



Tuberculosis

A social disease

BUKO
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Another Pharma-Brief Special on Tuberculosis was published in 2007. It highlighted not only the worldwide spread of TB, global strategies and risk factors like the double-infection with TB and HIV. It also presented important facts about transmission, diagnosis, medication, resistant TB-forms and the lack of drug research.

Imprint

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A plague as old as mankind itself

A historical outline of tuberculosis

The spinal column is bent double; the head is leaning forwards so that it almost touches the knees. The skeleton carries traces of bone tuberculosis. It has destroyed the spine so that the spinal column cannot support itself. In his lifetime it gave the person with the disease the appearance of a hunchback and caused pain every time he moved. The patient lived around 6000 years ago. The remains of prehistoric people show that tuberculosis like leprosy is one of the oldest infectious diseases.

Mycobacterium tuberculosis, the pathogen which causes tuberculosis is probably as old as mankind itself. Pulmonary tuberculosis could even be found in 5000 year old Egyptian mummies. Researchers determined that there was a comparatively low life expectation in Thebes, the capital of Ancient Egypt. The findings indicated that there was a widespread incidence of tuberculosis with half the population estimated to be carrying the tuberculosis bacterium.¹



The Egyptian sculpture "The Writer" from the Louvre. Mummies from ancient Egypt document that even then a significant portion of the population suffered from tuberculosis.

Photo: CC Guillaume Blanchard

Hippocrates of Cos, the most famous doctor of antiquity was the first person to provide an exact medical description

of both the clinical picture and the symptoms displayed by the patients: 'The fever does not go away. It is low during the day, but at night it flares up again causing copious sweating, the patients have a tickling cough but the amount of sputum brought up is negligible. The eyes lie deep in their sockets, the cheeks become red... the patients lose their appetite... those who spit frothy blood cough it up out of their lungs.'²

Tuberculosis and Europe

Around 200 years ago tuberculosis raged through the whole of Europe. A quarter of all deaths at the beginning of the 19th century were ascribed to consumption. In Southern

Europe the risk of infection had been recognised for a long time previously and rigorous measures were introduced on a limited scale; as early as 1700 there were cities which legislated against the spread of consumption. TB was a notifiable disease from 1751 in Spain, and from 1782 in Sicily and Naples. Doctors failing to report the disease were threatened with a prison sentence, for a repeat offence the threat was to be sent to the galleys. Patients were put into hospitals or banished. Visits were forbidden, personal effects and furniture were generally incinerated. In her book 'A Winter on Mallorca' the writer, George Sand reported very graphically the defensive stance people adopted towards the composer, Chopin during their stay

on the island.³ The population was afraid of becoming infected and compelled the guests to leave their holiday home.

Tuberculosis today

Western Europeans brought the disease to Central Africa, to South and South East Asia and to America causing huge epidemics. While the rate of occurrence of tuberculosis declined dramatically in the western industrialized

countries during the twentieth century, the rate remained unchanged at a high level in poor countries. In Western Europe today tuberculosis is perceived as being mainly a problem for fringe groups e.g. immigrants. The risk of tuberculosis for them is up to 50 times higher than that of the resident population. Up to 70% of all TB cases affect citizens born abroad. This increased risk lasts for up to 20 years after immigration.⁴

The Social History of Tuberculosis

Consumption as a social disease in the late 19th and early 20th centuries

In the 17th and 18th centuries consumption was romanticised as a romantic disease, an illness suffered by bohemians and by self-sacrificing lovers. Indeed this perception did not change until after the widespread occurrence of what became known as the White Plague in the 19th century. Tuberculosis then became the disease of working families, the disease of the proletariat.

The perception of tuberculosis and the depiction of people suffering from the disease have varied through the centuries. The formation of ideas about the disease and its perception arise against a background of the social system, and in the context of society at the time. What was important in the perception of tuberculosis was not (and is not) merely the statistics about the frequency of occurrence of the disease and the resulting mortality, but also it is the social discourse about it. The picture which a society forms about a disease in turn moulds the perceptions of people who are themselves suffering from the disease. They internalize and replicate this picture. In order to understand the nature of tuberculosis and in order to be able to fight it effectively, it is important then, as it is now, to observe the disease in its social dimension.

Here there are some astonishing parallels which can be drawn; the situation of sick people in Germany around 100 years ago in some ways resembles the life of patients in poor countries today.



Heinrich Zille: Famine

The Social Causes of Tuberculosis

For decades pulmonary tuberculosis was the most frequent single fatal disease. That meant that at the end of the 19th century and beginning of the 20th century no other single disease caused so many people to die. Because it was mainly members of the lower classes who suffered from TB it was considered at the time to be a disease of the working classes. In contrast to cholera or cancer, tuberculosis clearly reflected the social inequality; the lower wage earners died around four times more frequently than rich people.⁵

Potatoes, herrings and horse meat

The average income of a mine worker in the Ruhr was, for example, 1382 marks per year in 1910. After deductions for rent, water, electricity and tax the family had 22.83 marks per week to buy clothing, shoes, food and anything else they required. In 1911 and 1912 the social scientist, Li Fischer-Eckert investigated 495 households in Hamborn and came to the conclusion that many people were undernourished because they lacked the money to buy sufficient supplies of food. If a family could afford to eat meat at all then it was only horse meat. A family of 7 people could buy horse meat daily for 30 pfennigs. Other cheap staple foodstuffs were potatoes and herrings.⁶

The annual report giving medical statistics for the city of Stuttgart reveals how poor the general standard of nutrition was; only 20% of the children investigated were well-nourished. The largest part of the family income was used to guarantee survival. Putting something aside for hard times could just not be contemplated.⁷

War and famine

The lack of nutrition during the First World War was particularly dramatic: 'The (German) Imperial Corn Exchange was established as early as spring 1915... and the bread rationing card introduced. Rationing of the supply of potatoes followed soon afterwards... As early as winter 1916/17 there was a shortage of meat which led to a decrease to around one seventh

of the amount supplied in peace time. Milk had already become rationed by October 1916 after the supply for Berlin had dropped to 30% of the amount required. There then followed the rationing of eggs, cheese, sugar, fish; shortly afterwards all foodstuffs had gradually become rationed, so that one could justifiably speak of a rationed famine... If the conditions for obtaining nutriment were tolerable until spring 1916, then they became ominous after the winter of 1916/17 following a poor harvest of both grain and potatoes.'⁸ The poor nutritional situation endangered not only healthy people,



**Käthe Kollwitz:
Germany's children are starving!**

but also sick people for whom a diet rich in fats and protein was particularly important. There was the additional strain of work placed on the women and young people who now had to ensure the family income and in addition had to queue for hours to get food. This sapped them



Heinrich Zille: Backyard in Berlin

In 1870 Berlin still had no public sewage system. The toilets were in the backyards of the tenement houses. The pits underneath them had to be cleaned out regularly. Other waste water flowed into open gutters which were only partially covered by planks. An evil smell, risk of epidemics and a plague of rats were ever present.

of their physical strength. As a result of the war the mortality rate from tuberculosis for 1918 rose again to the level last reached in 1896.

Miserable living conditions

In the Ruhr working class families lived mainly in factory-owned accommodation which was not only cheaper but also better equipped than private accommodation. However, if a worker was discharged, dismissed or took part in a strike the entire family had to move out. Private accommodation was very small in comparison. Families with six or more children had frequently to share 2 to 3 rooms. In 20% of all households there were boarders who were given accommodation and meals by the family and whose rent contributed to the upkeep of the family.⁶

'The furnishing of the apartment is limited to only the most necessary objects and all too often one notices that it is only the paint that still holds them together. The beds are by and large no longer made; bundles of straw are placed in dirty grey sacks on the mattresses.' This was how Fischer-Eckert described the situation in which many workers lived. Many families lived in completely run-down living conditions: 'In one family ... the mother and

her four children were sitting on the ground as they all ate boiled potatoes which had just been cooked in a black cooking pot; this was their midday meal without anything to accompany the potatoes.'⁶



Heinrich Zille: Get away from the flowers and play with the bins!



Heinrich Zille: "Due to general improvements in conditions in Germany, writes the landlord, he can demand that we now pay peace gold rent for the cellar apartment."

Apartments kill like an axe

The situation of workers in Berlin was no better: surveys recording the accommodation available from 1900 to 1905 revealed such miserable conditions that a social democratic member of the German Parliament surmised that one could just as easily kill someone with an apartment as with an axe.⁹ Many families lived in the most cramped conditions in damp basement dwellings which had previously served as workshops. These cellar dwellings lay one to two meters below street level. More significant than the state of the building were the occupants of the dwelling: a medical text from 1911 noted that for Berlin 2143 people died from TB. Prior to their deaths 688 shared a room with three people, 580 shared a room with four people, 425 with five people, 229 with six, 136 with seven, 45 with eight, 25 with nine and 15 with more than eleven people.¹⁰

In fact according to building regulations from 1910 kitchens were no longer to be used as places for sleeping in, but requirements such as these were not enforced. Separation of sick people from healthy people was carried out equally rarely. The poor living conditions for people suffering from tuberculosis, and for healthy people alike, were a subject which



Heinrich Zille: "New tenant"

"You even managed to rent the room with no windows?" "Yeah, but to a blind piano player."

Children often had to huddle together on the floor to make room for paying tenants.

remained continually on the political agenda. A municipal doctor's report for Ulm in 1924 got right to the heart of the problem: 'Today the situation in the apartments of many people suffering from tuberculosis is such that moving into another room cannot even be considered; indeed none too rarely an urgently needed

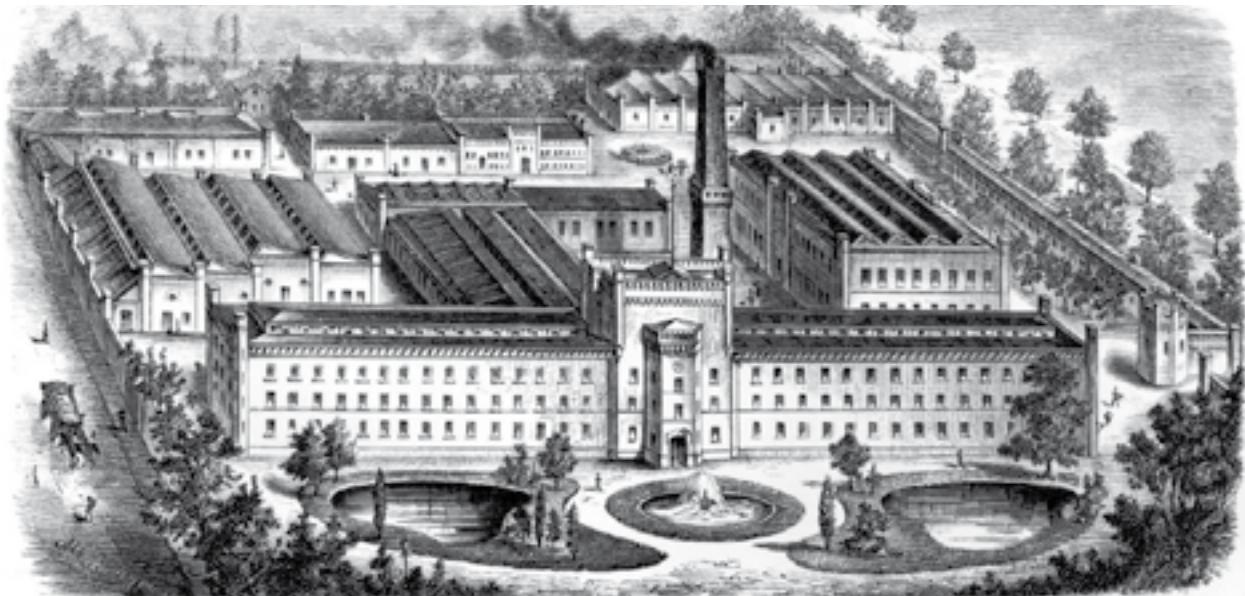
extra bed, which we were ready to provide for them, could not be set up because of lack of space.'¹¹ Seven years later this situation had scarcely changed: of 148 people sick people suffering from active tuberculosis, two did not have their own bed and 98 did not have their own bedroom.

Work which makes people ill

Very early on it was realized that there was a connection between certain jobs and TB diseases. Physical overexertion, the risk of accidents, acute or chronic poisoning, remaining in enclosed spaces, stooped posture, high temperature variations and excessive dust were all named as risk factors. A concentration of cases of tuberculosis was clearly shown in certain classes of occupation: While bank officials, teachers and doctors had a relatively low risk of becoming ill with TB, workers involved in jobs with a high exposure to dust had a risk of dying from TB which was up to eight times higher. Examples of workers employed in these jobs were quarrymen, mine workers and metal polishers.¹²

Inadequate protection of the workers increased the risk of tuberculosis. With industrializa-

tion the daily hours of work increased to 14 to 16 hours in around 1850; in 1890 the working day was about 11 hours. During the November Revolution of 1918 the Council of People's Deputies did indeed implement an 8 hour day, but as early as the economic crisis of 1923 the legislation had become undermined and a de facto 10 hour day was again adopted. The increased strength of the trade unions from 1927 led to renewed modifications to the exemptions which had undermined the 8 hour day. However at the start of the Second World War all occupational health and safety regulations were suspended. A decree of 31 August 1944 prescribed a 60 hour week for men and a 58 hour week for women and young people. A debilitated and overworked population caused the figures for TB to dramatically shoot upwards at the start of the Second World War.



From the outside the early factory buildings looked very impressive. The working conditions inside, however, were usually miserable. In the Ravensberg spinning mills opened in 1857 in Bielefeld, the workers often had to work standing in water.

Picture: Municipal Archive of Bielefeld, Order no. 400,3/photo collection

Social Legislation and Tuberculosis

In 1881 Bismarck – as a reaction to social unrest – announced a comprehensive social security system in a keynote speech in the Reichstag. This was to protect workers against accidents, disease, age and the inability to work. As a result social tensions, which had become more intense because of the repressive Anti-Socialist Laws, were intended to be eased.¹³

We have had Our conviction expressed that the healing of social damages will not be achieved solely by the repression of social-democratic upheavals, but equally by the positive promotion of the welfare of workers.

Message of Kaiser Wilhelm I on the opening of the German Imperial Parliament on the 17th of November 1881

In particular the Health Insurance Act passed shortly afterwards, and the Old Age and Disability Insurance Act of 1889 were of great significance in the fight against tuberculosis. Health insurance, however, only provided cover against short term loss of earnings. People suffering from tuberculosis who were usually incapable of work for many years obtained support from the disability insurance. TB patients accordingly placed a great strain on the pension funds. 30 to 50% of all pensions for 20 to 40 year olds concerned people suffering from tuberculosis. Up until 1911 health insurance benefits were increasingly upgraded. By means of curative treatments the granting of a pension was intended to be postponed for as long as possible.¹⁴

TB – a disease of the working classes

The cramped and, above all, unhealthy living conditions, insufficient nutrition and poor working conditions encouraged the spread of tuberculosis. According to a handbook on social hygiene written in 1912: "And because these conditions are mostly lacking in the classes of society who rely on manual work



**Social reforms to appease the masses.
Bismarck monument in Bielefeld.**

Photo: Barbara Frey

that is the reason why tuberculosis has spread to such a shocking extent, which justifies its designation as 'the disease of the working classes'."¹⁵ Every political and economic crisis, every strike and every lock-out represented a reduction in income and an associated reduction in resistance to tuberculosis, leading to an increase in tuberculous diseases.

The workers' rallying cry

Tuberculosis served as a rallying cry and was used again and again by social reformers, social democrats and trade unions for propaganda purposes. Kurt Löwenstein, chairman of the Movement for Children's Friendship wrote: 'The middle classes rob us of our children. Every

hungry, freezing child, every child afflicted with tuberculosis, and every exploited child is a victim of a crime committed by the bourgeoisie on the working class.'



**The 8-hour day protects against tuberculosis.
Combat slogan of the French trade union CGT
on the 1st of May 1906.**

*Picture from:
La Voix du peuple dated 1st May 1906*

The blame for the outbreak and spread of TB was placed on capitalism with the disastrous working and living conditions it imposed on working class families. The French trade union, CGT purposefully employed the spectre of tuberculosis as a disease of the working classes in its fight for the 8 hour day and used it in its political agitation on 1st of May.¹⁵ In their weekly magazine 'La Voix du Peuple' a cartoon appeared consisting of two pictures; on the left hand side there was an emaciated man with the caption '10 hours' and an explanation that long working hours contributed to the spread of TB; on the right there was a man bursting with health and energy with the caption '8 hours'.



Heinrich Zille: "If I want, I can spit blood in the snow!" (1904)

TB in Art

Socially critical artists such as Käthe Kollwitz and Heinrich Zille also showed tuberculosis as the result of emaciation and hunger in working class families. Zille's work with its derisive social criticism of the Wilhelmenian era did not always meet with approval. Behind his drawings which raged with anger there lay tragedy and deep despair.



Käthe Kollwitz: Weavers' revolt – deprivation

The Fight against Tuberculosis

Even long after Robert Koch had discovered the tuberculosis bacterium it was only hesitantly that the German states introduced legislative measures for the prevention of TB. Not until 1923 were TB diseases made notifiable in Prussia; despite this most cases of tuberculosis were not notified.¹⁶ On the other hand bacteria were kept at bay by means of spittoons and bans on spitting.¹⁷ 'This bad habit is still very widespread and is just as uncouth as it is dangerous to public health and safety,' according to pamphlets on poverty in 1910.¹⁸ Expectoration by sick people was considered to be the most significant method of transmission. People believed that the sputum would dry in the air and be inhaled by healthy people as a dust.¹⁹

At the end of the 19th century the Imperial Health Department began to distribute special pamphlets on tuberculosis. The state governments were supposed to be responsible for distributing them and to enlist the help of the clergy, doctors, teachers and employers in disseminating them. In the first pamphlet published in 1900, it said that women with tuberculosis should not breast feed or look after children.²⁰ This drastic demand must have caused great concern to many patients. In addition to the burden presented TB was now added the worry that their children or their pitiful auxiliary earnings could be taken away from them.



For the protection of public health, please refrain from spitting in the carriage

From Biberach in Württemberg a public health officer reported: 'The family doctor reported to me that as a result of the pamphlet one patient experienced a haemorrhage and another a severe depression... One of the women was therefore very agitated because she feared that her foster child would now be taken away.'²¹



Cleanliness and a bed of your own

The Central Committee for the Construction of Sanatoriums for People with Pulmonary Diseases was founded in 1895 (from 1905 the German Central Committee for Fighting Tuberculosis) was intended to not only support building sanatoriums for people on low incomes, but also to perform

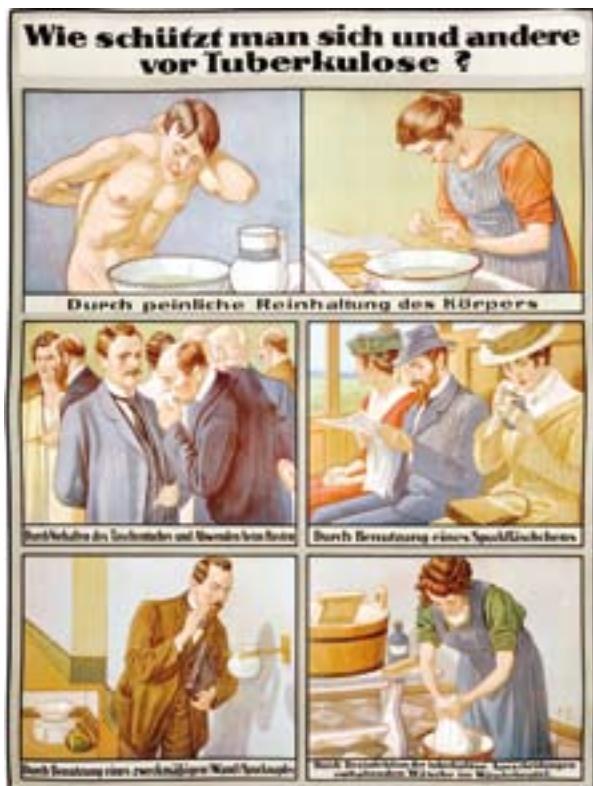
The "Blue Heinrich" Spit bottle for TB sufferers

Photo: German Hygiene Museum, Dresden

additional educational work. They published pamphlets, provided slide shows, posters and charts to help educate people about tuberculosis. The educational material was made available without charge to societies active in the fight against TB.²² The requirements for cleanliness and separate bedrooms were very much to the fore, which was however impossible in most working class families. The sick people should therefore at least sleep in an own bed separated by a screen.

Notices prohibiting spitting were placed in all public buildings, in schools, train stations, restaurants, factories, museums, even in churches.

Photo: German Tuberculosis Archive



"How do you protect yourself and others from tuberculosis?" Poster from the 1930s propagated by the German Hygiene Museum. The posters were to be placed in highly frequented places such as schools, factories and hospitals.

German Hygiene Museum

Around 1900 social welfare centres were established in order to assist in the early recognition of the disease. Members of staff were expected to detect cases of TB and provide supplies of invigorating foods, sputum bottles and other utensils necessary for sick people, as well as providing curative treatment and accommodation. It was mainly local charitable organizations which administered these services. They visited people with pulmonary diseases and strived to provide relief in some concrete form or other. In old reports it said, for example: 'Ochsenhausen: Kreszentia E. requests provision of a deck chair, Adolf R. requests a pocket spittoon. Steinhausen: Johannes H. requests a subsidy to improve the standard of his food. Hürbel: Magdalene Sch. likewise requests a subsidy to improve the standard of her food. Ellmasweiler: Karl W. lives

in the poor house in cramped conditions together with his family. This same person should be billeted out.'²³

In spite of the aid offered the working class families frequently tended to refuse this intrusion in their private lives.

People's sanatoriums and their therapeutic value

Since the end of the 1880s people's sanatoriums were established to admit poorer people with pulmonary diseases. The sanatoriums were intended to strengthen the patients both physically and mentally, and to restore their physical powers of resistance. Most of all they were to provide education about hygiene and preventative measures to be taken against epidemics.



For a long time, rest cures were the core of tuberculosis therapy in Germany.

Source: German. Tuberculosis Archive

There was also however more and more intense criticism of the sanatoriums for using public money for cures mainly from considerations of bacteriology, social hygiene and surgery. The failure of tuberculins for the curative treatment of tuberculosis had had an initial muting effect on this criticism. In the end the sanatoriums were again considered to be the only possible treatment. Koch himself attested to the value of sanatoriums, but later said that they were largely useless as therapeutic institutions. Other leading researchers into TB of the time expressed



The sanatorium patients were picked up from the train station with horse drawn carriages.

Historical postcard

similar opinions. George Cornet said: 'Fighting against TB using sanatoriums is no longer worthwhile; it is as if you wanted to treat hunger using caviar and oysters instead of bread and fat.'²⁴

In fact the success rate of these curative treatments was in medical terms rather modest. They did however have a definite sociopolitical significance; the insured person obtained as a result a share in services which were otherwise available only to wealthy people.

For 'fattening-up' in the sanatoriums

In the sanatoriums great value was placed on abundant supplies of nourishment; this earned treatment in a sanatorium to be derisively known as a 'fattening-up' cure. There was a never-ending discussion about the establishment of the correct diet for sick people. In the long run working people did not want to become accustomed to too much luxury. 'It has never ever occurred to me that every worker should receive champagne, oysters and partridges; he is... more satisfied if he gets wheat-beer, and beef with potatoes.'²⁵ Even the simple meals offered in the people's sanatoriums could not be afforded by working class families at home.

Furthermore the vast majority of people suffering from tuberculosis never visited a sanatorium. A large proportion of the people suffering from mild tuberculosis were neither members of the State Insurance Organization (Landesversicherungsanstalt (LVA)) or of the health insurance funds. Any possible curative treatment for the uninsured or those without means was doomed to failure largely due to the costs involved. Husbands carried on working for as long as possible in order to feed the family; it was difficult to receive a disability pension which was scarcely sufficient for a family to survive on. Sylver Rombach established that for Württemberg in 1909, the year with the greatest number of allowances, only around 10% of the people suffering from TB obtained a disability pension.

To ill to receive any treatment

Most sick people lived and died at home, mainly because they were too ill to be admitted to a sanatorium. Here only patients with prospects of being cured were treated. Moreover hospitals by and large avoided admitting people with severe TB because this required isolation rooms, nursing staff and caused costs to become higher.

It was not rare for patients to refuse curative treatment because they were afraid of discrimination, impoverishment and the long separation from members of their families. In addition mothers worried that their children would not be sufficiently well cared for during their absence.

Women and TB

Women with TB suffered particularly because of the disease for a number of reasons. Female workers in particular were advised to become sterilized as early as the period of the Second Reich if they became seriously ill with tuberculosis. Doctors frequently recommended termination of a pregnancy because of possible transmission of TB from the mother to the child. There was also the risk that latent TB could develop into active TB as a result of the pregnancy. For a long period of time pregnant women with tuberculosis were not admitted into sanatoriums because it was believed that there was no prospect of a successful cure. If a pregnancy was confirmed during a course of a cure then the woman was immediately sent home. The idea that pregnant patients required special care only gradually became accepted around 1914.²⁶



Many of the sanatoria were in idyllic locations. But the isolation was a problem for many. Dr. Walter's Sanatorium in Nordrach

Historical postcard

Isolated and lonely

The sanatoriums belonging to the LVA and the societies for People's Sanatoriums for the most part lay far away in the country. The isolation was not infrequently reinforced by fences and gates.

Joachim Ringelnatz, himself suffering from tuberculosis and who was a patient for four months in a Berlin People's Sanatorium wrote: 'Because the protective fence is still not complete M. and I visited the 'Wackelburg', (a nearby pub) for the last time. I had the opportunity to see the institution's official omnibus, an old fashioned carriage pulled by a horse. Local people called the carriage 'The Bug'... I think it looks like a carriage for carrying prisoners, but then again so much here reminds you of a prison.'²⁷

Patients in the sanatoriums suffered from the separation from their families. Many had never previously left the place where they lived and did not feel at ease in strange surroundings where they were domineered over by doctors and nurses. Condrau therefore talks about the patients' 'feelings of loneliness and alienation'.²⁸ Fears about their own health were mixed with depressive moods and feelings of guilt about having forsaken their families, or about having exposed them to risks to their health. 'One should avoid getting agitated in a sanatorium, but what could cause you to become more agitated than worrying about your loved ones back home? Do I have to remind myself that my wife and five children should feed themselves on 5.25 (marks) while I sit here everyday with full plates in front of me,'²⁹ wrote one patient.



Joachim Ringelnatz died on November 1934 of tuberculosis



on the 17th of
ulosis

The patients were surrounded by nursing personnel in the sanatoriums; death and disease were continually present. Ringelnatz wrote about it in his diary: 'Last night was very disturbed. The junker (or squire) kept on moaning and was crying for his 'Mummy'. Luba was crying all night long in pain and Sister E. assured her that she could not help because she was on her own.'³⁰

A rigid daily routine

The whole daily routine was subject to strict rules. Ringelnatz, who in addition suffered from laryngitis and was being treated for this, observed: 'In general it was like this during the day: eat – sleep – larynx – sleep – visits – sleep. Always the same sleep after everything. This sleeping sickness is getting worse.'³¹ Despite rest, recuperation and regular meals there was no improvement in Ringelnatz's condition. 'I cough too much. I am just so weak that I can scarcely shake the

mercury back down in the thermometer. So that is the result of 3½ months' stay here.'³² He wrote this on 10.9.1934 a good two months before his death. For others who had left the sanatoriums with their health in a stable condition the symptoms of the disease often returned soon enough. 'If you go back to the original causes of the disease i.e. into the dust of the factory, then sooner or later the old effects return... and all too quickly it had developed to the stage that I had to revisit that place where they destroy the bacteria.'³³

Colonies for TB-patients

As early as the Second Reich the idea germinated of settling people who could not be cured, and who had been released from curative treatment in a sanatorium, into what became known as tuberculosis colonies. These were set up either within the German Reich or else established abroad – perhaps in German colonies like German South West Africa. Proponents of this concept could develop their ideas further during the National Socialist or Nazi period. From this project for colonies to be settled by people with tuberculosis, the idea of the working sanatorium now arose.³⁴

The National Socialist Period and TB

From 'a healthy German population' to complete registration

During the second half of the 19th century, an understanding of disease and health developed that was typified by thoughts about performance and the 'German National Community' (Volksgemeinschaft). This relationship between productivity and health became ennobled as a maxim under National Socialism. Every individual had a duty to do everything to remain healthy. For people with tuberculosis that none too meant threats and repression. Sick people who had an 'incorrect' attitude to their illness were considered to be 'dangerous to the community' or 'recalcitrant'. As a result they therefore belonged to that large group of 'antisocial people' which included the work-shy,

tramps, habitual criminals, drinkers and drug addicts.³⁵ Andreas Schmitt speaks of a totalitarian redefinition of tuberculous disease.³⁶

Using police violence to effect a cure

In the years before the National Socialist period there were hardly any attempts to separate people with tuberculosis from others against their will. That changed in 1933. Compulsory measures were then enforced using police violence. These measures were the subject of intense discussion and were introduced into the statute book in stages.

The measures included, amongst other things, the withdrawal of public support for people suffering from TB who refused to take a cure in a sanatorium. Even completely normal TB sufferers who, lived orderly lives could suddenly be stigmatized as an 'antisocial sick person', if they refused to undertake a cure.



The National Socialists raised health to the status of a fundamental dictum. Propaganda poster of the NS People's Welfare

The first serious nationwide change concerned the welfare centres. These had until then remained mainly in the hands of insurance companies and welfare organizations. Their role was now transferred by law to the health authorities and in this way nationalisation of the health system was achieved.³⁷ The welfare centres thus became part of the National Socialist ideology: 'Our current welfare system may therefore no longer accept every person with tuberculosis and his dependents; it must separate those who are worth keeping from those who are worthless or even harmful.'³⁸

SS X-ray Campaign

The development of photofluorography in 1936 made large scale National Socialist x-ray screening possible. Stuttgart and Württemberg were strongholds of the X-ray survey. From 1940 People's X-ray Surveys were carried out by the SS X-ray Campaign with support from the National Socialist Welfare Organisation and the NS Women's League. It is reported that in 1941 alone X-rays were taken of 3 million people.³⁹

Complete registration

On 1.12.1938 the 'Regulations to Combat Transmittable Diseases' were issued nationwide. Amongst other things the regulations stipulated that there was a duty to notify the health authorities within 24 hours of every person with an infectious disease. The health authorities were to subsequently inform the local police. Furthermore people with tuberculosis were banned from employment in certain professions and their houses and apartments were to be labelled.⁴⁰

'Antisocial sufferers from tuberculosis' as defined by national socialist ideology were forced to enter asylums where they received inadequate medical and material care; they were already considered to be 'worthless' and their care should require the minimum possible cost. 'Malicious sick people' were compelled to complete work therapy e.g. in the Thuringian State Mental Hospital in Stadtroda. Confinement there was not for isolated cases but was a well-established practice. The institution resembled a prison: the windows were fitted with bars, the doors were locked and the garden surrounded by a fence. Even the intake of food that the sick people received was deliberately restricted: 'The inmates of this institution received the same kind of food as the mentally ill patients in the institution. Apart from the usual rest cure no particular curative treatment was in general use there; nothing at all was done which would have a decisive effect on the fateful course of their pulmonary diseases; there was nothing which could extend their lives which were of no

apparent use to the German National Community (Volksgemeinschaft).'⁴¹

Ban on marriage for TB patients

Tuberculosis sufferers were also labelled as carriers of 'inferior genes' and had to be excluded from the reproductive process as far as possible. It was necessary: 'To evoke the old instinctive aversion to marrying into families with tuberculosis and to warn



All sick people were regarded as "damaging to the people's community". Nazi propaganda poster

against entry into marriage with someone suffering from tuberculosis, or someone from a tubercular family who had previously had tuberculosis.'³⁸

Tuberculosis was however not in itself considered to be inheritable. An increased disposition towards tuberculosis within certain families was however deemed to have been proven. The concept of 'tubercular tribes' came into being, and as a result tuberculosis was opened up to investigation within the field of

eugenics.⁴² The murder of people with tuberculosis on a massive scale in concentration camps has been documented; it also appears to have definitely taken place within some institutions for tuberculosis.⁴³

TB as grounds for divorce

The Marital Health Law of 18.10.1935 forbade the marriage of people with infectious tuberculosis. It specified that a marriage was to be forbidden: 'If either of the engaged parties suffers from a disease associated with a risk of infection, which causes concerns about considerable damage to the health of the other party, or the health of their offspring.'⁴⁴ The health authorities determined whether a marriage was suitable or not. The health authorities in Herford-Land routinely asked the tuberculosis welfare centres whether people reported to them by the registry office were known to them.⁴⁵ A severe active case of TB entitled the healthy partner in a marriage to demand a divorce. Similarly family allowance was only granted when the applicant made a statutory declaration that neither tuberculosis nor any other inheritable disease had occurred in his family.⁴⁶

Accomplices

Doctors were not only responsible for the predominant scientific perception of TB; they also made a decisive contribution in moulding social perceptions of the disease.

That shows an article in a medical journal from 1936 concerning the ban on marriages for people suffering from tuberculosis: 'We must count as suffering from infectious forms of tuberculosis all those who, in the absence of a proven confirmation of the bacillus according to clinically and radiologically determined findings, still elicit the fear that the bacilli could spread at any time; this could possibly result in considerable damage to the health of the offspring.'⁴⁷ According to this it was not just the verifiably infectious sick people who were dangerous – in principle each and every person

with tuberculosis was suspect from considerations about the health of the offspring.

1944: the TB rate explodes

At the beginning of the war no consideration was taken of either the people suffering from tuberculosis, or the health of the workers. If previously an attempt had been made to forcibly remove sick people from the work place to avoid infection, then now everyone

who could still work was pressed back into employment. The tuberculosis welfare centres were instructed to distribute additional food-stuffs for those TB patients according to their capacity for work.⁴⁸

The numbers of people with tuberculosis exploded: in 1944 there were 31 deaths per 10,000 living people registered – almost four times as many as before the Second World War.⁴⁹

TB today: the Scourge of the Poor

Every 20 seconds someone dies from tuberculosis.⁵⁰ Just as in days gone by it is mainly the poor who are affected. Many patients live in the slums in the cities of Africa or Asia. Many are also carriers of the HIV virus. In addition to worries about their health they are tormented by worries about their own families and quite frequently worried about discrimination and the fear of being ostracized.

In 2007 the World Health Organization (WHO) gave the number of people throughout the world who were suffering from tuberculosis as 9.2 million. 1.7 million people died from TB. While the number of people with the disease has decreased globally since 2003, the frequency of the disease in Africa and Europe has increased.



Fred Hajuba takes his medication.

Photo: DAHW

This regression on both of these continents will surely lead to an inability to meet Development Target 6 of the Millennium Development Goals (MDG) of the United Nations; namely to halve both the death rate from TB and the number of new cases by 2015 (compared to the values in

1990). There is a shortage of sufficient finances available to combat TB: there is a shortage of US\$ 385 million for 2008. Only 5 of the 22 most affected countries reported no shortage of finance. There is also a gaping financial hole in the Global Plan to Stop TB to the value of US\$ 1 billion. According to WHO this can be blamed upon multiresistant TB and the increasing number of people who are HIV positive who have contracted TB.⁵¹ Around 700,000 of the new cases of TB in 2006 affected people who were HIV positive.

Resistance has never before been so common

'TB drug resistance needs a frontal assault' according to Mario Raviglione, head of the Stop TB department of the WHO. He continued that it is necessary to immediately improve the performance in diagnosing all TB cases rapidly and treating them until cured, which is the best way to prevent the development of drug resistance.⁵² Never before have there been so many cases of multiresistant TB as today. 5% of all the annually occurring 9.2 million cases of TB are multiresistant.⁵³ That means that each year there are half a



Social inequality and poor healthcare have allowed TB to develop even in Manhattan.

Photo: CC P. Kerr

million new cases against which rifampicin and isoniazid, the most important antibiotics against TB have no effect. In some countries of the former Soviet Union up to a quarter of all tuberculous diseases are multiresistant. In Baku in Azerbaijan more than a fifth of all TB patients are carriers of multiresistant bacteria; in Moldavia it is just under 20%. Extremely resistant forms of TB, which are only just treatable today, were reported from 45 countries.

The true measure of the epidemic is however unclear in many parts of the world; only six countries in Africa – the continent with the highest rates of TB – have information available concerning resistance to the disease. Other countries were unable to prepare reports, because they did not have the technical equipment available to detect multiresistant TB. 'It is very probable that there are outbreaks of resistant forms of TB, which go unnoticed and which we do not know about,' according to Abigail Wright, an expert on TB at WHO.⁵³

Tuberculosis does not stop at the borders

Tuberculosis is however still a problem in the western industrialized countries: over 8000 cases of tuberculosis were reported in England, Wales und Northern Ireland in

2006.⁵⁴ Multiresistant forms of the disease are spreading especially amongst marginalized groups of the population in cities like London. Migration and a changing population structure are the causes according to this recent report. The proportion of resistant cases increased from 5.6% in 1989 to 7.9% in 2005. People from the outer districts of London were mainly affected including increasing numbers of immigrants from sub-Saharan Africa and India.

One form of TB, which is resistant to the active substance, isoniazid, has been rampant since 1999 and has infected 300 people to date. However in this case it was mainly prisoners and drug addicts born in Great Britain who were affected. The authors emphasized the urgency of detecting cases early and the need for the rapid testing to check whether the disease responded to standard medicaments or not. More rigorous monitoring of TB was necessary and more intensive research was needed to find new diagnostic methods and substances which were effective against multi-resistant forms of the disease.

TB in the heart of New York

Even in Manhattan in the heart of New York in the USA the rate of occurrence of TB rose in 2007 by 11%, compared to the previous year, to



Slums are known worldwide as breeding grounds for tuberculosis

Photo: DAHW

re were more than three people sharing each room.

The situation appears to be similar to that in Bangkok in other poor countries. In the Philippines, for example, a third of the population in the

a total of 182 cases. An outbreak of tuberculosis in Harlem was responsible for the increase according to the health authorities. Although the frequency of occurrence of TB in New York has been decreasing for some years, it is still more than twice the national rate. Because of extensive cut-backs in the public healthcare system in New York in the 1970s the number of cases of disease increased rapidly there in the 1980s. Many patients could no longer receive their medication. More than 20,000 as a result suffered an avoidable infection from strains of the pathogens which were resistant to antibiotics. Migrants comprise over 70% of the new cases of the disease reported in New York today.⁵⁵

Life in the most crowded conditions

The huge conurbations of poor countries are much more badly affected by TB than the cities of the western industrialized nations. Between May and December 2003 a study from Thailand investigated all children and young people under the age of 15 in Bangkok who lived in the same household as TB patients.⁵⁶ The results were scarcely surprising: almost 50% of the children had a TB infection, although all had received a BCG vaccination as infants. Almost half the children and young people lived in the slums. In around 40% of the households the-

capital Manila live in the slums. Only one in every three slums is attached to a communal refuse disposal service and barely one in five houses have a supply of drinking water. The situation with regard to hygiene is chronic. Child mortality in the depressed quarters is three times as high. Dysentery is twice as frequent and cases of tuberculosis are nine times more common than in the rest of Manila.⁵⁷ Tuberculosis is one of the main causes of death in the Philippines. In spite of this until a few years ago only the people who were least ill benefited from DOTS. The small budget allocated to the health ministry permitted it to only make free medication available to a third of the patients. Patients who had no access to the DOTS programme had to buy the medication in private pharmacies – at five times the prices usually found in the public sector. Many patients therefore only took the medication until the symptoms had disappeared and in so doing aided resistance to the medication. Hospitals reported resistance in up to 40% of cases.⁵⁸

According to the WHO the Philippines achieved 100% availability of DOTS in 2003. The DOTS-Plus treatment against MDR-TB was started in Manila. In remote regions and on small islands monitoring of TB is however still a problem and the health service provision is only poorly developed.⁵⁹

Women are particularly affected

In the most poverty stricken parts of the world tuberculosis finds an ideal feeding ground. Even when receiving treatment people suffering from tuberculosis are forced by need to live in the most cramped conditions together with members of their families. 'I fear that I will infect my family with (MDR) tuberculosis, but I must look after my children. I, therefore have no choice and must live with them.'⁶⁰ said Monica. Monica is a mother to five



Child with AIDS and tuberculosis in Ethiopia

Photo: DAHW

children who suffers from AIDS and multi-resistant tuberculosis and shares one living room with her five children in a slum called Matharare in Nairobi in Kenya. Nairobi City has an estimated HIV rate of around 20% and is responsible for 20% of cases of TB in Kenya. Three quarters of people with TB live in the slums.⁶¹

Monica is careful and during the day wears a face mask in the house; she also wears it at night when she shares the bed with three of her children. Despite this her son and her grandchild have already been infected with this spiteful disease. The woman keeps the disease secret from her neighbours for fear of being discriminated against.

Being stigmatized because of tuberculosis is very widespread and extends to all members of the sick person's family. The effects are harder for women than they are for men. It is not rare for women to be left by their husbands if they contract the disease, or they have scarcely any chance of getting married and the prospect of social protection associated with it.⁶²



In the middle of the slums of Dar es Salaam in Tanzania men and women perform a play to educate people about AIDS and TB. The Pasada health project is supported by the DAHW.

Photo: DAHW

The epidemic is assisted by a lack of education

Socio-demographic factors are as vitally significant in the spread of TB as a lack of medical infrastructure or a lack of access to medication. Poor awareness of the risks involved frequently accompanies a poor level of education. An investigation in a slum in New Delhi in India showed that illiterate people had scarcely any knowledge of TB; women knew less than men.⁶³

Health service provisions only became comparatively reliable when establishments worked under the DOTS scheme. In the private sector knowledge about TB symptoms, transmission, diagnosis and treatment were relatively good. Doctors not working for the state were however poorly equipped to diagnose TB and they appeared to not be using a consistent therapeutic scheme. Even worse there were no

registered doctors and healers involved in the range of treatments on offer. They did not have the equipment required for either the diagnosis or the treatment of TB. 'The treatment rooms of the non-registered doctors were packed full of bottles which were filled with various brightly coloured pills. It was observed that the non-registered doctors usually prescribed medication for the treatment of common colds and fevers, even when the patient was suffering from TB.⁶⁴ Deeply rooted prejudices, flawed concepts and cultural reasons were considered to be the reasons for the spread of the epidemic. A range of health services were, however, perfectly accessible to the slum dwellers. The limited knowledge the people had about

TB caused them to prefer to visit more easily accessible and more closely situated non-registered doctors. Furthermore the majority of the people affected were day labourers and because the treatment for TB is very protracted, their lifestyles frequently prevented them from taking any long-term treatment.

Social, cultural and economic factors promote the spread of tuberculosis. Political strategies which get to grips with tuberculosis as a social disease are just as urgent as practical therapies. The fight against poverty, better chances of education, and gender equality – as targeted in the MDGs – are therefore milestones on the way to the eradication of TB.



The fight against poverty is a milestone on the way of the eradication of TB.

Photo: WHO, P. Virot

Interview on the situation in India

Where TB bacteria feel well

The Gudalur Adivasi Hospital is successfully fighting against TB and for social justice. A conversation with Dr. Nandakumar Mennon, manager of the hospital.

How is the TB situation in India?

India is one of the most affected countries. Two fifth of the 1.1 billion Indians are infected by the tuberculosis bacterium. Every year 1.8 million people become ill, approx. half of them are infectious. 370,000 die of TB every year, no other infection kills so many people in India.

Which are the exact difficulties in fighting the epidemic?

It is a big problem that we don't know how many people are infected with HIV. Last year UNAIDS made a downward correction of the numbers from 5 million to 2.5 million HIV-infected persons, however, we assume that this was a political decision and that at least 5 million people are still HIV-positive in India. 2 million of them are also infected by the tuberculosis bacterium. As HIV-infected persons have a much higher risk of becoming ill with and dying of TB, a million double-infected alone will die of TB in the years to come. However, as HIV/AIDS is still a taboo, this will also worsen the TB situation. Among Adivasis AIDS is no problem (yet). Poverty is the main problem. The people live crowded together in one room which is poorly ventilated and they are also undernourished. TB bacteria feel very well here.

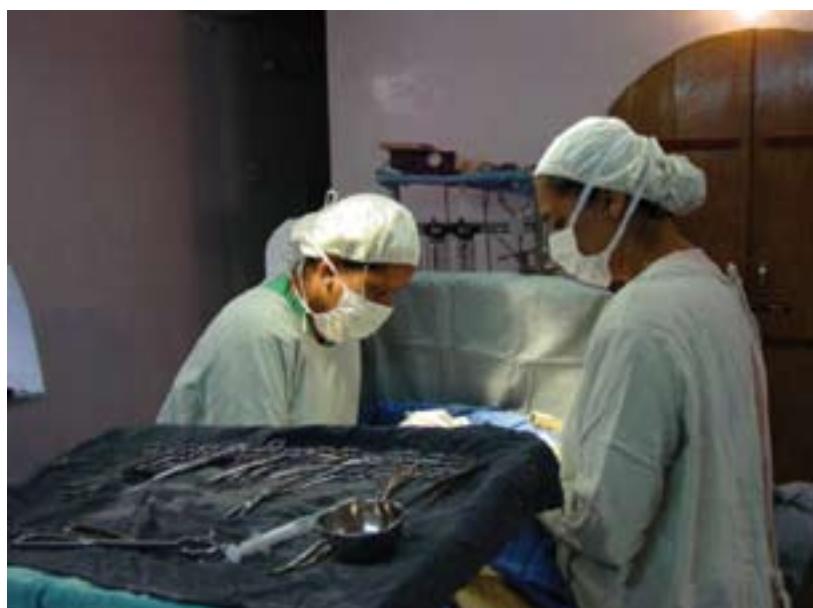
Which state measures are being taken to handle the problem?

India has wonderful laws, however, the state hospitals and programs in some parts of the country are often corrupt and then function badly. But since the state TB control program is

working together with NGOs, at least the tuberculosis program works much better. Most of the sick patients are now receiving health care and there is also the possibility to treat resistant TB. The World Bank, the Global Fund and the British Department for International Development (DFID) finance the program. Obviously, in the meantime the WHO targets are being reached, to recognise 70% of the open TB cases and to heal 85% of them. Compared to the situation some years ago, this is a big success.

Which meaning has the hospital and the village healthcare program for the Adivasis?

The hospital and the entire healthcare program contributed significantly to the social change for the Adivasis. Here, non-Adivasis have to follow the rules of the otherwise despised Adivasis. Men and women, e.g., are accommodated together in the hospital rooms, unthinkable among the rest of the Indian society. The Adivasis, the lowest rank of the Indian society structure, have the best



Operation in the Adivasi Hospital

Photo: ACCORD

hospital in the district. This helped to improve the social role of the Adivasis in Gudalur.

How is day-to-day working?

Our nurses and other employees have all been trained here. Most of them attended school for eight to 12 years, however, would have never been accepted at a state nursing school, as they have no approved school leaving certificate. Now they are the most qualified nurses of the whole district! Except the four doctors, all employees are Adivasis. They are responsible for the administration of the hospital and the village healthcare system.

Who pays for the hospital?

Usually health insurance does not exist in India and patients have to pay everything by themselves. Here, however, we have health insurance for 25 Rupees [less than half a Euro] per year and family, which covers all benefits of the healthcare system, including the own hospital. The average daily salary is 100 Rupees, so that every family can afford health insurance.

Whoever is not insured, will have to pay for the medication. As the Indian non-profit drug company, Locost, however, provides us with medication, it is very cheap. And TB drugs are free of charge, as our TB program is part of the national TB control program.

What are the problems you are confronted with most?

People die, because they do not reach the hospital or the next healthcare station in time. Often they are located in a two-hour walking distance which can hardly be managed by a sick person.

In regions which are in a far distance it is very difficult for the healthcare workers to monitor the administration of the drugs, so that some therapies are terminated. We are afraid that resistant germs may develop in such a way.

Who is particularly at risk?

Most of the time, the people in the villages are

living all together in one little room. There is no chance to isolate TB patients, i.e. without being treated, he or she will easily infect the members of family. In addition, the houses which the government built for the resettled Adivasis, are poorly ventilated and there are no smoke outlets. There are hardly less ideal conditions for the TB bacteria to spread. The

The Gudalur Adivasi Hospital

Dr. Nandakumar Mennon and his wife Dr. Shyla Mennon manage the Gudalur Adivasi hospital, the hospital of the Indian non-governmental organisation ACCORD, which supports the rights of the Adivasis (indigenous people) of the Gudalur valley in South India. The Adivasis are responsible for the administration of the hospital and most of the employees belong to one of the five Adivasi tribes of the Gudalur valley. ACCORD was founded in 1986, when people still worked in serfdom on the plantation, the mortality rate of mothers and children was extremely high and school education was an exception. This situation changed due to health, educational and economic programs.

Today, most of the Adivasis are able to read and write, have access to healthcare services and have some land. Having their own collective tea plantation also made a considerable contribution. The profit will provide permanent financial support for the school, the healthcare program, the house construction program, the land rights movement and the entire political work.

worse the nutritional situation, the easier the people are infected and the more probable they become ill with TB.

How do you find your patients?

Many villages are regularly visited by a village healthcare worker. She knows the symptoms: If cough, fever or diarrhea does not subside after a few days, she calls the ambulance to bring the patients to the hospital. All villages are visited once a month from barefoot doctors

looking for TB cases. Or patients contact the next healthcare centre. In case of suspected bronchitis, they get antibiotics there. If cough, fever or diarrhea continues for more than three to four weeks, the patients are hospitalized. There, we make a sputum test and may also prepare a culture. We can make X-ray pictures in another hospital. Then we start therapy. As soon as we know that the patients tolerate the drugs, their treatment continues at home. Unfortunately, they cannot remain hospitalized for cost



Smoke is a major health risk. Photo: ACCORD

reasons until the sputum test is negative. However, the risk of infection reduces very quickly under treatment. At home, the patients pick up their medication at the barefoot doctor or the village healthcare worker brings it. In far distant villages the drugs are sometimes also provided by relatives of the sick persons. After two and six months we make one more sputum test to examine therapeutic success. We achieve very good recovery rates with the DOTS program.

What does the project mean to the sick people?

They call it *nanga hapitar*, that means *Our hospital!*

Are the relatives included in the TB program?

In India and also among the Adivasis nobody goes to the hospital alone. Mostly, two to three

family members accompany the sick persons. Later, often relatives also take over the responsibility that the patients take their medicine.

Moreover we discuss our programs with the village council. It consists of men, women and children and makes the decisions in consensus. When we wanted to introduce that the huts are fitted with smoke outlets, this had to be discussed with the entire village council first. Now, in some villages a smoke outlet is built into every hut. This reduces the risk of tuberculosis significantly.

Do some sick persons withdraw from the treatment?

In some Kartunaik villages some people still believe that evil spirits are responsible for TB. They call the spirits and do not come for treatment. In the beginning this was a big problem. But now, many village priests cooperate with us and the spirits send the people to the hospital too. Yes, in India, even the spirits are included into the TB program and we really have very cooperative spirits.

Some people do not want to be treated, because they think that they will die anyway. Then, we have to wait until they are in such a bad condition that we can persuade the relatives. Then, part of the lung is already destroyed before we can start the treatment.

Is there any other way you provide help?

The hospital and the healthcare program is only one part of our project. Other areas are education, house building, the common law movement and an economic development. We can handle TB only by fighting poverty.

Which are the limits of your help?

Many years will have passed until we can equip all huts in all villages with smoke outlets! Even after 20 years of work the people are still poor. Until this has changed, 20 more years will pass.

Christiane Fischer from the BUKO Pharma-Kampagne made this interview

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Tuberculosis, alongside leprosy, is probably the world's oldest infectious disease. It has accompanied humanity for thousands of years, damning its victims to certain death. With the introduction of antibiotic therapy about 70 years ago, it was believed that tuberculosis, this old enemy of humankind, was finally conquered. Today the disease can be cured in most cases. But still many patients in poor countries are not being treated appropriately or they are not receiving any treatment at all. Not only financial problems are to blame for this health crisis, but also cultural and social reasons as well as a lack of information.

The present booklet examines tuberculosis as

a social disease around the turn of the 19th to the 20th century and today. In order to understand the nature of tuberculosis and in order to be able to fight it effectively, it is important then, as it is now, to observe the disease in its social dimension. Here there are some astonishing parallels which can be drawn; the situation of sick people in Germany around 100 years ago in some ways resembles the life of patients in poor countries today.

The conclusion: the fight against poverty, political strategies, better chances for education and equal rights for men and women are as urgent in the fight against TB as appropriate and affordable therapies.

BUKO

Pharma-Kampagne

BUKO Pharma-Kampagne is an independent non-profit NGO and part of the German Federal Coordination Internationalism (BUKO), a network of Third World solidarity groups. It promotes the global right to health with international lobby work and public awareness campaigns in Germany for more than 25 years. Pharma-Kampagne is one of the few organisations in Germany which exposes the dark side of the drug market in South and North. The campaign supports the right of access to essential medicines everywhere in the world. It promotes the rational use of drugs and the research for neglected diseases.

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