A Report:

# SOCIETY, WOMEN AND TUBERCULOSIS

Ekta Niketan TB Centre

2022-23

# *SOCIETY, WOMEN AND TUBERCULOSIS*

## A REPORT

## EKTA NIKETAN TB CENTRE

2023

This report has been prepared by Dr Manan Ganguli who trains, advises and helps diagnose tuberculosis patients visiting Ekta Niketan, a centre to treat tuberculosis in remote villages in the district of Deoghar, Jharkhand in India.

This report is a tribute to those unfortunate TB patients who died during 2022.

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You may also like to visit:
https://fourthworldaction.net





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## Abbreviations

| | |
|---|---|
| TB | Tuberculosis |
| ATT | Anti-Tubercular Treatment |
| NTEP | National Tuberculosis Elimination Programme |
| RNTCP | Revised National Tuberculosis Control Programme |
| WHO | World Health Organisation |





Another year passes and another global awareness campaign emerges. Politicians and world leaders, supported by specialists, think tanks, consultants, academics, sign up and commit to new campaigns. The Millennium Development Goals, Sustainable Development, Zero Catastrophic Cost and so forth aim to improve our worldly wellbeing.

India has recently made a commitment to 'eliminate' TB by 2025. For a country of 1.4 billion, this is indeed a challenge. Making India TB-Free is an attractive slogan. But how realistic is this goal?

Tuberculosis (TB) is popularly known as the disease of the poor. It cannot be addressed without addressing public wellbeing in tandem with economic development. Norway, Sweden, Switzerland, the United Kingdom, the United States have all reduced TB incidence to some 5 cases per 100,000 people. This is not, however, the case in India, which faces some of the world's highest TB rates.

India has substantially invested in soft and heavy industries, from metallurgy to digital technology. Its admirable levels of economic growth, however, parallel a growing poverty gap and prevalence of malnutrition amongst low-income households. TB continues to spread. India experiences one of the highest incidences of TB worldwide, with no less than 200 cases per 100,000 people in 2021.

This 'Society, Women and Tuberculosis' report reflects upon the spread of TB in marginalised communities. Our modest team at Ekta Niketan highlight learnings from the plight of women who contract TB; it focuses in particular on young married women who have shared their experiences.

Unlike a majority of mainstream TB centres, Ekta Niketan operates in a village far from the nearest town. Its health worker team is comprised of local residents, a majority of whom themselves have contracted and recovered from TB. Their socio-cultural experiences reflect those of the desperate patients that come for help.

Jharkhand state's National Tuberculosis Elimination Programme (NTEP) provides Ekta Niketan with anti-tubercular drugs free of cost and gives us leeway to work within a wider geographic area than is normally mandated. They also waive a standard requirement to have a medical doctor present seven days a week. This enables Ekta Niketan to facilitate grass-root services accessible to wider remote rural and tribal communities in the area. In addition to diagnosing and providing medication to over 600 patients annually, the TB centre provides nutritional supplements for very sick patients who cannot afford to buy egg or protein supplements. Ekta Niketan has become a community TB centre in the truest sense, in that it is managed by local villagers.

Dr Manan Ganguli

June 2023

## Tuberculosis in India and Ekta Niketan TB centre

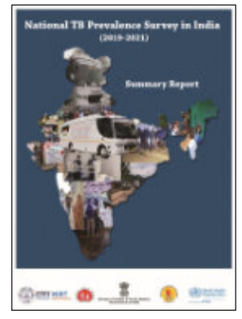
In 2020, India re-named its TB programme – from the Tuberculosis Control Programme to the National Tuberculosis Elimination Programme (NTEP), and has publicly promised to eliminate TB in India by 2025, five years ahead of the World


Health Organisation (WHO)'s global target. The WHO target (80% reduction in TB incidence to that of 2015, 90% reduction in TB deaths, no catastrophic costs for households to incur) by 2030, not to eliminate the disease by that time. Global experts have set a target of eliminating TB by 2050. NTEP specialists and policymakers, on the other hand, vow that TB in India will be eliminated within two years from the time of writing this report — a misleading promise.

Eliminating TB by 2050 as the global experts expect is itself challenging. The WHO's global report, meanwhile, stated in 2021 that "the COVID-19 pandemic has reversed years of global progress in tackling tuberculosis and for the first time in over a decade, TB deaths have increased". Meanwhile a 2019-21 National TB Prevalence Survey of India shows that the number of TB cases nationally are in fact much higher (312 TB cases per 100,000 people registered over this period) than the incidence of TB stated in the global TB report.

Eliminating TB in India, home to a quarter of global TB infections, will be challenging by any standards. Add to this equation its vast geographic surface and the prevalence of TB cases in very remote areas. Could it be that India's Prime Minister is simply attempting to assure domestic and international audiences of India's sterling progress in public service development? Whatever the reason, India has revamped its TB programme in the aftermath of this statement. But what impact has it had?

The spread of tuberculosis is intimately connected with the living conditions and incomes of the people who become exposed to this contagion. It is particularly prevalent in marginalised communities, where access to adequate food, medical treatments or the awareness of the importance of completing treatment courses is more limited. Health 'experts', politicians and urban-based health organisations in Delhi often do not appear to consider the link between TB and social conditions; such as living adjacent to mines which pollute local air and water sources, in hills and forests far from public medical facilities or in overcrowded ghettos where unskilled migrant workers eek out a livelihood. In the absence of concrete experience and understanding of the obstacles faced by disadvantaged communities disproportionately affected by TB, the NTEP will struggle. Promises of TB eradication are at risk of gradually fading. Another year might pass, as will new strategies



and statements, but with the absence of effective actions, TB will continue to spread. At a global level, the WHO similarly appears to be complacent about the steps needed to control TB worldwide.

Meanwhile, at a remote village level, Ekta Niketan operates in a world where TB is alarmingly pervasive.

*EKTA NIKETAN – a TB centre in the middle of a village where a group of villagers diagnose, treat and advise TB patients, and are skilled to keep records just as in an institution in a city. A TB centre unlike other TB centres.*

*Most TB patients at Ekta Niketan are very thin and weak; often they spend all their money at local jhola doctors or private doctors in town. To attend Ekta Niketan patients make long journeys – bus, train, auto-rickshaw, motor bike, bi-cycle or by foot. Ekta Niketan reaches the unreached.*






## Hard questions!

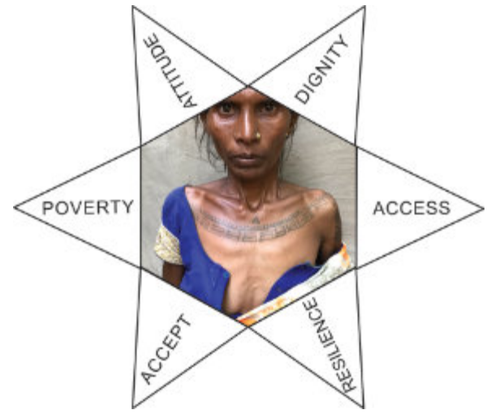
This 'Society, Women and Tuberculosis' report collates insights gained from TB patients and family members in marginalised communities coming for treatment at Ekta Niketan.' Drawing on such experiences, this report highlights a number of difficult questions regarding the spread of tuberculosis in remote villages. It shrugs off the notion that TB will be eliminated by 2025 and urges policymakers to consider empowering residents in remote villages with peer learning and better access to community-based services, in order to halt the unprecedented spread of this disease.

### TB is a marker of development but development is not geared to control TB. Why?

A worrisome focus on biomedical determinants such as diagnostic and prophylactic measures rather than societal determinants of TB suggest targets for eradication are doomed unless we focus, in equal measure, on who actually becomes infected.

Resources continue to be invested in new anti-TB drugs and vaccines to shorten treatment courses, but little emphasis is given to improving the conditions of people in disadvantaged areas.

Advances in science mean that the role of nutrients in controlling TB bacteria is now better understood; attempts have been made to improve diets and nutritional supplements as part of wider TB programmes. Sadly, none of these efforts have quite worked. Until life conditions for people living in poverty are addressed, it is unlikely that TB will be




eradicated. But even improving the economic welfare of marignalised communities forms only one element of a strategy to address poverty, just as improving nutrition amongst TB patients only partially addresses a cure for TB.

The fallacy of 'economic development' in the context of tuberculosis is effectively outlined in a 2017 Ted Talk by Dr Zarir F Udwadia, a leading Mumbai chest physician. He notes, in response to India's investment into the 500-km Mumbai-Ahmedabad bullet train project, that '150,000 Indians are with drug-resistant TB, Prime Minister Modi. Forget your bullet trains and help our patients. Give us social change, because TB is a perfect example of an imperfect civilisation'.

Economic development and societal development are two different entities. The status of the latter is reflected in a lack of access of marginalised communities to much-needed resources, their passive acceptance of such an inferior status and an admirable display of resilience and dignity when they do, in fact, contract TB. Ekta Niketan's TB patients share insights into such issues even as they struggle to survive.

## TB is rampant in remote rural areas - adivasi (indigenous) and non-adivasi communities alike. Why?

In the previous section we have underlined the value of a people-centric development strategy enabling government policies to effectively address social determinants of TB which economic growth alone will not.

Further factors contributing to the spread of TB in rural India, as described by Ekta Niketan patients and health workers observations, range from a lack of food to a lack of awareness of where to find free government TB facilities. This means patients often arrive after a round of irregular treatments with private practitioners, qualified or unqualified, who fail to diagnose TB infection in its early stages.

While creating hardship for patients with very limited finances who needlessly pay for catastrophic treatments, it means they must be treated again and at a time of weakened health. Some try to minimise costs by returning to work without completing a full cycle of treatment. This then leads to further spreading of more virulent forms of TB which no longer respond to standard medication. Some patients arrive very under-weight and sadly don't survive.





Is TB spreading fast in tribal communities in remote rural areas? Some studies show incidences of tuberculosis in India's indigenous tribal communities are much higher than elsewhere. Ekta Niketan can only reach a small part of India's vast rural areas but patient numbers from our clinic are on the rise (see Chart 1). In 2022 alone, a total of 622 TB patients – men, women, young and old, attended with pulmonary and extra-pulmonary forms of the disease - a 3 to 4-fold increase compared to 2019-2020.

While the growing popularity of Ekta Niketan might contribute to the rise in patient numbers, data in this regard (Chart 2) is cause for concern. And while our data cannot be considered as a clear indicator of national trends, given that it only reflects the experience of a small and remote Indian community, TB is most definitely on the rise locally.

## TB patients at Ekta Niketan are skin and bone. Why?

In 2016, Dr Soumya Swamynathan, former Director-General of the Indian Council of Medical Research and Chief Scientist at WHO, commented that 'reports from tribal areas of our country show that the average body weight of men and women with TB is 30-35 kg.'

Prevalence rates for TB directly correlate with patients' socio-economic status. Populations in the lowest economic quintile experience 3-4 times the rate of TB when compared with those in the highest' (the Hindu, 16 October 2016)'. Seven years on, India's road-rail networks have further connected an array of villages in remote areas with far away cities and industrial towns. Mobile phones have reached and continue to

Chart 1

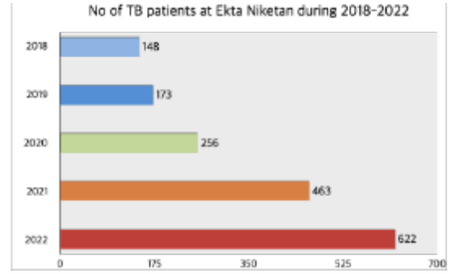
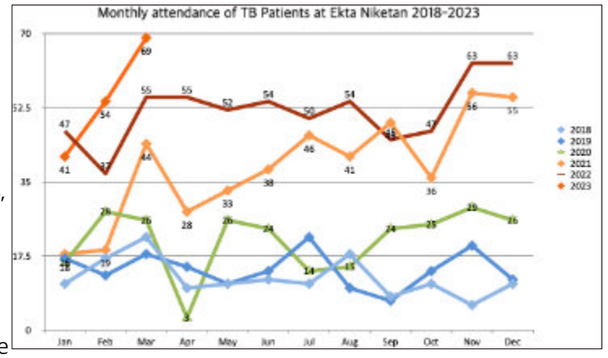



Chart 2




| Monthly attendance of TB Patients during 2022 | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| JAN | FEB | MAR | APR | MAY | JUN | JUL | AUG | SEP | OCT | NOV | DEC |
| 47 | 37 | 55 | 55 | 52 | 54 | 50 | 54 | 45 | 47 | 63 | 63 |

grow in presence in rural villages; it is possible that every household in rural India now has a mobile phone. Those same said villagers might eat rice and potatoes, occasionally vegetables or lentils, but rarely the luxury of both. Egg and meat rarely form part of rural diets, the phenomena of India's magical modernisation

*Ekta Niketan TB centre, right in the middle of a tribal village. (Photo: 1 April 2023).*

is underlined, sadly, by widespread and ongoing under-nutrition in rural areas.

TB makes people eat less. Once standard TB treatment starts, appetites return. An absence of protein in rural diets coupled with limited access to early treatments means that TB patients often arrive at Ekta Niketan thin and weak. Many arrive at a stage when the bones in their chest plate can be counted. A majority of adult patients pictured on page 12 weighed less than 35 kilos when they came to our services, with some weighing as little as 20-25 kilos.

## Migrant workers contribute to India's TB burden significantly but they are ignored. Why?

Unskilled migrant workers are crucial to building India's growing economy. They are also key actors in growing India's drug-resistant forms of the disease. Young boys and girls travel from remote rural roots where opportunities are scarce, to work in mines, factories, building works, 'hotels' and city restaurants. This low-paid, unskilled workforce is a gift to employers who offer casual contracts and poor working conditions that few would chose to sign up to if other choices were available.

Millions live in cities and industrial towns across India — and this number is increasing. Over the Covid period, the sight of young boys with backpacks flocking at railway booking counters and boarding long-distance trains was replaced by images of stranded migrant workers with no work, no income, no shelter, no food or protection.

Upon their return from cities, Ekta Niketan learns from returnee migrant workers that:

- It is not uncommon for 5-7 unskilled migrant workers to share a small, cramped room near workplaces or in city's ghettos;
- When faced with TB, many purchase cough syrups, tablets and try to carry on until their weakened bodies can do no more;
- Many are not aware that free government TB treatment centres are located across India;
- Having contracted TB in cramp quarters and workplaces, the vast majority of workers often return home for a 'quick cure' at private clinics, all the while spreading contagion amongst colleagues, on buses, trains and back in villages;
- In their haste to get back to work and earn much-needed wages, a proportion fail to complete a full course of anti-TB treatment;
- Many are not aware that a full course of treatment is critical to their recovery and that in its absence, they are more likely to develop drug-resistant forms of TB;
- We are yet to see an effective TB programme targeting such people in transit, in their hometowns and destinations;
- Of the total 622 TB patients who attended Ekta Niketan in 2022, some 10% were migrant workers presenting with various forms of pulmonary and extra-pulmonary TB conditions.





*(below) Stranded workers returning home. (Photo: Scroll; 2019)*

## People come from far away villages to Ekta Niketan TB Centre. Why?

Ekta Niketan TB Centre is in the village of Fatepur, some 20 kilometres from the town Madhupur in the district of Deoghar in Jharkhand. It is common for TB patients to make journeys of incredible distance on the back of a motorbike, a bicycle, a three-wheeler or combined train, bus and walking to get to Ekta Niketan. Ekta Niketan is unique - and its reputation is growing.

To cut down on patients' travel distances, Ekta Niketan has recently opened the Ekta Niketan Jugiatari outreach clinic some 70 kilometres away in the state of Bihar bordering Jharkhand where patients can be diagnosed, treated, and

*Ekta Niketan TB centre, Jugiatari at the outskirt of a tribal village. (Photo: 21 March 2023).*

collect their TB medicines for the duration of treatment. At the time of writing, 36 TB patients are on anti-tubercular treatment and collect their medication from this outreach centre.

Healthcare in the area where Ekta Niketan operates is in a sorry state. There is a super-speciality hospital but primary health centres do not function properly. People have little choice but to go to local untrained village 'doctors' or trained private practitioners in town who often fail to diagnose tuberculosis, inappropriately prescribing antibiotics rather than standard anti-tubercular drugs. This is a main reason why TB patients choose to make long journeys to come to Ekta Niketan for anti-tubercular treatment.

## Ekta Niketan is unlike other TB centres. Why?

Ekta Niketan patients wait under a tree and chat as they often do in their own villages. Some say it feels more like home to them than the alien environment of a medical clinic. Facilitated by villagers who share the socio- economic, cultural values and experiences of patients they treat, which makes the whole experience more accessible to patient peers, the centre operates under the supervision of an experienced doctor ensuring best patient care practices via in-person and online clinics.

After years of training, trials, supervision and experience, Ekta Niketan's village health workers are well equipped to examine sputum samples under a microscope and make accurate diagnoses of tuberculosis. They also dispense drugs and, where patients are severely under-nourished and lack funds to pay for much-needed nutrition, food and nutritional packs to ensure their full recovery. Each patient's


progress is followed with health workers making phone calls and, as needed, home visits, to make sure each patient's needs are met and that TB medication

treatment plans are followed in full.

Ekta Niketan is down to earth and

its infrastructure, location, and above all, commitment of its health workers make all the difference to the quality of care that it dispenses to patients.

Health workers with a minimal education are





trained and empowered to offer quality services, keeping detailed patient case records, analysing each patient's psycho-social status and economic needs as well as factors that might influence each patient's circumstantial capacity to complete a full course of treatment. Poverty, trust in Ekta Niketan, nutritional status, risk perception, alcohol dependency and pressures on household wage-earners all play a part.

Some ask health workers if they would consider setting up a TB centre in their area while others put their limited resource of money in the donation box, just as is done in temples. Some bring other TB patients for much-needed treatment. The quality of the relationship between care-seekers and care-providers is what set's Ekta Niketan apart.

The success of Ekta Niketan's approach also serves as a model for further community health care initiatives which empower men and, crucially, women in remote villages with the skills, knowledge, confidence and awareness to help reach TB patients. Peer learning is also a critical element of the programme, with simple health

messages shared with each new patient and their families.

## Despite various efforts, a section of TB patients at Ekta Niketan discontinue treatment. Why?

Diagnosing tuberculosis correctly and initiating treatment as early as possible, and more importantly, completing the full course of treatment are the three key issues in the control of the disease from the bio-medical point of view. There are very many reasons for TB patients to discontinue in the middle of their treatments – from a lack of awareness to the lack of determination to complete treatments, from disliking taking 'too many drugs' to pressures to earn a living or to get back to social life, from stigma related reasons to alcohol dependence, and so forth. The reasons are individual, social, class, race and economic specific. Ekta Niketan's TB patients tell us that the 'trust in treatment' tops the list of reasons to discontinue among patients in marginalised communities – other reasons are important but secondary.

The strategies that national TB control (or 'eliminate') programmes adopt to encourage patients to complete treatment give little attention to building trust among TB patients. And the strategies are blanket approaches rather than targeted. For example, the strategy to reduce stigma (fear of TB) among urban middle-class patients in India has little to do with Ekta Niketan's TB patients who are from communities in disadvantaged areas. In general, there is no stigma about TB among them. It is the pressure to return to work which compels a large section of Ekta Niketan's TB patients to discontinue.

Similarly cash incentives or similar rewards for adhering to treatment do not often work because other reasons override cash incentives.

Despite various efforts, a section of TB patients at Ekta Niketan discontinue their treatments – the majority of them during the first month, and the rest normally around the fifth or sixth month of their treatment. The TB centre has adopted strategies geared to building trust in these patients, as well as to determine individual patient's psychosocial status. Yet, there are factors that are beyond the TB centre's capacity to address.

## 'Jhola'[1] and 'private' treat TB. Why?
## &
## Private practitioners contribute to drug resistance, but they are encouraged to treat TB. Why?

A large percentage of TB patients try various treatments before coming to Ekta Niketan, be it with local untrained village 'doctors' or trained private practitioners in town who often fail to diagnose tuberculosis, inappropriately prescribing antibiotics rather than standard anti-tubercular drugs. Most do not advise patients to go to government TB centres where treatment is free. When patients do not get better, they try another clinic, a spirit doctor or alternative medicines. Finally, when nothing else works, they hear of, and make the long journey to Ekta Niketan.

Private practitioners,  trained and untrained alike, in villages and semi-rural towns across India mess up the national TB programme. They cause patients to delay standard anti-tubercular treatment (ATT), or to discontinue treatments as they cannot afford the full course of six months or so.

TB patients who do not adhere to treatment, also termed as 'defaulters', contribute to India's pool of drug-resistant TB. TB defaulters are often blamed for discontinuing their treatments, rather than finding out the reasons for not adhering to treatments. They are like 'criminals' in the eyes of TB programme managers!

[1] 'Jhola' doctors are those medical practitioners who treat patients without proper training, 'quack doctors' so to speak. The term 'jhola', ('bag' in Hindi) is popular among people in rural India as they arrive patient's doorstep on a phone call; they will have a bag containing a few injectables antibiotics and steroids, analgesics, cough syrups and vitamin 'tonics'. Some will have glucose or normal saline and transfusion sets. They provide the service where primary health care is in a sorry state – in rural India and city's slums.

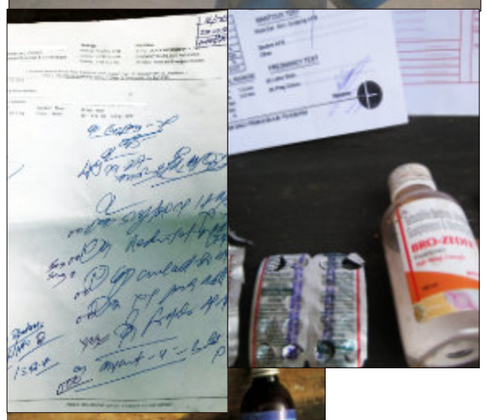


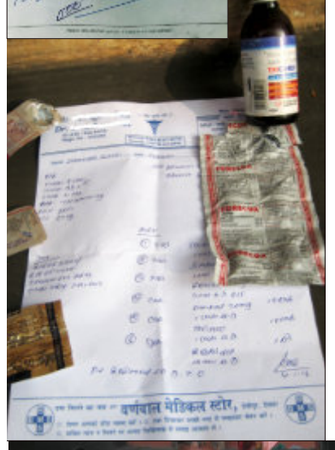


Of the very many reasons for defaulting regular treatments by patients in rural and semi-rural towns, private practitioners play a significant role. In other words, strategists and policy makers of WHO's Private-Public Mix (or PPM) or NTEP's Private Provider Support Agency (PPSA) carry some responsibility for patients in rural communities for defaulting. They get away for their mistaken strategies which allows 'jhola' and 'private' to treat TB without meeting the conditions and requirements needed to appropriately treat a TB patient. Private practitioners in question are not well-trained medical professionals like in cities or large towns or a few conscientious doctors in smaller towns.

Treating a TB patient does not end in prescribing anti-tubercular drugs, ensuring that the patient is completing the full course of his or her treatment does. Private practitioners in question do not follow up the full duration of a TB patient's ATT. Strategies to involve private doctors in TB control, WHO's Private-Public Mix (or PPM) or NTEP's Private Provider Support Agency (PPSA), how novel they may sound, such strategies are wrongly placed for the same blanket nature application.

The majority of Ekta Niketan's TB patients tell us that they previously went to 'Jhola' or 'Private' or both, and in the process have delayed by, on average, 4-6 months before attending the TB centre. Some of them bring reports of unnecessary tests they have had done at private clinics in towns – from urine, thyroid, liver function tests to ultrasound, too multiple x-rays and so forth. They say that they could not afford the costs of these tests and treatments and therefore discontinued.





## Extra-pulmonary TB patients are often missed out by private doctors. Why?

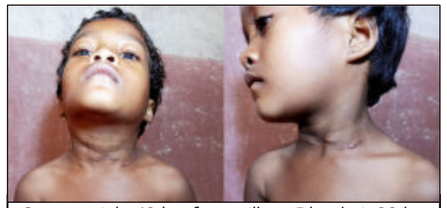
1 in 10 TB patients at Ekta Niketan are extra-pulmonary. That is to say, they do not present with typical symptoms of pulmonary TB like cough, chest pain, loss of appetite, weight loss or low fever. Features of extra-pulmonary TB depend on the organ affected, of which neck glands (cervical lymph nodes) are the most common. Patients also present with TB of the glands in the armpit, TB of the skin with deep oozing ulcers, of the abdomen, and of bone that cripples a patient to stand upright.

In 2022, 62 of the total 622 TB patients at Ekta Niketan presented with features of extra pulmonary TB. The number would possibly be higher still had Ekta Niketan's patients suffering from any of the above symptoms knew that they had TB. For them the TB centre is for patients who cough with or without spitting blood, or who have become skin and bone.

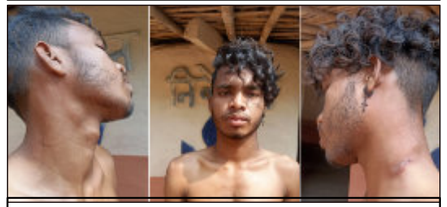
For most private doctors in towns in the area, and for 'jhola' doctors in villages, the knowledge of tuberculosis is limited to pulmonary TB. They have little clue that an oozing ulcer on their neck or skin could be a form of TB. Even medical staff at government centres do not have good training to recognise these various forms of extra-pulmonary TB. Some present with oozing wounds as private doctors wrongly incised a TB lymph node thinking it was a cellulitis. Patients at Ekta Niketan therefore come after trying various treatments that have not worked.

The experience of Ekta Niketan TB centre highlights that the prevalence of extra-pulmonary TB is much higher than what is reported, and that guidelines for diagnosis and treatment of such conditions need revising so that health workers and doctors at local levels are able to diagnose and treat such TB.

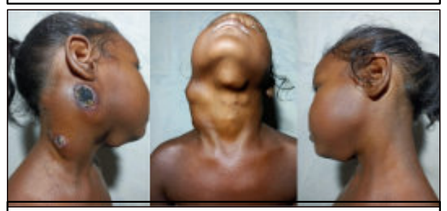
Here are a few examples of extra-pulmonary TB treated at Ekta Niketan – some are common, some not so common.



*8 yrs; weight 13 kg; from village Dhanbai; 22 km from Ekta Niketan; neck glands both sides; a private doctor tried to drain the glands without any success; came after 8 months.*



*18 yrs ; weight 46 kg; from village Shankardih; 46 km from Ekta Niketan; TB lymph nodes on both sides of neck; treated by a private doctor without any success; pulmonary TB with cough, fever, anorexia, weight loss, sputum positive; came after 4 months.*



*8 yrs; weight 17 kg; village Phulkari; 12 km from Ekta Niketan; neck glands on both sides; necrotising skin on her face; treated by jhola and private doctors without any success; came after 12 months.*

*33 yrs; weight 42 kg; village Chikhdih; 50km from Ekta Niketan; a private doctor tried to drain the oozing ulcers but the woulds did not heal; she had symptoms of pulmonary* TB too; *came after 12 months.*





## The teenager from Konji

Anil (name changed) is 17 years old from Konji, a Santal village in Bihar bordering the district of Deoghar in Jharkhand. Konji is 55 km from Ekta Niketan. When he was 15, he left home to work in a stone quarry near Bangaluru city some 2000 km away from his village. He was the only earning member of the family — his brothers were too young, and his father was not able to do hard labour.

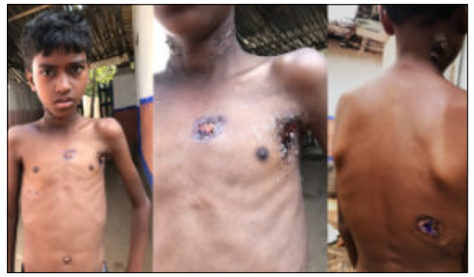
After two years, Anil returned home with severe back pain. The family went to a private clinic and spent money without results.
In February 2023, when his mother brought him to Ekta Niketa, he was not able to walk without any support. He had symptoms of TB and his sputum samples showed positive signs. Anil conitinues his anti-TB treatment.

He has improved but still needs a stick to walk.

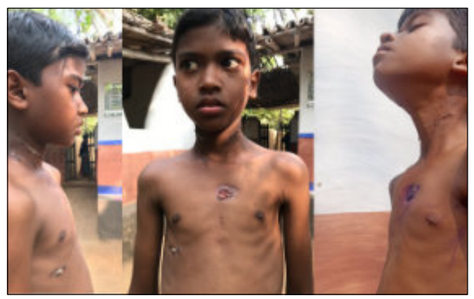
## And, the boy who is not so lucky

In December 2021, Ravinder Kisku (not his real name) of Jabardaha village, about 50 km from Ekta Niketan, came with an ulcer of his neck glands and on the front and back of his body. Needless to say, prior to his treatment at Ekta Niketan, his family had tried various treatments locally and visited private clinics in towns. Ravinder was put on anti-tubercular treatment; his skin ulcers and oozing neck glands started to heal.

Throughout the eight months course of treatment, his elder brother and occasionally his mother, came to Ekta Niketan to collect medicines regularly. His wounds healed completely.



But, after four months Ravinder returned with glands on his neck and armpits; skin ulcers that had healed started oozing again. He was referred to the district TB headquarters. Ravinder has been put on another course of treatment. Treatment continues.



## The lady from Dukhiadih

Lukhimuni from Dukhiadih, a tribal village 45 km from Ekta Niketan TB centre, came in a 3-wheeler vehicle or 'auto'. The skin of her right thigh had almost gone; she was in pain. Lukhimuni was examined inside the auto as she was not able to walk. It was May of 2022. She was treated by a local 'jhola' and a spirit doctor for about eight months before coming to the TB centre.

People in the village knew about Ekta Niketan. Despite a long journey, patients from Dukhiadih come to the centre regularly. Lukhimuni would come for treatment earlier, had the family realised that she was suffering from TB. Tuberculosis of skin of such nature (Lupus Vulgaris) is not common, but patients with similar conditions had come to the centre in the past. Lukhimuni was put on anti-tubercular treatment.

She responded to the treatment remarkably well. The second picture below was taken after 3 months of treatment.

Ekta Niketan's health workers went to Dukhiadi and connected with the family over a video link with the centre's doctor for follow up purposes.

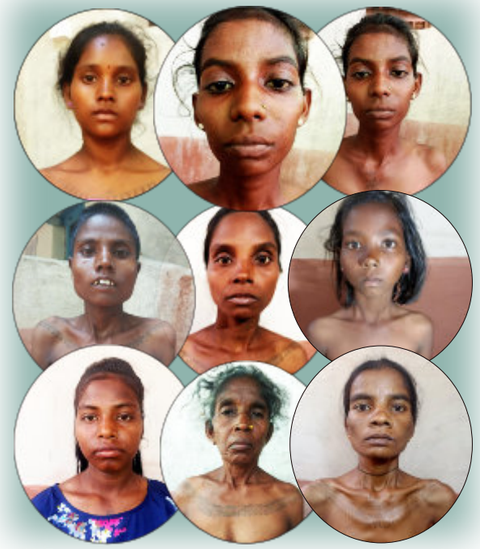
Each year in the month of March, Ekta Niketan organises discussions on tuberculosis. On 10 March 2023, the discussion was on the impact of TB on women. Lukhimuni attended the event.

At the event, she along with nine others – patients, family members or carers, were awarded for their roles in the control of tuberculosis. Lukhimuni and her husband were awarded for their determination to complete the full course of treatment.





# Society, Women and TB



Women of all ages come to Ekta Niketan, either accompanying family members who have tuberculosis or having contracted the disease themselves. For many, they became infected while looking after a TB patient in the family. In rural India, particularly in disadvantaged communities, women play a significant role in the control of tuberculosis. However, their role in TB control is not well understood by experts and policy makers.

For women with tuberculosis, it is customary for Ekta Niketan health workers to find out the patient's status in the family – particularly marital status, age of children and breastfeeding, economic status and the nature of support in the family (from husband and in-laws, if married). The TB centre offers counselling support to the family and nutritional supplements for certain patients to ease some of the pressure during the course of treatment. While there are remarkable stories of support within the family, there are unfortunate ones who remain neglected.

In this section, we put together a few such stories to understand the impact of tuberculosis on women in marginalised communities.

Elderly women,
Women with young children,
Young girls in vulnerable families,
Women with breastfeeding babies,
Married women with alcoholic husbands,
Women taking care of their sisters who have TB,
Married women caring husbands who returned home with TB,
Young married women with husbands working as migrant workers.

### Agony of a mother who lost her daughter

Chandmuni tried various places to save her daughter – local 'jhola', private doctors in the town and finally Ekta Niketan. When they (Chandmuni and her son) came to Ekta Niketan, the young girl had little energy left in her weak body. Even to stand on the weighing machine was a struggle for the girl. Her daughter was 18 at that time i.e. in

June 2022, weighing 25 kg. It was too late to save the young girl.

Chandmuni has been managing the family on her own; for the last ten years, her husband is mostly away working as a migrant worker. Now her son too is a migrant worker in the city of Kolkata, some 200 miles away from their village.

9 months later, after Chandmuni lost her daughter, an Ekta Niketan health worker visited her at her house to find out how she was coping.

### Pride of Surajmuni who saved her sister

Surajmuni from Dumria, a village 30km from Ekta Niketan, was invited to the 'Society, Women and TB' event mentioned earlier. At the event Surajmuni spoke about her sister Sameli and of her pride in her.

Sameli had little support at her in-laws when she contracted tuberculosis. She became skin and bone and weighed 20 kg. She would not have survived had she not fled when her husband started drinking heavily. Very weak Sameli managed to reach Dumria where her sister Surajmuni looked after her throughout. Sameli never returned to her in-laws. Sameli's story can be found in Ekta Niketan 2021 report.

While we talk about the role Surajmuni has played in Sameli's life, she had the support of her father-in-law. Like Surajmuni, he was equally concerned about Sameli's well-being; when Surajmuni was unable to come to Ekta Niketan, he came to collect Sameli's anti-tubercular medicines.

Sameli and Surajmuni's father-in-law

Ekta Niketan's health worker with Surajmuni and her father-in-law


Surajmuni and Sameli at Ekta Niketan





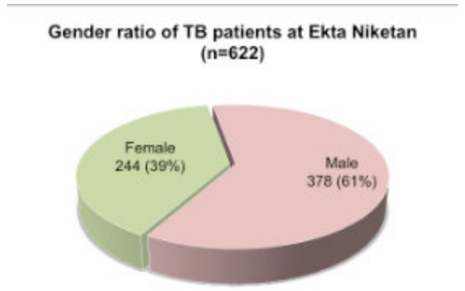
## Facts and figures

In this section we present some of the hard facts (data and charts). Villagers who manage the programme collect a range of information of TB patients and their families. Here are a few.

### Demographics and other facts

In 2022, a total of 622 TB patients were registered for treatment. 378 patients were male, the rest i.e. 244 patients were female.

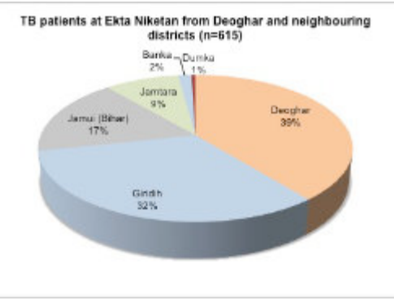
Chart 3




### Patients from Deoghar and neighbouring districts

The majority of the 622 patients are from the district of Deoghar (241), followed by neighbouring districts like Giridih (199), Jamui (106) and Jamtara (56), Jamui being in the state of Bihar. Chart 4 presents the distribution of TB patients from six districts in the area. Please refer to the map on page 15.

Chart 4




### 90% of patients are from tribal communities

Inhabitants of the districts mentioned above are mainly tribals (Santal tribe) and agriculture dependent. With the exception of coal mining in some areas, economic opportunities in these districts are scarce.

The majority of TB patients, 559 of the total 622 patients (90%), are from tribal communities; the rest 10% comprise non-tribals including Dalits (lower castes) and different religious backgrounds. Health workers of Ekta Niketan are all from Santal communities too.

### Under-nourished TB patients

Almost all TB patients who come to Ekta Niketan are undernourished. In 2022, about 30% of patients presented with extremely low body weight for their age. The BMI[1] calculated for 566 adult TB patients (of the total 622 patients), only 17% patients were with normal BMI range, 63% being moderate to extreme [Chart 5].

Undernutrion leading to nutritionally acquired immunodeficiency explains the higher incidence of tuberculosis among populations with low BMI, some studies indicating even 12 times higher. Please refer to 'Undernutrition, nutritionally acquired immunodeficiency, and tuberculosis

[1] Body Mass Index

control, by Dr Anuraga Bhargava, published in BMJ, 12 October. 2016[1]. Without addressing food, nutrition and development in vast rural India, the spread of tuberculosis in the country will continue to rise, so we learn from Ekta Niketan's TB patients.

Chart 5

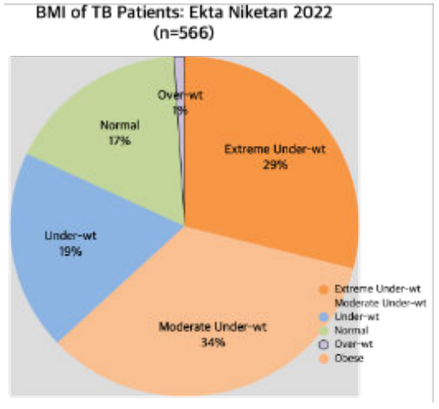



Table 1

| BMI of 566 TB patients (<18 yrs 46; no record - 10) | | | | | |
|---|---|---|---|---|---|
| Extreme | Moderate | Under wt | Normal | Over wt | Obese |
| <15 | 15 - 16.99 | 17 - 18.49 | 18.5 - 24.99 | 25 - 29.99 | >30 |
| **168** | **191** | **108** | **97** | **2** | **0** |
| **29.68%** | **33.74%** | **19.08%** | **17.14%** | **0.35%** | **0%** |

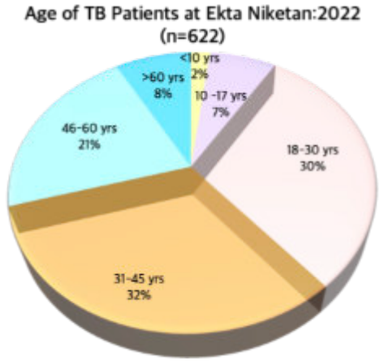
### 30% TB patients are Young adult

Young adults, aged between 18-30 years, make up 30% of the total number of patients who attended the TB centre in 2022; and adults of working age (18-45 years) comprise 62% [Chart 6]. The majority of young TB patients in villages are migrant workers who return home for treatment and care. We have discussed earlier how migrant workers contribute to India's TB burden.

Of the total 622 patients, 62 patients (10%) were migrant workers who returned home for care. The number of migrant workers with TB at Ekta Niketan is on the rise.

[1] https://www.bmj.com/content/355/bmj.i5407

Chart 6




### Money spent by patients on TB treatment

WHO global strategy is to bring the money spent by TB patients to zero, in short 'zero catastrophic cost'. In controlling the spread of tuberculosis in rural communities in India, an effective strategy of such a nature is highly significant, but the reality is different. If one has TB in the said communities, the family is often ruined because the little savings they have are exhausted in treatment at private clinics. As a result, the treatment is often discontinued or continued irregularly for as long as the family can afford it. Private doctors in question do not normally prescribe standard anti-tubercular treatment with the correct dosage, resulting in drug-resistant forms of tuberculosis due to irregular, incomplete and wrong treatments.

With a few exceptions, the majority of TB patients at Ekta Niketan present in this manner i.e. they go to their local 'jhola' or private doctors in towns before coming to the TB centre. In 2022, the majority of the total 622 TB patients spent between one to five thousand rupees at local 'jhola' or private doctors; 27 TB patients spent ten thousand or more, and six of them over forty thousand. In rural Jharkhand, very few families have savings





of one thousand rupees in cash unless they sell a goat or a cow or a tree. Families with TB becoming destitute is not uncommon.

### Patients bring along sputum samples

Some patients, 119 out of 622 TB patients, brought sputum samples when they came to Ekta Niketan with symptoms of tuberculosis. From other TB patients they knew about the importance of standard diagnosis and completing the full course of treatment. It is a slow process against all odds but a step forward to control tuberculosis in marginalised communities in India. Table 2 below indicates that the number of patients bringing their sputum sample is on the rise.

Table 2

**TB patients with sputum samples: 2022; Jan-Mar 2023**

| Month | 2022 | 2023 |
|---|---|---|
| Jan | **6**/47 | **12**/41 |
| Feb | **7**/37 | **18**/54 |
| Mar | **7**/55 | **12**/69 |
| Apr | **11**/55 | **15**/71 |
| May | **2**/52 | **15**/71 |
| Jun | **3**/54 | |
| Jul | **5**/50 | |
| Aug | **20**/54 | |
| Sep | **9**/45 | |
| Oct | **20**/47 | |
| Nov | **14**/63 | |
| Dec | **15**/63 | |
| **Total** | **119**/622 | **72**/306 |

### Treatment Outcome TB patients

Of the 300 TB patients who started treatment between January and June 2022, 82 of them i.e. 27% discontinued their treatment. This is no doubt an unsatisfactory outcome of any TB programme. Despite measures to encourage TB patients to continue and complete the full course of treatment, TB patients in rural communities discontinue for one reason or other.

On a closer look (Table 4), 64 of the 82 defaulters i.e. (78%) stopped taking anti-TB drugs during or after the first month of their treatment. Ekta Niketan conducts psychosocial analyses of TB patients in order to pre-determine whether the patient might discontinue treatment, and accordingly provides treatment to such 'likely to discontinue' patients for one or two weeks at the start. Most of the 64 patients

Table 3

| Treatment outcome: January-June 2022* | | | | | |
|---|---|---|---|---|---|
| **Month** | **Complete** | **Default** | **Transfer** | **Death** | **Total** |
| Jan | 26 | 13 | 3 | 5 | **47** |
| Feb | 25 | 11 | 1 | 0 | **37** |
| Mar | 32 | 21 | 0 | 2 | **55** |
| Apr | 36 | 14 | 1 | 4 | **55** |
| May | 36 | 12 | 0 | 4 | **52** |
| Jun | 39 | 11 | 0 | 4 | **54** |
| **Total** | **194** | **82** | **5** | **19** | **300** |
| * Complete data available at the time of analysis | | | | | |

Table 4

| Treatment discontinue month: January-June 2022* | | | | | |
|---|---|---|---|---|---|
| **Month** | **1st-2nd** | **3rd** | **4th** | **5-6th** | **Total** |
| Pt/Jan | 10 | 2 | 1 | 0 | **13** |
| Pt/Feb | 7 | 2 | 2 | 0 | **11** |
| Pt/Mar | 17 | 3 | 1 | 0 | **21** |
| Pt/Apr | 11 | 2 | 0 | 1 | **14** |
| Pt/May | 12 | 0 | 0 | 0 | **12** |
| Pt/Jun | 7 | 2 | 2 | 0 | **11** |
| **Total** | **64** | **11** | **6** | **1** | **82** |
| * Complete data available at the time of analysis | | | | | |

(1st –2nd month defaulters) belong to this category who did not turn up to collect the full month's medicines and could also not be tracked over the phone. Possibly these patients did not start their treatment. Taking this into account, the default rate is not as high as is looks. But these patients are potential spreaders of TB in their communities and may develop drug-resistant forms of the disease. Ekta Niketan has to address this category of patients.

## Team Ekta Niketan

Sunita Murmu (Coordinator); Birender Kisku (Records, Pharmacy); Hireshwar Hansda (Laboratory); Khiloni Murmu (House); Shiwan Hansda (Computer); Gudur Tudu (Garden); Tikla Tudu (Diagnosis)

## A few remarks

We summarise the report with some concluding remarks below, and with 'Reality to Survive' in the next section.

Despite tuberculosis being treatable and preventable, it remains the top infectious disease and kills 1.5 million people each year. In Europe, countries that have brought their TB rates down significantly have addressed societal factors of the disease – health care, education, economic security and so forth, across the population. This has never been the case in India, and is not today.

The failure to control tuberculosis worldwide is a reflection of the divide between the rich and the poor in society for which policy makers and political leaders are responsible. Public health experts are to take the blame too. They ignore the fact that TB is more than a medical condition.

India has declared that it will eliminate tuberculosis in the very near future. It is a huge task but is not impossible. Is there real commitment to control the disease in marginalised communities?

The growing number of TB patients at Ekta Niketan take difficult journeys from faraway villages, indicating the popularity of the TB centre, but also the sorry state of the government tuberculosis programme.

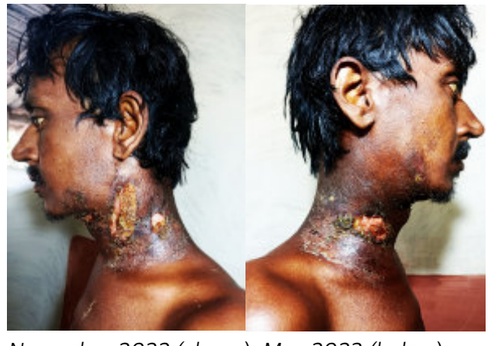
Ekta Niketan also questions the role of international organisations such as the WHO whereby TB remains one of the world's major killers despite the fact that anti-tubercular drugs of reasonable efficacy are available.



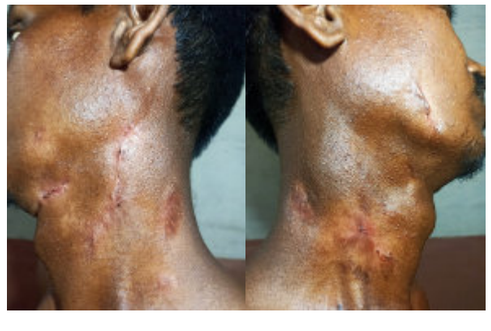


## Reality to Survive

As I am on the final page of the report, I met Hemlal (pictured below). Carrying the message 'Reality to Survive' on the T-shirt he was wearing, Hemlal (not his real name) sums up the reality of tuberculosis that this report is about. After seeing the patient who he accompanied, I checked Hemlal's wounds that he came with last year. Indeed, the wounds on his neck are now healed and he has a smile on his face. Hemlal looked thin but assured me that he was okay.



*November 2022 (above); May 2023 (below)*



Hemlal's wounds were due to a private doctor incorrectly making incisions on TB lymph nodes which caused his condition to worsen. Prior to Ekta Niketan in November 2022, he tried various treatments including the private doctor mentioned above. Hemlal feels that he is fortunate that he is cured. He now brings other TB patients from his village 65 km away.

This is not about extra-pulmonary TB of neck glands or how a TB centre in rural India can treat it successfully. This is about the reality of people like Hemlal to survive, the very message he has on his T-shirt.

Hemlals and others like his are not bothered about messages and slogans on walls. They are not bothered about promises that political leaders make in public meetings. They are not bothered that they do not have good food or new clothes to wear. They are happy in the world of their own. This is the reality of people in marginalised communities in India.

That TB is going to be eliminated does not excite the communities that Hemlals live in; they do not read WHO's global TB report.

Hemlal's T-shirt reminds me of T-shirts villagers used to wearing a few years ago, that said 'aachhe din aaenge' or 'good days are coming'. The slogan became popular in India in those days when the Indian Prime Minister used it at a gathering of 60,000 British Indians at Wembley stadium. David Cameron, British PM at that time, also tried the phrase in Hindi to please the audience gathered. Obviously, Hemlal and others who come to Ekta Niketan have no clue what I am talking about. They are not bothered.

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