A Death Every Minute

Dr. Raman Kakar

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By Dr. Raman Kakar

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INTRODUCTION

Having encountered so many patients suffering from tuberculosis in 25 years of my medical practice as a Chest & TB Specialist, I came across a number of unforgettable incidents that finally convinced me that something was seriously missing in our basic approach towards TB management and eradication. Out of these countless experiences, I would like to share two incidents that can help, to some extent, explain the motive behind this book:

- A silly mistake
- Suspecting TB is the first crucial step

A silly mistake

I was sitting in the courtyard of a house with many other people. The atmosphere was gloomy. Someone had died last night. They were talking in hushed voices. But I was quiet, staring blankly at the brick wall of the house that badly needed repairs. Having witnessed so many deaths ever since I became a doctor I have turned more of a stoic.

"How can God give such a deadly disease to such a noble person?" wondered the man sitting next to me in his nasal voice.

"Oh! A fatal disease for sure. Bad luck! None of his three daughters has been married yet", remarked an old man.

"This is what is called as destiny. Everything is *written*, you see", concluded the old lady on my left.

I felt uncomfortable. But she continued "I have not known anyone recovering from TB".

Feeling restless, I shifted a little in my seat.

"Once I came to know he had TB, I had practically written him off. I had advised his wife to be mentally prepared", quipped the man with the nasal voice.

I could bear the conversation no more and blurted out, "He did not die of TB".

The nasal tone became more pronounced as he tried to prove his point, " But Sir, his wife herself told me he had TB".

"No doubt he suffered from TB but he did not die of it", I clarified.

"What do you mean?", the old man was puzzled.

"He gave up TB treatment. Never completed the full course. That's what killed him", I explained.

"But that's only a petty mistake", said the lady.

"In TB, discontinuing treatment is disastrous", I asserted.

"You mean such a silly mistake cost him his life!"

"Yes. TB is nearly 100% curable. It is hardly fatal. Discontinuing treatment often is. The fate of a TB patient is often marred by some such silly mistakes."

One purpose of this book is to highlight those silly mistakes so that no one around us ever dies of TB.

Suspecting TB is the first crucial step

"Oh no, not again!", I mumbled as I saw him enter my clinic. I was exhausted from a full day of hobnobbing with so many obstinate TB patients.

He had been coming to me since last month with his ailing elder brother who suffered from TB and was undergoing treatment. Taller & healthier than his elder brother, he was very talkative, more fussy and difficult to handle. But this time he had come all alone " I haven't come for Virji. He's fine with your treatment", he declared as he sat down on the revolving stool meant for the patients, saying, "Please check me up. It is my turn now. I think I too have TB".

I was taken aback, "Where did you get such an idea from?"

"I have been having this cough. It bothers me. Although I have given up smoking. I am really worried. No harm in a check up, I guess!".

I could barely suppress a smile. I knew anxiety had gripped him. After a tentative check-up, I declared him fit and he left satisfied.

But he came back the next morning, “I could not sleep a wink the whole night, kept tossing in the bed. Are you sure there is no TB?” he pleaded. The matter had become quite serious now. The boy was obviously obsessed. This time I asked him to take off his shirt and I examined him hoping that the 10 minute drill will reassure him. I also gave him a tranquilizer along with an elaborate dose of my habitual counselling.

But I knew he will come back again & he did. He sat down. With a jerk he took out a film of his own chest X-ray from a big envelope and hoisted it in front of the tube light.

“I just got it done to be 100% sure”, he said apologetically.

“You are a real suspicious person”. I laughed as I revolved my chair to get a clear view of his X-ray, “ How many times have I told you….”.

“……Oh no”.

There was indeed a shadow, in the upper part of the left lung, a fluffy shadow with a central clearing, a brewing TB cavity. Unmistakable!

I was speechless!

That young boy had diagnosed himself.

And I had failed. Miserably.

From that day on I would never ever boast, “I can smell TB in a patient as if with a sixth sense!”. For a few days I suffered quietly and thought, “How come I failed and he diagnosed TB?”

How? Why?

Then it dawned on me.

He did one thing right, which I failed to do.

He took the first crucial step, which I did not.

He suspected TB.

I did not.

Conclusions:

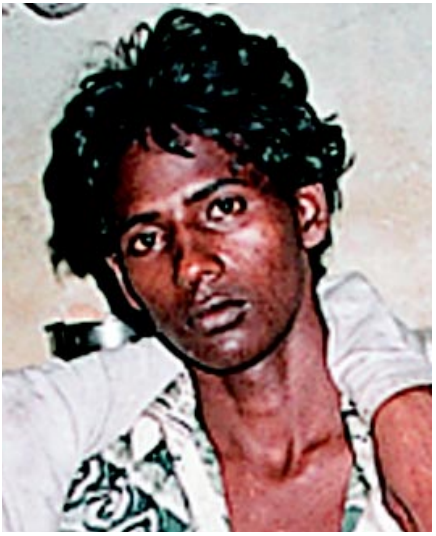
1. 'No suspicion means no diagnosis' in TB.
2. One does not have to be a doctor to suspect TB.
3. Anyone - a village old lady, a rickshaw-puller or even an illiterate labourer - can suspect TB. And help diagnosis even with minimal awareness.

Realising that a little bit of awareness can bring about a drastic change in the lives of TB patients and their families and that nothing is being done about it, I felt compelled to act. First 'Teen Batein', the 40 minute Hindi documentary film. And now this book - to create that basic awareness. The book covers the symptomatology of TB, investigations, diagnosis, its magnitude and pitfalls of treatment. It blasts all the myths that have been around for ages. I believe that it is the national duty of every citizen of India to learn a little bit about this disease so that we can all collectively fight this silent epidemic. The book will be especially helpful for TB patients, their family members, friends, health workers, nurses, medical students as well as general practitioners. It will empower anyone connected with decision making in TB control. NGO's working in TB or HIV will find it quite helpful.

Lord Byron, the famous poet, once wrote, "A drop of ink can make a million think".

I hope it is true!

DELAYED DIAGNOSIS



Ramesh had been sick for ten months and was gradually deteriorating all this time. He had gone to 4 different doctors. Unfortunately, they had one thing in common.They were all quacks. Ramesh did not know all that. For him a doctor was a doctor, a messiah of health.

Claiming panacea for all ills, each one had promised a cure, pocketed his money and given him treatment in some form or the other - pills and powders, capsules and concoctions, injections and glucose drips.

In spite of continuous fever, incessant coughing, and drastic weight loss they had been reassuring him that there was nothing to worry about.

It was only when he coughed out blood one day, that he was rushed to the government hospital where a qualified doctor finally got to

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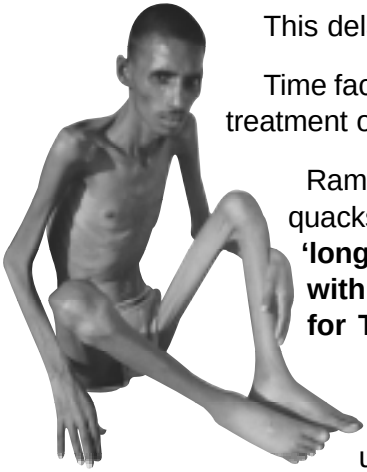


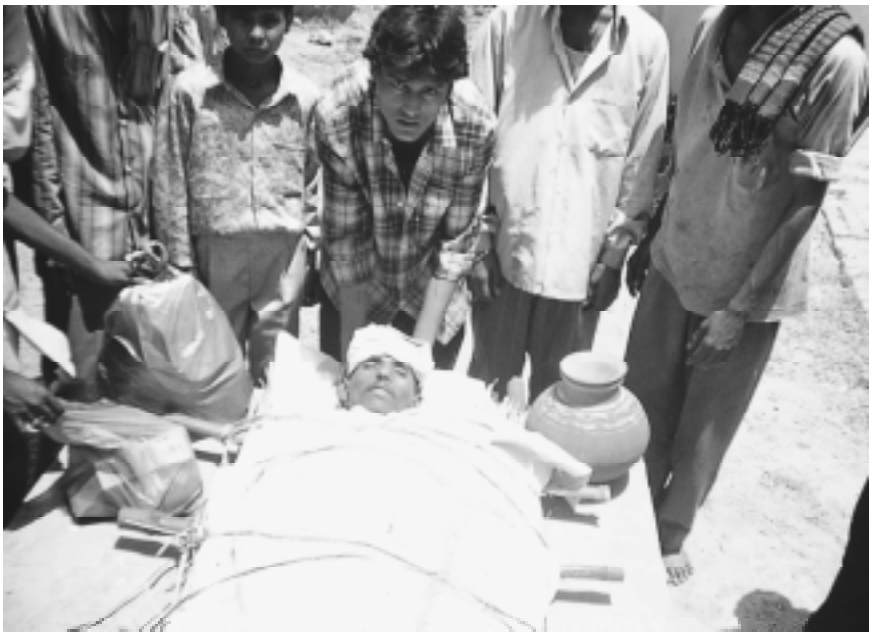
This delay in diagnosis cost Ramesh his life.

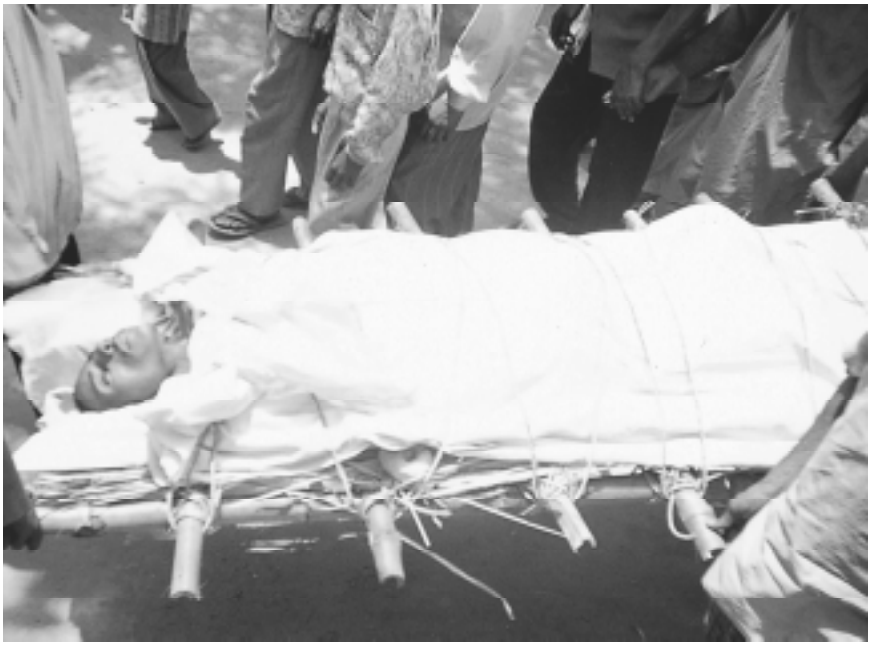
Time factor is quite crucial in the diagnosis and treatment of TB .

Ramesh, his family members and those four quacks were not aware of one simple fact that **'long standing cough and fever, coupled with weight loss' must be investigated for TB.**

Thanks to collective and complete ignorance they simply failed to come up even with a suspicion of the disease which is so common in India. If only someone in the family or neighbourhood had had the slightest idea about TB, Ramesh would have been saved through a timely diagnosis.

It took ten long months before someone, a qualified doctor, finally suspected TB. Once the suspicion arose it took only an hour to finally diagnose his problem by conducting two tests namely a chest X-ray





and a sputum test.

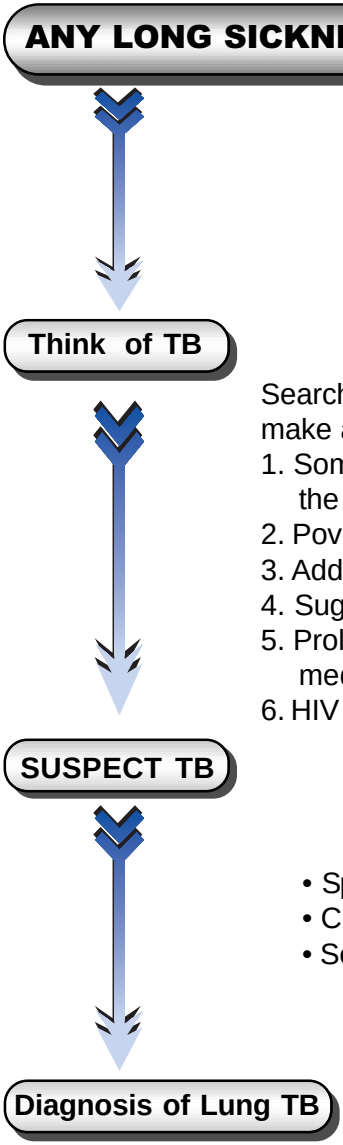
The usual symptoms of TB are quite ordinary e.g. fever, cough and chest pain. Moreover, these symptoms are often too mild to alarm a person to suspect TB or seek serious medical advice.

The real clues to TB in a person are persistence of these symptoms for a long time (say a month or more) with loss of weight. These clues i.e. 'long sickness with weight loss' become even more significant if the person is already weak and under-nourished or has had a close contact with an infective TB patient in the past. Moreover, all drug addicts, diabetics and HIV+ve persons, being more prone to TB, must remain alert if ever a 'long sickness with weight loss' should start occurring in them.

A high index of suspicion is the key to early diagnosis.

No awareness = No suspicion = No diagnosis = No treatment = No cure

HOW TO SUSPECT TB?



- 'A long standing cough & fever coupled with weight loss' must be investigated for TB.
- Every chronic patient losing weight is a suspect in Indian conditions.

ABOUT (MIS)TREATMENT

I AM OK NOW

Work from 8 a.m. to 8 p.m., 7 days a week. That was Ashok's life.

He worked as an unskilled labourer in a factory on daily wage basis, earning Rs.50/- (over a dollar) per day. Like an obedient son, he would hand over all his earnings to his mother. He was determined that his younger brothers and sisters got what he had missed, a good education. Such a dedication to the family made his poor parents feel proud of him.

Poverty and overwork finally had their effect on Ashok's health.

When Ashok first came to my clinic, I found he had been suffering from mild cough and fever for the last 6 months. Moreover, he had lost about 7 kilos of weight. The symptoms inevitably made me suspicious. I got his chest X-ray and sputum test done. The results confirmed my fears.

Ashok was suffering from tuberculosis, a disease which wrecks havoc with the Indian masses.

As many as 14 million Indians suffer from it. One Indian dies of it every minute. All this, despite the fact that TB is almost fully curable and excellent medicines are available in India at quite an affordable price!

Unfortunately, Ashok did not turn out to be a responsible patient. As soon as his symptoms of fever and cough would subside after a few weeks of medication, he would stop taking medicines. Disease would invariably relapse after some time.

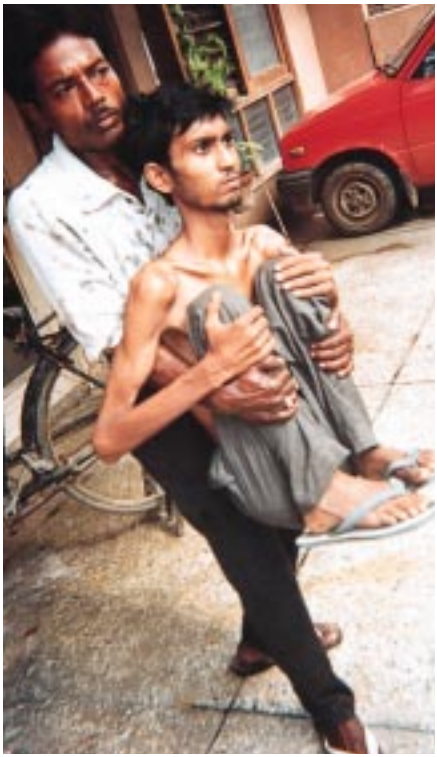
This cycle repeated itself as many as 4 times.

'Symptomatic Relief is equal to Cure' is a deep rooted human psychology which may be true in many diseases, but not in TB. The treatment of TB must be taken for a minimum period of 6 months for complete cure. However, symptoms of TB subside quickly. Believing that they have been cured, about 60% of TB patients in India (and 30% globally) give up their medication and fail to complete their course of treatment. Soon they will fall sick again. The cause of this typical stubborn behaviour is ignorance.

Incomplete treatment is the norm rather than the exception in India.

This enormous compliance failure by unaware patients is the single largest challange for all efforts of man to control TB on earth and which has necessitated the elaborate WHO initiative called DOTS (Directly observed treatment short-course).

DOTS is a comprehensive strategy especially designed to check default by patients. In DOTS, a very close watch is kept on the patient all along so that he simply cannot give up treatment midway. It is ensured that each and every patient completes his full course of medicines and gets fully cured.



I warned Ashok many times not to risk his life and to complete the full course.

"I am OK now. Why take more medicines?" was his logic. And then, he would get busy with his work.

Slowly but surely Ashok's health kept deteriorating. He became too weak to work or

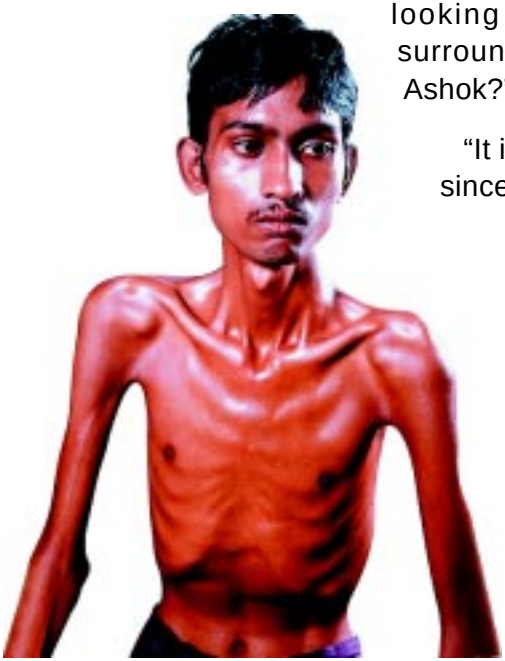
even walk. One day his friend carried him physically and brought him to my clinic. Ashok had become penniless too.

With a lot of hesitation he finally agreed to accept the help of a donor friend of mine who offered to pay for his medicines every fortnight.

Fortunately the arrangement seemed to work quite well. Once again he improved and that too quite dramatically. Though belatedly, he seemed to have understood the message and looked determined to complete his full course with the continuing financial help of that person.

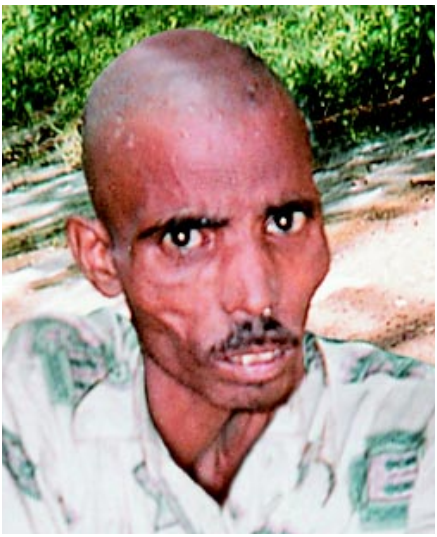
Thereafter, I got involved with making a documentary film on tuberculosis.Three years passed and he never came. One afternoon as I happened to be somewhere near his house, I decided to visit him.

As I knocked at his door I wondered whether he would recognize me or not. His father opened the door. I stepped inside. The small room was rather dark. I rubbed my eyes and looking hard into the hazy surroundings, I asked “Where is Ashok?”



“It is more than two years now since he died”, said his father.

DIFFERENT PRESCRIPTIONS



Seeta Ram was shocked. He couldn't believe his ears !

He only had a mild fever and cough and all along he had believed it to be just a seasonal problem. Disbelief soon turned into agony and fear. Fear of disease and death! Agony over uncertain future of his little son and daughter.

He did not know when he left the dispensary and rode his bicycle to his place of work. However, the first thing that he did notice was that his hands were trembling as he was trying to stitch the sole of a *chappal*.

"My shoes, Seeta Ram" the hoarse voice of a client finally woke him up and brought him back to reality.

As he wrapped the shoes in an old newspaper, he became conscious about his eyes being wet. Quietly he handed the packet to the client, who left without noticing his tears.

"Oh God! Men never cry" Seeta Ram told himself. As he slowly regained his composure, he knew what he had to do.

Not only Seeta Ram, anybody else would have gone through similar agony and fear at the mention of the word 'tuberculosis', a disease which claims one life every minute in India alone. That too despite the fact that TB is almost fully curable.

The same evening Seeta Ram was on a local bus bound for Karol Bagh. He got himself registered with a famous private clinic for TB treatment. During the next one month he visited the clinic quite regularly but without any relief.

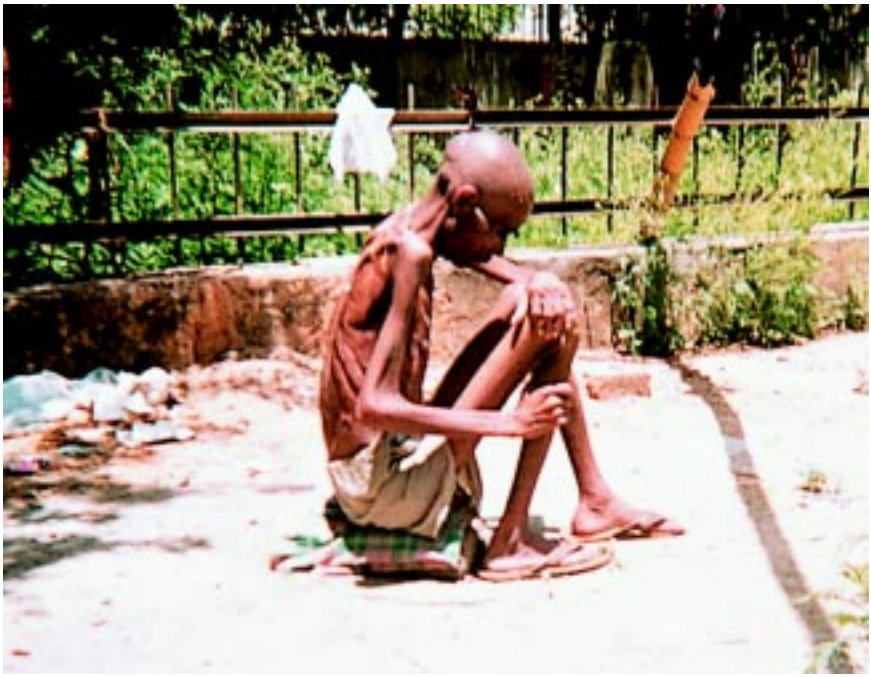
Disillusioned, he switched over to another doctor. Despite taking medicines regularly for three weeks there was simply no respite from cough and fever.

In the following three months he tried three more doctors - an old *Vaidji*, a local practitioner, and even a witch doctor who tried exorcism by religious orgies and *Jharphook.* Nothing seemed to work for Seeta Ram.

By now all his meagre savings had dried up. He was too weak to work. Otherwise also a cobbler in India does not earn much, not even Rupees 40 (US$ 1) a day!

Seeta Ram did not trust any government hospital. But that was the only option left with him, simply because the treatment would be provided free of cost. Unwillingly, he reached there and thereafter he started taking a handful of pills and an injection every day. But his condition kept deteriorating.

Finally he was admitted in the emergency room of Rajan Babu TB Hospital, Delhi as an unconscious skeleton fighting for life. This was one of the largest TB hospitals of Asia.



Fortunately, the medicines worked on him. Slowly he started improving. He regained full consciousness after about 20 days.

It was then that I met him and heard his story. I jotted it down in my diary while he was narrating it. Presuming that I was a press photographer, he minced no words in criticizing the doctors, clinics and *hakeems* who had left him with no money and that too without providing him with an iota of relief.

“From day one, I tried my best. Not a single day passed when I did not take some medicines or the other. What is my fault?” he asked me.

His question kept ringing in my ears as I sat on a wooden bench at New Delhi Railway Station waiting for the train to Faridabad. I knew how he felt. He was not the only one. Millions of other TB cases undergo similar traumatic experiences despite religiously complying with the treatment.

Surprisingly there is no uniform pattern of treatment amongst Indian doctors, eventhough TB is the most common chronic infection prevailing in India.

In a study conducted by Sheela Rangan and Mukul Uplekar in the state of Maharashtra, 100 doctors were interviewed. Unfortunately, about 80 different prescriptions for TB emerged. Every doctor is treating this disease in his own way - as per his own whims and fancies! Not as per WHO guidelines!

In India, out of 100 TB cases, 60 would first go to a private doctor. It is an open secret that many private doctors are unqualified quacks, who administer nothing but bad treatment. Bad treatment means faulty diagnosis, wrong drugs and doses, substandard drugs and even self-medication or changing doctors and drugs recklessly. Bad treatment in TB is not only useless but very dangerous. It results in converting simple, easy-to-treat TB cases into chronic cases who may subsequently become resistant to medicines and spread drug resistant disease in the society.

Seeta Ram, in the meanwhile, was discharged from the hospital. So one Sunday afternoon, eager to update my diary containing histories of TB cases, I was exploring the muddy streets of Nangloi, Delhi. I kept looking for that big *peepal* tree under which Seeta Ram repaired shoes. I couldn't even locate any *Hanuman* Temple near the cinema hall where that *peepal* tree was supposed to be. I looked once again at the crumpled piece of paper on which I had carefully drawn the map of the whole area under his direction while he was on his hospital bed. But even after three hours of search I failed to locate his house or place of work. A small hut in a slum hardly has any address.

What happened to Seeta Ram is not known to me. Four years have gone by. I wish and pray that he did not join the painful statistics of our country.

But I have my fears - as a doctor!

THE INSIGNIFICANT PEOPLE

"Amma pe jaoongi" cried Pooja in her Western U.P. dialect.

"I want to go to my grandmother", was what she meant while crying bitterly and trying to break free from the strong grip of an older inmate of Karm Marg.

Situated 5 km away from the city of Faridabad, Karm Marg is a wonderful home for the homeless and abandoned children where about 40 of them live as a family.

As we drove away on the dusty village road on my old scooter, I could feel that Pooja's grandfather sitting behind me had turned to look back at Pooja till she was out of sight. Choking with emotions he said, "She is so small, how will she bear this separation?".

But soon he gathered himself. He was determined to give Pooja a chance to make her future - away from the shadow of disease and death which had engulfed their family.

Pooja's father had been the first to succumb to tuberculosis followed subsequently by his younger brother. And later, Pooja's mother after a long protracted battle with TB had also been consumed by it.

So Pooja had become an orphan at the age of five and was left to cry in the lap of her grandmother, Kasturi.

Unfortunately, after some time, Kasturi too had fallen sick and had to be admitted in the govternment TB hospital, Faridabad in a serious condition.

It was in the overcrowded TB ward that I had first seen Pooja on

Grandfather : Sita Ram, TB in 1985

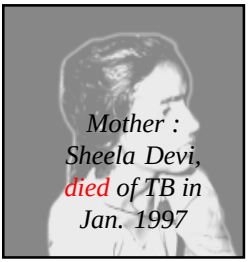
Grandmother : Kasturi, critically sick with TB

Uncle : Digambar, died of TB in 1996

TB wiped out pooja's family

Uncle : Jai Parkash, took treatment of TB in 1990

Father :Khem Chand, died of TB in 1994



Mother : Sheela Devi, died of TB in Jan. 1997

the bed of her sick grandmother who was spitting blood. The girl had been sleeping, blissfully unaware of the heat and the flies and the danger of catching infection or disease there. A child at that tender age with little immunity had no reason to be there.

“But there is no other option”, her grandfather had lamented.

“Except, of course, Karm Marg”, I had heard myself saying.

The irresistible dynamic energy and the spirit of freedom and joy flowing through Karm Marg finally helped Pooja to get over home sickness. Soon she settled down, mingling well with other children. She became chirpy and her health improved. Sensing that she was rather bright, it was thoughtfully arranged to send her to school. She started doing well in her studies.

It was after about a year that I saw her grandfather again. He came to my clinic straight from his native village in Hathras, U.P State.

I tried my best to convince him that a visit back home by Pooja at that juncture would distract her and risk her future.

“Kasturi is sick and dying. She has only one wish - to see her granddaughter just once,” he said adamantly.

He took Pooja away, promising to bring her back after the ….. last rites. Pooja did not come back.

Today, the thought that haunts me the most is that she had barely started her long preventive course of drugs when it got terminated prematurely. It was essential for her in order to prevent any future risk of tuberculosis, a preventable and curable disease, which had claimed 4 lives in the family.

Pooja's family is one example. In fact TB kills one Indian every minute, nearly half a million every year - so silently. At any given point of time, an estimated 14 million Indians suffer from it. India bears one third of the global burden.

Worldwide, TB is known to claim more human lives as compared to AIDS, Malaria or Hepatitis B. Just like Pooja, it creates more orphans than any other infectious disease.

Recent trends point towards its resurgence even in many developed countries in Europe and North America.

However, it remains mainly a disease of poor people and the developing countries. 95% of TB cases and 98% of global TB deaths occur in the developing countries.

It is estimated that more than $56 billion a year is spent globally on health research. About 90% of this R&D is directed towards the diseases of the rich. Even Science follows the market!

And 80% of the world's drug sales take place in North America, Japan and Western Europe. That is where the rich consumers, enjoying fat insurance covers, reside. That is where the prosperous governments lavish upon their citizens health plans with 'no limits'. And obviously, that is exactly where the focus of the pharmaceutical industry and researchers lies.

A study by Patrice Trouiller, of Médecins Sans Frontiéres (MSF) revealed that out of 1223 new compounds launched in the market from 1975 to 1997, only 11 were for tropical diseases.

Only 10% of the health R&D is for the poor who constitute 90% of the global population. It means that when new drugs or vaccines

are conceptualised and developed most of the world's population is left out of the picture. Not considered ! For the highly competitive pharma industry, profit comes first – not people. No wonder then that every other day, there are reports of some breakthrough in the field of - weight reduction, beautification! Cloning! Mood elevators! Viagra!!

Pharmaceutical industry would prefer to find a cure for a bald American rather than a dying African or Asian. Ironically the top scientists of Asia and Africa too end up joining the same rat race - through brain drain!

TB failed to muster in 8000 years what AIDS seems to be generating with in 20 years of its identification! Kofi Annan, the secretary general of the United Nations, has sent an SOS call for a war chest of $ 7 to 10 Billion annually to fight AIDS.

All aid for AIDS, little for TB. TB figures nowhere on the international agenda! Talk about equality! justice! human rights!

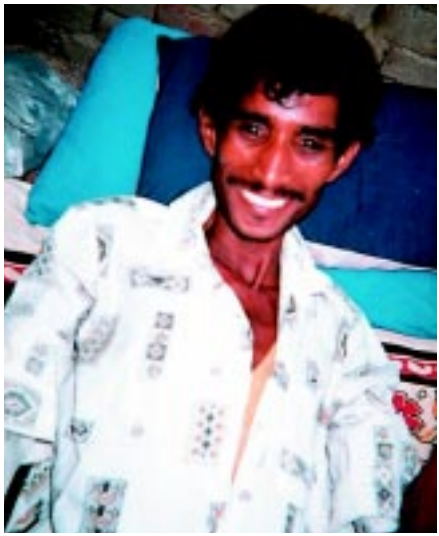
This global conspiracy of silence and inaction has led to the following consequences in the field of tuberculosis ...

- No perfect TB vaccine has been evolved till date. For prevention of TB, man continues to use BCG vaccine, which is 80 year old and not very effective.
- No new TB test discovered so as to replace the 120 year old sputum test.
- No new TB drugs invented in the last 35 years and sadly none appears to be in the R & D pipeline.

This germ continues to cause unimaginable suffering to millions of people in Asia and Africa. And it goes on and on - with very little hope, simply because the victims happen to be insignificant people. Their tragedy goes on unnoticed, untold, unheard, unwritten and unmourned.

Refrences : 1. "Balms for the poor" The Economist August 14th, 1999.
2. "Helping the World's Poorest", 'Sachs on Development by Jeffrey Sachs (Director of the Centre for International Development and Professor of International Trade at Harvard University) Published in 'The Economist' August 14th, 1999.

OBSOLETE TREATMENT



With a sparkle in his eyes, he smiled and declared 'Doctor *Sahib* I will stitch an *achkan* (coat) for you". I knew that he always kept his word.

Ateeq and his wife were always full of delightful energy. The birth of a son had added to their joy. Theirs was a very close knit joint family, living in a small two room brick house in village Khera, Ghaziabad in Uttar Pradesh.

His religious mother used to pray before each meal. Ateeq who was doing well as a tailor and was known for his hard work and dedication seemed to have a promising future.

His mother believed it was all Allah's will.

Misfortune descended on Ateeq in the form of tuberculosis and despite treatment he did not get better. His health kept deteriorating and he became too weak to work.

Finally he had to close down his shop.

And then he was taken by his mother to various government dispensaries in Ghaziabad, Meerut and Delhi. He was even admitted to Rajan Babu TB Hospital, one of the biggest TB hospitals in Delhi.

Unfortunately nothing seemed to work.

However, the family showed tremendous courage and remained united during this crisis. 'We will do everything to cure Ateeq' was the family spirit.

Even his married sister would visit them every weekend from Delhi to serve her ailing brother.

Gradually the family savings were gone. Two bicycles, all sewing machines, some jewellery of his mother, wife and his brother's wife were sold off. A buffalo which was always treated like a family member was reluctantly disposed off. They even took loans.

And later, Ateeq's family seriously considered the idea of selling even the house.

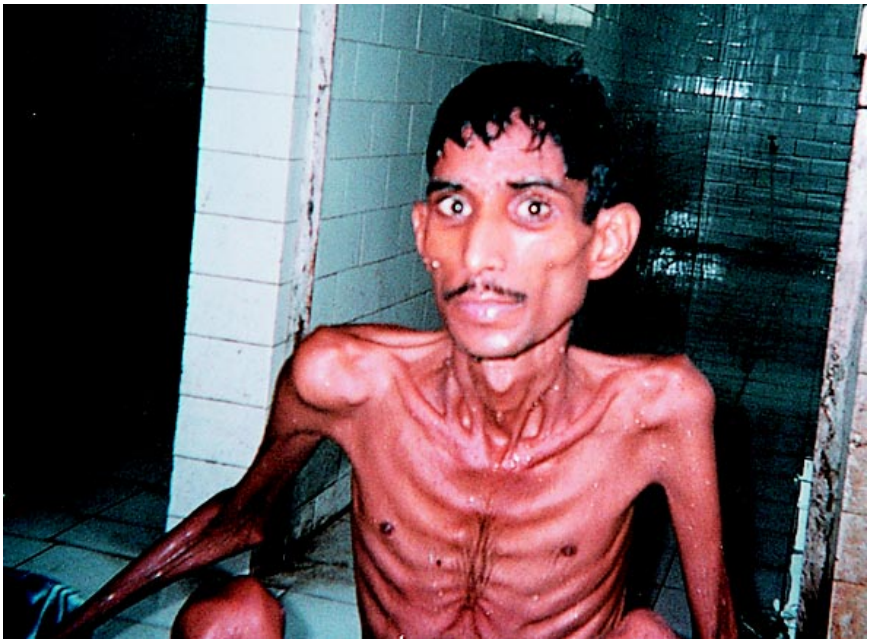
But somehow the need to sell the house did not arise. On September 11, 1997 Ateeq passed away.

He could not stitch a coat for me that he had promised.

Ateeq's elder brother is bitter about the government TB centres for complete mismanagement - long queues, rude behaviour of the staff, X-ray machines mostly being out of order and the medicines being out of stock. Sadly, he even had to bribe someone at one hospital to get treatment for Ateeq.

Ateeq's disillusioned mother asks just one question: "As citizens of this country, we went to government hospitals with total faith. They say that TB is curable. Then why did my son die?"

The million dollar question is as to what does an unsuspecting, innocent TB patient get in most government TB clinics in India?



Often, not the WHO recommended drugs!

Many times outdated combinations of drugs are given, including Thiacetazone, a tablet which costs merely 10 paisa. Thiacetazone has long been discarded in some countries for not being so effective and having serious side effects.

Sometimes Paracetamol and vitamin tablets are cleverly dispensed in place of the essential TB drugs which are in perpetual short supply.

A typical example of 'The fence eating the field'.

Many TB hospitals are no less than a hell. They are littered with pus, sputum and blood and the spectre of death looms large in the wards. There is no ICU. There is often a desperate shortage of doctors, staff and other facilities, and very serious patients are left unattended at God's mercy for hours.

Very few officials or politicians care to visit or inspect TB hospitals. Whatever goes on in there, mostly remains unknown to the outside world. This author who himself is a part of the whole system feels pained to divulge that sometimes a patient dies unattended during the night. Only his dead body comes to notice the next morning!

Like millions of other Indian TB patients, Ateeq had no insurance cover and got no help from any government agency or any NGO. As such there is no effective social security system in India where people die in large numbers due to many avoidable calamities like tuberculosis. A poor TB patient is simply on his own - against heavy odds.

Ever since the author became a doctor 25 years ago, everything in the country has improved - the buildings, the roads, the cars, the telecommunication systems, the media, the Internet. If there is one thing that has not changed, it is the fate of a poor TB patient.

DEATH WARRANT

I read the report. I was speechless!

I looked at Maya Devi, sitting meekly on the wooden bench of my clinic, blinking her small oriental eyes. Her husband stood anxiously over me smelling of *bidi* in his breath and staring at the report as if he was reading it.

It was in early 1998 that Maya Devi had first come to my clinic.

Considering her 12 year long history of bad treatment and sensing that the TB drugs had since stopped working on her, I had decided to take no chances. So I had sent her 'sputum sample' for a culture and sensitivity test.

Faridabad city with over 2 million population, amazingly, does not have any facility for this test. So I had to send it to New Delhi TB Centre, one of the best centers for the test.

However, I received her test report by post but not before 3 months.

The poor family had migrated from Nepal way back in early 1980s hoping for better avenues in India. Luck did not favour them. They had to go through tough times bringing up their small kids, arranging for their education and shelter moving from one slum to the other and also searching for jobs.

Adding to their misery, Maya Devi fell sick with tuberculosis of the lungs in 1986. Since then disease and poverty had been hounding them ceaselessly.

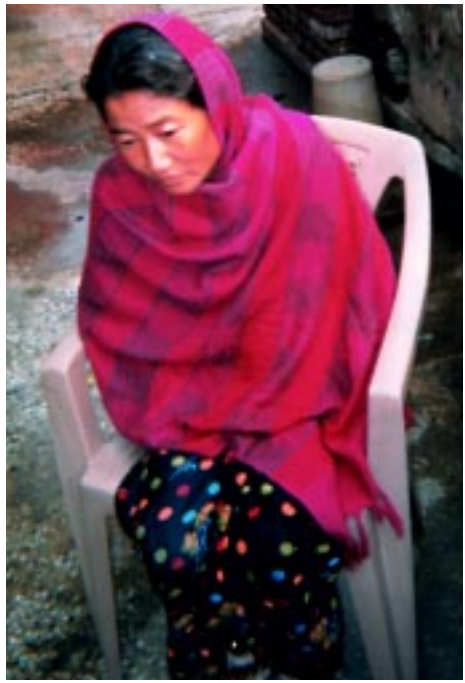
Her first course of TB medicines had been suddenly disrupted because she had to go back to her home-town in Nepal.

Soon after she returned from there, she suffered a relapse. Having spent all the savings on the long journey, she had to devise innovative

methods to cut corners. She resorted to self medication on the basis of the previous prescription slips. But she would purchase medicines selectively. Sometimes she would omit the 'costly' red capsule, or the 'bitter' white tablet and sometimes she would avoid the yellow tablet that caused 'too much gas'. She would readily settle for locally made cheaper substitutes offered by the 'nice & friendly' chemist. From time to time she would visit some 'famous doctors' too, the criteria not being their qualification but the long queues in their clinics and yet 'within reach' fees. She preferred quacks because they somehow provided quick relief and did not 'waste her time and money' on the 'cumbersome' sputum tests and X-rays etc. Obviously she changed doctors and drugs frequently. But she had never taken a full course of proper medicines for 6-8 months! She would give up treatment as soon as she felt better. Only symptomatic relief with half hearted irregular treatment was all that she had cared for.

Even the death of her uncle and brother due to TB had failed to warn her about the consequences of irregular treatment.

I took my eyes off Maya Devi and went through her report once again. TB germs in her sputum had been found to be resistant to most of the best TB medicines.



Technically speaking, she was a case of MDR TB (Multiple Drug Resistant Tuberculosis).

I was speechless because I believed that the report was in effect her death warrant.

Resistant TB cases are very difficult to treat even in the best of Institutions with unlimited resources and the best of doctors. The second line drugs which are used in such cases are very expensive, highly toxic and quite ineffective. Moreover, the

duration of treatment is about 2 years.

It was unthinkable that a poor patient like Maya Devi could ever afford this treatment. She was too poor to buy even the much cheaper drugs given in simple TB cases.

She had in the first place landed in the trap of resistant TB due to her poverty and lack of awareness.

It takes over 15 years and $500 million for the complete research and development of a TB medicine. In contrast, it may take only a few months of misuse of that medicine for the clever and resilient TB germ to develop resistance to it. That is why, unlike other diseases, TB is never treated with a single medicine but always with a combination of 2 to 5 medicines given simultaneously.

There are only 5 potent TB drugs known to man. As the germ gets smarter, as it learns to resist drugs, one after the other, man runs out of drugs with which to treat TB.

As on today no new drug is expected to emerge soon from the R&D pipeline.

Maya Devi died on October 16, 1998. Just like her, millions of cases are suffering & dying needlessly in the third world countries like India & Nepal for want of minimal awareness about this disease.

Single largest failure of all international & national agencies engaged in TB control lies in their failure to recognize the significance of creating sufficient general awareness about this ancient disease. The nightmare that haunts the author is that the same easily correctible lacuna may not ruin the prospects of DOTS, the latest TB control initiative. Resistant TB is on the rise and that too at an alarming rate. It is a race against time. Even at this belated stage an awareness campaign launched worldwide on a war-footing can stem the tide.

Otherwise our grandchildren may find themselves back into the pre-antibiotic era of our grandparents when there was no cure for TB.

THE HEALING TOUCH

All his mates in the factory called him *Guru* (Teacher).

Ram Bharose was respected by all his co-workers not only because he was an excellent skilled worker ever ready to help and guide them but also because he was honest and dedicated. He had chosen to stay on in this electroplating unit all these years despite getting better offers. He felt loyalty to the place where he himself had learnt every trick of the trade starting from a scratch.

One fine morning Ram Bharose arrived early and with a sense of urgency settled down to work. He was determined to make up for his recent absence from the factory because of his personal problems.

While he was working with all his concentration, his foreman came, signalled him to stop and took him to the office. He gave him some money and asked him to go home.

Go home!? He couldn't believe his ears. He, the *Guru*, was being fired and that too when he had done nothing wrong at all! Tears welled up in his eyes.

It was not the loss of job that bothered him.What hurt him was the cumulative effect of injustice and humiliation that he had been

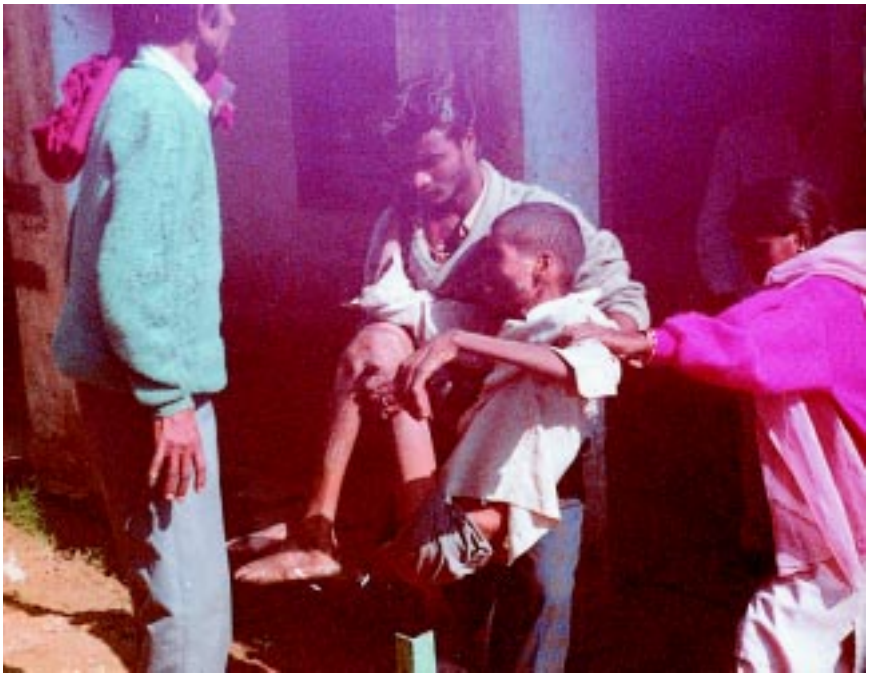
subjected to time and again during the last few weeks.

Strangely, none of his co-workers came forward to protest all this or to console him. They just watched as he gathered his belongings and quietly walked out of the tall iron gates suppressing his tears.

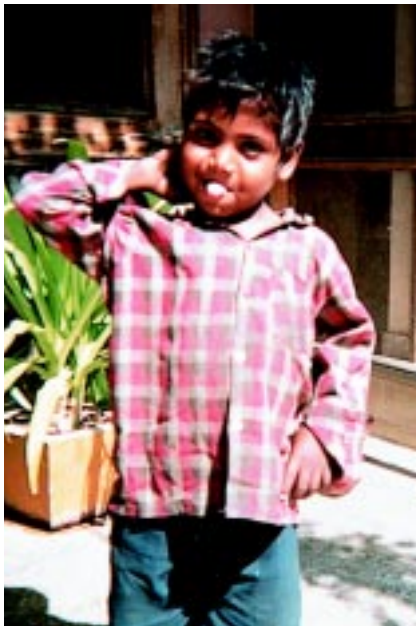
All he wanted to do was to embrace Sandeep and cry. Sandeep, his 6 year old son, was to him like his heart beating outside his body. But he was not there. Just 10 days ago his wife had abandoned him, taking Sandeep along with her to her parents' house.

And all this was happening to him while his own health was failing. He could never forget that fateful morning when his illness was diagnosed as 'Tuberculosis' and he was labelled as a TB patient. It had proved to be a very powerful label. He could feel its evil effect on all his relationships.

Within days, his whole world had come crumbling down causing much more suffering than the germs in his lungs. These emotional blows had left him too depressed to take care of his health.



Thereafter, his condition deteriorated fast. Soon he had to be admitted in the government TB hospital, Faridabad in a critical condition. As soon as the admission formalities were over his father too left.



He was left alone in a helpless, penniless and hopeless condition. The *Guru* lay on his hospital bed looking blankly at the ceiling and waiting for his end!

This is not an unfamiliar scenario in India. A chronic TB patient is sometimes considered a liability even by the blood relatives. They somehow manage to put him away in a TB hospital at the mercy of hospital staff who too treat him often without compassion.

The stigma attached to the disease is invisible yet quite palpable. It induces a stunning silence as the word 'tuberculosis' is never uttered.

A TB patient is like an outcaste in some villages and families. Many patients, fearing rejection from the society, hide their symptoms and disease. Many simply do not take treatment as they hate to be seen visiting a TB hospital. Many sick women are abandoned and workers like Ram Bharose are laid off.

Irreparable damage had been done to *Guru* because of the general inhuman and sadistic attitude towards TB patients prevailing in our Indian society which seems to have a penchant for creating untouchables on some pretext or the other - caste, colour, work, religion, language, region, financial status and what not.

Ram Bharose lay in a critical condition, his body consumed with sickness, muscles wasted, mind delirious, breathing erratic, pulse weak and thready and blood pressure barely recordable.

All parameters indicated one thing, the impending grave prognosis, a doctor did not have to be a genius to predict.

While a crowd of visitors and attendands impatiently waited to be let in to the ward as soon as the doctors' rounds were over, a small boy had sneaked in. The guard was calling after him. Unmindful of the warnings and the presence of awesome team of doctors the boy kept moving from one bed to the next closely looking at every patient.

Finally his search was over. He stopped near a bed. He slipped onto it embracing the patient.

The boy was none other than Sandeep with his eyes red and swollen. Obviously he had been crying to be united with his father.

Ram Bharose looked on dazed. Slowly his senses registered what was happening.

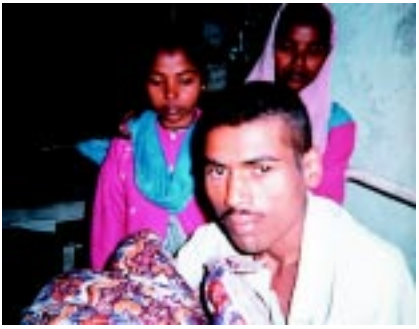
For the first time in many days Ram Bharose smiled.

About two months later, on Dec. 22, 1996, Ram Bharose was discharged. He walked out of the iron gates of the hospital with his son.

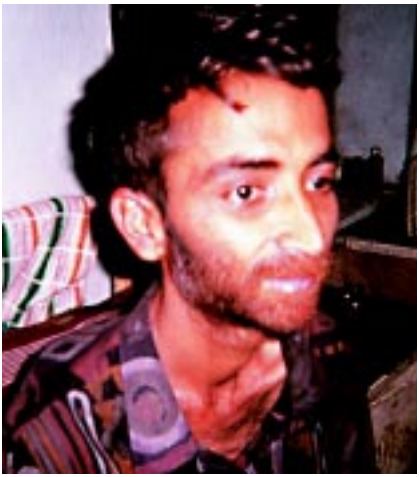
The little boy had provided to his dying father just what he had needed - a healing touch.

The recovery of this patient belied every scientific principle I have ever been taught.

It was just what a doctor is trained not to believe - a miracle.



THE MYTH



The movie was boring. The interval came as a welcome break, a time for snacks. I rushed out of the congested cinema hall for a breath of fresh air. Once outside, I was pulled towards the sizzling sound of deep frying of the *bread pakoras,* the popular Indian fast food.

A frail young man stood behind a four wheeled wooden cart. Having prepared a mixture of boiled potatoes, peas, chopped onions and green chilies, he stuffed it between two slices of bread and after dipping this sandwich in the *besan* paste, he delicately eased it into the sizzling hot oil in a big black pan placed over the gas stove. The oil hissed, spreading that familiar fragrance that always tantalized my taste buds.

It was only after I finished eating two bread *pakoras* with chilly sauce followed by a hot cup of tea that I looked up at the man to pay him. He was smiling at me.

'Dilip', I almost shouted as I recognized him.

Dilip had been visiting my clinic for treatment of tuberculosis. But like so many other TB patients, he had given up treatment without completing the course. What automatically followed was my well rehearsed lecture for such TB patients about the dangers of incomplete treatment. My sermon was cut short by a tug on my shirt from my daughter. Reluctantly I left Dilip to join my family in the cinema hall.

A few months later, one rainy morning Dilip entered my clinic along with his mother. Both of them were completely drenched. Dilip looked very sick and disturbed.

His land-lord had somehow come to know about his disease and had forced them to vacate the house. Their wet luggage was lying outside my clinic on the four wheeled cart that he would normally use for making and selling *bread pakoras.*

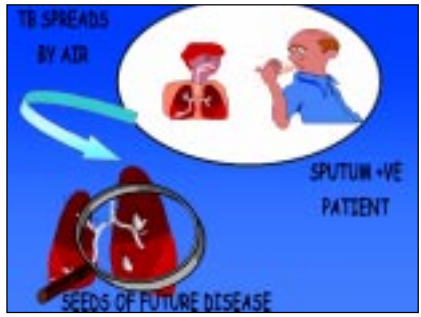
I phoned a doctor friend. The same afternoon Dilip was admitted in the government TB hospital, Faridabad. He and his mother at least got a place to sleep.

At the heart of Dilip's problem lies the prevalence of certain myths in our society.

Even today, in many third world countries TB is considered to be a curse of God. Contracting this disease is treated like receiving a death warrant despite the fact that very good medicines are now available and TB is almost fully curable.

Moreover, TB treatment is not very expensive. In India, the total cost of complete six-month-course of drugs (as recommended by WHO for category-1) is approximately Rs.1680 ($US 40).

'TB runs in the family' remains another deep rooted myth with disastrous consequences despite the fact that TB is neither a genetic nor a hereditary disease.



Very few people in such societies are aware that TB is caused by a germ called mycobacterium tuberculosis. This germ is transmitted through air. When a full blown TB patient coughs, these germs are thrown out into the air exposing other people. Anyone around him, who breathes in that air is likely to inhale these germs, taking them into his healthy lungs. Once in the lungs these germs may settle down as seeds of potential disease in the future. TB germ can remain dormant for many years in the lung without producing disease.

Moreover inhaling TB germs doesn't necessarily lead to clinical disease. A good body resistance is often quite effective against the germ. Only 10% of those fully exposed to this germ will end up developing clinical tuberculosis. That's why even after years of interaction with TB patients, this author is quite fit.

Contrary to the age old belief that every TB patient must be admitted in a hospital or a sanatorium, it is well established now that home treatment is equally effective.

Not all TB patients spread germs. Only 25% of all cases, mainly those who have germs in their sputum, may infect others. They too turn germ-free within 6 weeks of effective treatment, and can meanwhile minimize the chances of infecting others by observing certain precautions like:

- covering the mouth while coughing,
- not spitting indiscreetly,
- staying away from small kids, and
- spending most of their time out in the open - in a park, under a tree or on the roof.

ost cases are relatively harmless. Many forms of the disease pose little risk to others, e.g. childhood TB, lung TB when there are no germs in sputum or TB of other organs like bones, glands, brain, intestine and kidney etc.

Measles, mumps or Chicken pox may be much more infectious where a chance meeting or passing through the patient's room could be enough to land one in trouble. But only a prolonged indoor, close contact with a TB case who is sp+ and careless may lead to infection.

TB is transmitted through air and not through handshake or food or water.

The richest of the rich and poorest of the poor have at least one thing in common, the air they breath in. So no one is immune to being infected with TB. However, chances of being infected are much less, while we are outdoors, in a park or on the roof, as the germs, coughed out by the patient, get diluted in the atmospheric air and direct sunlight rapidly destroys them.

It is a shame that even in this era of advanced communication technology, common knowledge about TB is quite uncommon, and ignorance about it continues to play havoc with the lives of patients like Dilip.

I wonder what is causing man more suffering - the germ or the ignorance about it.

It was after a month or so that one of my patients informed me that Dilip had died, leaving behind his old mother all alone.

For the first time in her life at that ripe old age she had to start working. As a dish-washer.

But for the silly myths prevailing in the society, Dilip would have been alive. I still go to that cinema hall sometimes. The *bread pakora* doesn't taste the same any more.

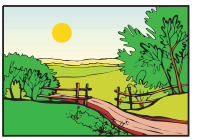
Do's & Don'ts for the TB Patients

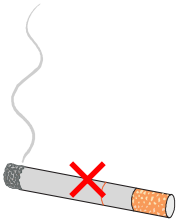
1. Cover your mouth with a hanky (a small piece of cloth) when you cough.

2. Keep this hanky in boiling water for 15 minutes every day before reuse

3. Never spit here and there. Spit only in a can. Keep its lid tightly closed. After 2-3 days pour some kerosene oil into it and burn it. Then bury the can under the soil. Take a fresh can.

4. Avoid closed rooms. Spend most of your time out in the open, in a field, in a park, in the courtyard or on the roof.



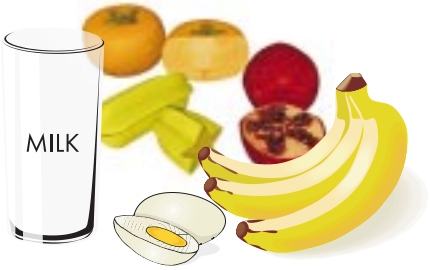


5. Stay away from small children.

6. Stop smoking, drinking or tobacco-chewing etc.

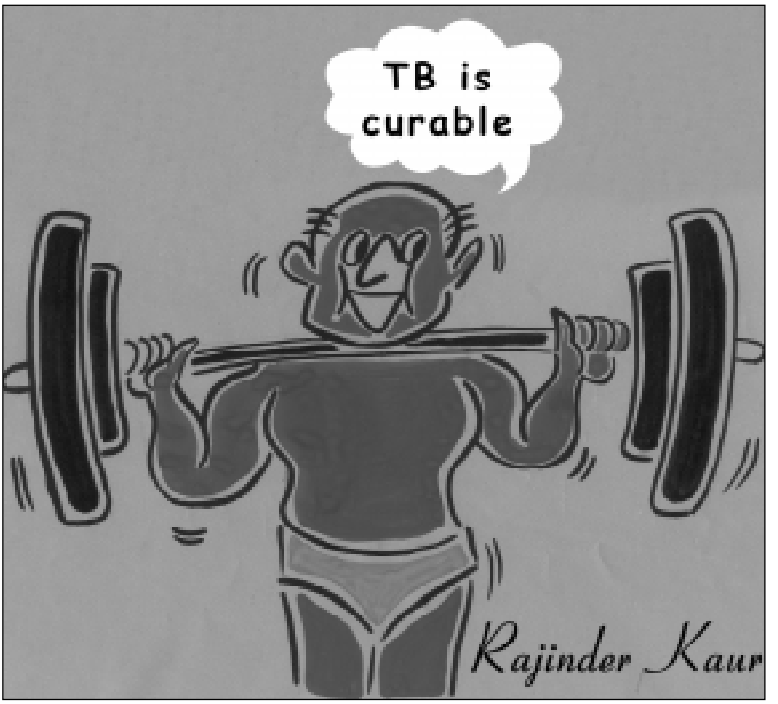
7. Never miss any dose of your medicine. Don't leave any tablet.

8. Eat a balanced diet including milk, green leafy vegetables, fruits, pulses (daals), eggs. etc. Non seasonal costly fruits can be avoided.

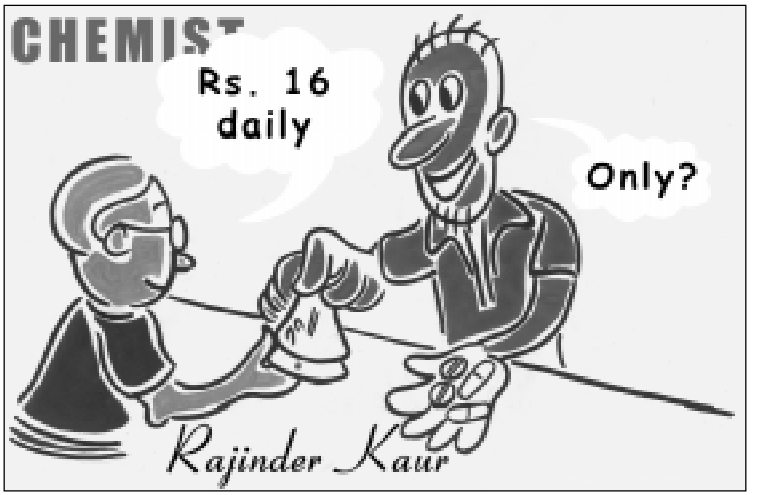


These precautions are most essential for all lung TB patients who are passing TB germs in their sputum.

GOOD BYE TB MYTHS

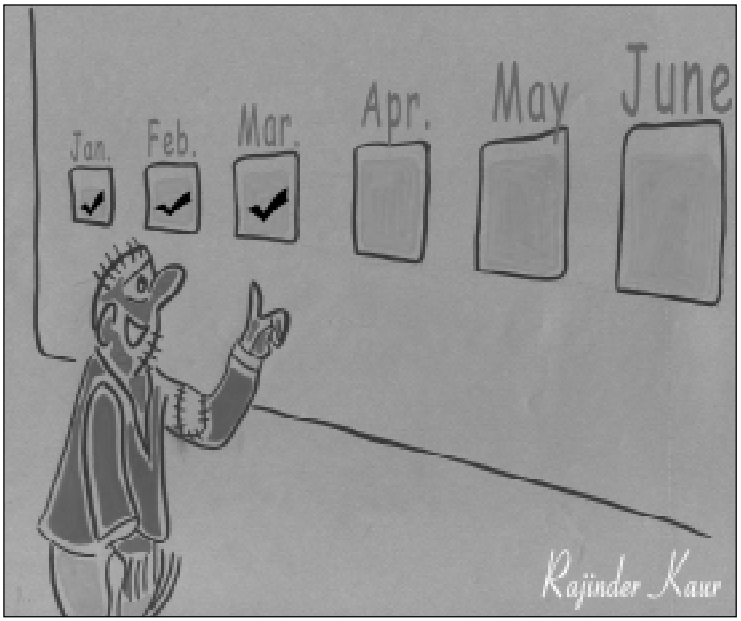


1 . TB is curable. Almost 100% curable. Excellent medicines are now available.



2. TB medicines are not very expensive. They are easily affordable.

3. Usually there is no need for hospitalisation. Home treatment is equally effective.



4. TB treatment takes 6 to 8 months for complete cure

5. Within 1 month of treatment, TB patient feels better. His symptoms disappear. Cough and fever subside. He thinks that he has recovered and he feels like discontinuing medicines.

But it is a blunder. He must take TB treatment for at least 6 to 8 months and as per doctor's advice. Otherwise he will fall sick again and endanger the lives of his family members and friends. TB is not fatal, to discontinue treatment is.

6. TB does not run in the family. It is not hereditary.

7. It is not highly infectious – only prolonged, intimate, indoor contact with a careless TB case may lead to infection.

However, chances of being infected are much less, while we are outdoors, in a park or on the roof, as the germs, coughed out by the patient, get diluted in the atmospheric air and direct sunlight rapidly destroys them.

WAKE UP DEAR TB PATIENTS

1. Take all your family members for a check-up to rule out TB.

2. Anyone around you who has long standing cough and fever and is also losing weight, must be taken for a check-up.

3. Never hide symptoms or disease for fear of society. Take treatment.

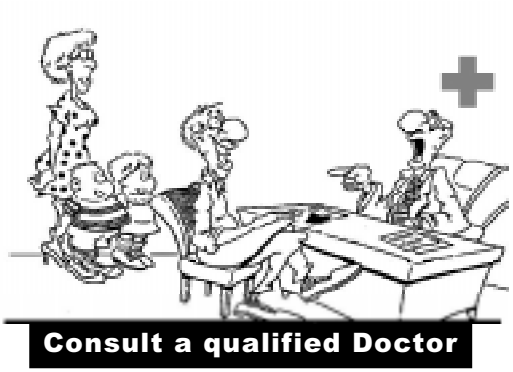
4. Ensure that every new born baby is given an injection of TB vaccine called BCG.

5. Ensure that the other TB patients in your area complete their full course of treatment.

6. Find out the location of nearest DOTS centre. Take poor TB patients there.

7. Never resist lung surgery if recommended by qualified doctors.

DANGER ZONE FOR A TB PATIENT



1. Taking TB treatment from a quack, chemist, pharmacist, hakeem, vaid, ojha, homeopath or an acupuncturist is very risky. Crucial time and money will be lost.

2. Even if you get some relief initially, it will be temporary! Always go to a qualified doctor.

3. Only a qualified doctor can know how to diagnose TB, prescribe the right medicines in proper dosage for an appropriate period of time.

4. Do not change doctors or drugs frequently and recklessly.

WARNING

There is need to get ALERT if even after 2 months of proper TB treatment:

1. Symptoms persist, cough and fever continue.

2. Weight loss is not arrested.

3. TB germs persist in the sputum.

4. Shadows in the chest X-ray worsen or fail to regress.

TB is not incurable, we fail to cure it

HELLO CHEMIST !

1. Always demand and take the bill of your TB medicines from the chemist.

2. Ensure that the medicines are from some renowned company like Glaxo, Cadilla, Novartis, Hoechst, Wokhart or Lupin etc. Do not accept medicines produced by a local unknown company.

3. Check the date of expiry.

4. No substitutes please.

5. Injection, if any, must be administered by a disposable syringe.

SIDE EFFECTS ? NO PROBLEM

1. TB medicine may turn your urine reddish.
2. Medicines can cause nausea or vomiting that generally disappears within a week or two.

3. Consult your doctor immediately in case of these side effects : Joint pains, Eyesight problem, Jaundice, too much itching, giddiness, hearing loss or numbness in hands and feet.

TB TREATMENT FOLLOW-UP

1. After confirmation of the diagnosis on the basis of the first X-ray and the initial 3 sputum tests, get these tests repeated after 2, 4 and 6 months of treatment.

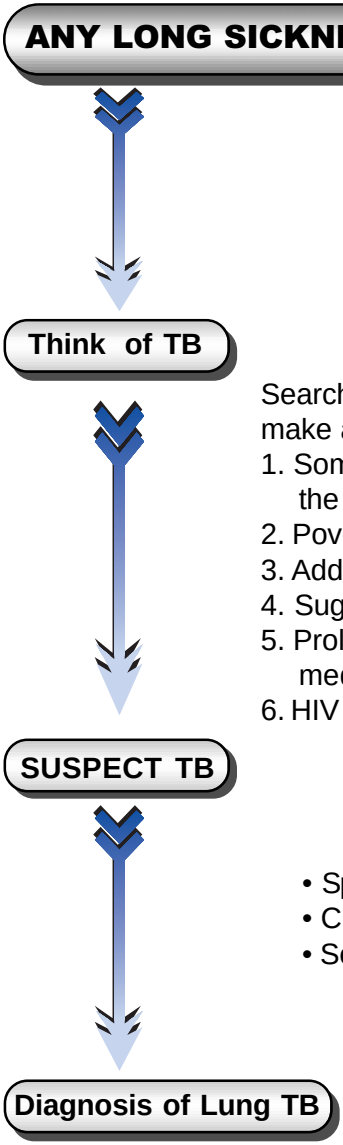
2. After being fully cured the patient should go for these tests once a year for 3 subsequent years.

3. Carefully preserve all your X-rays, sputum test reports, and prescriptions in your own safe custody for future reference. Never lose them.

4. Record your weight every 2 months in a diary.

5. Repeated sputum tests are very very important. Always give deeply coughed out sputum sample for testing.

HOW TO SUSPECT TB?



- 'A long standing cough & fever coupled with weight loss' must be investigated for TB.
- Every chronic patient losing weight is a suspect in Indian conditions.

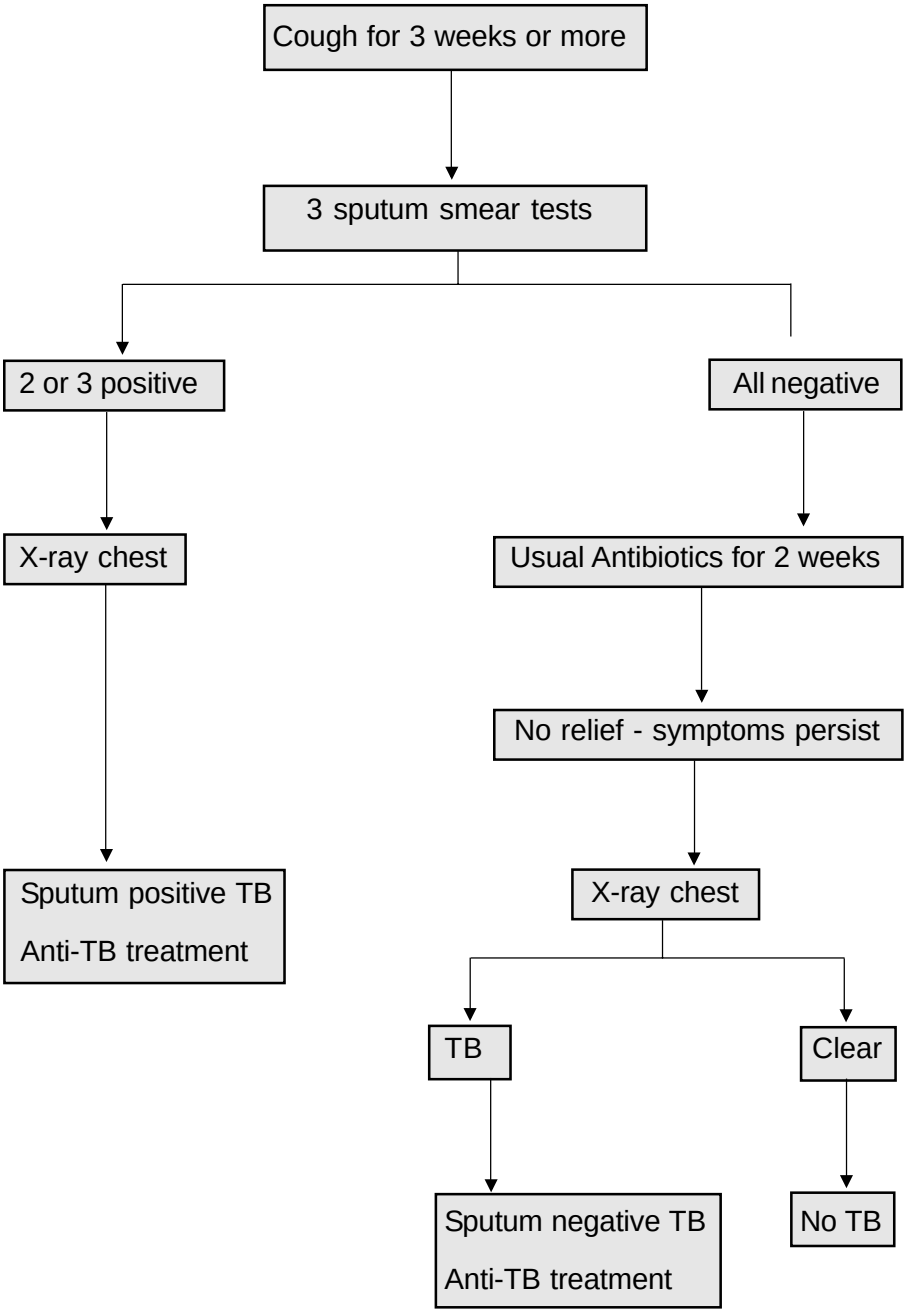
Which one of the following persons must be investigated for TB?

1.Sunil Kumar 25 years male	cough and fever : 3 months loss of weight : 4 kg father died of TB of the lungs last year
2.Ram Lal 35 years male	cough, sputum : 2 months loss of weight : 3 kg looks undernourished he is a very poor rickshaw puller
3.Meera Devi 50 years female	a known case of diabetes (sugar) cough and fever : 1 month
4.Surat Singh 40 years male	an alcoholic an old case of joint pains taking medicines (including steroids) fever for 2 months with weakness
5.Bobby 9 year boy	weaker than his class-mates swollen lymph glands on the left side of the neck : 5 months his mother cured of PTB 3 years back
6.Sheena 16 years girl	lean and thin, looks anaemic pain and swelling of the right knee : 1 year, feels feverish too

Each one of the 6 (above) is a TB suspect.

More important than the symptoms themselves is the long duration of sickness (over a month in each case) and loss of weight.

How to diagnose TB of the Lungs



TESTS FOR TB

Most often TB occurs in the lungs.

(A) TB of the Lungs

For all practical purposes there are only 2 tests for diagnosing TB of the lungs :

1. Sputum smear test for AFB

There is only one definite proof of TB of the lungs – a sputum smear positive report, wherein we see TB germs in a person's sputum under a microscope. Not only is it a 100% proof of TB but it also provides vital information that the patient is infectious for the society.

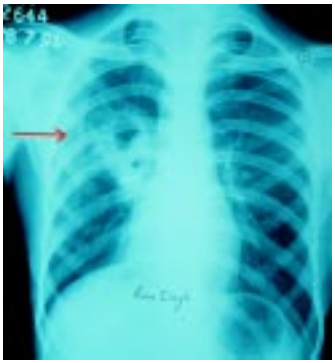
The germ as seen under a microscope

A sputum positive report is a priceless document. It gives the following million dollar information:

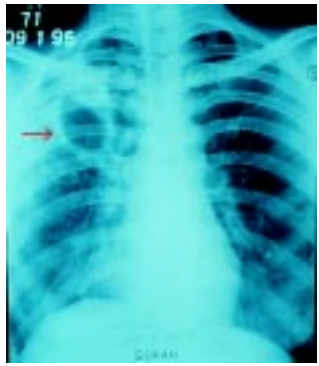
1. Yes, the patient has TB for sure.
2. He is highly infectious to others.
3. It is absolutely essential that he observes do's and don'ts of TB (see page 44, 45).
4. His treatment deserves top most priority as it will stop TB at source.

2. Chest X-ray

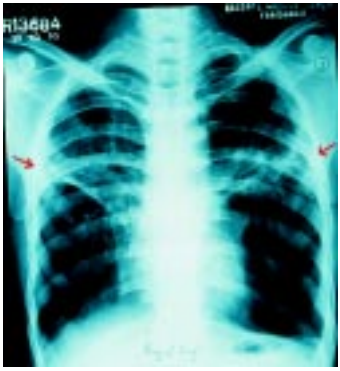
In a chest X-ray TB casts shadows of various shapes and sizes. A cloudy shadow with a central clearing, a cavity, fibrosis or calcification etc. do suggest TB especially if located in the upper portions of the lungs. But no pattern of shadows is absolutely typical of TB. Other chest diseases resemble TB and hence diagnosis by Xray alone is unreliable. Moreover Chest X-ray is an indirect evidence. Sputum smear test remains the gold standard test. But not each and everyTB patient is sputum positive(but only about 25% are sputum positve). So in case there are no germs in the sputum, one has to rely on chest x-ray to establish the diagnosis of sputum negative TB.



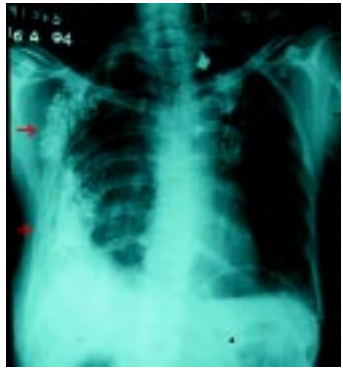
Cloudy with central clearing



Cavity



Fibrosis



Calcification

A series of X-rays is much more helpful than a single X-ray film. In a chest symptomatic one must remember a thumb rule that "in a sputum negative case, a normal X-ray chest rules out TB of the lungs".

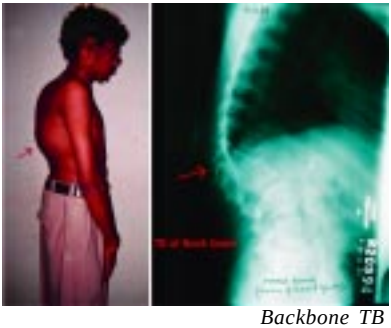
'Sputum for AFB culture and sensitivity' test is helpful in evaluating the suspected drug resistant cases.

Montoux (tuberculin skin) test is helpful mainly in childhood TB.

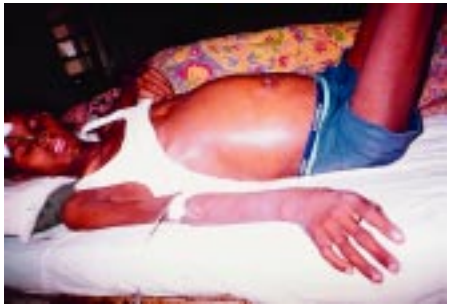
(B) TB in organs other than lungs

TB can occur anywhere in the human body from head to toe. For example in lymph nodes, bones, joints, brain, pleura, intestines, liver, kidney, heart or genital tracts etc.

Some of these patients will have an associated element of lung TB also, where sputum test and X-ray chest would help clinch the



Backbone TB



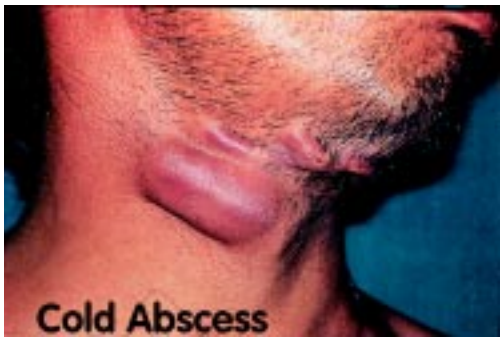
TB of Intestines

diagnosis. But in others, presence of TB germs can not be demonstrated. **Biopsy and histopathology** form the basis of diagnosis here. Interestingly, taking a biopsy or FNAC (Fine Needle Aspiration Cytology) is no more a blind procedure today. A modern surgeon can practically take a piece of any and every organ of the body with an endoscope or a laproscope under visual guidance of X-ray screening, ultrasound, Catscan or MRI.

The recent fancy tests like Eliza, PCR (Polymerse Chain Reaction), GLC (Gas Liquid Chromatography), MS (Mass Spectrometry), HPLC (High Performance Liquid Chromatography), Bactec Radiometric Essay or ADA estimation etc. are still at a research stage and/or are too expensive.

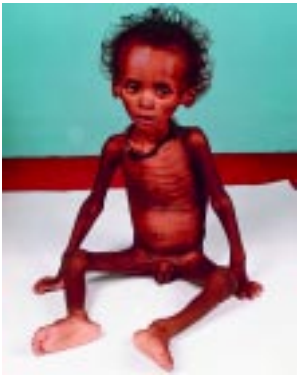
Often a doctor has no option but to resort to a presumptive diagnosis of TB and start treatment.

Gland TB

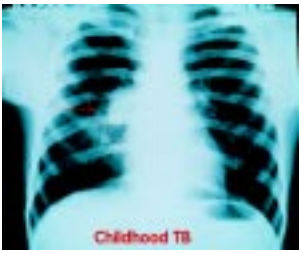


CHILDHOOD TB

Some of the following features help in the diagnosis of TB in children:



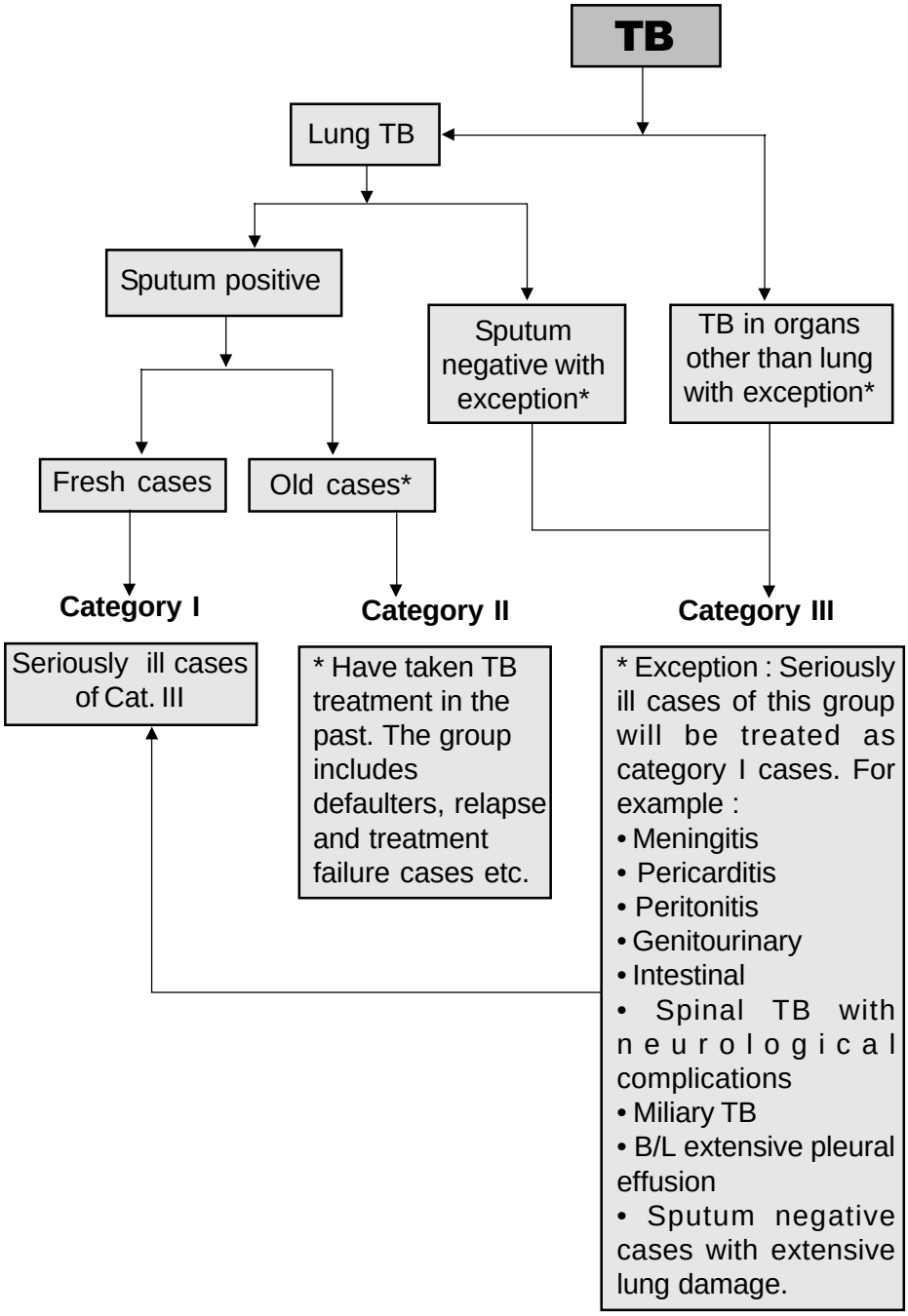
1. A family member of the child is known to have sputum positive TB.
2. The child is malnourished (and hence more prone to TB).
3. Child is not growing as expected or is losing weight.
4. Child has cough or fever for over 3 weeks or some other illness of long duration.
5. A recent episode of measles or whooping cough etc. weakening the child's immune system.
6. Child is known to be HIV infected.
7. BCG vaccination not given at birth (as confirmed by the absence of BCG scar on left shoulder).
8. Tuberculin skin test coming positive.
9. Palpable glands in the neck area or axilla.
10. Gland shadows or fluid (pleural effusion) in chest X-ray.
11. Any persistent swelling over a bone or joint, a deformity of the back bone, a mass or fluid in the abdomen.



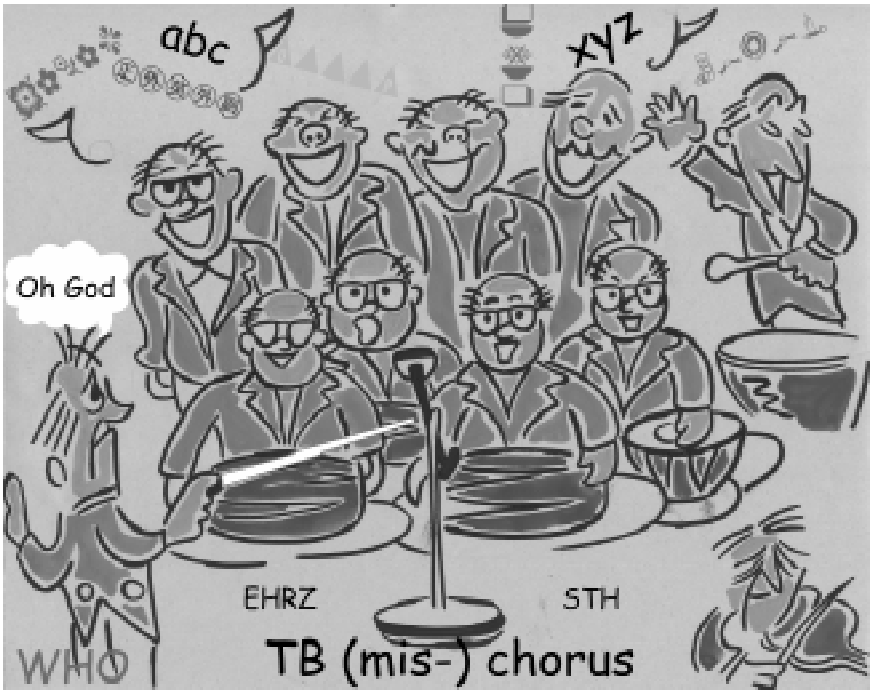
Gland Shadow

Invariably the source of infection is a sputum positive adult, mostly a family member. The child is a helpless victim of the society. He hardly ever transmits infection to anyone, as he simply can't cough out any sputum. The more serious forms of TB like meningitis or miliary TB occur mainly in children.

FOR TREATMENT PURPOSES TB PATIENTS ARE DIVIDED INTO 3 CATEGORIES:



TB ERADICATION



Every doctor seems to be treating TB in his own novel way, as per his own whims and fancies. Not as per WHO guidelines! 100 doctors were interviewed in the state of Maharashtra. About 80 different prescriptions for TB emerged!

When this be the level of awareness among the qualified doctors themselves, one can imagine the level of awareness in the public in general, the patients, their family members as well as the top non-medico-policy makers of India!

Why TB kills one Indian every minute?

Main causes, in brief, are :

1. **Premature Discontinuation of treatment** by patients as soon as they feel better. Patients are not aware that TB treatment must be taken for 6-8 months for complete cure (page 15).

2. **Delayed Diagnosis :**
   Ignorance about symptomatology of TB amongst general public, patients & their families. (page 10 - 12)

3. **Non-uniform treatment patterns:**
   Poor update of doctors regarding WHO guidelines on TB treatment which is merely a single page document! (page 20, 66)

4. **Myths and social stigma:**
   Lack of awareness among public about the real facts. (page 38 - 40)

5. Unchecked **Transmission of the germ** from patients to society:
   Ignorance of patients & their families regarding simple but vital precautions to be taken at least during the stage when the patient passes germs in his cough & sputum. (page 44, 45)

   Our health care system is oblivious of the absolute and urgent necessity to educate TB patients and their family members.

6. **Quacks** at every nook & corner of our country, creating a mess.

7. **Malfunctioning government dispensaries.** (page 27, 28)

8. **Neglected TB hospitals.** (page 28)

9. Production of **substandard TB drugs** by small-time companies mushrooming everywhere.

10. Continued production and usage of **Thiacetazone**, a 10 nayapaise drug of the past era. (page 28)

6, 7, 8, 9 & 10 are obviously the result of lack of awareness amongst bureaucrats, politicians & top policy makers of the government.

11. Little research on TB

Unrealistic understanding of grassroots realities by the highest echelons of the world bodies, funding agencies & the pharmaceutical industry. Lack of global vision! Poor appreciation of the 'all or none law' prevailing in TB whereby 'no one is safe till everyone is safe'. TB is not just someone else's problem. TB is a Global Emergency! (page 24, 25, 74)

12. Emergence of **Drug Resistance** - A result of all the other factors. (page 30, 31, 20)

13. Rise in HIV, further fuelling TB.(page 76, 77)

Directly or indirectly each cause can be traced back to the ROOT CAUSE namely **lack of awareness at some level or the other.**

Single largest failure of all international & national agencies engaged in TB control lies in their failure to recognize the significance of creating sufficient general awareness about this ancient disease.

SOLUTIONS SUGGESTED

How can we solve our nation's TB problem?

Steps that must be taken immediataly :

1. Government must implement DOTS with total commitment : WHO has launched a comprehensive TB treatment system, worldwide called DOTS (Directly Observed Treatment Short Course). Under this system the best available TB drugs are provided free of cost for a short course of 6-8 months. Patient stays at home but goes to & swallows each dose at a nearby DOTS Centre right in front of a health worker. The health worker even visits the patient's residence if he defaults at any stage. Onus of total cure is on health system.

The Government of India has adopted DOTS in some areas. It covers a population of 13 crore today & it is being expanded in a phased manner to cover 40 crore population by the end of year 2002. Government must implement DOTS with total commitment.

2. But not each & every patient in the areas covered by DOTS can avail this facility. Many prefer private sector which is not incorporated into DOTS programme. This large sector comprises of an overwhelming 80% of all qualified doctors, 75% of dispensaries & 60% of India's hospitals. So DOTS is still in its infancy in India and it will take at least 2 decades more for it to cover the whole of India. Till then we must ensure that every patient, even in those areas not covered by DOTS is treated as per the definite guidelines issued by WHO. For Example, for a simple TB case (of category 1), the recommended regime is 2 EHRZ + 4 HR & it costs Rs.1680/- (40$) in 6 months.

Treated thus, TB is nearly completely curable (98%). Therefore, **law must make it obligatory for every doctor, Government or private, to treat every TB patient strictly as per WHO guidelines.**

3. Update of doctors:

Every doctor encounters TB as it can occur in any part of the human body. Therefore:

A. **Medical Council of India** (MCI) must take these steps:-

a. Send a copy of WHO guidelines on TB treatment along with a simple questionnaire (to be filled in & returned) to each & every of the 5,46,897 registered doctors.

b. TB should be a separate subject in MBBS.

c. PG seats in TB must be increased.

d. 'Social & Preventive Medicine' should be accorded more importance. This subject should be taught in every MBBS professional.

e. Introduce a new subject called "Social Health Communication" in MBBS curriculum. It will teach doctors how to disseminate information. Innumerable doctors are living data banks with the society having no password to access them.

B. **Indian Medical Association** (IMA) must take these steps:

a. Send a copy of the WHO guidelines on TB treatment to each & every of its nearly 1,25,000 members.

b. Coax each of its 1600 odd branches to hold TB update workshops at least once every 6 months. Such workshops should be held all over India involving doctors, policy makers, media persons, etc. especially on the **World TB Day i.e. 24th March** every year.

4. TB awareness on a war-footing across the country:-

a. **NCERT** (National Council for Educational Reasearch and Training) should introduce TB awareness in the school curriculum.

b. Create awareness in the schools by way of workshops, debates, quiz, essay writing, poster making and film shows etc.

c. Ministry of Information & Broadcasting must observe **TB Information Week** around 24th March, 2002 and thereafter every

year through all its channels of Radio & TV, as well as by screening newsreels on TB in cinema halls. Thereafter, regular prime time slots for TB awareness on all state run media channels.

d. Compulsory TB programmes and spots on all private TV channels as well as all FM channels.

e. Railway Ministry should help spread messages on TB using bill boards, hoardings and public address systems on Railway Stations and in trains

f. Government & NGOs must spread awareness through newspapers & magazines etc.

g. Only doctors are aware of the crucial role of awareness in TB. But ironically they have no say in creating it. Bodies like Information Education Communication (IEC) and Central Health Education Bureau (CHEB) need to be reorganized to take this mission of spreading awareness with more conviction.

5. Prevention of Resistant TB

a. Only the pharmaceutical **companies with highest standards** should be given license to produce and market TB medicines. Substandard medicines are not only useless but very dangerous in TB. Manufacturing substandard drugs should be dealt with utmost severity under the law, declaring it a **non-bailable offence.**

b. Production & usage of **Thiacetazone**, an outdated medicine, should be **banned** in India.

c. Over the counter sale of TB drugs should not be allowed without the prescription of a qualified doctor, registered with MCI.

d. Innumerable quacks are further messing up the TB scenario. Either stop them or train them so that they know at least 'when to refer and where'.

e. Arrange for **Sanatoria** in remote areas for isolation of all confirmed multiple drug resistant cases.

f. Abolish excise & custom duty & sales tax on TB drugs to bring down their cost.

g. Administration of TB medicines on an alternate day basis has so far been tried, tested and recommended only in a 'Supervised Setting' as in DOTS. Hence no drug company should be allowed to produce & promote such intermittent regimens to unaware practitioners, till more research resolves the issue.

6. Private Sector

a. **DOTS must be modified so as to include all private practitioners** who cater to innumerable TB cases.

b. The most important test for TB i.e. Sputum Smear Test should be **subsidized** to Rs.10/- by all private labs across India. It is & will remain free of cost at government clinics.

c. Hospitals which get concessions from the government must run free TB clinics/DOTS centres.

7. Interrupting transmission and arresting high infection rates in India: About 25% of all TB cases, mainly those who pass TB germs in their cough & sputum may infect others. Such infectious cases will turn germ-free within 6 weeks of effective treatment and can meanwhile minimize the chances of infecting others by observing simple-but-vital precautions like covering the mouth while coughing etc. (page 44, 45)

Hence:

a. Each TB prescription must bear the 'list' of precautions in local language. (page 44, 45)

b. The list of precautions and the location of local DOTS centres must be displayed at public places, chemist shops.

c. Whenever a doctor comes across a TB patient, he should either treat him or ENSURE that he reaches a DOTS Centre, or another appropriate treatment facility, so that he does not get lost in the sea of humanity once again. Each TB case is a potential reservoir of infection for the society and hence deserves VIP treatment.

d. A technical committee should be appointed in order to frame guidelines as to how we can optimally utilize “Preventive Chemotherapy” in high risk populations.

e. Big windows, exhaust fans and coolers are quite essential in all TB clinics & wards.

8. Stop misuse of meagre health resources and divert them to TB & other ailments of the common man:

a. No Indian should be allowed to go abroad on public money for treatment.

b. Reimbursements to anyone from the public funds for treatment in non-government luxury hospitals should be banned.

c. Abolish VIP duty for busy government doctors as we barely have one qualified doctor per 2000 people.

9. Nowhere is the time factor (and hence communication) as crucial as in the case of a serious patient struggling for life. Government must put an obligation on Telecom Ministry to provide in all TB centers, civil hospitals and 23000 odd Primary Health Centres the latest inter-communication technology including Intercom networks & computers, etc. on top priority basis.

India possesses adequate medical infrastructure to diagnose & cure each & every TB patient and an excellent media environment to create sufficient mass awareness in a short span of time. Let us give ‘Health’ top priority, revising its painfully low budgets and do whatever it takes to eradicate TB because….

It can be done.

Actions required at the International level

(Please also read pages 24, 25, 68)

1. 40 years after drugs for TB were discovered, the rise in its morbidity & mortality itself speaks volumes about the attitudes, working & effectiveness of the world-bodies entrusted with TB control!

   A world tribunal should be set up to investigate & ascertain accountability for the acts of omission & commission by the world bodies which have brought the world to the brink of TB disaster that has caused so much avoidable suffering to the mankind.

2. Launch of ETA:

   The media environment the worldover is ripe for the launch of a new world-body for Eradication through Awareness (ETA) which can take up issues in which awareness is a crucial factor, as is in TB, and spread information effectively, creating sufficient awareness within a couple of years. This body will be specifically responsible for creating programmes, and audio visual and written material in many relevant world languages and to ensure effective dissemination of health information.

3. Nobel Foundation should declare in advance a Nobel Prize for anyone who discovers

- A potent TB Vaccine
- A potent TB drug that can cure TB overnight
- A potent TB drug which can eliminate the dormant germs that lie as seeds in a healthy person.
- A mask or methodology that can help check the transmission of the germ.

EMERGING NEW DIMENSION

THE FINAL BOUT

It was an old color photograph of a well built man. His biceps were bulging out of the half sleeves of the shirt. His front buttons were nearly breaking off because of the strong chest muscles.

"I used to weigh 89 kilos then. I was a wrestler, you see. In my weight category, I rarely lost a bout".

I shifted my eyes from the picture to the frail sick man sitting on the cot beside me under the tree. He looked much older than his 43 years.

Was he the same man in the picture!

"I am reduced to 36 kilos now", he said coughing while his wife brought his medical file and discharge papers and handed those to me.

I was puzzled. Normally TB was a disease of weak and malnourished people, I thought, as I sifted through his medical papers scanning them. Why, in the first place, would a person like him suffer from TB?

Suddenly it all became clear to me.

The report written in red ink stared at me. So that was it!

He was HIV positive!

Obviously the virus had knocked out all his powerful body defences paving way for the dormant TB germ to take charge.

The most powerful factor known to increase the risk of TB in a person is HIV infection. An HIV positive person is highly prone to developing TB. That is why whenever HIV infection spreads in a community, it brings in its wake numerous fresh TB cases. More so, if several members of that community already carry seeds of T.B. In India 40% adults are infected with T.B. germ.

TB is known to spread like wild fire in populations that have high rates of HIV prevalence. Nearly half of all HIV positive people would develop TB at some stage or the other.

Timebomb of HIV+TB is ticking away

TB, in turn, hastens their progression towards full blown AIDS.

One third of all AIDS related deaths worldwide could be attributed to TB.

Number 1 killer of all HIV positive people is actually TB.

HIV and TB have forged a deadly alliance, the devastating effects of which are currently being witnessed in Africa which is home to 2/3rd of the total 36 million HIV infected people worldwide.

Developing TB could sometimes be the first indication of the underlying HIV infection. In some of the worst affected nations of Subsaharan Africa, anybody who develops TB is straightaway presumed to be infected with HIV too, unless proved otherwise.

Without getting into the numbers game let us face the fact that HIV is on the rise in India. Some scientists believe that the situation in India today is comparable to what it was in the worst affected African nations about 15 years ago. Our trends of co-infection with 'HIV & TB' are ominously following the African graph.

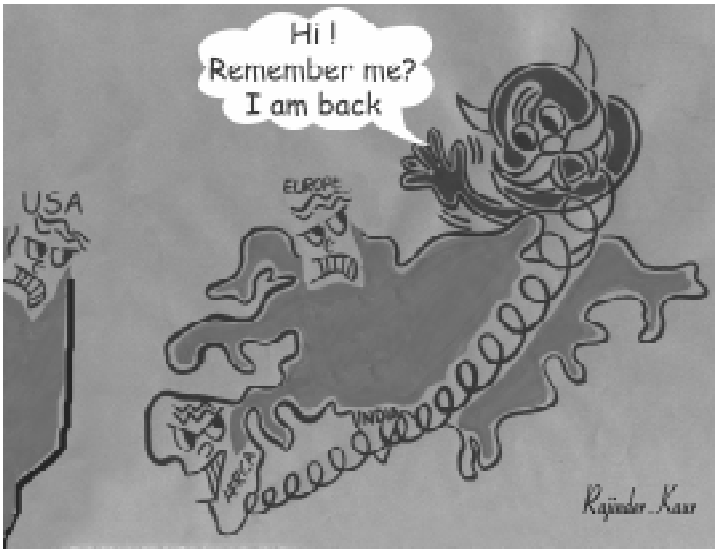
HIV/AIDS have added a new dimension to the already grim global TB scenario.

TB deaths in Europe, once quite rampant, began to decline after 1850's, surprisingly a century before any medicine for TB was discovered. It was due to their improved economy, nutrition, education, anti-spitting campaign and effective isolation of TB cases in sanatoria built in remote villages. And with the discovery of TB drugs from 1944 to 1966, TB literally started vanishing from the West. Scientists in the developed world were euphoric. And self-centred too. TB research worldover was dropped ignoring the third world which was still burning with this problem.

And then it happened!

HIV/AIDS emerged in the West in 1980's!

Easy air travel of the jet age, mass movement of the armies, refugees and animals & the phenomenon of globalization led to a thorough intermixing of human populations heralding a resurgence of TB in the West.



WHO woke up and declared in 1993 "TB is a global emergency". But from 1970 to 1993, an unprecedented neglect of R&D in the field of TB had already been committed.

"Milk, Doctor *Sahib*", the shrill voce of his wife broke my reverie.

I kept the medical file aside on the cot where I sat and took the hot cup of milk from her.

The million dollar question in my mind was that how this man had managed to get infected with HIV. As if reading my mind his wife explained, "He has never had any bad habits. He does not even smoke or drink. It is all due to dirty blood".

"Dirty blood?" I was confused.

"Since 1974, he has been suffering from an illness of intestines. Many times, he used to pass blood with his stools. Also, he met with a bad accident in 1995. As a result, on six different occasions he had to be given blood units. It was done in 4 well known hospitals of Delhi & Faridabad. Contaminated blood has ruined his life and our family", she said.

"A man made disaster", I mumbled.

"I am still wrestling……", he tried to smile, ".....with nature".

He lost the final bout on the midnight of 30.7.1998. The village people believed he had had a heart attack.

A FEW PAGES FROM THE HISTORY

Is it really a disease only of the poor ?

In the skeleton found in a mummy of the 21st dynasty of Egypt the typical deformity caused by tuberculosis of the backbone, Pott's disease, was established. Images of similar hunchbacks suggesting backbone TB have also been found on the walls of caves and among various engravings, statues and paintings left behind by ancient civilizations. From the skulls and bones recovered from different parts of the world, tuberculosis is evident in Neolithic man. The evidence of human affliction with this disease can be traced as far back as 8000 BC.

From the study of the recorded as well as unrecorded history of the catastrophe caused by this germ, a very basic fact comes to light. It does not discriminate among its likely victims. Tuberculosis can occur in any person, of any age or sex, of any caste, creed or colour, living anywhere on this earth, and in any organ of his body with a variety of symptoms. These awesome anys of TB have pursued mankind through ages.

Aristotle, the ancient Greek philosopher, expressed pity on the unfortunate consumptives (as TB patients were perceived at that time) and wondered that why anybody who came in contact with them suffered similarly which was so unlike as in other diseases.

Two of the most well known families of the Indian subcontinent that helped shape its destiny in the 20th century had to face the wrath of this silent germ.

Around her 21st birthday, Indira Gandhi, who later became the Prime Minister of India, suffered an attack of pleurisy. In those good old days of 1938 there was no medicine for TB. She later remained admitted in a sanatorium of the famous 'sun doctor' in French Swiss Alps, Switzerland. The heliotherapy that she had to reluctantly undergo included lots of fresh air, sunbath,

good food, rest and exercise. Fortunately she recovered.

But a couple of years earlier in another Swiss TB sanatorium she had already lost her mother Kamla Nehru, the wife of Pandit Jawaharlal Nehru, the first Prime Minister of India.

Unknown to the leaders of India and Britain, there was a seething sense of urgency in Jinnah's mind during the crucial final stages of the events which led to the creation of Pakistan. Mohammed Ali Jinnah, the tough negotiator for and the architect of Pakistan, was silently passing through the advanced stages of TB and lung cancer during those hectic days. Dr. Patel from Bombay who treated him was under oath not to reveal anything to anyone lest it changed the destiny of imminent Pakistan. After partition, Streptomycin, the first TB medicine which had just become available, was flown from Karachi with a microscope, a portable X-ray machine and a team of doctors to a hill resort in Pakistan where he lay dying. But all this failed to revive his lungs. Barely a year after the realisation of his cherished dream, he died.

Nelson Mandela, the black South African leader and the recipient of Nobel Prize for peace, fought successfully against his illness. But for his getting cured of TB the political destiny of South Africa might have been different.

It seems, the clever germ has meandered through not only the corridors of political power but also it has not shied away from taking a more aesthetic and literary path.

When the famous doctor turned poet, John Keats saw the crimson colour on his handkerchief, he wrote, "I know the colour of that blood. It's arterial blood.... That blood is my death warrant, I must die". Having lost his mother and younger brother to consumption (as tuberculosis was then known) he had an ominous premonition of his own future. With his medical knowledge he had no illusion as to what was happening to him. He died at the young age of 26 in Rome, Italy of tuberculosis, leaving behind one of the finest specimens of Romantic English poetry.

“This consumption is a disease particularly fond of people who write such good verses as you have done.....” consoled his friend and the great English poet, Percy Bysshe Shelley, the author of Queen Mab, Prometheus Unbound, Ode to West Wind and Adonais. He himself was a consumptive but was more fortunate than Keats for not having succumbed to the disease. But not for too long. He drowned during a storm at sea at the age of 30.

So many famous poets of the Romantic Era suffered from tuberculosis that this mysterious affliction came to be perceived as a sign of being genteel, sensitive and romantic. The ensuing agony and ecstatic prospect of confrontation with death was romanticised and was believed to make these authors more conscious. And more interesting. It was believed to heighten their powers of creativity in some inexplicable manner. As a result, the tubercular look became a model for aristocratic looks and a mark of distinction. It became glamorous to look thin and sickly, fashionable to be drained and pale.

It was this phenomenon which was reflected in the unfulfilled wish of the great poet, Lord Byron, a friend of Keats and Shelley. Looking into the mirror he exclaimed, ‘I look pale, ...I should like to die of a consumption.....’.

There seems to be no doubt that the slim female models on today’s fashion ramps ought to owe their success to the trend of romantic consumptive looks, set during that era.

Leigh Hunt, journalist and poet, who edited the radical weekly, The Examiner, and also a quarterly with Lord Byron, actively promoted the works of Keats and Shelley. Besides literary mannerisms that his protégé John Keats had adopted, he shared one more thing with him - consumption.

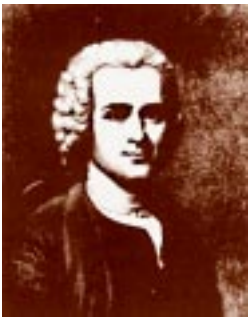
In those days, consumption was a convenient escape for the suffering poets and artists to spend the rest of their lives into a voyage of self-discovery while they moved from one hill resort to the next in search of pure air that could heal them. Invalidism became a pretext for retiring and giving up the worldly obligations to be able to live only for the sake of one’s art.

D.H. Lawrence roamed extensively in search of healthy climate. After World War I, to overcome the unhappiness caused by the German origins of his wife and his failing health, he travelled half the globe including Australia and New Mexico. Although today recognised as a major modernist novelist, he had to face a lot of controversy and needless legal action for obscenity in connection with his writings - Rainbow and Lady Chatterly's Lover (1928). He died of tuberculosis at Vence in France in 1930.

Similarly Robert Louis Stevenson of the fame of The Strange Case of Dr Jekyll and Mr Hyde and New Airbian Nights availed the opportunity provided by ill health to travel, which he loved so much. No wonder some of his best writings are stories of adventure like Treasure Island and essays of travel like An Inland Voyage and Travels with a Donkey in the Cevennes

The three Bronte sisters, all of them extremely talented writers, is a rare example in the history of English literature. Charlotte Bronte produced Jane Eyre, Emily Bronte wrote Wuthering Heights and Anne Bronte created the Tenant of Wildfell Hall. How much of their literary talents they inherited from their father Rev. Patrick Bronte may be debatable. But he is certainly credited to have been the likely source of infection which ultimately resulted in all his six children succumbing to consumption.

Similarly, the family of Ralph Waldo Emerson, the American anti-slavery campaigner and a great essayist, is also reported to have been wiped out with consumption.



Jean Jacques Rousseau, the most celebrated French philosopher, who authored the world famous Social Contract and a number of other writings which inspired the French Revolution of 1789, was himself no stranger to the suffering caused by this germ. His famous adage that men were born free but lived everywhere in chains, very much reflected his own life constrained by disease and turmoil.

Johann Wolfgang von Goethe, the most celebrated German poet, a formidable genius and a prolific writer, who left behind a literary treasure which includes Faust, Egmont and Götz was also not spared.

At the tender age of 20, Franz Kafka who wrote The Stoker, The Metamorphosis and The Judgement etc. started to feel "increasingly not altogether healthy". Many years later when clinical tuberculosis set in, he wrote that the "....illness which had been coaxed into revealing itself after (five years of) headache and sleeplessness" broke out - that "coughing up of blood" arrived as "almost a relief", ending for the time being, all "attempts at marriage" and also liberating him from his job at the insurance company. He died in a sanatorium in Austria in 1924.

Fyodor Mikhailovich Dostoevsky, an extraordinary Russian novelist of the fame of Crime and Punishment, The Idiot and The Brothers Karamazov, lived a turbulent life - a stint in the army, a death sentence that was finally commuted to imprisonment in Siberia, the closure of his outspoken magazine, The Times, his perpetual indebtedness and last but not the least his encounter with tuberculosis.

Another celebrated Russian doctor turned writer Pavlovich Anton Chekhov who wrote brilliant plays like The Cherry Orchard, Uncle Vanya and The Three Sisters that were both tragic and humorous clearly reflecting the social conditions of his time, too had his share of similar tragic circumstances on the health front.

Katherine Mansfield from New Zealand bore resemblance to Chekhov not only in the form and style of story writing but also in health condition.

The well-known English poet, Alexander Pope, who wrote The Rape of the Lock, was afflicted with sickness and a deformity which made him very moody and given to fits of temper. Often he exhibited these traits in print with tales and remarks about people around him. Thus this 4 feet 6 inches tall poet with deformed curvature of the spine, a condition common to backbone tuberculosis, left behind some of the most polished satire.

The English writer, lexicographer and wit, Samuel Johnson, who took eight painstaking years to complete his Dictionary of the English Language which shot him to instant fame, had an early encounter with this disease. Born to a bookseller, it was among books that he spent his childhood marred by ill health caused by tubercular infection from his wetnurse. It affected his eyesight and hearing. His face was scarred from tuberculosis of lymph glands of the neck area called Scrofula or King's Evil, a name derived from the myth prevalent in England during the middle ages that touching king's feet could cure it.

Famed author of Animal Farm and 1984, George Orwell too suffered.

Not only the writers and poets but many famous artists too had to contend with this malady.

Frederic Chopin, the famous Polish-born pianist who composed 24 studies, 24 preludes, nocturnes and ballades, contracted tuberculosis. His stormy love affair with the French writer Georges Sand made him neglect his work and also health. He explored the islands of Western Mediterranean hoping to heal himself. Finally his lungs collapsed and he died at 39.

The greatest violinist of all times from Italy, Niccolo Paganini could almost make his instrument sing. But the rhythm of his own life was disturbed by T.B.

So much had TB come to be associated with creativity that at the end of Romantic Era, some critics lamented that gradual disappearance of TB was responsible for the decline of literature and arts.

The great mathematician from India, Sriniwas Ramanujan, during his brief life span of 33 years, failed to calculate the volume of his own misery caused by tuberculosis and poverty.

Hermann Brehmer, a Botany student from Germany, suffered tuberculosis. On the instructions of his physician he travelled to the Himalayas. He returned home, cured. Then he studied medicine and published his thesis -Tuberculosis is a curable disease. His sanatorium in Gorbersdorf in the mountains of Silesia was a pioneer attempt and became a blue print for the sanatorium movement to follow.

A TB sanatorium

In USA, Edward Livingstone Trudeau broke down with tuberculosis. His recovery at a mountain resort brought about the establishment of the first sanatorium in New York.

At the dawn of the 19th century, two doctor friends were burning the midnight oil working ceaselessly to help mankind in understanding the disease. Gaspard Bayle painstakingly dissected the bodies of people dying of consumption & described many of the pathological changes. While performing autopsy studies he himself contracted the disease and died of it. The other friend, Rene Theodore Laennec, a genius Frenchman invented stethoscope, a magic instrument that tells so much what goes on inside the chest just by listening to the sounds within. It was to shape the history of not only the diseases of the lungs but also of the heart. But with this fame and glory also came his share of sorrow and pain. His mother, two uncles and younger brother died of tuberculosis. Finally he too succumbed to it. Thus was the great invention of stethoscope avenged by the germ.

REFERENCES

1. Tuberculosis by S.K. Sharma and A. Mohan (Chapter 2 : History) Published by Jaypee Brothers Medical Publishers (P) Ltd., New Delhi.

2. ‘History of Tuberculosis’ by K.N.Rao

3. “Illness as Metaphor” (Chapter 4) by SUSAN SONTAG Published by Penguin.

4. “INDIRA The Life of Indira Nehru Gandhi” by Katherine Frank Published by Harper Collins publishers.

5. “Jinnah of Pakistan” by Stanley Wolpert Published in 1984 by Oxford University Press.

6. 1000 Great Lives by Plantagenet Somerset Fry Published by Hamlyn Publishing.

7. Prentice Hall Guide to English Literature edited by Mario Wynne - Davies

8. “Keats’s Life and Poetic Works.”

9. Franz Kafka : Picture of a Life by KLAUS WAGENBACH published by Pantheon Books New York.