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Beliefs of patients about the causes of Tuberculosis in rural Andhra Pradesh

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This paper explores the beliefs concerning cause of tuberculosis (TB) in Nalgonda district, Andhra Pradesh (A.P.). Health care professionals primarily attribute TB causation to germs such as bacteria. However, patients with TB described the causation of their disease in multiple ways that differ significantly from that of health professionals. Results indicate that causation beliefs held by TB patients can be grouped into two broad categories: (1) natural and (2) supernatural origin. Despite the tremendous progress made in understanding TB causation, study results demonstrate the continued existence of folk theories of disease causation. For example, attributing TB disease to sin, wrath of deities, witchcraft, evil eye, fate, imbalance in hot-cold qualities in the body, bad blood, etc., are still evident in the study population. The study results also suggest that mind, body, spirit and other issues of social life are interconnected and disruptions in any one aspect can affect the health of an individual. Some of the implications of the findings of study for creating awareness about TB causation and transmission are discussed. The study argues that modern medicine has to engage with socio-cultural beliefs and practices of communities for TB treatment to be effective.

Key words: Hot-cold imbalance, witchcraft, natural origin, evil eye, explanatory model.

INTRODUCTION

In India, the social, psychological, economic, medical and public health burden of tuberculosis is enormous. India is the highest TB burden country in the world (WHO, 2006). Despite the existence of National Tuberculosis Control Programmes for more than 40 years, the treatment and control of tuberculosis pose serious challenges to clinicians, public health professionals and health policy makers in India. It is estimated that nearly 2 million people develop clinically active disease and 0.5 million die each year in India (Agarwal and Chauhan 2005).

More than 100,000 new tuberculosis cases occur in Andhra Pradesh annually, where more than 65%

of cases are in the economically most productive age group (15-54 years). In Nalgonda district, over 4000 new TB cases occur every year and it is one of the districts with the highest TB burden in A.P. (TB India, 2007).

Currently, in India, passive case finding (PCF) approaches for TB detection are applied. This means that individuals who suspect TB infection have to present themselves to health care facilities for screening and diagnosis. Hence, success of the PCF approach largely depends on the patients' disease awareness and ability to recognize the early signs/symptoms of TB. Medical anthropologists (Blumhagen, 1980; Nitcher, 1994) have argued that an effort must be made to understand lay interpretation of cause of a particular illness. This is because, an understanding of lay disease causation beliefs have important implications for utilization of health care services and health-seeking behavior.

Moreover, such awareness enhances the clinical

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Abbreviation: TB, tuberculosis.

interaction and communication between the patient and clinician. Several studies (Nitcher, 1994; Zvosec, 1996; Nachman, 1993) have indicated that there are differences between a health professional's view of the cause of TB and that of the patient. Treatment for TB today is structured on the biomedical model. The biomedical model works on three assumptions: illness has a single underlying cause; disease (pathology) or germ theory is always the single cause; and removal of the disease will result in a return to health (Wade and Halligan, 2004). The history of treating TB has shown the limitations and inadequacies associated with such assumptions. A linear cause and effect link, patients classified by disease category and the treatment of the specific disease are the approach followed in the biomedical model. A critique of such model raises several questions. How is the doctor-patient relationship setup? What is the role of the patient and doctor in this relationship? In the biomedical model is there any space for patient's or community's perception of illness? In many societies, including India often there is a disconnect between the perception of illness of a patient and that of the doctor. This is even more evident in the case of a chronic long lasting disease like TB. It is against this background that this study is envisaged.

METHODOLOGY

The study was carried out among TB patients undergoing treatment in rural areas of Yadagirigutta and Chintapally TB unit regions in Nalgonda district in A.P. in South India. The study included TB patients aged between 18 and 72 years. The sample consisted of 100 patients. The demographic information of the SAMPLE is summarized in Table 1.

Interviews of informants were guided by the explanatory model of illness suggested by Kleinman (1980:106) for assessing clients' beliefs about the cause of their illness. Explanatory models are sets of beliefs or understandings that patients, families and practitioners have about a specific illness. Explanatory models (EMs) of illness encompass a person's or physician's ideas about how an illness episode is caused, its mode of onset and symptoms, pathophysiology, and its treatment. Individuals in all sectors of healthcare develop their own explanatory model (EM) of disease or illness (Kleinman 1980). The main interview question was: What do you think has caused your TB? Socio-demographic data was obtained from the respondent's medical record. By design, this study is qualitative with the intention to elicit a range of TB causation beliefs through discussions. Informants' beliefs are presented in the form of narratives to illustrate the subjective opinions of patients.

RESULTS AND DISCUSSION

Causes of TB: beliefs of patients

In this study TB patients displayed a wide range of

traditional medical beliefs about TB causation. To the question, '*What do you think causes TB disease?*' patients suggested that a number of natural (such as smoking, alcohol consumption, poor diet, heredity, worries and emotional stress, hard work and exposure to sun, cold weather, dust, sleep deprivation, cold foods, close contact with the utensils/clothes used by a TB patient, being close to the patient and sex with prostitutes) and supernatural factors (e.g., divine retribution, witchcraft, fate, evil eye), could play a role in the causation of tuberculosis for other people. However, to the open-ended question, '*What do you think has caused your TB disease?*' Almost all the patients focused on just one factor as the most important cause of their TB. Patients' beliefs about causes of their TB are presented in Table 1. Patients' narratives of TB causation embrace the notion that disease causation understandings are grounded in the context of day-to-day living situations and experiences. The causal explanations for TB discussed by the patients in this study can be grouped into two broad categories: (1) natural and (2) supernatural causes. 10 respondents mentioned that they do not know what caused their disease.

It is evident from Table 2 that the four most commonly reported causes of TB were excessive alcohol consumption (27%), mental stress/strain (12%), infection (10%) and witchcraft (9%). Overall, this sample of TB patients predominantly (80%) attributed causation of TB to natural forces.

Natural causes

Excessive drinking of alcohol

Of the 100 patients, 27 (27%) patients reported heavy alcohol drinking along with poor diet as a possible cause of their TB. Several male patients stated that they sometimes coped with stresses and strains in life by turning to alcohol. The following account provides an insight into how alcohol is understood in the community to cause TB.

Chandraiah, a 42-years-old, farmer, said:

In my opinion, alcohol drinking is harmful to ones health because of the fact that it makes one neglect eating. You know, most of the alcoholics prefer tasty food (preferably made of meat/eggs) whenever they consume alcohol. But poverty prohibits the purchase of such food items. Basically alcohol kills the appetite and so one eats less. As a consequence, body becomes weak due to appetite depression and poor dietary habits. This causes weakness and puts a person at risk of developing different

Table 1. Socio-demographic characteristics of the study sample (n = 100).

Variable	No %
Age group (years)	
18-25	08 (08)
26-35	15 (15)
36-45	29 (29)
46-55	26 (26)
56+	22 (22)
Sex	
Male	76 (76)
Female	24 (24)
Marital status	
Married	84 (84)
Widow/widower	10 (10)
Single	06 (06)
Caste	
OC	04(4)
BC	62(62)
SC	26 (26)
ST	08(08)
Religion	
Hindu	92 (92)
Christian	05 (05)
Muslim	03 (03)
Education	
Non-literate	62 (62)
Primary	23 (23)
Secondary	12 (12)
College	03 (03)
Occupation	
Agriculture	34(34)
Labor	32(32)
Self-employed	20(20)
Private employee	04 (04)
Student	06 (06)
Others	04 (04)
Annual income	
10,000-20,000	12 (12)
21000-30000	25 (25)
31000-40000	32 (32)
41,000-50,000	13 (13)
51000-60000	08 (08)
61000-70000	06 (06)
> 80000	04 (4)

Source: Field-work, 2009.

Table 2. Perceived main cause of TB given by patients (n = 100).

Cause	N	Percentage (%)
Excessive alcohol consumption	27	27
Mental stress/strain	12	12
Infection	10	10
Witchcraft	9	9
Heredity	6	6
Bad blood	5	5
Fate	5	5
Hard work	4	4
Evil eye	3	3
Divine retribution	3	3
Cold foods	2	2
Cold weather	2	2
Sleep deprivation	1	1
Foods and drinks with high sugar content	1	1
Do not Know	10	10

Source: Field-work, 2009.

diseases including chronic cough and tuberculosis. I understand that alcohol acts like an acid and directly affects the lungs and stomach by causing holes in them. You know, germs thrive in the damaged parts of the lungs and cause TB.

Mental worry/stress

12% (12) of respondents mentioned certain life events such as death of a son, family conflicts, suicide or mental worries as possible causes of TB. The following quotes illustrate how psychological problems contributed to the development of TB. One patient described death of his son as a possible cause of his illness. He said:

My young son got killed in a lorry accident. It came as a total shock to me. I will never get over from this shock. My life ended with my son's death. He was a wonderful man. The past one year has been horrible for me. I strongly believe that mental stress played an important role in the onset of TB in my body.

Another patient, Anjamma, a 35-year-old mother of three young children, described her thoughts about marital stress as the cause of her illness. She said: My husband is an alcoholic. He abuses me verbally and physically. He is intimidating and irresponsible. We fight a lot. I was beaten several times. I am helpless. I was under a lot of stress lately. I worry about my kids' future. I am sure it was this stress that brought the tuberculosis on me.

Hot-cold imbalance

9 (9%) patients attributed their illness to hot-cold imbalance (humoral pathology) in the body. In the study area, hot-cold belief system is very popular.

The fundamental principle of this belief system lies in maintaining a proper balance between heat and cold qualities in the body and disease results when the equilibrium between these two qualities is disrupted. In the study area, a variety of diseases (such as cold, cough, TB and many other respiratory related diseases), are classified under cold disease category. Oranges, guava, lemons, custard apple and cucumber are often treated as cold foods.

According to the respondents a wide variety of factors including over consumption of cold foods and over exposure to extreme hot or cold temperatures may cause imbalance between hot-cold qualities and weaken the body.

Cold foods

Two participants attributed their TB illness to over consumption of cold foods. Sathemma, a widow aged 55-years, said that over consumption of cucumbers caused imbalance between heat and cold qualities in her body. She believed that excessive cold in the body could have chilled the lungs and caused build-up of mucus in the lungs. She thought that accumulation of mucus in the lungs must have contributed to the onset of TB.

Cold weather

Two patients attributed their illness to excessive exposure to cold weather. One participant, Ilamma, 38-year-old, laborer, for example, expressed that:

Exposure to cold weather can cause TB. You know, once cold wind enters the lungs it chills the lungs, which can cause cough and cold. This leads to build-up of mucus in the lungs and causes TB.

Bad blood

Five percent of total sample cited bad blood as a cause of their disease. When we asked what was meant by bad blood, patients said that bad blood refers to blood which has become '*spoiled*' as a result of overheat in the body. There is a widespread perception among the patients that over consumption of hot foods (such as mangoes) or excessive exposure to hot sun could spoil the blood and this spoiled blood gets accumulated in the form of lumps in the body. It was observed that basically extra-pulmonary patients who developed lumps in different parts of the body attributed overheat in the body as a cause of their disease.

Infection

10% of respondents considered the cause of their disease to be the contagious nature of TB. It is believed that TB can spread from one person to another through air and sharing clothes, food and utensils with the TB patients. It is also assumed that physical contact with urine and saliva of the TB patient also causes TB. The notion that tuberculosis is contagious and can be transmitted interpersonally is reflected in the following statements. One patient, Venkatesh bachu, a 46 year-old auto driver, said:

I got TB by using a plate that had been used by my late father, who had died of TB.

Another patient, Maheswari, a 29-year-old housewife, talked about contracting TB while caring for her mother. She stated:

I had cared for my mother who was a TB patient. We both slept in the same bed room. Since then, I have been having fever and cough. I have a strong suspicion that I might have contracted TB from my mother.

Heredity

Six patients having family history of TB believed that heredity played a role in causing their illness. Concerning heredity, for example, Lalitha, a laborer, 32-year-old, went on to explain:

If a mother or father has TB, then they will pass on TB to their children. My mother died of tuberculosis and my elder brother suffered from TB in the recent past. I think my mother might have passed on TB to me and as well to my brother.

Hard work

Four patients attributed their disease to hard work. An illustrative example was given by Gopi Buchaiah, a farmer, 67-years-old, when he commented on the cause of his tuberculosis:

I was a farmer. As a part of my work, I had to work strenuously under the hot sun for most part of the day. You know, I spent most of my life working in the agricultural fields. I think when you work hard under the hot sun, it weakens your body. It seems to me that physical weakness might have contributed to the onset of TB.

Sleep deprivation

One patient linked tuberculosis to sleep deprivation. Sathaiach, a 28 year-old laborer, said:

I had so much chronic pain in my left foot. Oh, it was a terrible experience. The pain was unbearable. I had trouble with my sleep. In fact I had no sound sleep during the night for more than one year. I never ever felt relaxed after sleep because of excruciating pain. I believe that sleep deprivation seriously affected my body and health, and I suppose sleep deprivation cause TB.

Diet high in sugar

One respondent linked his illness to consumption of foods and drinks with high sugar content. Mekala Nagaih, 53 years-old, rickshaw puller, said:

I had foods with high sugar content such as tea and sweet bread. I think sugar might have got accumulated in the blood and lungs.

Accumulation of sugar in the lungs might have caused cold and cough. You know, cough persisted for a long time and then it might have eventually resulted in TB.

One of the interesting findings of this study is that none of the patients mentioned sex with prostitutes or germs as a possible cause of TB. Studies from other parts of the world have identified extra-marital sex as a cause of TB but in this study no patient admitted this as a cause, though in discussions with the community there was a reference to it.

Supernatural causes

20 (20%) patients attributed their TB to supernatural forces such as witchcraft, divine retribution and evil eye. Evil eye, divine punishment and witchcraft as an etiological agent of illness are a timeless and universal phenomena (Stevens Jr. 1982; Buonanno, 1984). In several societies, serious and life-threatening illnesses, sudden death, certain types of mental diseases and treatments that do not respond to conventional treatments are perceived to be caused by supernatural factors (such as witchcraft). In the study population, witchcraft and evil eye accusations and suspicions usually manifested among neighbors or close blood relatives. The most commonly ascribed motives for causing harm are related to jealousy or hatred.

Witchcraft

Nine patients associated their illness state to witchcraft. A 35-year-old woman, stone crusher, had the following story to share:

My husband and his brother quarreled over the land rights. Discussions about sharing land became heated and ended in violence. My husband had not conceded to his brother's demands. You know, my brother-in-law became very jealous. I think he would have taken the help of a sorcerer to inflict a disease on me.

Another patient, 42 year old Laxmi, revealed:

I owed money to a person who happened to be a black magician. He has been very angry with me because I did not repay the money to him. I strongly suspect that he might have bewitched me. I went to the witch doctor to find out the source of my illness.

Witch doctor explained to me that a black magician bewitched me. You know, my illness is

not a regular type of illness, if it was a regular illness I could have recovered with pills and injections, but I have been sick for more than one year now.

Evil eye

Three respondents expressed evil eye as a cause of their disease. For instance, Budamma, a 52 year-old woman, attributed her illness to evil eye. She alleged that her neighbors had become jealous of her family because of the fact her husband had constructed a good house. Analysis of above narratives reveal that there is a belief within the community that an individual's upward social and economic mobility sometimes can result in feelings of envy and anger that can lead to witchcraft or evil eye.

Divine retribution

Three respondents attributed their illness to the acts of God. For example, Indira, a 40-year-old patient, noted that failure to adhere to religious observances caused her illness. She firmly believed that god has sent this illness as a punishment for neglecting religious observances.

Fate

Five respondents expressed fate as a cause of their TB. Individuals expressed occurrence of TB as God's will. Komariah, a laborer, 39 years-old, for example, commented that:

Life and death are in God's hands. If you are going get TB or for that matter any other disease, you are going to get it. Any how you got to die with something. I think it is God's will. There is nothing we can do about it.

Conclusion

It was apparent from the patients' narratives that patients focused on one particular cause when describing why they had tuberculosis. For example, at the time of group discussions, several patients suggested that different factors (such as alcohol, weakness, hard work, malnutrition, extra-marital sex and mental worries), could play a role in the causation of tuberculosis for other people. However, they chose to focus on a single cause, such as alcohol consumption or stress, when talking about what had caused their own tuberculosis. There are

several possible explanations that could be attributed to this finding. For instance, patients may seek simple explanations due to processing limitations, or may find that a single cause may lead to a greater sense of control. On the other hand, patients may have understood the question they were asked as seeking a single, major cause and therefore, obliged with single major cause.

Many findings of this study of TB patients' in Nalgonda district are similar to those of other earlier research studies (Nitcher, 1994; Zvosec, 1996; Carey et al., 1997). The results of this study suggest that there is a considerable disparity between the lay and biomedical explanations of cause of disease.

Patients with tuberculosis described the causation of their TB in ways that differed significantly from that of health professionals. Patients' descriptions were much personal and contextual. Patients concentrated on the underlying cause of a disease rather than on the underlying pathological process. These illness causation narratives clearly demonstrated that for the patients mind, body, and spirit are interconnected and disruptions in any one aspect can affect the health of an individual.

Findings also suggest that patients' knowledge about TB causation and transmission impacted on their health-seeking behavior. Such beliefs (e.g., TB caused by witchcraft or evil eye) may cause delays in seeking early care and non-adherence to TB medication. Moreover, erroneous beliefs about the cause and transmission of TB (e.g., transmission through sharing clothes or utensils) may lead to social stigma and isolation. The findings from this study seem to have important policy implications for health education. Most health education programmes for TB are designed in the biomedical framework and often do not related to the lives and experiences of the community. Health care professionals should make an attempt to develop culturally sensitive health educational programs and policies that reflect the beliefs and attitudes of people about TB. By dismissing such views and perceptions of patients as wrong and unimportant, mainstream health care providers are unable to see the larger picture. This is a major reason why most TB programmes have not been effective. The disconnect between the biomedical model and explanatory models needs to be addressed by the former if TB has to be controlled.

Limitations

One of the limitations of the study was small sample size. Another limitation of the study was that the participants came from rural regions of Nalgonda district. Since this is an exploratory, qualitative study, the conclusions of this study cannot be generalized to other rural populations. However, despite these limitations, we believe that the current findings contribute to new knowledge that could be useful in planning for effective TB educational programmes in order to create better awareness of TB among the rural communities.

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