



**MMS Bulletin #77**

Frauengesundheit

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**"We can't do anything against God's wish."**

## **Socio-Cultural Aspects of Tuberculosis Among Women in Western rural Maharashtra, India**

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*Tuberculosis (TB) is the leading single infectious cause of female deaths in the world, killing over one million women every year, mainly between in the reproductive age group of 15-44. Studies have shown that this disease affects women who have little power and autonomy in their households. Particularly daughters-in-law suffer more seriously affected with TB. This article presents a study on "Socio-Cultural Aspects of Tuberculosis among Women: Implications for Delivery of Services". The study has been conducted in a rural district in India with the objective to elucidate the socio-cultural and financial burden that TB poses on women and to what extent these factors affect help seeking behaviour. The study group were female TB patients, health care providers and non-affected community members. There are no simple answers, but efforts have to be undertaken from the health care provision side, in order to offer more responsive services, which meet the needs and expectations of female TB-patients. However, the real challenge remains with the community, which has to develop a more positive attitude to this enormous health problem.*

Severe cough is perceived as the leading symptom which prompts most (77%) of the female TB-patients to seek medical help. A majority mentions "physical symptoms" as the main distress of the disease, but for 28% sadness, anxiety and worry were the most disturbing problems related to the disease. Even patients who are treated in their natal village and who receive support from their parents reported psychological problems. Narrative accounts showed that they are worried about their husband's sexual behaviour during the period of their treatment and the risk of his marrying another woman. This worry and tension compel them to complete the treatment as soon as possible in order to go back home. They rely on medical assurance and a certificate to confirm that they are cured.

The most vulnerable group consisted of married women staying with their parents-in-law (28%). They were found to be severely affected by stigma. Many of these women are treated normally by their inlaws until the disease is diagnosed. Once TB is diagnosed, they are often

sent back to their natal home. Those staying in joint families (30%) reported that except their husband nobody in the family was aware of the disease and that they were always under the tension and fear of disclosure. Some of these women reported that they would hide the disease pretending that it was asthma. One patient reports "I tell people that I am taking medicines for asthma" Other coping mechanism which provide them immunity from stigma and social ostracism is to blame god and consider it as God's wish. One patient narrates "I got this disease because of Pandurang (god mostly worshipped in Maharashtra ) God wants me to take these medicines so I am taking". However, those staying in nuclear families perceive a high level of support from their spouses. Unmarried females often search treatment from a far away health care centre because they fear that disclosure of the diagnosis could cause them problems in finding a partner for marriage. Widows (17.5%) perceive a high level of emotional, psychological and economic burden if they are suffering from TB.

About half of the females who accepted their disease as TB reported that they were hiding the disease from the community due to the fear of social isolation and rejection. About two thirds of these women reported loss of self esteem due to the disease. TB patients who are older than 40 years, and who have completed their family responsibilities and roles (marriage and departure of children), feel lonely and have often no will to live and to be cured. TB is perceived as a " bad disease", "dangerous illness" or a "serious disease". Hence perceptions regarding the concept of cure are like " It may be cured completely but a small portion always remains uncured and can occur again in future". This perception has an impact of female patients' help seeking behaviour and leads often to missing doses and becoming eventually treatment defaulters.

## Help seeking behaviour

The help seeking behaviour of patients in this study is influenced by various cultural and social factors, such as marital status, status in the family and interpersonal relationship with family members and the community. Help seeking behaviour is also influenced by the cost, related to the treatment, such as fees of health care providers, travel cost and opportunity costs. For obvious reasons it is a more important barrier for women, who are poor and if they have lower status. Such factors often force women to stay within the governmental health care system, although the first help seeking is reported to be private providers at the village level.

Patients have to travel up to 15 kms for six months on alternate days to receive drugs if they follow the "Directly Observed Treatment Short Course" (DOTS). Most females (69%) responded that visiting health centres is not convenient for them because of their being in charge of small children, the travel expenses, transportation problems, physical inability to come to the clinic such as inability to walk, or simply weakness. Cultural factors also play a role as decision making patterns, cultural roles of women which restrict them from travelling alone and spending money on their own health.

Ignorance, lack of awareness of treatment availability at health facilities, time and financial constraints were found to be the factors responsible for delays in the diagnosis and the beginning of treatment.

## Causation of disease

20 % of women reported prior illness as the cause of TB. Explanation given was "I had cough and fever, didn't eat anything. That is why I got weakness and reduced my immunity and got eventually TB", which matches with the scientific reason for the onset of disease. Another 20% mentioned psychological problems as the cause of their disease and most of these women had some family member who suffered from TB in the past. Interestingly they are well aware that TB is transmitted through close contact with patients but their explanatory model for the disease attributed causes to "worry regarding course of disease", or "family tension". Some also reported proximity to patients as the cause of their disease, if they were taking care for a relative or friend suffering from TB. Social and cultural pressure forced them to take care of affected in the family as their role of caregivers.

When they were asked about expectations from health services, x-ray examinations, sputum check-ups, and the availability of admission were mentioned. Some women also expected moral support from providers.

It was reported that they would sometimes not know where and how to find adequate help to diagnose and treat TB. Sometimes providers are changed. Reasons for such change are: bad behaviour from staff or doctor; unsatisfactory explanation of questions and doubts

Private providers report that female TB patients sometimes try home remedies because of negligence and financial problems. Similar perceptions have emerged from non-affected community members. Community's perceptions of the disease TB influence their attitudes towards TB patients. Males reported that "when a woman is diagnosed as TB patient she is of no use in the family as it affects her working capacity".

Non-affected female community members believe that women patients are disturbed psychologically as they are isolated at family as well as at community level and hence try to hide the disease. They also perceive problems in arranging a marriage for unmarried girls, problems with in-laws and husband for married females.

## Conclusion

Physical recovery from TB is affected by female patients' psychological problems such as feeling of insecurity, fear of isolation, fear of spreading disease to children etc. and the lack of support at family and community level. Those females who received a high level of support from spouses are found to be more optimistic about cure and are also more mentally stable. It is therefore important to consider the involvement of family and community for an effective TB control program.

Disclosure of diagnosis to female patients often terrifies them. Female patients think only of their husband's, and in-laws reactions to the diagnosis. Consequently their condition becomes more pathetic and intense when they are sent back to their parent's place.

These patients turn to health care providers for emotional support. Efforts should be made to encourage health care providers in the formal system of rural areas to provide such emotional support. This study showed that it is necessary for the family, the community and the treating health care worker to understand the emotional, psychological and social problems and the behaviour related to TB in order to adequately treat this disease.

Rural Health care providers should act as catalysts in reshaping the behaviour of patients and the communities by providing proper explanation for their queries. If these questions are not explained, patients may become treatment defaulters. Patients need to be adequately motivated to complete the treatment. Providers should change their interaction with patients. For the time being this interaction reflects mostly providers' professional power over patients and rarely providers undertake the effort to listen to the patients. A change of attitude would help patients to complete the treatment and it would also alleviate their psychological problems related to the disease.

Female TB patients face problems in having access to TB services, particularly if services are not available close by. TB creates often problems related to the economic and family situation. On the other hand even if services are available at their doorstep the risk of social stigma plays a hindering role in access. Therefore it is also the community's responsibility to reduce inequalities in TB care within the social, cultural and economic context in which they occur.

The real challenge is on how to make a community responsible towards TB control.

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