

Report of Occupational Health: Incidence of TB among the Sipk Weavers of Varanasi

Date : 31-3-2005

Place : Community Centre, Nakkhighat, Varanasi

PARTICIPANTS

- ◆ *30 Tuberculosis patients from the Nakkhighat area*
- ◆ *Community leaders*
- ◆ *DOT provider of DOT center located in Bunkar hospital,*
- ◆ *Private practitioners of the area,*
- ◆ *Prof. B.N.Juyal, President of UPVHA*
- ◆ *Pradeep Srivastava, Program officer of UPVHA*
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Objective:

Taking into view the professional craftsmen especially the weavers' health problem, particularly relating to tuberculosis, a one-day workshop was organized by UPVHA at Nakkhighat. Apart from imparting awareness regarding the causes and precaution taken in tuberculosis the workshop also includes the evaluation of the awareness status regarding the reach of health facilities in the area amongst the people.

Process:

In order to check the extent and causes of epidemic in the area UPVHA held a one day workshop in which Dr. J.N. Singh and DOT center provider Dr. O.P. Singh examined the people. During the examination the people who were found ill under the menace of tuberculosis were asked about the results if they had previously consulted the dot centers for treatment while others were made aware about the facilities provided in the dot centers.

UPVHA members during the visit of the area assessed the problems of the residents and examined the lifestyle, living standards and the basic needs of the people. A public hearing was also organized in which people suffering from tuberculosis and other problems relating to breathing gave their views on the occasion.

Thus a report was made on the basis of the data collected through public meeting and the visit of the area.

Nakkhighat:

The 'basti' located in Nakkhighat area (on Varuna river) of Varanasi whose boundaries was merged with the Nagar parishad around 20- 25 years back took a shape of a urban dingy 'basti'. In the area Muslim population is in majority who financially depend on the work of sari weaving, **chai cleaning** and other small occupations. This area always had an edge over others in art of weaving even before the independence. Today also most of the weaving products manufactured in the area are hand made.

Due to the continuing downturn in the market of 'Banarsi saree' a sharp fall has been witnessed in the number of employees in the weaving business.

The area has become a dumping ground, as there is no proper drainage system for the outflow of dirty water. Non- availability of drinking water adds further to the problem. The environment is not conducive for healthy living. Many of the people are suffering from severe malnutrition. Most of the people reside in thatched houses with dirt and filth at their vicinity.

The major problem of the area is that most of the people are reported to be addicted to liquor, tobacco chewing, cigarette, 'bidi' and heroin.

The grievance of the natives seems to have increased manifold instead of registering a downfall even though the government has opened many welfare schemes.

Spread of tuberculosis in the area:

The area of Nakkhighat is under the influence of many diseases like Malaria, Tuberculosis, cholera, chickenpox, skin diseases, brain fever etc. But out of them Tuberculosis is most prominent among people. Though the area was affected by tuberculosis even much before the independence but its spread has rapidly surged in last 20-25 years. Initially the population in the area is around 14000 out of which 15-20% people are affected by the disease. In which 35-40% children are infected by the disease. However, from last 3 years Dot centers are running in the area but no decline in the number of tuberculosis cases has been so far reported.

Report:

The natives of Nakkhighat are forced to live a miserable life. The physical, economic, social and family life of the people is in appalling condition. Major population of the area belongs to Bharotia and the Ansari community, who were associated with the profession of silk weaving way back from the independence. But from last few years the downturn in the market of "Banarsi saree" has compelled the people to shift from their ancestral profession to other varied jobs like rickshaw pulling etc.

Many of the families with around 8-10 members (including children) are living in small houses having 2-3 congested rooms. In one room most of the families do the work of weaving or **chai cutting** while in other left room the members of the family reside. The houses are in a deplorable condition. The houses have dampened walls and the room is filled with fetid air, as the houses are not being painted from last many years. Due to improper drainage system the houses lie in the immediate vicinity of dirty water.

Poverty, lack of proper information and the filthy environment are the reasons for the worsening physical capability and weak immune system among the people. In order to earn the livelihood the small children of the locality get involved in the profession of weaving and other small occupations. The hard work involved in the profession is proving deleterious for the health of the children. Thereby most of the children are in the grasp of tuberculosis.

To make **RNTCP** programme a success many dot centers have been set up in the area. In spite of these measures the problem of tuberculosis still persists in the area.

By visiting the affected area and arranging meetings with the natives the UPVHA team tried to assess the causes for the spread of the disease and reasons for the lack of unawareness among the people regarding the facility provided by the dot centers.

Some case studies

It's not possible to go to DOT center at the cost of work (kam chod kar dava laye e hamar liye sambhav nahi)

From the last six to seven years Amina Bibi with a feeble body structure is suffering from Tuberculosis. She got married at the age of 12. Her husband and father in law were in the profession of weaving. Her condition deteriorated after 2-3 months of the birth of her son. After suffering from immense weakness, coughing and fever, she consulted the doctor. The medical reports confirmed it to be Tuberculosis. She took proper medical treatment for few days but after getting some relief she decided to discontinue the treatment. And the reason that she states is, *“Hafta bhar ki dvai ka 500 rupiya padata tha. Itna mengha illaj hum gareeb ke liya sambhav nahi.”* (Weekly expense on the medicine is Rs 400-500, which is too costly for poor people like me) When she was asked to get her treatment at the DOT center then she replies, *“DOT Center ka hota hai, e humaien maloom nahi tha”* (What is DOT center? I don't know about it). Few months back, her relative had told her about such center. She did go there. After five days, she even started getting the medicines but the doctors there use to call her after every five days. Then she is asked to get a receipt of Rs.5, which provides her with 5 tablets for five days. All this proved to be a tedious task for her, as according to her, she has to go for work each and every day, which would merely fetch her with a meal for two times a day. And she can't afford to miss her work at the cost of medicine.

Amina along with her family member lives in a small two-room mud house. In one of the rooms her father and father in law would do the weaving work. Due to the lack of proper drainage system, the house lies in the immediate vicinity of dirty water. Not only has the house lacked proper power facilities but also their no ventilators. The situation gets degenerated by the dampened walls. The whole house smells a bit fusty. Not a single child in the house is fully covered with clothes. Their nose running but unaware of the difficulties of life, they were busy playing in mud. In the name of education, Amina says, *“Bacchoon ko doo waqt ka khana mil jaye vahi bahut hai, school bhejne ki baat tho abhi hum soch bhi nahi sakte. Pati va sasur haddi todh mehnat karte hai tab jakar ek din mai 50-60 rupaya kama pate hai. 50-60 rupaya mai 9 logo ke bhojan ki vyavastha hi bamushkil ho pati hai, kabhi- kabhi tho bilkul kaam nahi hita. Aise mai pura parivar bhukhe he so jata hai.”* (It's not easy for me to provide my children with a meal for two times a day. Education is a distant dream. Although my husband and father-in-law work day and night yet they could

only earn a meager daily income of Rs.50-60. In Rs 50-60 it is difficult to manage food for 9 persons from such a derisory amount. Sometimes there is no work and in such case the whole family sleep without food).

As long as poverty and malnutrition continues, diseases like Tuberculosis would continue to take people in its grasp. Today Amina and her father in law are suffering from this dreadful disease and her children are not beyond reach. If unawareness among the people about the DOT centre and the negligence on the part of authority continues then people like Amina would hesitate and think long and hard before visiting these DOT centre. Besides this, lack of attention is paid to the problems faced by the workers of DOT centre which further puts the future of DOT centre in dark.

Muscle men have their influence even in DOT centres: (Dot centre main dabango ka dabdaba)

Munna Babu who is fifty years old appears to be 90 years old. His body has reduced to a skeleton due to tuberculosis. 3-4 years back, Munna used to work in Ahmedabad. It was at that time that tuberculosis grasped Munna. From many days in Ahmedabad, he was suffering from immense weakness, coughing and breathing problem. One day his condition deteriorated which compelled him to visit a private doctor. Medical reports confirmed it to be tuberculosis. After taking medicines for few days, he discontinued the treatment. Munna said, *“Ek hafte mai 400-500 rupaya ki dava aati thi. Itna mehnga illaz karana mujh gareeb ke liye asambhav tha”*(In one week I had to spend Rs. 400-500 on medicines and it is impossible for me to bore such expensive treatment). After no signs of improvement in his health he decided to leave for his house in Varanasi. He didn't take any medical treatment and this proved to be too deleterious for his health. When asked about the free treatment provided at the dot center, he said, *“Pahle kisis ne humse kabhi bataya tha ki humare bunker hospital mai DOT center hai. Hum ek do baar DOT center ka naam sunne the par humko yaha malum nahi tha ki DOT center T.B. ke illaz ke liye hota hai. Baad mai humare rishtedar ne bataya ki DOT center mai T.B. ki jaach kar muft dava di jaati hai. Yaha sunkar behenji hum bhi gaye, lekin vaha humari koi sunvai nahi hui. Jaach karane ke kuch din baad hufta dus din ki dava mili, uske baad jaane par kahte the ki dava nahi hai phir aana. Baar-baar koshish karne par bhi mujhe dava nahi mili”*. (Previously somebody has told me that we are having DOT centers in our Bunkar hospital. I had heard two- three times the name of the DOT center but was not knowing that there the treatment for tuberculosis is given. Later my relative told me that the free treatment is provided for tuberculosis in these centers. So I

went there but nobody paid any attention. After 7-10 days of my medical test I was given some tablets but after few days the workers at DOT centers asked me to come later as they had no tablets in store. I tried my best to get the tablets but was unsuccessful) Expressing his anger, Munna declaims, ***“Vaha par kewal dabang va netao ke kehne par hi dava milte hai, hum garibo ko nahi”*** (Only muscle men and leaders could get medicines at the dot centers and not the poor people like me).

The UPVHA tried to have explanation from the Samajwadi party leader Mohammad Ezaz of the area, he said, “Many patients come to me for help for getting the medicines. Sometimes I go with them or would write my name in a piece of paper as this would help them in getting the medicines.” At the UPVHA asked about the fate of those people who could not visit him or any other influential person, he replied, ***“Bahut mushkil hai”***. (It’s not easy for them). This clearly shows that the dot centers which was set up for the poor and needy people is working on the guidelines ***“Jiski laathi usi ki bhais”*** (Might is right).

Munna along with his 10 family members lives in a small two-room set. The whole house smells a bit fusty. The two sons of Munna had got married. One of his daughters is also suffering from tuberculosis. With two people suffering from tuberculosis the other members of the family especially the young children are at the risk of getting this contagious disease. Munna and one of his sons is in the profession of weaving. Although they work day and night yet they could merely manage a meal for two times a day. In such a situation if one of them falls ill, it becomes a tedious task to manage the food for the family. A healthy environment is an indispensable need for a healthy living. But the house of Munna lies amidst unhealthy and unbalanced environment.

Government Health Centre Loosing Reliability (visvasniyata khote sarkari Kendra)

At a glance it appeared that Mustari a 12-13 year old girl is also suffering from Tuberculosis, but after talking to her it was known that she is a 20-year-old married woman and is pregnant since 2 months. Lean and thin Mustari is so weak that she cannot talk properly and Breaths rapidly while talking. Her husband earlier use to work as weaver, but now he is into rickshaw pulling work.

Four months back from today Mustari’s health deteriorated and her condition worsened. She was admitted in a private hospital where on examination it was known she is suffering from T.B. After few days of Medical treatment in private hospital her family members brought her back to home, as the treatment in the private hospital was too expensive, and her family members couldn’t afford so much expensive treatment.

Mustari's father said that he inquired private doctor that if her daughter-in-law could get treatment from the facilities provided by the government but the doctor didn't gave him any information on this regard.

UPVHA team members provided the information about free medical aid from the government to T.B. patients and information regarding DOT Centre to Mustari, her husband and father-in-law in details. After listening to the details about DOT Centre Mustari said-“*Jaisa illaj private docter karte hai vaise sarkari aaspatal mein nahi hota. Private docter turrant paani chadate, jaanch katre aur dava dete hai. Jabki sarkari aaspatal mein chahe jitni tabayat kharab ho phele parche banvani padti hai. Aaise mein kaun sarkari aaspatal jana chayega.*” (Government hospital cannot give the same treatment given be private doctor. Private Doctor for the immediate relief examines the patient, gives glucose and also gives medicine. But on the other hand no matter how serious the condition of the patient is one have to first get an examination paper for the treatment. So who would like to go to Government hospital for treatment).

Mustari's condition is very serious, she is pregnant and has no money for medicine, but still she is not willing to go to the DOT Centre for free treatment. She believes that there is no use of going to the DOT Centre. Instead she must collect money and then go to private hospital for treatment.

At present under National Tuberculosis Control Programme DOT Centre and Microscopic Center are in operation, where the patient undergoes medical examination so as to detect whether the patient is suffering from T.B or not. After Detecting T.B. in a person the patient is provided with free medicine. But during the workshop the following factors came into light.

- People were of the opinion that the medicines provided by the DOT Centre are not much effective.
- Few people said that there is no use of going to DOT center, as we don't get required medicine.
- In order to earn money the people are cheated by the quacks as they are not given any proper advice and are also not encouraged to go to the DOT Centre.
- Some people said that they don't get medicine regularly in the Dot Centre. Hence they have to discontinue the treatment before their disease gets cured.
- Some stated that they have to pay for the medicine in the DOT center and as they don't have money there is no use of going to the DOT centers.
- Some said that the DOT centers and the Microscopic Centre are very far from their residence. So they don't go there.
- Some people stated that after doing lot of hard work they are able to manage for two times a meal. So it is impossible for them to leave their work and stand in long ques for hours to get medicine every day.
- A local leader stated that DOT providers themselves do private practice and gives the free medicine of DOT centers to the patients for money in their own private clinic.

Statement of DOT centers workers:

Giving information to the members of the workshop DOT Center workers said that medicines are regularly available in the DOT centers and around 90% patients are regularly taking medicines and only 105 patients has discontinued the treatment. They also added that the illiteracy and the inadequate awareness are the reasons due to which they visit the private doctors or fake doctors for treatment. It becomes very difficult for them to afford the expensive treatment of private doctors. Thereby the patients are entrapped by quacks. Nobody provide adequate information to the common man as such they are not able to go to Microscopic centers for the treatment. Because of this reason tuberculosis is not detected and hence the health of the person deteriorates. These patients infect other healthy patients too.

When UPVHA team asked the DOT provider, a doctor by profession and is also having chemist shop in the locality about the functioning of the DOT Center he said, "We are not provided any extra wages in return of our services in DOT Center. Hence if any person having rich background comes for his or his family member's treatment we give him private services but in case if the patient is poor then we ask him to register in DOT Center." The statement of DOT provider clearly highlights that even the worker of the DOT Center regard private treatment much better.

However it has been mentioned in RNTCP that after the successful completion of the diagnosis the DOT provider should be provided extra wages for encouragement but no such wages is provided to them. Thereby many of the local doctors prefer to work as DOT provider so as to expand their personal business.

Local doctor advice during workshop:

A local doctor who came to attend the workshop stated that the denizen of the area lacks in knowledge that's why they are not serious towards the primary symptoms of various diseases.

On suffering from cough and fever regularly the villagers go to quack and compounder for medical examination and get satisfied by colorful allopathic medicines. Quacks give them normal fever and cough medicine and entrapped the illiterate villagers, but when their condition deteriorates then they advice them to go to the hospital. Hence not only time but also a lot of money is also wasted in the process. There are many such weaver families who are not having sufficient money and so they are not able to get any proper treatment. Not only this but they also not having any proper knowledge regarding DOT center so they are not able to take benefit of it. The situation is such that inspite of getting cured from tuberculosis they are infection other healthy people with the disease.

According to him it is very essential to impart health education among the masses so that on detecting primary symptoms they could go to government hospital for treatment.

On the survey report by the UPVHA team the following factors are found responsible for the frequent spread of T.B.

- Poverty, illiteracy and lack of information in the region.
- The adverse effect of weaving and chai on the health.
- Lack of information about the DOT Centre.
- Non-availability of regular facilities by DOT Centre.
- Community do not rely on the quality of services provided by the Dot centre.
- Ignorance of seriousness of T.B. disease.
- Lack of knowledge about the primary symptoms, cause and precaution among the people.

While making of the programme or any plan by the government for any particular class, community and area, the social, religious and economic status of the people of the area is not examined properly. Due to which there is lots of difference between the programme structure and the real living standard of the benefited community. As such the results of the programme are not up to the mark. Following which there starts the mud slinging process. Similar of this kind also happened in DOT centers.

Firstly the common masses cannot correlate the name of DOT centers with that of tuberculosis. Even if the masses came to know the name of the DOT center they are not able to know for what the center is for? Apart from this witnessing the spread of the tuberculosis it has become essential to vigorously activate the RNTCP programme so that the patients are within the reach of the DOT provider. Along with this it was also essential to set up awareness camp in the areas highly affected by tuberculosis so as to aware the people about the causes, precautions and the primary symptoms of the disease. This will help people in attaching with the DOT centers.

It is important to-

- Similar to the pulse polio programme the RNTCP programme should also be made active from passive in the areas that are severely affected by tuberculosis.
- DOT provider should be from the same area who is well aware, sensitive and well recognized by the community. Along with it he/she must not be having any personal interest in joining the programme.
- During the procedure of making the medicines available to the patients the condition of the professional craftsmen and workers should be taken into consideration.
- Area wise health camp should be organised to identify the T.B. patients.
- DOT provider should play a role of proficient counsellor.
- Being as a active worker DOT provider should be in reach of the patients.

- Common man cannot relate DOT Centre with T.B. Hence it is essential that DOT Centre should be more publicized so that people can co-relate it with tuberculosis.
- Dot centre's name should be reframed so that the community can correlate it with T.B.
- In government hospital's the doctor and worker should have a sensitive attitude, so that there could be in touché with the patients.
- Under RNTCP it should be kept in notice that the programme should be interlinked with other various programmes, which are running in filthy colonies/urban poor. Duda's training center working at Nakkhighat is the best example. In such cases the use of DOT centers for such areas would prove better than in any other place, which is far from the colony. RNTCP has been started in the area where from beforehand Duda, U.B.S.P, and government / non-government organizations were already running. DOT centers should be set up only after talking and taking advice from the people associated with such organization.

INTRODUCTION:

About UPVHA:

UPVHA (Uttar Pradesh Voluntary Health Association) a state level affiliate of Voluntary Health Association of India (VHAI), It was established as a non-profit secular organization on March 1984, works in around 58 most poor and underdeveloped districts of Uttar Pradesh. Realizing the importance and priority of community health around 258 NGOs operating at grass root community level joined our fold. UPVHA works in collaboration with various partners besides VHAI, Ministry of Health & Family Welfare, GOI, State Govt and other. This project aims at the social and economic development of the villages by making people aware of their legal rights thus showing them the path of progress and betterment.

It has three Regional offices located at Dehradun, Lucknow and Varanasi with the central office also at Lucknow. Central office is housed in its own building in sprawling Gomti Nagar Township of Lucknow.

For the past several years, the socio-economic scenario of the rural sector has been deteriorating day by day, and the condition has gone from bad to worse. The government schemes in the rural areas lack proper implementation. UPVHA work in such districts where the process of development had never been initiated.

Objectives:

- 1) Health for all with a fundamental option in favour of the people in the lowest economic and vulnerable population conglomerations.
- 2) Participation in all that pertains to the promotion, preservation and improvement of the people and the communities and the healing of illness and trauma.
- 3) Rational drug therapy.
- 4) Effective alternatives to drug therapy.
- 5) Good working relationship between the voluntary sector of Health Care and all relative civic, government National and International organizations.

Issues:

- 1) Women and child health
- 2) Safe drinking water
- 3) Nutritional Deficiency disease
- 4) Vector and communicable diseases.
- 5) Sexual health
- 6) Legal aspects of health
- 7) Physical/ Mental disability

- 8) Primary Curative/ Health services
- 9) Environmental disasters, Epidemic management

Programmes and activities:

- 1) Community health programme
- 2) Reproductive child health
- 3) Parivartan Pariyojna (PACS)
- 4) Policy/ Advocacy programme