

Ekta Niketan

*"unlike
other
TB centres"*



A
Report



2021

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This report has been written by Dr Manan Ganguli.
Since the inception of Ekta Niketan TB centre 40 years ago, Dr Ganguli has remained associated with the work. He continues to advise, train and assess the progress of the TB Centre.

This report is much in line with the earlier '[Ekta Niketan TB & Poverty report](#), published in March 2021'.

Readers may like to consult that report in order to follow the progress during the year.

Miloni Hembrom featured in the March report has now completed her treatment course – she is one of the lucky ones who survived. There were others who were not.

This report is a tribute to those TB patients at Ekta Niketan who died during 2021.

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For more information about Ekta Niketan, you may like to visit:

<https://ekta-niketan.fourthworldaction.net>

A few words

Again and again, experts and policy makers are making plans to control the spread of tuberculosis (TB) across the world. They say they will halt the spread by 2030; some even go a step further and say they will eliminate TB by 2025. India has such ambitious targets – perhaps too ambitious. The country has again revised its already ‘Revised’ national TB control programme (RNTCP), and has started a nationwide programme with new vigour and a new name; changing ‘Control’ for ‘Elimination’ – from RNTCP to NTEP. But has the programme benefitted TB patients nationwide, particularly those in marginalised communities in remote villages? Eliminating TB in India, let alone across the world, remains a far way off. Experts at WHO in their Global Tuberculosis Report (2021) say, “we have made encouraging progress globally. But the Covid-19 pandemic has put these gains at risk”.

It is, however, the political economy of health (or ill-health) that determines the interventions, from global to national, for the wellbeing of people. In the case of TB, the wellbeing of people who are more likely to contract the disease is dependent on the political and economic considerations of the nation. TB is a disease of the poor, which explains why TB continues to spread across the world. There are very many reasons why TB is difficult to control, but the bottom line is that public health officials carefully avoid ‘poverty’, ‘economy’ and ‘politics’ when they talk about TB. We have touched upon the topic elsewhere in this report, under ‘Political economy & Eliminating TB’.

Ekta Niketan is a very small initiative to treat TB. Some say Ekta Niketan is an NGO, some say it is private, some say it is neither. Public health specialists may think that it is naive to set up a centre to treat TB with no trained doctor present. Yet the TB centre has continued and has remained popular among patients who cannot afford any addition to their diet of rice with either lentils or vegetables but not both. It is a TB centre that has travelled through the early pre-DOTS era, then DOTS, RNTCP, followed by MDG and then SDG targets. Having dealt with TB patients over three decades – in their remote villages, in their run-down houses, going through their prescriptions made by private practitioners, finding their apathy to access government TB centres, Ekta Niketan has its own perspectives about TB and its spread. It finds it difficult to recognise the ‘encouraging progress’, claimed by public health experts.

Ekta Niketan is not a model but has significant insight into controlling TB, particularly in marginalised communities where TB is rampant. And where government initiatives struggle to make inroads. Controlling TB is not a straightforward business in a country like India with its size and population. The learning of the TB centre is likely to benefit TB programmes elsewhere – Ekta Niketan has now entered into that phase.

Finally, Ekta Niketan hugely appreciates the support it now receives from the NTEP.



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1.0 Sameli and other women with TB

In October last year, Sameli came to Ekta Niketan with her elder sister Surajmuni. Sameli Kisku was one of the 38 TB patients who attended the centre in that month. Ekta Niketan is indeed a popular TB centre in the area. Right in the middle of Fatepur, a Santal village, much like the villages from which TB patients come, its popularity is for more than one reason. After all, health workers here are well trained to diagnose tuberculosis, just as medical doctors in towns. Most importantly, Ekta Niketan's health workers are much the same as their patients - socially, culturally and economically. They speak the same language!

A large number of TB patients, about 30 to 40%, travel a long way, 40-50 km or more, to reach the centre. Patients hire motorbikes, some come on bicycles, some take a bus or a train, then a shared auto-rickshaw (a three-wheeler vehicle) and finally walk about 3 km from the main road - a few who come from very far, hire larger vehicles. Ekta Niketan is a snap-shot of India's TB patients who are not reached by government's TB elimination programme.

Sameli came from Dumria, a tribal village, about 30 km south from the TB centre. This is where her sister lives. As there was little support at her in-laws, Sameli came to her sister's place for the care she badly needed. She was very weak, weighing a mere 20 kg - worryingly low for a young woman of 25 yrs. Sameli's sister and her husband hired an auto-rickshaw to bring her to Ekta Niketan.



Health workers examined Sameli, conducted a sputum test, and sent her records and photos to their doctor for video consultation. During the Covid pandemic, all TB patients were consulted through video call and thus Ekta Niketan has developed a system that can be replicated in other non-governmental TB centres. In countries like India, it is rare to find trained doctors in remote villages, and very few TB centres are in villages. TB centres need to be closer to people who suffer from the disease most - Ekta Niketan is an example.

Sameli started her treatment. Two weeks later health workers went to Dumria to encourage her to take medicines regularly. She was still poorly. But health worker Tikla Tudu felt that she might survive. Sameli's sister and her family took good care of her. Tikla knows that treatment of TB is more than dispensing anti-TB drugs.



16 October, 2021: health worker weighs Sameli at her sister's house in Dumri.



During the visit, Sameli narrated her story to Ekta Niketan's health worker. Here it is in her own words.

“We are two sisters and one brother - I am the youngest in the family. My sister is in Dumria - a joint family of eight. My my brother is in Loto, our ancestral house - about 10 km from Dumria. My brother has no children; they are a small family -



brother, his wife and my mother. And, I live in Chakdah with my husband and my daughter who will be five next month. Chakdah is quite far from Dumria and Loto - I visited my brother last during our festival in January. This time however I went to my sister - thought I would get better care there.

My husband drinks a lot, particularly since we lost our son. Prior to that our elder daughter died when she was only 2.

I became ill after the birth of my son; then for the last six months or so my health started deteriorating since our baby boy died about a year ago. He was one. My husband started drinking heavily; he stopped looking for work in the town. He was not interested to take me to a doctor - there was not enough money in the house that I could go to a doctor. I thought I was going to die. In the end I decided to go to my sister. A difficult decision to leave my daughter behind but I had no choice”.

Sameli's journey to Dumria was remarkable. When asked 'how did you manage to reach your sister?', she wept. Then narrated, 'it was not easy. I was very weak - with my health condition, I was not sure if I could reach Dumria. I could not walk properly, but I thought I better give it a try'. One morning Sameli got herself ready for the journey, took the money she kept herself, and then set off for the main road 2 km away without getting noticed. She stopped several times before reaching the main road, then took an auto-rickshaw to Karmatar. She

knew that she would get auto-rickshaws for Margomunda - the stop for Dumria was a couple of kilometres before Margomunda. She walked another kilometre and a half from the main road. Sameli reached her sister and then they brought her to Ekta Niketan on 6th of October.

Now in December, Sameli is on the mend, so it appears. She has gained weight, weighing 25 kg after six weeks' treatment. Ekta Niketan's doctor went to visit Sameli at Loto with Tikla. By now she has moved to her brother's place - possibly she did not want to trouble her sister more.



Sameli is not an isolated story. Many such young women in remote corners are

struggling to survive from TB. They weigh 20-25 kg trying to overcome poverty, neglect and the lack of care and treatment. Some survive; many do not.

The catastrophic impact of TB on women in remote villages, particularly when they themselves contract the disease, after childbirth or from looking after family members with TB, is yet to catch the attention of experts and policy makers - unfortunately they are far removed from TB patients who come to Ekta Niketan.

2.0 Political economy of health & Eliminating TB

[The author of this write up does not have all the answers of how to control the spread of TB but strongly feels that the world should do better to save those lives who silently die of TB in remote corners of India and elsewhere.]

Of course eliminating TB is not easy, particularly in a vast country like India - but all the efforts of recent years have had little effect so far, particularly in controlling the spread of the disease in remote areas. This is not a comprehensive analysis of the gaps in TB control ('elimination') programmes yet it highlights the missing ingredients. The insight gained from working with TB patients at Ekta Niketan for over three decades, this brief write up points out why experts and policy makers continue to fail in stopping the spread of the disease in marginalised communities.

Tuberculosis is not a new disease, also there is no shortage of information on TB. International organisations, pharmaceutical companies and research institutions discuss how to control the disease, but they have not been successful. For ages they have been discussing various strategies, conducting studies and producing research papers. But TB spreads silently throughout the year, not just in March, when we are reminded of the existence of the disease during World TB Day. We hear 'Tuberculosis tops the list of deadliest infectious diseases'; 'Tuberculosis kills as many people each year as Covid-19. It's time we found a better vaccine', and so on.

Way back in the early 80's, I started treating TB patients in a poor area of India. In those days, the few roads and surrounding forests made the area feel remote. Now after four decades, roads, bridges, transports, mobile phones and fewer trees have changed the remoteness of the same area, but patients with TB continue to come to our clinic - and in large numbers. The clinic has become a popular TB centre. TB patients at the centre are from 'remote' villages, the majority are from tribal

(indigenous) and other marginalised communities. We go to their villages, see them in their houses. We know how they live, what they eat. At the TB centre I learn the intricacies of TB. I continue to learn. Public health professionals and policy makers need to spend time in areas similar to where Ekta Niketan's TB patients come from. TB cannot just be learnt in conferences and from research papers. There are important issues other than vaccines or new drugs, that need addressing.

Although TB is an age-old disease, it seems only recently public health experts have begun to realise the catastrophic impacts of the disease. Yet the responses, at global and national levels, are far from adequate. The disease remains neglected by policy makers and politicians.

It was however not the case with HIV/AIDS. The Western world geared up to control the transmission of HIV virus in the developed world as well as the developing world. TB is not HIV - a disease that is mostly confined to the 'poor' world has failed to attract the attention the way HIV has. In recent years, however, the Multi drug-resistant (MDR) and Extensively drug-resistant (XDR) forms of TB have changed the dimension of the disease. TB has now received global attention. However, until people's benefit supersedes the political and economic benefits, TB will not receive the attention of policy makers.

To contain TB, we need to make standard anti-TB drugs available to patients and ensure that patients comply with treatments. The compliance to treatment depends on patients' access to healthcare, nutrition and above all a rational distribution of economic resources across the population. Until the political commitment to people-centric healthcare and economic development is in place, no national programme will be successful. TB will continue to spread in marginalised communities in remote villages.

3.0 Some truth about TB and its spread

Tuberculosis is a disease of people who do not have adequate food, a safe environment to live or money to buy essentials for a decent living. TB is a disease of the 'poor'.

The political commitment of people in power towards people who do not have basic essentials for their health, is always a low priority irrespective of the country's economic growth.

Health experts and policy makers are far removed from people who do not have conditions for basic living. Their TB policies are usually guided by the choice of political leaders.

Tuberculosis cannot be eliminated by standard medicines only - adequate food and nutrition for patients and their families are equally essential.

In India, the current government talks about eliminating TB ahead of the rest of the world. The efforts may signify the intention but the 'elimination' programme is yet to reach people who badly need to be reached.

In India, private practitioners, trained and untrained alike, in small towns and semi-rural market places are causing havoc with the spread of drug resistant forms of the disease.

In India, women in marginalised communities bear the brunt of TB - from cooking and looking after patients, to earning for their families (when patients are earning members). If they contract the disease themselves, and when the support from other family member is not adequate, particularly for married women at their in-laws, women are most vulnerable to TB - developing drug-resistance and death.

In India, another vulnerable group of TB patients are migrants who live in crowded accommodation at work places, contract the disease, spread in towns and then to their villages as they return home for care. They, combined with private doctors, are one of the key spreaders of multi-drug resistant (MDR) TB.



People who do not have conditions for basic living - adequate food, safe environment and money to buy essentials. Among them, women and migrant labourers are additionally vulnerable to TB.



4.0 Jharkhand TB authorities & Ekta Niketan 5.0 Facts & figures

Until recently Ekta Niketan was little known to the outside world. For TB patients in villages surrounding the centre, Ekta Niketan’s popularity is age old. In the last five years or so, the TB centre has become known to the authorities in the state of Jharkhand, particularly in Deoghar – the district where Ekta Niketan is situated.

Since 2019, the NTEP² in Jharkhand, its offices in the districts of Deoghar and Giridih, and its partner Alert India help to run the TB centre (please refer to [Ekta Niketan TB & Poverty report](#) March 2021). Ekta Niketan greatly appreciates the support.

The TB centre is now registered with the national TB elimination programme that engages private clinics. The centre benefits from the scheme with supplies of anti-TB drugs and specialised diagnostic support – a tremendous help for its patients.

Ekta Niketan is more than a private clinic though. Do private practitioners, trained and untrained, in small towns and semi-rural markets in Jharkhand help control the spread of TB? Or do they help spread the resistant forms of the disease? Ekta Niketan encourages TB experts and policy makers to look into this.

Finally, Ekta Niketan expects further support from the NTEP to help control the spread of TB in remote villages in Deoghar and adjacent districts.



Microscopy quality control by the District TB Laboratory officer. District TB Officer, Deoghar and his team at Ekta Niketan [Dec. 2021].

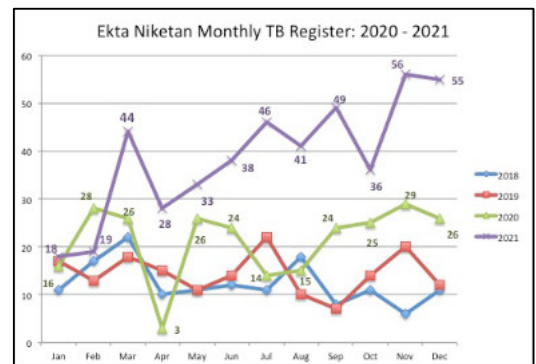
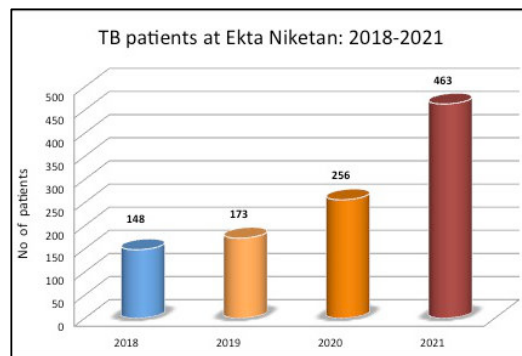


Ekta Niketan’s records presented here give an impression of the TB centre’s performance during the year. We have compared data with that of previous years, just as we have done in the [March 2021 report](#). For any clarification, please write to Dr Manan Ganguli, the author of the report.

Fact 1: At Ekta Niketan TB patients are on the rise

Patients with tuberculosis registered during 2021 has risen to 463 – a sharp increase from the previous year, and over three-fold rise from that in 2018. The monthly attendance has risen proportionately – for most months almost doubling compared to the previous year (Charts 1 & 2).

Chart 1 & 2: TB patient – annual & by month



Is the spread of TB in India on the rise then? The above data reflects the TB centre’s increasing popularity in the area rather than the rising spread of TB in the country. But the figures make us believe that TB is not on the decline.

Fact 2: Majority are Santals

Over 90% of TB patients at Ekta Niketan are Santals i.e. from tribal (indigenous) communities in the area.

[A recent study by Beena E Thomas et al](#) among tribal populations across India has established that

Table 1: Race/religion of TB patients at Ekta Niketan

| Santal | Kol | Hindu | Muslim | Christian | Other |
|--------|-----|-------|--------|-----------|-------|
| 424 | 8 | 24 | 6 | 1 | 0 |

the prevalence of tuberculosis among indigenous population is much higher (3 times or so) than in the general population. Such results are only an indication of the problem. In order to address the problem, there is a need for a thorough study among tribal TB patients compared to that of other communities with similar social and economic backgrounds, their access to standard anti-TB treatments, taboos and practices, habits and habitat (particularly their exposures to pollutants from mines and similar industries) and so on.

A very high proportion of TB patients at Ekta Niketan being from tribal communities (Table 1) is however due to the TB centre itself - in the middle of a tribal village, the centre being similar to other mud houses in the area, the majority of staff being tribals with similar social and economic status as their patients - in short, social, cultural, linguistic and economic parity between patients and their care givers.

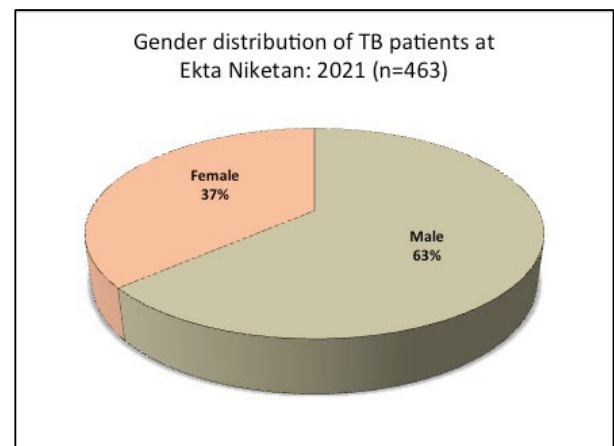
In 2021, TB patients at Ekta Niketan from other communities, particularly Hindus and Muslims, was higher than in previous years. With the increasing popularity of Ekta Niketan, we are likely to experience even higher number of TB patients in the coming years until the prevalence of tuberculosis has truly declined in India.

Fact 3: 37% of TB patients are women

While men are more likely to become exposed to TB bacteria and contract the disease, the prevalence of TB among women in marginalised communities is significantly high and demands attention.

In 2021, of the total 463 TB patients, 169 i.e. 36.5% were women (Chart 3). Through cases like Sameli, this report highlights the plight of these women. We hope that TB specialists and policy makers will give attention to addressing TB among women in marginalised communities as a special category, so also to unskilled migrant labourers.

Chart 3: Gender distribution of TB patients



Additional attention to these two categories of TB patients will help limit the further spread of the disease, reduce drug resistance, and mortality.

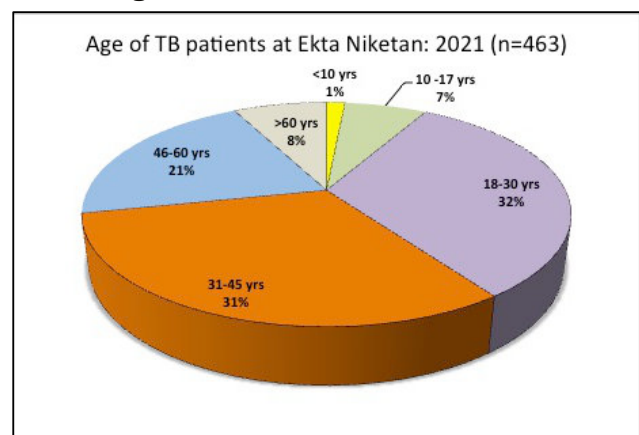
Fact 4: A third of TB patients are young adults

The age distributions of TB patients at Ekta Niketan are presented in Table 2 (absolute) and Chart 4 (percentage) below.

Table 2: Age distribution of TB patients at Ekta Niketan

| <10yrs | 10-17yrs | 18-30yrs | 31-45yrs | 46-60yrs | >60yrs |
|--------|----------|----------|----------|----------|--------|
| 7 | 31 | 147 | 147 | 96 | 35 |

Chart 4: Age distribution (%) n=463



Of the total 463 TB patients, 147 patients, i.e. about 32% are from the age group 18-30 yrs. The male proportion of these young adults, about 57% (84 out of 147) are earning members of their families, many of whom are migrant workers. India's unskilled migrant workers, a huge pool of cheap labour, often return to work after contracting TB without completing the full course of treatment, contributing to India's pool of drug-resistance forms of TB bacteria.

Of the remaining 63, mostly young married women, bear the brunt of TB as they carry out household work (fetching water, cooking, maintaining the house) and looking after children until they are too weak to continue. For care, many end up at their parents or sisters place leaving in-laws like Sameli (page 5), and Miloni (refer [March 2021 report](#)). Mortality of young women with TB is a cause of concern.

Fact 5: Patients are prepared to make incredible journeys to reach the TB centre that is managed by village health workers

With various means of transport - bicycles, motorbikes, trains, buses and hired vehicles, TB patients travel long distances to reach Ekta Niketan. Patients come from all directions from villages in the area - a section of them (16%) are from far away villages, more than 50km away. The majority of them are from communities about 20-40km away. Table 3 is a summary of that. TB patients travelling such distances to access

Table 3: Distance/no of TB patients at Ekta Niketan

| | 0-15 km | 16-30 km | 31-50 km | 51-70 km | >70 km | Total |
|-------------|---------|----------|----------|----------|--------|------------|
| 2021 | | | | | | |
| No | 96 | 170 | 120 | 57 | 20 | 463 |
| % | 21% | 37% | 26% | 12% | 4% | |
| 2020 | | | | | | |
| No | 56 | 107 | 61 | 25 | 7 | 256 |
| % | 22 | 42 | 24 | 10 | 2 | |

Ekta Niketan where microscopy, diagnosis and treatment are managed by a group of trained villagers represents the popularity of the TB centre among patients from villages in the area, but also indicates the sorry state of health care. [Diagnosis and treatment are under the supervision of an experience medical doctor. Also, managing such a large number of patients with minimum resources has been possible with the assistance from the NTEP Jharkhand who provide medicines and laboratory support.]

Fact 6: 68% of TB patients are moderately to extremely under-weight

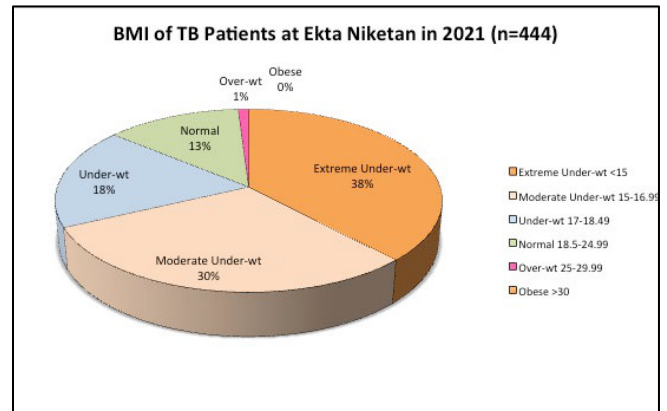
It is no surprise that TB patients are normally under-weight. But patients at Ekta Niketan, are, in general, under-weight even before they contract the disease. A large number of patients in 2021,

167 out of 440 (38%), recorded their BMI as less than 15. It is no doubt the outcome of treatments of these poorly nourished TB patients is often poor.

The government's TB programme, NTEP, has made provisions of cash so that TB patients can procure themselves a nutritious diet. This does not always work in disadvantaged families where the whole family suffers under-nutrition and lacks basic essentials for living. Therefore the cash patients receive is used on other essentials for the family, not necessarily for the patient. After all, in most cases the cash does not arrive during the patient's treatment!

Chart 5 represents the BMI pattern of 444 TB patients who attended the TB centre during 2021. [Note: 19 missing records include patients under 10 years of age and those whose heights could not be measured as they were too weak to stand. Also, during May-June at the peak of the second surge of Covid-19, health workers were asked to stop measuring heights in order to maintain a safer distance from patients.]

Chart 5: BMI of TB patients during 2021 (n=444)

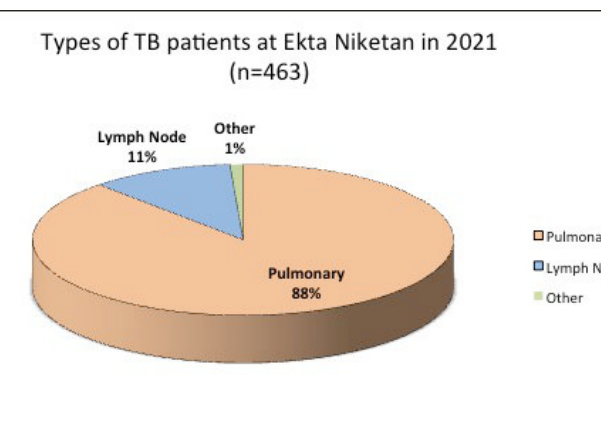


Fact 7: 88% of patients are with pulmonary TB

In 2021, of the 463 TB patients who registered for treatment at the TB centre, 408 (88%) had pulmonary complaints; 52 patients had their cervical (neck) or axillary lymph nodes infected with TB; and, 3 patients had abdominal or skin TB. See Chart 6 on page 13.

In 2021, patients with extra-pulmonary TB were considerably lower than in previous years. This is not a hugely significant fact. But the fact that pulmonary TB patients were in large numbers, is significant as these patients had the potential to further spread the disease.

Chart 6: Types of TB patients



Fact 8: Most TB patients first go to Jhola Chhap and private doctors and exhaust their money

Jhola Chhaps (untrained practitioners) in villages are a menace. So-called 'trained' private doctors in rural and semi-rural Jharkhand (possibly in other states too) are no better, and contribute to the spread of tuberculosis. Both prescribe wrong treatments - antibiotics, steroids, cough syrup and what not, some add anti-TB drugs but often in wrong dosages. In addition,

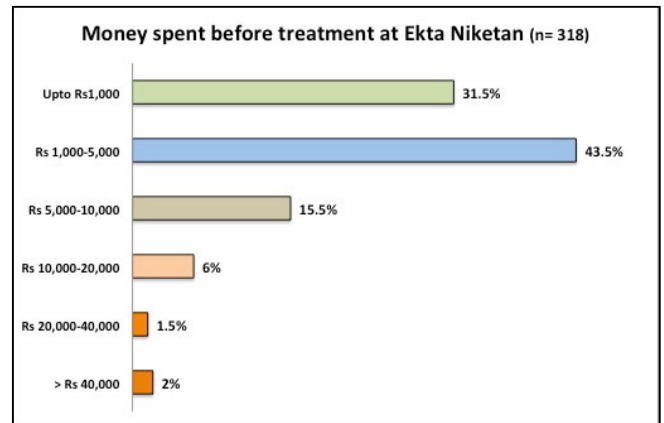


private doctors often request irrelevant tests. Patients cannot afford the expense; and therefore, after a month or so they stop treatment. If

symptoms reappear, they try another clinic before finally opting for standard anti-TB treatment. For the authorities, policy makers and TB specialists at the national and international levels, this is not a new fact. Yet the practice continues. The political economy of TB is better understood when we look into Jhola Chhap and private doctors in TB control.

The global strategy for TB has focused on the 'catastrophic' cost that TB patients in marginalised communities bear. A target to bring the cost down to zero was adopted. Has it been achieved? The information from TB patients at Ekta Niketan does not say so. Chart 7 is not a comprehensive analysis of costs TB patients at Ekta Niketan incurred prior to starting treatments at the centre, and the data is incomplete too. But it gives an impression of the situation. Of the 318 TB patients, three-quarters of patients spent up

Chart 7: Costs patients bear before Ekta Niketan



to Rs 5,000 on 'Jhola' and 'private'. For the majority of these patients, Rs. 5,000 is a substantial amount of cash. The chart also indicates that about a fifth of patients spent between Rs 5,000 and Rs 20,000. More importantly, patients delay in starting standard treatment at the centre (see Chart 8).

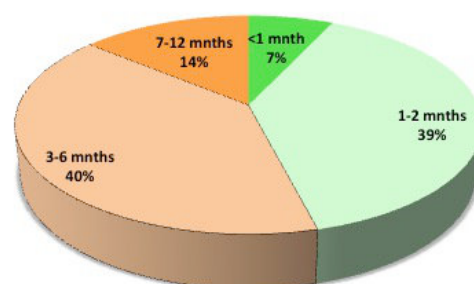
Jhola Chhaps are more than 'quacks'. Together with private 'doctors' in small towns and semi-rural market places in Jharkhand, this duo is causing huge challenges India's TB control. For more on Jhola Chhap, click [MDR TB and Jhola Chhap Doctors](#).

Fact 9: 40% of TB patients delayed starting standard treatment at Ekta Niketan by 3 to 6 months

No one will deny that patients in small towns and semi-rural areas prefer private clinics to government hospitals. For tuberculosis, patients' choices are similar - Ekta Niketan's TB patients further

Chart 8: Treatment delay is a cause of concern

Delay in starting treatment at Ekta Niketan: 2021 (n=441)



establish that fact. In recent years the trend has shifted a bit - a small section of patients have started coming to the TB centre without going to a 'Jhola Chhap' or a private doctor. Yet the majority fall into the trap of injections, tonics and syrups and powerful antibiotics.

During 2021, before starting at Ekta Niketan 40% of 441 TB patients (22 not recorded) delayed their treatments for 3–6 months (Chart 8). The ‘delay’ has its impact on treatment outcomes – although a large section of patients responded to treatment, a section did not.

Fact 10: Completing the full course of treatment is a challenge

Ensuring that TB patients complete the full course of treatment is a difficult task. And in marginalised communities where patients’ economic resources are scarce, and where health care is in a poor shape, the task is even more difficult. Ekta Niketan operates with such TB patients who are severely undernourished, travel long distances to reach the TB centre, have tried local ‘doctors’ first, do not go to nearby government TB centres, and who are tempted to start manual work or travel as migrant labourers in the middle of treatment. In 2021, the lockdown imposed to contain the Covid-19 pandemic was an additional challenge for follow up.

Table 4 & 5 below show treatment outcomes of TB patients at Ekta Niketan during the first half of 2021. The number of defaulters i.e. 58 is a cause of concern and will raise eyebrows for those who deal with TB. But a closer look into the figures make us believe that the overall performance is not too bad. Of the 58 patients who have discontinued treatments, 25 patients (3rd and 4th month) are the difficult patients who would have

Table 4: Treatment outcome January–July 2021

| Month | Total pt. | Complete | Default | Transferred | Death |
|-------|------------|------------|-----------|-------------|-----------|
| Jan | 18 | 15 | 2 | 0 | 1 |
| Feb | 19 | 16 | 2 | 0 | 1 |
| Mar | 44 | 30 | 10 | 1 | 3 |
| Apr | 28 | 22 | 5 | 0 | 1 |
| May | 33 | 16 | 13 | 1 | 3 |
| Jun | 38 | 21 | 12 | 0 | 4 |
| Jul | 46 | 23 | 14 | 4 | 5 |
| | 226 | 143 | 58 | 6 | 18 |

Table 5: Treatment discontinue January–July 2021

| Default Month | | | | | |
|----------------|------------------|-----------|-----------|-----------|-----------|
| Total patients | Total defaulters | 1st-2nd | 3rd | 4th | 5th-6th |
| 226 | 58 | 15 | 12 | 13 | 18 |

discontinued even if the lockdown was not in place. 18 patients who discontinued during the last month are the ones who would have completed if the TB centre could follow up such patients closely. [For further explanation, please contact Dr Manan Ganguli]

Fact 11: TB is a silent killer in marginalised communities - patients die unnoticed in large numbers

During the year, 19 TB patients (1 more since August) did not make it. Phulmuni who featured in the earlier interim report is among these unfortunate patients (refer [March 2021 report](#)). Of these 19 TB patients, six were young adults in their twenties; eight of them women. Miloni, Sameli and a few more (mentioned elsewhere in this report) could have joined the list, but they are now cured from the disease.

Here is a quick summary of those who silently passed away during 2021.

* Male, 21 years, weighing 40 kg; treated by Jhola Chhap for over 3 months (BMI 14.7) * male, 26 years, weighing 41 kg, over 2 years had treatments at private clinics and a government centre (BMI 14.35) * female, 25 years, treated at a government centre but discontinued because the drugs were too powerful for her, so the family thought. BMI could not be measured - too weak to take weight or height * female, 57 years, weighing 29 kg; treated by Jhola Chhap, and then at the government centre; delayed for four months (BMI 13.23) * male, 55 years, weighing 25 kg; treated by Jhola Chhap, prior to that at a private clinic for six months (BMI 10.28) * female, 25 years, weighing 34 kg; treated by Jhola Chhap (BMI 15.95) * male, 49 years, weighing 39 kg; treated at a private clinic for about 10 months * female, 25 years, weighing 27 kg; treated by Jhola Chhap and private doctor for about 7 months * female, 65 years, weighing 32 kg; treated by Jhola Chhap for about 2 months * male, 45 years, weighing 41 kg; treated by private doctor * male, 62 years, weighing 25 kg; treated once at Ekta Niketan a few years back (BMI 10.7) * male, 37 years, weighing 34 kg; treated by Jhola Chhap (BMI 15.11) * male, 56 years, weighing 33 kg; treated by a private doctor (BMI 14.09) * male, 47 years, weighing 39 kg; treated by a private doctor for about 3 months (BMI 15.62) * male, 65 years, weighing 28 kg; treated by a private doctor for about 4 months (BMI 10.93) * female, 21 years, weighing 32 kg; treated by a Jhola Chhap (BMI 15.21) * female, 45 years, weighing 31 kg; treated by Jhola Chhap for four month (BMI 14.74) * female, 55 years, weighing 33 kg; treated by Jhola Chhap for two months (BMI 12.89) * male, 51 years, weighing 26 kg; treated at a government centre, then a private clinic (BMI 10.41)

6.0 Final remarks – putting facts together

At Ekta Niketan TB patients are on the rise; the majority are Santals; 37% of TB patients are women; a third of TB patients are young adults. Patients are prepared to make incredible journeys to reach the TB centre that is managed by village health workers; 68% of TB patients are moderately to extremely under-weight; 88% of patients have pulmonary TB; most TB patients first go to Jhola Chhap and private doctors and exhaust their money; 40% of TB patients delayed starting standard treatment at Ekta Niketan by 3 to 6 months. Completing the full course of treatment is a challenge; TB is a silent killer in marginalised communities - patients die unnoticed in large numbers.

Despite the fact that a number of TB patients at Ekta Niketan have discontinued in the middle of their treatment, there are some good lessons to be learnt from the TB centre. During the last three years, the default rate is estimated to be around 20% - Ekta Niketan aims to reduce the rate to 10% during 2022. This is not an easy task but time will tell.

The TB centre has benefitted immensely from the NTEP in Jharkhand, from the district of Deoghar in particular. Yet this is not going to halt the spread of the disease in the area, the surrounding remote villages within 40-50 km from the centre, in the district of Deoghar as well as adjacent districts of Giridih, Jamtara and Jamui in Bihar. Not only is there a need to further improve working between the NTEP and a non-profit initiative like Ekta Niketan, but the NTEP itself, at Deoghar and surrounding districts, have to improve the way they function. TB patients prefer to make long journeys for their anti-TB medicines from Ekta Niketan than from their nearby government TB centres - a fact that needs looking into.

Ekta Niketan is not unique but it is different from the rest - governmental and non-governmental. To reach its current state - a centre where TB patients feel at home, where economic level and social and cultural values of health workers are much the same as their patients, where health

workers with basic education are competent to diagnose clinically and microscopically, and able to dispense anti-TB drugs correctly - Ekta Niketan has gone through trials over a long time. To reach out to TB patients in remote rural areas, it is worth looking into different models that the TB centre has adopted.

Finally, to halt the spread of tuberculosis and minimise unnecessary deaths, Ekta Niketan will continue to promote patients' access to health care and will demand political commitments to people-centric economic developments.



Dukhiadhi's Sonamuni found

PART THREE

In 2019, in the month of January, Sonamuni came to Ekta Niketan. All three came - Sonamuni, her husband Jhore and their two months old baby girl. Sonamuni was very thin and weak from TB. Her baby too was poorly as Sonamuni did not produce any breast milk.

In this land where the majority lack basic essentials for a decent living, a section live on the edge. Somehow they survive. But an event like TB or a death in the family completely disrupts their 'routine' survival. They struggle to cope with any additional economic burden. In villages where everyone is 'poor', such families stick out - their mud houses badly needing repairs, dirty torn clothes piling up, messy courtyards and frequent quarrels in the family. Dukhiadhi's Sonamuni is one such family.

In January this year (2022), after three years, Sonamuni is back at Ekta Niketan with her baby girl who is now three. This time Jhore did not accompany them. He is at the market town - a regular daily wage labourer. Sonamuni looks well; clothes are clean - not torn and dirty. She has gained weight - every sign on her face.

Sonamuni and her baby, both survived. The impact of her contracting TB and no money in the family (Jhore had to look after the baby - two months old at that time) was huge for this 'on the edge' family but they somehow survived. Part one (see page 18) written in 2019 is republished here, so too is Part two.

Sonamuni and two other TB patients from Dukhiadhi together hired a three-wheeler van to reach the TB centre. Sonamuni is not a patient anymore. She heard that the government's TB programme gave money to TB patients as an incentive to continue and complete treatment. Sonamuni's trip was for that purpose. She tried to convince Ekta Niketan's health worker that she had completed the full course of treatment! In Part two (see page 20) health workers made several trips to Dukhiadhi, later to her sister, then to her brother taking medicines for Sonamuni; but they could not track her down.

Even though Sonamuni did not complete the full course of her treatment, it was good to see that she and her baby were alive. Poverty and TB together did not manage to ruin the family.

I will have to go to Dukhiadhi to write Part four. I have to find out why Sonamuni moved from place to place leaving her husband behind, where did she finally go, why did she return to Dukhiadhi - in short, how did the family survive from poverty and TB?

Intricacies of poverty are not straightforward - I am yet to learn.



APPENDIX

Dukhiadih's Sonamuni

In search of Sonamuni of Sukhiadih - the land of happiness!

PART ONE

When Sonamuni Murmu told me that she was from the village of Dukhiadih, I thought it was rather a strange name. 'Dukhiadih' means the land of sadness - it is unusual to find a village with a name like 'Dukhiadih', equally unusual is Sukhiadih - 'the land of happiness'.

I have lived in this area for many years - in a mud house right in the middle of a tribal village where Ekta Niketan TB Centre is. It is a Santal village just like Sonamuni's Dukhiadih - a stream that flows at one end of the village separating it from the other; date-palm trees stand in rows by the stream with pots hanging to collect juice (to make alcohol); cows in the field graze to eat grass that is dry and brown; mud houses with tiled roofs have courtyards with broken rope-beds at the corner. I know the life here quite well - men work on roads and bridges or in towns carrying heavy loads to earn some money; the date-palm wine seller passes by pushing his bicycle with blue plastic containers tied on either side; women wash up by the well; children in school uniforms play all day long; flocks of young boys with black shoulder-bags are at the railway station waiting for trains to Chennai, Mumbai or Surat; and Santals play loud Hindi film music blending with Hindu religious songs for festivals and funerals alike. No one here seems unhappy.

I have come across Dukhiadih village - now I search for Sukhiadih.

Dukhiadih's Sonamuni

In January this year Sonamuni came to Ekta Niketan TB Centre. She was very ill - too weak to step out of the



auto-rickshaw¹. A middle-aged woman accompanied her to the patient waiting area. Patients coming from far usually come by auto-rickshaw - they get off on the road near Fatepur and walk about 2-3 km to reach Ekta Niketan. For patients like Sonamuni, too ill to walk, families often hire an auto-rickshaw that brings them straight to the centre - just as Jhore Murmu had brought his wife Sonamuni.

Sonamuni Murmu, a 30 year old Santal woman, lives in Dukhiadih. Jhore and Sonamuni are a small family with only one child of 2 months old. Jhore, like other villagers in the area, works as daily wage labourer in nearby towns. Jhore's parents died when he was small - that meant he was the only earning member in the family. When he is away working as a labourer Sonamuni looks after the house. The piece of land they have is very small - not enough paddy to last all through the year. Like many families, Jhore has no choice but to work as a labourer - on roads or carrying heavy loads in Giridih (the nearest town) or anywhere where there is work.

Sonamuni had all the signs of TB. She possibly developed the disease when she was in the later phase of pregnancy. She was very weak and weighed only 28



kg. At Ekta Niketan, we have many young TB patients who weigh no more than 30 kg.

Sonamuni's name was added to Ekta Niketan's TB register - one more TB patient who had first tried a local 'jhola chap' doctor, then

private doctors in towns or their nearby government TB centre, and finally Ekta Niketan. We started her treatment with standard anti-TB drugs.

A 'Jhola Chap' doctor (doctor with a bag over his shoulder) is the popular name for untrained practitioners

¹ An auto-rickshaw (or a three-wheeler vehicle) is a popular form of transport in this area. Auto-rickshaws run on any narrow road through villages and fields that larger vehicles cannot. Ekta Niketan is not on any popular route - it lies in the middle of a village called Fatepur.

to whom villagers normally go first if they are ill. They come to villagers' houses, give injections, and take payment in cash or kind - paddy, a tree or a bullock. They are not qualified doctors but perhaps acquired some kind of certificate. One such jhola chap doctor in Jagdishpur once started his career by repairing bicycles, later tailoring, before finally becoming a popular 'local doctor'! There is often little difference between 'private' trained doctors and these 'Jhola Chap' doctors - both prescribe strong antibiotics, often in the form of injections and charge a huge amount of money. The difference is that the former provides a piece of paper with a printed letterhead i.e. a 'prescription'. This is of course not true of all trained doctors in India, particularly in large cities like Delhi or Mumbai or Chennai, but in small towns in states like Jharkhand, many are making their fortune on patients from marginalised communities.

I was not sure if Sonamuni would survive, and thought the baby would probably die before her. Thin and weak her milk had already dried up, the baby was therefore on powdered milk. Babies in poor families in such situations become malnourished because the milk is not prepared properly and they are often at risks of infection if milk bottles are not cleaned adequately.

I travelled to Dukhiadih to see Sonamuni. I went with Ekta Niketan's health worker, Tikla. The village is about 35km from Fatepur - first you reach Jagdishpur, then Budhudih, after that a winding road passes through villages and fields, and finally you will find a stream that has date-palm trees with pots hanging. Dukhiadih is on the other side of the stream. Jore and Sonamuni's house is right at the end of the village - the



same mud house with tiled roof and a broken rope bed in the courtyard as in Fatepur. Their house was not so well kept though. To my surprise I found both Sonamuni and her small baby were alive.



I was not expecting any change in Sonamuni's health in such a short time - after all she had just started the treatment. She still looked very weak - but I thought I saw a flicker of smile on her face. Sonamuni did not want to die.

We made another visit to Dukhiadih within a month. This time the roads seemed more familiar - the journey felt shorter. Sonamuni was cheerful - her thin legs that could not bear any weight were already stronger - she could move around with ease. More importantly, Sonamuni had started feeding the baby with her own breast milk.



Like Sukurmuni of Fatepur, Sonamuni is going to survive, so it seems. On the way back from Dukhiadih, I felt very happy, but only for a while. I started thinking will Ekta Niketan ever bring happiness in this land?

At Budhudih market, I asked a tea-seller if he knew where Sukhiadih was. The tea-seller, thinking I was seriously looking for a village called Sukhiadih, replied 'there is no Sukhiadih here, but there is Dukhiadih'.

Dukhiadih's Sonamuni on the run

PART TWO

Dukhiadih is about 35km from our TB centre. For an outsider like me it is hard to find the village that is tucked away from the main road - narrow windy paths or streams to cross. During my second trip, even our health worker took a wrong road at the Budhudi market and we ended up to a stream but further upstream from Dukhiadih. But we reached Sonamuni's house in Dukhiadih. That was in February 2019.

After a month's medications, Sonamuni seemed to be on the mend - she looked much better, still thin but was able to move around. Even her baby started to suckle. I began to believe that both mother and the baby might survive.

But next month i.e. in March, Jhore did not turn up to collect medicines. Neighbour told health workers that they had had a quarrel and Sonamuni left Dukhiadih.

Health workers tried to track her down and finally found Sonamuni at her sister's place in Ranitar, another 15km further south from Dukhiadih.

Sonamuni and her baby were doing well but she became irregular in taking medicines. Sonamuni started to drink. Her sister was doing her best to help Sonamuni but started to getting annoyed with her.

On their next visit, Ekta Niketan health workers made Jhore to come to Ranitar. They hoped that if the family reunited, Sonamuni would complete her treatment course while in Dukhiadih.

Sonamuni left Ranitar without telling her sister where she was heading for. She did not return to Dukhiadih.

Health workers went to Khambarbad where Sonamuni's parents lived. She was not there. Nobody knew where she had gone. By then Jhore, her husband, left Dukhiadih letting their mud house ruin. The family disappeared.

Despite Ekta Niketan's efforts, the TB centre could not reach out the family. It is not unusual for TB patients to discontinue treatment, and there are very many reasons for that. But I could not figure out Sonamuni's case. After all she wanted to get better for the shake of her child. Will I ever know.



Photos (three from top): Sonamuni after a month's treatment. House needs repair but clean. Still weak but is able to do housework. Jhore has started looking work. Health worker checks her medicines - Sonamuni has missed some dosages - she makes her excuses!



Photo (below): Sonamuni left Dukhiadih - now living with her sister. After four months' treatment, she is better - her baby too.



Photo (above): Sonamuni's sister receives medicines pack from Ekta Niketan health worker.