The spread of tuberculosis amongst Varanasi's out-of-work weavers

Jin Ju, Researcher, Asian Human Rights Commission

After suffering from tuberculosis for approximately 10 months, 15-year-old Iqbal Ahman died with a rawboned body in August 2007. Prior to his death, Iqbal worked as a weaver in a sari shop and earned 700 rupees a month (USD 17.8). Iqbal's father died of tuberculosis eight years ago, while his mother died of cancer two years ago.

[photo1] Iqbal, two months before he died

As Iqbal was unable to attend the local tuberculosis centre which was too far from his home, he sought medical attention from the government hospital, as suggested by his neighbors. There, he was asked to pay for his treatment and medicine since he had no red or white ration card[1] signifying his poor economic condition. However, regardless of their ration cards, many government doctors demand additional money—in the name of treatment cost—from patients.

Iqbal's yellow ration card only allowed him to obtain kerosene, but no food. After Iqbal was infected with tuberculosis, he could not work anymore. He was living with his 10-year-old sister and two old aunts, who were making tassels for saris. His aunts were each getting 20 rupees (1 USD = 39 rupees) a day, while his sister was paid 10 rupees a day. Although Iqbal applied for a white ration card in April 2007, it was never issued.

Their miserable living conditions made it difficult for Iqbal's family to manage his treatment as well as one meal a day, eventually leading to his death. Unfortunately, these conditions are far from unique to Iqbal's family. The decline of India's weaving industry, particularly the hand woven sari trade of Varanasi--which once enjoyed great prosperity—has led to many deaths, from hunger and tuberculosis. The Asian Human Rights Commission (AHRC) has reported numerous such cases over 2006-07.[2] While the cases involving malnutrition and starvation clearly indicate the complete failure of India's food distribution system and relevant government bureaucracies, the cases of tuberculosis infection spotlight the country's failing health care system. It is impossible—and of little use—to view the two systems separately, or to analyze them in isolation from government corruption and India's overall rule of law system.

Who is exposed to tuberculosis?

According to the Revised National Tuberculosis Control Programme's 2007 report, the usual victims of tuberculosis are migrant labourers, slum dwellers, residents of backward areas, and tribal groups. Known as the disease of the poor, tuberculosis often appears where malnutrition, shanty housing, and overcrowding are common. Despite treatment for the infectious disease, living and working in a small space without adequate ventilation can seriously affect patients suffering from tuberculosis. It is therefore no surprise that so many weavers are infected with tuberculosis; working in closed spaces filled with dust and thrums (from their looms and cloth) for a prolonged period has great risk of infection. Moreover, the

[1] According to the Public food distribution system (PDS) of India, people can be issued three types of ration cards. The yellow card is issued to those living above the poverty line, and only allows individuals to obtain kerosene oil at a low price. The white and red cards (Antyodaya Anna Yojana; AAY) are issued to those living below the poverty line, of which the red card is issued to the most marginalized individuals. With both cards, people can buy rations like rice, wheat, sugar and kerosene oil from the ration shop at a lower price than with yellow ration card. Both white and red cards also provide largely free medicine and treatment at government hospitals. The issue of ration cards ultimately depends on the different states.

[2] For more cases regarding hunger and tuberculosis, see the following the hunger alerts and statements issued by the AHRC: HAC-001-2008, HU-005-2007, HA-012-2007, UG-003-2007, AS-172-2007.

cure for tuberculosis requires the consistent intake of a large number of drugs, which is difficult to manage for many patients.

Since 1929, when India became a member of the International Union Against Tuberculosis (IUAT), there have been attempts to eradicate the disease, including the establishment of several research centers. Most recently, the government introduced the Revised National Tuberculosis Control Programme (RNTCP) in 1992, moving its focus from the development of medicines to the "weakness in the process of practice". In particular, the introduction of DOTS (Directly Observed Treatment-Short course) was a hope for keeping people away from tuberculosis. It literally means that a doctor or health worker will supervise the tuberculosis patient's medication until the patient is completely cured. According to the RNTCP's report, more than 6.7 million patients have been put on DOTS, which has geographically expanded to achieve nation-wide coverage in March 2006, while maintaining a success rate higher than the global target of 85%. Moreover all government health facilities, sub-centres, and an increasing number of community volunteers including Anganwadi (child care center) workers, private doctors and NGOs, have been involved in the provision of DOTS. Accredited Social Health Activists (ASHA) under the National Rural Health Mission (NRHM) are also being trained to participate as DOT providers in rural areas.

The darker side of the system however, reveals a failure of tuberculosis diagnosis, inefficient and inadequate health service and a failure in reaching rural areas where there is greater poverty and where people—including the weavers of Varanasi—are at greater risk of infection. Systemic corruption is another key issue; in 2006 the World Bank reduced its health care funding—including for tuberculosis—in the country, after observing fabricated reports and corruption within the system.[3]

People's tribunal

To hear the stories of these weavers firsthand, a people's tribunal for weaver's and artisans was organized by the Varanasi-based People's Vigilance Committee (PVCHR), in collaboration with Action Aid International India (AAIA), the AHRC and Bunkar Dastakar Adhikar Manch (BDAM) on 18 December 2007.

[photo2] People's tribunal panel members
[photo3] Weavers listening to stories and testimonies

The Paradkar Smriti Bhawan press club was filled with several hundred weavers from the villages of Lohta, Bagerdiha, Lalapura and Mohan Sarai, among others. They all wanted to share the threat and despair under which they have been living. They noted that not only did government schemes regarding tuberculosis fail to reach them, but that there have been cases where doctors have misdiagnosed or refused to treat the disease, indicating a failing health system and untrained workers. Their stories made few distinctions between Muslim, Hindu or Dalit; yesterday your Muslim husband died of tuberculosis, and tomorrow it may be my Dalit child.

'Not tuberculosis'
[photo_4] Mrs Mobina and her baby

"My husband died of tuberculosis, but he was not diagnosed by the doctor as a tuberculosis patient." With anger for her husband's death, Mrs Mobina Bibi appealed to the tribunal members and other weavers. Far

[3] See 'World Bank 'uncovers India fraud'', *BBC News South Asia*, 11 January 2008, at http://news.bbc.co.uk/2/hi/south_asia/7184345.stm and Ramesh Menon, 'TB: gravest danger to India – II', *India Together*, 22 November 2006 at http://www.indiatogether.org/2006/nov/hlt-tbdanger2.htm.

from being treated, her husband was not even diagnosed as suffering from tuberculosis, which resulted in his death. Carrying her baby, Mrs Mobina worried as to how she would obtain daily food.

No livelihood, no ration card; no survival
[photo_5b] Sirajuddin

Sirajuddin, a 47-year-old traditional weaver from Bagerdeeha, has not worked for the past two years, since he was infected with tuberculosis. He underwent surgery twice, which merely left him with two gaping holes in his back; Sirajuddin hobbles around and can no longer walk erect. His elder daughter sews clothes and earns around 30-35 rupees a day. Despite such hardship, Sirajuddin has not been issued with a red ration card allowing him to get food and medicine at a low cost.

Like Sirajuddin, many weavers are facing a vicious circle of poverty and tuberculosis, which is threatening their lives. As Sirajuddin's case indicates, they are deserted by the government, belonging neither to the official class of poor, nor seen as a particular working group at risk of an infectious disease.

Industry decline
[photo_6] Jamaluddin

The decline of the handloom weaving industry—caused by the introduction of the power loom, cheap imports and a lack of government intervention—has led to many weavers being out of work. These weavers were proud of their occupation, which was a family trade, passed on through several generations. One such weaver, Jamaluddin, who has been working as a weaver for about 20 years, is racked with illness and weakening eyesight. He has now given up weaving and taken to carpentry, a trade alien to him. He earns only 20 -25 rupees a day, with which he cannot make ends meet. His child is also sick, but he cannot afford medical treatment for his child or himself. Jamaluddin told the tribunal that he burns up all the medical prescriptions in rage and frustration.

'No government policy'
[photo_7a] Sumsulhakh

Weaving has also been a family occupation for Sumsulhakh, whose father, grandfather and great grandfathers were all weavers. "When my parents weaved for a living, we had good food and clothes. I had meat every other day when I was young, but now we eat meat twice a month. It is the worst time for us to survive. My father had a lot of work and got about 100 rupees for one sari at that time."

Sumsulhakh's brother was also a weaver but quit due to the lack of work. Now he works irregularly as a casual laborer, which earns him 70 rupees a day. However, Sumsulhakh notes that his brother is only paid 35-50 rupees, while the rest of his payment is kept by the building contractor as a 'deposit'.

Although Sumsulhakh is unaware of any government policy towards the weaving industry, he says that Varanasi's sari weaving should be revived. In his village of Lohta, many weavers had to quit weaving and have been suffering from tuberculosis. Some of these cases have previously been documented by the AHRC. [4]

"I am still weaving since I have no other means of living. I have been sick for the past three years due to tuberculosis. I have just restarted weaving three months ago. I have done a little work today. Usually I

[4] Please refer to HU-005-2007 and HA-012-2007.

work 5-6 hours a day since I am not fully recovered. It takes 10 days for me to finish one sari. While I couldn't work, my wife and eldest daughter used to work for a living. They make 35-40 rupees a day."

In 2006, Sumsulhakh obtained a health insurance card for weavers. He had to pay 200 rupees to the community leader who helped him get the card, which expired in January 2007. Although he applied for a renewal of the card, there has been no response so far.

"I went to the government hospital after that health card has been issued. I used to go to the private hospital which is 1km away from our village, whereas the government hospital is 10km away. When I went to the government hospital for the treatment of tuberculosis, I had to pay 40 rupees for transportation, 5 rupees for registration, 5 rupees for X-ray examination and 2 rupees for other examinations. I was provided medicine as well and have been treated for four months. However, I am still weak and not completely recovered.

"Over the past two years, I have taken a loan of 8,000 rupees from a middle merchant and a bank because my wife, children and I were all sick and weak, and I could not work at all. Six months ago, my wife and children were hospitalized for five days. My youngest son has been recently admitted at the hospital for four days due to malnutrition. I spent 2,500 rupees for his treatment. I tried to save money by eating less. We have a yellow ration card with which we can only buy kerosene."

[photo_7b] Sumsulhakh's wife and youngest son

As written in his ration card of 2006, Sumsulhakh's yearly income is 18,000 rupees. Since he was unable to work for the past three years, his family's irregular income of 30-40 rupees a day is much less than 18,000 a year. On the contrary, Sumsulhakh is getting deeper into debt while illness and poverty continue to haunt his family. No government policy for the poor or for weavers has reached them.

However, according to Anil Kumar Srivastava, field officer of the Handloom Department, Uttar Pradesh there are several government health schemes for handloom weavers. He explained these schemes at the tribunal, including the Mahatma Gandhi health Scheme, ICICI Lombard health scheme, Integrated Handloom Cluster Development Scheme.[5]

Needless to say, the weavers attending the people's tribunal said they have never met even one staff working on those schemes in the field.

According to the RNTCP report, successful cases of curing tuberculosis indicate that patients require help in regularly obtaining medicine from the hospital, and need to take time off from work during their treatment. In the experiences described above, patients found it difficult to find doctors and health workers adequately trained in the treatment of tuberculosis, let alone obtaining consistent help from them.

The relevant government policies need to be more active in approaching and detecting patients, rather than waiting for patients to show up. This is particularly true in rural areas. These policies should also take into account possible groups at risk of infection, such as the weavers in Varanasi. By aligning its health and social policies, the government would be more successful at eradicating tuberculosis as well as alleviating poverty.

[5] These three schemes were introduced in 2005-2006 by the Indian government for the handloom weavers. Under the Mahatma Gandhi Health Insurance Scheme (Mahatma Gandhi Bunkar Bima Yojana), the weaver who dies of natural causes gets 50,000 rupees (1,278 USD) and the weaver who dies by accident gets 80,000 rupees (2,045 USD). The Health Insurance Scheme provides 15,000 rupees for four family members in medical treatment a year. Under the weavers cluster scheme, the handloom weavers are provided rayon at a subsidized price, but according to the weavers, in practice the price is more expensive.

As an immediate attempt to help this community, and to fill the gap in the public health system, the AHRC has called for qualified local doctors to assist in the identification and treatment of tuberculosis in Varanasi.[6]

[6] See the AHRC's announcement, AHRC-ANM-002-2008.