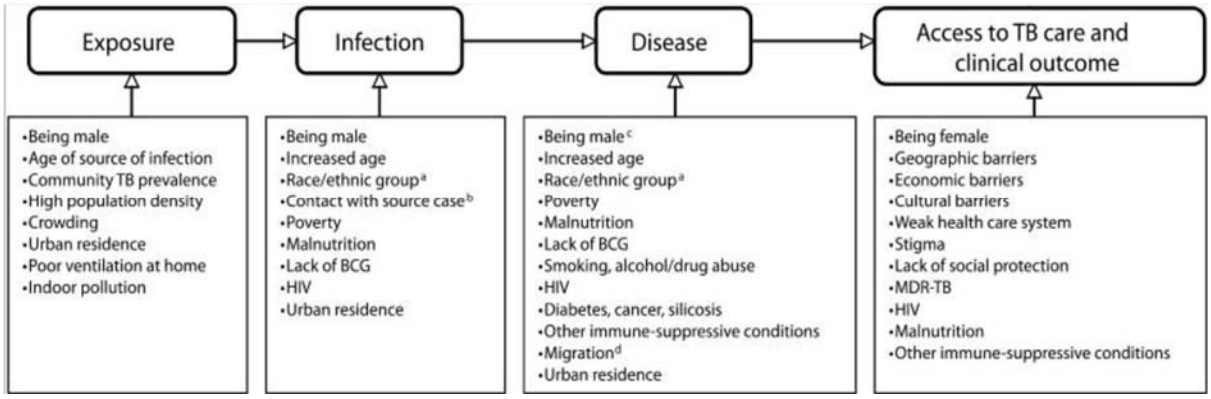
PILLARS AND COMPONENTS

1. **INTEGRATED, PATIENT-CENTRED CARE AND PREVENTION**
   - A. Early diagnosis of TB including universal drug–susceptibility testing, and systematic screening of contacts and high-risk groups
   - B. Treatment of all people with TB including drug-resistant TB, and patient support
   - C. Collaborative TB/HIV activities, and management of comorbidities
   - D. Preventive treatment of persons at high risk, and vaccination against TB
2. **BOLD POLICIES AND SUPPORTIVE SYSTEMS**
   - A. Political commitment with adequate resources for TB care and prevention
   - B. Engagement of communities, civil society organizations, and public and private care providers
   - C. Universal health coverage policy, and regulatory frameworks for case notification, vital registration, quality and rational use of medicines, and infection control
   - D. Social protection, poverty alleviation and actions on other determinants of TB
3. **INTENSIFIED RESEARCH AND INNOVATION**
   - A. Discovery, development and rapid uptake of new tools, interventions and strategies
   - B. Research to optimize implementation and impact, and promote innovations

[a] Targets linked to the Sustainable Development Goals (SDGs).

Source: World Health Organization, 2018a.

EXHIBIT 3
Social Determinants of Tuberculosis (TB)



Source: Hargreaves, et. al., 2011. Reproduced with permission from The Sheridan Press.

EXHIBIT 4
Availability of Human Resources in India

Table 1: State-wise availability of doctors, dentists, nurses and midwives – 2009

States	Population (million)[a]	Health-worker numbers[a]				Health-worker density per 1000 population				Ratio of nurses and midwives per doctor
		Doctors	Dentists	GNMs	ANMs	Doctors	Dentists	Nurses and midwives	Combined[e]	
Andhra Pradesh	83.11	62 349	6510	136 477	112 269	0.75	0.078	2.99	3.74	3.99
North-east states[b]	49.84	19 324	944	20 285	23 375	0.39	0.019	0.88	1.26	2.26
Madhya Pradesh	70.28	25 662	2002	96 574	27 566	0.37	0.028	1.77	2.13	4.84
Bihar	100.94	36 559	2807	8883	7501	0.36	0.028	0.16	0.52	0.45
Chhattisgarh	24.85	2746	407	3945	1900	0.11	0.016	0.24	0.35	2.13
Goa	1.37	2716	687	N/A	N/A	1.99	0.503	N/A	N/A	N/A
Gujarat	58.76	45 058	2684	88 258	36 427	0.77	0.046	2.12	2.89	2.77
Haryana[c]	24.51	4132	2059	17 821	13 727	0.17	0.084	1.29	1.46	7.64
Himachal Pradesh	6.72	705	772	8550	10 152	0.10	0.115	2.78	2.89	26.53
Jammu and Kashmir	12.22	10 906	1090	N/A	N/A	0.89	0.089	N/A	N/A	N/A
Jharkhand	32.06	2933	NA	1998	3405	0.09	NA	0.17	0.26	1.84
Karnataka	59.86	83 177	25 612	136 421	48 509	1.39	0.428	3.09	4.48	2.22
Kerala	32.90	37 835	6655	85 624	28 378	1.15	0.202	3.46	4.61	3.01
Maharashtra	109.27	134 859	18 159	93 032	33 158	1.23	0.166	1.15	2.39	0.94
Orissa	41.20	16 734	537	63 167	49 170	0.41	0.013	2.73	3.13	6.71
Punjabc	27.07	38 434	7348	45 801	18 152	1.42	0.271	2.36	3.78	1.66
Rajasthan	66.42	27 654	364	37 667	22 239	0.42	0.005	0.90	1.32	2.17
Tamil Nadu[d]	71.20	84 525	11 609	186 972	54 124	1.19	0.163	3.39	4.57	2.85
Uttar Pradesh	192.62	55 355	5572	21 042	27 328	0.29	0.029	0.25	0.54	0.87
West Bengal	89.65	58 059	2054	48 470	56 302	0.65	0.023	1.17	1.82	1.80
Uttaranchal	9.82	3085	451	92	700	0.31	0.046	0.08	0.39	0.26
Delhi	15.83	8999	6280	26 547	2160	0.57	0.397	1.81	2.38	3.19
India	1183.56	761 806	104 603	1 127 626	576 542	0.64	0.088	1.44	2.08	2.24

GNM = General Nursing and Midwifery, ANM = Auxiliary Nurse Midwifery, N/A = data not available aPopulation data and health-professional statistics for 2009 from references 9-14; binclude Assam, Manipur, Meghalaya, Mizoram, Nagaland, Tripura and Sikkim; cinclude data from Chandigarh proportionate to state populations, dincludes the Union Territories, i.e., Chandigarh, Puducherry, Daman and Diu, Lakshwadeep, Andaman and Nicobar and Dadar Nagar Haveli; eincludes doctors, nurses and midwives

Source: Hazarika, 2013.

REFERENCES

1. Akella, B. (2017, November 1). India's ASHA workers: The backbone of primary health care in the country's 600,000 villages. *The News Minute*. Retrieved from https://www.thenewsminute.com/article/indias-asha-workers-backbone-primary-healthcare-country-s-600000-villages-70904
2. Balarajan, Y., Selvaraj, S., & Subramanian, S. V. (2011). Health care and equity in India. *The Lancet*, *377*(9764), 505–515. doi.org/10.1016/S0140-6736(10)61894-6
3. Centers for Disease Control and Prevention. (2013). Tuberculosis (TB): TB personal stories. Retrieved from https://www.cdc.gov/tb/topic/basics/mabrukastory.htm
4. Das, V. N. R., Pandey, R. N., Kumar, V., Pandey, K., Siddiqui, N. A., Verma, R. B., … Das, P. (2016). Repeated training of accredited social health activists (ASHAs) for improved detection of visceral leishmaniasis cases in Bihar, India. *Pathogens and Global Health*, *110*(1), 33–35. DOI: 10.1080/20477724.2016.1156902
5. Fathima, F. N., Raju, M., Varadharajan, K. S., Krishnamurthy, A., Ananthkumar, S. R., & Mony, P. K. (2015). Assessment of 'accredited social health activists'–a national community health volunteer scheme in Karnataka State, India. *Journal of Health, Population, and Nutrition*, *33*(1), 137–145. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/25995730
6. Global TB Caucus. (2017). The price of a pandemic 2017. Retrieved from https://docs.wixstatic.com/ugd/309c93_56d4ef0e87d24667b1d3edae55f6eeb5.pdf
7. Hargreaves, J. R., Boccia, D., Evans, C. A., Adato, M., Petticrew, M., & Porter, J. D. H. (2011). The social determinants of tuberculosis: From evidence to action. *American Journal of Public Health*, *101*(4), 654–662. doi.org/10.2105/AJPH.2010.199505
8. Hazarika, I. (2013). Health workforce in India: Assessment of availability, production, and distribution. *WHO South-East Asia Journal of Public Health, 2*(2), 106–112. doi:10.4103/2224-3151.122944
9. K4Health. (n.d.). India's ASHA program. Retrieved from https://www.k4health.org/toolkits/decision-making-tool-chw-programs/indias-asha-program
10. Know India. (n.d.). States and union territories. Retrieved from http://knowindia.gov.in/states-uts/
11. Li, J., Liu, X.-Q., Jiang, S.-W., Li, X., Yu, F., Wang, Y., … Wang, L.-X. (2017). Improving tuberculosis case detection in underdeveloped multi-ethnic regions with high disease burden: A case study of integrated control program in China. *Infectious Diseases of Poverty*, *6*(151). doi.org/10.1186/s40249-017-0365-4
12. Noble, A. G., Dayal, P., & Dutt, A. K. (2018). Bihar State, India. *In Encyclopædia Britannica online*. Retrieved from https://www.britannica.com/place/Bihar
13. Nyamathi, A., Ekstrand, M., Salem, B. E., Sinha, S., Ganguly, K. K., Leake, B., & Marfisee, M. (2013). Impact of Asha intervention on stigma among rural Indian women with AIDS. *Western Journal of Nursing Research*, *35*(7), 867–883. doi.org/10.1177/0193945913482050
14. Operation ASHA. (2013). Annual Report 2013–14. Retrieved from https://www.ngoadvisor.net/wp-content/uploads/2016/01/Operation-ASHA-Annual-Report-2013-2014.pdf
15. RESULTS Canada. (2014). History. Retrieved from https://www.results-resultats.ca/en/about-us/history/
16. RESULTS Canada. (2018a). TB REACH in Action: Care, cure, and prevention for the hardest to reach. Retrieved from https://www.results-resultats.ca/en/?s=hardest+to+reach

17. RESULTS Canada. (2018b). Advocacy Day on the Hill: Background Brief.
18. Saprii, L., Richards, E., Kokho, P., & Theobald, S. (2015). Community health workers in rural India: Analysing the opportunities and challenges Accredited Social Health Activists (ASHAs) face in realising their multiple roles. *Human Resources for Health*, *13*(95). doi.org/10.1186/s12960-015-0094-3
19. Sateesh, B., & Kumar, M. A. (2017). Quality and success of training programmes to ASHAS: A critical appraisal. *International Journal of Commerce and Management Research, 3*(10), 45–49.
20. Singh, A. R., Pakhare, A., Kokane, A. M., Shewade, H. D., Chauhan, A., Singh, A., … Thakur, P. S. (2017). 'Before reaching the last mile' – Knowledge, attitude, practice and perceived barriers related to tuberculosis directly observed therapy among ASHA workers in Central India: A mixed method study. *Journal of Epidemiology and Global Health, 7*(4), 219–225. doi.org/10.1016/j.jegh.2017.07.002
21. Singh-Cheema, M. (2017, November 3). India's healthcare paradox. *The McGill International Review*. Retrieved from https://www.mironline.ca/indias-healthcare-paradox/
22. Stop TB Partnership. (2018). About TB REACH: Background. Retrieved from http://stoptb.org/global/awards/tbreach/about.asp
23. Survivors Against TB. (2018). Nandita Venkatesan. Retrieved from http://www.survivorsagainsttb.com/en/OurSurvivorsDetails?OSD=3
24. United Nations. (2018). World Leaders Reaffirm Commitment to End Tuberculosis by 2030, as General Assembly Adopts Declaration Outlining Actions for Increased Financing, Treatment Access. Retrieved from http://www.un.org/press/en/2018/ga12067.doc.html
25. United Nations Development Programme. (2018). Sustainable Development Goals. Retrieved from www.undp.org/content/undp/en/home/sustainable-development-goals.html
26. Viner, R. M., Ozer, E. M., Denny, S., Marmot, M., Resnick, M., Fatusi, A., & Currie, C. (2012). Adolescence and the social determinants of health. *The Lancet, 379*(9826), 1641–1652. doi.org/10.1016/S0140-6736(12)60149-4
27. The Wharton School of Business. (2018). Operation ASHA: Scaling up to eradicate tuberculosis in 25 Years. Retrieved from https://www.wharton.upenn.edu/story/operation-asha-eradicating-tuberculosis/
28. World Health Organization. (2010). *Treatment of tuberculosis: Guidelines*. Geneva, Switzerland: World Health Organization.
29. World Health Organization. (2018a). Global Tuberculosis Report. Retrieved from apps.who.int/iris/bitstream/handle/10665/274453/9789241565646-eng.pdf?ua=1
30. World Health Organization. (2018b). Tuberculosis. Retrieved from http://www.searo.who.int/india/topics/tuberculosis/en/
31. World Health Partners. (n.d.). Impact Bihar. Retrieved from http://worldhealthpartners.org/where-we-work/india/bihar/

INSTRUCTOR GUIDANCE

The Missing Four Million: Working to Increase the Case Finding Rate for People With TB

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BACKGROUND

Paru Hari, an Accredited Social Health Activist (ASHA), lives in Bihar, India, one of the poorest states in the country. Paru is involved in daily outreach within her community to facilitate community member access to health care facilities, administer medications, treat minor ailments, and generate health awareness. The majority of her work involves antenatal checkups, immunizations, and mild sickness treatments. However, with Bihar reporting approximately 70,000 new cases of tuberculosis (TB) annually and many cases going unreported and undiagnosed (Fathima, Varadharajan, Krishnamurthy, Ananthkumar & Mony, 2015; RESULTS Canada, 2018b), Paru decided to take action. She proposed that ASHAs act as TB educators and household screeners for patients who have TB because she was tired of watching people in her community suffer and die from a treatable disease.

Paru decided to visit Dr. Tisha Guru, Bihar state's Regional ASHA Program Director, to share her concerns about how best to integrate TB educational activities and household screening programs into her daily routine. For Paru to gain a clear understanding of what she needs to know to identify TB patients and what they require during diagnosis and treatment, Dr. Guru suggested that she accompany patients from the initial stages of their diagnosis through to treatment. Although Paru did not have an extensive medical background, she knew that the ASHA program required a great deal of funding to ensure it was sustainable and that the necessary resources were available for TB testing and care to be integrated into their daily work. Paru knew action needed to be taken, not only to continue the ASHA program but, more importantly, to help patients who were being overlooked by the current health care system. Paru worked alongside Dr. Guru to identify the key stakeholders who could effectively communicate the critical need for improved TB surveillance, educational activities, and household screening programs into the services ASHAs provided.

The goal of this case is to provide readers with the opportunity to develop a real-world, case-based, health care narrative by applying the key theories and concepts learned in the classroom. These concepts include:

1. the knowledge of international health care system components (governance, finance, and organization)
2. potential issues and/or barriers in health care implementation and achieving the Sustainable Development Goals
3. the importance of health equity and cultural competence
4. the relationship between primary health care and public health care, and
5. the seven steps to achieving informed decision making.

The Missing Four Million: Working to Increase the Case Finding Rate for People With TB

This case will provide students with the opportunity to define the challenges associated with developing effective and equitable health care programs, and to understand and explain how people with infectious diseases are impacted by the social determinants of health (i.e. the role these determinants play in disease development). Students will also be able to brainstorm strategies for:

- identifying and engaging stakeholders and building partnerships for influencing public health outcomes;
- generating culturally appropriate public health content that can be delivered verbally and in writing to marginalized populations;
- applying the social determinants of health to health care and health outcomes; and
- creating effective responses that have culturally and context-relevant strategies for improving population health and reaching marginalized populations at the community level.

OBJECTIVES

1. Describe the challenges in developing effective programs in terms of health care and health equity in India.
2. Understand and explain the impact that social determinants of health have on people who have TB, and the role these determinants have in disease development.
3. Propose strategies to identify and engage stakeholders and build partnerships for influencing public health outcomes.
4. Identify culturally appropriate public health content for TB educational programs that can be distributed, both in written and verbal form, to the marginalized populations of Bihar.
5. Formulate an effective response that includes community level approaches and culturally and context-relevant strategies to improve population health for the marginalized populations of Bihar, India who are facing high rates of undiagnosed and unreported TB cases.

DISCUSSION QUESTIONS

1. What is the main problem or issue discussed in the case?
2. Who are the key players in the case and what are their roles?
    a. Do you feel that the ASHA program is appropriate for increasing the TB case-finding rate?
    b. Do you have any other ideas or strategies for creating sustainable programs that would be effective in this scenario?
3. What are the differences between the social and structural determinants of TB?
4. How could Dr. Guru and Paru create a comprehensive and culturally appropriate training manual that can benefit all ASHAs working in the villages of Bihar?
    a. Do you think creating such a manual is possible? Why or why not?
5. How could Dr. Guru and Paru ensure sufficient monitoring and surveillance of the manual's success?
    a. Can you think of any techniques, strategies, theories, or frameworks they could use?
6. What methods could Dr. Guru and Paru use to assess the effectiveness of the training?
    a. Would you use quantitative or qualitative data collection methods, or are both appropriate?
7. How would Dr. Guru and Paru cover the costs needed for program development and implementation?
8. Which stakeholders need to be engaged to ensure the training is effective and implemented at the community level?

KEYWORDS

ASHAs; case-finding rate; health equity; social determinants of health; TB burden; tuberculosis