

Perceptions and Experiences of Rural Patients with Tuberculosis: A Study of Nalgonda District, A.P.

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By

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CERTIFICATE

This is to certify that the thesis entitled “*Perceptions and Experiences of Rural Patients with Tuberculosis: A Study of Nalgonda District, A. P.*”, submitted by B.Venkat Raju, bearing Regd. No. 05SRPH01 in partial fulfillment of the requirements for the award of Doctor of Philosophy in Regional Studies is a bonafide work carried out by him under my supervision and guidance.

The thesis has not been submitted previously in part or in full to this or any other University or Institution for the award of any degree or diploma.

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DECLARATION

I B. Venkat Raju hereby declare that this thesis entitled “*Perceptions and Experiences of Rural Patients with Tuberculosis: A Study of Nalgonda District, A. P.* ”, submitted by me under the guidance and supervision of Prof. Sheela Prasad is a bonafide research work. I also declare that it has not been submitted previously in part or in full to this university or any other University or Institution for the award of any degree or diploma.

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LIST OF ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
A.P.	Andhra Pradesh
ARTI	Annual Risk of TB Infection
BCG	Bacille Calmette Guerin
CAM	Complementary and Alternative Medicine
DOTS	Directly observed therapy- short course
DTO	District Tuberculosis Officer
HBCs	High TB Burden Countries
HDI	Human Development Index
HIV	Human Immunodeficiency Virus
IEC	Information, Education and Communication
MDR-TB	Multi-Drug-Resistant Tuberculosis
NFHS	National Health and Family Survey
NSN	New Smear Negative
NSP	New Smear Positive
NTP	National Tuberculosis Programme
PHC	Primary Health Care
RMPs	Rural Medical Practitioners
RNTCP	Revised National Tuberculosis Control Programme
TAD	Treat After Default
TB	Tuberculosis
THs	Traditional healers
TU	Tuberculosis Unit
WB	World Bank
WHO	World Health Organization

CHAPTER

1

Introduction

Disease has become the focus of the technologic and market-driven medical system while illness and socio-cultural aspects of medicine have blurred into the background. Yet, the healing tools and instruments of science are blunt and ineffective when used blindly in ignorance of the meaning and context of a patient's illness. We need to foster attitudes, values, and communication skills that focus on illness, not just disease, to prepare ourselves for the challenges ahead.

(Green 2002: 143)

1. 1 Introduction

Health, disease and illness are universal facts of human life. In the scientific paradigm of Western biomedical model, disease refers to a specific clinical entity characterized by deviations and malfunctions in the structure or function of any part, organ or system of the body (Fabrega 1975; Burgess 1986). *“The biomedical model has been defined as characterized by a focus on the treatment of the body alone as a pathogenic agent independent from the social and psychological context of the patient. It is thought to be based on scientifically accepted knowledge and rationalistic thought processes from which diagnosis is derived and therapies determined”* (Kornfield 1986:367). That is, biomedical model proposes that each disease is an abstract biological ‘thing’ or condition that is, generally speaking, independent of social behavior (Helman, 1978). From a biomedical model perspective, disease management tends to be limited to efforts to correct abnormalities in the structure and/or function of any part, organ or system of the body. 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.

Illness, on the other hand, is a much broader concept that refers to the “*subjective response of the patient to being unwell; how he, and those around him, perceive the origin and significance of this event; how it effects his behavior or relationships with other people; and the steps he takes to remedy this situation*” (Helman 1981:548). Several authors (Ware & Kleinman 1992; Kleinman 1995) contend that all illnesses have a social course in that interpretation of symptoms, help-seeking, diagnosis, choice of treatment, and evaluation of outcome of treatments are all significantly influenced by economic, cultural and psychosocial factors acting in tandem with biological processes. Schneider & Conrad (1983:3) argue that “*while illness and disease are related, they are not the same. Disease is understood best as an undesirable physiological process or state. Illness, in contrast, has less to do with problems of body per se than with the social and psychological phenomena that accompany these putative physiological problems*”.

Ruiz (1985) argues that physicians generally pay more concentration to identifying the patho-physiological cause of a disease, and implementing the appropriate treatment regimen, however, once the diagnosis is established and the treatment regimen prescribed, hardly any attempt is made in understanding the physical, social and psychological suffering of patients. Kleinman *et al* (2006:146) suggest that:

The biomedical view of clinical reality, held by modern health professionals in developing as well as developed countries, assumes that biologic concerns are more basic, “real,” clinically significant, and interesting than psychologic and sociocultural issues. Disease, not illness, is the chief concern: curing, not healing, is the chief objective. Treatment oriented within this view emphasizes a technical “fix” rather than psychological management. It is less concerned with “meaning” than other forms of clinical care. It deals with the patient as a machine.

Similarly, Green (2002) argues that modern medicine faces a number of crucial and conflicting challenges. Green contends that tremendous surge in medical technology has driven the medical system even further toward a ‘disease-based’ approach to medical care that views individuals as cases and undervalues psychosocial aspects of patient care. Kleinman (1978:88), a much referred medical anthropologist, suggests that

“professionals see sickness only as disease and proffer explanations that transmit technical information and treatments that are technical “fixes”, whereas patients seek not only symptom relief, but also personally and socially meaningful explanations and psychosocial treatments for illness”. Ruiz (1985) holds that in order to treat people effectively, medical practitioners should supplement theoretical ideas with knowledge about the patients’ subjective experiences dealing with illness. Illness experience may include judgment about when and how to initiate treatment, concern over lost health, disturbances in interpersonal relationships, loss of self-esteem, altered body image, disability, and fear of dying. The experience of illness cannot be considered in isolation from the cultural context in which it occurs. Cultural perceptions and beliefs play a significant role in shaping illness experiences. This is especially the case for socially stigmatized illness such as Tuberculosis (TB).

The occurrence of TB illness is much more than a biophysical event; it has far-reaching social, economic, psychological and spiritual implications on the sufferers and as well as on the community members. The occurrence of disease not simply incapacitates an individual in some mechanical sense, but rather it affects an individual’s capacity and performance as a participating member of a highly interdependent group (Fabrega, 1975). Hence, illness in general and serious and stigmatized illness in particular, is considered as biographical disruption of a person’s ongoing life. This is because, illness affects equilibrium in social relationships by impairing one’s ability to perform social roles, obligations, and social relationships at a number of levels. In other words, illness frequently threatens the taken-for-granted world of everyday life. Indeed, as Freund *et al* (2003:127), point out in an article titled ‘*The Social Meanings of Sickness*’:

Illness represents a threat to the order and meanings by which people make sense of their lives and organize the routines of their everyday existence.

Arthur Kleinman (1980), suggests that to provide care that effectively meets the patients’ and their family members’ psychosocial needs, a culturally sensitive clinician not only focus on disease and its treatment, but on patients’ ideas about what is wrong with them, their fears about severity of illness, the impact illness has on their physical

and psychological functioning, and their expectations about what should be done. According to Kleinman (1980) patients have different view of the illness, its origin, its severity and its treatment than that held by the modern biomedical practitioners. Understanding patients' subjective perceptions and experiences living with illness is very crucial for the delivery of better medical care. In other words, an exploration of what it is like to actually live with illness provides key insights into the problems and needs held by patients living with illness. Prevention and education programs that ignore lay illness perceptions and experiences are unlikely to be effective. Exploring subjective experience of illness is particularly relevant in the case of TB, where patients and physicians have divergent perceptions, concerns and goals. Green (2002:141) rightly argues that "*a medical system that allows physicians to refocus on the patient-centered, personal, and unique experience of "illness" is an imperative for our time*".

1.2 Background to Study

Despite the tremendous advancements made in the field of medical sciences over past few decades, it is disheartening to note that infectious diseases remain the leading cause of morbidity and mortality, and continue to be major public health problems across the globe. According to Inhorn & Brown (2000), since 1973, more than thirty new infectious diseases have been recognized including HIV/AIDS, hantavirus pulmonary syndrome, ebola hemorrhagic fever and legionnaires disease. Moreover, a number of age old infectious diseases such as cholera, malaria and TB once considered to be under decline or control, have emerged as serious public health threats worldwide, and are once again threatening the lives millions of people in resource poor countries (WHO 1998).

TB has been historically one of the greatest infectious killers of all time, and has brought untold miseries to communities and nations since antiquity. In 1993, 111 years after the causative organism was identified, and half a century after the introduction of anti-tuberculosis drugs, the World Health Organization (WHO) declared TB a '*Global Emergency*' (Long *et al* 1999). This was the first and only disease ever singled out in this manner by the WHO. Even in the 21st century, TB continues to rank among the world's most profound public health problem despite being a curable and treatable disease. The goal of control of TB with efficacious drugs continues to be elusive.

From a global perspective, the political, social, psychological, economic, medical and public health burden of TB is enormous and incalculable (Ilongo 2004). Even today, people in different parts of the world have a universal fear of TB. The impact of TB is felt in all sectors of society in terms of lost productivity, lost income, emotional distress, fear, social isolation, stigma and discrimination. TB creates thousands of orphans worldwide each year (Long *et al* 1999), and pushes many vulnerable and marginalized families into vicious cycle of poverty. “*TB impoverishes families, undermines economic development, impedes human development and traps the world’s poorest and the most marginalized in a vicious cycle of disease and poverty*” (ICMR 2002: 1). It is noted that every year, globally, TB related morbidity and mortality cause the loss of millions of potentially healthy and productive years of life. This is all in the face of an available, cost-effective treatment and cure (WHO 2001).

TB holds the seventh rank among the top ten causes of morbidity and mortality in the world, and is likely to continue in the same position up to 2020 (Montoro & Rodriguez 2007). The stark reality is that TB is the leading cause of death among the young and adult population from a single infectious pathogen (Mohan & Sharma 2001), and kills more women, than all the causes of maternal mortality. It is estimated that over half a million children and 250,000 women die from this disease every year (WHO 2006). TB causes more deaths in those over age 5 than any other infectious disease alone and more than the deaths from malaria, diarrhea, AIDS, and other tropical diseases combined (World Bank 2003; Mohan & Sharma 2001). About one-third of the global population (nearly 2 billion people), is infected with *Mycobacterium tuberculosis*. In 2009, conservative estimates suggest there were 9.4 million active TB cases worldwide, and more than 3 million deaths. Women account for more than 3 million (35% of all TB cases globally) cases worldwide (WHO 2010). Of all the estimated 9-10 million new TB cases occurring annually on a global scale, approximately 81% of total new TB cases occur in 22 developing countries, defined as high TB burden countries (HBCs). The stark reality is that India ranks first among the list of 22 high TB burden countries in the world (WHO 2010).

Despite the introduction of TB control programs since 1962 in India, TB still remains a leading killer of economically and reproductively active adults. The number of

TB cases continued to increase in proportion to the growth of the population in India. Factors such as deterioration in living conditions, population explosion, overcrowding, environmental degradation, substandard sanitary measures, inadequate public health services, spread of HIV/AIDS and Multi-Drug Resistant TB (MDR-TB) may further worsen the situation of TB in the country. In India, it strikes millions of people each year exacting a toll higher than many tropical diseases put together. Each year 2 million people develop active TB and over 0.5 million die of this disease in the country. More than 75% of the total TB cases in India are in the age group of 15-54 years, the economically most productive section of the society. The situation of TB in the country is likely to worsen further as a result of emergence and spread of HIV/AIDS epidemic and MDR-TB. A former Director General of the WHO once remarked “*the whole world benefits from the fruits of Indian (tuberculosis) research – the whole world, except India*” (Khatri & Frieden 2002: 1420). In the state of Andhra Pradesh (A.P.), TB poses a very significant public health burden. More than 100,000 new tuberculosis cases occur in A.P., annually, where more than 65% of cases are in the economically most productive age group (15-54 years). TB constitutes an important cause of morbidity and mortality among poor people, and causes enormous social, economic, and psychological burden in the district of Nalgonda, A.P. 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).

TB continues to pose serious challenges to clinicians, public health professionals and health policy makers in India. Recognizing the seriousness of the TB situation in India, the WHO has warranted that if effective measures are not initiated to curb the TB epidemic in the country, consequences of the disease are likely to be detrimental to the vulnerable and marginalized populations in the country. From the perspective of the biomedical model, if the TB patient is treated regularly for the required period of time, the TB germs are controlled and the patient will recover effectively; uninterrupted and standard treatment for TB is all that is required.

Why then, has TB, a curable and treatable disease, become so resistant to eradication and control on a global scale? Why, in fact, are the numbers of new TB cases more importantly multi-drug resistant TB cases, rising dramatically worldwide? Scholars acknowledged that delays in seeking treatment (Cambanis *et al* 2005), non-adherence to

anti-TB treatment, drug resistant TB, and stigma (Sumartoja 1993), are the most serious barriers to the control and elimination of TB in large number of developing countries, India is no exception. Patient delay (i.e., the time between onset of symptoms to first consultation with qualified practitioners) constitutes one of the important barriers to successful control of TB. Delays in seeking care for TB may not only be detrimental to the individual patient, but also to the community. This is because, a single untreated smear-positive TB patient may infect 15 other individuals in a year (Wandwalo & Morkve 2000). Delays in diagnosis of TB worsen the disease condition in affected individuals and increase their risk of death (Cambanis *et al* 2005). Non-adherence to TB medication may result in higher rates of relapse, drug resistance, treatment failure and persistent infectiousness on the part of the patients. Social stigma associated with TB disease is also one of the major impediments to control of TB. Many studies (Jaramillo 1998; Kelly 1999; Auer *et al* 2000; Johansson *et al* 2000; Eastwood *et al* 2004; Atre *et al* 2004; Chesney & Smith, 1999) have shown that TB-related stigma substantially interferes with prevention efforts, emotional coping, successful disease management and treatment.

1.3 Statement of the Research Problem

The WHO recommended Directly Observed Therapy Shortcourse (DOTS) was introduced in India in 1993 as Revised National Tuberculosis Control Programme (RNTCP). RNTCP programme emphasizes TB cure strictly in bacteriological terms. There is no effort made to address the social and psychological needs of the patients under this programme. The treatment for TB today is structured on the biomedical model of disease. The history of treating TB has shown the limitations and inadequacies associated with the biomedical model's assumptions. Studies have found that the problematic aspect of having TB for several patients appears to be psychosocial rather than medical. A vast body of literature suggests that in order to control TB successfully, focusing on anti-TB drugs and advanced diagnostic techniques is not adequate. Several authors (Rubel & Garro 1992; Fox 2005) argue that a comprehensive understanding of social and cultural meanings that patients give to their illness experience is indispensable for the purpose of providing "*sensitive, empathetic, humanistic care that is respectful of*

patients, involves effective patient-centered communication, and responds to patients' psychosocial issues and needs" (Fox, 2005:1316).

Several studies have been conducted on the lay beliefs and perceptions about TB (Moloantao 1982; Metcalf 1990; Nachman 1993; Nitcher 1994; Zvosec 1996; Carey *et al* 1997; Vecchiato 1997; Banerjee *et al* 2000; Junekar *et al* 1998; Nagamvithayapong *et al* 2001; Knight *et al* 2001; Auer, *et al* 2000; Eastwood *et al* 2004; Cott 1987; Thomas, *et al* 1999; Liam *et al* 1999; Rajeswari *et al* 2005; Liefoghe *et al* 1997; Rajeswari *et al* 2002; Diez *et al* 2005; Saunderson 1995; Uplekar *et al* 1996; Wandwalo & Morkve 2000; Lonroth, 2001; Sudha *et al* 2003). However, most of these studies are quantitative in nature, and these studies largely ignored psychosocial suffering, and subjective experiences of people living with TB from an emic perspective.

Currently there are not many qualitative studies that explore social and cultural meanings that TB patients give to their illness experience in Andhra Pradesh, South India, and among rural TB patients in particular. Assessing the perceptions and experiences of TB patients about their illness, their reactions to initial diagnosis, the impact of the disease on their health (both physical and mental) and social life, and health seeking behavior is very crucial for improving the quality of a life of the TB patients. Long-term medical management for TB is inadequate unless a comprehensive approach is implemented. The present study was prompted by the recognition that, if a TB control programme is to succeed, socio-cultural barriers to effective TB treatment need to be overcome.

This study basically addresses the following key research questions:

- What symptoms do TB patients in rural areas of Nalgonda district, A.P., recognize as TB?
- How do patients interpret and respond to initial symptoms of TB?
- What kinds of lay theories and explanations patients develop to account for the causation of their illness?
- What is the reaction of patients on being told about their diagnosis?
- How do these explanatory TB causation beliefs guide health-seeking behavior?

- At what point and for what reasons do patients consult physicians and traditional healers?
- What are the socio-cultural factors that cause delay in seeking care?
- What is the impact of social stigma in the lives of TB patients?
- What are the knowledge levels of Rural Medical Practitioners (RMPs) about TB?
- What are the differences between the perceptions of patients and practitioners about TB?

An exploration of these research questions is crucial for providing quality care to the patients. For instance, exploring with patients why they believe they developed TB exposes important disconnects between the biomedical understanding of disease etiology and indigenous views of disease causation. Patients may be less likely to follow clinical recommendations if they do not accept clinical explanation of what is occurring in their body. The dissonance between patients' and professionals' explanatory models of disease causation may cause delays in seeking appropriate care. Understanding TB patients' explanatory models of TB illness sheds light on people's beliefs and attitudes about disease, risk of transmission and infection. Furthermore, an awareness of the life-world of the TB patient may facilitate a more profound understanding of the impact of illness on the patient.

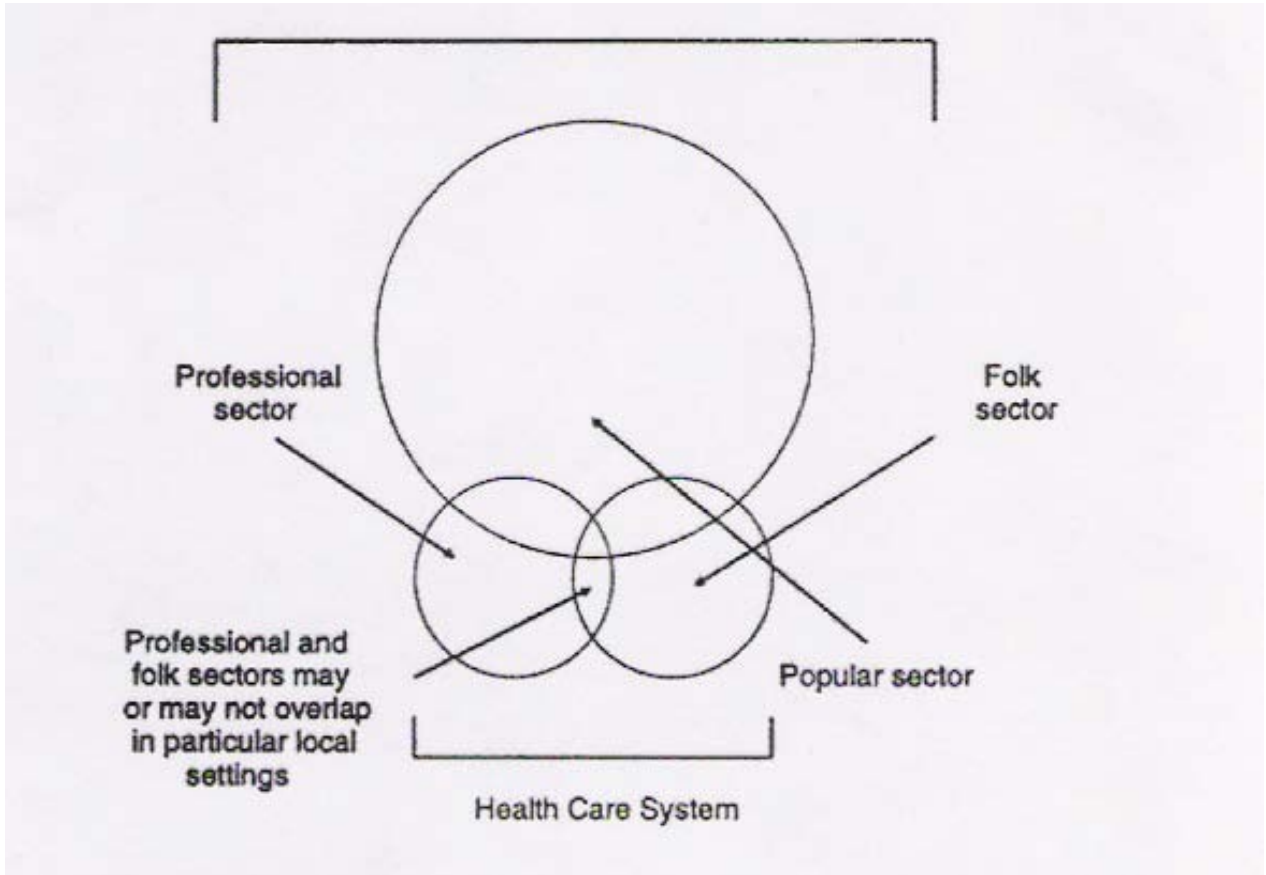
Explanatory models (EMs) are sets of beliefs or understandings that patients, families and practitioners have about a specific illness (Kleinman 1980). Explanatory models of illness framework provide a theoretical framework for understanding and explaining an individuals' perception of disease, and thus facilitate an understanding of context and meaning of illness. EMs contain explanations of any or all of five issues: **i)** etiology, **ii)** time and mode of onset of symptoms, **iii)** pathophysiology, **iv)** nature and severity of illness, and **v)** treatment. A physician's explanatory model of illness which is generated from biomedical knowledge answers most or all of the five questions mentioned above. However, patient models, which focus on illness experience, often do not answer all of these five questions. A patient may answer these same questions in a

different framework: What caused my illness? Why it started when it did? What is the nature of my sickness? How serious is my sickness? What kind of treatment should I receive? How does this illness affect my mental and physiological conditions? What will be the outcome of this illness?

Empirical evidence suggests that patients and families are often reluctant to disclose their own explanatory models of illness to their clinicians for various reasons including fear of derision or rejection. Hence, social scientists argue that clinicians must understand the fact that patients' beliefs and experiences related to illness are genuine and should be incorporated for clinical management. Kleinman (1981: 375) argues that "*explanatory models can lead the clinician to a multi-perspective pluralistic view of sickness that liberates him from a naive and severely limiting single-sided professional perspective. The explanatory models approach does not create a stereotyped rational man for clinician or researcher. It situates them in the patient's personal and social world, and makes unavoidable the human antecedents and consequences of illness, thereby humanizing medicine by anthropologizing it*".

Kleinman's (1980) concepts of tripartite model of the health care system, explanatory models of illness and the disease-illness dichotomy (Kleinman 1980), basically serve as the theoretical framework for the proposed study. Kleinman (1980) provides a useful typology for healing activities in complex societies. According to him, most health care systems consist of three overlapping categories or sectors within which sickness is experienced and reacted. These are: i) *popular*, ii) *folk* and iii) *professional*, (Fig 1). According to Kleinman, these three sectors or categories constitute the *local health care system*. "*Each sector can be seen as a separate subculture with different values, beliefs, practices, ways of communicating, and rules of behavior*" (Beech & Goodman 2004:197). Cultures vary considerably in the way they combine these three sectors of local health care system.

Fig. 1. Local Health Care System



Source: Kleinman (1980)

Popular sector (or lay health care sector), refers to the lay, non-professional, non-specialist, popular culture arena in which symptoms of ill health are often initially perceived and described, and treatment activities are initiated (Kleinman, 1980). The popular sector is described as a multi-level matrix consisting of individual, family, and “social nexus arenas in which decisions about illness and care are made and treatment is carried out” (Kleinman & Sung 1979: 8). The *folk sector* is the “non-professional, non-bureaucratic, specialist sector of health care that overlaps with the professional sector at the one extreme and the lay sector at the other” (Pool & Geissler, 2005:41). Folk sector includes sacred (e.g., spiritualists, witches, sorcerers, priests, diviners, and shamans) and secular (e.g., herbalists, midwives) folk healers. Although folk sector is frequently divided into secular and sacred therapists, in practice, this separation is often obscured

and the two usually overlap (Kleinman, 1980). *The professional sector* includes the organized health professions such as biomedicine, ayurveda, unani, acupuncture. Most symptoms of illness are accommodated within the popular sector. Kleinman acknowledges that three sectors of health care primarily mentioned above interact and overlap. In other words, the distinction between sectors is not complete. For instance, folk healers may adopt biomedical practices (e.g., stethoscope, injections, pharmaceutical drugs, etc.), and popular sector may embrace folk healing practices (e.g., herbs, diet, prayers, etc.). Kleinman argues that patients during an illness episode freely move among the three sectors of local health care system in sequential, alternative or simultaneous manner. For example, with the hope of a quick recovery from illness, individuals often seek treatment from two or more sectors (concurrently or consecutively) for the same health problem. In those societies where professional medicine is absent, the popular and folk health care sectors constitute the complete health care system (Kleinman, 1980). This study focuses on patients' explanations of the etiology of the illness and on their descriptions of symptoms, initial reactions to diagnosis of TB, TB related stigma, and treatment, including use of traditional remedies. In the process the study also seeks to understand the use, connections and overlap between the three sectors of the health care system.

1.4 Study Setting

The study was conducted in two Tuberculosis Units - Chintapally and Yadagirigutta (Fig 3), in Nalgonda district (Fig 2) of A.P. South India, covering a population of 4,25,812 and 3,99,206 respectively. Nalgonda district is one of the high TB burden districts in the state of Andhra Pradesh. The choice of Nalgonda for this study was governed by the following factors :

- the researcher belongs to this district which is in the Telengana region of A.P.,
- the district is close to Hyderabad and this facilitated field visits and follow up to the selected sites,
- the district is characterized by low levels of development (both economic and social) , poor health facilities, a high disease burden and a large rural population,

- further, the population of the district comprises a diversity of social groups.

All these factors played a role in the selection of Nalgonda district for this research.

Of the total population in Chintapally TB unit, 19% were tribals. In case of Yadagigutta TB unit, the percentage of tribal population was 10%. The selection of Chintapally and Yadagirigutta TB Units as the setting for the study was mainly for the following reasons. First, the District TB officer and TB supervisors expressed their willingness to participate in the study. Second, the investigator knew some health care workers who could introduce him to TB patients in the study areas. This helped the investigator in establishing rapport with the patients. Third, since the investigator was interested in the application of social science research to the improvement of health of rural people, it was felt that the chosen study areas should have typical rural features with low development, and similar TB incidence. Yadagirigutta and Chintapally TB units satisfied this criterion. Fourth, the study is intended to understand if differences exist between social groups, tribal and non-tribal patients' health-seeking behavior and TB causation beliefs, and the chosen areas represented different social groups and enabled a mixed sample for comparison. Fifth, the traveling distance between the study areas and the university where the researcher was located is short, and these areas are easily accessible by motorcycle.

A total of 110 patients, 20 RMPs, 10 Physicians and 4 Traditional Healers, were selected for detailed interviews using purposive sampling technique and data was analyzed based on the general guidelines of grounded theory. Grounded theory is a research "*strategy whose purpose is to generate theory from data*" (Punch 1998:163). This theory was proposed by Glasser and Strauss (1967) for studying complex social behavior. Glasser & Strauss contend that grounded theories offer insight, enhance understanding, and provide a meaningful guide to action since they are drawn from field data. The information that was needed for this study was very sensitive and highly personal. Hence, it was felt that the research objective was better addressed through a qualitative and explorative method.

1.5 Objectives of the Study

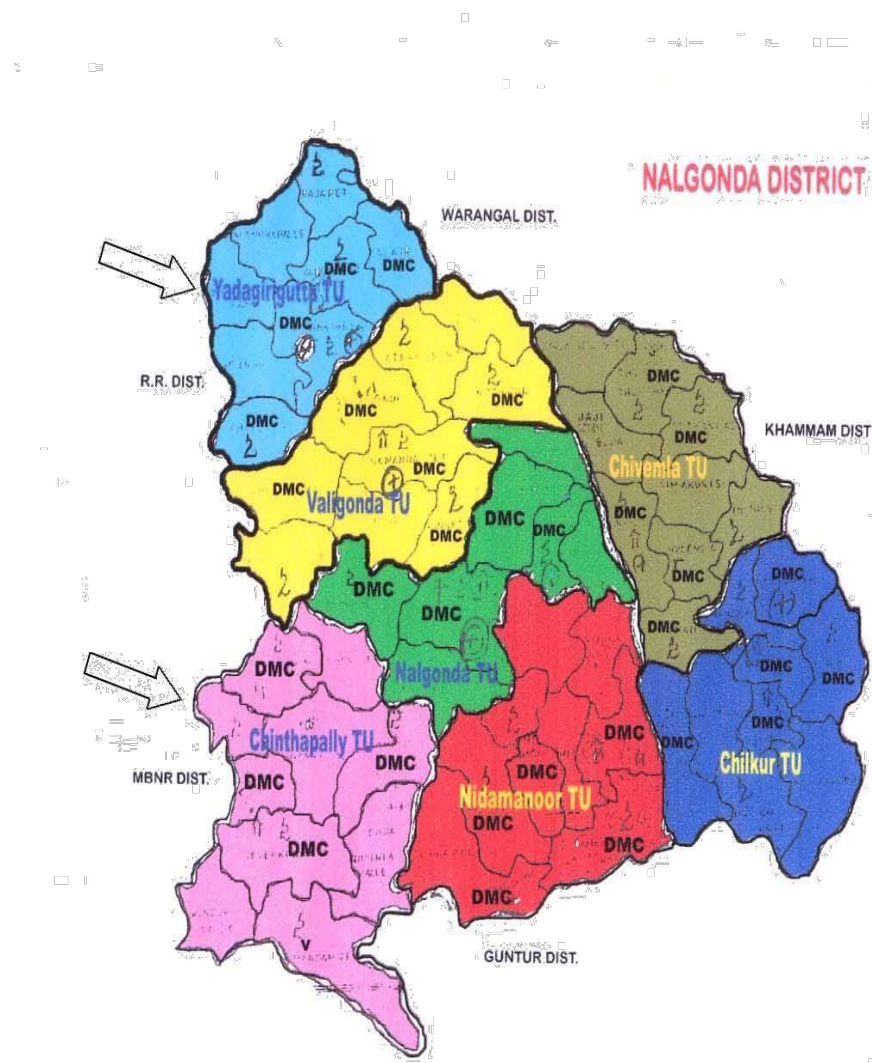
The specific objectives of this study are:

- To study beliefs held by TB patients about the cause of their TB.
- To study psychosocial reactions of patients to the diagnosis of TB.
- To explore stigma experiences of patients in their community.
- To understand the influence of socio-cultural factors in patient delay in seeking medical care.
- To study general patterns of health-seeking behavior among TB patients- the use of the three sectors popular, folk and professional.
- To understand knowledge about TB among rural health practitioners.
- To explore differences between patients' (emic) and medical practitioners' (etic) views on TB.

Fig. 2. Andhra Pradesh District Map Showing Nalgonda district



Fig. 3. Map of Nalgonda District showing the Location of Study Areas –TB units



1.6 Significance of the Study

Understanding what it is like to be sick with TB in society is crucial for various reasons: i) an awareness of perceptions and experiences of patients living with TB enables the physician to personalize his/her approach to patient care, and to motivate, inspire or negotiate with patients more effectively; ii) it is argued that a deeper awareness of the TB patients' experiences will lead to improved communication between the physicians and patients, and better patient outcomes; iii) knowledge of experiences of patients living with TB helps the health care workers in gaining a deeper understanding of the role of socio-cultural factors that influence an individual's willingness to seek care, how choices are made about treatment, socio-cultural factors that influence patient delays in seeking appropriate medical care, and psychosocial aspects of patient care; iv) a careful analysis of the illness experiences of TB patients will help in the planning of more comprehensive efforts to improve patients' quality of life; v) the findings of the study will be useful for providing an effective and culturally sensitive health care to the patients. Effective and culturally sensitive health care is an intervention that responds to the physical, mental, social and spiritual needs of the patients, and helps the patients to confront and cope with illness; vi) the outcome of this study would also enable RNTCP managers in India to plan future public health educational initiatives and public health communication programs for increasing knowledge and awareness of TB among rural populations; and vii) the findings of this may serve as a basis to shape psychological and social support interventions for patients with TB that will ensure effective care for patients.

The re-emergence of TB cases worldwide suggests the failure of TB control programmes based on the biomedical model. The biomedical model's assumptions, such as physical reductionism, mind-body dualism and mechanical metaphor cannot provide a complete understanding of human suffering. The socio-cultural diversity and the plurality of health care resources and practices that one finds in India certainly require a different framework of engagement in understanding of disease. Furthermore, TB being a chronic and stigmatized disease needs a different way of understanding the disease for treatment to be culturally sensitive. Review of literature suggests that non-compliance to TB medication is considered as a major problem in TB control. The failure of TB control

programmes is often attributed to non-compliance in taking the medicines regularly. There is a need to understand why different groups fail to comply with TB treatment regimen. Why do patients not take medicines regularly? There are social, cultural and economic factors for this that needs to be explored. Hence, there is an urgent need to look at other models that take the whole person and their socio-cultural context into account in treating of disease. Recognition of the explanatory models of TB illness is one of the most sensitive frameworks to practice patient-centered care and to improve the quality of the life of the patients.

1.7 Chapterization

The thesis is organized into eight chapters. The first Chapter, 'Introduction', provides a background to the broad research area, the statement of the research problem, key research questions, objectives, scope and significance of the study. It also presents the organization of the thesis into different chapters.

Second Chapter, 'Review of Literature' examines the literature on understanding disease and health care from a social science perspective. It covers studies on: culture, health and health care; lay beliefs and perceptions about causation of TB; reactions to diagnosis of TB; factors associated with patient delay in seeking early treatment; social discrimination and stigma associated with TB, and general pattern of health seeking behavior of TB patients. It also deals with the history of evolution of TB treatment.

Chapter Three, 'Research Design and Study Area', discusses the theoretical framework of the research, and research methods employed for the collection and analysis of data. The chapter also presents a profile of Nalgonda district. An attempt is made to briefly describe Nalgonda district in terms of its general geography, demography, development, available health care services and disease profile.

Chapter Four, 'Epidemiology of Tuberculosis', summarizes the data on the epidemiology of TB at global, national (India), state (A.P.) and district (Nalgonda) levels.

The Fifth Chapter 'Tuberculosis: The Experience of Illness', concentrates on three main themes based on experiences of TB patients in Nalgonda district. The first section looks at the causal factors considered by the TB patients in the development of their TB. Second section focuses on patients' psychosocial reactions to the diagnosis of TB.

Section three explores the stigma associated with TB, it examines the patients' experiences of stigma in the everyday local worlds (i.e. the every day, non-trivial, interpersonal transactions involving family members, partners, friends and colleagues). .

Chapter Six 'Delays in Seeking Care, and Health-Seeking Behavior', is divided into two sections. Section one explores the reasons why patients delay seeking treatment for TB. The decision to seek formal health care does not necessarily coincide with those expectations held by biomedical professionals. In some cases, lay individuals may not accept or understand the information offered by their doctors. Section two discusses the general patterns of health seeking behavior of TB patients, and the pursuit and practice of alternative therapies by TB patients.

Chapter Seven 'Perception of Practitioners on TB : RMPs, Physicians and Traditional Healers', is divided into two sections. Section one deals with knowledge about TB among the rural medical practitioners (RMPs) in the Yadagirigutta and Chintapally TB unit regions of Nalgonda. Section two explores differences in views on TB between patients and TB physicians. This also includes beliefs of traditional Healers on TB.

Chapter Eight 'Conclusion,' summarizes the major findings of the study. Implications of the study findings with regard to health education and providing culturally sensitive care are also discussed. Finally some possible areas for further research are outlined.

CHAPTER

2

Review of Literature

If you wish to help a community improve its health, you must learn to think like the people of that community. Before asking a group of people to assume new health habits, it is wise to ascertain the existing habits, how these habits are linked to one another, what functions they perform, and what they mean to those who practice them.

(Paul 1955:1)

This chapter reviews the research on mainstream concepts in medical anthropology and sociology; beliefs and perceptions of TB among lay communities, general pattern of health seeking behavior of TB patients, and evolution of TB treatment.

2.1 Key Concepts in Medical Anthropology & Sociology

There is unanimous agreement in the social science community today, that understanding how the patient perceives of disease, its etiology, prognosis and treatment is indispensable for the purpose of providing culturally sensitive care. To understand how members of different cultural groups perceive, explain and treat disease, it is necessary to first explore some of the key terms, concepts, definitions, general foundations, and theories developed in the field of medical anthropology and sociology. In this first section, the following key concepts in medical anthropology and sociology are discussed: the concepts of health, disease and illness; cultural influences on recognizing and interpreting symptoms; lay theories and disease causation; medical pluralism; sectors of

local health care system, symptom iceberg; health-seeking process, assumptions and criticisms of the Western biomedical model; biopsychosocial model; Kleinman's explanatory model of illness; health belief model; and medical efficacy. The chapters that follow use some of these foundations, and assist the medical practitioners, health care policy planners, and students in medicine, nursing, health administration and public health, in better understanding the processes, issues, and challenges to be faced in the promotion of health, in the disease prevention activities, in the enhancement of quality of life, and in the development of health care policies in a pluralistic health culture.

2.1.1 The Concepts of Health, Disease and Illness

Any critical discussion of the relationships between culture and health care practices must first attend to the definitions of *health*, *disease*, and *illness*. These definitions are of crucial importance, because these definitions help us great deal in understanding how people belonging to different cultural contexts and traditions conceptualize and experience health, disease and illness.

Health

Health is an important asset of a community, and is the most basic and paramount need of an individual. This is because, health plays an indispensable role in influencing an individual's everyday activities, and shaping his/her attitude towards life (Pokarna, 1991). Thus, a state of good health is very important for the adequate functioning of any individual (Cockerham, 1978). According to Pol & Thomas (1992), the term 'health' is one of those terms which most people find difficult to define even by example. This is because, health is a relative concept in that what is viewed as health in a particular society or community may not be viewed so in another society or community. A wide range of definitions (e.g., *negative, positive, functional and experiential definitions*), have been proposed to interpret the meaning of normal healthy state, all of which have certain short comings.

An example of positive definition of health is given by the World Health Organization (WHO 1978). It defined health as "*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*". This definition is

very comprehensive in nature, and provides a framework for studying health in a broader and holistic perspective that includes social, psychological and subjective dimensions. Thus, this definition recognizes the influence of the various social, economic and environmental factors on a person's well-being. However, this definition has been criticized by many people for two important reasons. Firstly, it has very limited practical use, and secondly, this definition is composed of indefinable terms. For example, what does 'disease', 'infirmity', and 'social-well being' mean in the WHO's definition of health? Furthermore critics argue that this definition of health is too idealistic which is unattainable. For instance, no individual would ever describe himself/herself as being in a state of complete physical, mental and social wellbeing. That is, this utopian vision of health is certainly an unattainable ideal, bearing no relation to struggles, failures and suffering of people in real life situations in an imperfect world (Dubos 1965). Dubos (1965:346) for instance, notes that:

The concept of perfect and positive health is an utopian creation of the human mind. It can not become reality because man will never be so perfectly adapted to his environment that his life will not involve struggle, failures and suffering.

By contrast, an example of a negative definition of health is that offered by biomedical profession. Medical model of health defines *health as the absence of disease or biological disturbance*. Implicit within this definition is the belief that an individual is classified as unhealthy (i.e. diseased), when the functioning of one or more parts of the organs/systems of the body is impaired. Thus, this definition is essentially a negative one in the sense that health exists only when an individual is free from disease (Green, 1992). This definition has been criticized because it is too narrow and it “*does not seem to do justice to the full human experience of feeling well (or not feeling well)*” (Wright, 1985: 287).

A functional perspective of health is proposed by Talcott Parsons (1979). This definition focuses particularly on the ability to participate in normal social roles.

According to Parsons (1979:132):

Health may be defined as the state of optimum capacity of an individual for the effective performance of the roles and tasks for which he has been socialized. It is thus defined with reference to the individual's participation in the social system. It is also defined as relative to his "status" in the society, i.e. to differentiated type of role and corresponding task structure, e.g., by sex or age, and by level of education which he has attained and the like.

Critics argue that this definition lays emphasis on the optimum capacity of an individual, anything other than this not considered as health. Therefore, it fails to allow for the existence of variations in health.

Another approach to definition of health is via the examination of people's experiences and perceptions of health. Sociological and anthropological research studies (Bauman, 1961; Herzlich, 1973; Blaxter & Patterson, 1982; William, 1983; Calnan, 1987), on lay concepts of health suggest that people hold a wide variety of beliefs concerning health, and such beliefs vary across cultures. Lay concepts and logic about health (also illness) are not those of science or modern medicine, "*although they may be borrowed, accurately or inaccurately, from those formal systems of knowledge*" (Freund *et al* 2003:171). Rather, socio-cultural factors such as age, gender, ethnicity, social class, socialization, cultural background, education, socio-economic condition, cultural beliefs, physical and mental condition, personal aspirations, religious affiliation, social network, etc., play an important role in shaping an individual's conceptualization of health (Freund *et al* 2003). Evidence from a variety of studies with children, adolescents, and old people on concepts of health generally suggest that health is described in different ways: *negatively* as the absence of illness, *functionally* as the ability to cope with everyday activities and being able to do the desired and/or required activities, or *positively* as fitness and well-being, feeling good, and able to cope with stresses and crises in life.

Baumann (1961) conducted a study on diversities in conceptions of health and physical fitness among medical students and patients of Out-Patient Clinic of the New York Hospital. He found that respondents defined health in terms of three major orientations: i) *Feeling-State Orientation* (a general feeling of well-being); ii) *Symptom Orientation* (absence of illness); and iii) *Performance Orientation* (performance of

activities of daily living). Baumann observed a 'feeling-state oriented conception of health more frequently in patients than in medical students. Formal education was associated with a symptom orientated definition of health, and lack of education was associated with feeling oriented state of health. Baumann reported that for many respondents health was essentially a multidimensional concept.

Following from Baumann's work, a series of studies on lay concepts of health have been carried out in many parts of the world. For example, a study carried out in France among predominantly middle-class people by Herlizh (1973), identified health in terms of three different dimensions; i) *Health in a vacuum* - this view of health simply implies the absence of illness; ii) *Health as an equilibrium* - people described a state of equilibrium in terms of happiness, relaxation, feeling strong, and having good relationships with people; and iii) *Health as a reserve of strength* – health is seen as an asset which empowers an individual to resist illness and maintain a good physical strength to carry out daily activities/tasks.

Williams (1990) in his study of health beliefs of elderly people in Aberden, came with similar conclusions, and reported that older men and women talked about health in terms of *health as an absence of illness*; *health as dimension of strength*; and *health as functional fitness*. Review of literature on lay concepts of health also suggests that different social groups vary in terms of relative emphasis focused on different dimensions of health. For example, majority of respondents from working-class backgrounds paid more emphasis on functional definition of health in terms of the ability to carry out daily normal activities compared to non-working class people (Blaxter 1983).

Examination of the various definitions of health leads one to conclude that a wide variety of lay beliefs about health exist. Medical anthropologists and sociologists, medical professionals, psychologists and lay people still show a notable lack of consensus concerning the concept of health. Nordenfelt (1984:xii) explains the following summation of this problem:

The entire medical enterprise-theoretical and clinical research as well as medical practice - has human health as its ultimate end. Health, as well as disease and illness, must be in the focus of medical attention ... In spite of their central place, however, and in spite numerous efforts directed to the clarification of the concepts of health and disease, there is far from universal agreement about their nature. In fact, the controversies are quite

profound ... [O]ne encounters anthropological, sociological, psychological and biological theories, as well as combinations of these. The contents of the various theories are quite different and often quite difficult to compare.

In summary it can be argued that lay peoples' beliefs about health, illness and healing may differ significantly from culture to culture and group to group (Freund *et al*, 2003). This is because, each society functions within the constraint of its own unique system of social structure, language, communication, beliefs, customs, attitude, behavior, etc. Social scientists have argued that the acceptable definition of health varies from culture to culture and group to group since health is essentially a subjective concept, the only valid measure to accept is people's own definition of whether they are healthy or not.

Disease

Western biomedicine assumes disease as an undesirable deviation from a measurable biological (somatic) norm (Engel, 1977). From a biomedical perspective, for example, deviations in body temperature, blood pressure levels, white cell count, red cell count, cholesterol level, bone density, etc., are seen as signs of disease. According to Burgess (1986), disease is a professional construct and is an objective phenomenon defined basically in biomedical terms by the medical professionals.

Illness

On the other hand, illness is fundamentally a psychosocial construct, and is a subjective phenomenon (Kleinman 1980). Subjective feelings of pain, discomfort, nausea, giddiness, weakness, aches, depression, etc., are examples of illness. Kleinman (1980:72) argues that:

Illness includes secondary personal and social responses to a primary malfunctioning (disease) in the individual's physiological or psychological status (or both). Illness involves processes of attention, perception, affective response, cognition, and valuation directed at the disease and its manifestations (i.e., symptoms, role impairment, etc.).

The Disease – Illness Dichotomy

A basic dichotomy between two aspects of sickness: *disease and illness* occupies a key position both in medical anthropology and sociology. Kleinman (1980) contends that disease basically affects the single individuals, illness on the other hand, affects the family, social network and sometimes the entire community. As Cassell (1976:48) notes *‘illness’ stands for what the patient feels when he goes to the doctor, and ‘disease’ for what he has on the way home. Disease, then, is something an organ has; illness something a man has*”. Given these definitions, Blaxter (1987) (cited in Hardey 1998: 29) argues that illness may occur in the absence of disease (and vice versa). According to him:

If ‘disease’ is defined as biological or clinically identified abnormality, and ‘illness’ as the subjective experience of symptoms of ill-health, then it is obviously possible to have disease without illness, and to have illness without disease.

For instance, individuals may consult doctors with symptoms of pain, stress, severe depression, etc., and might think themselves as ill. But on examination and testing, a physician or a health consultant may not detect any pathological abnormalities, thus no apparent disease. According to Taylor *et al* (2003), about 50% of patients who attend their doctors present complaints and symptoms that do not conform to an identifiable disease in biomedical terms. Such people are classified as suffering from psychosomatic disorders, hypochondria or even malingering. On the other hand, sometimes people might have an undesirable deviation from a Western biological norm, but feel healthy. Hypertension, early stages of carcinoma, HIV infection, and initial stages of diabetes are all instances where people feel healthy but have an identifiable disease in biomedical terms. People with the above mentioned conditions may not experience any symptoms of disease, or might notice symptoms but do not consider themselves as ill, and hence, feel healthy. In conclusion, it is possible to feel *‘ill’* without having disease or vice versa.

2.1.2 Cultural Influences on Recognizing and Interpreting Symptoms – Some Examples

Helman (1994) in his book titled ‘Culture, Health and Illness’, gives an elegant description of culture. According to Helman (1994) (cited in Sussman 2004: 37-38)

Culture is a set of guidelines (both explicit and implicit) which individuals inherit as members of a particular society, and which tells them how to view the world, how to experience it emotionally, and how to behave in it in relation to other people, to supernatural forces or gods, and to the natural environment....To some extent, culture can be seen as an inherited “lens,” through which the individual perceives and understands the world that he inhabits, and learns how to live within it. Growing up within any society is a form of enculturation, whereby the individual slowly acquires the cultural “lens” of that society. Without such a shared perception of the world, both the cohesion and continuity of any human group would be impossible. One aspect of this “cultural lens” is the division of the world, and the people within it, into different categories... For example, “kinsfolk” or “strangers,” “normal” or “abnormal,” “mad” or “bad,” “healthy” or “ill.” And all cultures have elaborate ways of moving people from one social category into another (such as “ill person” to “healthy person”), and also of confining people---sometimes against their will---to the categories into which they have been put (such as “mad,” “disabled” or elderly”).

Rubel & Garro (1992:627) described health culture as “*the information and understanding that people have learned from family, friends, and neighbors as to the nature of a health problem, its cause, and its implications. Sick people use their health culture to interpret their symptoms, give them meaning, assign them severity, organize them into a named syndrome, decide with whom to consult, and for how long to remain in treatment*”. According to Fruend *et al* (2003) members raised in different cultural settings learn their group’s beliefs and practices about health, illness and healing, including what is health? What can cause illness? Why has this happened to me at this particular time? What is the nature of the illness? Why to me? Why now? What should I do about this illness? What will happen if nothing is done about it? Whom should I consult during an illness episode? Medical beliefs and practices are not separate elements, but are deeply influenced by socio-cultural and environmental factors in which the person is brought up and lives. As Sussman (2004:53) notes:

Medical beliefs and practices are integral parts of the cultural heritage of patients. They frequently reflect deep-seated moral and social values, worldviews, and religious beliefs that transcend specific beliefs about human anatomy, physiology, and pathology.

Individuals from different cultures may have different experiences or interpretations of bodily symptoms and what constitutes a disease. Rhodes & Watson (1987:242) defined a symptom as a “*subjective phenomenon regarded by the individual as an indication or characteristic of a condition departing from normal function, sensation, or appearance*”. Dodd *et al* (2001: 668) defined a symptom as “*a subjective experience reflecting changes in the biopsychosocial functioning, sensations, or cognition of an individual*”. Symptom is subjective and experiential in nature.

Numerous studies (Zborowski 1952; Saunders 1954; Zola 1966; Mechanic, 1968; Mull & Mull 1988; Winkelman, 2009) have provided evidence of how cultural values and beliefs influence an individual’s subjective definition of the illness, its symptoms and meaning. For example, sweating, diarrhea and coughing are regarded by many Mexican-Americans in the Southwestern United States as conditions of every-day experience and not as symptoms of illness that require medical attention. Similarly, Mull & Mull (1988) noted that some rural Pakistani mothers consider diarrhea in their infants as normal condition and do not choose to administer the often life saving oral rehydration therapy to their child in the belief that it would be dangerous to try to stop it because the ‘heat’ in it could be trapped and spread to the brain and cause fever. Malaria is not treated as illness in some parts of Africa, because malaria occurs very frequently and is seen as the normal state of man. In some cultures, supernatural powers are attributed to an epileptic, while in certain other cultural groups, for example in Indian culture, epilepsy is a stigmatized illness condition, and epileptics are considered as mad people. In many Western societies hallucinations are considered as signs of psychosis, but in some other cultures such as in Mexican culture hallucinatory experiences are seen as normal (Winkelman, 2009).

Dyschromic spirochestosis, a skin disease characterized by spots of various colors was very common among some South American tribes, and tribes who did not have this disease were seen as abnormal, and men without it were ridiculed and even excluded from marriage (Mechanic, 1968). In some cultures (e.g. Amish tribe), the obese women are not considered as unhealthy persons, in fact high body weight of woman is viewed

positively as a means to keep up one's strength to carry out required activities. In these societies obese women are seen as an object of envy and desire, whereas in Western societies obesity is regarded as a physical and emotional disease (Mechanic, 1968:17). Egyptian boys in the Nile delta commonly excrete blood stained urine due to infestation with a *Shistosoma mansoni*, pathogenic blood fluke. Yet the Egyptians of north Cairo do not recognize these boys as diseased, and the blood in the urine is referred to as '*male menstruation*', and is seen as normal. Zola (1966: 617-618) states:

For the population where the particular condition is ubiquitous, the condition is perceived as the normal state. This does not mean that it is considered "good" (although instances have been noted where not having the endemic condition was considered abnormal) but rather that it is natural and inevitable and thus to be ignored as being of no consequence. Because the "symptom" or condition is omnipresent (it always was and always will be) there simply exists for such populations or cultures no frame of reference according to which it could be considered a deviation.

A number of studies suggest (Zborowski 1952; Saunders 1954; Mechanic 1968), important ethno-cultural differences in attitudes and responses to illness. For example, Saunders (1954) (cited in Mechanic, 1968), found that 'Anglos' and Spanish-speaking persons in the American South West differed in response to illness and in the utilization of health care facilities. Saunders observed that Anglos preferred biomedical physicians and hospitalization for the treatment of a variety of illnesses. On the other hand, Spanish-speaking people showed inclination towards traditional folk medicine and family care and support which was more congruent with their traditional cultural beliefs.

Culture exerts a great deal of influence on pain expression. Although physiological pain thresholds do not seem to differ greatly from one culture to another (Garron & Leavitt, 1979; Lipton & Marbach 1984), reaction to pain varies and reflects the socio-cultural beliefs and attitudes of the group (Zborowski 1952; Zola 1966). Mark Zborowski (1952) (cited in Cockerham, 1978), studied expression of pain among patients belonging to Jewish, Italian, Irish and Old American ethnic backgrounds, in a New York City hospital. Although pain is essentially a biological phenomenon, Zborowski found that reactions to pain are not always biological but vary significantly among different ethnic groups. Zborowski observed that Jewish and Italian patients responded to pain in an

emotional and sensitive fashion, and also exaggerated pain experiences. In contrast, Old Americans were more stoical and objective, and Irish patients tended to deny pain more often. A well-known study by Zola (1963) among the patients of Irish and Italian origin in New York, demonstrated that each racial group differed in the definition and communication of their symptoms.

A review of anthropological literature reveals that there are certain symptoms, signs or discrete patterns of behavior that seem to be unique to a particular culture or a group of related cultures. These specific illnesses are generally referred to as ***culture-specific diseases or culture-bound syndromes***, and most of the culture-bound syndromes do not correspond to recognized Western disease categories. “*Culture-bound syndromes are generally limited to specific societies or culture areas and are localized, folk, diagnostic categories that frame coherent meanings for certain repetitive, patterned, and troubling sets of experiences and observations*” (Guarnaccia & Rogler 1999:1322).

Some examples of folk illnesses that are popularly known as culture-bound syndromes include *Amok* and *Latah* in some Malaysian and Indonesian groups; *Koro* (*Genital retraction syndrome*), in some Chinese and Malaysian populations in South-East Asia; *Ghost sickness* among the Navajo of the southern United States; *Anorexia nervosa* mainly reported among some Euro-American adolescent girls in USA, *Susto* (also known as fright or soul loss) in some Spanish-speaking populations in Europe, North and South America (Bonder *et al* 2002); *Taijin-kyofusho* (*fear of people or TKS syndrome*) in Japan, *high blood, colds and chills* in USA, *Nervous breakdown* in Canada and USA (Helman, 2000); *Dhat* (*semen-loss anxiety*) in the Indian subcontinent (Sumathipala 2003). *Dhat* is a form of sexual neurosis associated with excessive loss of semen due to frequent intercourse, masturbation, nocturnal emission or passing of white turbid urine which is believed to contain semen. Men suffering from *dhat* syndrome become extremely anxious, and feel a sense of weakness, because it is assumed that excessive loss of semen may cause sexual dysfunction.

Culture-bound syndromes, thus, may seem exotic to biomedical practitioner. However, from the analysis of ethnographic data it was found that experiences of culture-bound syndromes are psychologically and physically real. Each culture-bound syndrome is a unique disorder which is meaningful to individuals from particular cultures.

Clinicians must be aware of their cultural prejudices and recognize that patients' expression of symptoms may vary. A failure to understand and appreciate culture-bound syndromes can have serious implications to facilitate the desired health-related behavior change. Thus, it can be argued that culture is the lens or template used in constructing, defining and interpreting the symptoms of illness. Medical practitioners need to be aware of the fact that people belonging to different cultural contexts and traditions conceptualize and experience illness in very different ways.

2.1.3 Lay Theories and Disease Causation

Several empirical studies have been carried out in different cultures to elicit lay theories about disease causation. Some scholars have made an attempt to place illness causality into different categories as a way of helping to make sense of and classify lay theories of illness. According to Patel (1995), and Mutambirwa (1989), in general, most illnesses are considered as normal illness in the initial stages, however, if they persist for a long time, then such illnesses are categorized as unnatural, and are attributed to supernatural agents.

Although lay medical beliefs about illness causation may vary substantially from culture to culture, one theme that exists in many societies all over the world is the concept that illness may be caused by multiple factors. For example, people may identify a single cause for some illnesses, such as change in weather, while for other illnesses, particularly chronic life-threatening illnesses, people may suspect and address multiple causations over time. In general *“for simple and easily cured ailments natural causes are imputed. But for more complex, serious and prolonged illnesses both natural and non-natural causes may be invoked. Thus, one cannot easily suggest a neat division of illnesses into natural and non-natural. Instead, it becomes useful to regard illness as a complex phenomenon, one which derives its definition from the patient himself and those around him”* (Chilivumbo 1976: 69-70).

Helman (2000) for instance, classified folk ideas about the causes of illness essentially into four categories: i) *individual*, ii) *natural*, iii) *social*, and iv) *supernatural* causes, with overlap between the categories. Helman (2000) argues that people attribute illness to single factor or multiple factors.

i) Individual Etiologies

At the individual level, occurrence of illness may be attributed to various factors including: a) heredity; b) lifestyle (e.g., sedentary lifestyle); c) risky health behaviors (e.g., smoking, alcohol consumption, drug abuse, and lack of exercise); d) emotional states (e.g., sorrow, fright, stress, anger, anxiety); e) diet (e.g., diet rich in fat, salt, sugar, meat); f) foods (e.g., spoiled food, dirty foods, sweets, raw foods); g) sexual (e.g. sex with forbidden person, over indulgence in sex, extra-marital sex); and h) old age.

A study by Bailey (2004), investigating the causes of hypertension among the African American patients in Detroit Metropolitan area found that informants attributed hypertension to multiple factors including poor nutrition, inadequate rest, and 'richy foods' such as heavily salted greens, pork, meat and sweets. In many cultures there is a belief that consumption of excessive amounts of sweets cause different types of illnesses including coughs, colds and fever in children. In several cultures there is a belief that an individual's wrong actions can cause another person ill. For example, a man who engaged in extra-marital relationship or sex with menstruating women may explain his wife's consequent reproductive disorders as punishment for his irresponsible behavioral acts.

ii) Natural Etiologies

In the natural world causation category - most people attribute disease causation to a wide variety of animate and inanimate factors including exposure to microorganisms (e.g., bacteria, viruses, worms, flies, parasites); climatic conditions (e.g., extremes of heat, cold, wind, rain, or snow); environmental irritants (e.g., smog, pollen, toxic gases, water pollution); natural disasters (e.g., earthquakes, floods, fires); accidents (caused by birds, animals, fish, etc.), and humoral pathology.

The most widespread concept in natural world causation category is the concept of balance, in which healthy body is seen as a state of proper balance or harmony, and ill health as a result of imbalance or disharmony. Traditional disease causation beliefs based on the classical Hippocratic *humoral theory of disease* (also referred to as *Hot-Cold theory of disease*), is most widespread in the folk and popular cultures of Asia, Africa and

Latin America (Manderson, 1987). It should be noted that Hippocratic humoral medicine is one of several equilibrium models, other versions of which include the *Yin-Yang* of the Chinese philosophical tradition and the Ayurvedic *doshas* (*Vata*, *Pitta*, and *Kapha*) of the Hindu tradition.

Humoral pathology is concerned with the balance between four bodily humors and their qualities: *blood* (warm and moist), *phlegm* (cold and moist), *yellow bile* (warm and dry), and *black bile* (cold and dry) (Harwood, 1999; Jones, 2004). In the hot-cold belief system, according to Foster (1988:121):

Health is equated with bodily temperature equilibrium. Illness is explained as loss of equilibrium, an imbalance caused by exposure to powerful thermal heating or cooling experiences, or by ingestion of or other contact with foods, herbs, and other substances believed marked by metaphorically "Hot" or "Cold" values or qualities that have no direct relationship to thermal temperature.

Foods, herbs, illnesses, mental states, medicines, natural and supernatural forces are categorized metaphorically as hot, cold or cool according to their effects on the body, and are used therapeutically to restore the body to its correct natural balance (Logan, 1975). It should be noted that the categorization of foods, herbs, illnesses, medicines, etc., into hot or cold does not refer to the actual temperature, but to a variety of other factors. For example, in the Mexican Yucatan Peninsula, tubers are classified as cold foods because they are grown in the cold ground. In Tecospa, in the valley of Mexico, ice is, for example, classified as hot because it burns the skin. Classification of foods, medicines, herbs, etc., as hot or cold varies from one territory to another (Bonder *et al* 2002).

When a person becomes ill, health is restored by re-establishing body's supposed temperature balance. Thus, according to this model, cold illnesses are treated with hot medicines and foods, and hot illnesses are treated with cold medicines and foods. That is "*the patient is treated by selectively consuming only those items possessing a quality opposite to that believed responsible for the illness, thereby neutralizing its effects*" (Logan, 1975:8). For example, in Mexican American cultures, a sprain (cold disease) is treated by application of raw Weasel meat (hot). A spider bite (cold disease) is treated with black coffee (hot) (Bonder *et al* 2002).

Folk remedies, as with any other remedy, cannot necessarily be thought to be 100% effective. Bonder *et al* (2002) argue that adherence to hot-cold classification of foods may have untoward consequences. In Haiti, for example, consumption of foods based on the hot-cold classification during lactation may lead to severe malnutrition among women, and may result in significant infant mortality. Wiese (1976) (cited in Bonder *et al* 2002), notes that thirty seven food varieties available to rural Haitians, twenty seven food types (including river fish, mango, avocado, grapefruit, lime juice and sweet potato) are forbidden for lactating women. Thus, maternal malnutrition is not only caused by impoverished economic conditions, but also on the use of hot-cold classification to determine what foods to eat during lactation (Bonder *et al* 2002).

Incorporation of medicines into hot-cold classification may raise several key issues for those who practice medicine with cultural groups that adhere to hot-cold classification. For instance, communication gap may occur between the medical practitioner and the patient if the medical practitioner fails to balance the type of medicine (hot or cold) with the type of illness (Harwood, 1999). When a physician recommends a medicine known locally to be cold for the treatment of a cold disease then such a prescription would be inappropriate because the prescribed regimen may violate the patient's conception of culturally appropriate treatment. As Logan (1973: 385) argues that:

When prescribed treatment ignores the humoral concept, or creates unacceptable contradictions between modern and native philosophies of health, such treatment is likely to be less effective than if native concepts were incorporated into the prescribed therapeutic program.

iii) Social Etiologies

At the social world level, illnesses are most commonly attributed to acts of witchcraft, sorcery and evil eye. Evil eye, sorcery or witchcraft as an etiological agent of illness is timeless and universal phenomena, found in all societies, and at all levels of society in the world (Stevens Jr. 1982; Buonanno, 1984). It is believed that some people with supernatural powers cast evil eye deliberately or unwittingly on someone to cause harm, misfortune, ill health and death, because they are jealous of others. “*The evil eye is the conscious or unconscious product of human envy*” (George, 2004:684). Young

children and pregnant women are believed to be particularly vulnerable to the effects of the evil eye. Several types of protective devices such as amulets, red hats, and a red and black string around the wrist, are worn to prevent the evil eye.

Witchcraft can be defined as the intentional or unintentional act of a person possessing evil powers that causes illness in a targeted person (Dobkin & Rios 1976). Sorcery differs from witchcraft in that it is a learned magical skill, and may include the use of materials, objects, rituals, spells, or poisonous medicines to invoke the supernatural to cause harm. Reactions to witchcraft can be violent, and result in witch hunts and death to those identified as witches. In several non-western 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 witchcraft or sorcery (Mutambirwa 1989). It is believed that sorcerers and witches possess malevolent powers, and use their malevolent powers to harm other people. The most commonly attributed reasons for harming are mainly related to jealousy and hatred. Thus, accusations of witchcraft or sorcery often occur between neighbors, clan members, and rival groups, reflecting tensions resulting from altercations in connection with land, money, houses, animals or family disputes.

iv) Supernatural Etiologies

Supernatural etiologies are broadly divided into two groups: i) *human origin* (e.g., ghosts and ancestral spirits), and ii) *non-human origin* (gods and spirits) (Ember & Ember 1985). In the supernatural domain, illnesses are attributed to wrath of deities, ancestral spirits, ghosts, soul loss and spirit possession. Possession by various types of spirits is a very well-known belief system in several parts of the world. Spirit possession is the concept that malevolent spirits, demons, ghosts, or other disincarnate entities may temporarily take control of a person, and cause dramatic symptoms of illness and change in the behavior (Dobkin & Rios 1976; Ember & Ember 1985).

Several traditional communities believe that wrath of deities and ancestor spirits can make people ill in several ways. For example, deities and ancestor spirits are angered if they are not revered properly, and such offended deities and ancestor spirits directly intercede in human life, and cause illness, misfortune and death. For example, in

Rajasthan in India, small pox and measles are attributed to wrath mother goddess *Barimata* and *Chotimata* respectively (Bhasin, 2003). Illnesses such as leprosy and insanity are commonly attributed to wrath of deities and spirits in many parts of the world.

Belief in soul loss is widespread throughout the world. Soul loss can be caused by things such as fright, bewitching, and demons. It can occur in adults and children. Soul-calling ceremonies are performed to retrieve the soul with the help of priest, diviner, witch or sorcerer. All over the world people believe that illnesses can be caused by violation of taboos or moral injunction. These taboos consists of prohibitions on the consumption of certain foods and killing of certain totemic animals, contact with people in certain ritual states, breach of appropriate behavior towards kinsmen, trespass, theft, use of sinful words, urination on religious sites, incest, pre- or extra-martial sex and so forth. Scientific medicine is believed to have no remedies for these afflictions.

Thus, it can be concluded that in traditional cosmology, illness may be caused by individual, natural, social or supernatural forces. Although lay medical beliefs about illness causation may vary substantially from culture to culture, one theme that exists in many societies all over the world is the concept that illness may be caused by multiple factors. For example, people may identify a single cause for some illnesses, such as change in weather, while for other illnesses, particularly chronic life-threatening illnesses, people may suspect and address multiple causations over time. Despite Western influence and the tremendous growth in medical knowledge and technology, traditional ideas of health, illness, and healing are still thrive and remarkably stable. Hence, the practitioner must be aware of the fact the nature and presumed causes of illness determine the treatment options. Furthermore, an understanding of the cause of illness may have crucial implications for treatment and health education programmes.

2.1.4 Medical Pluralism

Every society has a multiplicity of options for the treatment of diseases and illnesses as part of its health care system. *“The health care system of a society can be broadly defined as a set of ideas, practices and organizations which have been developed to deal with problems of health and illness in the society”* (Lee, 1982: 629). All health

care systems have a set of ideas of the body, health and healing, and have a coherent system of knowledge of the ways in which illness is handled and prevented. Medical anthropologists have used the term *medical pluralism* to refer to societies that have several therapeutic systems. According to McGrath (1999) medical pluralism not only implies the existence of a number of explanations and typologies of illness but also the utilization of more than one healing system. The therapists available vary from one region to another, and span from traditional herbalists to modern biomedical practitioners to psychological and spiritual healers. Medically pluralistic health care systems provide a diverse range of treatment alternatives (biomedical physician, pharmacist, bone setter, midwife, faith healer, shaman, snake doctor, fortune teller, priest, herbalist, etc.), that patients may choose to utilize exclusively, successively, or simultaneously. *“Often, these alternatives are held to represent various systems of medical practice and ideology, each deriving from a separate historical and philosophical basis and each providing a different mode or theory of treatment for the individuals who use them”* (Stoner 1986:44). Medical anthropological and sociological studies in several parts of the world (e.g., Sub-Saharan Africa, Latin America, Europe and Asia) have revealed that medical pluralism is in no sense limited to the developing countries. In fact, medical pluralism can be regarded as a global phenomenon. Thus, it can be argued that the co-existence of different medical traditions appears to be a norm throughout the world (McGrath, 1999). Frankel & Lewis (1989) (cited in McGrath, 1999: 484) stated that *“pluralism is the rule, and reliance on a single medical ideology the exception”*. Alternative and complementary medicine (CAM) is a general label applied to some healing traditions that do not fall within the framework of scientific biomedicine. That is, the treatment approaches used are either an alternative to or complementary to western medicine (Levinson & Gaccione, 1997).

However, it should be noted that *“various medical traditions do not coexist with an equal standing in the society; they differ in terms of the level of dominance, thus creating hierarchical pluralistic structure within the health care system”* (Lee, 1982:629). It usually involves a modern biomedical health care system as dominant player in coexistence with alternative medical traditions. For example, in India, biomedicine dominates but coexists with other therapeutic systems, such as faith healing, herbalism,

homeopathy, ayurveda, unani, yoga, naturopathy and healing traditions of tribal and ethnic communities.

2.1.5 Sectors of Local Health Care System

Popular Sector

In the popular sector illness episode is first experienced and defined by individuals and their families (Sussman, 2004). In fact, the popular sector practices (self, family, and community-based care) are the most extensively used part of every health care system in Western and non-Western societies. The majority of the illness episodes are managed entirely within this sector. For instance, Kleinman (1980) estimates that in the United States and Taiwan, about 70 to 90% of all self-recognized illness episodes are managed completely within the popular sector with no recourse to specialists. Kleinman argues that in this sense, the popular sector functions as the key source of care in any given local health care system.

According to Kleinman (1985:142) the popular sector consists of a wide number of practices, including health maintenance and curative interventions:

Of which the most commonly utilized are diet; special foods; local herbs and other traditional and contemporary indigenous medicines; massage; blistering and other manipulative techniques; exercise; changes in lifestyle habits; use of biomedical drugs and apparatuses; symbolic interventions, ranging from charms and amulets to prayer, healing rites, and including various kinds of talking therapies.

The popular sector of cultural health care system is made up of informal healing relationships that occur within one's social network. Typically, in the popular sector, an ill individual consults family, friends, relatives, neighbors, close acquaintances and/or social network for help and health care information. Within this sector, both care recipient and lay referral network share the same cultural values and beliefs about health and disease, and treatment strategies. Therefore, misunderstandings are comparatively rare, and therapeutic encounters occur without fixed rules governing behavior or setting (Helman 2000).

According to Helman (2000) there are certain individuals who tend to act as a source of health advice more often than others in the popular sector. These individuals include: i) those with prolonged familiarity with a particular type of illness or treatment; ii) those with immense knowledge of certain life events, such as women who raised several children; iii) the paramedical professionals (such as nurses, pharmacists, or physiotherapists); and iv) the members of the healing cults or religious institutions (e.g., temples, churches, etc.). The healer's credentials are based mainly on experience rather than professional education, social class or licensure. For example, a woman who has had several pregnancies, for example, can give informal advice to a newly pregnant woman, telling her what symptoms to expect and how to deal with them. Kleinman (1980:51-52) argues that in the popular sector:

We can think of the following steps occurring, at least initially: perceiving and experiencing symptoms; labeling and valuating the disease; sanctioning a particular kind of sick role (acute, chronic, impaired, medical, or psychiatric, etc.); deciding what to do and engaging in specific health care seeking behavior; applying treatment; and evaluating the effect of self-treatment and therapy from other sectors of the health care system.

The Folk Sector/Traditional Sector

The folk or traditional medical practices are widespread across a wide range of cultures throughout the world. The folk medical beliefs and practices can be broadly categorized into sacred (e.g., spiritualists, witches, sorcerers, priests, diviners, etc.) and secular (e.g., herbalists, midwives, etc.) (Kleinman 1980). Sacred folk healers particularly play an active role in cultural groups where ill health and other forms of misfortune are blamed on social causes (e.g., witchcraft, sorcery or evil eye) or supernatural causes (e.g., gods, spirits or ancestral ghosts). For example, a lay person may consult a sacred practitioner to understand why a healthy child died suddenly? Basically, a sacred practitioner acts as a mediator between the human world and the world of spirits, between the living and the dead. In fact, a sacred practitioner fills many social and religious roles including those of soothsayer, interpreter of dreams and causes of illness, and therapist. Spiritual healers have little formal education and most are believed to receive healing powers through family position, and inheritance.

The Professional Sector

The professional health care sector is the organized, regulated, legally sanctioned health profession, such as biomedicine in most societies across the globe (Kleinman 1980). But in some societies, however, this professional sector may include professionally organized indigenous medical systems, for example, ayurvedic and unani medicine in South Asia, herbal medicine and acupuncture in the People's Republic of China, and chiropractors in the United States of America. Practices in the professional sector remain dominated by biomedical model of disease and treatment. Biomedicine is strongly underpinned by objectivity, observation, rationality, experimentation, discoveries, facts and truths (Levinson & Gaccione 1997).

2.1.6 The Health Care-Seeking Process – The Lay Perspective

Symptom Iceberg

Several community health surveys and disease prevalence research studies conducted in Britain (Wadsworth *et al* 1971; Hannay 1979; Nations *et al* 1985), and in other parts of the world showed that symptoms and illnesses brought to the notice of the health professionals represent only the tip of *symptom iceberg* or the *'pool of unwellness'*; the majority of symptoms are either treated in the popular sector, disregarded, or merely endured. Symptom iceberg exists because of the fact that significant numbers of treatable diseases are never brought to the notice of the formal or professional health care providers. For example, Wadsworth *et al* (1971) found that 95% of their respondents (n = 3153) in two London boroughs had at least suffered one or more episodes of ill health for which they did not seek any medical advice. Scambler (1993:45) argues that *“people who define themselves as ill rarely anticipate, let alone secure, consultations with physicians. Nor are consultations merely a function of the severity of symptoms”*.

A number of studies (Mechanic, 1968; Zola, 1973; Scambler 1993) suggest that decision to consult a doctor is a complex process, and does not depend entirely on severity of symptoms and stoicism. Social and behavioral scientists (Mechanic, 1968; Zola, 1973) note that non-physiological factors play an indispensable role in influencing

an individual's desire to seek professional medical advice. Some of the important non-physiological factors that influence an individual's decision to seek medical help or care include: i) symptoms that are perceived to interfere with work, family, personal, and other social activities, or social or personal relationships; ii) pressure or advice from patient's social network (e.g., friends, family, employers, folk healers), to seek medical help or care; iii) signs and symptoms that are exceptionally visible (e.g., skin conditions); iv) signs and symptoms that are perceived to indicate critical disease; v) socio-cultural background of an individual, and cultural conceptions of health, illness and healing; vi) a present and future oriented apprehension with regard to the experience of symptoms; vii) availability of health services, physical distance, economic costs, social stigma, feelings of humiliation, embarrassment; viii) the frequency of the occurrence and reoccurrence, and persistence of signs and symptoms; and ix) temporalizing of symptoms, where a time limit is placed on the illness. People will often make a decision that they will consult the physician if the symptoms do not disappear within a given time frame (Mechanic, 1968; Zola, 1973; Taylor *et al* 2003).

The decision to act upon symptoms not necessarily taken exclusively by the sufferer, but it is often the result of discussions with a range of people such as family, friends and colleagues. In fact, many people suffering from illness episodes discuss their symptom experience with lay consultants (e.g., friends, relatives, colleagues) prior to or after consulting a health care practitioner. Patients also consult lay network to share the experience of the symptoms, anxieties and inconveniences associated with illness. The term lay consultation refers to the seeking of counsel about health problems from people other than health professionals (Furstenberg & Davis, 1984). Freidson (1970) refers to this network of friends, relatives and colleagues as the ***lay referral system***. Lay consultations have multiple consequences (Ory & DeFries 1998). As Ory and DeFries (1998:32) rightly point out that:

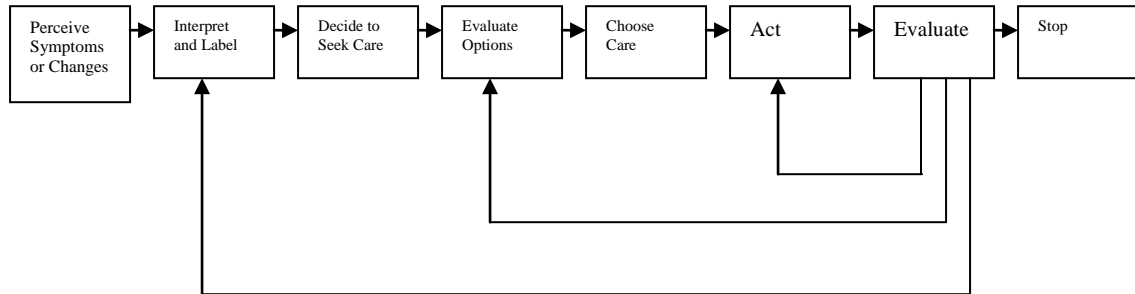
Lay consultants can teach and reinforce patterns of self-care, validate or contradict people's interpretations of their symptoms, encourage or discourage professional consultation, provide reassurance, or simply listen to complaints and concerns, thus affirming the person's importance and supporting self-esteem.

Several scholars (Freidson 1970; Furstenberg & Davis, 1984; Ory & DeFries 1998) have argued that lay referral network serves several functions. For instance, members of the lay referral network provide emotional sympathy and empathy, and social support and comfort to the sufferer. Furthermore, lay referral network also helps in identifying a plausible cause of illness and as well as providing information about the type of practitioner need to be consulted for treatment.

Health-Seeking Process

The health care-seeking “*process is a decision-making process engaged in by lay individuals*” (Sussman, 2004:40). It includes steps taken by an ill individual about the need for help, health care choices and maintenance of health. Sussman presents a model (Fig. 4) of health-seeking process. The health-seeking process is conceptualized as a complex process and does not proceed in a straight path from one stage to another. The actual process of seeking health care usually involves multiple steps, which are influenced by a host of complex psychosocial and cultural factors such as lay notions of etiology, diagnosis and perceived severity, previous self-help attempts, prior experience with illness, practitioner accessibility; the micro-economics of health care seeking, the reputation of particular practitioners for curing specific illnesses, cultural preferences, and cultural notions of and expectations from therapy, gender, age, level of education (Shaik & Hatcher 2005; Ahmed *et al* 2003). An important concept developed in the field of medical anthropology and sociology for explaining the events that take place when a person is ill is ***health-seeking behavior***. Health-seeking behavior refers to “*the steps taken by an individual who perceives a need for help as he or she attempts to solve a health problem*” (Chrisman 1977:353). The process of health-seeking behavior usually begins when a noticeable change in bodily function is interpreted as a symptom of ill health. It is initiated with symptom definition, whereupon a strategy for treatment action is devised (Christakis *et al* 1994). The relationship between culture, symptom-related perceptions and health-seeking behavior is complex in nature.

Fig. 4. Health-Seeking Process



Adopted from Sussman (2004:40) 'The Role of Culture in Definitions, Interpretations, and Management of Illness' in *Handbook of Culture, Therapy and Healing*, Gielen *et al* (eds), New Jersey: Lawrence Erlbaum Associates, Inc., Publishers.

“Personal experiences, attitudes of the social network, and health beliefs interact and influence health-seeking behavior” (Liefoghe *et al* 1997:810). According to Hunte & Sultana (1992) lay communities in different parts of the world today are presented with multiple treatment choices when ill. According to McCombie (1996: 933) *“multiple resorts are often used, especially when a treatment fails. In some cases certain illnesses are seen as amenable to treatment by modern practitioners, while others are considered best treated by traditional methods”*. A body of literature on health-seeking behavior of lay people suggest that the choice of treatment appears to be influenced by a wide variety of factors, including the perceptions of disease seriousness, the perceived underlying cause of the disease (natural or super natural origin), accessibility (Reeler, 2000); the recognition of disease symptoms (Colson, 1971); cost, distance, religious beliefs and quality of health care (Airey, 1992; Beckerleg, 1994); the availability of a provider within the community, and attitudes towards the health care providers (McCombie 1996).

2.1.7 The Western Biomedical Model: Assumptions and Criticisms

Biomedicine (also referred to as *allopathic, western, scientific, conventional, cosmopolitan* and *modern medicine*), is the name given to a form of Western medicine that holds that disease is primarily caused by deviations from measurable biological norms (Gaines, 2006).

Assumptions

As mentioned in Chapter 1, biomedicine represents certain assumptions about the nature and function of the human body, and causes of health and disease. It is primarily based on what has become known as the biomedical model. The key assumptions of this model are:

Mind-Body Dualism – Rene Descartes, a philosopher of Renaissance period proposed the Cartesian dualism, in which there is a separation of the mind and physical body (Pearson *et al* 1996). The concept of dualism is the fundamental assumption of the biomedical model. This assumption emphasizes a viewpoint that the body is separate and independent from psychological and social processes of the mind (Engel, 1977). From this perspective, when treating disease, the mind and body are viewed as separate and independent entities (Barry & Yuill 2002). This model presupposes that all diseases and physical disorders are mainly caused by biological agents (Hirsch 2004). Kleinman (1995) argues that “the biomedical model, like scientific models more generally, assumes that the nature of illness is physical and that illness operates according to the causal principles of the physical world”. Thus, the biomedical model eschews that all diseases are located within the individual’s physical body. Implicit in this assumption is that the broader social, psychological, and spiritual factors play a very insignificant role in the cause, maintenance and treatment of illness. Thus, the biomedical model presumes that diseases can be understood and treated largely in isolation from the whole individual (Engel, 1977; Weitz, 2001; Giddens & Griffiths, 2006).

Mechanical Metaphor - Biomedicine conceptualizes the human body as a complex biochemical machine, in the sense that patient is viewed as a machine composed of individual body parts, which can be fixed or exchanged with new parts, when broken. According to Marcum (2003):

The body as parts is made of different anatomical systems, such as the respiratory or cardiovascular systems. These systems are, in turn, made up of various organs, such as lungs and hearts, which are made up of epithelial, muscular, nervous, and glandular tissues. Finally, to complete the reduction, these tissues are composed of different cellular types that are made up of a variety of molecules.

For the mechanized body model, disease results due to breakdown of some of its constituent parts and/or mechanisms. For instance, HIV disease is typically attributed to a mechanical failure of the body's immune system (Freund *et al* 2003; Weitz 2001).

Physical Reductionism – Reductionism refers to the view that an individual can be understood and explained by examining his or her smallest constituent body parts and biochemical processes in the body (Engel, 1977). From this perspective, human body is reduced into ever smaller fragments – first systems, then organs, then tissues, then cells and finally to single molecules (Marcum 2003). The medical model assumes that all diseases can be reduced to biochemical or neurophysiological disorders in the body.

Doctrine of Specific Etiology - The concept of *doctrine of specific etiology* or 'germ theory' constitutes the influential intellectual framework or paradigm within which modern medicine works. In the 18th century, the works of Louis Pasteur, Robert Koch, and others in bacteriological research led to the formulation of germ theory of disease. According to this theory, diseases are largely caused by specific infectious agents (such as bacteria, viruses or parasites) in the environment. The basic premise of this theory is that every disease has a specific pathogenic cause, and is sometimes referred to as the *doctrine of specific etiology* (i.e., each disease is caused by a specific, potentially identifiable agent) (Dubos, 1959).

Disease is Universal – Modern medicine tends to regard diseases as universal entities, characterized by identical, specific and distinguishing features, symptoms, causes and processes (Winkelman, 2009). In other words, this assumption implies that each disease manifests itself in the same manner irrespective of culture, time, and place. In this sense, a bacteria is a bacteria no matter where it occurs. Disease etiology, symptoms and signs, natural history, treatment and prognoses are considered to be similar in whatever individual, culture or group they occur (Helman 1981).

The Scientific Neutrality of Medicine – From biomedical perspective, the definition, diagnosis, and treatment of disease are scientific, morally neutral, objective and culture-free in nature (Weitz 2001; Winkelman, 2009).

Empirical – Knowledge is generated by observation and can be confirmed through a process of scientific experimentation.

Technological Imperative- This refers to the significance attached to medical methods of intervention, whether pharmacological or surgical, in treating the body. In the biomedical model, hospitals, medicines, laboratory tests and surgeries are seen as most appropriate for treating diseases (Marcum 2003).

Materialism - Materialism is the view that individuals are physical beings whose existence and functions can be studied and understood exclusively by the principles of physiology, anatomy, and biochemistry.

Critique of the Biomedical Model

Western medicine, as a profession and as a body of scientific knowledge has dominated the field of health care for over 200 years, and continues to do so. Indeed during the past fifty years, biomedicine successfully eliminated, co-opted, or subordinated all traditional systems including professionalized traditional medical systems such as unani, ayurveda and homeopathy. Western medicine ultimately established a clear political, economic and ideological hegemony in health care.

The benefits of modern medicine are immense, and over the last century, biomedicine helped immensely in alleviation of suffering and discomfort of millions of victims of illnesses and accidents. The epochal discovery of antibiotics and vaccines have marked the beginning of true chemotherapeutic era in the fight against a number of lethal communicable diseases (such as TB, polio, plague, cholera, measles, leprosy and typhoid), that had threatened the humanity for thousands of years. Furthermore, scientific advances in medical sciences helped to prolong life expectancy, to develop effective plans of treatment for debilitating diseases, to elucidate the underlying biological and pathological processes at the cellular and molecular levels, to terminate severe illnesses, to prevent crippling, to postpone untimely death, and to cure and/or prevent many dreaded diseases. Despite great advances in medical science and technology, today we

are now witnessing a deep crisis in health care in developing and developed countries for various reasons. Biomedical model's assumptions are criticized for various reasons:

First, critics argue that medical model assumes that the medical professionals' knowledge and interpretations are vastly scientific and rational to lay people's interpretation of health and disease. Within the medical model of health care practice, doctors and other medical practitioners are considered as experts in the study and treatment of health and disease. In contrast, lay beliefs are perceived as superstitious, ignorant, unscientific, non-rational, ill-informed and foolish. Critics argue that medical professionals often disregard and devalue the beliefs and perceptions of patients whom they seek to treat. As Giddens & Griffiths (2006:262) note:

Because medicine is supposedly based on objective, scientific understandings of the causes and cures of specific physical ailments, there is little perceived need to listen to the individual interpretations that patients give to their conditions.

Second, critics indicate that the machine model of the human body has profoundly transformed the patient-physician relationship. For the mechanized body model, the patient is a machine and the physician a mechanic or technician, and the doctor's role is to intervene, either physically (such as through surgery or radiation), or chemically (such as through drugs), to treat symptoms of disease (Marcum 2003). Biomedical practitioners are criticized for being more interested in treatment of symptoms than in attending to the psychosocial needs of their patients. In treating the disease, biomedicine exclusively focuses on the defective or impaired body part/s rather than the individual. Such a treatment does not necessarily restore the patient to health, even if the treatment is successful. For example, medical cancer therapy may result in the complete regression of a tumor without making the patient well for different reasons. For instance, emotional problems may continue to affect the well-being and recovery of the patient. And if patients concerns are not addressed satisfactorily, patients may continue to suffer from anxiety and stress, which is likely to make his/her symptoms worse (Taylor *et al* 2003).

Third, critics maintain that one of the negative impacts of the mechanized body model on the patient-physician relationship is passivity on the part of the patient and dominance on the part of the physician. The physician's relationship to the patient is one

of dominance in terms of technological knowledge, power, expertise, and access to technology.

Fourth, critics suggest that biomedicine does not consider various socio-cultural (e.g., social class, ethnicity, education, employment, lifestyle, etc.), behavioral, environmental and psychological factors that influence a person's susceptibility to infection. Rather, reductionist biomedicine concentrates exclusively on the analytical breakdown of the body into smaller and smaller parts in order to identify the single smallest biochemical factor as the cause of the disease (Marcum 2003). Hence, in diagnosing and treating disease, modern medicine often loses sight of the patient as a whole human being. Critics contend that humans are much more than biochemical machines. Humans are social beings with history and culture. This reductionism is not merely flawed but also insulting.

Fifth, medical sociologists and anthropologists have argued that with advances in medical technology and diagnostic methods, the importance of patient's own opinions, feelings, and experiences of illness in diagnosing and understanding the nature of disease has declined (Hardey, 1998). According to critics, before the enlightenment period, physicians examined the patient's body indirectly, mainly through patients' own observations and narratives of illness, and doctors mainly visited patients homes to practice '*bedside medicine*'. However, various technological developments such as invention of microscope, laryngoscope, x-rays, stethoscope, etc., shifted the attention of physicians from patient to disease. This is because, advances in medical technology enabled the doctors to identify the sites of infection within the body without needing the active participation of the patient. Such developments changed the nature of the doctor-patient relationship by placing the physicians firmly in superior position over their patients, and thus, biomedical model basically considers a patient to be a passive informant (Hardey, 1998).

Sixth, critics hold that biomedicine's emphasis on the doctrine of specific etiology and germ theory of disease assisted in the transformation of health into a commodity in a capitalist system (McKee, 1988). Consequently, health care services are regarded as commodities, amenable to sale in the market. McKee (1988:777) argues that:

Germ theory provides a framework that promotes technology as the solution to disease, since technology is required to produce antibiotics, vaccines and other drugs to combat pathogens. With the cause of the disease is located in the external pathogens, there is limitless demand for technology, since symptomatic treatment cannot cure the ailment that affects the whole body, and new imbalances result from the side effects of drugs designed to treat only the part rather than the whole. And as one pathogen is eradicated or becomes immune to a drug, a new, more virulent pathogen often evolves, requiring an ever new wonder drug. Scientific medicine is more capital intensive than other forms of medicine, and is dependent on the clinical laboratory for diagnosis, and the industrial laboratory for its cures. To the extent that technology and drugs are promoted for the purpose of profit at the expense of health needs, health suffers.

Thus, critics hold that in capitalism, the health itself assumes a commodity form within a market place, where health professionals are regarded as service providers and patients as health care consumers (Taylor *et al* 2003).

Seventh, critics asserted that, mechanical model of body assisted the development of Western medicine into different specialties such as pediatrics, surgery, orthopedics, internal medicine, neurology, etc. The trend toward specialization has caused several problems in medical care. According to some critics, specialization in medical care caused deterioration in physician-patient relationship. This is because under the mechanized model of the body, specialists confine their attention exclusively on a particular age group, disease or part of the body, and neglecting to deal with the patients' opinions and experiences they seek to treat. The trend toward medical specialization also caused dramatic decline in the number of personal physicians. For example, in America, a generation ago, general practitioners constituted more than 50% of the total medical practitioners, however, now over 75% of the total medical practitioners are specialists (Marcum 2003). Decrease in general physicians affected medical care services significantly, and people are faced with a question of where to find a physician who will deal with their simple day-to-day health requirements.

Eighth, several social scientists have argued that the practice of medicine has shifted from the office of the general physician to large professional institutions such as hospitals. Critics maintain that patients placed in hospital environments may sometimes feel helpless and frightened. Furthermore, in such foreign environments doctors may pay very limited attention to individual cultural interpretations that patients give to their

conditions. Thus, these developments caused progressive depersonalization in medical care practice.

Ninth, critics argue that the costs of medical care have escalated in recent years. The costs of treatment, hospitalization and drugs continue to spiral out of control in recent years. Increasing costs of medical care have been steadily contributing to the heavy burden on a common man. The public is becoming increasingly dissatisfied with escalation in medical costs.

Tenth, critics maintain that doctors of Western medicine as a profession lay more attention on curative techniques and methods over prevention measures. For example, Hahn (1983) (cited in Baer *et al* 1997), notes that biomedicine spends large amounts of money on hospitals, clinics, ambulance services, equipments, drugs, and miracle cures than it does on improving public health facilities, preventive education measures, improving the environmental conditions, reducing stress and other risks associated with modern way of life. Several factors (such as nutrition, employment, population density, housing, lifestyle, education, reducing inequalities, etc.), that are crucial to the improvement of health conditions of people are not sufficiently discussed in medical schools, and thus there is little room for preventive health care in contemporary medicine (Marcum 2003).

Eleventh, according to some critics, activities of the medical profession quite often cause suffering and disease, even more than they cure. A prominent medical critique Ivan Illich (1975) in a polemical book titled '*Medical Nemesis*', even asserted that modern medicine has done more harm than good. He argues that medicine is a source of *iatrogenic* illness (i.e. harmful effects caused by medical intervention), and he described three sources of iatrogenic illness.

The first form of medical harm described by Illich was *clinical iatrogenesis*. This results when illness is caused by diagnosis or medical treatment undertaken by biomedical practitioners. In other words, doctors, hospitals, and modes of treatment are themselves the agents of disease. Clinical iatrogenic illnesses include hospital-related infections, adverse reactions following excessive prescription of drugs and treatments, the immoderate use of interventionist technology, diagnostic errors, inappropriate prescription of drugs, risks of surgery, anesthesia, and immunization. For example,

indiscriminate use and misuse of antibiotics in humans and other animals is the main reason for the development of superbugs (i.e., antibiotic resistant microbial strains). Some of the examples of superbugs include Methicillin-Resistant *Staphylococcus aureus* (MRSA), Penicillin-Resistant *Streptococcus pneumonia* (PRSP); *Clostridium difficile*, and MDR-TB. The emergence of superbugs are a major cause of concern for public health, as they represent a major threat to patients' health, more particularly to patients with low levels of immunity. Wound infections, gonorrhea, TB, pneumonia, septicemia and childhood ear infections are some of the diseases that have become difficult to treat with antibiotics.

The second type of iatrogenesis, Illich talks about is *social*. “*Social iatrogenesis refers to the expropriation of health through overmedicalization and the encouragement of people to become passive dependents*” (Bean 2003:288). Several scholars such as (Freidson, 1970; Zola, 1972; Illich, 1975), maintain that monopolistic, preeminent status, and socio-political power of biomedicine has had a profound influence in giving the medical professionals jurisdiction over a wide range of human behaviors. Thus, biomedicine today, exerts a great deal of influence over health care and, enjoys a clear state-legitimated monopoly and professional hegemony (a domination of health care by medical ideas, concepts and practices), over the health care business. Today, biomedicine has become an important institution of social control and its authority surpasses cultural boundaries around the globe. Social scientists have developed the concept of *medicalization* to explain the ways in which the non-medical problems are defined and treated as medical problems usually in terms of illnesses or bodily disorders. Zola (1972) (cited in Cox & Mead 1975: 180) writes:

From sex to food, from aspirins to clothes, from driving your car to riding the surf, it seems that under certain conditions or in combination with certain other substances or activities or if done too much or too little, virtually anything can lead to certain medical problems.

The net effect of this trend has been the increasing ‘medicalization’ of everyday life. For instance, hygiene, exercise, alcoholism, gambling, homosexuality, hyperactivity in children, and the entire life course of the female reproductive system (i.e., from menstruation to pregnancy and childbirth), drug addiction, suicide, obesity, emotional

stress, ageing, and many other aspects of daily lives are increasingly placed under the domain of biomedical treatment, in the name of health (Zola, 1972; Conrad, 1992; Weitz, 2001). Several authors argue that social iatrogenesis is therefore a kind of medical imperialism, with doctors identifying illness in ever more aspects of an individual's life.

The third type of iatrogenesis identified by Illich is *cultural*. Cultural iatrogenesis sets in when the biomedicine undermines the people's autonomy and freedom to cope with challenges (e.g., pain, suffering, death, impairment), of everyday life. According to Illich, death, pain and sickness are part of human experience, and hence, to face and accept death, pain and sickness are not necessarily negative life experiences. Illich, however, argues that modern medicine has turned these into technical matters. By denying these experiences and turning them into technical matters, modern medicine therefore undermines the cultural and individual capacities to cope with death, pain and sickness.

2.1.8 Biopsychosocial Model

The limitations of the biomedical perspective that disease is basically physiological and that mental and psychosocial issues are irrelevant led Engel (1977) to propose the biopsychosocial model. According to this model, health and illness are determined by the interplay of biological, psychological, and social factors. This model allows the researchers to take into account the interaction of genetic, biological, emotional, behavioral, and cultural factors in the pathogenesis of disease (Solomon & Temoshok, 1986). It is well established that apart from biological and genetic factors, a wide variety of social and psychological factors such as living and working conditions, employment status, education, individual life styles, nutrition, water, sanitation, housing, health care services, harmful behaviors (such as smoking, drinking, and overeating), and psychological problems (such as worries, depression and anxiety) influence health status of an individual. Hence, understanding the nature of health and disease requires a proper understanding of interplay of psychological, cultural and social factors affecting health and well-being. The basic premise of this model is that *mind and body* act together to determine health (Edelmann, 2000). However, it should be noted that biopsychosocial

model basically remained as an ideology and has not become a general guide to daily practice.

2.1.9 Explanatory Models of Illness

An explanatory model of illness emerged in the 1970's, and was developed by Arthur Kleinman and his colleagues. This model provides insight into the dynamics of practitioner and patient processes in a clinical encounter. 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 health care develop their own explanatory model (EM) of illness. As mentioned earlier, lay persons and health care professionals often have different models, particularly when patients and health professionals are from different cultural backgrounds (Kleinman 1980). Biomedical explanatory models tend to be highly technical, elaborated, and specific. Whereas, according to Blumhagen (1980:199):

An individual's 'explanatory model' should not be viewed as something which is necessarily unchanging. Instead, it is a concise statement of the individual's illness beliefs which are deemed relevant to a particular aspect of that person's experiences at a particular time. As the aspect of interest is changed, as the experiences change, the explanatory model will change, sometimes with amazing rapidity.

Kleinman *et al* (2006) argue that patients and family explanatory models of illness are influenced by a number of socio-cultural factors such as social class, cultural beliefs and perceptions, education, occupation, religious affiliation, and past experience with an illness episode and health care providers. Kleinman contends that to provide care that effectively meets the patient's and family members needs, health care workers must elicit patients' and family members' explanatory models of illness. Kleinman *et al* (2006:147) contend that:

Comparison of patient model with the doctor's model enables the clinician to identify major discrepancies that may cause problems for clinical management. Such comparisons also help the clinician know which aspects of his explanatory model need clear exposition to patients (and families), and what sort of education is most appropriate. And they clarify conflicts not related to different levels of knowledge but different values and

interests. Part of the clinical process involves negotiations between these explanatory models, once they have been made explicit.

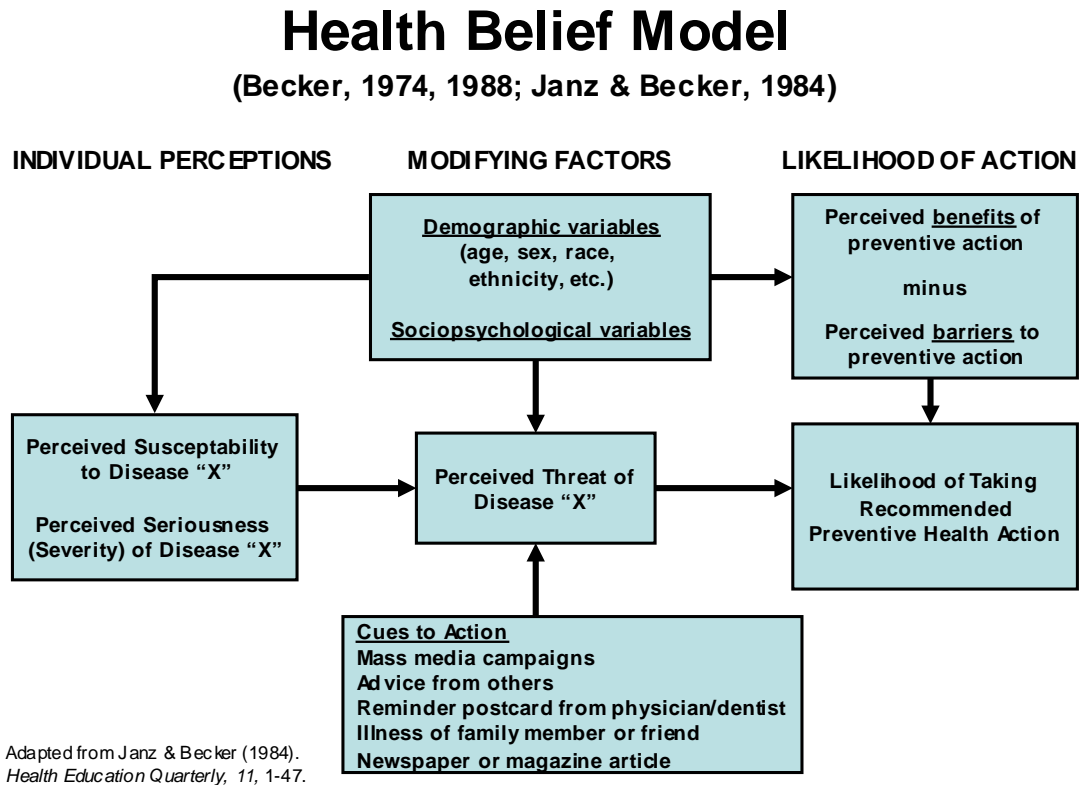
2.1.10 Health Belief Model

Health Belief Model (HBM) (Fig. 5) was originally introduced in the 1950s by social psychologists (Rosenstock, Kegels, Hochbaum, and Leventhal) working in the United States Public Health Service. This model was developed to understand why many people didn't take advantage of free immunization and screening services provided by the federal government in the United States. This model assumes that people's motivation to change their preventive health behavior is influenced by their beliefs of susceptibility to a disease, severity of the disease, benefits of changing behavior, perceived barriers and cues to action (Janz & Becker 1984).

The following assumptions serve as the important components of health belief model:

Concept	Definition
Perceived Susceptibility -	One's subjective belief /opinion of getting a disease/condition.
Perceived Severity	An individual's belief about the seriousness or severity of disease.
Perceived Benefits	An individual's belief that performing the behavior is beneficial. That is, an individual's belief that costs (such as pain) does not outweigh the benefits of the health action.
Perceived Barriers	An individual's own evaluation of the barriers in the way of him or her adopting a new behavior
Cues to Action	Demographic and socio-psychological factors, mass media reports and campaigns, illness of a family member or friend, and experience affect an individual's perceptions of illness, and thus influence health-seeking behavior.

Fig. 5. Health Belief Model



2.1.11 Medical Efficacy

Allan Young (1982) introduced the medical efficacy concept. He argues that medical anthropologists who work on explanatory models of illness are practically interested in the issue of medical efficacy. Young contends that medical anthropologists augment the effectiveness of clinical medicine in the context of the healing process. For instance, they play an important role in enhancing culturally appropriate patient education, providing remedies for problems of non-compliance, and challenge maladaptive courses of treatment.

2.2 Perceptions and Experiences of People about TB

This section examines the literature pertaining to: lay beliefs about the causation of TB, patients initial reactions to diagnosis of TB, patient delays in seeking medical care, TB and stigma, and general patterns of health seeking behavior of TB patients.

2.2.1 Lay Beliefs about Causes of TB

Several research studies (Moloantao 1982; Metcalf 1990; Zvosec 1996; Carey *et al* 1997; Vecchiato 1997; Banerjee *et al* 2000; Nitcher 1994), suggested that there is a considerable disparity between the lay and biomedical perspectives on the causes of TB. In South Africa, Moloanto (1982) conducted a study on traditional beliefs of TB patients of Ga-Rankuwa and Boekenhout hospitals, about causation of TB. The author found that patients attributed causation of TB to a number of factors such as excessive alcohol consumption, heavy cigarette smoking, inhalation of benzene, inadequate intake of food, adultery/infidelity, witchcraft, poisoning by enemies via food, mysterious worms in the lungs, overcrowded housing conditions, inheritance, and germs in the air.

Metcalf *et al* (1990) conducted a community-based survey on knowledge and beliefs about TB among non-working women in Cape Town. Study participants were selected using a cluster sampling method. A structured questionnaire was administered to 30 clusters of 5 people. Study results indicated that respondents identified cold weather, smoking, malnutrition, poor eating habits, overcrowding, alcohol, infection/germs, wet weather, and poor housing as possible causal factors of TB.

In India, Subramanian (1990) conducted a study in rural, urban and metropolitan areas of Tamil Nadu. The total sample size was 73094. Of the total 73904 sample, 18,395 were from rural, 17,409 were from urban and 37,290 were from metropolitan areas. The proportions of chest symptomatics identified from these samples were 5.8% from rural, 5.5% from urban and 4.7% from metropolitan area, and were selected based on cluster sampling method. Findings of this study suggest that above 30% of the sample from all the three areas had no clear idea about the factors that cause TB. About less than one third of the patients attributed TB causation to factors like consumption of cold foods such as tomato, climate change and unhygienic conditions. 4% from rural, 14% from urban and 8% from metropolitan area reported that germs play a role in the causation of

TB. 2% of rural symptomatics explained that TB can be caused by divine retribution, evil spirits or fate. 21% from rural, 16% from urban and 9% from metropolitan area mentioned smoking and excessive alcohol consumption as the cause of TB. In this study, some patients suggested that multiple factors were involved in the development of TB.

In Philippines, Nitcher (1994) conducted a study to understand the perceptions and experiences with TB illness, and factors that predispose an individual to TB. He chose 50 lower class literate mothers belonging to a rural coastal area of central Oriental Mindoro, Philippines, for the study. Respondents explained that a number of factors predispose an individual to TB. These factors include germs, fatigue, overwork, carelessness of the body, unsanitary environment, poverty, very little food, untimely eating, sleeping on cold floor, excessive smoking and drinking, lack of vitamins, contagion and weak lungs.

Carey et al (1997) conducted a survey among 51 Vietnamese refugees in two New York counties to understand their beliefs about causes of TB. Refugees were asked open ended questions on the possible risk factors for development of TB. The researchers reported that Vietnamese refugees endorsed factors such as alcohol consumption, poor nutrition, heredity, exposure to others with TB, living in unhygienic conditions, breathing dirty air, and weak immune system as contributory factors for development of TB.

Vecchiato (1997) studied beliefs about causes of TB in 217 Ethiopian adults. Respondents were selected through quota sampling method. Study findings suggested that factors like excessive work, contagion, malnutrition, exposure to sun, heredity, evil spirits, evil eye, and decreased blood level can lead to TB.

Banerjee *et al* (2000) conducted a study to understand local perceptions of TB in a rural district of Ntcheu, Malawi. A total of 10 traditional healers were interviewed using semi-structured questionnaire. Study findings indicated that traditional healers basically attributed TB causation to four important causes: i) angry spirits; ii) bewitchment; iii) careless sexual behavior and iv) god's will or bad luck.

Auer *et al* (2000) investigated health seeking and perceived causes of TB among patients in Manila, Philippines. In general, patients attributed TB causation to drying sweat on the back, smoking, microbe, drinking alcohol, dirty environment, fatigue, hard work, frequent pneumonia, lack of food, poverty, inheritance, and many sex partners. 62% of the study participants (n=319) gave more than one cause. Respondents mentioned

smoking, alcohol consumption and hard work more frequently than mechanistic causes, for example, human-to-human transmission.

2.2.2 Patients' Initial Reactions to Diagnosis of TB

Diagnosis of TB is potentially an emotional and traumatic event for many TB patients. Studies on patients' reactions to diagnosis of TB have shown that patients' initial reactions to diagnosis of TB varied from worry, depression, fear of death, denial, and suicidal thoughts (Rajeswari *et al* 2005; Thomas *et al* 1999); shock, fear of spreading disease to others, fear of losing job, social stigma, and fear that TB is not curable (Liam *et al* 1999).

Rajeswari *et al* (2005) conducted a study on the 'perceptions of TB patients about their physical, mental and social well-being' in the state of Tamil Nadu. In this study, 610 patients (males 404; females 206), registered for treatment with two government TB units in Tiruvallur district of Tamil Nadu State, South India, were interviewed. The study results demonstrated that patients' reactions to diagnosis of TB varied from worry (Males (M) 50%; Females (F) 58%), normal (M 31%; F 24%), suicidal thoughts (M 9%; F 9%), denial (M 4%; F 2%), depression (M 7%; F 10%), and fear of death (M 2%; F 3%).

Liam *et al* (1999) conducted a study on attitudes and knowledge of newly diagnosed TB patients regarding the TB disease. The study sample consisted of 135 patients (males 76 and females 56), and were selected from the University Hospital, Kuala Lumpur, Malaysia. The study findings suggested that patients expressed a variety of reactions to diagnosis of their TB – not worried (36%), disbelief/shock (22%), fear of spreading disease to others (22%), fear of losing a job (6%), fear of social stigma (6%), fears about incurability of TB (3%), and afraid of dying from TB (1.5%).

2.2.3 Socio-cultural Factors and Patient Delay in Seeking Medical Care

Studies (Liefoghe *et al* 1997; Rajeswari *et al* 2002; Diez *et al* 2005), have suggested that early signs and symptoms of TB do not always prompt individuals to seek appropriate care. Delay in seeking diagnosis and appropriate treatment for TB presents a significant health problem in developing countries. It is established that delays can occur from two important sources: i) providers and ii) patients. *Patient delay* can be defined as

the period between the onset of symptoms to the first visit to a qualified health care worker. *Health system delay* can be defined as the period between the first medical visit and initiation of anti-TB treatment (Diez *et al* 2005). Several studies clearly suggested that patient delay remains by the far most significant cause of delay in seeking treatment for symptoms of TB.

Research studies (Liefoghe *et al* 1997), conducted in different parts of the world indicate that people remain unaware of the significance of the early symptoms of TB and of the importance of early diagnosis and treatment. Several research studies have suggested that a number of factors were associated with patient delays including poor socio-economic condition, alcoholism, domestic preoccupation, and distance (Rajeswari *et al* 2002); traditional disease causation beliefs (Long *et al* 1998); gender, stigma (Ngamvithayapong *et al* 2000); old age, lost work and income (Needham *et al* 2001); illiteracy, treatment cost, attribution of symptoms to less serious illnesses (Liefoghe *et al* 1997) and self treatment (Rubel & Garro 1992).

In a qualitative study conducted by Liefoghe *et al* (1997) in Uasin Gishu, Kenya, suggest that all the TB patients (n=49) waited for several months, sometimes a year or more before seeking appropriate care. In this study, several patients waited for a long time because they believed that their symptoms were not serious, and thought they were suffering from an illness other than TB.

In a study conducted by Zhang *et al* (2007), in rural Mongolia, China, respondents reported that that people delay decision to seek proper treatment for TB for the following reasons: i) lack of knowledge of the important signs and symptoms of TB, its transmission and its curability; ii) fear of social stigma; and iii) socio-economic reasons.

In Manila, Phillippines, Auer *et al* (2000) carried out a study among 319 sputum positive patients in order to understand their health-seeking behavior. In this study, it was noted that, of the 319 total patients, 228 patients had delayed seeking care for more than 15 days. Because, these patients had thought that the symptoms were harmless (59%), and lack of money (22%), self-treatment (4%), preoccupation with work (7%) and other reasons (8%). The study findings demonstrated that considering symptoms to be non-serious and harmless was the most important reason for delay. Similar perceptions and attitudes are reported in India (Subramanian 1990).

Studies conducted on socio-cultural beliefs and perceptions of TB have found that people attributed symptoms suggestive of TB to different folk illnesses. For example, a study conducted by Rubel & Garro (1992) among Hispanic communities in America found that many Hispanics attributed symptoms of TB to folk illnesses such as ‘*wasting sickness*’ or *grippe* or *susto*. In Philippines, Lieban (1976) noted that parents attributed their TB symptoms to the folk illness called *piang* rather than to TB. Such lay diagnoses resulted in considerable delays in seeking early care. Some other studies suggested that patients did not attribute symptoms to TB, because they did not perceive themselves to be at risk of developing TB.

The use of traditional medicine also contributed to patient delays. In Blantyre, Malawi, about 40% of the smear-positive TB patients sought treatment from traditional healers prior to the diagnosis of their TB (Brouwer *et al* 1998).

A considerable number of studies clearly noted that ‘wait and see’ approach caused considerable patient delay. For example, Cambanis *et al* (2005) found that rural Ethiopian TB suspects wait until they no longer able to perform their normal day to day activities before seeking medical treatment. Cambanis *et al* (2005: 333) argue that “*poverty often precludes health seeking until the ill person is no longer able to contribute to the livelihood of the family or household*”.

The findings of the above studies indicate that patients’ understanding of their symptoms, and their actions in relation to these symptoms, were strongly influenced by the broader context of their daily lives.

2.2.4 TB and Stigma

Noted sociologist Erving Goffman (1963) in his classic treatise on stigma, defines stigma as “an attribute that is deeply discrediting” and proposes that the stigmatized person is reduced from a whole and usual person to a tainted, discounted one”. According to Goffman (1963:9), stigma is viewed as “*the situation of the individual who is disqualified from full social acceptance*”. Stigma is basically a “devaluing social identity”. Goffman (1963) divided this “experience” of stigma into felt and enacted stigma. The former refers to people’s feelings about their condition and their expectations

about others' reactions towards them and the latter to the actual experiences of stigma and/or discrimination.

Literature review pertaining to stigma experiences of TB patients (Rajeswari *et al* 1995; Liefoghe *et al* 1995; Uplekar & Rangan 1996; Liefoghe *et al* 1997; Jaramillo 1998; Long *et al* 1999; Auer *et al* 2000; Atre *et al* 2004; East wood & Hill 2004; Hoa *et al* 2004; Cambanis *et al* 2005) suggest that TB remains a highly stigmatized disease in several parts of the world. In different parts of the world, "*tuberculosis has been and still often considered a dirty disease, a death penalty or as affecting guilty people*" (Macq *et al* 2006:346). Misinformation about the transmission (such as through sharing clothes, towels, utensils and bed sheets), of TB appear to contribute to the persistence of TB related stigma (East wood & Hill 2004; Cambanis *et al* 2005). In fact, most of the social stigma and discrimination experienced by TB patients was related to prejudice surrounding the transmission of TB.

A number of studies (Atre *et al* 2004; Uplekar & Rangan 1998; Liefoghe *et al* 1997) have reported that people with TB, particularly women, have low esteem and faced number of social problems. In India, married women expressed a concern that their husbands and in-laws would subject them to harassment and discrimination because of their illness (Rajeswari *et al* 2005). A study conducted by Liefoghe *et al* (1995) in Pakistan revealed that women patients faced a number of problems such as abandonment, job loss and divorce on account of their TB. Rajeswari *et al* (1999) found that 15% of the married women (n=120) were rejected by their family members because of their TB. Studies found that women may suffer violence, verbal abuse and abandonment once their TB positive status becomes public. In India, about 100,000 women are abandoned by their families because of their TB every year (RNTCP Status Report, 2005). A study conducted by Lonroth *et al* (2001) in Ho Chi Minh city, Vietnam, noted that one traditional TB causation belief among Vietnamese lay communities is that TB is hereditary, and woman suffering from TB should not marry. Thus, women with TB in Vietnam maintain secrecy about the nature of their illness. In India, similar observations were made by Rajeswari *et al* (2005). These studies indicated that perceived stigma is more common among majority of respondents with TB. For example, Rajeswari *et al*

(2005) found that stigma is major cause of concern for TB patients in South India, and it interfered with social interactions, such as visiting friends and relatives.

Other studies (Nitcher, 1994), suggested that people with TB conceal the nature of their illness from others to avoid stigma and social rejection. In Philippines, Nitcher (1994), noted that respondents attributed their TB infection to '*weak lungs*', which is a less stigmatized illness and is not considered contagious. Stigma affects the both the patients and his/her family members. Consequently, family often conceals the nature of the illness from their community members. Hence, managing TB status remained a matter of concern for many patients, particularly for women patients, and often represented a major challenge in their lives.

2.2.5 General Patterns of Health Seeking Behavior of TB patients

Patients suffering from chronic illnesses actively search for a variety of health care options to get relief from symptoms. TB patients in developing countries go through different TB treatment transitions. These are self treatment, public health care facilities, private health care facilities, traditional healers. Patients easily move from one medical system to another for various reasons. Nyamongo (2002) for example, argues that the notions about the causes of an illness may change over a period of time and gradually the patient may assign a new cause to an illness. For instance, in the case of TB such new causes may be attributed if the patient did not get much needed relief or takes more time to recover from the illness. "*Assigning new causes usually also signals a shift in treatment*" (Nyamongo 2002: 382). Patients generally move progressively from self-treatment, to the use of private and government health services, or magico-religious healers if the illness lasts for an extended period of time. Sudha *et al* (2003) conducted a study on factors influencing the care-seeking behavior of chest symptomatics in rural and urban areas of south India. The authors found that 51% of the urban chest symptomatics (n=340), and 43% of the rural symptomatics (n=349), consulted more than two health care providers during the course of their illness.

Health seeking behavior usually begins within the family where symptoms are initially perceived, defined and treatment is initiated. Self-care remedies is the first step in the health-seeking process (Rubel & Garro 1992; Liefoghe *et al* 1997; Cambanis *et al*

2005). Over-the-counter drugs (e.g., pain relievers, muscle relaxants, fever reducers, analgesic creams and traditional herbal teas and medicines) are very popular self-care remedies. Greater accessibility, more convenience, lower cost of medical care and transportation, less time, non-severity of symptoms, and past experiences with symptoms of cough, cold, fever, etc., were some of the factors that influence choice of self care (McCombie 1996). When the symptoms persist or progress despite of self-treatment, patients switch from self-care treatment to other alternative sources of health care.

Several studies indicated that individuals diagnosed with chronic long standing diseases such as TB often turn to some form of complementary or alternative medicine (CAM) in addition to western medicine in the belief that such therapies might cure the illness. These include spiritual or faith healing, special diets, massage, herbal treatment, and prayer. Prayer is the most important complementary therapy among most patients suffering from chronic illnesses such as TB. Several studies established that people suffering from serious illnesses coped with their predicament by praying and putting their fate in God's hands. Patients reported that prayers contribute to their well-being in number ways. For example, prayers play an indispensable role in enhancing hope, coping abilities, positive health beliefs, positive health-care behaviors, and positive health-care outcome. In addition to folk and professional medicine, faith healers and healing temples, churches, Muslim darghas, etc., provide curative and restorative health care services to the patients. Generally, it was found that patients usually consult witches or religious priests when a variety of other resources, particularly, allopathic treatment fail to provide expected relief. The principal form of therapy employed by witches (*mantragadu*) is exorcist ritual. Dwyer (2003:54) argues that "*the belief that a supernatural agent is likely to be responsible for causing a person to become sick is almost invariably the reason why an ailing individual goes to visit a traditional healer or diagnostician*".

General health seeking pattern of chest symptomatics clearly suggest that private practice is the most important source of first contact for majority of patients, including people from poor socio-economic strata (Uplekar *et al* 1996; Wandwalo & Morkve 2000; Sudha *et al* 2003). A majority of patients basically switch from private health care services to government health services for economic reasons. Several studies (Saunderson 1995) clearly established that TB patients incurred considerable direct costs

(such as consultation fees, transportation and hospitalization charges, treatment and medicine costs, etc.), before diagnosis of TB in the private sector. These direct costs placed a heavy economic burden on the individual patient and his/her family. Ngamvithayapong *et al* (2001), in Thailand, for instance, found that patients sold assets such as land, cows, gold, houses, etc., in order to meet treatment expenses. Patients also borrowed money from their relatives and neighbors to meet the expenses.

2.3 Evolution of TB Treatment

2.3.1 The Discovery of the Tubercle Bacillus

On March 24, 1882, Robert Koch (1843-1910), German physician, delivered a dramatic lecture to the Physiological Society of Berlin on the discovery of the bacillus, and this lecture marks an important turning point in the history of TB. Robert Koch provided irrefutable experimental evidence that a specific thin rod shaped bacteria *Mycobacterium tuberculosis* as the biological cause of TB, and demonstrated experimentally that it as an infectious disease (Ayvazian 1993). He also invented a staining technique (a combination of methylene blue with a small amount of potash), for visualizing this bacteria within the tuberculosis tissue in a most conclusive manner, and developed culture media for the purpose of growing tubercle bacilli in laboratory conditions (Teller, 1988; Schluger, 2005). Koch thus conclusively demonstrated that TB was not attributed to heredity, superstitions, air pollution, polluted blood, lack of exercise, but to a specific organism *M tuberculosis*.

2.3.2 Evolution of TB Treatment

Before the introduction of anti-TB drugs in the 1940s, a variety of measures such as horse riding, sea voyages, graded exercise, absolute bed rest, blood letting, injections of extracts of gold or other heavy metals, artificial pneumothorax, thoracoplasty, and various other exotic measures had been advocated, but none showed any significant efficacy (Jawar, 2004). Most 19th century physicians looked upon TB as a hopeless disease, and argued that there was no measure available to prevent or resist a disease that

was hereditary in nature. As faith in medicine declined, many 19th century physicians relied primarily on natural remedies (i.e., fresh air, moderate exercise, bed rest, sunshine and nutritious diet), for treating TB, and they argued that natural remedies play an indispensable role in strengthening the body's defense against TB bacillus. In the middle of the 19th century, the primary therapy for TB was prolonged bed rest, nutritious food, fresh air and change of climate, and such therapies were practiced usually in the setting of a sanatorium (Mohan & Sharma, 2001).

Sanatorium Treatment

The word sanatorium is derived from Latin word *Sanatorius* meaning “an establishment providing therapy” (Madkour *et al* 2004). The introduction of the sanatorium cure provided the first real step against the management of TB. According to Joseph (1956:7) sanatoriums were established “*for the treatment of tuberculosis because of the certain characteristics of the disease itself. The fact TB is a dreaded infectious disease made it necessary that the sufferers should be separated from the healthy, and placed in institutions where special provisions are made for personal hygiene and prevention of infection. Secondly, the disease in the majority of the cases being of long and chronic nature, it was found desirable that arrangements should be made for patients to settle down for months or years together and adopt a restful regulated mode of life with provision for a liberal supply of good food. Thirdly, since no medicinal or other forms of direct attack on the disease were known and treatment was mostly “nature cure” emphasis came to be laid on climate, fresh air, and surroundings*”.

George Bodington (UK), Hermann Brehmer (Germany), and Trudeau (USA), were all laid the ground work for the introduction of sanatorium type of treatment. In 1836, George Bodington, Birmingham, UK, for the first time, proposed isolation of consumptives in a separate house for providing therapy to the consumptives. He believed that diet, physical activities and fresh air was essential for treatment, however his suggestions failed due to lack of support (Madkour *et al* 2004). In 1854, Dr. Hermann Brehmer, built a sanatorium in Gorbersdorf, Germany, in the middle of a pine forest. This was the first sanatorium opened for the treatment of patients with pulmonary TB, and it became the model for all sanatoria across the world. Hermann Brehmer, a botanical

student from Silesia, Germany, himself a suffer from the disease, was instructed by his doctor to seek a healthy climate. Brehmer traveled to the Himalaya Mountains, where he pursued his botanical studies while trying to rid himself of the disease (Mohan & Sharma, 2001). He returned home cured, and began to study medicine. In 1854 he presented his doctoral dissertation bearing the title *Tuberculosis primis in Stadiis Semper Curabilis* (*Tuberculosis is a Curable Disease*). He believed that mountain air, exercise and nutritious food were essential for healing the disease (Basel, 1998). The advent of the 20th century saw the increased popularity of sanatoriums in different parts of the world including India.

Sanatorium: Methods of Treatment

An important feature of sanatorium treatment was diet. It was assumed that increase in weight of a patient was an important indication of the success of the treatment. Hence, each patient was weighed every week under the supervision of a qualified dietician and the weight was noted on a chart. Special diet was given to the weak patients to build up their physical strength and immunity power to fight off the disease. Thus, diet constituted the most important feature of sanatorium treatment. An American Sanatorium physician Lawrason Brown put it “*the kitchen is the only pharmacy that many patients should know*” (Quoted in Teller, 1988: 25).

The second significant aspect of the sanatorium treatment was exercise. The exercise regimen mainly consisted of walking at a slow pace. It was assumed that exercise increases lungs strength and breathing power. Physicians prescribed rest and exercise just in right proportion in each individual case, giving due consideration to the patient’s body temperature, weight, cough, sputum condition, fatigue levels, etc. The patients were advised to never exercise when the body temperature was high, when the sputum was bloody. Patients were also warned to never run or walk fast, never get tired and never get out of breadth.

The third notable facet of sanatorium treatment was exposure to fresh air. The belief was that fresh air and sunshine was important for curing the disease. Therefore, the patients were allowed to come indoors only once per day to bathe and otherwise not

allowed inside. Summer and winter alike the residents of the sanatorium ate, slept, socialized and died on these porches.

Fourth important hallmark of sanatorium treatment was heliotherapy (Sunlight therapy). Natural sunlight treatment was used in the treatment of non-pulmonary TB, for instance, joints, skin, eyes, etc. It was believed that sun light acts as a bactericidal, and kills TB bacillus when a patient is exposed to moderate temperatures for a considerable period of time. Ultraviolet sunlamp treatment was employed when the weather conditions were unfavorable. Rest including both mental and physical rest was another essential feature of sanatorium treatment (McCarthy 2001).

The End of Sanatorium Era

By the second decade of the 20th century it became apparent that the sanatorium treatment was not the right type of treatment to combat the problem of TB. Although some patients benefited well under sanatorium treatments, the long term results were fairly depressing (Teller 1988). *“Whether tuberculosis patients were treated in a sanatorium or not treated at all, half of them died”* (Reichman & Tanne 2002: 21). A study conducted in America to study the effect of sanatorium treatment on curing TB showed that *“over 60% of patients discharged from sanatoria died of their disease within six years, and thus had little appreciable effect on reducing death rates from TB”* (Basel, 1998:10). However, sanatoriums met the basic psychological need of community to check the spread of infection by isolating its sick (i.e., the source of infection).

Final breakthrough in the treatment of TB came with the discovery of antituberculosis drugs like streptomycin, rifampicin, isoniazid, ethambutol, and pyrazinamide between 1940's and 1960's, heralding the antituberculosis 'chemotherapeutic era' in the fight against TB. These developments triggered the disappearance of hundreds of open-air sanatoriums that until that time had been the dominant mode of treatment, and sparked a radical change in the focus of national TB control programs across the globe including in India. The sanatorium approach changed to clinical/hospital approach in providing treatment to patients close to where they reside, and such developments have revolutionized the whole concept of the management of TB all over the world.



Fig. 6. Sanatorio Pineta del Carso Sanatorium, Italy

Bed-rest, fresh air and good nutrition were the hallmarks of sanatorium cure.

Source: Cardoso *et al* 2007: 36

Modern Drug Treatment

For the first time a revolution in the treatment of TB came with an epochal discovery of streptomycin a highly effective anti-tuberculosis drug in 1944 by Selman A. Waksman. However, clinical studies revealed that organisms developed resistance to streptomycin readily. A rapid succession of TB drugs like p-aminosalicylic acid (PAS), in 1946, and isoniazid (INH), in 1952 were introduced. When these two drugs were used in combination with streptomycin, it prevented the TB bacteria becoming resistant, and marked the beginning of the true ‘chemotherapeutic era’ in the fight against TB. However, duration of the treatment was considerably high (18 to 24 months). The discovery of rifampicin in the late 1960’s and the rediscovery of antimycobacterial activity of pyrazinamide soon after, have revolutionized the treatment of TB. Such

developments helped to shorten the duration of treatment from 18-24 months to the present-day six-month short-course chemotherapy (Jawar, 2004).

Randomized clinical trials conducted by the British Medical Research Councils (BMRC) in East Africa and Hong Kong, and Tuberculosis Research Centre (TRC) of the Indian Council of Medical research (ICMR) in Chennai, India, have revolutionized the management of TB all over the world. These studies had established that TB could be treated effectively on an outpatient basis, and hospitalization and bed rest was not necessary. The landmark studies carried out under 'Home-Sanatorium study' at the Tuberculosis Research Centre, Madras (Chennai) in the late 1950s and early 1960's demonstrated that TB patients can be treated effectively on an outpatient basis provided adequate chemotherapy was prescribed and taken. These pioneering studies demonstrated the efficacy and safety of outpatient treatment of TB, and the necessity and feasibility of treatment observation in the community - now called **DOTS** (Directly observed treatment, short course). The global impact of the findings of this study is now well recognized and domiciliary treatment for TB became the therapeutic policy for developing countries. Many of the principles DOTS which are now globally recommended were established in India (Jawar 2004).

2.4 Summary

The aim of this review of literature is to emphasize the fact that perception of health, disease, illness and health needs are largely determined by the environment and health culture in which an individual is brought up in and lives. The interpretation of symptoms, illness perceptions, and health-seeking behavior are shaped by local traditions and cultural beliefs. People's perception of health, disease and illness, and treatment choices vary from culture to culture. Culture influences the expression and communication of illness, discomfort, or distress. A number of scholars contend that medical practitioners and health policy planners should understand the influence of society and culture on medical beliefs and practices. Because understanding the role of culture on peoples medical beliefs and treatment practices have important implications for provision of culturally sensitive health care. Prevention and educational programmes that ignore cultural factors are unlikely to be successful. Understanding illness

experiences of people contribute to a great extent in the successful implementation of disease control measures. It is argued that disease control programmes could improve considerably if more consideration were given to the health culture of patients, and this is especially true in the case of TB, a long drawn disease.

In spite of tremendous progress made in medical science and technology, today we are now witnessing a deep crisis in health care in developing and developed countries for various reasons. Biomedicine is mainly concerned with relieving physical or bodily suffering by medicines and/or surgical interventions. The limitations of the biomedical perspective that disease is basically physiological, and that mental and psychological aspects are irrelevant led several scholars such as Engel (1977), Kleinman (1980) and others to propose alternative models of health care which take whole person into consideration or a more holistic view (i.e., social, mental, emotional and spiritual well being).

Review of literature on lay beliefs about causes of TB suggests that there is a considerable disparity between the lay and biomedical perspectives on the causes of TB. Health care professionals primarily attribute TB causation to germs such as bacteria. However, studies conducted in various parts of the world indicated that lay people attribute causation of TB to a variety of individual (e.g., alcohol consumption), social (e.g., witchcraft), natural (e.g., exposure to cold weather) and supernatural (e.g., divine retribution) factors.

Diagnosis of TB is a traumatic event for many TB patients and causes psychological problems such as depression, fear, anxiety, etc. Patient delay constitutes by far the most important cause of delay in seeking appropriate care for TB related symptoms. TB still remains a highly stigmatized disease in many parts of the globe. This stigma is not only confined to harboring negative feelings and attitudes about the person suffering with TB, but also takes the form of behaviors such as social rejection, discrimination and prejudice. A wide variety of factors influence health seeking behavior. Some of these factors include: the perceptions of disease seriousness, the perceived underlying cause of the disease, accessibility, the recognition of disease symptoms, cost, distance, religious beliefs, reputation of provider, quality of health care, and the availability of a provider within the community.

This review of literature pertaining to beliefs, perceptions, and health seeking behavior of TB patients suggests that much of the available literature from a social perspective is based on use of quantitative methods. Thus, this review highlights the need for exploration of experiences of patients living with TB from an insider's perspective using qualitative methods.

The theoretical framework for this research is provided by this review of literature. The present study draws on Kleinman's Explanatory Models and his tripartite classification of health sectors and Helman's four disease causation categories. Although Kleinman's model of the local health care system serves as a theoretical framework for understanding health seeking behavior of TB patients, some of the variables of the Health Belief model are also useful in understanding the health seeking behavior of TB patients.

CHAPTER

3

Research Design & Study Area

This chapter is broadly divided into two sections. Section one deals with research methods employed for the collection and analysis of data. In section two an attempt is made to briefly present Nalgonda district in terms of its general geography, demographic and developmental characteristics, available health care services and disease profile.

3.1 Research Design

The validity, meaningfulness, and insights generated from qualitative enquiry have more to do with the information richness of the cases selected and the observational/analytical capabilities of the researcher than with the sample size. (Patton 1990: 185)

The field work for this study was conducted during 2008-2009 and took place in two selected TB Units (Chintapally and Yadagirigutta). This study focused only on rural TB patients. The main aim of the study was to explore perceptions and experiences of patients with TB. This study mainly focuses on the explanations of the etiology of the TB illness and on their descriptions of symptoms, initial reactions to diagnosis of TB, TB related stigma, and treatment, including use of traditional remedies by TB patients.

3.1.1 Methodology

As the aim of the study was to highlight subjective experiences of patients, a qualitative method was chosen for this study. Several authors have argued that qualitative approach is highly useful to explore personal meanings, emotional subtleties, and experiences associated with highly stigmatized illness such as TB. Major issues in dealing with TB are often more likely to be psychosocial than biological. For these reasons, in this study qualitative method was employed. Interviews of patients were

guided by the explanatory model of illness suggested by Kleinman (1980). Kleinman has introduced the concept of explanatory models of illness to elicit an individual's interpretation and meaning of illness. Kleinman (1980:106) devised open-ended questions to elicit details of patient's explanatory model of illness.

What do you call your problem? What name does it have?

What do you think has caused your problem?

How serious is it? Will it have a short or long course?

What are the chief problems your sickness has caused for you?

What do you fear most about your sickness?

What kind of treatment do you think you should receive?

What are the most important results you hope to receive from this treatment?

As mentioned earlier, explanatory models are held by both health care providers and clients, and each may have their own version. To enable a comparison, this study included perceptions of patients and practitioners on TB. The patients' explanatory models of illness provide personal and social meaning to the illness experience, and guide choices about prevention, seeking treatment, and adherence.

The analysis and interpretation of data were grounded on the accounts of patients, RMPs and Physicians and Traditional healers. Data was analyzed using the general guidelines of Grounded Theory (GT). *"GT is a valuable method for understanding "what is going on" in a given situation and provides researchers with the tools to develop theories that explain what is occurring. This qualitative method involves using increasingly abstract levels of coding to examine data, with the goal of identifying a core category that explains what is occurring in the practice setting"* (Sheila et al 2008: 510).

3.1.2 Respondents

a) Patients

A sample of 110 (age range 18-72) newly registered TB patients were selected from a list of patients registered for treatment between December 2008 to May 2009, in Chintapally and Yadagirigutta TB units. In order to recruit respondents, investigator contacted TB supervisors, described the study and requested a list of TB patients undergoing TB treatment, who were willing to be interviewed and were capable of

participating in the study. TB data with regard to patient's age, gender, TB type (i.e., pulmonary and extra-pulmonary TB), and HIV status was extracted from TB treatment registers. Socio-demographic characteristics of patients are summarized in Table 1. Of the total 110 respondents, 81 (73.6%) were males and 29 (26.3%) were females. Of the total TB cases, 80 (72.7%) were non-tribal and 30 (27.2%) were tribal. Of the total 110 cases, 14 (12.7%) belong to the age group of 18-25 years; 22 (20%) belong to the age group of 26-35 years; 26 (23.6%) belong to the age group of 36-45; 28 (25.4%) belong to age group of 46-55; 16 (14.5%) belong to 56-65 years; and 4 (3.6%) belong to the age group of 66-72 years. The mean age of the patients was 39 years. Of the total patients, 95 (83.6%) were Hindu, 10 (9%) were Muslim and 5 (4.5%) were Christian. Of the total patients, 92 (83.6%) were married, 10 (9%) widowed and 8 (7.2%) single. Of the total 110 respondents, 6 (5.45%) patients were found to be co-infected with HIV and TB.

Amongst the 110 patients, 67 (61%) were illiterate, 26 (23.6%) had primary education, 14 (12.7%) had secondary and 3 (2.7%) had college education. Of the total patients, Backward Classes (BC) constitute 55 (50%); Schedule Tribes (ST) constitute 30 (27.2%); Schedule Castes (SC) 21 (19%) and Open Category (OC) 4 (3.6%). Majority of the patients were poor and belonged to socially and economically marginalized social groups thereby establishing a positive co-relation between poor socio-economic conditions and TB. Several studies have attributed a high prevalence and incidence of TB cases among marginalized communities to conditions of malnutrition, overcrowding, poor living conditions, harmful lifestyles, poor working conditions, homelessness, low per capita income, illiteracy and lack of access to basic health services, all of which are more common among people living under poor socio-economic conditions. A close link between poverty and TB infection can be partly explained by the fact that socio-economically deprived conditions (e.g., malnutrition) enhance an individual's susceptibility to infectious diseases by lowering his/her immunity levels. TB has been designated by many as a '*social disease*'.

b) Practitioners

i) Rural Medical Practitioners (RMPs)

20 RMPs working in the study area were interviewed to understand knowledge and perceptions about TB. Of the total RMPs, 10 were from Chintapally TB Unit and 10 were from Yadagirigutta TB Unit. The 20 RMPs interviewed ranged in age from 25 to 54 years. Of the total 20 RMPs, 18 were males and 2 were females. Of the total RMPs, 50% and 40% had received intermediate and high school education respectively. 10% had college education. Table 2 illustrates socio-demographic characteristics of the RMPs.

ii) Physicians

10 Physicians (Allopaths) working in government TB clinics were interviewed. Their ages ranged from 36 to 54 years. All the physicians had worked in the TB clinics for more than two years. Eight were males and two were females.

iii) Traditional Healers (THs)

4 Traditional healers working the study area were interviewed. Of the total healers, 2 were from Chintapally TB unit, and 2 were from Yadagirigutta TB unit. All the healers were males. 2 had primary education and another two had secondary education. Of the four healers, 3 were herbalists and 1 was a faith healer. Table 3 illustrates the socio-demographic characteristics of the Traditional healers.

Table 1. Socio-Demographic Characteristics of the Patients (n=110)

	Number of patients	%
Age in Groups		
18-25	14	12.7
26-35	22	20
36-45	26	23.6
46-55	28	25.4
56-65	16	14.5
66-72	4	3.6
Sex		
Male	81	73.6
Female	29	26.3
Marital Status		
Married	92	83.6
Widow/Widower	10	9
Single	08	7.3
Caste		
BC	55	50
ST	30	27.3
SC	21	19
OC	04	3.6
Religion		
Hindu	95	86.3
Christian	05	4.5
Muslim	10	9
Education		
Non-literate	67	61
Primary	26	23.6
Secondary	14	12.7
College	03	2.7
Occupation		
Agriculture	38	34.5
Labor	33	30
Self-employed	24	21.8
Private employee	06	5.4
Student	02	1.8
Others	07	6.4
Annual income		
10,000-20,000	15	13.6
21,000-30,000	31	28.1
31,000-40,000	33	30.0
41,000-50,000	13	11.8
51,000-60,000	08	7.3
61,000-70,000	06	5.4
>70,000	04	3.6
TB type		
Pulmonary	99	90
Extra-pulmonary	11	10
HIV status		
Positive	06	5.4
Negative	104	94.5

Source: Fieldwork (2008-2009)

Table. 2. Socio-Demographic Characteristics of RMPs

Variable	No. of RMPs (n=20)	%
Sex		
Male	18	90
Female	02	10
Age		
25-35	05	25
36-45	12	60
>45	03	15
Education		
High School	08	40
Intermediate (10+2)	10	50
Degree	02	10
Marital Status		
Married	19	95
Single	01	05
Locality		
Rural	20	100
Urban	-	-
Years of Experience		
1-5 years	03	15
6-10 years	11	55
> 15 years	06	30
Caste		
BC	13	65
SC	02	10
ST	03	15
OC	02	10

Source: Fieldwork (2008-2009)

Table. 3. Socio-Demographic characteristics of Traditional Healers

Variables	No. of Traditional Healers (N= 4)
Type of Healer	
Herbalist	03
Faith Healer	01
Gender	
Male	04
Female	-
Age	
50-60 years	02
>60 years	02
Education	
Primary	02
Secondary	02
Caste	
BC	02
OC	01
ST	01
Years of Experience	
15-20 years	02
> 20 years	02

Source: Fieldwork (2008-2009)

3.1.3 Methods of Data Collection

A copy of brief explanation of the statement of the research problem, study objectives and the scope of the study was submitted to Joint Director, TB, Hyderabad, and District TB Officer, Nalgonda. Both of them granted permission to conduct the study. Respondents were selected using purposive sampling technique. TB supervisors

approached TB patients known to them who were on TB medication under DOTS programme. Those patients who agreed to be interviewed gave their consent for the TB supervisors to release their names for the current study.

The research objectives were also explained to the study participants in simple terms, and given the fact many of the patients were illiterate, oral informed consent was obtained from them before administering the research instruments. Considerable amount of time was spent in developing rapport with the patients and their family members before conducting interviews. Rapport building was very difficult in case of women patients, because they didn't want to be identified by community members as TB patients. Several difficulties were faced in trying to get co-operation from the women patients. My close involvement with several local health care workers benefited this research in many ways.

The patients' semi-structured interview schedule was largely guided by Kleinman's explanatory models of illness, and the semi-structured interview schedule was designed to elicit data on the meaning of their illness. Each interview session lasted from 30 minutes to one and half hours. Patients were given freedom and flexibility to express their experiences with TB illness.

Patients' semi-structured interview included these questions: *What do you think has caused your TB disease? How did you feel after you found out the diagnosis? What is the very first thing you did when you got concerned about your symptoms? What are the different treatments sought to get relief? How has the disorder influenced your social and home life?* In probing social stigma and discrimination, participants were asked about various forms of negative attitudes and discriminatory reactions experienced by them because of their illness.

Semi-structured interview schedule was used for the collection of data, and in-depth interviews were conducted face-to-face with the patients, RMPs, THs and physicians. A small pilot test was carried out prior to the main field work. Changes in wording and sequencing of interview questions were made and questionnaire was shortened as a result of pilot study. Field notes were taken extensively. Qualitative data was recorded immediately by filling up interview schedule. Whenever necessary, extra visits were paid to the patients, RMPs and physicians either to get more information or to check the

validity of the information obtained. Interviews with the patients, RMPs, THs and physicians were conducted in native language (*Telugu*). Male patients were interviewed primarily in their respective homes, whereas, female patients were interviewed mostly in the homes of female health care workers. Several interviews were also held with the community members and local health care workers to check the validity of the information obtained from patients and other respondents.

The primary source of data was field interviews. The data collection methods include face-to-face interviews, case studies, participant observation and focus group discussions (FGDs). In each TB unit, a total of two focus group discussions were held with the assistance of local health care workers. Focus group discussions helped a great deal in understanding community beliefs, attitudes and perceptions about TB, and patients' experiences with the illness. About 4-5 patients participated in each of these group discussions. Case study technique was particularly employed to elicit information on the health seeking behavior and rationale behind resorting to alternative medical practices.

3.1.4 Data Analysis

Handwritten field notes were translated from Telugu to English. Field notes were analyzed inductively, and a list of categories of themes was identified, and the qualitative data were coded into following main categories: i) patients' beliefs about causes of TB, initial reactions to diagnosis of TB, felt and enacted stigma experiences, reasons for patient delay in seeking health care, general patterns of health seeking behavior and the rationale behind resorting to alternative practices; ii) RMPs and THs beliefs about TB causes, transmission, and symptoms, duration of TB treatment, sites of TB infection, and HIV/TB association; iii) views of physicians with regard to TB causation, symptoms, transmission, risk factors, TB severity, reasons for treatment default, and major problems. These categories were used as the basis for writing the text-based chapters of this dissertation. Data collected was verified by cross-checking with the patients' family on various issues in general and shopping for treatment in particular. The study is enriched by actual quotes from participants wherever needed. Most quotes may not be verbatim,

rather they are a close approximation of what was stated during the interview sessions and captured in the field notes.

3.2 Limitations of the Study

This explorative research study has certain limitations. First, this study is based on a small sample size, and hence, results can not be generalized to a broader population of TB patients at the state or national level. That is, the samples were not selected randomly, and hence, they are not statistically representative of populations beyond them. Second, there is a possibility for recall bias given that the data was collected retrospectively and was based on patients' recall of events that can be possibly inaccurate. A bias towards under reporting of utilization of magico-religious can not be ruled out. Third, the influences of socio-demographic variables (such as age, gender, education, occupation, social class, etc.), on the perceptions and experiences of TB illness was not the major focus of this study though it is extremely important. Finally, tribal women patients showed reluctance in becoming part of the study and narrating their illness experiences because of social stigma, and as a result the researcher couldn't elicit detailed responses from them. However, despite these limitations, findings contribute to new knowledge that would be useful in planning for effective TB educational programs for creating better awareness about TB among the rural communities.

3.3 Description of Study Area : Nalgonda District

According to the Census of 2001, the state of Andhra Pradesh has a population of 76,210,007. Nalgonda district ranks 13th in terms of population in the state with 3,247,982 people. The study area Nalgonda district is situated in the middle of the state. It lies 16° 25' and 17° 50' north and 78° 40' and 80° 05' east. It covers an area of 14,240 sq. kms, making it the 9th largest in terms of area among the 22 districts of the state of A.P. Nalgonda district is bounded on the North by Medak and Warangal districts, on the South by Guntur and partly Mahabubnagar district, on the East by Khammam and Krishna districts and on the West by Rangareddi and Mahabubnagar districts. The administrative head quarter of the district is located at Nalgonda town which is about 105

kilometers from Hyderabad, the capital of Andhra Pradesh. The district is administratively divided into 4 revenue divisions, 59 mandals and 1148 villages. Total number of inhabited villages as per 2001 census was 1124.

3.3.1 Nalgonda : Demographic Profile

Of the total population of 3,247,982 in Nalgonda, males constituted 1,651,990 (51%) and females 1,595,992 (49%). 14% of the population was 0-6 years of age. Sex ratio (females per 1000 males) was 966. Child sex ratio (0-6 years) was 952. The district registered a decadal population growth (1991-2001) of +13.55%. The scheduled tribe population in the district was 3,42,676 which amounts to 10.5% of the total district population. Lambada tribe constitutes more than 90% of the total tribal population in the district. The total scheduled caste population was 5,75,788 (i.e. 17.7% of the total population). The density of the population per sq.km. was estimated to be 228. As per the census 2001, total number of households was 7,23,015 and the average household size was 4 per household. The population of the district is highly heterogeneous, and is represented by different religious, social and tribal groups such as Hindus, Muslims, Christians, Sikhs, Buddhists, Jains, and tribal groups (such as Lambada, Chenchu, Koya, Yerukala, Sugali and Thoti). While Hinduism is the principal religion in this area (93.6%), the district has a sizable Muslim and Christian population. Telugu is the main local language. About 86.6% of the population was rural. Urban population makes up 13% of the total district's population (Census 2001). There are three urban centres in Nalgonda district: i) Suryapet, ii) Miryalaguda and iii) Nalgonda. As per the census 2001, the percentage of households occupying permanent settlements was 50%, semi-permanent 27% and temporary 23%. The demographic profile of the district is summarized in Table 4.

Table. 4. Fact File on Nalgonda District (Census 2001)

Population		
Total population		3247982
Males		1651990 (51%)
Females		1595992 (49%)
Total number of Households		723015
Average size of the household (per household)		4
Density of Population (Per Sq.Km.)		228
Sex Ratio (females per 1000 males)		996
Child Sex Ratio (0-6)		952
Percentage of Scheduled Caste population to – total population		17.7
Percentage of Scheduled Tribe population to – total population		10.5
Percentage of Urban population to – total population		13.3%
Decadal population growth (1991-2001)		+ 13.5
Hindus		93.6%
Muslims		5.25%
Christians		1%

Source: Census of Andhra Pradesh, 2001

3.3.2 Nalgonda : Development Profile

Nalgonda district is one of the less developed districts of A.P., in terms of both economic and social development. In terms of the Human Development Index (HDI), Nalgonda district ranks low among the 23 districts of A.P. with a HDI rank of 18 in 2001 (HDR, A.P., 2007). HDI is a summary indicator of the level of achievement in human development. It measures achievements in the basic dimensions of human development – health, education and income.

As per Human Development Report, 2007, A.P., the percentage of gross irrigated area to the gross cropped area was 42.1. Total number of commercial bank branches available for one lakh population was 5.72. Percentage of villages connected with electricity was 99.9. Number of telephone connections and post offices per one lakh population was 3121 and 23 respectively. 91% of villages had bus services. 83% and 16.5% of villages had paved and mud approach roads respectively. 73% of villages had post, telegraph and telephone facilities (Census 2001).

A few select indicators are presented below to emphasise the poor status of development in Nalgonda district.

Basic Amenities

As per Census 2001 estimates, 29.7 and 33.4 percent of households had no access to electricity and tap water respectively. Furthermore, a high percent of households (78.7%) used traditional fuels such as charcoal, firewood, straw, grass, etc., for cooking. An overwhelming majority of households (73.4%) had no toilet facility. These indicators clearly suggest that sanitation and hygiene levels are poor in the district. The data on the use of traditional fuels for cooking show that women particularly are at risk for developing respiratory related illnesses due to exposure to smoke from these cooking fuels. A number of studies suggest a positive correlation between use of traditional fuels and incidence of TB. This high dependence on traditional fuels and the poor sanitation facilities all contribute to a high health risk.

Occupation

The main income generating activity of the people is farming. Majority of the farmers are either marginal or daily wage earners. As per 2001 census, overwhelming majority (68.3%) of the population was dependent on agriculture and allied activities. Of this cultivators and agriculture laborers formed 25.49% and 42.09% respectively. About 4.42% of district's workforce was engaged in household industry. A small proportion of district's population was engaged in petty business such as selling of bread, tea, fruits, vegetables, etc. And the remaining 27.3% of population was engaged in other activities.

Literacy levels

According to Census 2001 estimates, the total percentage of literates in the district was 57.15%, male and female literacy rate was 69.23% and 44.7% respectively. Nalgonda ranks 12 with respect to educational attainment indices among the districts of A.P., in 2001. According to Census 2001, the literacy rate of Scheduled Caste (SC) population in the district was 43%, with a male and female literacy rate of 27.4% and 15.6% respectively. The literacy rate among the Scheduled Tribe (ST) population was 28.8%, with a male and female literacy rate of 20.9% and 7.9% respectively.

As far as the Gender disparity in education is concerned, Nalgonda is in a better position compared to many other districts in the state. The GDI-E (Gender Disparity

Index in Education) is 9 in 2001 (HDR, 2007 A.P.). Significant progress has been made in the last two decades in Nalgonda in terms of increasing educational infrastructure (public and private), and thereby increasing literacy levels among the younger age groups. However, large numbers of adult population, particularly rural population, are illiterate which is a major cause of concern.

Infant Mortality Rates

As per Human Development Report, 2007, A.P., total infant mortality rate in Nalgonda district is 48. Infant mortality rate is the number of deaths of infants less than one year of age per thousand live births. In terms of infant mortality rates, the district's performance was below the state average of 43. Rural-urban-wise infant mortality rates reveal that rural areas had high infant mortality rates (51) compared to urban areas (30). Higher infant mortality rates in rural areas can be attributed to poor sanitation and hygiene, lack of access to safe drinking water and toilets, poor health facilities, and malnutrition.

Per Capita District Domestic Product and Human Poverty Index (HPI)

The per capita District Domestic Product (DDP) in 2001 was Rs. 1028 which is lower than the state average of Rs.1300. The Human Poverty Index (HPI) in 2001 was 0.513. It is higher than the state average of 0.469 (HDR 2007, A.P.). Nalgonda ranks 18 in terms of the human poverty index among all the districts of A.P., in 2001. The low poverty index is not surprising given the poor amenities/infrastructure, low literacy, poor health services and large numbers of small and marginal farmers.

3.3.3 Nalgonda : Health Profile

Government Health care services

According to Human Development Report, Andhra Pradesh, 2007, in Nalgonda district, there are 59 government doctors per ten lakh population which is well below the state average of 101 doctors per ten lakh population. The government doctors are far less than what is required to provide better health care services to the people in the district.

Governmental health infrastructure in the district comprises of: 2 general hospitals, 4 area hospitals, 67 Primary Health Centres (PHCs), 493 Primary Health Sub-Centres, 4 Post Partum (PP) units, 7 TB units, and 720 beds (see Table 5).

Table. 5. Government Health Care Institutions in Nalgonda District, 2009.

Name of the health institution	Total Nos.
General Hospitals	2
Area Hospitals	4
Community Hospitals	3
Community Health Centres	4
Primary Health Centres (PHCs)	67
Primary Health Sub-Centres	493
Post Partum Units	4
TB units	7
Beds	720

Source: DM&HO Nalgonda

At the district level, District TB Centre (DTC) is the principal organizational unit in the Revised National Tuberculosis Control Programme (RNTCP), and DTC is responsible for overall implementation of RNTCP in the district. DTC is assisted by sub-district TB units (TUs). The district is divided into 7 TB units: i) Nalgonda, ii) Chilkur, iii) Chintapally, iv) Chivemula, v) Nidamanoor, vi) Valigonda, and vii) Yadagiriguta. (see Fig. 2 in Chapter 1) At the TU level, one medical officer, supervisory staff, the Senior Treatment Supervisor (STS) and Senior Tuberculosis Laboratory Supervisor (STLS), are appointed to implement the RNTCP in their respective TUs. One Designated Microscopy Centre (DMC) is set up for every 100,000 population. DOTS programme was introduced in the year 2003. Under DOTS strategy, swallowing of drugs by the patients at the health centre or home must be supervised. A vast number of DOTS centres have been established in the district so that the patients can have easy access to TB treatment. TB drugs are provided free of charge to all patients in public hospitals.

With regard to health infrastructure (both physical and manpower), though there has been major improvement over the last few decades, health care facilities are still inadequate, particularly in rural and tribal areas. For instance, according to government policy, there must be one PHC for 30,000 people (20,000 in hilly areas) (HDR, 2007, A.P). However, there are only 67 PHCs in the district which means that 41 more PHCs are required. Rural people are most disadvantaged in terms of access to health care services because of inadequate health care facilities in rural Nalgonda.

Private Health Care Services

Various kinds of health care options are available for the district's population. A characteristic feature of the health care in the district of Nalgonda is the multiplicity of treatment options. The district reports a plurality of medical systems that comprise the folk and professional health sectors. Folk sector includes herbalists, Dargah, faith healers (church), temples and magicians. Professional sector includes Allopath doctors, RMPs, Homeopathy, Ayurveda, Unani and Naturopathy practitioners. Over the last few decades, it is observed that most patients (urban and rural) have shifted from using government health facilities to the private health sector in Nalgonda. This trend is seen in most parts of A.P. Only the poor now largely use the government health services. Private health services play a crucial role in providing health care to the people in the district. These are characterized by private doctor clinics, RMPs, and nursing home facilities in towns and mandals.

Disease Profile

HIV, TB, malaria, diarrhea, acute respiratory infections constitute more than one third of the disease burden in the district. The percentage of antenatal women who tested positive for HIV was 2 (www.prb.org/pdf06/factsFigures). Maternal, perinatal and childhood conditions account for another significant percentage of disease burden, particularly among the socio-economically backward communities. Malaria is one of the major causes of morbidity in the district. The greatest burden of malaria is found in the irrigation canals region. Malaria transmission is perennial, however, cases peak during or soon after the rains. Fluorosis is another important cause of morbidity in the district.

Nalgonda disttict is highly affected by fluorosis in the state of Andhra Pradesh. It is estimated that about 60,000 people are affected by fluorosis and about 10,000 people badly crippled as a result of skeletal deformities like genu varum, genu valgum, kyphosis, joint pain, neck rigidity, etc., caused by fluorosis. Nalgonda district is similar to many other districts in the state where malnutrition is one of the significant causes of childhood morbidity and mortality. Nutritional disorders, food poisoning are also notable causes of morbidity in the district. Chikengunya, filariasis, Japanese encephalitis, and dengue are other causes of morbidity in the district.

Table. 6. Disease Burden for the years 2007-2009, Nalgonda District.

Name of the disease	2007	2008	2009
Diarrhoea	413	139	135
Gastroenteritis	40	-	-
Food poisoning	284	83	65
HIV	2958	2891	2670
Malaria	311	556	585
Japanese encephalitis	1	1	1
Dengue	14	09	06
Filaria	15	15	13
TB	4180	4369	4401

Source: DM&HO, Nalgonda

Among all the diseases in the district, Table 6 clearly indicates that TB is most prevalent with the highest number of cases. Data on HIV morbidity in the Nalgonda district shows declining trend between 2007 and 2009. TB cases increased marginally between 2007 and 2009. Available data for the year 2007-2009 indicates that the total TB cases registered for treatment under DOTS programme in Nalgonda district increased to 4401 in 2009 from 4180 in 2007.

Data on TB and HIV diseases indicate that these diseases pose a major health burden with more than 4000 and 2500 cases occurring every year respectively. Food poisoning cases declined considerably in the district, from 284 in 2007 to 65 in 2009. Diarrhoea cases also have fallen considerably, from 413 in 2007 to 135 in 2009. This

decline can be attributed to improvements in sanitation, and access to clean drinking water. Malaria cases in the district have been increasing since 2007. In 2007, there were 311 cases, in 2008 there were 556 cases and in 2009 there were 585 cases. Dengue cases have been declining since 2007. In 2007, there were 40 gastroenteritis cases, but no cases of gastroenteritis were reported between 2008 and 2009. However, it needs to be noted that all figures mentioned in the above Table 6 were confined to cases that came to the government hospitals/clinics, and hence, these figures do not represent the total disease burden in the district.

This profile of Nalgonda suggests that it is a high risk district for TB. High poverty levels and low development impact on prevalence and treatment of TB, as this is a disease associated with poverty, malnutrition, poor living conditions and inadequate health facilities – all of these are characteristic of Nalgonda district.

CHAPTER

4

Epidemiology of Tuberculosis:

Global, National, State, and District Level

Nowhere in these ancient communities of the Eurasian land mass, where it is so common and feared, is there a record of its beginning. Throughout history, it had always been there, a familiar evil, yet forever changing, formless, unknowable. Where other epidemics might last weeks or months, where even the bubonic plague would be marked forever afterwards by the year it reigned, the epidemics of tuberculosis would last whole centuries and even multiples of centuries. Tuberculosis rose slowly, silently, seeping into homes of millions, like an ageless miasma. And once arrived, it never went away again. Year after year, century after century, it tightened its relentless hold, worsening whenever war or famine reduced the peoples' resistance, infecting virtually everybody, inexplicably sparing some while destroying others, bringing the young down onto their sickbeds, where the flesh slowly fell from their bones and they were consumed in the years long fever, their minds brilliantly alert until, in apocalyptic numbers, they died, like the fallen leaves of a dreadful and premature autumn.

The Forgotten Plague: How the War against Tuberculosis was Won - and Lost

Frank Ryan (1992) (cited in Cardoso *et al* 2007: 25)

This chapter presents the incidence of TB at various levels: global, national (India), state (A.P.) and district (Nalgonda).

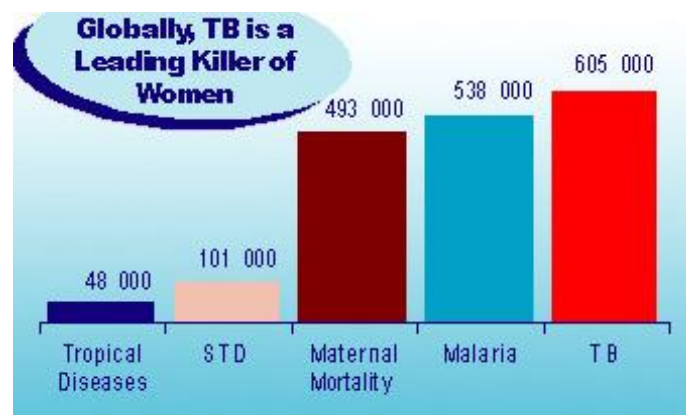
4.1 Global Tuberculosis Situation

Today, TB has re-emerged as a serious threat to public health globally. An expert committee instituted by the Institute of Medicine, United States (1992), defined emerging infections as “*new, re-emerging, or drug resistant infections whose incidence in humans*

has increased within the past two decades or whose incidence threatens to increase in the near future” (Institute of Medicine, 1992: 3). The current re-emergence of TB on a global scale can be attributed to interaction of multiple factors. These factors include: i) HIV/AIDS epidemic; ii) drug abuse; iii) uncontrolled urbanization; iv) rapid population growth; v) migration and displacement of a large number of people due to wars, ethnic conflicts and natural calamities; vi) inadequate funding for TB control programmes; vii) the viral ‘superhighway’ paved by increase in international trade and travel; viii) malnutrition; ix) poverty; x) spread of MDR-TB; xi) poor sanitation and living conditions; and xii) overcrowding (Bloom & Murray 1992; Buskin *et al* 1994; Worthman & Kohrt, 2005).

Currently it is estimated that approximately one third of the global population or close to two billion people are infected with *Mycobacterium tuberculosis* and at risk of developing active TB disease. According to the WHO report, each year, an estimated 9-10 million new TB cases and more than 2 million deaths occur every year globally (WHO 2010). Of these 9-10 million new cases, about 44% are infectious (Woith & Larson 2008). Globally, nearly 5000 deaths occur per each day, and one person dies of this disease per every minute (Singla *et al* 1998). Over 20 million people suffer from clinically active disease at any one time. Between 10-20% of total new TB cases occur in children. TB kills more women than maternal mortality but the latter is generally perceived as the bigger killer (Fig. 7). Women account for 35% (3.3 million cases) of total TB cases globally (WHO 2010).

Fig.7. Deaths of Women



About 3% of all the new TB cases that arise worldwide every year are estimated to be multi-drug resistant. The term multi-drug resistant TB is defined as a strain of *Mycobacterium tuberculosis* that is resistant to at least isoniazid (INH) and rifampicin (RIF), the most effective drugs used in the treatment of TB (CDC 2008).

The incidence of TB represents unequal world-wide distribution. For example, 95% of new TB cases and 98% of TB deaths occur in developing countries, where some 75% of new TB cases occur among the productive and economically active age group (i.e., 15-54 years) of the population. In contrast, in industrialized countries nearly 80% of infected individuals are in the age group of 50 years or above (Murray, 2004; Suri & Sen, 1998). In the developing countries, TB accounts for an estimated 6.7% of all deaths, 18.5% of all deaths among adults aged 15 to 59, and 26% of potentially preventable deaths in developing countries (Bloom & Murray 1992).

Within the developing countries, the incidence and prevalence of TB is higher among the poor and other marginalized groups of society. Even within the technologically developed nations, cases of TB generally occur among disadvantaged populations (Enarson *et al* 2004). The African region has the highest incidence rate of 351/100,000 population annually, followed by South-East Asian region 183/100000 population and Western Pacific region 109/100000 population. WHO region of America has lowest TB incidence rate of 31/100000 population (Table 7).

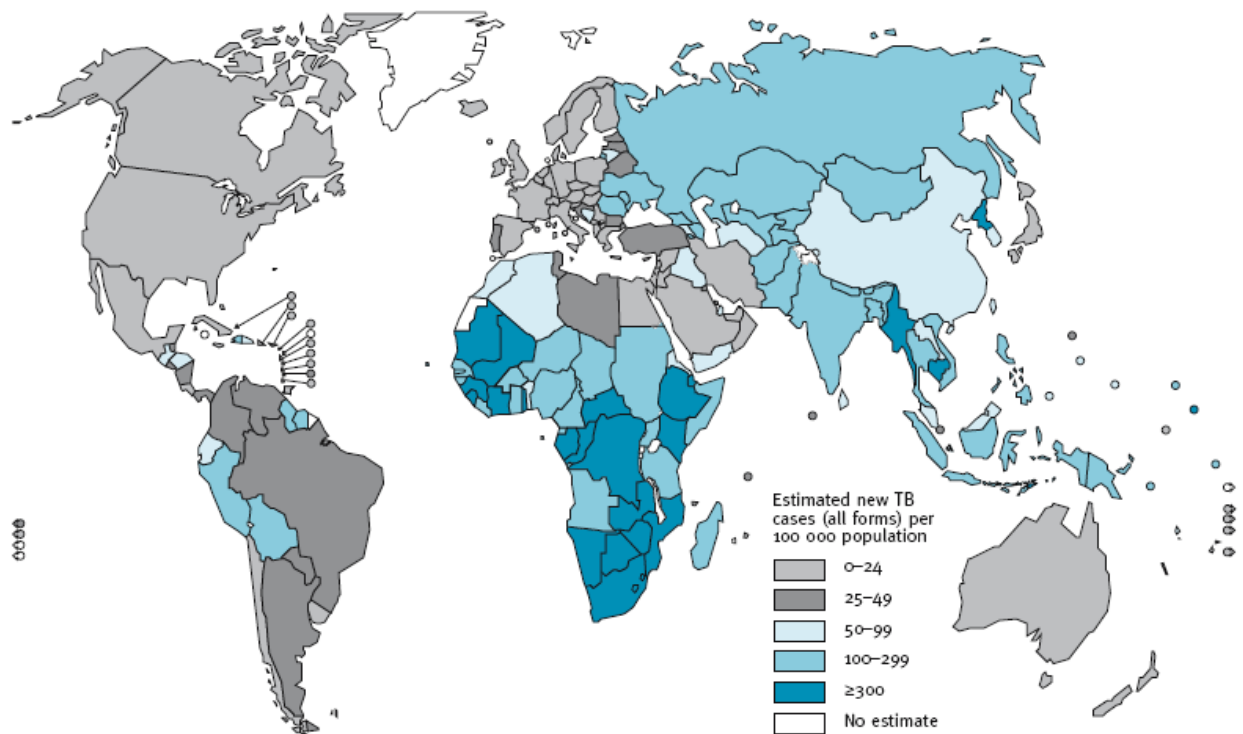
Table. 7. TB Incidence, Prevalence and Deaths by Region, 2008

WHO Region ^a (# of HBCs)	Incidence		Prevalence		Deaths	
	No. in thousands (%)	Per 100,000 Pop	No. in thousands	Per 100,000 Pop	No. in thousands	Per 100,000 Pop
Global Total (22)	9,369 (100%)	139	11,096	164	1,324	20
Africa (9)	2,828 (30%)	351	3,810	473	385	48
Americas (1)	282 (3%)	31	221	24	29	3.2
E. Mediterranean (2)	675 (7%)	115	929	159	115	20
Europe (1)	425 (5%)	48	322	36	56	6.3
South-East Asia (5)	3,213 (34%)	183	3,806	216	478	27
Western Pacific (4)	1,946 (21%)	109	2,008	112	262	15

Source: The Henry J. Kaiser Family Foundation, California. The Global Tuberculosis Epidemic Fact Sheet, 2010.

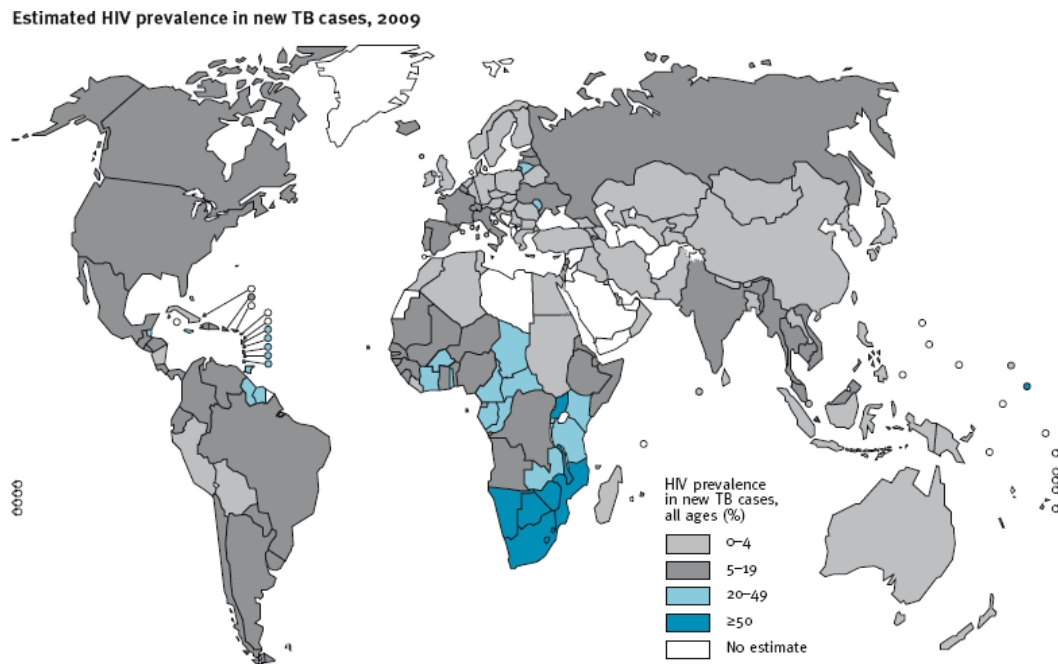
However, the most populous countries of the Asian region harbor largest number of TB cases in the world. The five most populous countries - Bangladesh, China, India, Indonesia, and Pakistan together account for about half of the new cases arising each year worldwide (WHO 2006). The estimated global incidence rates for the year 2009 are shown in Figure 8. The estimated HIV prevalence in new TB cases for the year 2009 by country is shown in Fig. 9.

Fig. 8. Estimated TB incidence Rates by Country, 2009



Source: WHO Report 2010, Global Tuberculosis Control, page 6

Fig. 9. The Estimated HIV prevalence in New TB cases by country, 2009

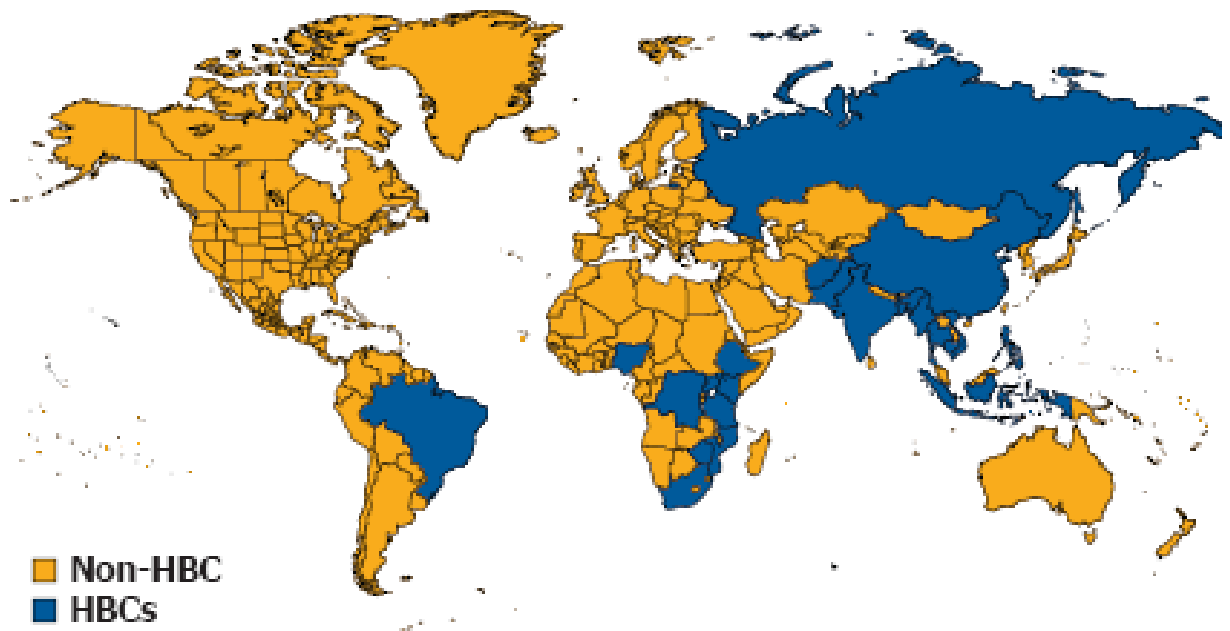


Source: WHO Report 2010, Global Tuberculosis Control, page no 6

Of all the estimated 9-10 million new TB cases occurring each year, approximately 80% of new TB cases occur in the 22 countries defined as high-TB burden countries (Woith & Larson 2008). The high-TB burden countries are India, China, Indonesia, South Africa, Nigeria, Bangladesh, Ethiopia, Pakistan, Philippines, DR Congo, Russian Federation, Vietnam, Kenya, UR Tanzania, Uganda, Brazil, Mozambique, Thailand, Myanmar, Zimbabwe, Cambodia and Afghanistan. Even the industrialized countries, where the disease incidence showed declining trend for many decades, are experiencing a substantial re-emergence in active cases of TB since mid-1980s. *“Re-emergence comprises the appearance of more virulent forms of previously*

tractable infectious diseases or increased incidence of previously infrequent or declining diseases” (Worthman & Kohrt, 2005:867). HIV/AIDS epidemic probably is the most significant factor that played an indispensable role in increasing the global burden of TB. This is because, TB is the most common opportunistic infection occurring among the HIV positive persons.

Fig. 10. High TB Burden Countries (HBCs)



Source: The Henry J. Kaiser Family Foundation, California. *The Global Tuberculosis Epidemic Fact Sheet*, 2010.

Because, HIV weakens body's immune system, *“the presence of HIV infection appears to enhance and accelerate the development and progression of tuberculosis at virtually every stage in its natural history, from implantation of *M tuberculosis* in the lungs to death from advanced disease”* (Enarson *et al* 2004:21). Studies suggest that in persons co-infected with both HIV and *Mycobacterium tuberculosis*, the risk of reactivation to active disease increases to 5-10% per year, while in persons infected only with *Mycobacterium tuberculosis*, the risk is between 5 and 10% *per life time* (Enarson *et*

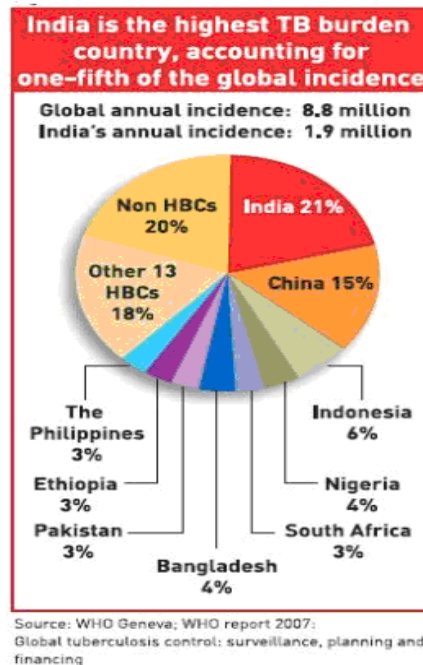
al 2004). Ngamvithayapong *et al* (2000:1413) argue that “*the interaction between the TB and the HIV epidemics is particularly lethal. TB adds to the illness burden of HIV-infected patients and shortens their life expectancy, while the HIV epidemic stimulates TB spread*”. Globally, TB is the leading cause of death among the people suffering from HIV/AIDS, accounting for a third of AIDS related deaths globally (Reichman & Tanne 2002). The HIV and TB co-epidemic is growing at alarming rate and leading to an upsurge of TB cases in many parts of the world particularly in the Asian and Sub-Saharan region.

4.2 Situation of TB in India

TB has been known to be a major public health problem for several centuries in India. India is the highest TB burden country in the world (Fig. 11), accounting for nearly one fifth of the new TB cases globally, and 2/3rd of the cases in South-East Asia. The country ranks first among the list of 22 high-TB burden countries. The number of TB cases continued to increase in proportion to the growth of the population in India. The WHO recent estimates indicate that, in India, nearly 2 million people develop clinically active disease each year, of which about 0.8 million are smear-positive pulmonary TB cases, with an incidence of 75/100000 population (Chadha 2005). 0.5 million people die from this disease every year in this country (Agarwal *et al* 2005).

Two of every five people (i.e., more than 400 million people), in India are infected with *Mycobacterium tuberculosis*. Currently, close to 5% of new TB cases that arise in India each year are attributed to HIV infection (Steinbrook, 2007). TB remains the major infectious cause of morbidity and mortality among the economically most productive adult population (15-54 years) of the country.

Fig. 11. Incidence of TB in India



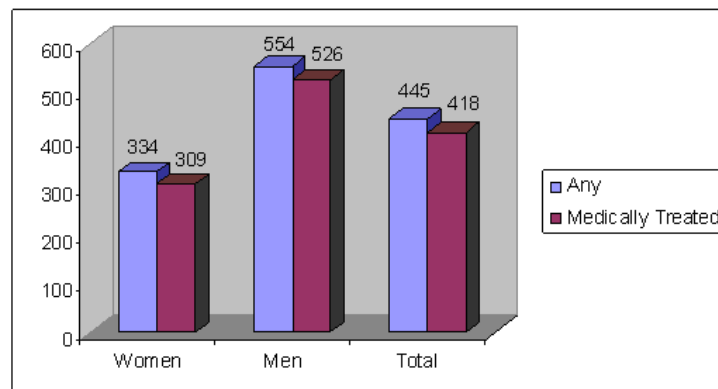
4.2.1 Prevalence of TB by Gender, Residence and Age in India

According to National Family Health Survey (NFHS-3, India, 2005-06), the number of persons suffering from TB varies considerably by gender, residence, and age. Overall, prevalence of TB is much higher for men (526/100,000) than females (309/100,000), (Fig 12), and much higher for rural residents (469/100,000) than urban residents (307/100,000) (Fig 13). NFHS- 3 results suggest that prevalence is very high in oldest age group, and the estimated prevalence in oldest age group is 998/100,000 (Fig 14). Prevalence in the oldest age group is about twice as high as prevalence in the age group of 15-59 (519/100,000) and nearly nine times as high as prevalence among children < 15 years (110/100,000). *“Both sex and age differentials are more pronounced in rural areas than they are in urban areas”* (NFHS- 3, 2005-06:412).

Fig. 12. Prevalence of TB among Men and Women, NFHS -3, 2005-06

Prevalence reported as well as medically treated TB higher among men

Per 100,000 persons



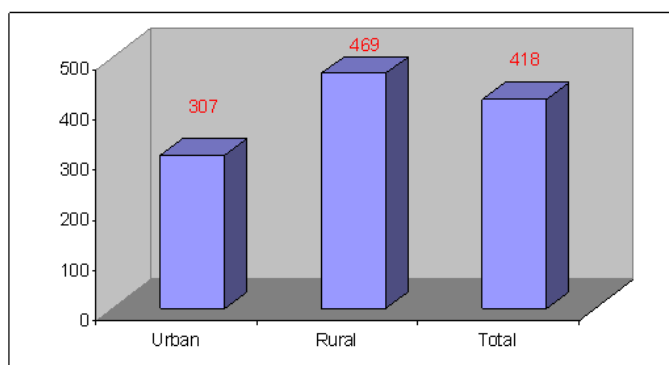
Since NFHS – 2 , reported TB has declined by 18% but the level of medically treated TB has not changed

Source: NHFS-3, 2005-06, India

Fig. 13. TB Prevalence in Urban and Rural areas, NFHS-3, 2005-06.

TB prevalence is higher in rural areas
(by 57%)

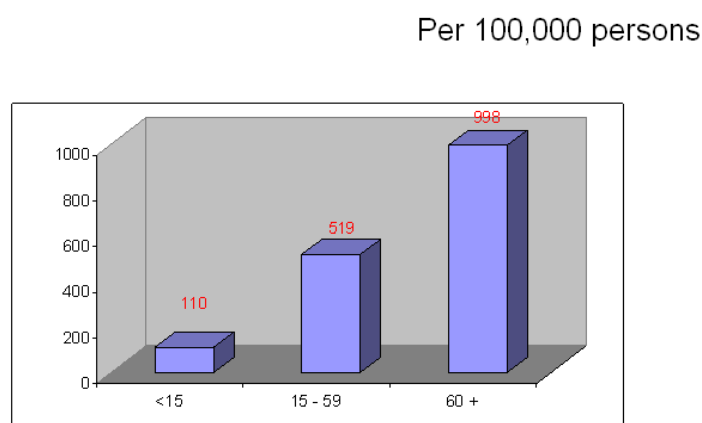
Per 100,000 persons



Source: NHFS-3, 2005-06, India

Fig. 14. TB Prevalence by Age

TB prevalence higher among older persons and least among children



Source: NFHS-3, 2005-06, India

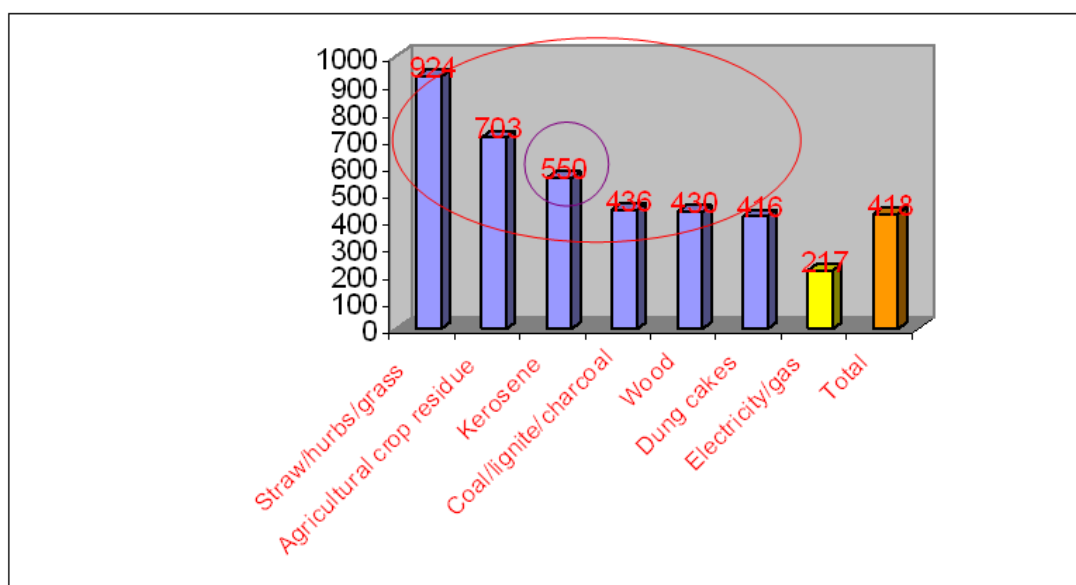
4.2.2 Prevalence of TB by Type of Housing and Fuel

Prevalence of TB varies by house type and type of fuel of used for cooking (Fig 15). Risk of TB is much higher for households (924/100,000 population) using straw, shrubs, or grass for cooking than households using electricity, liquid petroleum gas, natural gas or biogas. According NFHS-3 data, TB prevalence in households cooking in the house without a separate kitchen room is 518/100,000, compared to households cooking food with a separate kitchen room in the house (294/100,000 population).

Fig. 15. TB Prevalence of by Type of Fuel

Prevalence highest in households using solid fuels for cooking

Per 100,000 persons



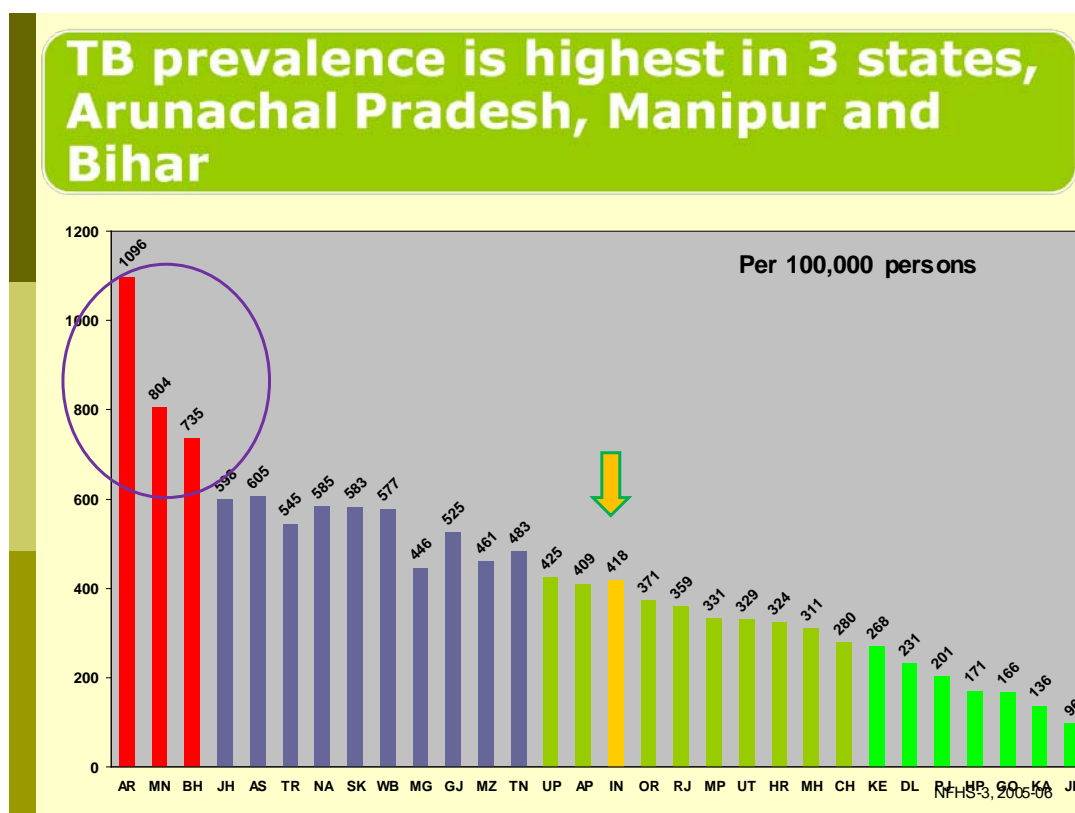
Source: NFHS-3, 2005-06, India

4.2.3 Prevalence of TB by State

Prevalence of medically treated TB varies considerably from state to state. According to NFHS- 3 data the prevalence of medically treated TB in India is 418/100000 persons (Fig 16). The number of persons suffering from medically treated TB ranges from as low as 96/100,000 in Jammu Kashmir to as high as 1096/100000 in

Arunachal Pradesh. Between these two extreme levels of prevalence, there are states exhibiting all levels of prevalence.

Fig. 16. TB Prevalence by State



Source: NHFS-3, 2005-06, India; [NFHS-3 TB and Lifestyle - National Family Health Survey](#), www.nfhsindia.org pp

AR- Arunachal Pradesh; **MN**-Manipur; **BH**-Bihar; **JH**-Jharkhand; **AS**-Assam; **TR**-Tripura; **NA**-Nagaland; **SK**-Sikkim; **WB**-West Bengal; **MG**-Meghalaya; **GJ**-Gujarat; **MZ**-Mizoram; **TN**-Tamil Nadu; **UP**-Uttar Pradesh; **AP**-Andhra Pradesh; **IN**-India; **OR**-Orissa; **RJ**-Rajasthan; **MP**-Madhya Pradesh; **UT**-Uttaranchal; **HR**-Haryana; **MH**-Maharashtra; **CH**-Chhattisgarh; **KE**-Kerala; **DL**-Delhi; **RJ**-Rajasthan; **HP**-Himachal Pradesh; **GO**-Goa; **KA**-Karnataka; **JK**-Jammu & Kashmir.

Table 8 shows the number of persons suffering from medically treated TB in the states of India.

Table. 8. India: TB Prevalence by State

STATE	Number of persons per 100,000 household residents suffering from medically treated TB by state, India 2005-06
INDIA	418
NORTH	
Delhi	231
Haryana	324
Himachal Pradesh	171
Jammu & Kashmir	96
Punjab	201
Rajasthan	359
Uttaranchal	329
CENTRAL	
Chhattisgarh	280
Madhya Pradesh	331
Uttar Pradesh	425
EAST	
Bihar	735
Jharkhand	598
Orissa	371
West Bengal	577
NORTH-EAST	
Arunachal Pradesh	1096
Assam	605
Manipur	804
Meghalaya	446
Mizoram	461
Nagaland	585
Sikkim	583
Tripura	545
WEST	
Goa	166
Gujarath	525
Maharastra	311
SOUTH	
Andhra Pradesh	409
Karnataka	136
Kerala	268
Tamil Nadu	483

Source: NFHS-3, 2005-06, India

TB prevalence of medically treated TB is highest in Arunachal Pradesh (1096), Manipur (804) and Bihar 735 per 100000 persons. The high prevalence of TB in north-eastern states can be attributed to factors such as high humid weather conditions, and lifestyle (alcohol consumption and smoking). High humid weather conditions provide the TB bacilli longer survival periods and as a consequence people become more susceptible to TB infection. Several studies have found that tobacco consumption and alcohol are important risk factors for TB related morbidity and mortality. Seven states exhibit prevalence levels between 500 and 700 per 100,000 persons: Gujarat (525), Tripura (545), West Bengal (577), Sikkim (583), Nagaland (585), Jharkhand (598) and Assam (605). In addition to Jammu Kashmir, states like Karnataka (136), Goa (166) and Himachal Pradesh (171) exhibit prevalence levels below 200/100,000 persons. The prevalence levels of TB according to state suggest geographical clustering of TB (Table 8). In eastern and north-east region, the TB prevalence levels are above national average of 418/100000 people. The prevalence levels in eastern (except Orissa) and north-eastern states are above the national average. In northern states, the prevalence levels are well below the national average. States belonging to central region exhibit middle levels of prevalence. Southern region states show mixed prevalence: low in Karnataka (136) and Kerala (268), and higher in Andhra Pradesh (409) and Tamil Nadu (483).

4.2.4 TB Mortality by State

It is evident from Table 9 that the average reported TB deaths/100,000 population is 0.82 in 2003. States like Andhra Pradesh, Arunachal Pradesh, Goa and Uttar Pradesh showed increasing trend in TB deaths from 1991 to 2003. Andhra Pradesh (0.19/100,000 people in 1991 and 1.46/100,000 population in 2003), Arunachal Pradesh (1.5 and 2.57), Goa (2.99 and 4.54), and Uttar Pradesh (0.39 and 1.51). TB deaths in Goa state sharply increased to 7.44 in 2000 from 2.99 in 1991. Maharashtra state presents an interesting scenario and has reported a systematic decline in TB deaths from 46.14 in 1961 to 0.84 in 2003. In Delhi state, TB related death rates declined from 41.86 deaths/100,000 population in 1961 to 15.4 deaths in 2003. Analysis of death rates from 1961 clearly suggest that Delhi is the only state in India that reported the maximum number of deaths from TB: 41.86 (1961); 20.6 (1991); 17.7 (1993); 11.12 (2000); 12.08 (2001) and 15.4

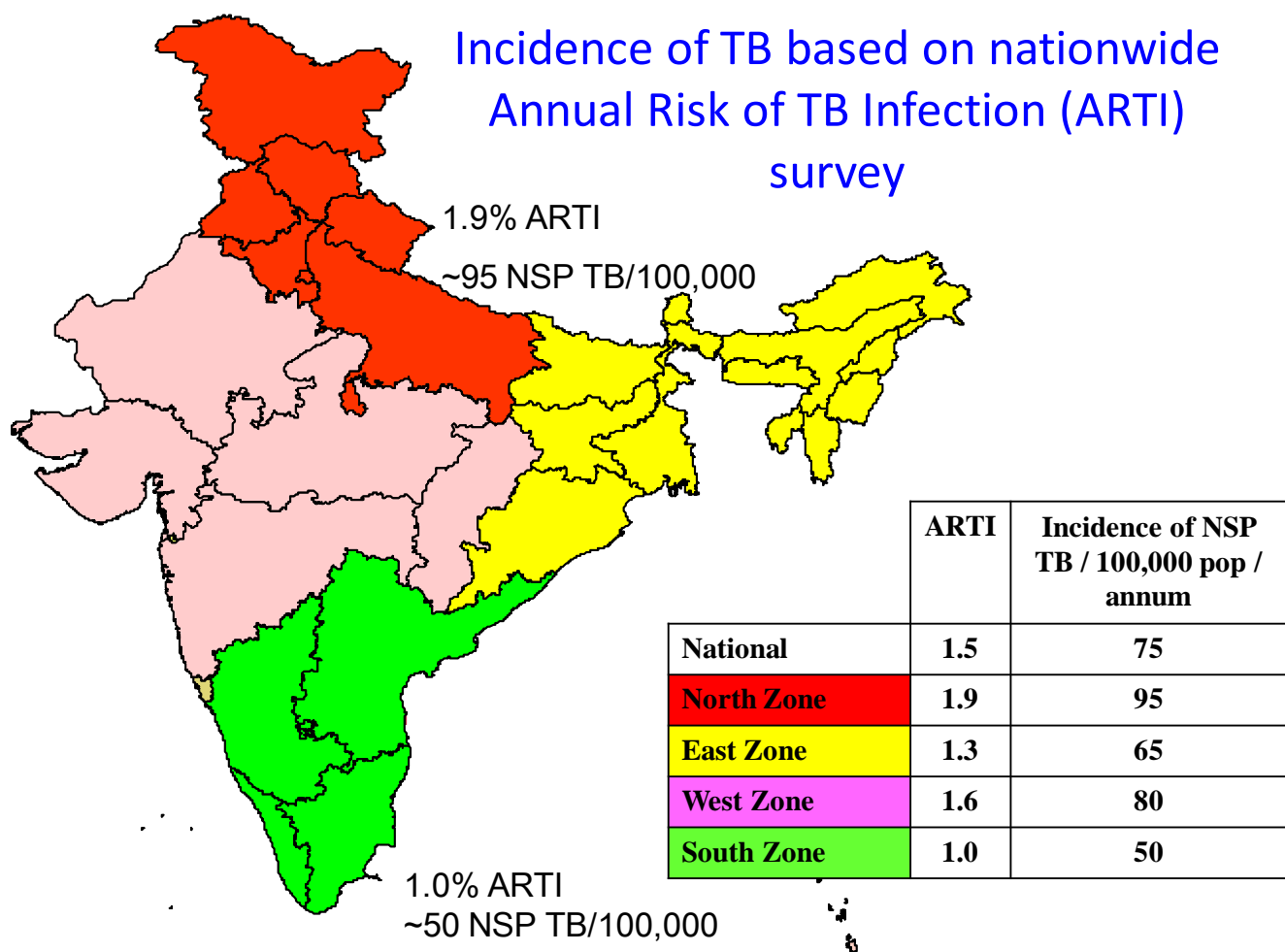
(2003). One possible explanation for this trend is that Delhi has better facilities for recording TB deaths. Another possible explanation could be that Delhi being the capital of India, has better medical facilities compared to many other states in the country. Hence, many people from other parts of India come to Delhi to avail TB services and some may die here.

Table. 9. Mortality in various States (Reported deaths) Per 100,000 Population

States	1961	1991	1995	2000	2001	2003
Andhra Pradesh		0.19	0.11	0.20	1.72	1.46
Arunachal Pradesh		1.50	0.35			2.57
Assam	2.39	0.66	0.54			
Bihar	0.26	0.00				
Goa		2.99	0.77	7.44	4.99	4.54
Gujarat	1.76	1.49	0.30	0.20	0.17	0.24
Haryana		2.44	1.48	1.43	1.07	1.13
Himachal Pradesh	2.45	4.74	5.28	4.08	3.31	2.48
Jammu & Kashmir		0.03	0.01			0.01
Karnataka	30.34	1.83	2.06	2.21	1.72	1.86
Kerala	18.16	0.81	0.63	0.54	0.72	0.55
Madhya Pradesh	7.08	0.05	0.03	0.01	0.13	0.16
Maharashtra	46.14	1.15	1.08	1.02	0.92	0.84
Manipur		0.44		1.14	0.75	0.38
Meghalaya		0.79	0.39	3.27	2.56	2.04
Mizoram		1.45	1.16	1.16	3.03	2.36
Nagaland		0.14	0.08	0.25		
Orissa		1.65	0.63	1.02	0.59	0.37
Punjab	16.33	0.47	0.47	0.11	0.69	0.61
Rajasthan	4.25	0.75	0.22	0.70	0.70	0.81
Tamil Nadu		1.16	0.54	0.36	0.26	0.24
Tripura					0.13	
West Bengal	8.21	0.21	0.37	0.12	0.05	0.07
Uttar Pradesh	13.59	0.39	0.94	1.60	1.61	1.51
Delhi	41.86	20.60	17.70	11.12	12.08	15.40
INDIA		1.10	0.87	0.89	0.81	0.82

Note: population figures have been used for the census years; Source: For the year 1961, vital statistics of India, 1961
For the rest of the years, health information of India, 1995, 1996, 2000, 2001, 2003.

4.2.5 Zone-Wise Incidence of New Smear Positive TB Cases in India



Source RNTCP, India, MoH & FW, India, 2009

Fig. 17. Estimated Incidence of New Smear Positive TB Cases in Different Zones of India.

Fig 17 suggests that the incidence of new smear positive (NSP) TB cases (95/100,000 population per year) is highest in north zone, followed by West zone (80), east zone (65) and south zone (50). According the ARTI (Annual Risk of Tuberculosis Infection) survey the incidence of NSP TB cases per 100,000 population per year in India is 75.

4.3 The Evolution of the TB Control Programmes in India

In India, the history of modern anti-TB movement dates back to early 1900s. In the pre-independence era, the initial measures undertaken to provide TB services to the public were totally unplanned and purely *ad hoc* in nature because of scarcity of resources, lack of political will and preoccupation with other epidemics. The initial measures to control and manage TB cases were mainly confined to a limited number of hospitals, TB clinics and TB sanatoria (Agarwal *et al* 2005).

Historically, the journey of modern anti-TB movement began with the introduction of sanatorium type of treatment. Christian Missionaries working in India played a pivotal role in establishing the first few sanatoria in India. The first sanatorium in India was started in 1906 in Tilaunia near Ajmer, Rajasthan. This was followed by one in Almora in the Himalayas in 1908, the Union Mission Tuberculosis Sanatorium (UMTS) Madanapalle, A.P., in 1915, 'Hardinge Sanatorium' in 1909 in Dharampore (Shimla Hills), and King Edward Sanatorium in Bhowali in U.P., in 1912 (Kumar 2005; IJT 2002).

Based on the recommendations of the Bhore committee (1946) report, the government of independent India shown keen interest in tackling the problem of TB. In the early 1950s, the public health policy makers came to the conclusion that the cost of establishment of a large number of TB clinics and TB beds to address the menace of TB problem in the country was not an operationally and economically feasible option. BCG vaccination against TB was considered the most important cost-effective avenue available for protection and prevention of TB at that time.

From 1955 to 1958, Indian Council of Medical Research (ICMR) carried out a systematic National Sample Survey (NSS), of TB to estimate the magnitude of TB

problem in India. Nation-wide survey findings revealed that prevalence of TB was almost equally distributed in urban and rural areas, and was not an urban phenomenon or confined to certain sections of the population as previously believed. The findings of National Sample Survey (1955-58) by ICMR, the discovery of effective anti-TB drugs in the 1940s, the landmark clinical trials of TRC, Madras, in developing appropriate chemotherapeutic regimens, and the path-breaking researches on epidemiological, sociological, economic, administrative as well as operational aspects of TB control by the National Tuberculosis Institute (NTI), Bangalore, enabled the public health policy planners in formulating organized strategies to tackle the problem of TB in the country. In 1962, an integrated strategy called National Tuberculosis Programme (NTP) was formulated to deal with the problem of TB (Agarwal *et al* 2005). This programme was considered to be a landmark development in the history of modern anti-TB movement in the country. This was a significant step forward when compared to erstwhile approach of provision of TB services to a limited number of patients in sanatoria, hospitals and TB clinics (Jagota 2002; Mukherjee 1995).

The aims, objectives, implementation and performance of NTP was evaluated by national and international agencies continuously over the years. Despite the existence of NTP for thirty years (i.e., from 1962 to 1992), no substantial change in the epidemiological situation of TB was observed. Against this backdrop, in 1992, the Government of India (GoI), WHO and Swedish International Development Agency (SIDA) jointly reviewed the functioning of NTP comprehensively. The GoI, WHO, and SIDA's expert committee found glaring deficiencies in the NTP. Some of the deficiencies of the programme highlighted were: **i)** the rate of completion of treatment was less than 30%; **ii)** over-reliance on x-ray diagnosis instead of sputum microscopy for diagnosis of TB cases; **iii)** inadequate budgetary outlays; **iv)** multiplicity of drug regimes; **v)** poor quality of sputum microscopy; **vi)** irregular supply of drugs; **vii)** inadequate organizational set up and support for TB control; **viii)** poor adherence to anti-TB treatment; **ix)** non-availability of trained staff; **x)** more emphasis on detection of new cases rather than on cure of patients; **xi)** managerial weaknesses in the implementation of the program; and **xii)** lack of systematic information on the treatment outcome of the patients (Mukherjee, 1995; Sarin & Dey 1995) Review committee reported that only 30%

of patients were diagnosed and, of the total diagnosed patients, about 30% were successfully treated (Chauhan & Agarwal 2005: 24).

The joint review committee recommended that certain remedial measures must be taken in order to strengthen the shortcomings and weaknesses observed in the existing NTP (Sarin & Dey 1995). On the basis of the recommendations of the joint review committee, a revised approach to TB control was formulated, and this strategy was termed as RNTCP. RNTCP is an application of the WHO recommended strategy of DOTS. As mentioned earlier, under DOTS strategy, swallowing of drugs by the patients at the health centre or home should be supervised. RNTCP builds on the substantial infrastructure and network established by the previous NTP (Unnikrishnan *et al* 2000). The RNTCP aims to break the chain of transmission of TB in the community as well as to reduce morbidity and mortality, gradually till it ceases to be major public health burden in the country (Mukherjee 1995).

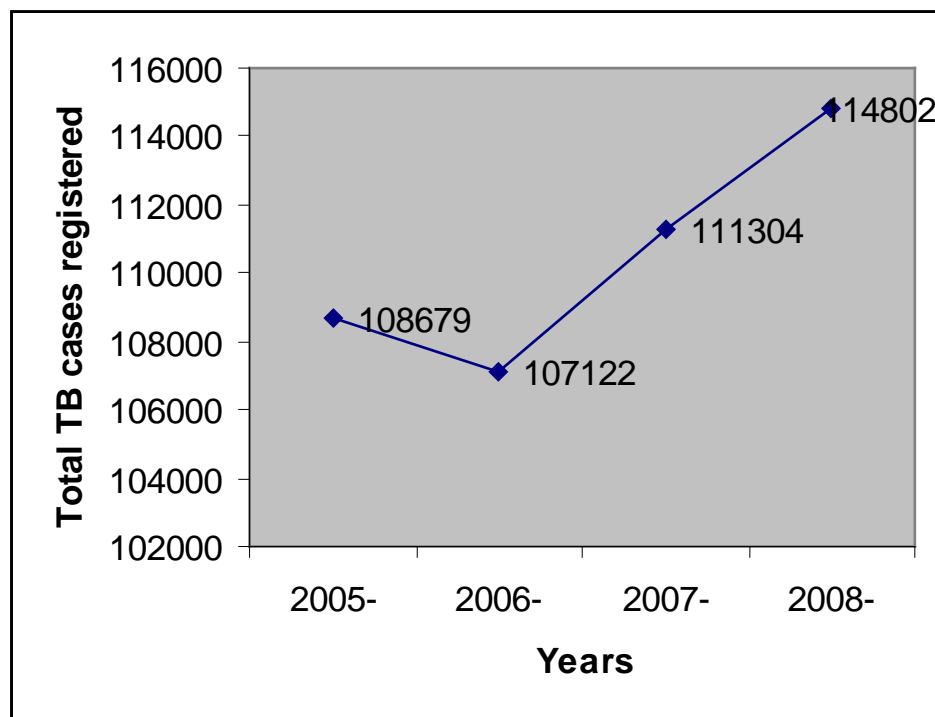
Government of India, formally launched RNTCP as a comprehensive national strategy for TB control in the year 1997. Large scale implementation of the program began in 1998, and by 31st March 2006, the program was implemented throughout the whole country. In fact, RNTCP is the second largest health program in the world (Jagota 2002). Despite the existence of national TB control programmes for more than 40 years, TB control and management in the country remains elusive. GoI has devised alternative, innovative and cost-effective measures to expand, sustain and support DOTS services in the country. GoI made collaboration with NGOs, medical colleges, and Private Practitioners, to harness their co-operation so as to provide easy access for DOTS services for the poor and marginalized.

This overview of the history of TB control in India clearly reveals the inadequacy of the biomedical model to control the disease. The understanding and treatment of TB has largely been dominated by the biomedical framework as observed in this review. TB being a 'social disease' such a limited understanding adversely affects treatment and control programmes. This hegemony of biomedicine may largely explain the failure of TB control programmes in India. The socio-economic diversity that comprises the Indian population requires a different, more culturally sensitive engagement that the explanatory model provides in our understanding of TB.

4.4 Situation of TB in A.P.

In Andhra Pradesh, TB poses a very significant public health burden where more than 100,000 new TB cases occur every year (Fig 18), more than half of them are infectious in nature (RNTCP Andhra Pradesh 2005-2008). Available data for the years 2005-2008 suggests that the total TB cases registered for treatment with government TB clinics in Andhra Pradesh increased to 1,14,802 in 2008 from 1,08,679 in 2005. Such increase in TB cases is possibly attributed to various factors including ageing of the general population, population growth, improvement in case finding, the emergence of multi-drug resistant TB strains, and the increase in number of HIV positive TB cases (RNTCP Andhra Pradesh 2005-2008).

Fig. 18. Total number of TB cases registered for treatment, A.P., 2005-2008.



Source: State TB Control Society, Directorate of Health, Hyderabad

A review of official RNTCP Status Reports, Andhra Pradesh (2005-2008), gives the following main epidemiological dimensions of TB in the state of Andhra Pradesh. A total

of 4,41,907 TB patients had been registered for treatment at government TB clinics between 2005 and 2008. Of the 4,41,907 cases, 3,57,674 (81%) were newly detected TB cases. Of the 3,57,674 newly detected cases, 3,16,413 (88%) were pulmonary (smear negative and positive cases) cases and 12% were extra-pulmonary cases.

Analysis of Annual RNTCP Status Report, Andhra Pradesh – 2008, provides clear picture into the TB situation Andhra Pradesh. It is estimated that there were 114802 incident cases of TB in 2008 in the state. Of the total 114802 cases, new cases were 72% (82890/114802). Of the total 82980 new cases, 86% were pulmonary cases and 14% were extra-pulmonary cases. Table 10 shows the estimated incidence rate of new pulmonary cases by district, A.P., 2008. The average estimated incidence of new pulmonary cases (NSP) in the state in 2008 was 100 cases per 100,000. Table 10 also shows that there is much intra-district variation in the incidence rates among the districts of Andhra Pradesh. Khammam district had a highest NSP incident rate of 146 cases per 100,000 in the state. Various possible reasons can be attributed to the high incidence of TB in Khammam district. Factors like poverty, malnutrition, illiteracy, lack of access to medical services, lack of access to safe drinking water, overcrowding, use of traditional fuels for cooking, etc., can be attributed to the high incidence of TB in this district. The estimated new pulmonary TB incidence rates for the state of Andhra Pradesh for the year 2008 is shown in Fig 19. Seven districts (Chittor, Mahabub Nagar, Ranga Reddi, Hyderabad, Nalgonda, Warangal and Karim Nagar) exhibit NSP incidence levels (new pulmonary cases) between 81-90/100,000 population. Ongole, Prakasam, Krishna, West Godavari, Vishakapatnam, and Adilabad exhibit incidence levels between 91-100/100000 population. Anaparthi, Cudapah, Nellore, Nizamabad and Vizianagaram show incidence levels between 101-110/100,000 population; Kurnool, Guntur, Khammam, East Godavari and Srikakulam show incidence levels > 110; and only Medak district has lowest incidence rate of 73/100000.

Table. 10. District-wise New Pulmonary TB cases Profile in Andhra Pradesh (2008)

Sl. No	Name of the district	Population (2008)	Total patients registered for treatment	No. of new pulmonary patients out of total cases registered	Incidence rate of new pulmonary cases per 100000 population
1	Adilabad	2690603	3306	2637	98
2	Hyderabad	4000569	6694	3742	94
3	Karimnagar	3773348	4092	3064	81
4	Khammam	2784001	5169	4070	146
5	Mahabubnagar	3805684	4428	3332	88
6	Medak	2889140	3208	2122	73
7	Nalgonda	3489942	4356	2996	86
8	Nizamabad	2542424	3089	2637	104
9	Rangareddi	3805460	5249	3368	89
10	Warangal	3506490	4163	2842	81
11	Kurnool	3811533	6195	4471	117
12	Chittoor	4053465	5090	3273	81
13	Cudapah	2792758	4356	3076	110
14	Ananthapur	3949395	5954	4155	105
15	Nellore	2886281	4394	3054	106
16	East-Godavari	5287800	8336	6265	118
17	Prakasam	3315241	4062	3164	95
18	Krishna	4577851	5965	4354	95
19	Srikakulam	2743934	4110	3066	112
20	Visakhapatnam	4112740	5678	3895	95
21	Vizianagarm	2436400	3804	2494	102
22	Guntur	4780899	7081	5405	113
23	West-Godavari	4119599	6023	4145	100
	Total A.P. population	8215557	114802		

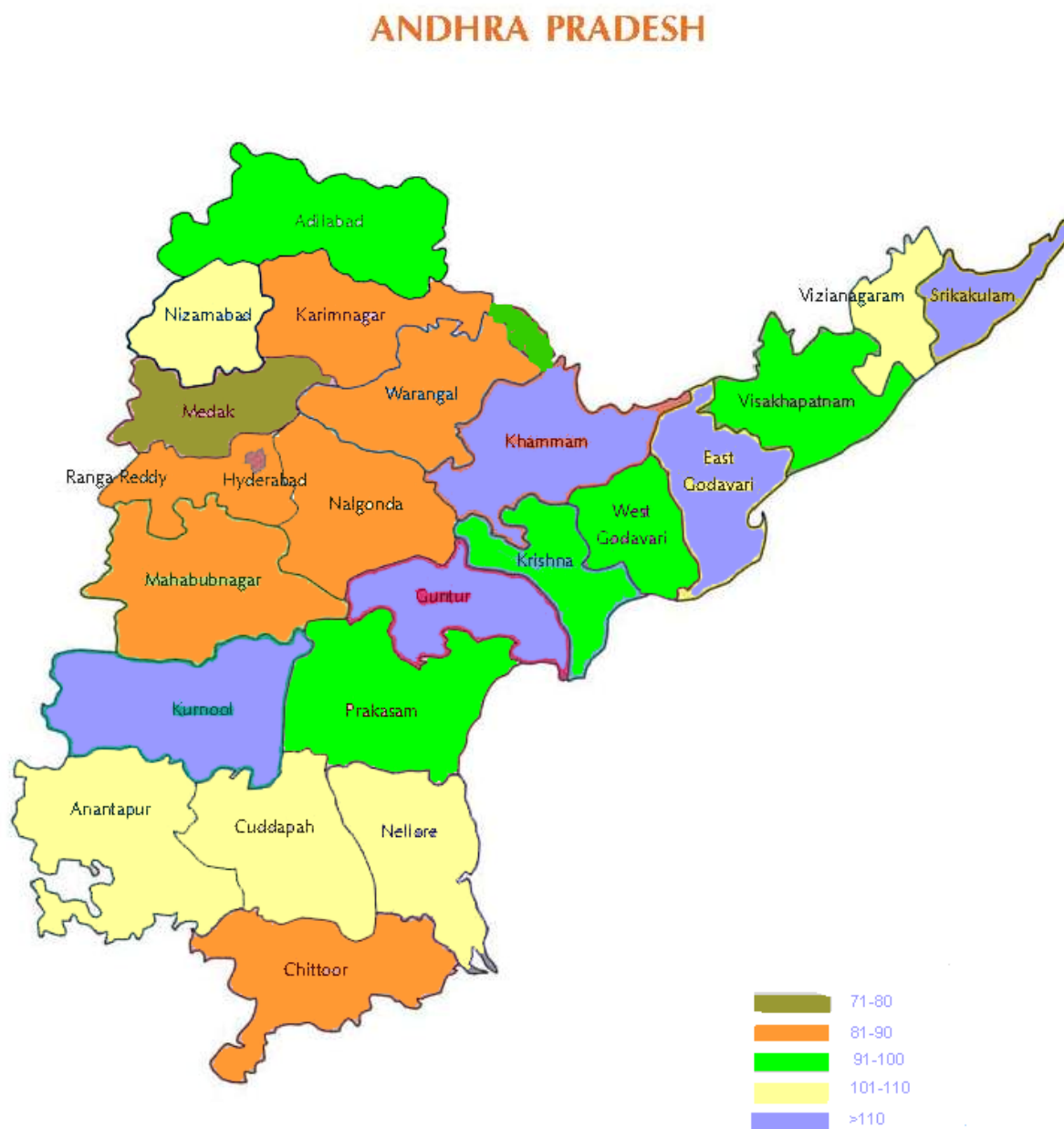
Source: RNTCP Annual Report 2008, A.P.

State TB Control Society, Directorate of Health, Hyderabad

$$\text{Incidence rate} = \frac{\text{Number of New Pulmonary Cases}}{\text{Total Population (2008)}} \times 100,000$$

Total patients registered for treatment includes new sputum smear positive cases, new smear negative cases, new extra-pulmonary cases, relapse, failure, Treatment After Default (TAD) cases and others.

Fig. 19. Estimated TB Incidence Rates of Pulmonary Cases by District, A.P., 2008



4.5 Situation of TB in Nalgonda district

In Nalgonda district, every year more than 4000 people develop active TB disease (Table 11). Data on TB disease suggests that that TB is a major public health burden in the district. Available data for the years 2004-2010 suggests that the total cases registered for treatment decreased to 4284 cases in 2010 from 5132 cases in 2004.

Table. 11. Total TB cases registered for treatment for the years 2004-2010, Nalgonda District.

Year	Total cases
2004	5132
2005	4673
2006	4256
2007	4180
2008	4369
2009	4401
2010	4284

Source: District TB Office, Nalgonda

Analysis of year 2008 epidemiological data suggests that the estimated average incidence of new pulmonary TB cases in 2008 was 85 per 100000 population. To know which areas of the district are the leading source of infection, TB Unit-wise incidence rates of TB is crucial. It is quite evident from Table 12, that Chivemula TB unit had the highest new pulmonary TB incidence rate of 122 cases per 100,000 population followed by Chilkur (97), Chintapally (82), Nalgonda (80), Nidmanoor (80), Valigonda (75), and Yadagirigutta (51) per 100000 population.

Table. 12. Pulmonary TB Incidence Rates TB unit-wise, Nalgonda district

Sl. No	Name of the TB Unit	Population 2008	Total cases registered for treatment	Total new pulmonary cases registered	Incidence rate of new pulmonary TB cases per 100000 population
1	Chivemula	513105	852	624	122
2	Chilkur	540270	737	527	97
3	Chnitapally	453243	543	371	82
4	Nalgonda	434282	560	347	80
5	Nidamanoor	546699	652	436	80
6	Valigonda	466448	534	352	75
7	Yadagirigutta	535895	491	306	51
Total		3489942	4369	2693	

Source: RNTCP Annual Report 2008, A.P.

Source: State TB Control Society, Directorate of Health, Hyderabad.

4.5.1 TB situation: Chintapally and Yadagirigutta TB Units

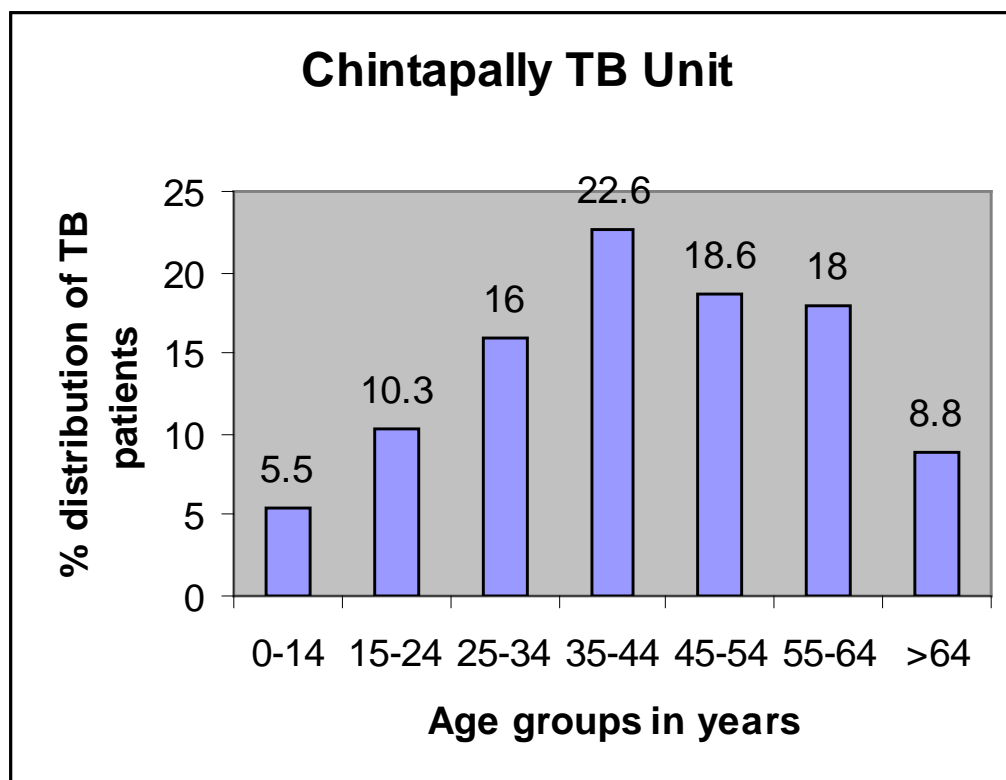
Secondary data was collected from two TB units (i.e., Chintapally and Yadagirigutta) to understand and compare the situation of TB at the TB unit levels. The details of the patients registered for treatment under DOTS during year 2008 were collected from the TB registers maintained in the Chintapally and Yadagirigutta TB units. Data with regard to patient's name, age, sex, case type (i.e., new, relapse, treatment after default, failure and other), HIV status (HIV positive or negative), and TB type (pulmonary and extra-pulmonary) was extracted from the TB treatment registers. The age of the patients ranged from 1 to 75 years with a mean of 41.3 years. During the year 2008, a total of 543 and 491 patients were enrolled for treatment at Chintapally and

Yadagirigutta TB units respectively. These patients were divided into 7 age categories: 0-14, 15-24, 25-34, 35-44, 45-54, 55-64, and > 64 years.

Chintapally TB Unit

Of the total of 543 TB patients registered at Chintapally TB unit in 2008, 406 (74%) were males and 139 (26%) were females. Of the 543 patients with TB, 15 (3%) patients were found to be co-infected with HIV and TB. Figures 20 and 21 show the age, and age and sex distribution of TB patients registered respectively.

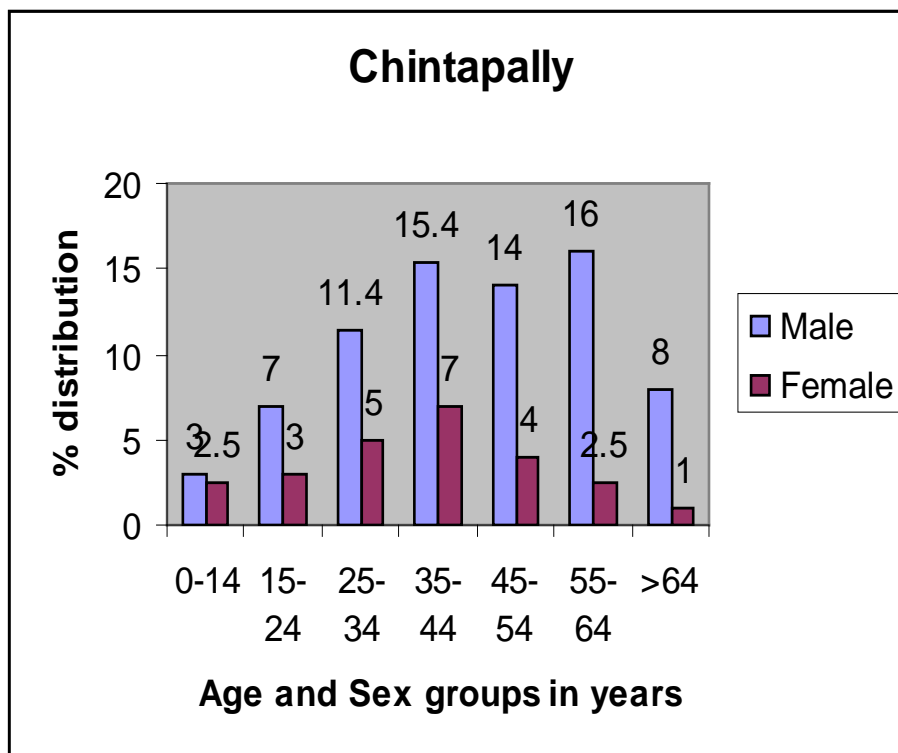
Fig. 20. Distribution of TB cases by Age Group



Source: DTC Nalgonda, 2008

Of the total 543 TB cases, 5.5% belong to the age group of 0-14; 10.3% belong to the age group of 15-24; 16% belong to the age group of 25-34; 22.6% belong to the age group of 35-44; 18.6% belong to the age group of 45-54; 18% belong to the age group of 55-64; and 8.8% belong to the age group of >64 years.

Fig. 21. Distribution of TB cases by age and sex group - Chintapally



Source: DTC Nalgonda

Of the total 406 male TB cases, 3% belong to the age group of 0-14; 7% belong to the age group of 15-24; 11.4% belong to the age group of 25-34; 15.4% belong to the age group of 35-44; 14% belong to the age group of 45-54; 16% belong to the age group of 55-64; and 8% belong to the age group of >64 years. Of the total 139 females TB cases, 2.5% belong to the age group of 0-14; 3% belong to the age group of 15-24; 5% belong to the age group of 25-34; 7% belong to the age group of 35-44; 4% belong to the age group of 45-54; 2.5% belong to the age group of 55-64; and 1% belong to the age group of >64 years. For males maximum cases were in the 55-64 age group, while for females it was in the 35-44 age group.

Of the total 543 cases, 509 (94%) were pulmonary cases and 34 (6%) were extra-pulmonary cases. In all there were 414 (76.2%) newly diagnosed cases, 105 (19.3%) were retreatment cases, and 24 (4.4%) were other cases. Of the 414 newly detected cases, 380 (92%) were pulmonary cases. Of these, 228 (60%) were smear positive pulmonary cases, and the remaining 152 (40%) were smear negative cases. Figures 22 and 23 present

the distribution of newly diagnosed smear positive and smear negatives pulmonary cases by sex.

Fig 22 Sex-Wise Distribution of New Smear -positive pulmonary cases

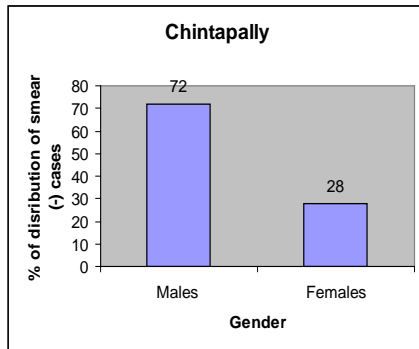
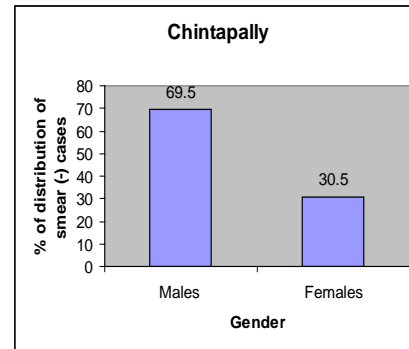


Fig 23 Sex-Wise Distribution of New Smear-negative Cases

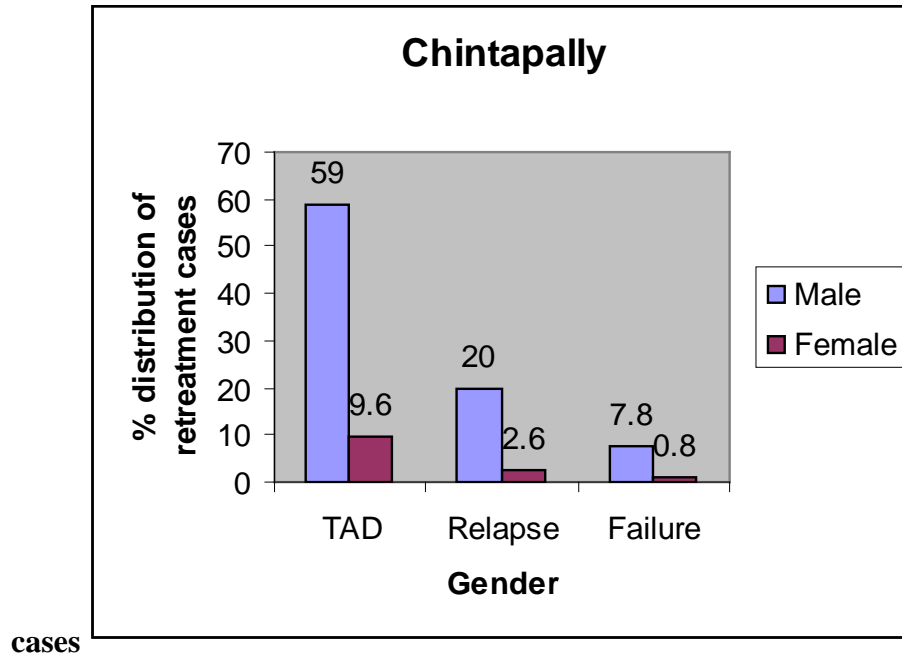


Source: DTC TB Register, Nalgonda, 2008

Of the 228 newly diagnosed smear positive cases, 165 (72%) were males and 64 (28%) were females (Fig 22). Of the 141 newly detected smear negative patients, 98 (69.5%) were males and 43 (30.5%) were females (Fig 23).

Of the total 105 retreatment cases, treatment after default (TAD) cases were 71 (68%; 71/105), relapse cases were 24 (23%; 24/114), and failure cases were 10 (9%; 10/114). Figure 24 presents the percentage distribution of retreatment cases according to sex.

Fig. 24. Sex-Wise Percentage Distribution of Retreatment TB



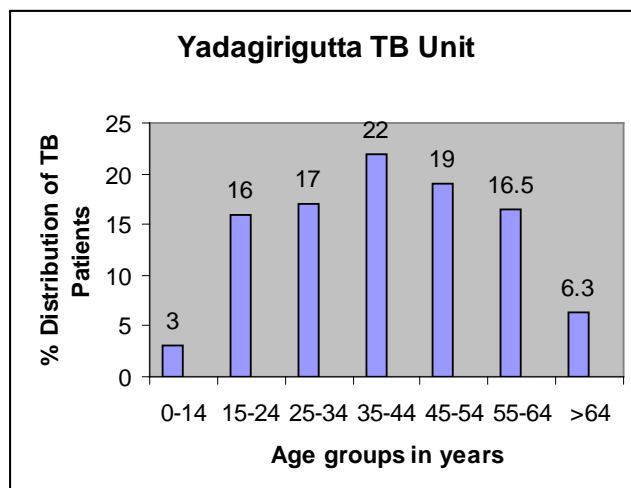
Source: DTC TB Register, Nalgonda, 2008

Fig 24 suggests that in Chintapally TB unit, treatment after default, relapse and failure cases were significantly higher among male patients compared to female patients.

Yadagirigutta TB Unit

Of the total 491 patients, there were 345 (70%) males and 146 (30%) were females. The mean age of the patients was 39 years. Figures 25 and 26 show the age, and age and sex distribution of TB patients registered respectively

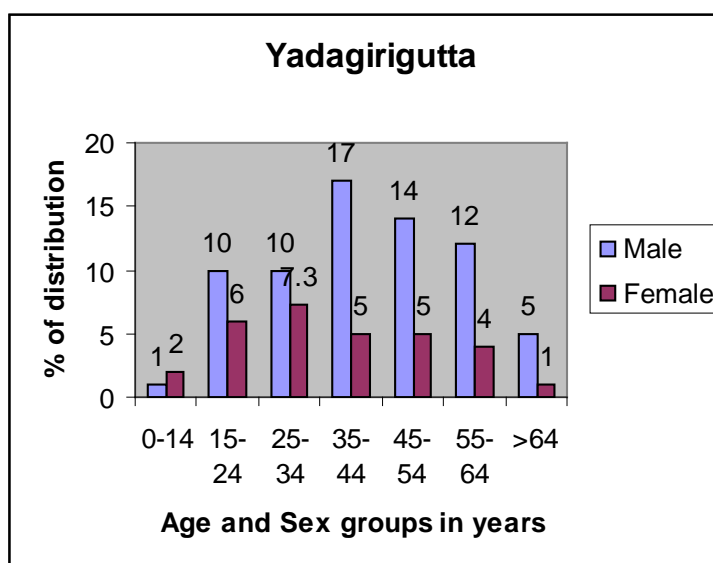
Fig. 25. Age Distribution of TB Patients - Yadagirigutta



Source: DTC TB Register, Nalgonda, 2008

Of the total 491 TB cases, 3% belong to the age group of 0-14; 16% belong to the age group of 15-24; 17% belong to the age group of 25-34; 22 % belong to the age group of 35-44; 19% belong to the age group of 45-54; 16.5% belong to the age group of 55-64; and 6.3% belong to the age group of >64 years.

Fig. 26. Age and Sex Distribution of TB Patients - Yadagirigutta



Source: DTC TB Register, Nalgonda, 2008

Of the total 345 male TB cases, 1% belong to the age group of 0-14; 10% belong to the age group of 15-24; 10% belong to the age group of 25-34; 17% belong to the age group of 35-44; 14% belong to the age group of 45-54; 12% belong to the age group of 55-64; and 5% belong to the age group of >64 years. Of the total 146 females TB cases, 2% belong to the age group of 0-14; 6% belong to the age group of 15-24; 7.3% belong to the age group of 25-34; 5% belong to the age group of 35-44; 5% belong to the age group of 45-54; 4% belong to the age group of 55-64; and 1% belong to the age group of >64 years. For males maximum cases were in the 35-44 age group, while for females it was in the 25-34 age group.

Of the 491 cases, 432 (88%) were pulmonary cases, 35 (7%) were extra-pulmonary cases, and 24 (5%) were other cases. Of the 491 cases, 341 (69%) were newly detected cases. Among the total 341 new cases, 306 (90%; 306/341) were pulmonary cases. Of the total 306 pulmonary cases, 216 (70.5%) were smear positive cases, and 90 (29.5%) were new smear negative cases. Of the 216 smear positive patients, 147 (68%) were males and 69 (32%) were females. Of the 90 new smear negative patients, 55 (61%) were males and 35 (39%) were females. Figures 27 and 28 show the percentage distribution of new smear positive and new smear negative TB cases respectively. Of the 491 patients with TB, 28 (6%) were found to be HIV positive. Of the total 105 retreatment cases, TAD cases were 26 (25%), relapse cases were 55 (52%) and failure cases were 10 (9%). Figure 28 presents the percentage distribution of retreatment cases according to sex.

Fig. 27. Sex-Wise Percentage Distribution of new smear – positive TB cases

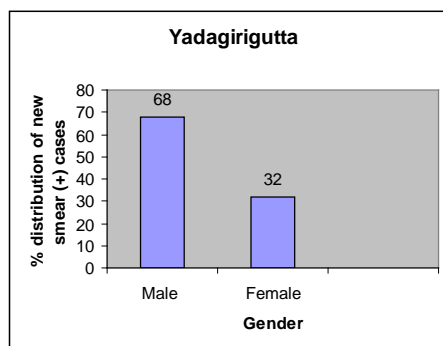
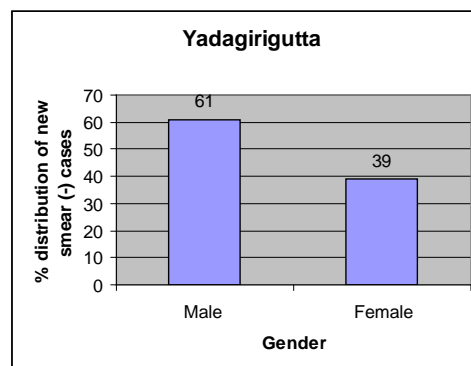


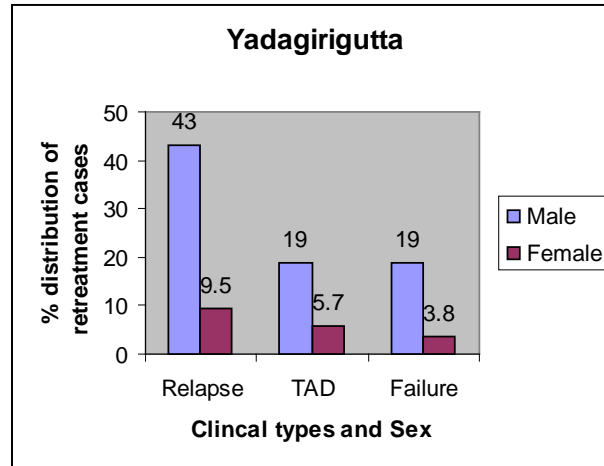
Fig. 28 Sex-wise percentage distribution of new smear-negative TB cases



Source: DTC TB Register, Nalgonda, 2008

Of the 216 newly diagnosed smear positive cases, 68% were males and 32% were females (Fig 27). Of the 90 newly detected smear negative patients, 61% were males and 39% were females (Fig 28).

Fig. 29. Sex-Wise Percentage Distribution of Retreatment TB cases.



Source: DTC TB Register, Nalgonda, 2008

Fig 29 suggests that in Yadagirigutta TB unit, treatment after default, relapse and failure cases were significantly high among male patients compared to female patients.

4.5.2 Comparison of Chintapally and Yadagirigutta TB Units

It was found that total number of TB cases were higher in Chintapally than Yadagirigutta. The occurrence of high number of TB cases in Chintapally TB unit region suggest that TB incidence cases are high among tribal population for various reasons including poverty, lifestyles, lack of sanitation, and overcrowding. Minor differences were observed in the overall distribution of new and retreatment cases between Chintapally and Yadagirigutta TB units. Failure cases were higher in Yadagirigutta TB unit, when compared to Chintapally TB unit. Also relapse cases are more in Yadagirigutta, while TAD cases are higher in Chintapally TB unit. A possible explanation for this given by a TB supervisor in Chintapally was that TB workers regularly made follow-up visits to the patients and as a consequence, TAD cases are recorded promptly, and were referred to the TB care centers. However, these minor

differences were not significant. Major findings from the comparison of data of Chintapally and Yadagirigutta TB units are briefly discussed below:

1) The analysis of age distribution of patients demonstrate that the age group 35-44 years had the highest percentage of TB cases, and 0-14 age group had the lowest percentage of cases both in Chintapally and Yadagirigutta TB units. In both TB units the second largest percentage of TB cases was in the age group of 45-54 years. However, these figures do not provide a clear picture to estimate the impact of TB on different age groups. In order to understand the impact of TB on different age groups, age groups of total patients have been divided into three major age groups (Table 13). Table 13 shows that TB affected all age groups, however, the maximum numbers of cases were concentrated in the economically most productive adult population in Chintapally as well as in Yadagirigutta TB units. It was also observed that a considerable proportion (>20%) of TB cases occurred in elderly age group (55 years and above). For women the highest number of TB cases were in the 25-44 age groups, while for men it was in 35-64 age groups.

Table. 13. Age Groupings of TB Patients

Age	Age Group	Total TB Cases			
		Chintapally (%)		Yadagirigutta (%)	
0-14	Children	30	(5.5%)	15	(3%)
15-54	Most productive adult population	364	(67%)	364	(74%)
>55	Elderly	149	(27%)	112	(23%)

Source: DTC Nalgonda

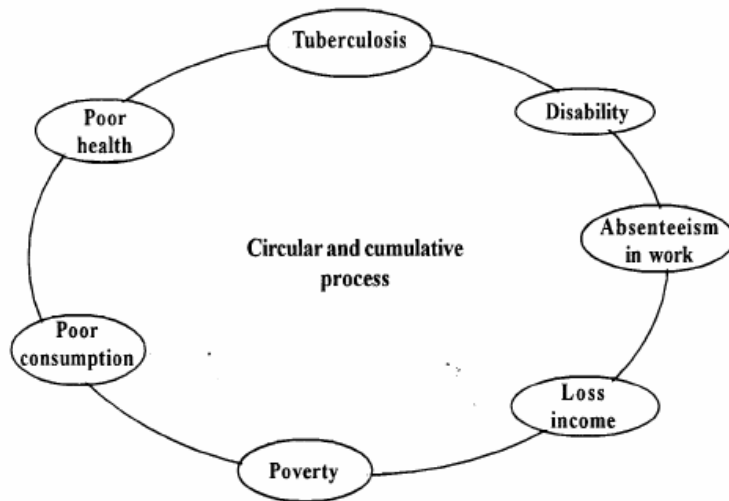
2) Significantly a large proportion of TB cases were pulmonary, and were bacteriologically active (i.e., smear positive cases). Smear positive cases constitute the greatest risk from the epidemiological stand-point, and thus influence the epidemiological situation of TB in the community. Pulmonary patients can serve as a major source of infection to their families and to their community members, thereby perpetuating the pool

of infection in the community. The notification of new TB cases was high among males than females. This finding is similar to those of earlier community based epidemiological studies conducted in several parts of the world. A number of studies (Balasubramanian *et al* 2004) have established that males have a higher prevalence and incidence of TB than females for a wide variety of reasons. “*Worldwide, about two-thirds of all known people with tuberculosis are men, whether this proportion indicates a true difference in frequency between the sexes or an under notification of female cases is subject to speculation*” (Thorson *et al* 2000: 1823). Several studies (Atre *et al* 2004) have revealed that males are more vulnerable to TB than females. A number of scholars have argued that these differences between males and females could be explained by the fact that males in general interact with people in a much wider social circle outside the home, including people with TB, and hence, they have more chances of acquiring infection. Researchers also argued that certain behaviors (e.g., smoking and alcohol abuse) among males appear to increase TB infection that may progress to active disease.

As discussed earlier, in all age groups the percentage females registered for treatment was low. This under-notification of TB cases among women can be partly attributed to different socio-cultural factors such as restricted access to health care services, under-reporting of respiratory related illnesses, and social stigma (Balasubramanian *et al* 2004). Studies from across rural India reported that women access health services less than men. Research conducted in several parts of Asia have revealed that significantly a greater number of men attended the health clinics with symptoms of cough as compared to females patients with signs and symptoms of cough. Consequently, more men were investigated for TB and hence great number of males were diagnosed with bacteriologically confirmed TB.

3) A large number of TB cases occurred among the economically most productive and reproductively active segment. This population has the greatest number of dependents to support. And as a consequence, the disease can have tremendous economic and health impact on families, further trapping the marginalized communities into a vicious cycle of poverty (Fig. 30). Families face severe economic hardships when a wage earner and/or primary household manager becomes too ill to work and requires medical treatment. Studies suggest that one single TB patient on average lose 3 to 4 months of

productive work time, which results in average loss in potential earnings of about 20% of annual household income (ICMR 2002).



Source: ICMR Bulletin (2002) Vol. 32 (3)

Fig. 30. Vicious Cycle of Tuberculosis and Poverty

The economic consequences of loss of 20% of annual household income can have a devastating impact on the poor households. When women are affected, the disease not only affects their earnings outside the household, but also household activities such as cooking, cleaning, washing, serving food and child care. TRC, Chennai, undertook a study to estimate the socio-economic impact of TB in the country. The study concluded that TB costs India more than \$300 million and \$ 3 billion (more than 13,000 crore) annually in direct and indirect costs respectively. Studies conducted by Rajeswari *et al* (1999) at the TRC, Chennai, India, on the impact of TB on patients and families indicated that poor households incur substantial direct (e.g., consultation fees, diagnostic and treatment costs, travel and food expenditure), and indirect costs (e.g., loss of wages due to illness, patients' or their caregivers' reduced earning ability due to disease). Out-of-pocket expenditure for the diagnosis and treatment of illness potentially impoverishes household, and can adversely affect family members, especially the health and welfare of the children (Geetharamani, 2001). Thousands of children discontinue schooling on

account of their parental illness, and many of them take up employment so as to support family income. In India, every year, it is estimated that more than 300,000 children of infected individuals drop out of school permanently to supplement the family income and to help take care of siblings. “*Thus, tuberculosis which is already a social menace leads to another social evil*” (i.e., child labour) (Geetharamani, 2001:94).

4) The proportion of new and retreatment cases (i.e., relapse, failure and treatment after default cases) were exceptionally high among males compared to females. Several studies have indicated that adherence to TB preventive therapy among females is high compared to males for different reasons.

Several scholars have argued that married women and widows were motivated to adhere to treatment because they wanted to prolong their ability to take care of their children and other family members. Non-adherence to TB medication seems to be a serious problem in both the TB units and needs to be understood and explained. Review of literature relevant to non-adherence to medication indicate that defaulting from treatment are associated with a wide variety of factors such as job migration (Jaggarajamma *et al* 2006); pressure of work, family or social obligations (such as marriages, religious functions, deaths, etc.), alcoholism, adverse toxic effects of medication (Suhadev *et al* 1995); domestic and agricultural problems, forgetfulness, relief of symptoms (Singh *et al* 1976; Srivastava *et al* 1981); lack of faith in the treatment, long distance (Jain, 1992); illiteracy, poverty (Singh *et al* 1976); poor quality of relation and communication between health providers and patients, past history of TB, misunderstanding about the duration of the therapy; long course of treatment; and poor/negative behavior of health care workers.

5) A considerable number of TB cases occurred in the elderly people. According to several scholars several factors such as under nutrition, weak immune system, debilitating diseases, smoking, concomitant drugs, poverty, etc., predispose the development of TB in the elderly. High incidence of TB among elderly has implications linked to poor financial security and less attention from care givers.

The above findings have important implications for TB control and health education. Studies conducted in central India, and Malawi, suggest that patients who adhered to the full course of treatment had better understanding of the duration of TB

treatment than patients who interrupted treatment. Several authors have argued that a good relationship between the health care providers and participants can enhance adherence. Health care workers need to be aware of the fact that a patients' trust in the treatment they are receiving is crucial if they are to continue with such a long treatment regimen. Motivation of TB patients at the start and through the course of treatment is a crucial element as far as case holding is concerned, as the average patient is largely ignorant of the importance of regular and complete treatment that TB involves.

4.6 Summary

In many parts of the world the prevalence of TB is rising and worsening. In recent decades, TB has reemerged as a major public health burden globally. TB is unequally distributed in the world with highest incidence rates found in developing countries. In recent years, active TB cases have begun to increase even in developed countries for various reasons including spread of HIV/AIDS, migration, and MDR-TB. HIV infection is the most important force driving the global resurgence of TB. Despite the introduction of effective anti-TB drugs, the prevalence and incidence of TB cases continues to be very high in many developing countries such as India, Bangladesh, Pakistan, China, Indonesia, Nigeria, Congo, Kenya, Tanzania and Uganda. TB is a major killer of economically productive population in the world. India accounts for nearly 1/3rd of the global TB cases, and ranks first among the list of 22 high-TB burden countries in the world.

TB control programmes were implemented on a large scale both globally and in India with an aim to break the chain of infection in the community as well as to reduce TB related morbidity and mortality. In India, despite massive, multi-fold increase in the health infrastructure and manpower at all levels, there has not been much improvement in the epidemiological situation of TB in the country. The prevalence, incidence and annual risk of infection continues to be very high despite the existence of the national TB control programmes for more than 40 years. A critical review of the evolution of TB control programmes in India suggests that TB control programmes largely focused on diagnosing and treating TB disease only. Although Western medicine has made major advances in the treatment of TB over the past few decades, the human and social aspect of care received minimal attention. The current RNTCP emphasizes high quality diagnostic

services (microscopic services) to establish diagnosis, assures uninterrupted supply of anti-TB drugs and uses standardized patient outcome definitions. The overall aim of RNTCP is to detect at least 70% of sputum positive infectious cases that arise each year in the population, and to achieve a cure rate of at least 85% among these newly detected infectious cases through administration of anti-tb drugs under direct observation of a DOT provider. Under this programme, cure is defined purely in bacteriological terms. Identification and treatment of TB symptoms is the top priority of biomedical practitioners.

In the state of Andhra Pradesh, TB poses a very significant public health burden with more than 100,000 new TB cases every year, more than half of them are infectious in nature. Analysis of RNTCP data of Nalgonda district clearly indicates that significantly large proportions of TB cases were pulmonary, and were bacteriologically active, and a large number of TB cases found among the economically most productive and reproductively active segment of the population. Furthermore, the proportion of new and re-treatment cases were exceptionally high among males compared to females. A comparison of the two selected TB units in Nalgonda suggests the highest incidence rate among the productive age groups and the elderly. Fewer women are diagnosed with TB which probably reflects the stigma and denial associated with the disease and the fact that women access health services less. Non-compliance with the TB treatment regime is high in both these TB units. This analysis of the TB situation in India, specifically in rural Nalgonda district suggests the need for alternative frameworks for understanding TB, instead of just the biomedical model.

A critical review of TB control programmes in India as well as in several parts of the world suggests that these programmes do not take into account the socio-cultural factors influencing TB treatment. No effort is made to evaluate patients' social and psychological status under this programme. However, to be effective, the treatment should not be based just on the pathophysiology of the conditions alone, but also consider the social and psychological factors. Several scholars argued that addressing the social and psychological impact of TB disease is important for improving the quality of life of TB patients. In order to design client-oriented comprehensive control programmes for TB, understanding the experience of patients is very essential.

The aim of the TB control programmes should not only be to treat the patient's body part, but to help the patient resolve the disruption in the patient's life world, and the anxiety and fears associated with TB illness. This can only be achieved by taking into account the patient's lived experience of TB illness. Exploring subjective experience of illness is particularly relevant in the case of TB, where patients and physicians have divergent perceptions, concerns and goals. Therefore, this study would like to argue that the recognition of the explanatory model of TB illness is a more effective means to understand TB disease, and to practice patient-centered care thereby improving the quality of life of patients. The chapters that follow based on intensive field-work and the explanatory model of illness further reinforces this argument.

CHAPTER

5

Tuberculosis:

The Experience of Illness

In search for better understanding of human disease --- health professionals often focus on the control of physiological processes rather than on the social and cultural meanings that patients give to their illness experience.

(Ailinger & Schweitzer, 1993: 340)

5.1 Illness Experience

According to Engel (1977:130) “*the dominant model of disease today is biomedical, with molecular biology its basic scientific discipline. It assumes disease to be fully accounted for by deviations from the norm of measurable biological (somatic) variables.....the biomedical model embraces both reductionism, the philosophic view that complex phenomena are ultimately derived from a single primary principle, and mind-body dualism the doctrine that separates the mental from the somatic*”. Such a physiologically based-definition of disease is useful for physiological and medical research purposes, however, this definition is not adequate for understanding socio-cultural meaning and experience of illness.

According to Kleinman (1980) an alternative of way of understanding the meaning of illness is to view it in terms of every day folk (emic), rather than empirical, medical or scientific (etic) discourse. The experience of chronic illness such as TB is embedded in traditions, culture, societal values and beliefs and the social construction of knowledge. A

serious illness such as TB is a threatening experience for many patients. Patients need to be able to understand and make sense of their illness so as to follow a course of action to rid themselves of the illness and the threat it presents. ‘Explanatory models of illness’ provides a useful method for eliciting patients’ understanding of their illness.

To attain patient participation and design socio-culturally acceptable TB control strategies, health care workers and planners must be familiar with perceptions and experiences of patients with TB. Several medical anthropologists and sociologists (Blumhagen 1980; Greenfield *et al* 1987; Ailinger & Schweitzer, 1993), have argued that an effort must be made to understand the patients’ every-day experiences connected with illness. Patients “*rationalize their illness experience through a complex web of personal experiences and belief systems ingrained in their cultural and social world*” (Green 2002:142). Understanding every-day experiences of patients living with TB can have important implications for health professionals working with TB patients. For example, Greenfield *et al* (1987) contend that an understanding of patients’ illness experiences enhances the clinical interaction and communication between the patient and clinician, and enables the clinicians in gaining a deeper understanding of the role of socio-cultural factors that influence an individual’s willingness to seek care, and how choices are made about treatment. Furthermore, it has important implications for the psychosocial aspects of patient care.

This chapter explores what it means to have TB and how patients experience TB illness in their everyday lives. It is based on field work among 110 TB patients in Chintapally and Yadagirigutta TB units in Nalgonda district. Relevant questions for studying the experience of patients living with TB include: ‘how patients notice something is wrong’? ‘what kinds of lay theories and explanations they develop to account for the causation of their illness’? how they come to seek medical care for their symptoms? what are the social implications for the lives of the patients? and, what are the psychosocial reactions of patients on being told their diagnosis’?

This chapter concentrates on three main themes. First section looks at the causal factors considered by the patients in the development of their TB. The presence of TB typically evokes questions such as ‘Am I sick?’ “What kind of disease do I have?” “What caused this disease?” Why did it happen to me (of all people)? For the TB patient who is

a heavy alcoholic and smoker, it may not explain why a friend, who drinks more heavily and smokes, does not have the disease as well. Some patients confronted with this highly stigmatized disease may begin to search for reasons beyond their own control or understanding. Attempting to account for a serious disease opens the door to socio-culturally shaped beliefs about disease causation. This section draws largely on Helman's four categories of disease causation referred to in Chapter 2.

Second section focuses on patients psychosocial reactions to the diagnosis of TB. Disclosure of diagnosis of TB can be a traumatic event in the lives of patients. The experience of serious illness changes the way individuals think about themselves, their present and their future as well as the past. Several studies indicated that TB destroys the taken for grantedness of everyday life and results in fear and suffering. Casell (1982:639) refers to "*suffering as relating to a number of interconnected threats and losses: losses to personhood; threats to the identity; threat's to the person's future; threats to self-image; a perceived lack of options for coping; a sense of personal loss and a lack of a basis for hope*". Understanding the psychosocial reactions of patients can have important implications for health professionals working with TB patients. Failure to understand the psychosocial needs of patients might result in an overemphasis on physical symptoms and the neglect of underlying psychosocial distress.

Section three explores stigma from the subjective perspective of patients. This section basically examines TB patients' experiences of stigma in the everyday local worlds (i.e., the everyday, non-trivial interpersonal transactions involving family members, partners, friends and colleagues), in which they live, work and struggle. Of all infectious illnesses, TB is one of the most stigmatized. Studies conducted in several parts of the world have revealed that TB patients experienced alienation, embarrassment, shame, fear of rejection from family, and social withdrawal. Numerous studies have indicated that the stigma associated with TB is higher for females compared to males, and the consequences can include ostracism, abandonment by the husband, divorce, loss of social and economic support, access to one's children, etc. (WHO 2001).

5.2 Causes of TB : Beliefs of Patients

Ideas about the nature and cause of illness often occur in the form of stories “situated” in a particular socio-cultural context. (Farmer & Good 1991)

All patients have certain culturally embedded beliefs and perceptions about why they become ill. *“Patients frequently maintain their own culturally determined explanations even when physicians inform them of medical etiology. Patients’ private explanations are rarely shared with health professionals because physicians seldom ask, and the patients, for their part, fear ridicule”* (Eisenbruch & Handekman 1990:1295). According to Eisenbruch & Handekman (1990) one of the most important objectives of clinical medical anthropology is to understand how a patient’s culture influences his/her disease causation beliefs.

One of the important questions patients often ask themselves is why it has happened to them and what might have caused their disease. The Western interpretation of disease relies mostly on germ theory and on the principles of science. On the other hand, lay people pay more concentration to the underlying cause of a disease rather than to the underlying pathological process, and clinical symptoms (Lewis, 1975; Glick, 1977). Taieb *et al* (2010:597) argue that *“any illness or disease tends to generate questioning about the causes and even more so about the meaning of the illness: Why me? Why here? Why now? The answers provided by sufferers to these questions reach beyond a search for cause and become a search for meaning”*.

According to Lewis (1975) lay communities pay more consideration to what the patient had done to expose him/her to the cause of a disease? What had he/she done? What had he/she eaten? Where had he/she been? With whom had he/she had dealings lately? He further argues that lay people also examine recent events, activities and social relationships to pick out actions that were wrong or immoral that might have played a role in the cause of a disease. For persons afflicted with serious and highly stigmatized disease the search for an explanation for their misfortune is severe. The search for diagnosis ends only when the patient comes to assume that his/her problems can be

understood, at least partially. As Bury & Wood (1979) (Quoted in Blaxter 1983:59) have said:

The disturbing reality of disease experience gives rise to questions: Why me and Why now? The offering of a diagnosis or label is not enough, and anxiety will be alleviated only if some indication is given of how the situation might have come about.

Several medical anthropologists and sociologists (Blumhagen 1980; Hoa *et al* 2003), have argued that an effort must be made to understand the lay peoples' knowledge of causes of TB. This is because, understanding culturally held TB causation beliefs have important implications for health seeking behavior, and patient-physician communication. Hoa *et al* (2003) suggest that an awareness of lay peoples' cultural beliefs about causes of TB is crucial for facilitating communication about the nature of the disease to the community in general and patients in particular.

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 individual (e.g., smoking, alcohol consumption along with poor diet, heredity, mental stress/worry, hard work), natural (e.g., exposure to cold weather, infection), social (e.g., evil eye, witchcraft) and supernatural factors (e.g., divine retribution) could play a role in the causation of TB 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.

As mentioned in Chapter 1 Helman (2000) classifies lay beliefs about the causes of disease into four major etiologies: individual, natural, social and supernatural. Following Helman's (2000) classification of lay etiologies of illness, the causal explanations for TB discussed by the patients in this study can be grouped into four broad categories: I) individual, II) natural, III) social and IV) supernatural. There is another group of patients (6.4%) who felt that they did not know what caused their TB. Patients with no knowledge of cause of their TB admitted their lack of knowledge by stating "*I really don't know*", "*I don't know*", "*I can't say*", and "*I don't have any ideas about what could have caused TB*". Patients' beliefs about causes of their TB are presented in Table 14. The five most

commonly reported causes were alcohol consumption (35.4%), infection (12.7%), mental worry/stress (10%), witchcraft (8.2%), and fate (6.3%),

5.2.1 Individual Factors

61 (55.4%) patients attributed their TB to individual factors. At the individual level, patients attributed occurrence of TB to various factors that include: excessive alcohol consumption along with poor diet; ii) mental worry/stress; iii) heredity; iv) hard work; v) sleep deprivation; vi) diet high in sugar; vii) over consumption of hot and cold foods.

Excessive Alcohol Consumption along with Poor Diet

A detailed analysis of the patients' responses shows that among individual factors, patients focused mostly on alcohol consumption along with poor diet as a possible cause of their disease. Of the 110 patients, 39 (35.4%) patients (exclusively male patients) reported heavy alcohol consumption along with poor diet as a possible cause of their TB. None of the female patients stated alcohol consumption as the cause of their illness. Like in several other areas in India, alcohol appears to be widely consumed in the study area, more particularly in the tribal areas. Nearly all the tribal patients unanimously agreed that alcohol consumption is very rampant in their hamlets. Of the total 30 tribal patients, 19 attributed their TB to alcohol consumption. Interviews with the tribal patients revealed that the problem of drinking is very serious in their communities for various reasons such as easy access, low cost and cultural practices. Many tribal families are involved in the production of country made cheap liquor.

Patients having a history of alcohol consumption explained 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. A 42-year-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. And 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 diseases including respiratory related illnesses such

as chronic cough, asthma and tuberculosis. I understand that alcohol acts like an acid, and directly affects the lungs and stomach by causing holes in them. Basically alcohol eats your lungs and stomach. You know, germs (purugulu) thrive in the damaged parts of the lungs, and germs cause daggu (cough) and dammu (beathlessness) rogam (TB).

Concerning alcohol consumption, a 42-year-old, tribal laborer, went on to explain:

Being an alcoholic and smoker from very young age, I think it is alcohol consumption that caused severe damage to my lungs. Alcohol ate my lungs and caused holes in them. I am sure it was this alcohol consumption that brought the tuberculosis on me.

The above illness causation narratives reflect the views of many male patients and community members with regard to the role of alcohol in the causation of TB.

Mental Worry/Stress

10% of respondents attributed mental worry/stress as a cause in the development of their TB. Respondents mentioned that certain life events such as death of a son, family conflicts, suicide, etc., resulted in severe emotional stress and trauma, which played a role in the development of their TB. The term stress is more broadly applied by TB patients to describe feelings of being overwhelmed by obligations and commitments, experiences of loss, or feelings of loneliness and isolation. The following quotes illustrate how mental worry is seen to contribute to the development of TB. A 65-year-old widower, ex-railway employee, described the 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 development of TB.

A 35-year-old mother of three young children, described her thoughts about marital stress as the cause of her illness. She reported that her family life was awful. She wept as she said:

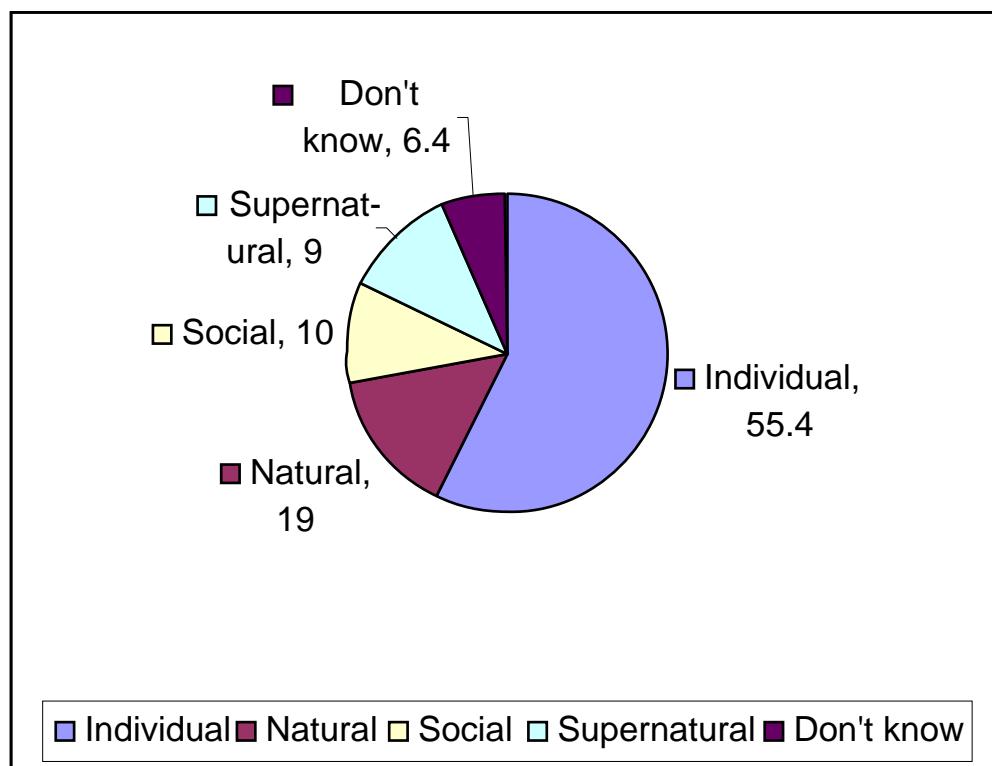
My husband is an alcoholic. He abuses me verbally and physically. He is intimidating, and irresponsible. We fight a lot. I was beaten several times. Another source of my worry was that my parents died few years ago. I am helpless. I was under a lot of stress lately. I worry about my kids' future. I am sure it was this stress that brought the TB on me.

Table. 14. Patients' Belief of the Most Important Cause of their TB (n=110)

Cause	N	%
Excessive alcohol consumption	39	35.4
Infection	14	12.7
Mental stress/worry	11	10
Witchcraft	9	8.2
Fate	7	6.3
Hard work	4	3.6
Exposure to hot sun	4	3.6
Heredity	3	2.7
Divine retribution	3	2.7
Cold weather	3	2.7
Evil eye	2	1.8
Cold foods	2	1.8
Sleep deprivation	1	0.9
Foods and drinks with high sugar content	1	0.9
Don't Know	7	6.4

Source: Field-work (2008-2009)

Fig. 31. Percentage of the main Causal Factors of TB Disease given by Patients



Source: Field-work (2008-2009)

A 32-year old muslim woman said:

I have been suffering from mental depression lately. You know, my husband drinks alcohol quite a lot, and he never supports me in family matters. I get very upset all the time about his careless attitude. I always worry about future of my three little kids. I don't get proper sleep during the night due to mental tensions. I believe that mental tensions affected my health badly and it was this mental tension that caused my TB.

Another patient, a businessman, 58-years-old, stated that prior to the onset of his TB he had particularly stressful few years in terms of his family relationships. He narrated his experience as follows:

I have been under stress for almost a year. Basically my depression comes from quarreling with my wife and children. My wife ignored me completely, and children do not listen to my suggestions any more. Another source of my worry was that I could not earn money. Without money there is no life at all. You know, I am physically very weak. I was very much alone, and depressed. I had no support whatsoever from my family members. I have lost

my self-confidence too. I had turned to alcohol to cope with the stress and strains in life. I think it was the mental stress that caused TB.

Another patient, a 45-year-old widow with two children talked about her depression that played a role in the causation of her TB. She explained that she has been under depression for the last two years for various reasons, including death of her husband, lack of support from her relatives after husband's death, and the responsibility of raising her children by herself. She attributed her TB to mental depression.

Heredity

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

If a mother or father has TB, then they will pass on TB to their children. Ours is an unlucky family. My mother died of TB, 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

4 patients attributed their disease to excessive hard work. An illustrative example was given by a 67-year-old male farmer, when he commented on the cause of his TB:

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

Sleep Deprivation

1 patient linked TB to sleep deprivation. A 35-year-old male factory worker described it this way:

I had so much chronic pain in my left foot that I cannot explain in words. 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 health, and I suppose sleep deprivation caused TB.

Diet high in Sugar

1 respondent linked his illness to consumption of foods and drinks with high sugar content. A 48-year-old male rickshaw puller explained his illness to accumulation of sugar in the blood and lungs. He said:

I acquired TB through drinking a lot of tea and eating sweet bread all the time. 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.

Over consumption of cold foods (Hot-Cold imbalance)

2 patients attributed their illness to cold foods. In the study area, hot-cold belief system (humoral pathology) is very popular. As mentioned in Chapter 1, the fundamental principle of this belief system lies in maintaining a proper balance between heat and cold in the body, and disease results when there is an imbalance between these two qualities in the body. 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. Interviews with the patients revealed that that a wide variety of factors including over consumption of cold or hot foods, and over exposure to extremes of hot or cold temperatures may cause imbalance between hot-cold qualities in the body. A widow aged 55 years-old, said that over consumption of cold foods such as 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 could have contributed to the onset of TB.

5.2.2 Natural Factors

In the natural world causation category, 19% of the total patients attributed causation of TB to factors like exposure to cold or hot weather, and infection.

Exposure to Cold Weather

3 patients from this study believed that cold weather was the main cause of their illness. A 52 year-old, muslim patient expressed that:

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

Infection (Contagious nature of TB)

14 (12.7%) respondents considered the cause of their disease to be the contagious nature of TB. They believed that TB can spread from one person to another, through close contact with the sufferers, and sharing clothes, bed sheets, bathroom, food or utensils the afflicted has touched. It is also assumed that physical contact with urine saliva or sexual fluids of the TB patient also causes TB. The notion that TB is contagious and that it can be transmitted interpersonally is reflected in the following statements. A 40 year-old male auto driver said:

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

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 few years ago. We both slept in the same bed room. Since then, I am having fever and cough. I had a strong suspicion that I might have contracted TB from my mother. You know, several people told me that close association with a TB patient can cause TB.

Another patient, a 19-year-old female student explained in similar vein:

If a relative, family member, friend or colleague is infected with TB and you continue to associate with him/her, you might as well get infection. I firmly believe that I had contracted TB infection from my aunt who was a TB patient.

Excessive Exposure to Hot Sun

4 patients cited bad blood (*chedu raktham*) as a cause of their disease. When I asked what was meant by bad blood, patients said that bad blood refers to blood which has become ‘spoiled’ as a result of overheating in the body. There is a widespread perception among the patients and community members that excessive exposure to hot sun could spoil the blood (*chedu raktham*), 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 overheating in the body as a cause of their disease.

5.2.3 Social Factors

At the social world level, 10% of the patients attributed their TB to social factors. Of the 11 patients who attributed TB causation to social forces, 9 and 2 patients associated their illness state with witchcraft and evil eye respectively. Patients’ illness narratives suggested that witchcraft and evil eye accusations and suspicions usually manifested among neighbors and close blood relatives. Speculations about malevolent intrusions mainly arise in the context of social conflicts, when a series of misfortunes in the family occurs or when somebody already has a long history of witchcraft experiences. The most commonly ascribed motives for bewitchment are related to jealousy or hatred. An interesting finding of this study is that of the total 11 patients who attributed their illness to social forces, 8 were females and 3 were males, suggesting that women report social causation factors more than men.

Witchcraft

Witchcraft beliefs and accusations have long been recognized to be part of the fabric of everyday social life of rural people in India as well as in other developing countries. The following case provides an example of how existing social conflicts result in witchcraft accusations. A 48-year-old woman, laborer, had the following story to share:

My husband and his brother quarreled over the land rights. Discussions about sharing land became heated, ended in violence. My husband hadn't 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 witch to inflict TB disease on me.

The following case provides an example of how occurrence of a series of misfortunes in the family are attributed to witchcraft. A 45-year-old woman laborer, described witchcraft as a possible cause of her illness. These are her words:

I owed money to a person who happened to be a black magician. He (the magician), has been very angry with me because I didn't repay 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. He (witch doctor) explained to me that money lender in my village 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. You know, a series of misfortunes occurred in my family in recent years. My son met with a serious accident last year, my younger son and husband had been unwell for a considerable period of time now.

Evil Eye

2 respondents expressed evil eye as a cause of their disease. *“The belief that simply regarding a person, animal, or object with an intense gaze while holding an invidious attitude can be destructive to the entity at which the gaze is fixed is wide spread”* (Stephenson, 1979:247). Izquierdo & Johnson (2007) hold that in communities where poverty, deprivation and social inequality is the general rule, and anyone's good fortune and wealth will inevitably trigger feelings of envy and jealousy in less fortunate others. *“In such a situation suspecting that others are envious and harbor malicious intentions are not simply a projection, it is also a realistic assessment”* (Izquierdo & Johnson 2007: 423). Their study on the illness narratives among the Matsigenka community of Kanisea, in the Peruvian Amazon, revealed that community members expressed that a person can be made sick under very specific circumstances, particularly:

When somebody wants something that you have, they want it and they can make you sick; If people see you too happy they will wish sadness for you; Some people will be happy when you are sick. If you develop economically they will do harm so that you will no longer remain economically strong (Izquierdo & Johnson 2007:434).

In this study, similar responses were noted among few patients. Analysis of witchcraft and evil eye cases in this study 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. For instance, a 52 year-old housewife attributed her illness to evil eye. She alleged that her neighbors had become jealous of her family because of the fact that her husband had constructed a good house. She expressed a conviction that her neighbors had caused harm to her health by casting an evil eye. Reference to witchcraft and evil eye as a cause of TB was noted among the non-tribals, none of the tribal and muslim patients attributed TB to either witchcraft or evil eye

5.2.4 Supernatural Factors

At the supernatural world level, patients attributed their TB to factors like divine retribution and fate. 9% of the 110 patients interviewed attributed their illness to supernatural factors.

Divine Retribution

At a community level, the perception that neglect or violation of religious codes of conduct and taboos will bring about serious diseases (such as cancer, TB or leprosy), or misfortune is prevalent. 3 patients attributed their illness to divine retribution. These three patients associated their illness to their past behavior that was inappropriate or wrong according to their individual or societal moral standards, for which they were punished by the onset of serious disease. For example, a 40-year-old- woman laborer, explained that her clan god (*Mallana*) has sent TB illness as a punishment for neglecting a shrine of *Mallanna* and religious observances for several years.

Fate (*Karma*)

7 respondents expressed fate (*karma* - which is typically used as a cultural metaphor for fate), as a cause of their TB. Individuals associated occurrence of TB as God's will or the way God meant for them to suffer. Bermudez *et al* (2010:5) contend that "*this reflects*

an external locus of control in which people perceive the events that occur as happening as result of luck, fate, or powers beyond their control instead of dependent on their own behavior". Of the 7 patients who assigned fate as the cause of their TB, 5 were elder patients (> 50 years old). A 59 years-old male patient, 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. There is nothing we can do about it. Can we? God created human beings. We are not going to live on this earth for ever. We all eventually will die from some disease or other. I think it's God's will or the way God meant for me to suffer with TB.

It was observed that mainly elder patients expressed that certain events in life are inevitable and if something is to happen, it is to be "God's will". Elder patients appeared to be fatalistic about life events than younger patients for various reasons. In this study it was noted that elder patients were socially and economically disadvantaged because of lack of support from their families. There is a fatalistic attitude among these patients that whatever shall be, shall be.

5.2.5 Beliefs regarding the main cause of TB by Socio-demographic Variables

Table 15 and 16 show that all the religious (Hindu, Muslim and Christian), social (tribal and non-tribal), caste (SC, ST, BC, and OC) groups, and both literate and illiterate, patients identified excessive alcohol consumption, contagious nature of TB (infection), mental worries and fate as etiological factors of TB. It is believed that heavy alcohol consumption leads to loss of appetite, and as a result people who drink excessively do not take food in time, and take food sporadically. It is assumed that alcohol weakens and causes holes in the lungs and digestive system. Alcoholics become weak and loose considerable weight due to malnutrition. This puts a person at risk of developing TB and other respiratory related illnesses. However, alcohol consumption as a cause of TB was reported significantly by more tribals when compared to non-tribals.

Patients belonging to different religious, social, caste, and educational groups mentioned that that TB is highly an infectious disease. The public image of TB illness is

predominated by the view that TB is a dirty disease. The fear of contracting TB through contact with TB patient's clothes, bed sheets, utensils, food, saliva and sexual fluids, and through breathing the air expelled by the TB sufferers is widespread among all the groups, including among the literates.

Irrespective of caste, religion, education and ethnic group, patients identified mental worries (such as worrying too much about family conflicts, ill treatment by husbands or in-laws, future of children, loss of family members or not being able to support children and family in times of financial crisis) as a cause of their ill health.

One of the interesting findings in this study was that tribal patients did not attribute their illness to social and supernatural factors such as witchcraft, evil eye or divine retribution. Tribal patients interpreted their TB illness as a natural event rather than as the result of the action of social and supernatural factors. Interviews with the tribal patients and community members revealed that the disease profile of tribal areas is characterized by a high incidence of diseases such as diarrhea, TB, and malaria. The causation of TB to natural forces by tribal patients can be attributed to the fact that in tribal areas TB incidence is very high, and the patients and their family members must have known people who suffered from TB in the past. In fact, focused group discussions with the tribal communities revealed that almost all the adults in their community had seen several people with TB illness. Hence, most of the tribal patients attributed their illness to individual and natural factors. In tribal communities, nutritional levels are poor, health facilities are scarce, and it was observed that majority of the houses had poor ventilation, and were overcrowded. Such adverse conditions might have played a role in the exposure and spread of TB in the community. Furthermore, the high incidence of TB in tribal communities may be attributed to poor environmental health and harmful lifestyles (e.g., high alcohol consumption). It is also evident from Table 15 and 16 that none of the Muslim and Christian patients attributed their illness to witchcraft, divine retribution or evil eye. However, because of small number of Muslim and Christian patients in the sample, these observations can only be tentative.

Table 16 reveals that illiterate patients attributed their illness to evil eye, witchcraft and divine retribution. This response indicates that illiterate patients in the study area

have a very low level of awareness about cause of TB. Those with higher education did not attribute their illness to supernatural and social causes.

Like many communities in the world, rural people in Nalgonda believe that equilibrium between hot-cold qualities in the body results in good health. Imbalance between these two qualities results in illness. A common complaint of disturbance in the hot-cold qualities of the body among the rural people is said to be due to over exposure to hot or cold temperatures, or to eating too much cold or hot foods. Muslims, Hindus, SCs, STs, BCs, and both literate and illiterate (except for patients with college education) patients believed that disruption in hot-cold qualities could affect health of an individual. All categories of patients perceived health and illness in holistic terms, and recognized that mind and body are interconnected. None of the Christian patients, and patients having college education attributed their illness to hot-cold imbalance in the body. However, it should be noted Christian sample is very small, and hence results can not be generalized. All the religious, tribal and caste groups expressed fate as a cause of their TB. Informal discussions with community members in the study area revealed that fatalistic attitudes are common in their communities.

However, it was more apparent among the elder and poor people, and people living in poor socio-economic conditions. There is a fatalistic attitude among the elder people that whatever shall be, shall be. However, it should be noted the above results are only tentative. One of important limitations of this study is the small sample size of Christian, Muslim, upper caste patients. Extensive research needs to be carried out with large numbers of patients of different social, religious, caste, and educational background to understand if differences in causes of TB among the different groups exist.

Table 15 Perceptions of the main cause of TB among various social groups

Social Group	INDIVIDUAL FACTORS						NATURAL FACTORS		SOCIAL FACTORS		SUPERNATURAL FACTORS	
	Alcohol consumption	Mental stress	Over work	Heredity	Lack of sleep	Diet High in sugar	Hot-Cold imbalance	Infection (contagious nature of TB)	Witchcraft	Evil eye	Divine retribution	Fate
Hindus (largely being OBCs and Dalits)	√	√	√	√	√	√	√	√	√	√	√	√
Tribals	√	√		√			√	√				√
Muslims	√	√					√	√				√
Christians	√						√	√				√

Table. 16. Beliefs regarding the main cause of TB by Socio-demographic Variables

No. of patients (N=110)													
	Alcohol Consumption n = 39	Infection n =14	Mental Worries n =11	Witchcraft n =9	Fate n = 7	Hard work n = 4	Hot-cold Imbalance n = 9	Heredity n = 3	Divine Retribution n = 3	Evil eye n = 2	Sleep deprivation n = 1	Diet high in sugar n = 1	Don't know n = 7
EDUCATION													
Illiterate	21	6	4	8	4	4	5	3	3	2	-	1	6
Primary	8	3	6	1	2	-	2	-	-	-	-	-	1
Secondary	10	2	1	-	1	-	2	-			-	-	-
College	-	3	-	-	-	-					1	-	-
CASTE													
OC	1	1	1								-	-	
BC	11	3	6	6	3	3	3	2	2	2	1	-	4
SC	08	4	3	3	2	1	4	1	1	-	-	1	1
ST	19	6	1		2	-	2	-	-	-	-	-	2
RELIGION													
Hindu	34	11	9	9	4	4	8	3	3	2	1	1	5
Muslim	4	2	2		2	-	1	-			-	-	2
Christian	1	1			1	-					-	-	
SOCIAL													
Tribal	19	6	2		2	-	2	-	-	-	-	-	2
Non-tribal	20	8	9	9	5	4	7	3	3	2	1	1	5

5.3 Reactions of TB Patients on being told their Diagnosis

Disease is a natural part of our biological lives; to our social beings, however, illness is unnatural, a threat, an uncertainty. Serious illness in particular evokes strong emotional response which is culturally channeled into symbolic images and behavior. (Long & Long, 1982: 2101)

TB has always been associated with the idea of a deadly and dirty infectious disease and with a sense of uncertainty, confusion, anxiety and death, by patients and their family members. The news of TB diagnosis often destroys the taken-for-granted world of everyday existence even in the best of circumstances, and thereby sets off a crisis in the lives of patients. Studies have found that receiving a TB diagnosis is a traumatic event or crisis, physically and psychosocially. Studies have found that successful management of TB treatment requires that clinicians understand the psychosocial reactions and needs of the patients. This is because, information on patients' initial reaction to diagnosis of TB has important implications for meeting the psychosocial needs of the patients. For example, Cott (1987) argues that health professionals can provide better service to the patients through recognition of the patients' fears, expectations and cultural meaning of their illness. Similarly, Gotay (1984:605) contends that understanding psychosocial concerns of patients "*assists researchers and health care providers in sharing the perspectives of patients and families, in anticipating difficulties they may face, and in providing effective support*".

The following discussion focuses on patients' psychosocial reactions to the diagnosis of TB. The main research question was: *What are patients' subjective experiences of being informed that they are TB-infected?* Every patient relived their reactions when they were informed of their TB infection. Several patients couldn't describe the episode without bursting into tears. Participants expressed a wide variety of responses on hearing the news that they were TB infected (in some cases HIV and TB). The diagnosis of TB aroused strong negative psychological distress, and the experience of receiving a diagnosis of TB appears to be a traumatic event for many patients. Most patients responded to TB diagnosis with feelings of disbelief, worry, shock, sadness, devastation, embarrassment, anxiety, fear of death, fears about the future of children,

feelings of uncertainty, depression, helplessness or anger. The initial reaction of patients to the disclosure of the diagnosis of TB varied from sadness/shock/worry (42.7%), surprise/disbelief (27.3%), scared/feared of death (10%), God's act/fate (9%), embarrassed (5.4%), not surprised (3.6%) and relieved that it was just TB (1.8%).

Reaction to diagnosis	No. of patients	%
Sadness/shock/worry	47	42.7
Surprise/disbelief	30	27.3
Fear of dying	11	10
God's act/fate	10	9
Embarrassed	06	5.4
Relieved that it was just TB	02	1.8
Not surprised	04	3.6

Table. 17. Main Reaction to Initial Diagnosis among TB patients (n=110)

The narrative accounts below from interviews with patients illustrate how patients initially reacted upon being told that they had TB.

5.3.1 Sad/Worry/Shock

43 patients (42.7%) patients expressed sadness/worry/depression when they were informed of their TB infection. For some patients, like, the 45-year-old woman, the experience of diagnosis of TB was a great worry. She explains:

It came as a total shock. What wrong have I committed? Why has God given me this disease? I was worried for my poor children. I'm all they got and I was quite concerned about what will happen to them if I die. You know, I just broke down and cried. I was worried about how this disease would affect me and my children. A deep sense of depression and worry encompassed my heart.

This woman has two children, ages 4 and 6 years. She sells fruits for a living. Her husband died of HIV and TB one year prior to this interview. Six months after the death

of her husband, she was admitted for worsening cough, intermittent fever and shortness of breath. Shortly after, she tested positive for HIV and TB. She was the only care giver in her family and was the only source of help for children. Most of her close blood relatives (including father and mother) died. She expressed a worry that her children would end up in the streets if something should happen to her. She said that no one can provide the same kind of comfort and love to her children that she can.

Another sufferer of TB, a 36-year-old male, said:

I was totally stunned to hear that I had TB. I kept thinking, why did it happen to me? It was a traumatic event for me. I had gone through many emotional feelings – shock, sadness, depression, etc.

A house wife, in her early thirties, recounted the following reactions when she was diagnosed with TB for the first time.

I was shocked about how the disclosure of my TB infection would affect my personal relationships within the family, particularly with my in-laws. I was really scared about what their reactions would be.

This woman patient disclosed her disease status to her husband, but not to her in-laws. Almost all the married patients felt that disclosure to sexual partners was important. Lack of disclosure to partner could raise tension in a relationship. There is widespread belief among the community members that a TB patient must avoid sex for at least six months. Failure to adhere to this taboo may worsen the disease condition and some times may result in death.

On being told that they had TB, some patients reacted with a deep sense of sadness. Their depression and sadness was particularly evident in their inconsolable crying. For example, a housewife in her late forties, put it:

When the doctor told me that I had TB, I broke down into tears. It was a terrible feeling. I really sank into bouts of sadness. You know, I cried and cried.

Some patients responded to TB diagnosis with feelings of severe anxiety, particularly about the future of their children. A 32-years-old agricultural laborer put it:

It was an earth shattering experience. My major concern was my new born baby, aged 9 months. I was feared for my young kid. I kept thinking what if my kid contracts the disease from me? Will the kid survive from this disease? Oh, my God, what did I do to deserve it? You know, I cried quite a lot by myself.

5.3.2 Disbelief/Surprise

The most common emotional state participants reported upon learning that they had TB was surprise/disbelief. 30 respondents (27.3%) reported feeling shock or disbelief at hearing news. This is because an overwhelming majority of patients believed that they were not at risk of acquiring TB infection because their families have not had a past history of TB. Comments like the following were typical when a 45-year-old male patient heard the diagnosis of TB - the feeling was one of disbelief:

I felt complete disbelief. In fact, disbelief and denial were my initial reactions. I kept asking my self, why me? I thought that it would never happen to me. You know, there was no one with TB in my family. It was hard to accept (diagnosis). In fact, I went to another doctor. And then it was confirmed.

Similarly, a 40-year-old woman laborer, recalling the time of diagnosis, said:

My immediate response was of one of complete disbelief. We never experienced TB in our families. I kept thinking, why have I got this disease. You see, I've never done anything wrong. I hadn't indulged in sex outside marriage. How could I possibly get this disease?

In similar vein a 29 year-old laborer said:

I had strong reasons to disbelieve that it was TB. You know, I never ever thought that I would get TB because none of my family members (parents, grandparents, uncles) had suffered from TB before. At first, I did not believe that I got TB.

A 53-year-old muslim patient confessed:

It came as a total disbelief. I was never a drinker and I don't smoke. I was a fit person. How could I possible get this disease? I kept thinking 'why me'? I always thought at the back of my mind that it wasn't TB.

A 32 year-old muslim woman said:

I never believed that I had TB even after doctor told me that I had TB. I thought that my symptoms (loss of appetite and intermittent fever) were typhoid related. I am the only person in the family ever to be suffering from TB. How could this happen to me? You know, this is really a shocking news for me. It took me sometime to accept that I have TB.

The patient narratives aptly demonstrate that past history of TB in the family, sexual promiscuity, alcohol consumption constitute important predisposing risk factors for TB according to the patients. While most patients recognized sexual promiscuity as a risk factor for TB, none of them admitted to this being a cause for their TB.

5.3.3 Fear of Dying

10% of patients were frightened upon learning the diagnosis, and particularly HIV positive TB patients. These patients perceived HIV and TB as a death sentence. Majority of HIV positive TB patients reported that they immediately sensed imminent death on learning the diagnosis. Some like, a laborer, HIV positive TB patient, 33-year-old male, reported that he immediately sensed death upon learning the diagnosis of TB and HIV. He wept as he said:

I immediately felt death. I understood that I wouldn't survive for too long. In the past I watched patients (HIV positive TB patients) dying from this horrible disease in my village. It really terrifies me. But, I don't want to die. I have the same dreams and aspirations as every father has. You know, things like sending children to school, taking better care of kids, etc. But, I felt I can't fulfill my dreams, as I am physically and mentally very ill. I felt very guilty about that. I was infected with HIV and TB. Death is inevitable. I will never see my children again. I wonder, you know, what's going to happen to my children after my death.

This patient was married, with two children one 3 years and a baby 3 months old. He expressed a concern that he would never see his children grow up, and his wife would be

widowed. He also expressed a concern about how his disease would affect the future of his children and wife.

As another HIV infected TB patient put it:

I was very frightened when I learned that I had HIV and TB. First thing I thought was: Oh, God, I am going to die. I knew I wouldn't last for too long. I just thought it was the end of the world. You know, I was very much frightened by the words TB and HIV. I am very much concerned about the possibility of imminent death.

A 52-year-old muslim patient, said:

When I first knew that I was infected with TB, I felt very scared, and I thought I was going to die.

5.3.4 Fatalism

10 respondents (9%) turned to fatalism in accepting their diagnosis. Patients having fatalistic attitudes described fatalism as belief that some health issues are beyond human control on the basis of certain views about luck, fate and destiny. TB fatalism is a situational manifestation in which individuals felt powerlessness and helplessness in the face of serious illness. It was observed that elder, and HIV infected TB patients described a feeling of fatalism at hearing the diagnosis. For some HIV infected TB patients, the perception of HIV and TB as a death sentence emerged. Some elder TB patients reported occurrence of TB as God's will or the way God meant for them to die. For example, 65 years-old male patient said:

I think it's God's will or the way God meant for me to suffer. There is nothing we can do about it. Can we? I have to die of something. Death and disease is inevitable part of life. Whatever is going to happen, will happen.

5.3.5 Embarrassment / Shame

6 patients reported that they became embarrassed (*Ijjath*) upon discovering they had TB. Study findings suggest that TB remains a much stigmatized disease within rural communities in Nalgonda district. A 68-year-old patient, noted that:

I'm really embarrassed. I felt a great social stigma attached to it. You know, in my society, people generally avoid TB patients because of infectious nature of TB. People normally say that, Oh, this person has TB, and better not interact closely with him/her. This is really embarrassing.

The vast majority of patients in the study often didn't like to admit that they have TB. Many patients, for instance, remarked that disclosure of TB could bring shame on the family.

5.3.6 Not surprised

4 patients reported that they were not surprised upon learning that they had TB. The views of few patients having no reaction are characterized by this 70 year-old patient:

I didn't feel any thing about it. I don't have anything to worry about. I had gone through all the important phases in my life. It is God's act. We can't do much about it, can we? To tell you the truth, if you're going to get it, I think you're going to get it. It is not in our hands.

5.3.7 Relief at the Diagnosis

Two patients with extra-pulmonary TB described sense of relief upon learning the diagnosis. These patients expressed a sense of relief on hearing the final diagnosis after a long period of confusion and uncertainty. Patients expressed relief as the whole family had been tormented for several months without a proper diagnosis. For example, an extra-pulmonary spinal TB patient, in his late forties, said there was a sense of relief that at least it isn't paralysis. He said:

When I was diagnosed as having TB, I felt some kind of relief to learn it was TB rather something worse (paralysis?). I suspected a tumor on my spine was some thing very serious. Luckily, it wasn't as serious a disease as I thought to be. That was a kind of relief to me and to my family members. You know, a number of doctors had examined me, and none of them seemed to know what was wrong with me. TB is not a horrible disease. I will not die from it. It gives me a sense of relief and hope.

This patient was exhausted from consulting different practitioners and was burdened with the costs of treatment. He expressed a great deal of anger and frustration at RMPs and physicians, who, he believed, ignored his symptoms for almost one year. After a series of medical consultations with several allopathic physicians, a doctor suggested he see a TB specialist. He expressed a great deal of relief upon knowing his diagnosis.

5.4 The Stigma Experiences of Patients with TB

Stigma is an attribute that marks a person as tainted, calls their identity into question, and allows them to be devalued, compromised, and considered “less than fully human”.

(Pescosolido *et al* 2008: 21)

It is striking to see that stigma is at the center of global strategies to fight AIDS and it is so little present in the international priorities of TB control. Furthermore, an additional problem is that, when studied, TB stigma is approached more as a problem for the control of the disease than for the people affected by TB.

(Macq *et al* 2006: 351)

According to Visser *et al* (2009:197) “*stigma can be described as a social construction of deviation from an ideal or expectation, contributing to a powerful discrediting label that reduces the way individuals see themselves and are viewed as persons*”. Mark *et al* (2006:1913) argue that “*stigma of infectious diseases can be as devastating to the infected individuals as the diseases themselves*”. Several research studies (Kelly 1999) have shown that individuals with TB have been isolated by community members. Fear and isolation of patients with TB is very common, even among their families and friends. Sontag (1978) argues that TB is much more than a disease, and is identified with death itself. Sontag (1978) contends that TB patients find themselves being shunned by relatives, families and members of social network, and are the object of decontamination by members of household. Sontag (1978:6) argues that “*contact with someone afflicted with a disease regarded as a mysterious malevolency inevitably feels like trespass; worse, like the violation of taboo*”. Sontag is of the view as long as a particular disease is regarded as an evil, not just a disease, most will be

depressed by learning the diagnosis of their disease. Few decades ago, learning that one had TB was equal to hearing a sentence of death, and very name of the disease was thought to have a magic power. Patients who have such a disease tend to very secretive about their nature of disease, because it can jeopardize one's interpersonal relationships, one's job, one's marital relationships, etc. Furthermore, Sontag suggests, for example, no one thinks of hiding or concealing the truth from a cardiac patient. Cardiac disease implies mechanical failure of heart organ. There is no shame, nothing of the taboo that surrounds those who have TB. *"The metaphors attached to TB – imply living processes of a particularly resonant and horrid kind"* (Sontag 1978:9).

TB related stigma appears to be a worldwide phenomenon (Jaramillo 1998; Kelly 1999; Auer *et al* 2000; Johansson *et al* 2000; Eastwood *et al* 2004; Atre *et al* 2004), with serious implications for the lives of the people living with TB. Person with TB may internalize stigma reactions resulting in depression, increased anxiety and decrements in social performance, lower self-esteem, and the adoption of secrecy and withdrawal as coping strategies. Thus, TB-related stigma poses detrimental consequences for the quality of life of TB patients. The presence of depressive symptoms could amplify the physical symptoms, cause functional impairment, and reduce treatment compliance and quality of life of TB patients. The stigma of TB has been deemed one of the major setbacks to the successful implementation of TB control programs in most countries including India. The stigma of TB has a number of adverse consequences. For example, fear of being identified as having TB may discourage a patient from getting tested, from accessing medical services and medications, and from disclosing their TB status to others. Furthermore, TB related stigma and discrimination substantially interferes with prevention efforts, disease management and treatment (Chesney & Smith, 1999). Several studies (Johansson *et al* 2000) have documented that stigma led to delay in presentation to health services and poor anti-TB therapy adherence. Furthermore, it was found that stigma associated with TB can also create tension and anxiety within the household.

Mark *et al* (2006:1914) hold that *"currently most of the public education programs focus on dissemination of knowledge, with the view that enhanced knowledge about a disease can reduce public bias against the disease"*. However, several research studies revealed that instilling knowledge is insufficient to produce attitude change. Rather,

specific cognitive and emotional representations of the disease need to be addressed and changed in order to reduce TB related stigma. Given the adverse negative effects of stigma on the lives of persons with TB, it is imperative that health policy makers and clinicians discover ways to reduce and ultimately eliminate stigmatizing attitudes and behaviors. Research on the mechanisms of stigma can help as a guide for the formulation of anti-stigma educational programmes (Mark *et al* 2006).

The findings of this study revealed that there is a significant burden of stigma in persons living with TB in rural areas of Nalgonda district as in other parts of the country and world, and stigma negatively affected the lives of people with TB. When TB occurs, shame seemed to engulf many patients and their family members. Respondents' feelings about their condition were characterized by depression, low self-esteem, isolation, shame, verbal abuse, and rejection by partners, sons or in-laws. Respondents explained that they were aware of the stigma surrounding TB, and believed that it is based on people's misconceptions about transmission of TB. TB related stigma occurs because of socially stereotyped beliefs that TB is transmitted through sharing clothes, utensils, bed sheets, toilets, bathrooms or being close to the patients. Golden *et al* (1998) made a clear distinction between *enacted stigma*, which is the actual discrimination that occurs, and *felt stigma*, which is the fear of such discrimination. Likewise, Anderson *et al* (2008:791) also grouped stigma into two broad categories: i) *felt* and ii) *enacted* stigma. The former refers to people's feelings about their condition and their expectations about other's reactions to them; the latter to the actual experiences of stigma and discrimination.

In this section an attempt is made to understand the enacted and felt stigma experiences of TB patients. Stigma experiences of study participants can be broadly grouped into two categories as suggested by Golden *et al* (2008 p791). The interviews with the patients provided numerous examples of felt or perceived and enacted stigma.

5.4.1 Felt Stigma Experiences

In this study patients' narrative accounts suggested that the fear of felt stigma was very high. Almost all the patients expressed a fear that they would be stigmatized if their state of health became public knowledge. Not surprisingly very few respondents spoke openly of their TB outside of their families. In fact, more than 90% of the respondents did

not disclose the diagnosis to people who had not earned the status of a close relative or friend. The general reluctance to disclose to outsiders was primarily due to perceived stigma. The parents of young patients, particularly parents of young women patients, took extreme caution not to reveal that their son/daughter had TB due to difficulties that may arise in marrying them. Because of the considerable social stigma associated with TB disease, for almost all the patients, non-disclosure was a first line of defense, and managing their TB status remained a matter of major concern for the patients, particularly for women patients, and often represented the single most important challenge in their daily lives. TB patients avoided using the TB label for fear of discrimination. TB status was kept secret in the belief that it would help minimize future experiences of enacted stigma. Almost all the patients mentioned other non-stigmatized illnesses (such as typhoid, ulcer, malaria, or skeletal disorders), as an explanation of their ill health to their neighbors and relatives.

The following patients' narratives illustrate the reasons for felt stigma. In the words of a 27 year-old auto driver:

If you've got heart disease or some other illnesses like that, people don't keep away from you. The minute they hear that you are a TB patient, they try to avoid you. For example, they may not give you water whenever you go to their home. People think less of you and look down upon you --You know, it is simply because of your low status in the community that they feel you got TB.

A 57-year-old farmer said:

When my community members come know about my condition, they will certainly discriminate me and may not give me respect. People don't like to admit that they have TB. You know, TB is a shameful and embarrassing disease. So people call it Upirithithulaku neeru vachindhi, which means wet lungs. Another common local term for TB is daggu dammu rogam (cough and breathlessness disease).

A 43-year-old father of a young girl patient said:

I didn't disclose TB status of my daughter to any body. I am worried that if her disease status becomes public knowledge, then my daughter would be teased or gossiped by my neighbors. You know, her friends may ridicule her, and may say, Oh, see she is a TB patient. You see, people may spread the news of my daughter's disease

status around, and may make it a big public issue. Furthermore, her friends and relatives may sever ties with her. I don't think my daughter could handle this situation. My wife had died of AIDS recently. I am also a AIDS patient. I had lost my eyesight partially. I believe that this disease was God-given and I had accepted positively. Every one is going to die one day, you see, I may die bit earlier than others. That's about it I want say to you.

A 44 year-old stone crusher said:

I cannot be open about my illness. I fear someone telling my condition to others. Hence, I had hidden my illness from others. This is the only option available for me. You know, in my community people consider TB a dangerous and dirty disease. I had restricted my social activities considerably, out of shame (ijjath) and fear that others would discover that I am ill. I didn't want people to say: Oh, see, he is a TB patient. I am afraid that people would discriminate me.

The issue of the fear of social consequences of TB (i.e., isolation from family members particularly in-laws, relatives, etc.) figured more prominently among the women patients. Few young married women reported that their in-laws may throw them from their home if the TB status was revealed to them. How one female patient, a 32 year-old, housewife, expressed the fear of social consequences of TB is illustrated in the following quote.

I kept nature of my disease condition secret from my mother and father-in-laws and neighbors. You know, maintaining secrecy was only strategy available for me to minimize the risk of rejection and discriminatory treatment from my in-laws and neighbors.

It is found that women faced greater internalized stigma, feeling unwelcome to participate in social events and in discussing their illness with neighbors. A 52-year-old, widow said:

I have had very less contact with my blood relatives since diagnosis of TB. I do not go to my relatives' house. If they know about my TB, they may think less of me. Basically, I think less of myself because I am suffering from a dirty disease.

This patient said that she is not participating in family functions to the extent she once did because she no longer feels comfortable.

A 48-year-old woman patient said that she avoided disclosing her diagnosis to her stepchildren for the fear of the adverse discriminatory reactions it might cause. One middle aged women patient said that she was not participating in social functions since the diagnosis. She said that she no longer feels comfortable to participate in social activities because of sense of guilt, shame, and embarrassment, and fears of discovery. She said:

If I go out, people will ask me several questions. I am afraid that they might ask me why I had become so thin and skinny. Once they come to know about my condition, I am afraid that they would discriminate me. You know, it would be better for me to keep it (TB) secret.

Some patients intentionally did not disclose their illness to their children because they feared that such news may cause emotional trauma and strain in their children. Thus, it can be argued that not disclosing TB status to others may be a protective behavior for TB patients who perceive high levels of stigma in the community. HIV-infected TB patients perceived a significantly higher level of perceived stigma.

Illness narratives of women are shaped by socially constructed gender differences in responsibilities and duties. The narrative accounts of social responsibilities indicated that a woman was obliged to support her husband with TB disease, but man did not have the same obligation to support his wife. A 43-year-old sweeper said:

According to our tradition, a woman has to fulfill several household responsibilities. If her husband suffers from TB, she has to look after him. You see, to take care of husband is her primary responsibility. But, she can't expect this kind of help from her husband if she falls ill with TB. In fact, I had seen cases where men sent their wives to their parent's home when they fell ill with TB. This is the situation in rural villages.

5.4.2 Enacted Stigma Experiences

In an open-ended question, study participants were asked to explain incidents of discrimination that they had experienced. Some patients reported that they experienced some form of discrimination and stigma from their own family members. Manifestations of stigma and discrimination ranged from abusive words to isolation. Anderson & Bury (1988: 8) argue that “*chronic illness may modify family dynamics and power, so that both*

the objectives and strategies of patients and families are, at certain stages of illness, in conflict with each other”.

A 52-year-old widow wept inconsolably and spoke of her experience concerning TB related stigma in the following terms:

My daughter-in-law kept separate plate, glass and bed sheets for me. My son, daughter-in-law and grand children stayed away from me. They are afraid of me. Whenever my grand children come close to me, my daughter-in-law takes them away from me. I was not allowed to take care of my grand children any more. You know, it hurts so much when members of your own family keep their distance from you. I am really suffering from mental depression, and I don't feel like living any more.

The moment my son heard about my condition, he said, Oh, I have two kids and so you can't stay in the house. He refused to allow me to enter his home. He was afraid that his children might get this disease. My son and daughter in-law kept a distance from me. They even told their children to keep a distance from me. No one comes near to me. I feel very bad about it. You see, I am a dependent and I am powerless. I don't have a separate house for myself. I had to confine my self to the veranda only. I feel so hopeless because I am alone. You know, I am worthless and depressed. (65-year-old, male laborer).

My wife discriminated me upon learning that I am HIV and TB positive. She looks down upon me and hurts me deeply with her abusive words. She yells at me all the time. She sees me as not having any value. She stayed completely away from me for the fear infection. I have the feeling that I am inferior in the eyes of my wife. Deep in my heart, there is an immense depression and sadness. I feel helpless because I don't get support from my wife. My wife doesn't like me much and this is very difficult to bear. I don't think my wife cares whether I live or die. You know, my mother takes cares of me. She is only the person in this world who takes care of my daily needs.

(Male, age 33, laborer)

You know, most of my relatives and neighbors severed all ties with me once they found that I am a HIV positive TB patient. Some of my neighbors did not allow their children to play with my children. Very rarely do relatives and neighbors ask about my health condition.

(45 year-old woman patient with TB and HIV)

My sister-in-law stayed away from me and my children. She (sister-in-law) didn't let my kids to play with her kids.

(36-year-old male laborer)

My wife and children completely abandoned me. They do not respect me. They do not listen to me anymore.

(A 58-years-old male)

Young married women patients reported that they had not disclosed their TB status to their in-laws because of fear that in-laws may tell others. The perception among the many young married women patients was that in-laws would subject them to discrimination, isolation, anger, verbal abuse, and in certain cases expulsion from their homes on the account of their disease status.

When I was diagnosed with TB, my mother-in-law had sent me to my mother's house. She told me that I had a dirty disease, and asked my husband to keep a distance from me. She had expressed a concern that her son's life would be in jeopardy if I stayed at their home. She forcefully had sent me to my mother's house. She had not shown any concern for my health and well-being.

(Female, 28 years-old, housewife)

Some women patients faced discrimination from their husbands. One woman patient, for example, who acknowledged a history of marital tension, described that her husband refused to provide foods items (such as eggs, milk and meat) essential for improving her health. She said:

My husband does not look after me well. He always listens to his mother and father. He neglected me badly ever since I was diagnosed with TB. He often asks me to get money from my father and mother to meet food and other expenses. You know, he is very abusive.

During focused group discussions some patients gave few accounts of cases where husbands divorced their wives on finding out that the other partner was suffering from

TB. Some female patients explained that that their illness resulted in marital problems. For instance, a 48 year-old woman patient said:

My husband often forces me to have sex with him. But, you know, it is very dangerous to have sex while suffering from this dreaded disease. Such an act (sex) could kill me. My husband abuses me physically and verbally in front of my adult children. You know, it is really shameful for me. He started to suspect my fidelity because of the fact that I had refused to have sex with him. What can I do? This issue has become a big nuisance in my life.

She said that her husband suspected her modesty because of the fact that she had refused sex with him. She cried and said that her husband basically suspects her modesty in front of her adult children. This upset her more deeply than her illness condition. From the above narratives it can be assumed that women are particularly vulnerable to TB stigma and its consequences because of the existing gender-related imbalances in social, cultural and economic power structures in rural society. In this study fear of Stigma associated with TB, however, was commonly observed to be more extrafamilial than intrafamilial. A large proportion of patients explained that their family members did not alienate them on the account of their TB.

5.5 Summary

The findings of this chapter suggest that patients linked causation of TB to various individual, social, natural and supernatural factors, and did not interpret their ill health as being due to objectively verifiable pathogens. It was apparent from the patients' illness causation narratives that patients focused on one particular cause when describing why they have had TB. Participants may have interpreted the question they were asked as seeking a single, major cause, and obliged with a single cause, irrespective of what they thought.

Overall, this sample of TB patients predominantly (55.4%) attributed causation of TB to individual factors. The interview extracts clearly suggest the varying and differing understanding of the causes of TB held by TB patients. Patients' illness causation narratives clearly demonstrated that for patients mind, body, and spirit are all interconnected, and disruptions in any one aspect can affect the health of an individual.

Studies from other parts of India (Ganapathy, *et al* 2008) and world (Banerjee *et al* 2000) have found that extra-marital contact and careless sexual behavior as a possible cause of TB. However, in this study, none of the patients attributed extra-marital sex as a cause of their TB, though in discussions with the community there was some mention of it. Despite the tremendous progress made in medical sciences in understanding TB causation, study results demonstrate the continued existence of folk theories of disease causation. Such responses were anticipated given these rural patients' low level of literacy, awareness and knowledge about TB causation.

It is clear from the findings of this study that besides the clinical burden, patients have to shoulder a high psychosocial burden associated with TB. The experience of receiving a diagnosis of TB appears to be a major traumatic event/crisis for many patients in this study. The narrative accounts of reactions and experiences of patients being diagnosed with TB indicate that the problematic aspect of having TB for many patients appears to be psychosocial rather than medical. TB diagnosis is followed by a series of challenges that intensely affect the patients psychosocially. Patients expressed a variety of negative emotional reactions such as sadness/depression/worry, shock/disbelief, fear of dying, fate, embarrassed, and relief. Almost all the patients regarded TB diagnosis as a depressive, shocking and devastating event. In fact, patients diagnosed with HIV and TB regarded the diagnosis as a death sentence. But almost all the TB patients got over their initial negative attitudes to a large extent, and became hopeful after being put on TB treatment, and consulting former TB patients, friends or other members of the lay network. For example, one patient said:

I am no longer as frightened as I was at the beginning of my TB. I came to know that it is not a serious and frightening disease. I have been managing my symptoms well for the last three months with the help of anti-TB drugs, and there is a considerable improvement in my health condition over the last few months.

The results of this study clearly suggest that stigma associated with TB is prevalent in the study communities. The stigma of TB had a profound negative psychological burden in patients living with TB. Stigma associated with having TB not only affected the sufferers but also their family members. Root causes of stigma and discrimination appear to be fear of TB infection, and misconceptions about TB transmission. Women

seemed to be the most affected psychologically. Women patients are particularly vulnerable to TB related stigma because of existing gender related inequalities in social, cultural and economic power relations in rural societies. Almost all the patients feared being rejected and discriminated by others because of their TB. An overwhelming majority of patients did not disclose their TB status to others because of fear of perceived stigma. Health care workers should make an attempt to allay patients' and their family members' concerns and fears about TB.

It was observed that non-tribal patients had high negative feelings toward TB patients than tribal patients as the latter mainly perceive TB as resulting mostly from natural and individual causes and hence the fear of TB is less. Also the tribal community is small and closed and TB is more accepted as it is a major health problem among them. Hence, social stigma and discrimination, gender differences and negative feelings about TB may be less among the tribals compared to non-tribal patients. Non-tribal people perceive TB both as a social and a physiological problem.

CHAPTER

6

Delays in Seeking Treatment, and Health-Seeking Behavior

In order to plan appropriate treatment interventions and reduce patient delays in seeking appropriate care, it is essential to understand factors influencing patient delays in seeking medical care for TB symptoms and the general patterns of treatment seeking for TB. This chapter is broadly divided into two sections: section one deals with socio-cultural factors influencing patient delays in seeking medical care for symptoms of TB. Section two discusses general patterns of health-seeking behavior of TB patients.

6.1 Beyond Demography: Factors influencing Delays in Seeking Medical Care

People do not always feel ill on the basis of a biologically determined abnormality nor is illness always backed by a corresponding deviation from a biological norm. It is on the basis of their experience or the feeling of illness, rather than the biological indicator, that people tend to seek therapy.

(Heap & Ramphele, 1991: 120)

Early diagnosis and prompt initiation of treatment are prerequisites for successful implementation of TB control programmes. Currently, in India, passive case finding approaches (PCF) 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' awareness of disease, and ability to recognize the early signs/symptoms of TB. Despite heightened global and national efforts to achieve case detection and treatment targets for TB control, delays in effective diagnosis and treatment initiation still persist which is a serious cause of concern for public health planners in India and other developing countries. Longer delays (especially of smear-positive TB cases), may exacerbate the disease among symptomatic individuals, increase their risk of morbidity and mortality from TB, and enhance the risk of transmission in the community (Long *et al* 1999). The median patient delay varies from 21 to 120 days in developing countries (Cheng *et al* 2005). Patient delays in TB diagnosis and initiation of treatment among women are a major concern. For example, Long *et al* (1999:388) argue that "*delays among women may have more adverse effects, as the health and welfare of children and other family members is closely linked to that of the mothers*".

Most studies (Lawn *et al* 1998, Rajeswari *et al* 2002, Wandwalo & Morkve 2000) were focused on influence of socio-demographic factors on delay in TB diagnosis and initiation of treatment. Investigators have found that factors such as age, gender, education, poverty and access to health care play an important role in patient delay. However, Dracup (1997: 259) argues that "*such research can help clinicians identify which patients are more likely to delay coming to the hospital, but it does not provide guidance for patient education and counseling interventions or community education programs to reduce delay*". In contrast, identification of socio-cultural processes used by patients to evaluate and interpret symptoms, and how patients make decisions to seek treatment is vital for TB control. For example, understanding of socio-cultural factors in delay may help health care workers and policy makers in providing counseling to the patients as well as to their families about the importance of early care. Furthermore, a better knowledge of socio-cultural factors influencing delay is vital for planning community education programs in order to reduce patient delays.

This section explores the influence of some of the socio-cultural factors in causing patient delay. The results of this study clearly demonstrate that delay is a serious problem among rural TB patients in general and extra-pulmonary patients in particular. Study findings showed that about 68% of patients waited two months or more before seeking

biomedical care. In the case of TB, a disease that is highly infectious, delays in seeking appropriate treatment means that the likelihood of infecting other people increases.

Participants of this study explained that a number of factors contributed to delay in seeking treatment for early symptoms. Some of these factors were: failure to recognize the significance of the initial symptoms, 'wait and see' approach, traditional disease causation beliefs, incorrect interpretation of symptoms, attribution of symptoms to less serious illnesses, self medication, negative family history for TB, alcoholism, low perceived susceptibility to TB, no interference with daily activities, economic and time constraints, herbal treatment, and absence of typical/classic TB symptoms. The results presented below suggest that delay in help seeking for TB symptoms is influenced by complex interaction of socio-cultural factors. Almost all patients gave multiple answers for causes of delay in seeking early medical care.

Reasons for Delay

6.1.1 Alcohol and Smoking related problem

The psychological characteristics of alcoholic patients seemed to influence patient delay in availing health services. Male respondents who had a history of high alcohol consumption and smoking interpreted early symptoms (such as cough, loss of appetite, breathlessness), as alcohol and smoking related problems as opposed to being associated with TB. A good example of this was presented by a 56-year-old farmer. When asked why he had waited for several months to seek formal health care, he told a story that represents the experience of a majority of respondents with a history of smoking and alcohol consumption. He said:

I first noticed the symptoms of cough roughly 11 months ago. I didn't take much notice of these symptoms at that time. I just thought it was one of those things that would clear up. I thought symptoms of cough were understandable, because I was an alcoholic and smoker for several years. You know, a lot of smokers and alcoholics experience cough quite frequently. And I just put it (cough) down to smoking and alcohol consumption.

Alcohol consumption appeared to be a chronic problem in this study area in general and tribal areas in particular. With the chronicity of alcohol consumption and smoking in the study region, it is possible that the presence of cough, loss of appetite and weakness has become ‘normal’ to alcoholics and smokers. Thus, it can be hypothesized that patients who had a history of alcohol consumption and smoking did not recognize their symptoms as being associated with TB, and hence delayed medical care. This is an important finding which concurs with other studies in different parts of the world (Auer *et al* 2000).

6.1.2 Perceived Susceptibility to TB

Perhaps one of the important factors that caused delay in seeking appropriate medical care could be attributed to patients’ as well as their family members’ lack of knowledge about susceptibility to TB. In fact, a large number of patients expressed shock and surprise on being told about their diagnosis of TB. The illness narratives of patients in this study indicated that patients did not perceive themselves to be at risk for TB. When asked “*Did you ever think that you could be at risk for TB disease?*”, more than 90% of the study participants said “No”. Delays in the decision to seek medical treatment occurred frequently because patients did not perceive themselves to be at risk for TB. A 49 year-old, male patient’s narrative suggests clearly how even the early TB symptoms can be misinterpreted if the individual does not view himself/herself at risk of TB disease:

I never suspected that I can have TB for two important reasons. One, no one in my family ever suffered from TB in the past. Second, I didn’t cough up blood/sputum, and I didn’t develop skinny body. You know, these are the important symptoms of TB. Hence, I didn’t think that I was at risk of TB.

There was a widespread belief among the study participants and community members that having TB in the family greatly increases their vulnerability to TB. A 43-year-old tribal patient said:

If TB was present in the family, it was believed that family members would get it, and conversely, if it wasn’t in the family, one wouldn’t get it.

Such perceptions among the patients caused considerable delay in seeking medical care.

6.1.3 Herbal Treatment

Several patients attributed their initial symptoms to a folk illness called *Pasakalu/Pasirikalu*. *Pasakalu/Pasirikalu* is a local name for jaundice. Of the 110 patients interviewed, 38% of patients consulted traditional herbalists prior to the diagnosis of their TB disease. Attribution of initial symptoms of TB to *Pasakalu* caused considerable patient delay. According to their cultural belief system, an individual develops *pasakalu/pasirikalu* if he/she consumes meat while suffering from illness. The symptoms of this folk illness include weight loss, weakness, intermittent fever, yellow or pale eyes, yellow color urine and pale skin. The treatment for *pasakalu/pasirikalu* is considered to be exclusively the domain of the traditional herbalist, and people stated that there is no biomedical remedy for it. As one 36-year-old, wife of a patient explained:

When my husband developed symptoms of pasakalu, I took him to the traditional herbal healer as the traditional herbal healer is the only source of treatment for this condition. I didn't take him to a biomedical practitioner because there is no biomedical cure for it.

Patients, community members and traditional herbal healers explained that delay in seeking herbal treatment for *pasakalu* worsens the disease condition, and may result in death. Consequently, patients who attributed their symptoms to this folk illness turned to traditional healers for treatment. It was noted that some patients had consulted more than one herbalist for treatment prior to the diagnosis of their TB. Three herbal healers were interviewed also attributed the main cause of the *pasakalu* to consumption of meat while suffering from illness. They advised their patients not to consume meat, yoghurt, brinjal, potato and oily foods for about one month. Herbal healers were against the use of any form of western medicine while under treatment for *pasakalu*. Treatment usually lasts for one month. Consequently, disease condition in patients who sought treatment from herbalists worsened, and this resulted in a considerable delay in receiving professional treatment.

Studies conducted on socio-cultural beliefs and perceptions of TB in different parts of the world have found that people attributed symptoms suggestive of TB to different folk illnesses. For example, a study conducted by Rubel & Garro (1992) among Hispanic communities in America found that many Hispanics attributed initial symptoms of TB to folk illnesses called '*wasting sickness*' or *grippe* or *susto*. In Philippines, Lieban (1976) noted that patients attributed their early respiratory symptoms to a folk illness called *piang* rather than to TB.

6.1.4 Traditional Disease Causation Beliefs

An in-depth study was undertaken to explore the health seeking behavior of extra-pulmonary patients with symptoms of lumps. It was found that the patients allowed their painless lumps to progress into advanced stage before seeking medical treatment. The study observations revealed that health care seeking decisions for lumps was influenced by various cultural beliefs and interpretations about the cause and management of lumps. Extra-pulmonary patients with lumps explained that they did not possess knowledge about the significance of the presence of a lump, they were not aware of the need for prompt medical diagnosis and treatment for painless lumps for various cultural reasons. For instance, 39 year-old woman, with three children, failed to seek professional advice for lumps for a period of 12 months as she convinced herself that it was just a normal lump caused by *heat-cold* imbalance in the body. She noticed a lump in the neck region approximately 12 months prior to the interview. However, she claimed she had really only started to take notice of it within the last six months since it had begun to interfere considerably with her life, forcing her to curtail her daily activities. She explained in the following excerpt that traditional beliefs about causation of lumps contributed to a considerable delay in seeking help.

Interviewer: *How long did you wait between finding the lump in your neck region and going to a qualified doctor?*

Patient : *I suppose roughly 12 months.*

Interviewer: *What did you think that the lump was when you first noticed it?*

Patient : *I didn't take much notice of these symptoms at that time I just thought that excessive exposure to sun and consumption of hot foods like mangoes could have caused it, you know. So, I didn't think it was anything serious. My neighbors and friends also told me that I needn't worry about it. They told me that impurities in the blood clump together in one place in the form of a lump. So I didn't think much about it.*

Interviewer: What finally made you to consult a specialist?

Patient : *You know, I had applied herbal extracts, allopathic ointments and bandages on the lump, but it did not disappear. But, then it began to increase in size. In addition to this lump, several smaller lumps also emerged in the neck region. Pain was unbearable. I could not perform normal daily activities because of pain and severe headache. On the advice of friends and neighbors I had consulted a specialist doctor. He told me that I had TB (extra-pulmonary).*

Many other extra-pulmonary respondents had similar stories to tell about delaying seeking care from the formal health care system.

6.1.5 Economic and Time Constraints

Economic and time constraints are also cited as reasons for delay in seeking care. For some respondents the disease was something which had to be actively resisted and fought back against. Resisting the illness does not involve pretending that there is no illness. Several patients said that they can not afford to submit to the illness for different reasons including economic reasons. For instance, a 38-year-old, lorry driver, said:

For majority of poor people, meeting the demands of daily existence are very important that little time is left to be worried about minor symptoms such as cough, cold or intermittent fever. Taking time off for consultation with doctor means lost work and income. You know, I can't afford to take time off for trivial problems because my whole family is dependent on me. You see, I will tell you the truth. I will not have money if I stop working. Without money, how can I support my family. I have no choice but continue working in spite of persistence of symptoms. You know, this is the fact of life for many poor people.

Because of family and financial pressures, people continue to go to work unless symptoms are debilitating and interfering with daily activities. In this study woman patients explained that the demands of household work, caretaking of children and other role responsibilities caused them to postpone seeing a qualified doctor until the symptoms

were severe. There appears to be a gender dimension to seeking health care with women reporting longer delays than men.

6.1.6 Absence of Typical TB Symptoms

There is a universal belief among the study participants that TB devours its victims badly. It begins inside and then slowly eats the body muscles and organs particularly rib bones. One informant, for example, said “*it (TB) eats away the bones and muscles*”. The idea that TB eats away the bones and muscles gives an indication as to why people look skinny, and lose much weight when they have the disease. Such beliefs did not encourage patients to seek early treatment. Respondents and community members equated TB with coughing up blood and/or sputum, a skinny body and wasting away. The belief that having TB disease must involve coughing up blood and/or sputum, and having skinny body meant that the early symptoms of cough, intermittent fever or loss of appetite are considered insignificant. The following quote illustrates how one patient described absence of classical symptoms of TB caused delay in seeking medical assistance:

You know, I get cough and cold every now and then. And I believed that these symptoms would disappear without much intervention. I thought that symptoms were too mild to be TB disease. You know, if I had continuous cough, coughed up blood stained sputum, and lost considerable weight (thin body), then I would have thought that it was TB disease. You see, I didn't think that I had TB, because my ribs and muscles were in very good condition. You know, the definitive and typical symptoms of TB are: persistent cough, coughing up blood/sputum and thin body and ribs. If we see some of these symptoms in an individual, we can certainly recognize that he/she has TB.

6.1.7 No Interference with Daily Activities

Many patients believed that they were dealing with a recurring ordinary cough and not TB or any other serious illness. The symptoms of TB are initially similar to other diseases and it is not unusual for patients to consider that the symptoms of cough, weakness or intermittent fever could be simple to treat or resolve. Patients saw their initial symptoms as harmless, and symptoms did not interfere with their daily activities. Such a perception is reasonable for various reasons. For example, people like to think of themselves as normal, and slight deviations from normal body functioning are in

themselves quite common. Having ‘cough’ would not usually be viewed by most people as anything other than normal. The frequency with which respiratory infections occurred in the study community influenced health seeking behavior. It was observed that respiratory infections were very common occurrences in the study area, and the frequent occurrence of respiratory infections in the community appeared to prevent patients from interpreting their cough as an early symptom of TB. However, not until their symptoms became significant and interfered with daily tasks (such as farm work) did the respondents begin to consider that they might have been experiencing some major illness.

A 45-year-old patient, who experienced symptoms of cough, loss of appetite and intermittent fever for 8 months prior to diagnosis, explained how his symptoms interfered with his daily activities and forced him to consult a qualified health care professional:

I first observed symptoms of cough, loss of appetite, intermittent fever 8 months prior to diagnosis. Initially, I thought these symptoms were trivial, harmless, and do not require medical action. But four months prior to the diagnosis, I felt that my cough wasn't a normal one, and I believed that there was something really wrong with my health. Symptoms of cough and breathlessness got worse and worse overtime. These symptoms considerably crippled me, and interfered with my daily activities. I became very pale. It was only when my condition deteriorated that I became concerned about my health. First I purchased cough syrup from medical shop and used it for several days but the symptoms didn't disappear. Later I had consulted a couple of local medical practitioners without much success. Later, I had consulted a chest specialist on the advice of my family members and friends. Sputum and x-ray examinations were carried out at this clinic, and based on the investigations they told me that I had TB.

From the above account it can be concluded that this patient's condition came to the attention of the formal health care system only when his symptoms began to interfere with his daily activities thereby forcing him to consult a qualified health care professional.

6.1.8 Stigma

Although literature (e.g., Auer *et al* 2000) points primarily to stigma as being a major impediment to early diagnosis and treatment, in this study, however, only one patient mentioned this as a factor. While this study did not find stigma to be a major

reason of patient delay in seeking health care, it may need more intensive interviews and a larger sample to emerge as a direct factor for delays in seeking health care. At an indirect level, stigma may be probably influencing denial of TB and hence delays in seeking care, which patients may not be willing to admit or report.

6.1.9 Self Medication

Prolonged self treatment practices also caused considerable delay in seeking care. As mentioned in earlier paragraphs many patients did not recognize their initial symptoms as being associated with TB, instead they associated their symptoms with minor illnesses such as cold or flu. Hence, patients resorted to self treatment (over-the-counter-medicines, herbal teas) to get relief from symptoms of cold and fever. Some patients in this study chose to wait and see, and this choice was maintained by a hope that their symptoms would resolve without much medical intervention.

However, it should be noted that patients were not the only collaborators who delayed the diagnosis of TB. Most RMPs, private allopathic medical practitioners and/or traditional healers when consulted for the symptoms of cough, weakness and intermittent fever offered normalizing definitions such as ‘nothing to worry about’. Such kind of normalizing definitions caused delay in diagnosis of TB. For example, a male patient (spinal TB patient) said he had been diagnosed as having several other medical conditions including anemia and musculoskeletal abnormalities. His doctors did not pursue the symptoms as a sign of extra-pulmonary TB. When asked if any of the medical practitioners told him he might have TB. He said no. He explained that he had seen five doctors including qualified professionals before being finally diagnosed. Some other patients received diagnoses other than TB. The most common alternate diagnoses were malaria, jaundice, typhoid or asthma. Such false diagnosis also contributed to delay in the diagnosis of TB.

6.2 Health-Seeking Behavior

Patients' interpretation of symptoms, decisions on when and from whom to seek help, and their response to medical regimens conform to their own explanatory model of illness.

(Rubel & Garro 1992:628)

This section is further divided into: i) general patterns of health-seeking behavior of TB patients; ii) complementary and alternative therapies; and iii) use of complementary and alternative medicine by patients with TB.

General Patterns of Health-Seeking Behavior of TB Patients

According to Paul (2006:3) health seeking behavior refers to the sequence of actions that sufferers and/or their family members “*undertake in order to recover and/or seek relief from a perceived or actual illness*”. A better awareness of factors that make people decide Why, When, and Where to seek care can play an indispensable role in improving the treatment programs that focus on TB management and health education in communities. Understanding different socio-cultural beliefs and behavioral factors that influence health-seeking behavior in a pluralistic setting has important implications for providing effective care, reducing patient delays, and improving treatment adherence.

Like in many areas of the world, medical pluralism or the existence and use of multiple therapeutic systems is the characteristic feature of health care in Nalgonda district. Healing resources in Nalgonda reflect a ethnic, religious and cultural diversity that exists in this district. A wide variety of treatment alternatives available to people in this district include self-care remedies, biomedicine, pharmacists, RMPs, ayurveda, homeopathy, unani, magicians, fortune tellers, diviners, church priests, Muslim dargah, and Hindu temples and shrines. Sick individuals actively try different treatment options exclusively, simultaneously, or alternatively in the hope of getting a speedy cure. Paul (2006:3) argues that “*because of the existence of several distinct therapeutic systems in a single cultural setting, with their distinctive ideologies about disease causation and the*

nature of medical intervention, health-seeking behavior in such societies is a complex process". Patients and their family members move freely between one sector to another, as if different sectors of health care system are complementary rather than contradictory. In Nalgonda district, as in all parts of India, use and practice of folk remedies has historically been one the most important forms of responding to ill health. The elements of folk medicine and the use of folk remedies are the part of oral tradition of Indian society, transmitted from one generation to another. Folk medical therapies are widely utilized in all parts of India including in rural areas of Nalgonda district.

As mentioned in Chapter 1, sick individuals seek help from three overlapping sectors: (i) popular or lay sector, consists of family members, members of social network, and patients themselves; (ii) the folk or traditional sector, consists of traditional healers; and (ii) the professional sector, consists of professionally trained practitioners of biomedicine. Broadly speaking, Kleinman's tripartite model of the health care system - popular, folk and professional sectors is applicable to the health seeking behavior of TB patients of Nalgonda district. The specific aims of this section is to understand patients' choices in seeking treatment options in the context of the local health care system and culture of rural Nalgonda district.

It is observed that all the patients had discussed their symptoms with family members, friends and neighbors, and received guidance from them in the form of treatment suggestions and explanations about possible causes of illness. In the study area, health care seeking behavior usually begins within the household, where the symptoms of ill health were initially perceived, described and evaluated, and treatment activities initiated. In this study self-care was the most common first step in the health seeking behavior process among almost all the study participants. Levin (1977:115) described self-care as "*a process whereby a lay person can function effectively on his or her own behalf in health promotion and decision making, in disease prevention, detection and treatment at the level of the primary health resource in the health care system*".

More than 85% of patients explained that they used some form of self-care remedy to get relief from their initial symptoms. Over-the-counter drugs (e.g., pain relievers, muscle relaxants, fever reducers) and traditional herbal teas were very popular self-care remedies. Patients' narratives revealed that a variety of factors influence the use of self-

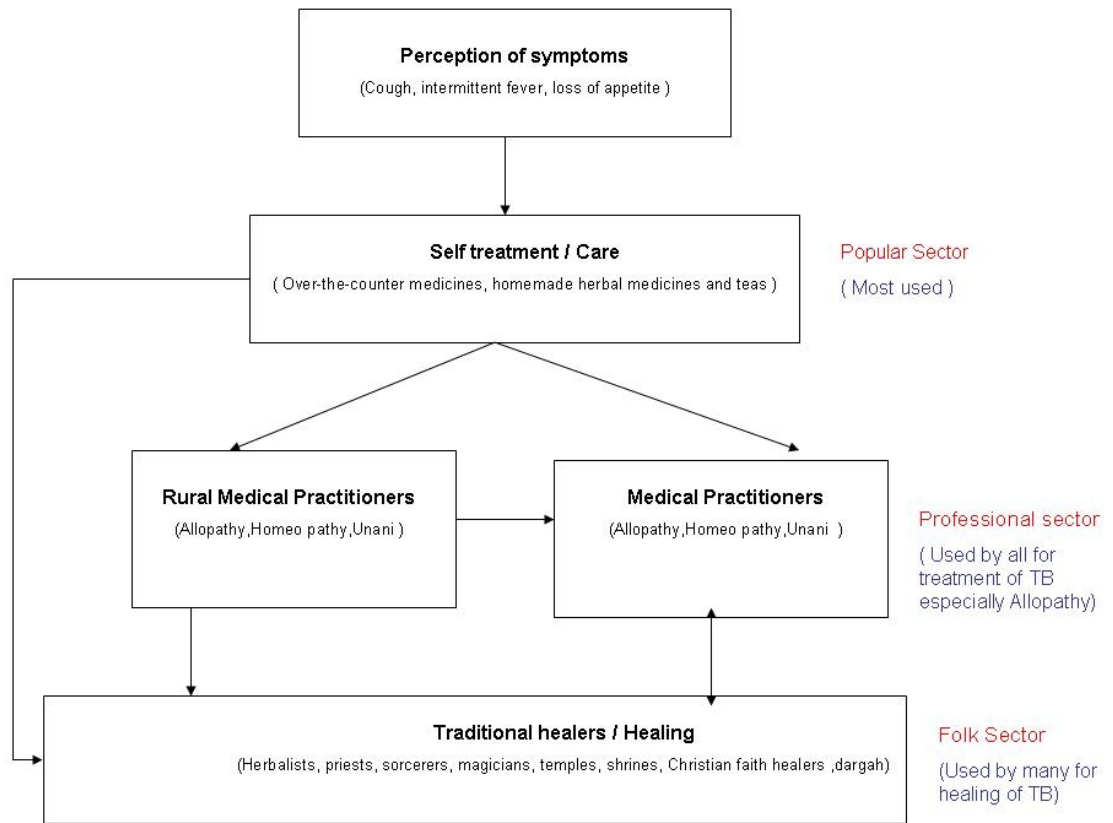
care treatment including greater accessibility, convenience, lower cost of medical care and transportation, less time consuming, non-severity of symptoms, and past experiences with symptoms of cough, cold and fever.

A 30-year old, farmer, talked about the motives for resorting to self-care. He stated:

You know, I thought that my initial symptoms were minor and trivial. I get cough, cold and fever every now and then. In fact, fever, cough and cold were common routine occurrences in my village. Whenever I get cough and cold, initially I do not consult a doctor. You see, the consultation fees, combined with costs of medication and transportation would cost me at least 100 rupees, but self treatment will cost me only 20 rupees. Why waste money and time in consulting professionals when same medicines can be obtained cheaply and easily from medical stores.

Study results indicate that self-treatment was the most common response of study respondents. This finding is similar to other studies conducted by several workers in different parts of the world (Rubel & Garro, 1992; Auer *et al* 2000). Igun (1979) attributes two possible reasons for the evolution and adoption of self-treatment. First, from the peoples experience point of view, it has been established that self-care remedy works. Secondly, of all the available alternative treatment options, self treatment is the cheapest in terms of time and money and is the most convenient. It has been observed that self-medication in the form of dietary modifications, massage, and over-the-counter drugs usually continue throughout the process of health-seeking behavior. The patients' reliance on members of social network for guidance during the course of illness is very common. When the symptoms persisted or progressed despite self-treatment, patients switched from self-care treatment to other alternative sources of health care. Majority of the patients (74%) approached RMPs as the first point of contact for treatment. The remaining 26% patients consulted allopathic practitioners and others (Table 18).

Fig. 32. General Patterns of Health-Seeking Behavior of TB patients in Rural Nalgonda.



Source: Based on Kleinman's Model

Proximity, greater convenience, easy access, low cost, better interpersonal relationships were the most important reasons mentioned by the patients for choosing RMPs as the first point of contact. It is obvious that in seeking professional health care, most patients approach the Allopathic system for treatment, whether through RMPs and then doctors.

Table. 18. First Health Seeking Source of Patients

Source	N	%
Local R.M.P	81	74
PHC	06	5.4
Private Allopathic doctor	23	20.9
Traditional herbal healer	00	00
TB hospital	00	00

Persistence of symptoms or reoccurrence of symptoms over a period of time, despite treatment by RMPs or allopathic practitioners called for a review of symptom definition in the case of 42 (38%) patients. During this stage, lay consultation was very common. Patients and their family members discussed symptoms and treatments adopted with friends, neighbors and relatives. At this stage, 42 patients attributed their symptoms such as loss of appetite, intermittent fever and loss of weight to a folk illness called *pasakalu*. These patients sought treatment from herbalists prior to the diagnosis of their TB. However, the consultation with the traditional herbal healers was short lived. All the patients switched to biomedical professionals as their physical health deteriorated. Most of the patients who consulted herbalists explained they were not satisfied with the treatment. If the medical professional consulted did not cure the illness, other specialist doctors were consulted until the proper diagnosis was made. Majority of patients approached private allopathic doctors (75%) compared to government health care providers for various reasons. In the study area, dissatisfaction with the government health facilities and health care providers was widespread among the patients and community members. One patient explained that government medicines are of low quality and he remarked:

Yow know, government doctor prescribes same kind of medicines irrespective of illness type and severity. They will give you white colored tablets. I don't think they are of good quality. That's the reason I do not go to government hospital.

For majority of patients in this study, the diagnosis was established at private clinics/nursing homes. However, almost all these patients switched to government sector after the diagnosis, because they couldn't afford costs of medicines, consultation, and diagnostic charges in the private sector. According to Jaramillo (1998:143) “*most TB patients in Cali, as everywhere, are among the poorest people, and for them having to buy an ‘anti-cough’ syrup or having to pay for an unnecessary chest X-ray can make the difference between having something to eat or not*”. Patients mainly opted for

government TB care services because TB treatment and diagnostic services were provided free of cost.

After starting the TB treatment, 17% of the patients consulted faith healers (such as witches, diviners, or priests) as a complementary to biomedical TB treatment. Patients who resorted to faith healers reported that their confidence in the efficacy of TB treatment and health care workers waned considerably for various reasons including, long course of TB treatment, side-effects, little relief from the symptoms, and beliefs regarding the causes of their TB. These patients initially attributed the etiology of their TB illness to individual and natural factors, but later gave different interpretation when there was little improvement in their health condition. When TB symptoms are not cured rapidly, its cause and management is shifted to a different realm, social and supernatural (e.g., divine retribution) causes were blamed. According to Hielscher & Sommerfeld (1985:480) traditional illness causation concepts “*are unstable and are adopted or discarded in the course of the search for treatment. It is argued that if no relief is obtained, then the illness must have been wrongly classified. Consequently, a new classification and a new treatment follow*”.

Such changes in initial tentative categorization of illness from individual and natural categories to social and supernatural categories is not unique to the people of Nalgonda district, but are reported in number of studies in various parts of the world (Ten *et al* 2008; Mochache & Nyamongo 2009). There is a widespread belief among the rural people of Nalgonda that biomedical treatment is ineffective when dealing with illnesses perceived to be caused by witchcraft, evil eye or divine retribution. It is believed that such an illness will not be cured permanently and effectively as long as the witches, evil spirits, and/or deities are not appeased and propitiated appropriately. This is related to their cultural belief that evil spirits and/or angry deities are responsible for certain illnesses and therefore, no other treatment would be effective until these are dealt with.

Over 95% of all respondents used some form of alternative therapies (such as prayer, massage, special foods or faith healing). All of the patients tried multiple treatment strategies. Switching between different health care providers was very universal. If the medicines given by one health system or provider do not relieve symptoms, patients often seek treatment from other health care system or another health

care provider. Patients reported that their choice of care is influenced by a wide variety of factors such as attribution of causes, effectiveness of the selected treatment strategy, accessibility and affordability of treatment options. Outcome of the selected treatment is one of the important indicators for continuing or discontinuing the treatment. Wife of a patient said:

I think if herbal treatment works, it should show some results within fifteen days. Since we have tried it for one month and have not observed any relief from symptoms, I think we need to think about a different treatment alternative, and there is no need to continue with the herbal treatment.

When the patients perceived that there was no relief in their symptoms, they approach another health care provider or another resource, depending on their accumulated knowledge and suggestions gathered from friends, family members, neighbors and others in the community. For example, when the patients and their family members believed that an exposure to cold weather might have caused symptoms of cough and cold, they tried to treat with hot foods and over-the-counter medicines so as to restore the balance between hot-cold qualities in the body. Similarly, when the patients perceived the causes as supernatural, they resorted to magico-religious healers. Likewise, when the patients believed that consumption of meat during an illness episode might have caused *pasakalu*, they resorted to herbal medicines. It can be argued that treatment choices evolved during the health-seeking process as the patients and their family members gained more knowledge of symptoms, acquired more information from social network and health care providers, and gained more experiences interacting with health care providers, herbalists, RMPs, or magico-religious healers.

There are no major differences observed in treatment seeking patterns between male and female patients, and between tribal and non-tribal, Muslim and Christian patients regarding the broad choices of modern and traditional care. It can be argued that a clear sequence or hierarchy of health care system does not exist. Patients freely move from one sector to another sector until they are cured or feel relief from the symptoms, and thus, health seeking behavior is a dynamic process and pluralistic in nature. While medical pluralism is popular, it is also evident that all TB patients do engage with the Allopathy system on a longer basis for treatment of the disease.

6.3 Complementary and Alternative Therapies

Ho *et al* (1984:751) argue that “*patients with chronic conditions are more prone to change to another form of treatment especially when the persistence of illness is attributed to ineffectiveness of the previous treatment method used*”. For many people, seeking help for health or illness includes several options in addition to orthodox medical care. Alternative and complementary medicine is a general label applied to some healing approaches that do not fall within the framework of scientific medicine. That is, the approaches employed are either an alternative to or complementary to modern medicine (Levinson & Gaccione, 1997). Alternative medical practices are highly diverse include faith healing, divination, magic, sorcery, possession, shamanism, exorcism, hypnosis, laughter therapy, mental imaging, herbs, vitamins and mineral dietary supplements, chiropractors, massage, touch therapy, acupuncture, etc. Alternative therapies often renew hope in patients with a fatal disease or a serious chronic illness that does not respond to conventional treatment. Today, a considerable number of patients with cancer, arthritis, chronic back pain, HIV, gastrointestinal problems, chronic renal failure, etc., are choosing alternative medicine in addition to conventional medical care, or instead of it (Eisenberg *et al* 1992).

The Effectiveness of Alternative Healing

Several medical anthropologists and sociologists (Mutambirwa, 1989; Al-Krenawi & Graham 1999; Freund *et al* 2003; Cant & Sharma, 2004) suggest that traditional healers have several advantages over western trained doctors for various reasons. First, traditional or unorthodox healers attribute illness to wider cultural, social, psychological, spiritual and biological realities. As a logical sequence, indigenous healers allocate adequate amount of time listening to their patients’ concerns about the socio-cultural, psychological, spiritual and biological circumstances that led to their illness. Second, unlike biomedical medicine, alternative therapists provide satisfactory explanations for the questions Why me? Why now? Traditional healing basically seeks to provide a meaningful explanation of illness (Lupton 2003). Third, traditional healers provide

comprehensive health care by addressing problems associated with a person's physical body, the mind-soul, as well as social and spiritual environment (Mutambirwa, 1989). Fourth, in most cases, traditional healers commonly share the same language, culture, world-view (Al-Krenawi & Graham 1999), dialect, idioms and other communication symbols, both verbal and non-verbal of the communities in which they live. In other words, both the healer and the client subscribe to the same cultural beliefs and the world view. Traditional healers' prescriptions are culturally meaningful and psychologically effective. The relationship between traditional practitioner and client is characterized by mutual respect.

Fifth, a traditional healer approach is usually is a holistic one, in the sense that healing involves the whole person, including his/her physical, psychological, spiritual and social aspects, and relationship with other people, with the natural environments and supernatural forces. In other words, traditional healers take a whole person in to account, not simply the diseased organ of the human body which is the focus of biomedical practitioners (Mutambirwa 1989). Patient is not treated in isolation from the rest of his/her social group. Family members are almost always involved, and the healing process is further facilitated by including members of the community. The aim of healing is removal of anxiety in the individual. According to Freund *et al* (2003:191) traditional healing *"utilizes symbols and ritual action, meaningful to believers or members of that culture that can produce change on several levels: social, bodily and emotional"*. In this way, healing meets psychological and emotional needs and leads to successful recovery on various levels. In addition, traditional healing has a dichotomous role: it is designed to promote the well-being of the individual and to maintain the continuity of the way in which society functions.

Thus, folk healers have several advantages over western doctors, who are often separated from their patients by social class, economic position, specialized education, and sometimes cultural backgrounds. The relationship between traditional and professional healers tends to be marked by mutual distrust and suspicion. In the western world, modern medicine views most traditional healers as 'quacks, 'charlatans or medicine men, who pose a danger to their patients' health. But, it is crucial that medical practitioners must have knowledge of what kind of alternative and complementary

therapies (e.g., homeopathy, ayurvedic medicine, unani, chiroprathy, faith healing, herbal healing, dietary modifications, etc.), their patients may be using in addition to the prescribed and advised biomedical therapies and health management plans. Health care professionals must recognize the fact that the resources of popular and folk sectors constitute the most important aspects of local health care system.

According to Mutambirwa (1989:931) *“the Western and traditional medicine dichotomy is rooted in the fact that modern medicine is viewed as unsurpassed in concerning itself with the physical or bodily aspects of health. It is viewed as specializing in the relief of physical or bodily suffering by prescriptions of scientifically prepared medicines in injections, or surgical interventions of which local traditional medicine has little or no experience. On the other hand traditional medicine is viewed as providing comprehensive health care services in which the individual in his totality is treated. These include health problems associated with a person’s physical body, the mind-soul, the social and spiritual environments”*. Several studies indicated that individuals diagnosed with chronic long standing diseases such as TB often turn to some form of traditional medicine in addition to western medicine in the belief that such therapies might heal their illness. It is vital to understand an essential distinction between healing and curing. *“A cure is an externally applied medical intervention that removes all evidences of the diagnosed disease. Healing is an internal process of recovery that takes place on the physical, emotional, mental or spiritual level and results in the person’s having a sense of being complete in balance or harmony with self and surroundings”* (Chez &Jonas 1997:1157). The culturally sensitive provision of health care services requires that medical practitioners be aware of use of alternative medical practices among patients.

6.3.1 Use of Complementary and Alternative medicine by Patients with TB

Several medical anthropologists have argued health care workers should make an effort in understanding the reasons why patients with TB seek alternative treatments. Such awareness is helpful in identifying the unmet needs of patients and limitations in the conventional medical care. In response to the question, “what types of alternative treatments are used in the management of your TB illness?”, the respondents reported

using a variety of alternative treatment strategies to cope with their illness (Table 19). It can be hypothesized that use of alternative treatment methods by TB patients may be related to socio-cultural congruence. That is, “*alternative therapies are attractive because they are seen as more compatible with patients’ values, worldview, spiritual/religious philosophy, or beliefs regarding the nature and meaning of health and illness*” (Astin 1998:1548).

Table. 19 Nalgonda: Alternative Treatment Practices related to TB

Religious activities (e.g., Prayer).
Restriction in use of alcohol and smoking
Homemade remedies (e.g., ginger tea, hot baths).
Use of protein rich diet (e.g. meat, eggs, milk).
Resort to magico-religious healers (e.g., witches, diviners, priests).
Avoidance of sex by married patients
Massage
Use of non-prescribed over-the-counter medicines (e.g., pain relievers, cough syrup, fever- reducers)
Avoidance of certain foods (e.g., potato, sweet diet, brinjal, dry fish).

For almost all respondents, having TB illness meant modifications in life styles (Table 20) and daily behavior. What they have done routinely prior to the onset of their illness, is now modified to recover from the illness. For example, a 44-year-old patient said:

I was very much concerned about my cough and breathlessness conditions. My family members and neighbors motivated me to restrict the use of alcohol and smoking. You know, I used to take alcohol very heavily and I was a chronic smoker. I quit smoking and alcohol after being diagnosed with TB. I am feeling much better now. You see, adoption of a healthier lifestyle helped me and there is a huge relief from symptoms of cough and breathlessness now.

Table. 20. Lifestyle changes of TB patients

Life Style Changes after diagnosed with TB		TB patients
Food	Recommended foods	Potato, brinjal, dry fish, sugar, guava, custard apple are restricted during the course of illness. It was believed that consumption of these foods would aggravate cough, fatigue, skin rash and breathlessness.
	Special foods	Meat, eggs, milk and leafy vegetables are recommended for building up physical strength.
Tobacco and alcohol consumption		Most patients refrained from consuming alcohol and cigarettes. It is believed that mixing alcohol and TB drugs can be detrimental to the health, and could result in death.
Sex (Married patients)		Married patients avoided sex during the course of illness. It is understood that having sex while suffering from illness could deteriorate the patient's health condition considerably, and may result in death.
Social Relationships and activities		Most patients withdrew from social activities while coughing symptoms existed and resumed normal relationships when the symptoms subsided considerably.
Working		Majority of patients stopped working for 2-3 months and then resumed for economic reasons.
Prayer		Majority of patients employed praying as an important coping strategy. Patients coped with their predicament by putting their trust in god.
Massage		Massage is a regular practice among all the patients. Patients employ massage to get relief from stiffness and soreness in the joints and muscles.
Over-the-counter drugs		Almost all the patients use over-the-counter medicines (e.g., pain relievers, fever reducers) regularly to deal with symptoms of fatigue, fever and cough.

A high percentage of patients (>90%) made use of prayer, special foods and massage to address their illness related problems. The most commonly cited health problems treated with alternative therapies were cough, fatigue, headaches, sore throat, sprains/muscle strains, and spiritual. Few case studies are presented below in order to illustrate how patients understand use of alternative therapies- the meanings they attached to these therapies, why they found them appropriate, and what they expected to get from using these therapies. Major importance is placed on studying patient's actions and rationale in terms of the meanings that they constructed for their actions. As Calnan (1987:8) argues "*the lay person is typified in this approach as one who is active and critical, who has his or her own complex system of ideas about health and its maintenance and illness and its management, who manages their own health requirements, and who is discriminating in their use of professional medical advice and expertise*".

Prayer

Prayer is the most universal practice in all religious systems. Generally prayer, understood as a human communication with divine and spiritual entities, has been present in most of the religions in human history. According to Banzier *et al* (2006) an individual who prays attains a feeling of inner peace, of relief, and of power and support. Banzier *et al* (2006:103) further contend that "*prayer conveys and reinforces various meanings of life and life events and as a result prayer makes life meaningful, endows people with strength, and makes them feel good*". Prayer was the most important complementary therapy employed by the study patients, with almost all patients seeking psychological benefits from this therapy (most commonly having a sense of control over their illness). Patients offered prayers in the hope that gods/goddesses would listen to their appeal for help in overcoming illness and adversity. In this study, several patients explained that they remembered God for help, and employed prayer as an important coping strategy to deal with illness. Women patients in particular reported that they coped with their predicament by praying and putting their fate in God's hands. There was a wide spread perception among the study participants that prayers contribute to well-being of people in number of ways. Patients' narrative accounts suggested that prayers played an

indispensable role in enhancing hope and coping abilities. In the study area it was observed that women patients prayed and worshipped god more often than male patients.

Case Study 1 - Prayer

A 45-year-old, widow, HIV positive TB patient, attributed her recovery from illness to prayer. She described it this way:

I have been using TB medicines for the last three months, but there was little improvement in my condition. I was very ill and could barely walk and even feed myself. I got weaker and weaker over a period of time. Every one thought that I will not survive from this horrible illness. I had decided to visit a Christian faith healing church after hearing miraculous powers of Jesus Christ. I went to a Christian faith healing church at Karnapuram, Warangal district, known for curing hundreds of people afflicted with serious illnesses such as cancer, AIDS, TB, witchcraft, etc. At this stage, I put my life in the hands of Jesus Christ, and prayed for his help. I became very confident and hopeful after attending the prayers. Prayers brought me inner peace, enhanced my self-confidence. I remained confident that Jesus would listen to my appeal. On the first day, I made a deal with Jesus. If he would alleviate my suffering, I would convert to Christianity. I lived in the church compound for about one week and prayed every morning and evening. Since then, prayer has become an important part of my daily life. You know, I prayed quite a lot and something inside me kept saying that Jesus would come to my rescue. Few days after attending the prayers at faith healing church, my health condition improved markedly. Jesus Christ certainly heard my appeals and petitions. You know, if I hadn't prayed, I would not have survived. Then, my children would have become orphans by now. I am grateful to Jesus for his miraculous healing powers. You know, I had honored the agreement made with Jesus, I had converted to Christianity. Now, I am a devoted a Christian. I feel that Jesus had performed a miracle in my life. I am indebted to Christ for his help in saving me and my children.

Karnapuram Christian Faith Healing Centre

Every Saturday faith healing service takes place in a church compound at Karnapuram village which is about 35 kms from Yadagirigutta TB unit. Father of the church (Balaiah) calls himself a servant of God. Every Saturday hundreds of people from different parts of Andhra Pradesh visit the Church to attend healing ceremony. Before the start of the healing ceremony, people sing religious songs, and after completion of songs session, father starts prayer in which he presents Jesus Christ as saviour of the world. He reads verses from the bible and explains the miracles of Jesus. He says--- 'Jesus is almighty', 'He forgives your sins', 'He changes your life and puts you in a right path'.

During the healing ceremony father makes it clear that true believers of Christ will be cured from ailments and other problems if they are willing to pray Jesus daily. After the prayer, father asks some sick persons if they already notice recovery. For example, has your knee pain already disappeared? he asks a man who suffer from arthritis. Later, he asks people to gather near him. Many people with different kinds of problems come forward and queue up in front of the father. Father touches them all one by one. During the ritual of laying on of hands, he prays for the patients and assures the people that Jesus will certainly help them in overcoming from their problems. During the ritual of laying on of hands, he says---- '*Jesus will heal you*', *Pray to Jesus, he will take care of you*'. Father blows the prayer on to water and the patient and his/her family members have to drink it. After the laying on of hands ceremony, the healing service is rounded off by singing religious prayers. Every visitor is asked to pray to Jesus.

Case Study 2 - Prayer

A 46-year-old farmer, attributed his recovery from illness to prayer. He said:

I had spinal pain for few years. I had applied herbal extracts and ointments on the body for a long time. There was some relief. But then, I noticed a few months ago that there was a lump on my spinal region just above the buttocks. I just thought that dirty blood might have accumulated in the form of a lump in the body. You know, I am a farmer and worked strenuously in the hot sun for the most part of my life. Excessive exposure to hot sun could have spoiled my blood, and this spoiled blood could have accumulated in the form of a lump. In initial stages, I didn't think it was anything serious. But, then the lump began to increase in size. I went to a traditional herbalist in my village, but he couldn't heal me effectively. The symptoms of pain and fatigue worsened and crippled me badly. I went from one medical practitioner to another, none of them seemed to know what was wrong with me. I was desperate and terrified. I had lost considerable weight and paralyzed partially. I could barely stand and walk, and I was bedridden. Pain was unbearable. I had developed numbness in my both legs. My family had been tormented for several months without a proper diagnosis. On the advise of some community members, I went to a specialist doctor in Hyderabad. I was diagnosed for spinal TB and given anti-TB medicines. I have been using TB medicines for the last three months. These medicines provided some relief to me. But, still I was bedridden, and there was no relief from numbness in my legs. One night when I was sleeping, God spoke to me and told me that I should visit shrine of lord Shiva in Cheruvugattu village, and offer prayers. My wife took me to the shrine of lord Shiva, and we stayed there for few days. You know, the temple of lord Shiva in Cheruvugattu is a place of last resort for me. I and my wife prayed fervently, many times a week. I put my faith in lord Shiva and prayed for

his help. By the grace of lord Shiva my symptoms went away, and I am much better now. Before coming to this shrine we went to many doctors and hospitals. No good came of this, though it cost us dearly in terms of money, time, and loss of wages. I honestly believe that by the grace of god, my health condition improved greatly. Praying god is, for me, an important part of my daily life and a source of emotional comfort.

Case Study 3 - Prayer

A Hindu laborer, in his early fifties, attributed his recovery from illness to prayer in a Dargah. He said:

I have been suffering from fatigue, chest pain and intermittent cough and fever for the four months. Initially I thought it was an ordinary fever. A local RMP examined me and prescribed injections and tablets for two weeks. But I didn't get better. My family members discussed my symptoms with one of my neighbors. My neighbor told me that I am suffering from pasakalu. I went to an herbalist, and used herbal medicines prescribed by him for one month. But there was no respite from symptoms. In fact, my health condition worsened. The local RMP referred me to a chest specialist in Hyderabad who examined and told me that I had TB. My immediate response was of complete disbelief. You see, none of my family members suffered from TB before. Nevertheless, I accepted the diagnosis, and I have been using anti-TB medicines since last two months. But anti-TB medicines were not effective in completely removing my symptoms. I became very depressed and cried a lot. I and my family members couldn't understand what was wrong with my health. I kept thinking, why have I got this disease. One of my neighbors told me that I should visit a dargah. My wife brought me to the dargah at Komapally which is 25 kms from Yadagirigutta town. Sahib (priest) of the Dargah touched me and told me not worry. He asked me to take a ritual bath in the Dargah, and told me to pray to Allah for 20-30 minutes by touching the walls of the Dargah. I followed his instructions, while I was praying my whole body shivered. You know, God appeared while I was in this state of shivering, and told me that I will get better if I keep faith in him. I felt relieved with his assurance. I explained the incident to the Sahib. He also asked me to pray and believe in Allah. He recited rituals, burnt incense, and threw lemons and ash over my head. And he told me that he freed me from my affliction. We stayed in the dargah for one week and participated in daily prayers. The Sahib gave me amulets, and he told me that Allah will take of my health. My life is different since I attended prayers at the dargah. I have been praying frequently, and I became very optimistic about the future. I am no longer a depressed person. Recently, I have been seeking more comfort through prayer, and asking god to give me strength and energy to overcome this illness. I believe that Allah performed a miracle in my life, and I am feeling much better now.

It needs to be mentioned here that for many rural patients in Nalgonda, going to places of worship of other religions is common at times of stress and desperation. It is largely Hindu patients who seek solace in Dargahs and Churches if the Temple fails them.

Magico-Religious Healers

In addition to folk and professional medicine, faith healers and healing temples, churches and darghas provided curative and restorative health care services to the patients. For patients, in times of desperation, the religion of a healer does not seem to constitute a barrier for seeking treatment. Relief from distressing symptoms is more important than the religious background of a healer. This suggests the pluralism of the help-seeking behavior. The healer's credentials are based mainly on experience rather than professional education, social class or religion.

Of the total 110 patients, 17% of patients resorted to faith healing practices. These patients sought allopathic professionals (TB medication) and spiritual therapists (e.g., witches, priests, faith healing) simultaneously. Faith-based healing was generally sought by patients who attributed their illness to supernatural agents such as witchcraft, divine retribution or evil eye. Several studies (Good 1987; Frierman 1985; Pool, 1994) have established that in the case of chronic or serious illnesses, when treatment does not provide expected cure, suspicions of evil forces such as witchcraft/sorcery or spirit possession emerge. Frierman (1985) contends that in several cases, illness episodes which are recognized as 'natural' at an early stage are later explained in terms of supernatural forces such as witchcraft. In areas where biomedical facilities are relatively accessible and modern medical treatment is generally the main therapy choice for natural illnesses, the suspicions of evils forces may arise if the illness fails to respond to biomedical treatment (Good 1987). The reinterpretation of illness from 'natural' to supernatural causes marked the important turning point in health-seeking behavior. Dwyer (2003:54) argues that *"the belief that a supernatural agent is likely to be responsible for causing a person to become sick is almost invariably the reason why an ailing individual goes to visit a traditional healer or diagnostician. Thus, supernatural malaise is usually suspected by the sick person before he or she seeks help from a healer"*.

In this study it was found that patients usually consulted witches or religious priests when a variety of other resources, particularly, allopathic treatment had failed to provide expected relief. In other words, patients resorted to faith-based healing towards the later

stage of health-seeking behavior. Like in many rural communities in the world, magico-religious curing techniques of rural people of Nalgonda include a great diversity of diagnostic and therapeutic procedures (such as spells, incantations, prayers, amulets, exorcism, etc.). Although patients (and also their family members) reported faith in modern TB medicine, as they did not get expected respite from their symptoms, they looked to magico-religious healing as a complementary source of help with biomedicine. As Mechanic (1978:419) noted *“traditional healers are frequently more attuned than doctors to the psychological needs of their patients, and often the theories of disease they advocate are culturally and psychologically consistent with aspirations of their patients. On the contrary, scientific medicine frequently clashes with patient’s cultural beliefs and view points, and with their psychological needs, and thus scientific medicine does not always take full advantage of the treatment context for bringing about patient improvement through encouragement, support and suggestion”*.

Case Study 4 - Witchcraft

This case study reveals that resort to magico-religious healers or religious priests was not the first resort, but rather a ‘desperation measure’, after various treatments had brought very little relief. In desperation to get relief from illness, wife of a patient said that she had taken her husband to different magico-religious healers and priests in the hope of finding a speedy cure. She said:

My husband took TB medicines hardly for one month. Then, he dropped out of treatment completely. He vomited badly whenever he had taken the tablets. Then, we realized that this is not a normal illness. I took my husband to a mantragadu (witch). While in a trance state, he diagnosed that witchcraft was the cause of my husband's illness. He performed elaborate rituals and told us that he expelled evil spirits which interfered with the health of my husband. A goat was sacrificed to appease the evil spirits. But there was no improvement in the health condition of my husband even after performing sacrificial rituals. Some one suggested to me that I should take my husband to a Muslim dargah, I had taken him to dargah. We stayed there for five days, but without much success. His physical condition deteriorated badly. Then, on the advise of neighbors and relatives, I took him to a Christian faith healing church. We had converted to Christianity, and hoped that this move would certainly help my husband. We stayed in the church compound for more than 10 days, and had participated in the morning and evening prayers. I made fervent appeal to Jesus for the well-being of my husband. But it didn't work. My

husband's health condition got worse and worse over a period of time. So I was disappointed with this type of healing. We reverted back to Hinduism. I can't understand what step I should take next. I am really tired. I had spent lot of money on transportation, consultation fees, medicines, and other expenses. I had borrowed money from others to meet the treatment and transportation expenses. I can't afford any more costs. Once again I took him to government TB clinic. My strong suspicion is that some one bewitched my husband very badly. That is the reason why he is not recovering from the illness. It is all up to the God to decide the fate of my husband. I can't do anything.

Case study 5 - Witchcraft

A 45-year-old woman, was put on anti-TB treatment four months prior to the interview. In the following narrative she gave reasons for interpreting TB in terms of witchcraft, and turning to a witch for help. She said:

I have been using anti-TB medicines for the last four months. But, these medicines did not provide much relief to me. Instead, they caused severe vomiting, drowsiness and loss of appetite. I found side-effects of TB medicines intolerable. My condition deteriorated over a period of time. You see, I had consulted number of doctors and also few herbalists, but my condition had not improved. I lost weight and became very thin. At this stage, I really got very much frustrated. I felt some thing was really wrong with me. I suspected the role of evil forces in the causation of my illness. You know, if it is a natural illness, I could have got cured with injections and tablets. But this did not happen at all. You see, two years back, my husband quarreled with my brother-in-law over sharing the agricultural land. Since then, we were in constant conflict with him. Fierce arguments have been taking place between my family and my brother-in-law's family for the last couple of years. Last year my healthy child died in mysterious circumstances. Soon after, I was diagnosed with TB and HIV. I strongly suspected that my brother-in-law might have bewitched me and my child. I went to a mantragadu (witch) to find out the underlying cause of my illness. He went into trance and told me that a close blood relative of mine bewitched me out of hatred and jealousy. The explanation given by the healer confirmed my suspicion. Healer gave amulets to all my family members, and asked us to wear them around the neck. He exorcized and removed black magic. He also advised us to sacrifice a goat to appease and ward off evil spirits. We performed sacrificial rituals and invited relatives for this ceremony. After this ritual, I am feeling little better. You see, mantragadu removed the underlying cause of my illness (witchcraft). As a result, the efficacy of TB medicines improved. Now I am recovering from this illness gradually. You see, modern medicine is useful for treating symptoms but not the underlying cause of illness.

Case Study 6 - Witchcraft

The following case study illustrates the belief that witchcraft is responsible for causing a person to become seriously sick, is almost invariably the reason why an ailing individual goes to visit a magician or diagnostician. A 28-year-old widow attributed her illness to witchcraft. She said:

In less than two years, one tragedy after another befell on my family. My young husband died of a mysterious disease last year. My mother-in-law was diagnosed with diabetes and arthritis. Her symptoms became so worse that she had to stop working completely. My husband had been examined by many doctors and had tried different herbal, ayurvedic and allopathic medicines including anti-TB medicines. Healers neither could explain why my husband's illness started nor why it failed to respond to treatment. My husband died after a long battle with a mysterious illness. I was diagnosed with TB last year. Anti-TB medicines caused side-effects particularly vomiting. I lost considerable weight and became very thin. Despite the use of anti-TB medicines my symptoms such as loss of appetite and intermittent fever still remained. I could not understand why a series of misfortunes occurred in my family. I suspected the possibility of witchcraft. My husband had worked in a private company. We have cows, buffaloes, agricultural land, and a good house. You know, a major dispute occurred between my husband and my relatives over land. My relatives were very jealous of us. I feel that this might have been the reason my relatives resorted to witchcraft. I had consulted a diagnostician. Diagnostician told me that my family was possessed by an evil spirit. This is because of witchcraft. Magician placed his hands on me, and uttered rituals to exorcise the evil spirit. I am feeling much better now. I have also observed some recovery in my mother-in-law's health.

This case illustrates that accusations of witchcraft often occur between blood relatives, reflecting rifts or ruptures resulting from fierce arguments/altercations in connection with property money matters.

Case Study 7 - Witchcraft

A 48-year-old woman, reported witchcraft as a possible cause of her TB. She said:

I became very sick suddenly few months ago. My husband took me to the local RMP. He examined me and prescribed medications for a few days. But I didn't get any better. Later, my husband took me to a local government PHC, where the Doctor examined my sputum and seeing my x-rays reports, told me I had TB. I couldn't believe this as we never experienced TB in my family. So I thought I can never be at risk for contracting TB. You know, I kept thinking for days, why this dreadful disease occurred to me? And why now? You know, we owed money to a person who happened to be a black magician. I remember now that my illness suddenly began shortly after a major dispute with this person over the repayment of money. He has been very angry with us

because my husband didn't repay money to him. I feel that we were bewitched by him. You know, a series of misfortunes occurred in my family in recent times. We became homeless, my son met with an accident, and my husband had been unwell for a long time. I had consulted a magician of a neighboring village to find out the source of our family miseries. He told me that we were bewitched by an angry and jealous person belonging to my village. The explanation given by the magician made perfect sense to my family members. I strongly believe that it was witchcraft that caused my illness.

Case Study 8 – Evil Eye

A 52-year-old woman attributed her illness to evil eye. She alleged that her neighbors were jealous of her family. She had the following story to share:

I have been suffering from breathlessness, cough and intermittent fever for the last one year. I had consulted medical professionals, but the treatment prescribed by them did not provide expected relief. Initially, TB medicines caused more harm than good. I have been on TB medication for the last four months. Medicines made my symptoms worse, and caused severe side-effects (drowsiness, vomiting and breathlessness). The breathlessness got worse and worse over time. Sometimes it (breathlessness) was so bad that I just prayed God to keep me alive. You know, some times, I felt that I may die from this horrible problem (breathlessness) at any moment. In fact, this problem crippled me physically and mentally. A series of misfortunes occurred in my family - my husband had a heart stroke suddenly and mysteriously. My adult son became very rebellious. I became restless and nervous. I was worried, could not sleep, and had lost lot of weight. I consulted number of medical professionals, but none of them able to cure my illness completely. This indicated to me that there was some underlying cause behind my illness. On the advise of my close relatives, my husband took me to a Muslim priest. Sayab (Muslim priest) at dargah who explained to me that evil eye was the cause of my illness. My family members totally agreed with his diagnosis for different reasons. You know, many people in my village are jealous of my family. You see, my husband is a central government employee. He had constructed one of the best houses in my village. He also purchased three acres of fertile agricultural land which is very near to my house and village. Because of these reasons, many people are very jealous of my family's economic growth. You know, my illness is not a natural one. If it is a natural illness, I could have got cured a long back. Muslim priest gave amulets to all my family members. He sprinkled holy water and ash on me, my husband and son. And he chanted prayers and told me that he expelled the evil spirits from my body. After this ritual, I am feeling better. TB medicines were working effectively. I strongly felt that expulsion of evil spirits strengthened the efficacy of TB medicines. There were no side-effects. I had gained considerable weight, and the problem of breathlessness lessened to a considerable extent. My son got married, and he is leading a responsible life. My husband also recovered from heart stroke. I believe that sayab (Muslim priest) performed a miracle in my life.

Case Study 9 – Evil Eye

A 36-year-old woman, reported evil eye as a possible cause of her TB. She said:

Doctor diagnosed my problem as TB recently. It came as a total shock to all my family members. What wrong has our family committed? We have not harmed anybody. We are religious and offer prayers to god everyday. You know, my mother-in-law and husband suffered from TB in the recent past, and now it is my turn. I have not seen any family suffer like us. The truth is that my close relatives are very jealous of our family. You know, we are economically very strong. We have a tractor, a good house and 15 acres of fertile agricultural land. Ours is hard earned money, and we never cheated anybody. We spent most of our lives working in the agricultural fields. But my relatives (my brother-in-laws' wives) do not understand this. Instead, they become very jealous of our family's rising income level, and they fight a lot with us. They want to harm us so that we no longer remain financially stable. I strongly feel that my brother-in-laws' wives caused harm to my family by casting an evil eye and that is why I too now have TB.

Case Study 10 – Divine Retribution

The following case study clearly suggests that when patient is believed to be seriously ill with a life threatening disease, the patient, his/her family members and close friends, try and think what the patient might have done wrong which resulted in a serious and life threatening illness. A blacksmith in his late forties, explained that divine retribution was a cause of his illness. He said:

For the last one and half year, I had been suffering from chronic cough and intermittent fever. You know, I had tried TB medicines, self-care remedies and a variety of herbal medicines, but all these remedies provided very little relief. My symptoms remained, and my health condition worsened day by day. I vomited a lot. I became very much restless. I dropped out of treatment for some time. My wife and I began to think why this illness has not been responding to different types of treatments. We thought over this issue for some time seriously. Several questions came to my mind: Is there a person who dislikes us? Have I had arguments with my neighbors? I can't think of any person who may have reasons to harm me. You see, we are poor people and we don't have any valuable assets. So I never suspected the role of witches in the causation of my illness. However, I suspected that some mystical force was behind my illness. If it was a natural illness, my illness could have responded to TB medicines for sure. You know, I have observed several TB patients in my village and outside of my village who got cured completely with TB medicines supplied by the local hospital. I had consulted a local priest to find out the underlying cause of my illness. He is widely known for healing illnesses thought to be caused by supernatural

causes. He told me that mother goddess Uppalamma was angry with me because I had offended her in some way. You know, the explanation given by the healer made a perfect sense to all my family members. I was really shocked to know this news. I remembered that my illness began soon after the relocation of the shrine of Uppalamma from inside of my house to the backyard. Now it became very clear to me that Uppalamma was not happy with me at all. She certainly cursed me for offending her. The priest performed pujas (prayers), and rubbed enchanted lemons all over my body. I felt relieved from mental agony soon after the rubbing of lemons all over my body. Priest asked me to sacrifice a goat to appease angry goddess Uppalamma. I had offered a goat to Uppalamma. Blood of the sacrificed animal was sprinkled on the walls of my house. He performed rituals at my house to appease goddess Uppalamma., and gave amulets to all my family members. I had spent one week in a healing temple of lord Shiva. I took part in the daily prayers in the temple. I am feeling much better now because of the fact that I propitiated Uppalamma. My illness is responding to TB medicines well now. This is because, the priest removed causal agent responsible for my misery. As of a result of this, the efficacy of TB treatment increased. This is the first time in my life that I had turned to God for help. I understood the supreme powers of almighty. I have been performing special prayers in the name of Uppalamma every Saturday of the week. You know, If I had not appeased Uppalamma, I would have died from this deadly disease. I returned to TB treatment after one month of lapse in treatment. I am fine now.

Case Study 11 – Divine Retribution

A 40-year-old laborer, reported divine retribution as a possible cause of her TB. She said:

About eight months ago I had developed symptoms of cough and throat pain. I did not pay much attention to these symptoms and considered them to be minor ailments resulting from exposure to cold weather. My husband gave me herbal drink and over-the-counter medicines. But these remedies didn't help me much. Later, I had consulted local RMPs, and was given tablets and injections. But there was no significant improvement in my health condition. Whenever the symptoms of throat pain and intermittent fever worsened, I tried various home remedies, over-the-counter medicines for relief, and occasionally I also took injections from local RMPs. However, after few months I had experienced debilitating bouts of fatigue, and throat pain. Throat pain troubled me quite a lot. I had lost considerable weight, and my health condition deteriorated badly. I couldn't breathe, talk and eat well. I had lost my voice badly, and I was upset. I felt desperate and helpless. I thought I was going to die. My mother took me to a qualified medical professional. He gave me tablets, but there was no relief from the symptoms. On the advise of my neighbors, my husband took me a to specialist doctor in Hyderabad. I had undergone X-ray, sputum and blood tests. Doctor told me that I had TB. I couldn't believe it. I was totally stunned to hear that I had TB. It can't happen to me. There was no one with TB in my family. I realized that the situation is unusual. I kept thinking, why have I got this disease. I think it is more than TB, I think it's something else, some supernatural surprise. I had consulted a diviner who lives in a near by village. In a divinatory state, the diviner informed that the god cursed me because I offended him in some way. You know, in fact I had stopped offering

worship to our clan god (Mallana), located in agricultural field since last two years. I am convinced that it's a punishment for neglecting shrine of my clan god. You know, god wanted to teach a lesson to me because I had neglected him intentionally. My husband organized a grand festival in the name of god Mallana. I asked God for forgiveness. My God listened to my prayers. I am feeling much better. I strongly believe that the God healed me.

Patients who attributed their TB to evil eye, witchcraft or divine retribution, believed that the lasting cure for this kind of illnesses lies in magico-religious therapies. Patients who adhered to this type of belief system did not reject modern medical treatment. Instead, they explained that lasting cure is possible only when the patient undergoes magico-religious treatment. Patients who sought treatment from magic-religious healers explained that they felt better after seeking treatment from them.

The above narrative accounts clearly indicate that patients are actively occupied in a dynamic process of constructing understandings and explanations of their experience of symptoms of disease. That is, patients illness explanations are dynamic entities, molded in and by the certain socio-cultural situations in which they lived. Hunt *et al* (1989:954) argue that *“illness explanations do not represent static mental templates that provide patterns for action. Rather, they are dynamic entities that fluctuate through time in ways that allow them to be meaningfully incorporated into mesh of ongoing life circumstances... Illness meanings are specific to the context in which people live...and people experience, understand and deal with illness as part of their day-to-day lives”*.

TB represented a situation of anxiety and profound psychological depression within the lay patient's experience of illness. Resort to magico-religious healing and prayer may be few ways of affirming control over events and the threat which TB illness represents. Kronenfeld & Wasner (1982:1124) argue that *“patients in a hopeless situation will turn to any possible source of hope. While this may represent illogical behavior from a scientific medical point of view, when one considers the alternatives in hopeless illness for the patient, the rationality of their behavior from their perspective begins to appear”*. Magico-religious therapies are basically used as an adjunct to biomedical treatment. It appears that the lack of immediate positive responses with TB therapy, and disease causation beliefs are major factors influencing choice of magico-religious therapy. Furthermore, with the lack of psychological and spiritual support in modern medicine, magico-religious healers such as priests, witches, diviners, etc., provide an alternative to

TB patients to cope with anxieties and depression. It appears that one of the most striking aspects of magico-religious healing is the holistic approach and the orientation towards the meeting the patients' psychosocial felt needs, rather than the clinically determined need for healthcare.

Thus the analysis of the above case studies clearly suggest that patients were attracted to alternative therapies for various reasons that include an appeal for help in overcoming the illness, to appease supernatural deities, exorcise evil spirits, and/or endure the stress of living with TB.

Massage Therapy

Self massage therapy is another popular alternative treatment noticed among the TB patients. Most TB patients in this study presented physical symptoms such as muscle aches, fatigue, dizziness, and weakness. Patients complained that muscle aches and fatigue were the most distressing symptoms of their illness, and these symptoms had a considerable impact on their everyday lives. Many patients reported self massage is highly useful for getting relief from muscle pain. The most frequent reasons for use of massage were muscle ache, head ache and fatigue.

A 38 year-old, farmer said:

I generally purchase zandubalm (pain reliver) from local grocery stores which I massage it over head, neck, knee and chest region. This helps in soothing muscle pain, and provides a much needed temporary relief from muscle pain.

Massage is believed to have significant therapeutic effects. It is believed that massaging the body with ointments or homemade oils help in removing stiffness and soreness in the joints. Furthermore, it is understood that massage loosens the blood vessels thereby restoring free flow of blood to the body. Coughs, colds and muscle aches are understood locally in terms of the imbalance of hot and cold qualities in the body. Patients mentioned that cough, cold and TB are regarded as wet/cold diseases. For coughs, colds and muscle aches (cold illnesses), heating substances are generally used in body massage to restore to hot-cold imbalance in the body. Heating oils (e.g., mustard

oil) or over-the-counter ointments (e.g., Vicks vaporub), is therapeutically effective, for it is believed to have heating qualities.

Diet Therapies

All the patients agreed that dietary modifications during the illness will have beneficial effects. In both TB units, informal interviews with the community members revealed that foods such as meat, eggs, milk and green vegetables may play a critical role in facilitating the recovery of TB patients. It is also strongly assumed that food restrictions are very essential for restoration of health. Foods are classified into ‘hot’, ‘cold’, ‘irritating’, etc. Table 21 and 22 lists the food items for TB patients that are recommended and restricted respectively.

Table. 21. Foods items Recommended for Ameliorating TB

Food items	Reasons
Meat, eggs, milk and leafy vegetables	Provide energy, important for building up physical strength, facilitate quick recovery, balance hot-cold qualities in the body.
(Meat, eggs are classified as hot foods)	

Table. 22. Foods items Restricted for TB

Food items	Reasons
Potato, brinjal, dry fish, sugar, custard apple, guava	Worsens cough condition, cause irritation, fatigue, skin rash.
(These foods are classified as cold foods)	

Meat, eggs and milk came up as the most important food items that a person suffering from TB should take. All the patients and their family members considered that protein rich diet (i.e., meat, eggs, milk) is important for building up physical strength and thereby improving their health. TB is viewed as a disease involving excessive coldness in the body, and the special food intake is mainly aimed to counteract this coldness effect. The rationale for food recommendations for TB is more traditionally oriented. It indicates clearly the traditional concepts of heating foods for a 'cold' condition and the dietary goal of restoring body harmony. Members of the lay network unanimously agreed that TB patients should avoid certain food items such as brinjal, potato, sugar, dry fish, banana, guava and tamarind. Because, it was believed that the consumption of these foods would aggravate cough, fatigue, muscle aches, or breathlessness, and hence should be avoided strictly. While the lay beliefs recommended meat, eggs and milk, this diet is endorsed by modern medicine too. A diet rich in proteins was seen as one of the ways to counter TB during the Sanatorium era. It is only after the emergence of antibiotics that modern TB treatment ignored nutrition as a major factor in fighting the disease.

6.4 Summary

In this study overwhelming majority of patients delayed seeking care by two or more months before seeking effective treatment. None of the patients in this study considered the first signs as indicating the onset of TB. It was observed that there was a strong tendency to explain the initial episode in benign terms. In the first instance, symptoms of cough, intermittent fever, and loss of appetite and/or weakness were merely regarded as a nuisance. The onset of TB is often insidious, the symptoms of cough, intermittent fever, lack of appetite, and fatigue were attributed to trivial illnesses. Patients happened to recognize the possibility of serious illness only when these symptoms persisted despite self care and treatment sought from RMPs. The reasons for delay in presentation to TB health care services were complex. The study findings suggest that a complex interaction of socio-cultural factors contributed to patient delay. These factors include: i) lack of knowledge about susceptibility to TB; ii) traditional disease causation beliefs; iii) absence of typical symptoms of TB; iv) lack of knowledge of severity of

symptoms; v) non-interference with daily activities; vi) self medication; vii) attribution of symptoms to less serious illnesses such as flu, cold or fever; viii) traditional herbal treatment; ix) wait and see approach; x) economic and time constraints, and xi) excessive alcohol consumption.

Patients with early symptoms delayed consultation because they had thought the symptoms were not serious, and would go away. Most of the patients believed that symptoms were caused by something they had eaten, hard work, exposure to sun, cold weather, smoking or alcohol consumption. Patients equated TB disease with chronic cough with sputum, coughing up blood stained sputum and wastage of muscle tissues and skeletal bones, and as these expectations did not match the symptoms experienced by the patients, this caused delay in seeking medical care for initial symptoms. In the case of extra-pulmonary patients with symptoms of lumps, longer delays were observed (more than six months). Almost all the extra-pulmonary patients believed that their symptoms (i.e., lumps) were not at all TB related, because of the absence of classical symptoms of TB, for example, coughing up blood/sputum.

This delay in seeking health care is blamed on the patient who is often made to feel guilty about it. While the findings of this research do suggest that there is a time lag between onset of TB and seeking health care, there is a need to understand the complex range of reasons behind this delay. It is hoped that some of the responses that emerged from the study are considered favorably by health professionals, and patients not blamed for delays in seeking health care. Health care professionals have to be sensitized to the different socio-cultural contexts and belief systems that their patients come from which determine variations in health seeking behavior. Normative universal models of behavior that the biomedical model expects need to be questioned and modified based on experiences of patients.

The patterns of health-seeking behavior found in this study clearly confirm the pluralistic nature of health care services in Nalgonda district. In the medically pluralistic setting which typifies Nalgonda district, a variety of therapeutic choices exists, as well as an array of options with which patients comprehend and gain some degree of control over illness. Patients actively shopped for a variety of treatment options (such as over-the-counter-drugs, herbal medicine, Dargah, temple, Christian faith healing, biomedical

physicians, magico-religious and spiritual healers), in their search for cure. TB patients relied on self-treatment as a first choice, and there is a considerable reduction on use of self-treatment in subsequent choices for treatment. Patients freely moved from one health care sector to another as if the different therapeutic resources are complementary rather than contradictory. One of the important factors in determining alternative therapies like magico-religious healing for the rural TB patients is their beliefs about illness causation. Patients mentioned that one of the main reasons for using alternative treatments is to improve physical and emotional well-being. None of the patients refused standard TB treatment. Rather, alternative treatments were used as an adjunct to conventional TB treatment. Alternative healing practices offer a wide range of choices to patients, and tend to care for the whole person, taking into consideration their social, mental, and spiritual well-being.

Findings of this study suggest that there is a need on the part of health care workers to explicitly acknowledge the existence of alternative therapies and to incorporate these treatment modalities when formulating treatment plans for TB patients. In other words, health care workers need to recognize the use and practice of alternative treatments as legitimate and should improve their knowledge base to be able to educate patients appropriately.

CHAPTER

7

Perceptions of Practitioners on TB : Rural Medical Practitioners, Physicians and Traditional Healers.

This chapter is divided into three sections. Section one deals with knowledge about TB among the rural RMPs of the study area, section two explores differences in views on TB between patients and TB physicians, and section three briefly explores beliefs and perceptions of traditional healers about TB.

7.1 Knowledge about TB among the Rural Medical Practitioners (RMPs) in the Yagagirigutta and Chintapally TB Unit Regions of Nalgonda

In rural areas, when the symptoms of TB persist despite self-treatment, a large number of patients most commonly approach RMPs as the first point of contact for treatment. RMPs are a strong presence in rural India and practice modern medicine (largely Allopathy) without any formal training. Majority of them have learnt the basics of modern medicine while working for a few years as compounders with a qualified doctor. Rural people choose unqualified RMPs because of shortage of public health infrastructure (both physical and manpower), in most villages in India. Several studies

have revealed that there is no allopathic doctor either in the public or private sector in majority of villages in A.P., to provide basic health services and to attend to routine health problems like cough, fever, headache, etc. Consequently, the increasing demand for basic health care services in rural areas is mostly met by RMPs.

In fact, RMPs are filling the void/vacuum left by the qualified doctors. RMPs perform two very crucial functions- i) they are far more easily accessible and affordable to people than either the private doctors or the government health centres, and ii) they are very adept and quick in administering basic relief and basic curative drugs and injections. Thus, RMPs play a predominant role in providing most of outpatient care in rural areas. A study carried out by the Centre for Economic and Social Studies (CESS), Hyderabad, in 2003, revealed the predominance of RMPs in providing health care to the rural masses of A.P. There are, on an average, 21 RMPs for one qualified doctor in the studied area, 12 RMPs per ten thousand persons. It is even much higher in tribal areas, with 31 RMPs per one qualified doctor (HDR, A.P., 2007).

In this study over 70% of the TB patients reported that their first contact with the health care system was with the local RMP. The utilization of RMPs by a large number of rural populations highlights the need to engage these practitioners in the referral of TB patients to qualified health care providers. In other words, since RMPs are in direct contact with rural communities, they can play a vital role in the referral of TB patients to qualified health care practitioners. To improve the effectiveness and relevance of the TB health care services in rural areas, it is necessary to recognize the role of RMPs play in rural health care and understand knowledge of rural RMPs about medical aspects of TB and its treatment.

This section is based on interviews with 20 RMPs and describes their knowledge about TB. Their level of knowledge about TB and its treatment were addressed by the following questions: i) what is the disease that your community is most afraid of? why? ii) what is the cause of TB? iii) what are the symptoms and signs of TB? iv) is TB infectious? v) which parts of the body does TB affect? vi) would you regard TB a serious disease? vii) how does TB spread from one person to another? viii) is TB curable? ix) what is the duration of treatment for TB? and x) are HIV/AIDS related? The following

section presents the responses of RMPs to these questions which are summarized in Table 23.

7.1.1 Most Feared Disease

Table 23 indicates that 75% of the respondents reported that AIDS is the most commonly feared disease in the study area. TB and cancer were identified as most feared diseases by 15% and 10% of the respondents respectively. AIDS is thought to be a most feared disease for three major reasons: i) AIDS is an incurable and infectious disease; ii) AIDS related stigma; and iii) AIDS affected individuals are labeled as being sexually promiscuous. People affected with AIDS are often judged to have brought the disease upon themselves by engaging in sexually promiscuous behaviors. In other words, AIDS transmission is closely associated with stigmatized behavior like multiple sex partners. Furthermore, in the case of AIDS, infected persons are generally perceived as carriers of deadly transmissible disease, and such infected individuals are rejected from the society. Social exclusion is one of the important negative consequences of AIDS stigma. The close association between AIDS and sexual promiscuity, social stigma, and the incurable and infectious nature of AIDS has all acted to promote fear of the illness among the community members.

7.1.2 Causes of TB

When asked what causes TB, the most common answers were: bacteria (45%) and airborne infection (40%). Two respondents mentioned that multiple factors such as malnutrition, heredity, bacteria, airborne infection and/or sharing clothes and utensils results in TB, while one respondent said malnutrition causes TB. No respondent attributed the cause of TB to a curse or punishment from spirits, witches, deities or other supernatural forces.

7.1.3 Symptoms of TB

All the respondents generally described that TB essentially affects the lungs, and recognized prolonged and persistent cough as a major TB symptom. Few respondents also mentioned intermittent fever as a symptom of TB. No one mentioned weight loss, chest pain, weakness or night sweats as possible symptoms of TB.

Table. 23. Knowledge about TB among RMPs

Responses to Questions	No.of Respondents (N=20)	%
Most feared disease in the community		
AIDS	15	75
TB	03	15
Cancer	02	10
Causes of TB		
Bacteria	09	45
Air borne infection	08	40
Heredity, malnutrition, airborne infection, and/or sharing clothes, and utensils	02	10
Malnutrition	01	05
Symptoms of TB		
Cough	14	70
Intermittent fever and cough	06	30
TB is an infectious disease		
Yes	20	100
No	-	-
Mode of transmission		
Airborne	13	65
Sputum	05	25
Sharing clothes, utensils, or sexual contact	2	10
Sites of TB		
Lungs	11	55
Lungs and rib bones	09	45
TB is a dreaded disease		
Yes	10	50
No	10	50
TB is curable		
Yes	20	100
No	-	-
Duration of TB treatment		
6 months	18	90
3 months	02	10
TB and HIV/AIDS are related to each other		
Yes	19	95
No	01	05

Source: Field-work (2008-2009)

7.1.4 TB Transmission

All the respondents knew that TB is an infectious disease. RMPs responded that TB is transmissible from patients to healthy individuals through air, sharing utensils, contact with clothes, or sexual intercourse. A large proportion of the interviewed respondents (65%) indicated that breathing air infected with TB germs as the most common route of TB transmission. Of the total respondents, 25% reported that TB is transmitted through sputum, and nearly 10% of the total sample identified multiple modes of transmission: sexual intercourse, contact with the utensils and sputum, sharing clothes, or through air.

7.1.5 Curability, and Duration of TB Treatment

Regarding the knowledge about curability of TB, all the respondents considered TB a curable disease, and are aware that it involves taking anti-TB drugs. 90% said that treatment takes 6 months, while 10% felt that treatment takes only 3 months. All the respondents recognized the importance of anti-TB drugs in the cure of TB.

7.1.6 Common Sites of TB

Lungs were identified as the most common site of TB by all the respondents. Of the total respondents, 45% of explained that TB affects both lungs and rib bones.

7.1.7 HIV/AIDS and TB

Almost all the respondents (95%) are aware of the fact that there is an association between HIV/AIDS and TB. It is believed that having HIV/AIDS predisposes an individual to acquisition of many diseases including TB. RMPs argued that HIV/AIDS patients are at greater risk for TB and other diseases because of their low levels of immunity.

7.1.8 Views on Alternative Therapies

RMPs views on the use of alternative therapies by TB patients were generally in agreement with the medical professionals' views on alternative therapies. Similar to

medical physicians, RMPs were also very skeptical about the effectiveness of alternative therapies in treating TB. RMPs perceived patients' beliefs (such as witchcraft, evil eye, divine retribution, hot-cold imbalance as etiological agents of TB) as superstitious, ignorant and irrational. RMPs strongly believed that anti-TB drugs and consistent long term therapy is important for treating TB. RMPs mentioned that TB disease condition worsens in those patients who take treatment irregularly. It is quite obvious from these responses, that RMPs, though rural based and untrained in formal medicine, share a view of TB dominated by a biomedical understanding of disease.

7.2 A Comparison of Physicians' and Patients' Perceptions of TB

Practitioners should not "blame the victim" for their beliefs and that it is not the patients' responsibility to change their beliefs in response to biomedical culture. But rather, it is biomedical culture that should be modified to be culturally appropriate to the patient. Adopting this approach would provide an opportunity to improve the cultural competency of practitioners. Despite the importance of popular health beliefs, rarely are physicians taught to recognize them or to assess their impact on clinical care.

Dein (2004:123-124)

In the search for better treatment of human disease, health professionals often focus on the control of physiological disorders than on the social and cultural meanings that patients give to their illness experience. Dr. Ronaldo Collado (cited in Rubel & Garro 1992: 627) conducted a survey among Mexico's State TB control directors to understand the problematic nature of TB control in their locality. *"Asked, to what do you attribute the problematic nature of tuberculosis control in your jurisdiction? the directors overwhelmingly laid the problem at the door of their patients' shortcomings: 'poverty', 'lack of education', 'poor motivation' 'superstition' and 'failure to comprehend the importance of compliance with treatment recommendations'. When subsequently asked, 'what would you do if it was within your power to find ways to resolve this problem? the consistent reply was, invest resources in the search for a new, improved medication. The same inconsistency is repeatedly revealed in the health policies of many nations as the search continues for a pharmacological solution to a far more complex problem".*

Contributing to the complexity is the fact that the health culture of the lay people differs from that of health care professionals. Patients' explanation for their illness may be considerably different from those of the health care professionals. Although biomedical professionals may understand TB as being identified with objective and measurable physical and physiological changes, patients may experience it differently. The limitations of the biomedical perspective that disease is purely biological and that the body is separate and independent from psychological and social processes of the mind led to formulation of alternative models to account for the patient's whole body. These models make an attempt to capture the wholeness or integrated unity of the patient's body, especially within the lived context.

According to Kleinman (1980) and Cohen *et al* (1994) health care professionals may not be fully aware of the differences between their perception of disease and that of the patient. He argues that mismatch between physicians' and patients' beliefs negatively correlated with patient outcome variables such as adherence to treatment regimen, satisfaction with consultation, recall, treatment response, subsequent use of health care services, reporting of side-effects of medication, and psychosocial problems. Ineffective communication between practitioners and patients has been established as one of the major obstacles in effective clinical care (Cohen *et al* 1994; Ogden *et al* 2001; Baer *et al* 2004; Woods & Critchley 2000). Communication gaps often accentuated when cultural and socioeconomic background of practitioners differs from their patients. Hence, several authors have argued that a strong doctor-patient relationship is crucial to the successful treatment and management of serious illnesses such as TB. In the case of TB, which requires prolonged care, better patient-physician relationship and communication is crucial for the successful treatment process since patients tend to experience anxiety, depression, and social stigma.

Kleinman (1980) argues that culture influences a person's perspective of health and illness. Personal experience, family attitudes and group beliefs shape patients' illness beliefs. Physicians' beliefs, on the other hand, are formed by the biomedical model, learned in medical training. Similarly, Nations *et al* (1985:223) argue that "*patients simply have their own ideas, often culturally-shared about illness which differs from biomedical explanations of disease found in standard medical textbooks. If such*

differences are ignored by physicians, especially in cross-cultural encounters, the doctor-patient interaction often becomes a perfunctory exchange marked by patient or physician stress, non-compliance, misdiagnoses and extraneous laboratory work-ups". Kleinman et al (2006:147) contend that:

Comparison of patient model with the doctor's model enables the clinician to identify major discrepancies that may cause problems for clinical management. Such comparisons also help the clinician know which aspects of his explanatory model need clear exposition to patients (and families), and what sort of education is most appropriate. And they clarify conflicts not related to different levels of knowledge but different values and interests. Part of the clinical process involves negotiations between these explanatory models, once they have been made explicit.

Hence, it is imperative to compare the views of physicians and patients with regard to TB causation, symptoms, transmission, risk factors, severity, major concerns, choice of treatment, and reasons for default and noncompliance. In this section an attempt is made to compare the views of doctors and patients on the above mentioned aspects of TB. 10 physicians were interviewed who were working in the government TB clinics in Nalgonda. Table 24 summarizes the views of patients and medical practitioners and clearly indicates that there are several mismatches between their views on TB..

7.2.1 Name of the Disease

Physicians

TB and Koch's disease are the terms practitioners applied to TB disease.

Patients

The two most commonly used local names for TB in the study area are *Upirithithulaku* (lungs) *neeru vachindi* and *daggu dammu rogam* which refers to accumulation of watery fluids in the lungs, and cough and breathless illness respectively. Patient's don't like to say that they are suffering from TB instead they use the terms like *Upirithithulaku neeru vachindi*, *pakkatemulaku neeru vachindi* or *daggu dammu rogam*. Patients use these local

terms instead of TB to minimize stigma associated with the disease. Local terms reflect that TB is a disease which basically affects lungs, and causes cough and breathlessness. Almost all mentioned that TB is a disease of lungs, and TB does not affect brain, kidneys, heart, etc.

7.2.2 Views about Cause, Transmission and Risk factors of TB

Physicians

Physicians explained TB in terms of Western biomedical model. According to TB practitioners TB is an infectious disease caused by *Mycobacterium tuberculosis*. TB is classified into two types: i) pulmonary TB (affects lungs), and ii) extra-pulmonary TB (affects any organ or tissue outside the pulmonary system). Pulmonary TB accounts for over 80% of total TB cases, and is infectious in nature. The biomedical view of TB is a disease transmitted from one person to another through respiratory route in droplet nuclei generated by persons with infectious TB. When a person with pulmonary or laryngeal TB coughs, sneezes, speaks, or sings, particles that contain tubercle bacilli are expelled into the air. Transmission occurs when a susceptible individual inhales droplet nuclei that contain tubercle bacilli. When inhaled, droplet nuclei typically take root in the air sacs of lungs known as alveoli. Tubercle bacilli usually spreads from the initial location (i.e., alveoli in the lungs), to other parts of the body (e.g., liver, kidney, urinary tract, etc.) through blood stream or lymphatic system.

In majority of the cases, within few weeks after infection, cell mediated immunity develops, and a competent immune system limits the multiplication of tubercle bacilli. However, in small number of cases, TB bacteria are not killed and lie dormant in the alveoli. This condition is known as latent TB infection. An individual with latent TB infection is not ill (asymptomatic), and is not infectious. However, when cell-mediated defense mechanisms are impaired, the inactive bacilli become metabolically active, and they begin to multiply. This is known as reactivation, which is the usual pattern of disease development in most cases of active TB.

Table. 24. Perceptions of Practitioners and Patients on TB

	Patients	Practitioners
Name of Disease	TB, Upirithithulake neeru vachindi, pakkatemulaku neeu vachindhi.	TB, Koch's disease
Cause	Fate, evil eye, witchcraft, divine retribution, sleep deprivation, mental stress, infection, heredity, exposure to cold climate, hard work, excessive alcohol consumption, hot-cold imbalance, diet high in sugar.	<i>Mycobacterium tuberculosis</i>
Symptoms	Coughing up blood and/or sputum, skinny body, wasting away	Cough, fatigue, loss of appetite, night sweats, intermittent fever, loss of weight.
TB transmission	Contact with an ill person's utensils, clothes, bed sheets, urine, and sexual fluids. Breathing the air expelled by the sufferers.	Airborne infection
Nature of disease	Very serious and dreaded disease	Not a serious disease
Choice of treatment	Anti-TB drugs, good food, prayer, massage, faith healing self care, herbal drinks, magical spells.	Anti-TB drugs, good food
Major concerns	Shame, social isolation, marital tensions, fear of death, fear of future of children, sexual problems, depression, anxiety, loss of self esteem, conflict with mother-in-laws, fear of spreading the disease to family members, fear of relapse of TB.	Treatment default, emergence of MDR-TB cases, treatment failure.

Continued

	Patients	Practitioners
Reasons for delay in seeking - health care	Alcohol and smoking related problem, attribution of symptoms to other illnesses, absence of defining symptoms of TB, non interference with daily activities self medication, wait and see approach, harmless symptoms no history of TB in the family, hot-cold imbalance.	Illiteracy, treatment with RMPs, ignorance.
Reasons for default	Side effects, pill burden, symptom relief, hot nature of TB medicines, economic reasons, habit of alcohol consumption .	Negligence, indifference, symptom relief.
Risk factors for TB	Alcohol consumption, poor diet intake, contact with utensils, clothes, sexual fluids and urine, sexual promiscuity, heredity.	Drug abuse, HIV, poor socio-economic conditions, malnutrition.

Physicians explained that factors such as low level of immunity, malnutrition, overcrowded living conditions, poor socio-economic conditions, HIV infection, ageing, alcohol abuse and smoking make the people more prone to contracting and developing the disease. HIV infection is one of the significant risk factors due to its effect on the host immune system. TB occurs commonly among HIV patients because of their weakened body's immune system. Physicians argued that malnutrition lowers body's immune system, and predisposes an individual to the development of various infectious diseases including TB.

Patients

Patients, in contrast, attributed diverse causal factors to account for their TB. The diversity of these factors varied from explanations that the occurrence of TB was due to: excessive alcohol consumption along with poor diet, mental stress, witchcraft, divine retribution, evil eye, fate, hard work, exposure to hot sun, hot-cold imbalance in the body, heredity, infection, sleep deprivation, and a diet high in sugar. 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.

Patients mentioned that TB is a highly contagious disease, and is transferred through contact with TB patient's clothes, bed sheets, food, utensils, urine, saliva and sexual fluids, and through breathing the air expelled by the patient. Overwhelming majority of patients described that they kept their eating utensils, bed sheets and other belongings separate from their family members in order to prevent disease transfer to their family members. Married patients said that they avoided sexual intercourse with their respective partners, because it is thought that sexual relations place their partners at high risk for contracting TB. From patients' point of view, excessive alcohol consumption, poor diet, sharing clothes and utensils, sexual promiscuity, and sex with TB sufferers are the important risk factors for contracting TB.

7.2.3 TB symptoms

Physicians

Physicians reported that clinical symptoms of TB are varied and depend on the site of infection. General signs and symptoms such as intermittent fever, loss of appetite, night sweats, and fatigue occur with any site of infection. Persistent cough is the characteristic symptom of pulmonary TB. The typical symptoms of extra-pulmonary TB depend on the sites of infection.

Patients

When patients were asked what they think about the signs and symptoms characteristic of TB, almost all the patients reported coughing up blood and/or sputum, skinny body and wasting away. There is a widespread belief among the patients and community members that TB devours its victims gravely, and eats the body muscles, particularly rib muscles. In patients' illness representation of TB, coughing up blood and/or sputum, skinny body and wasting away are considered as the defining and characteristic symptoms of TB.

7.2.4 Treatment Default/Non-adherence

Physicians

Concerns about treatment default, patient delays in seeking professional care, and the emergence of MDR-TB cases was voiced during interviews held with practitioners. Practitioners have argued that most patients interrupt or discontinue treatment for different reasons including lack of interest and motivation, symptom relief, negligence, illiteracy, stigma, and lack of awareness about the importance of adhering to full course (6 months) of treatment. Under DOTS strategy, the standard treatment for TB is six months, which consists of a two month *intensive phase* and a four month *continuation phase*. Practitioners argued that, patient condition improves considerably after the end of the intensive phase in general. Disappearance of symptoms at the end of the intensive

phase of treatment often leads most patients to believe that they were cured, and hence, they no longer need any treatment. Practitioners expressed a concern that irregular treatment may lead to treatment failure and thereby enlarging the pool of infectors in the community. Furthermore, treatment interruption increases the risk of development of MDR-TB strains. Practitioners are of the opinion that drug resistant strains not only make the patients chronic incurables but also seriously undermine the progress of TB control programmes in the country. Practitioners strongly assert that despite health education, many patients often do not understand the importance of adhering to full course of treatment in order to achieve complete cure. There is a tendency by the doctors to blame the patient for this, while the biomedical approach to TB control (that fails to recognize the influence of socio-cultural factors) is not critically questioned by them.

Patients

Anti-TB drugs are very important to TB patients. If medicines were essential, why do so many patients take medicines on-and-off, discontinue treatment or stop medication altogether. Interviews with the patients, revealed multiple reasons for interrupting medication. These reasons include severe side effects of drugs, too many medicines (pill burden), economic reasons, symptom relief (disappearance of symptoms), powerful and hot nature of TB medicines, stigma, and lack of social support. Many patients said that they occasionally missed taking their medicine. Study findings clearly suggested that side effects which made their life difficult, led to interruption or termination of medication. Majority of patients expressed a grave concern about side effects (such as vomiting, dizziness, giddiness, stomach burn) of TB drugs. For example, one patient explained how he felt when he took his medication:

You know TB medicines caused more harm than good to me. I really found side-effects particularly vomiting and drowsiness intolerable. I had vomited very badly whenever I had taken the tablets. You know, I had no choice except for interrupting medication.

Some patients mentioned that having to take too many powerful pills at a time is one of the reasons for discontinuation of treatment. One patient, for instance, said:

I am really alarmed to take seven tablets at a time. You know, I am physically very ill. How can I tolerate these powerful medicines? Every time I tried I kept having vomiting and stomach burn. Honestly, I don't like TB tablets at all. I rather die than take these tablets.

Some patients said they had no other choice than discontinue treatment and return to work. Majority of the patients in the study area are daily wage earners who found it difficult to take leave from attending work for economic reasons. For example, one male patient explained why he had to interrupt treatment, he said:

You know, every time I tried TB medicines I kept having severe drowsiness/giddiness. It is very difficult to concentrate on work when you are in a state of drowsiness. Hence, I missed medication several times to attend work. You know, I can't afford to miss work because my school going children are dependent on me for their daily needs and school fees.

Interruption or non-adherence to TB medication is very common among alcoholic patients. Several patients who were alcoholics said they did not take medications if they were going to drink alcohol. They believed that mixing TB medicines and alcohol is highly detrimental for health. It is assumed that mixing alcohol and medicines could result in death. Thus, many alcoholic patients interrupted or altogether stopped medication to avoid potential health risks from mixing alcohol and TB drugs.

Symptom relief also affected compliance to treatment. It was observed that some patients took medicines when they were hindered by the troublesome symptoms and dropped out of treatment when they felt better. Some patients said they usually pay attention to TB medicines only when symptoms become significant, and interfere with daily activities. One patient, for instance, said:

Usually I don't pay much attention to TB medicines once the symptoms disappear. I take medicines only when symptoms reappear, and interfere with day-to-day activities.

Another patient explained in a similar vein:

I take medicines on-and-off. You see, I only take medicine when symptoms interfere with my daily tasks, and dropout of treatment when symptoms disappear. You know, TB medicines are very powerful, and being

dependent on these powerful medicines is certainly not good for my body. In fact, I don't want to become too dependent on these medicines.

Strong social stigma associated with TB also appears to affect compliance with treatment. In this study, a small number of patients (3%) denied that they had TB. These patients avoided TB medications completely so as to not to be classified as suffering from TB by their community members.

Some patients continue to have symptoms even when they follow prescribed medication. If medication seemed to make no difference, respondents were more likely to consider interrupting treatment. One woman patient described why she stopped treatment when she followed practitioner's treatment recommendation. She said:

I have been taking TB medication for the last two months as per practitioner's advice, but these medicines did not provide much needed relief. In fact, my health condition deteriorated badly. I felt that these medicines are not helpful, and so I stopped medication.

7.2.5 Major concerns

Physicians

As mentioned earlier, from physicians perspective, treatment default, patient delays in seeking care, and the emergence of MDR-TB cases are the major obstacles to treatment success.

Patients

The patients, in contrast, seemed relatively unconcerned about treatment default, emergence of MDR-TB and consequences of non-compliance. Patients, however, expressed concern about social discrimination, depression, sexual problems, fears about future of children, fears of death, fears of relapse of TB, emotional problems, economic burden, interpersonal problems, loss of self esteem, shame, fear of spreading disease to family members, particularly to children, marital problems, fatigue, and breathlessness. When patients were asked to explain what community members thought about TB disease, they used the phrase *ijjath* (shame). Shame surrounding the disease is most

commonly reflected in patient narratives. Many informants expressed a concern about harmful side effects of TB medication

Summary of Reasons for non-compliance with TB medication

- Side-effects of TB drugs
- Pill burden (too many medicines)
- Symptom relief
- Lack of family support
- Denial of TB status
- Misunderstanding about duration of TB treatment
- Powerful nature of TB drugs
- Alcoholism
- Work related problems
- Economic problems
- Stigma
- No relief from symptoms
- Change to alternative therapies
- Controlling dependence on TB medicines

A fear of disease relapse was also the most common fear noted among the patients. All the patients experienced more than one problem by being a TB patient. In the following paragraph some major problems experienced by patients themselves are discussed briefly. Statements made by patients bear eloquent witness to the mental and emotional ravages of the disease. Comments like the following were common:

After I got HIV and TB, my neighbors and brother-in-law shunned me and my children. In fact, my neighbors as well as my own brother-in-law didn't let my kids play with their kids.

My son asked me not to enter his house, and told me to confine to the veranda only.

What is left in life when your own son and daughter-in-law do not let you to interact with them and my grand children?

After being diagnosed with TB, I restricted my social interactions considerably out of shame and fear that others would discover that I am a TB patient.

I kept my disease secret from my in-laws, because they may abandon me if they come to know about my disease.

I am nervous and scared how the disclosure of my TB disease would affect my personal relationship with my in-laws and my husband.

When doctor told me that I had TB, I cried a lot, and felt death. I wonder what would happen to my children after my death.

My children and wife abandoned me. They do not respect me any more.

My husband suspected my fidelity because of the fact that I had refused to have sex with him.

I kept thinking, why have I got this dreadful disease. I have never done anything wrong. How could I get this horrible disease?

7.2.6 Views about Delays in Seeking Health Care, Treatment, and Alternative Medical Practices

Physicians

Physicians explained that patient delay represents one of the major obstacles to treatment success. According to practitioners, factors like illiteracy, lack of awareness of symptoms, consultation with RMPs, and social stigma contribute to lengthy patient delays in seeking professional care. Rural patients who have symptoms possibly indicative of TB initially seek treatment from local RMPs. Physicians voiced the opinion that patients get only temporary relief when they seek treatment with RMPs. However, patients feel that they are completely cured, and assume that their symptoms are not very serious. Physicians suggest that because of inadequate diagnostic skills on the part of

RMPs, many potential TB cases are misdiagnosed, and as result, many months of potentially effective diagnosis and treatment is lost. Patients generally go to TB clinics or private hospitals only when symptoms persist or recur despite seeking treatment from RMPs several times. Physicians also explained that patients often deny and/or conceal their symptoms, and delay seeking professional care because of fear of social stigma by community or family members. Patients delay treatment because it is believed that getting treatment from TB clinics constitutes public acknowledgement that he or she is suffering from TB. A 33-year-old doctor said:

People are afraid of TB. So if a person suspects that he/she has TB, he/she will not go to TB clinic for examination. Because, people are worried that their family members or neighbors may isolate them, and keep away from them.

According to biomedical physicians, TB drugs (isoniazid, rifampicin, pyrazinamide, ehtambutol, streptomycin), and good food is necessary for treating TB, and they emphasized the need for adhering to consistent long term DOTS therapy (6-8months). TB physicians attitudes towards alternative medical practices (such as faith healing, incantations, spells, etc.), can be described as rather skeptical. Physicians regarded alternative practices unscientific and argued that such practices compromise cure, cause drug resistance, and treatment failure.

Patients

Patients who delayed seeking professional medical care explained that they attributed their symptoms to other illnesses such as fever, flu, *pasakalu*, alcohol related, or hot-cold imbalance in the body rather than to TB, and hence felt no urgency to consult medical practitioners regarding their symptoms. Several patients delayed in getting tested by qualified practitioners because they were not experiencing any of the defining or characteristic symptoms (coughing up blood/sputum, skinny body or wasting away), in their illness representation of TB. Almost all the patients mentioned that they did not perceive themselves to be at risk for TB, since there had been no cases of TB in their family history, and hence, they did not recognize that they might have TB. There is a

widespread belief in the community that having TB in the family significantly increases the vulnerability of others to TB.

Many patients said that they chose to wait and see, in the hope that their symptoms would resolve without professional intervention. Financial and time constraints are also mentioned as factors for delay in seeking early care. Patients also sought different types of alternative therapies including faith healing, special diets, massage, herbal medicine, prayer, etc. In this study, patients who sought care in the form of alternative medicine did not reject or forgo standard anti-TB treatment. Rather they used alternative practices as an adjunct to conventional TB treatment. Outcomes of selected treatments were used by patients as indicators for continuing or discontinuing the treatment. Patients said that their preference of treatment was influenced by different factors including attribution of causes, effectiveness of chosen treatment strategy, accessibility and affordability. In many patients, alternative therapies such as faith healing, magical spells or prayers appear to fulfill psychological needs that are not met in the biomedical setup. For example, patients' narratives suggest prayers or faith healing practices played a critical role in enhancing hope and coping capabilities.

7.3 TB Knowledge and Beliefs of Traditional Healers

Similar to other regions across the world, in Nalgonda, there is a parallel traditional medical system to the professional medical system in the form of traditional healers (e.g., herbalist, snake doctors, midwives, priests, witches, and diviners). *“A traditional healer is a person who has no formal medical training, but is recognized by the community in which he/she lives as being competent to provide health care by using plant, animal and mineral substances and certain other methods based on social, cultural and religious background as well as the knowledge, attitudes and beliefs that are prevalent in the community regarding physical, mental and social well-being and the causation of the disease and disability”* (WHO 2002). Many rural people rely on traditional healers (THs) for health care because their treatment is affordable, and more importantly they share their patient's cultural beliefs, and understand their expectations of treatment. Furthermore, the theories of disease the THs advocate are culturally congruent with the

beliefs and perceptions of their patients. The approach of THs is seen as holistic in nature.

Review of literature on national TB control programmes in India suggests that TB control programmes are not very successful. THs could play an important role in referral of TB suspects to health care professionals. Some of the potential advantages of working and collaborating with traditional healers include: high degree of accessibility and acceptability of traditional healers in remote rural areas, cultural congruence and better awareness of community beliefs and perceptions about disease etiologies and treatment. It is important to have a better understanding of knowledge and perceptions of THs, and such knowledge helps in assessing the nature of knowledge required in order to encourage THs to be actively involved in TB control programmes. The following section explores briefly THs perceptions and beliefs about causes, symptoms, transmission and curability of TB.

All the THs knew about TB, and mentioned that TB is a contagious disease. Regarding knowledge about causes of TB, Herbalists mentioned a variety of factors for causation of TB. These include: dust, pesticides, fertilizers, excessive alcohol consumption, smoking, hot-cold imbalance in the body, breathing the air expelled by the TB patient. In this study, none of the herbalists attributed TB to social or supernatural factors. It is the Faith Healer who argued that apart from individual and natural factors, supernatural (e.g., divine retribution, evil spirits, and fate) and social (e.g., witchcraft, evil eye) factors also cause diseases in humans (e.g., cancer, paralysis, AIDS, TB, and measles). In other words, it can be interpreted that faith healers work within a folk medical system wherein evil spirits, god's will, fate, divine punishment, bad luck, and witchcraft, are seen as causes of diseases in human beings.

THs appear to share the same knowledge about symptoms and routes of transmission of TB with their lay community. Regarding the knowledge about curability of TB, all the THs agreed that TB is curable disease, and anti-TB drugs are very essential for the treatment of TB. All the healers said that they would refer a TB suspect to a hospital for treatment. However, faith healer maintained that evil spirits, angry deities or witchcraft might prevent TB medicines from working. He is of the opinion that western medicine can not cure the patient completely if the actual cause, for example, witchcraft,

is not addressed. Hence, he advocates the need to perform elaborate rituals in order to expel the evil spirits. The above observations clearly indicate that there is a close correspondence between patient's and traditional healer's knowledge and beliefs about TB. There are no differences between THs and their patients in terms of conception of TB illness and its treatment. The study findings suggest that THs need to be recognized and involved in TB control programmes and provided with information about the importance of early diagnosis and treatment of the disease.

7.4 Summary

This study revealed that RMPs had reasonably good knowledge about TB. Respondents cited Information, Education and Communication (IEC) campaigns about TB as the important source of information on TB. Although a large proportion of RMPs had good knowledge about TB transmission, curability, treatment duration, and common sites of TB infection, the study, however, revealed RMPs have limited knowledge about its cause, routes of transmission and symptoms. About 55% of the respondents were not aware of the fact that TB is caused by bacteria, and the assumptions that TB is caused by sharing utensils and clothes, and contact with sexual fluids prevail. Although respondents recognized cough as an important symptom of TB, none mentioned weight loss, chest pain, weakness or night sweats as possible symptoms of TB. Interviews with the traditional healers revealed that there are no differences between them and patients in concepts of symptoms, causes, curability, and transmission of TB.

The results of this study clearly suggest that practitioners (both RMPs and doctors) and patients differ considerably in perceptions of TB. Patients and physicians are usually from two different backgrounds. Patients were of low socio-economic status and were mostly illiterate. On the other hand, physicians belonged to higher socio-economic status and were highly educated. Consequently, these two cultural belief systems inform dissimilar understandings on TB, its cause, transmission, treatment, fears, etc. Table 26 summarizes the Explanatory Model of TB of patients, physicians, RMPs, and THs and brings out the variations in understanding of the disease among them.

The differences between patients and practitioners reflect emphasis on different domains of explanatory models of TB. Patients mostly emphasized the problems in the psychosocial domain and expressed concern about the impact of TB on their daily lives and interpersonal relations. Professionals, on the other hand, saw TB basically as a biological problem with primary impact on patient's physical body. Physicians explained treatment interruption or non-compliance by blaming patient ignorance, negligence, lack of motivation, illiteracy, and harmful lifestyles. In contrast, interviews with the patients revealed that several obstacles affected compliance with TB treatment. Some of these obstacles include loss of daily wages, habit of alcohol-intake, symptom relief, troublesome side effects, lack of social support, denial, and social stigma. It can be argued that from the patients' perspective, the issue of non-compliance/treatment interruption is more clearly one of responding to the meaning of medication in day-to-day life situations than compliance with practitioners' recommendations. The two most important reasons for interrupting TB medication are: i) troublesome side effects, and ii) symptom relief. Patients interrupted treatment when they observed that their medication was hindering the ability to participate in routine work. When medication is seen not efficacious it is likely to be stopped.

All physicians discussed about lengthy patient delays in seeking appropriate medical care, emergence of drug-resistant TB, and treatment default as major problems. While patients talked about psychosocial problems such as disruptions in interpersonal relationships, social stigma, depression, fears about future of children and fears about death. None of the physicians discussed any of the psychosocial problems which patients expressed. Patients' views about causes of TB are clearly different from those of the practitioners. Physicians reported that tubercle bacillus is the causal agent of TB. On the other hand, patients did not interpret their ill health to objectively verifiable pathogens. Rather they attributed causation of TB to life events (e.g., death of a family member), interpersonal conflicts (e.g., conflict with relatives over land sharing, marital tensions), environmental factors (e.g., exposure to cold or hot weather), harmful lifestyles (excessive alcohol consumption), diet (e.g., excessive consumption of cold foods), close contact with the TB sufferers, and hard work. The results of this study also demonstrate that patients and practitioners differ in their perceptions of transmission of TB. For

practitioners TB is an airborne infection, and is transmitted from one person to another through the air by droplet nuclei. While patients said that TB is transmitted through contact with TB patient's clothes, bed sheets, food, utensils, urine, saliva or sexual fluids. With regard to theoretical implications, these results reaffirm the notion that patients and practitioners have different explanatory models of illness.

Such differences between practitioners and patients primarily have implications for treatment and management of TB. The major emphasis on diagnosis and treatment rather than communication with the patients has been one of the major shortcomings of TB control programmes. The differing perceptions clearly indicate that practitioners must make an effort to understand their patients' psychosocial world. The study observations suggest that physicians need to make every effort to discuss with their patients the psychosocial problems that the patients may have in order to help treat the patients more effectively. As a part of medical history taking skills, practitioners and other health care workers should elicit patients' psychosocial concerns, and these concerns should be addressed. Health workers need to avoid cultural stereotypes and victim blaming. Eliciting and acknowledging psychosocial concerns of patients opens up communication between patient and health care workers, and creates a better therapeutic environment for successful TB care and management. In other words, to provide culturally competent care, the practitioner must be prepared to accommodate the patho-physiology of TB as well as the experience of illness as it is perceived by the patient, his/her family and community. Health care workers need to employ a comprehensive model of treatment that incorporates not just biological factors, but psychological, social and cultural factors as well.

Several authors have argued that a good relationship between the health care providers and participants can enhance adherence. Health care workers need to be aware of the fact patients' trust in the treatment they are receiving is crucial if they are to continue with such a long treatment regimen. Motivation of TB patients at the start of treatment is a crucial element as far as case holding is concerned. The average patient is largely ignorant of the importance of regular and complete treatment and hence, needs to be motivated and counseled, not only at the start of treatment but repeatedly from time to time.

CHAPTER

8

Conclusion

Despite the tremendous progress made in understanding of biomedical features of TB disease, and serious efforts to control it, the disease continues to rank among world's most serious health problems, with important negative social, economic and psychological consequences. TB is the leading cause of death among adults from a single infectious agent. It is estimated that nearly two billion people worldwide are infected with *Mycobacterium tuberculosis*, with an estimated 9-10 million new TB cases and about 3 million deaths every year. One of the major concerns is that more than 80% of the total TB cases are found in just 22 high TB burden countries. India ranks first among these high TB burden countries, with increasing numbers of MDR-TB cases. This problem is further fueled by both delay in seeking treatment and non-adherence to TB medication. In India, it is estimated that about 2 million people develop TB every year, and 0.5 million die from this disease every year. This profile has been worsening due to the HIV epidemic in the country.

Review of literature on implementation of TB control programmes in different parts of the world clearly suggest that: i) focusing on anti-TB drugs and advanced diagnostic techniques is not adequate for successful control of TB; ii) the TB control programs that failed to recognize and work with indigenous cultural beliefs and practices have failed in achieving their desired goals; and iii) the occurrence of TB disease cannot be considered in isolation from the socio-cultural context in which it occurs.

However, the current TB control programmes in various countries including India, are structured exclusively on the principles of biomedical model of disease. TB control programmes largely ignore the physical, social and emotional contexts of the patients. Instead, it basically focuses on achieving microbial cure. In other words, its focus is on disease, not on the illness. In many societies, including in India, often there is

incongruence between the perception of illness of a TB patient and that of medical professional. A better understanding of the perceptions of patients and medical practitioners on TB will have important implications for patient care and health education programmes. Attempting this has been a major objective of this study. Table 28 presents a comparison between perceptions of patients and practitioners about TB. Study findings are also in agreement with observations made by Kleinman (1980) that disease is understood as an undesirable patho-physiological process or state, and illness on the other hand, is a much broader concept, and includes a network of meanings for the sufferer: personal trauma, life stresses, fears and expectations about the illness, social reactions of friends and authorities, and therapeutic experiences.

8.1 Major Findings

The study had an explorative aim, and the specific aims of this study were: i) to study beliefs held by TB patients about the cause of their TB; ii) to study psychosocial reactions of patients to the diagnosis of TB, iii) to explore stigma experiences of TB patients; iv) to understand the influence of cultural factors in patient delay, v) to study general patterns of health-seeking behavior among TB patients, vi) to understand knowledge about TB among RMPs, and vii) to explore differences between patients' and medical practitioners' views on TB. The main findings of this study are presented in the following section.

8.1.1 Causes of TB: Patients' Beliefs

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 factors such as smoking, alcohol consumption malnutrition, heredity, mental stress/worry, hard work, exposure to cold or hot weather, infection, witchcraft divine retribution, fate, and sexual promiscuity could play a role in the causation of TB 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. One of the possible reasons for this answer could

be that patients may have interpreted the question they were asked as seeking a single, major cause, and obliged with a single cause, irrespective of what they thought.

Patients' narratives of TB causation embrace the notion that disease causation understandings are grounded in the context of day-to-day living situations, and the causal explanations for TB discussed by the patients in this study can be grouped into four broad categories based on Helman's classification: i) *individual* (e.g., excessive alcohol consumption along with poor diet, mental stress, heredity, sleep deprivation, diet high in sugar); ii) *natural* (e.g., exposure to cold or hot weather, infection); iii) *supernatural* (e.g., divine retribution, fate) and iv) *social factors* (evil eye, witchcraft).

Results indicate that five most commonly reported causes of TB were excessive alcohol consumption (35.4%), infection (12.7%), mental stress/strain (10%), witchcraft (8.2%), and fate (6.4%). Overall, this sample of TB patients predominantly attributed causation of TB to individual factors. However, it is also observed that belief in witchcraft, evil eye, divine retribution and fate as etiological factors is very much prevalent among many patients in the study area. Such varied responses were anticipated given these patients' low level of education and lack of knowledge about TB causation as offered in biomedical model. One of the interesting findings of this study was that none of the tribal patients attributed their illness to supernatural factors such as witchcraft, evil eye or divine retribution. Tribal patients interpreted their TB illness as a natural event rather than as the result of the action of supernatural forces. This finding may be related to the fact that tribal patients and their family members had known large number of people with TB in their community, and this prior experience may have influenced their knowledge and beliefs about the causes of TB. Muslim and Christian patients also did not attribute their TB to witchcraft or evil eye. However, because of smaller number of Muslim and Christian patients, these observations can only be tentative. Extensive work needs to be carried out with large numbers of patients of different social background to understand potential differences in causes of TB.

Many of the 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; Nachman 1993). TB patients described the causation of their TB in a way that differed significantly from that of health professionals. Health care professionals primarily

attribute TB causation to germs such as bacteria. In contrast, patients' descriptions were much broader. They did not interpret their TB to objectively identifiable pathogens. Rather they attributed causation of TB to life events (e.g., death of family members) interpersonal conflicts (e.g., conflict with relatives over land sharing, conflict with spouse), environmental factors (e.g., exposure to cold weather), harmful lifestyles (e.g., excessive alcohol consumption), infection (e.g., infection through contact with utensils, clothes and/or air (expelled by the TB sufferers), and punishment (e.g., punishment for offending the deities).

It appears that modern medicine has had little impact on the patients' views on the etiology of TB. For the patients the cause of TB is multi-factorial. Patients' 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. Thus, health and illness are perceived in holistic terms. According to this view, illness affects the whole person, not simply the body or its organs. Despite the tremendous progress made in TB control and awareness programmes, the study results demonstrate the continued existence of folk theories of disease causation. Studies from other parts of India (Ganapathy, *et al* 2008), and world (Banerjee *et al* 2000), have found that extra-marital contact and careless sexual behavior as a possible cause of TB. However, in this study, none of the patients attributed extra-marital sex as a cause of their TB, though in discussions with the community members and patients there was some reference to promiscuous behavior. Table 25 summarizes causal etiologies given by patients, traditional healers, RMPs and physicians.

8.1.2 Psychosocial Reactions

All respondents in this study experienced their diagnosis of TB, in general, to be a surprise, and an unexpected explanation for their symptoms. The narrative accounts of reactions and experiences of patients being diagnosed with TB indicate that the problematic aspect of having TB for many patients appears to be psychosocial rather than just medical. Patients expressed a variety of emotional reactions including sadness/shock/worry (43%), surprise/disbelief (27%), fear of dying (10%), fate (9%), embarrassed (5%), and relief (2%). The diagnosis of TB was generally seen as shocking

and devastating experience. Future of children remained the most important concern for several patients particularly for women patients. Patients stated psychosocial concerns such as depression, interpersonal relationship problems, fears of death, fears of relapse of TB, loss of self esteem, shame, fear of spreading the disease to family members, future of children, and sexual problems. Shame surrounding the disease is most commonly reflected in patient narratives. It is clear that besides the clinical burden, patients have to shoulder a high psychosocial burden associated with TB. Most had regarded the diagnosis as a shattering experience, however, many got over their initial pessimism after coming in contact with TB service organizations.

8.1.3 Stigma

Patients' narratives reflect stigma as the principal source of distress of being a TB patient. Understanding stigma through the concepts of Felt and Enacted stigma, it is observed from the study that felt stigma is high compared to enacted stigma. But number of patients, particularly women and the elderly report high enacted stigma. TB related stigma and discrimination is a major issue for patients living with TB in rural society.

People in rural communities in Nalgonda, perceive TB as a dirty and feared disease because of its contagious nature. Stigma affected patients in a variety of ways: emotionally, mentally, physically and socially. The diagnosis of TB placed tremendous psychosocial burden on the patient and his/her family. Almost all the patients reported they had not mentioned about the nature of their disease to others in their community because of fear of social isolation and discrimination. The fear of contracting TB through sharing clothes, utensils, bathrooms, etc., continues to be very much prevalent in local rural communities.

Almost all of the participants in this study mentioned that felt stigma acted as a powerful disruptive force in their lives. For example, almost all the patients feared being rejected and discriminated by others because of their TB. Because TB was associated with a negative social stigma, patients as well as their family members deliberately had hidden their disease from others in society in order to avoid stigma associated with TB. Occupying a subordinate place in rural social structure, and being dependent on husbands and in-laws, women expressed a fear that they would be socially isolated, rejected or

abused by husbands and in-laws in particular. Not surprisingly, very few respondents spoke openly about the nature of their disease with other people. In fact, non-disclosure was the first line of defense for many patients. Almost all the patients mentioned other common illnesses (such as ulcer, malaria, typhoid or skeletal disorders), as an explanation of their ill health to outsiders. Unmarried young patients, particularly young unmarried women, expressed a concern that TB may jeopardize their marriage prospects. Discrimination from in-laws, and husbands figured more prominently in the narrative accounts of female patients. Long *et al* (1999) and Rangan & Uplekar (1998) made similar observations among the Vietnamese and Indian women patients respectively.

Enacted stigma caused considerable pain and distress among the patients. Some patients explained that they had experienced some form of discrimination from their own family members. Manifestations of stigma and discrimination ranged from abusive words to isolation. For instance, one elder male patient said “*what is left in life when your own son does not let you to enter his house?*” Some female patients explained that their illness resulted in marital problems. It was found that women faced greater internalized stigma, and avoided attending social events. For example, one woman patient said that she was not participating in family functions to the extent she once did, because she no longer feels comfortable as a result of her own sense of guilt and shame. In different parts of the world, women with unequal access to social, political and economic resources are forced into situations of dependence and powerlessness, making it difficult for women to express control over their lives. These findings concur with findings reported by several investigators (Liefoghe *et al* 1997; Jaramillo 1998; Long *et al* 1999; Auer *et al* 2000; Rajeswari *et al* 2002; Atre *et al* 2004; East wood & Hill 2004; Hoa *et al* 2004; Cambanis *et al* 2005). Table 26 summarizes cause, management, and consequences of TB related stigma.

8.1.4 Patient Delays in Seeking Medical Care

Practitioners said that patient delays, emergence of MDR-TB cases and non-compliance to TB medication represent major obstacles to treatment success. Practitioners attributed patient delays to factors like illiteracy, lack of awareness of symptoms, consultation with RMPs, and social stigma. Practitioners opined that most

patients generally decide to go to TB clinics or private hospitals only when symptoms persist or reoccur despite seeking treatment from RMPs. Practitioners also explained that patients often deny or conceal their symptoms because of fear of social stigma, and hence, delay seeking health care.

In contrast, patients explained that a complex interaction of socio-cultural factors contributed to patient delay. These factors include: i) lack of knowledge about susceptibility to TB; ii) traditional disease causation beliefs; iii) absence of typical or defining symptoms of TB; iv) lack of knowledge of severity of symptoms; v) non-interference with daily activities; vi) self medication; vii) attribution of symptoms to less serious illnesses such as flu, cold or fever; viii) traditional herbal treatment; ix) wait and see approach; x) economic and time constraints, and xi) disbelief in urgency. Patients explained multiple factors as a cause of their delay, 69% of the patients waited two months or more before seeking professional care.

The findings of this study clearly suggest that symptom iceberg exists in the study area. A large number of patients did not bring their initial symptoms to the notice of medical professionals for treatment for various reasons. For instance, patients considered their initial symptoms such as cough, loss of appetite as trivial and non-life threatening and felt it was a routine minor ailment. Furthermore, patients reported that their initial symptoms didn't interfere with their daily life. Hence, they felt no urgency to go to a medical doctor for treatment. The above two important factors influenced an individual's willingness to seek medical care. Much of the early symptoms of TB do not reach medical attention. The term 'symptom iceberg' which has been used to describe this phenomenon, is observed in the study area.

Similar to people of rural areas in India and other developing countries, rural patients of this study area have a wide spread perception that illness is not serious in its initial manifestations. Patients allowed disease symptoms to persist for a considerable period of time before seeking formal care rather than seeking treatment at an earlier stage hoping self care remedies (over-the-counter medicines, herbal teas or medicines), might initially suffice. Perhaps one of the strongest influences on patient delay in seeking health care in this study was that none of the patients viewed themselves at risk of developing TB. Patients made comments like, *'I was totally stunned to hear that I had TB'*, *'I never*

ever thought that I would get TB because none of my family members had suffered from TB before'. There was a strong cultural belief among the patients and the community members that only a past history of TB in the family increases one's susceptibility to TB. Thus many patients did not perceive themselves to be at risk for TB, and hence delayed seeking care.

Longer delays were observed among extra-pulmonary patients with symptoms of lumps. Extra-pulmonary patients with symptoms of lumps explained that they did not possess knowledge about the significance of the presence of a lump. There is a widespread cultural perception among the extra-pulmonary patients that excessive 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. Extra-pulmonary patients considered that their lumps were not serious enough to warrant seeking medical care until it was so crippling that it could no longer be tolerated. Some patients delayed seeking treatment for more than one year because lumps were painless and did not interfere with day-to-day activities. Cross-cultural qualitative studies in Nepal, Philippines, and Bangladesh reveal similar understandings of the body, where hot and cold reasoning underlies perceptions of illness, causality and prevention.

It was observed that a delay in the decision to seek treatment was very common among the alcoholic patients. These patients associated their initial symptoms with smoking and alcohol consumption. Alcohol consumption appears to be a major problem in the study region. With the high level of alcohol use and smoking in this region, it can be assumed that the presence of cough, loss of appetite, and weakness is seen as normal to alcoholics and smokers. Hence, these patients believed they were dealing with common symptoms and not TB or not any other major illness, and delayed seeking medical care. This finding concurs with other studies conducted, for example, in Philippines by Auer *et al* (2000).

It was also found that delays in bringing symptoms to a physician's attention were due to attribution of symptoms such as intermittent fever and loss of appetite and weight to a folk illness called *pasakalu*. There was a universal agreement among the patients and community members that there is no biomedical cure for *pasakalu*. Patients who assigned their initial symptoms to this folk illness resorted to traditional herbal treatment. 38% of

patients sought treatment from traditional herbalists prior to the diagnosis of their TB. Resort to traditional herbal treatment caused considerable patient delay. Disease in such patients worsened a great deal. Similar observations were made by Rubel & Garro (1992) among Hispanic Americans in America. Rubel & Garro in their study found that many Hispanic Americans attributed symptoms of TB to folk illness called *grippe* or *susto*.

Economic constraints and family responsibilities were also cited as reasons for delay in seeking care. Women patients mainly explained lack of time as one of the reasons for delay. Women patients explained that the demands of household work and caretaking of children caused delay. Attaching insufficient meaning or significance to the early signs and symptoms of TB also contributed to delay in availing health services. Study patients equated TB with coughing up blood/sputum, a skinny body and wasting away. Absence of such symptoms led to incorrect interpretation of symptoms or attribution of symptoms to a less serious illness, and led to delay in seeking treatment.

Prolonged self treatment also appears to be one of the major reasons for delay in seeking appropriate treatment. Similar findings have been reported by Allan *et al* (1979) in Hong Kong. Although stigma has been associated with delay in seeking treatment (Auer *et al* 2000; Atre *et al* 2004; Liefoghe *et al* 1997), this study did not find stigma to be predictor of delay. This finding was not surprising given that only one participant in this study suspected he had TB prior to the diagnosis of his TB. If a person does not suspect that he/she has a stigmatizing illness, stigma may not be a factor in their decision to seek treatment. Though, it may be possible that the fear of stigma associated with TB, may have made most of these patients subconsciously, to deny that they may have TB.

8.1.5 Health Seeking Behavior

In this study, the health seeking behavior of TB patients clearly suggests that patients in general operate within the three sectors of Kleinman's (1980) model: popular, folk and professional. All the patients tried diverse health care resources in the hope of getting relief from the symptoms. These diverse health resources ranged from the use of self-care, home remedies, herbal medicine, faith healing, prayer, massage, magical spells, sacrifices, and western medicine. Thus health-seeking of TB patients in this study can be described as pluralistic in nature (Table 27). Patients freely move from one sector to

another sector until they are cured or feel relief from the symptoms. Outcome of the selected treatment is considered one of the important indicators for continuing or discontinuing the treatment in a particular sector. When the patients perceive that there was no respite in their symptoms from one system, they approached another health care provider or another health care resource, depending on their experiential knowledge. Thus, health seeking pathways are not determined a priori. As time passes, and if the symptoms persisted, patients used multiple health care choices. A variety of factors influenced this multiple health seeking behavior including perceived efficacy of a given treatment, nature and severity of symptoms, accessibility and affordability of treatment costs, advice of family and community, and attribution of causes. For example, when the patients and their family members believed that an exposure to cold weather might have caused symptoms of cough and cold, they tried to treat with hot foods and over-the-counter medicines so as to restore the balance between hot-cold qualities in the body. When the patients perceived the causes as supernatural, they resorted to magico-religious healers. Similarly, when the patients believed that consumption of meat during an illness episode might have caused folk illness *pasaklu*, they resorted to traditional herbalists. It can be argued that treatment choices evolved during the health-seeking process as the patients and their family members gained more knowledge of symptoms, acquired more information from social networks and health care providers, herbalists, RMPs, or magico-religious healers.

Self care was the most common response in the health seeking process at the first stage. Patients used some kind of self care remedies to get respite from initial symptoms. These self care remedies include over-the-counter medicines, herbal teas, massage, prayer, and changes in diet. While on TB treatment, a vast number of patients (>80%) reported that they offered prayers in the hope of getting blessings from god in order to cope with the illness. Patients explained that traditional therapies helped them a great deal in overcoming anxiety, stress and depression. This study supports the earlier findings that prayer is a significant coping mechanism for a large number of respondents. Engaging in prayers and other folk healing mechanisms resulted in an immense sense of control and relief from the trauma of TB disease for many patients. A majority of patients mentioned religious faith and prayer as a major source of support in coping with TB.

When the symptoms persisted despite self care, patients switched to other alternative sources of health care. For majority of patients (74%) RMPs were the first point of contact. However, all the patients switched to biomedical physicians as their symptoms worsened. For a majority of patients TB diagnosis was established at private nursing homes/clinics. However, all these patients switched to government TB services as they could not afford the long treatment costs.

The study findings suggest that use of alternative treatments is very common in TB patients. Alternative therapies are used as an adjunct to TB treatment. Users of alternative medicine did not reject Western TB medication, but simply looked for ways to supplement, augment, and complement the therapies that Western medicine offered. In many patients, alternative therapists such as priests, diviners, and witches appear to fulfil psychological needs that are not provided by biomedical providers. In a way, TB patients do sense the limitations of Western medicine while recognizing its efficacy. While the TB drugs treat the disease, alternative therapies to heal the self are seen as equally important in the cases of TB. After embarking upon RNTCP treatment, 17% had consulted faith healers such as priests or witches as a complementary to biomedical TB treatment. Patients patronized spiritual healing centers or magico-religious healers because they are famous in their community or were introduced to them by people whose sickness was cured by them. Patients turned to faith or magico-religious healers out of anxious feelings, perhaps from an unfavorable prognosis, and the long drawn nature of TB treatment. Perhaps the most attractive aspect of many of these treatments is the holistic approach and the orientation towards the individuals' felt needs, rather than the clinically determined need for health care.

Witchcraft, evil eye or curse are the most common disease causation models among the patients who had consulted magico-religious healers and faith healing temples. There is widespread belief, among the patients who attributed their illness to witchcraft, evil eye or divine retribution, that treatment and cure of illness are quite distinct. TB drugs are believed to remove the symptoms of TB, while faith healing is believed to be effective in removing the underlying cause of TB. There is a wide spread perception among the community members that when the symptoms do not provide expected cure even after prolonged treatment, suspicions of witchcraft, evil eye or divine retribution may emerge.

Patients who resorted to faith healers reported that their confidence in the efficacy of TB treatment and health care workers waned considerably for various reasons including, the long course of TB treatment, side-effects, little relief from the symptoms, and beliefs regarding the causes of TB. These patients initially attributed the etiology of their TB illness to individual and natural factors, but later gave different interpretation when there was little improvement in their health condition. Such changes in initial tentative categorization of illness from individual and natural categories to social and supernatural categories is not unique to the people of Nalgonda district, but are reported in a number of studies in various parts of the world (Ten *et al* 2008; Mochache & Nyamongo 2009).

In summary, health seeking behavior of TB patients suggests that patients are interested in the management of their illness and will explore all avenues to try and overcome the illness. This study reveals that the popular sector is the most important source of care for patients. It is within this sector, patients, family members and community networks determine when to seek consultation, which practitioner to consult, whether the treatment is effective, whether to change practitioners or seek care from alternative system practitioners, whether to change treatments, whether or not to adhere with therapeutic recommendation, and whether they are satisfied with the quality of care. This observation is in accordance with observations made by Kleinman (1980). It is the popular sector that guides the use of professional and folk sectors. But an engagement with the professional sector is inevitable for all the TB patients, as all patients finally realize that modern medicines are critical in the treatment of TB.

Table. 25 Summary of the Causal Etiologies given by Patients, Traditional healers, RMPs and Physicians

VARIABLES	ETIOLOGICAL CATEGORY				
	Individual	Natural	Social	Supernatural	Biological
Patients	√	√	√	√	
Traditional healers	√	√	√	√	
RMPs	√	√			√
Physicians					√

Table. 26. TB and Stigma

TYPE AND EXPERIENCE OF STIGMA	<p><u>Felt stigma</u></p> <p><u>Enacted stigma</u></p>	<ul style="list-style-type: none"> - All the patients experienced felt stigma. - Expressed a fear that they would be stigmatized if their state of disease became public knowledge. - Some patients experienced discrimination from their husbands, in-laws, sons or wives.
CAUSE OF STIGMA		<ul style="list-style-type: none"> - Contagious nature of TB, and history of isolation of patients - Coughing up sputum; fear of contracting TB infection.
MANAGEMENT OF TB STIGMA		<ul style="list-style-type: none"> - Did not disclose TB status to outsiders, and within family to in-laws. - Informed other people as having other non-stigmatized illnesses (e.g., pneumonia, ulcer, malaria). - Limited social activities/relationships - Maintained some distance from other people (e.g., neighbors, in-laws)
CONSEQUENCES OF STIGMA		<ul style="list-style-type: none"> - Isolation, shame, discrimination, abuse, and psychological burden.
GENDER DIFFERENCE		<ul style="list-style-type: none"> - Women patients experienced stronger felt stigma than male patients. - Some married women feared rejection, discrimination, harassment or abandonment by husbands and in-laws.

Table. 27. Medical Pluralism

SECTORS	PRACTICES and BELIEFS of PATIENTS
POPULAR SECTOR	<ul style="list-style-type: none"> • Over-the-counter medicines, local herbal teas, prayer, massage, special foods, changes in lifestyle habits (e.g., restriction in use of alcohol and smoking, avoidance of sex), are the most common popular sector practices. • Patients consult members of social network (e.g., family members, friends, relatives, paramedical professionals, priests) for guidance and health care information. • Symptoms are perceived and diagnosis is made. • Efficacies of different treatments are evaluated.
<p>FOLK SECTOR</p> <p><u>Secular practices</u></p> <p><u>Sacred Practices</u></p>	<ul style="list-style-type: none"> • Folk sector practices can be broadly grouped into secular and sacred practices. • Herbalists are consulted for treatment of folk illness (<i>pasakalu</i>). Generally herbalists are consulted prior to the diagnosis of TB. • The treatment of <i>pasakalu</i> is regarded exclusively as the domain of the traditional – herbalist, and there is no biomedical cure seen for this illness. • Sacred remedies include the worship of deities, the propitiation and appeasement of angry deities and evil spirits, and the wearing of amulets. • Sacred healers include magicians, witches, priests, faith healers and diviners. • Social and supernatural causes are suspected by the sick person before he/she seeks - treatment from a witch or faith healer.

	<ul style="list-style-type: none"> ● It is believed that evil spirits and angry deities prevent TB medicines from working, and this is why patients who attributed their illness to malevolent spirits and angry deities sought help from magico-religious healers to appease or expel evil spirits. ● Patients resort to magico-religious healers towards the later stage of health seeking behavior. ● Treatment by magico-religious healers is holistic in nature.
PROFESSIONAL SECTOR	<ul style="list-style-type: none"> ● Medical practitioners and RMPs provide professional Allopathic health care services. ● Patients generally approach RMPs as the first point of contact for treatment. ● Proximity, greater convenience, easy access, low cost, better interpersonal – relationships are the major reasons for choosing RMPs as the first point of contact. ● Generally most patients consult medical professionals when symptoms - persist despite treatment by RMPs, and in some cases by herbalists. ● Biomedical treatment is important and inevitable for all the TB patients. ● with reference to treatment of TB none went to Homeopath or Unani doctor after diagnosis of TB.

Table. 28 Summary of the Patients', Traditional healers' and Physicians' Explanatory Model of TB

EXPLANATORY MODEL	Patients	Traditional Healers	Physicians
TERMINOLOGY OF TB	TB, Upirithithulake neeru vachindi, pakkatemulaku neeu vachindhi.	TB, Upirithithulake neeru vachindi, pakkatemulaku neeu vachindhi.	TB, Koch's disease
CAUSE	Fate, evil eye, witchcraft, divine retribution, sleep deprivation, mental stress, infection (contagious nature of TB), heredity, exposure to cold climate, hard work, alcohol consumption, hot-cold imbalance, diet high in sugar.	Pesticides, fertilizers, infection, hot-cold imbalance in the body, excessive alcohol consumption, evil spirits, god's punishment, witchcraft, breach of religious taboos.	Bacteria (<i>Mycobacterium tuberculosis</i>)
SYMPTOMS	Coughing up blood and/or sputum, wasting away, thin body	Coughing up blood and/or sputum, wasting away, thin body	Cough, fatigue, loss of appetite, night sweats, intermittent fever, loss of weight.
TB TRANSMISSION	Contact with an ill person's utensils, clothes, bed sheets, urine, and sexual fluids. Breathing the air expelled by the sufferers.	Close contact with the TB patients, contact with sexual fluids, bad air expelled by the TB patients	Airborne infection
CURABILITY	Curable	Curable	curable
NATURE OF DISEASE	Very serious and dreaded disease	Serious disease	Not a serious disease
CHOICE OF TREATMENT	Anti-TB drugs, good food, prayer, massage, faith healing, self care, herbal drinks, magical spells.	Anti-TB drugs, good food, prayer, exorcism of evil spirits, sacrificial rituals, faith in god, amulets, communal feasts, appeasement of deities.	Anti-TB drugs (DOTS), Protein rich diet.

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EXPLANATORY MODEL	Patients	Traditional Healers	Physicians
TERMINOLOGY OF TB	TB, Upirithithulake neeru vachindi, pakkatemulaku neeu vachindhi.	TB, Upirithithulake neeru vachindi, pakkatemulaku neeu vachindhi.	TB, Koch's disease
CAUSE	Fate, evil eye, witchcraft, divine retribution, sleep deprivation, mental stress, infection (contagious nature of TB), heredity, exposure to cold climate, hard work, alcohol consumption, hot-cold imbalance, diet high in sugar.	Pesticides, fertilizers, infection, hot-cold imbalance in the body, excessive alcohol consumption, evil spirits, god's punishment, witchcraft, breach of religious taboos.	Bacteria (<i>Mycobacterium tuberculosis</i>)
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8.2 Implications of the Study for Patient and Health Care Professionals

Since the folk medical beliefs of patients inevitably influence their relations with physicians, the influence is likely to be an adverse one when the physician does not recognize the existence of such beliefs or persists in seeing them as evidence of ignorance or superstition. When the doctor is aware of folk beliefs and is sensitive to the meaning they may have for patients, the beliefs can be used to obtain cooperation in the relationship. Recognition and understanding of folk medical beliefs and practices by the doctor does not mean that such beliefs and practices must be accepted as scientifically valid. It is only necessary to recognize that they exist, that they can influence the outcome of treatment in many cases, and that they can sometimes be used to benefit the patient.

Fosu (1981:480).

The study results clearly demonstrate that patients' beliefs and perceptions about TB differ from biomedical practitioners. The different views captured in this study can be related to the anthropological terms '*emic*' (ideologies of local cultures), and '*etic*' (ideologies of practitioner outside culture). The incongruence between patients and practitioners emphasize the different domains of explanatory models of TB. Patients mostly emphasized the problems in the psychosocial domain and expressed concern about the impact of TB on their daily lives and interpersonal relations. In contrast, practitioners viewed TB basically as a patho-physiological problem with primary impact on patient's physical body. Nations *et al* (1985) strongly argue that patients simply have their own cultural beliefs and perceptions about an illness which differ from biomedical model's explanation of disease found in medical textbooks. If such differences are ignored by physicians, the doctor-patient interaction often becomes a perfunctory exchange marked by patient-physician stress, miscommunication, non-adherence, dissatisfaction with treatment, etc.

This study clearly demonstrates and endorses the view suggested by renowned medical anthropologist Arthur Kleinman (1980) that studying perceptions and experiences of patients helps in understanding of social dimensions of illness better

compared to biomedical studies. The current RNTCP TB control strategy in India largely ignores psychosocial needs of the patients. Instead, it focuses on achieving microbial cure, with emphasis on the need for consistent long-term therapy. From the findings of this study, it could be argued that the too narrow focus on treatment of TB disease under RNTCP is not adequate for providing effective care to the TB patients as evident from the failure of these TB control programmes. TB control programmes must address not only microbial cure, but also patient's physical and psychosocial needs and quality of the life of the patients. Addressing the physical and psychosocial needs of the patients' can lead to client oriented-comprehensive care and improving the quality of life for TB patients.

The narrative accounts of reactions and experiences of patients on being diagnosed with TB, indicate that patients are more concerned about psychosocial problems than patho-physiological problems. Hence, it is important for medical practitioners to gain insight into the reactions and beliefs of TB patients on being told about their diagnosis. Careful enquiry into patients' psychosocial reactions may help in understanding the psychosocial needs of the patients. From a clinical perspective it seems essential for health care professionals to provide psychosocial support to their patients. Health care workers should also encourage the patients to share their concerns and anxieties associated with TB. As mentioned in a previous chapter, TB is a 'social' disease, and any TB control programme has to engage with and address the social world of the patient.

This study confirms that there is a delay between the onset of symptoms and initiation of appropriate treatment among TB patients in rural Nalgonda. Almost all the patients gave more than one reason for the delay in seeking early health care. In the biomedical framework, this delay in seeking health care is blamed on the patient who is often regarded as illiterate, negligent, ignorant, and who is made to feel guilty about it. However, the findings of this study clearly suggest there is a need to understand the complex range of socio-cultural factors behind this delay. Health care professionals need to be aware of the fact that patients' socio-cultural belief systems influence variations in health-seeking behavior. Normative universal modes of behavior that the biomedical model expects need to be questioned. It is hoped that some of the responses that emerged

from this study are considered positively by health professionals and patients not blamed for delays in seeking appropriate medical care.

A major question that needs to be posed is, 'What is appropriate care'? In the biomedical model only western medicine or Allopathy, is seen as good care and not to be questioned. In other words, Allopathy is the only system seen as appropriate, while all other systems of health care are unscientific, inadequate, not recognized, and to be discouraged. For the rural patients, alternative health care systems are complementary to Allopathy, as they reflect and are a part of their own familiar social worlds. For them the practice of medical pluralism is therefore complementary and not competitive. The language and practice of Allopathy is viewed as unfamiliar, and hence intimidating. While the other social health systems are familiar, part of their everyday world and acceptable, and practice is thus easier. In a sense, it may be argued that Allopathy, in its ignoring of the 'social', has created a sense of alienation among both the patients and the practitioners. This partly explains why patients delay seeking health care and are non-compliant

The results of this study provide valuable information on the culturally based misconceptions about causes and transmission of TB. Study findings clearly suggest that patients' and RMPs knowledge about TB causation and modes of transmission and symptoms was different. Such perceptions (e.g., TB caused by witchcraft or through sharing utensils, bathrooms, etc.) may lead to social stigma, social tensions, and contribute to myths and misconceptions. Considering TB as a punishment or due to witchcraft reflects the control of social world in the study population. Study findings suggest that there is a need for innovative approaches to disseminate information about cause and transmission of TB to patients and community members. Many of the misconceptions surrounding TB transmission need to be first contextualized and then dispelled rather than rejected. Educational programs should not only address facts about TB transmission, but also the basis of pre-existing prejudice, stereotypes and discrimination about TB. Such health educational programs play an indispensable role in reducing TB related phobia.

For prevention programs of infectious diseases such as TB to be effective, the associated stigma must be actively addressed. The effective implementation of anti-

stigma programmes in schools, and communities may contribute to positive health outcomes. Breaking the discrimination based on stigma can only be successful by joint efforts of patients, relatives, family members, professionals and the public. Tackling stigma and discrimination requires the need to address deeply entrenched perceptions about transmission of TB. The following few measures may help in reducing the stigma associated with TB to a certain extent: i) Culturally embedded attitudes, beliefs and misconceptions about TB cannot be expected to change overnight. Hence, anti-stigma programs must last for a long time, and health care workers must devote a considerable amount of their resources and energy in reducing social stigma. ii) The goals of anti-stigma programmes must have local relevance, and must be culturally sensitive. iii) The program must deal with the problems experienced by TB patients and their family members. The best way to identify what are the most disturbing experiences is to ask those who are affected by stigma, about changes that they would see as being important in terms of improving their social situation. iv) One possible factor in the continued high stigma associated with TB is the fact that TB clinics/chest hospitals are all located separate from general hospitals/clinics. This physical isolation of the TB ward/clinic/hospital has possibly contributed to the continued stigma regarding the disease in the public imagination in rural areas. A visit to the primary health centre or general hospital can be for any ailment but a visit to a TB clinic or hospital is clearly identified with this disease- there is no anonymity about your ailment, you get marked as having TB. Added to the history of stigma linked with TB because of its highly contagious nature, the isolation of TB clinics/hospitals to bring down infection rates, actually pushes TB patients into a vicious cycle of further stigmatization in rural areas.

It was observed that multiplicity of treatment options (such as self-care, herbal medicine, magico-religious healing, faith healing, cosmopolitan medicines) is the characteristic feature of health care system in Nalgonda district. The study findings suggest that the use of multiple therapies by TB patients is very common, and patients see no conflict or dichotomy between these plural systems. The results of this study clearly suggest that health care workers involved in the treatment of patients with TB should be willing to recognize and discuss the use and practice of alternative treatments and to try to identify and deal with the unmet needs of patients, in order to make patients more in

control of their situation. Such a shift in thinking will impact on reducing ‘non-compliance’ seen as a major deterrent to successful TB control programmes.

Concluding Comments

In conclusion, this study contributes in a modest way towards understanding the limitations of the biomedical model. It also makes a case for a new type of practitioner: reflexive and culturally sensitive and able to combine the roles of a skilled and empathic physician with those of an applied medical anthropologist and sociologist. The biomedical approach to TB treatment is extremely important, as long as its limitations are recognized. Biomedical practitioners and health policy makers need to be aware of the fact that the biomedical model’s assumptions such as physical reductionism, mind-body dualism and mechanical metaphor cannot provide them with a complete understanding of human suffering. This is because, illness results from the interplay of mind, body, and environment. Hence, to treat TB patients effectively, the medical practitioners approach should be a holistic one, in the sense that the whole person should be taken into account, not simply the diseased organ of the human body which is the main focus of the biomedical practitioners. Effective care for TB requires a broader approach beyond the mere medication regimens. Biomedical practitioners need to focus on the whole person, taking into consideration their social, mental, emotional, and spiritual well-being. Health care workers must play an active role in allaying fears and concerns of patients and their family members. In addition to patient education, social support structures need to be strengthened.

Today, public health care services are challenged to employ innovative methods in treating TB patients. As a necessary first step, health care providers need to understand influence of culture on patients’ understanding of their TB. They can do this by acknowledging the explanatory models that patients hold about their TB. Studying patients’ explanatory models of illness can liberate the clinician from a simplistic and limiting single focus biological perspective, and help them in viewing illness in a multi-perspective pluralistic nature. Furthermore, this will improve culturally sensitive communication between patients and their health care providers. As Ailinger & Dear (1997:530) rightly point out that “*cultural relevance assumes additional importance as a*

factor influencing the successful management of TB preventive therapy programs. More than ever, providers must focus their treatment plans and programs within a context that recognizes the sociocultural experience from which their clients' views of illness emerge". For medical care to be most effective-and-acceptable to patients, general practitioners should treat both illness and disease in their patients at the same time. They should also be aware of how the perspectives of the lay and medical models of ill health differ and should recognize the clinical implications of these differences. Major emphasis on the treatment of disease without considering the illness dimension may cause dissatisfaction among the patients, may lead to non-compliance, self-medication or consultation with the unqualified practitioners who are more willing to deal with the illness dimension.

Health policy planners and health care workers need to recognize that factors such as fears, anxieties and socio-cultural beliefs about TB provide important inputs for any effective treatment of the disease as highlighted in the study. TB is more than just a biomedical phenomenon. It maintains its grip on those human populations already suffering from poverty, overcrowded living conditions, inadequate housing, malnutrition, and lack of access to medical care.

Any TB control programme needs to therefore move beyond 'medicalization of the disease', to include the socio-cultural dimensions that impact disease and its treatment. The findings of this study provide justification for such an inclusive and interdisciplinary approach. Finally, it must be admitted that this present research is only a small contribution to the limited literature on TB in India from a socio-cultural perspective. Further micro-level studies of perceptions of TB based on gender, caste, tribal, religious beliefs are required to provide better insights to our understanding of TB. It is hoped the findings of this study will encourage such future research agendas.

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Annexure

A) Definitions under RNTCP

Pulmonary tuberculosis, smear positive – TB in a patient with at least 2 initial smear examination (direct smear microscopy) positive for AFB (Acid fast bacilli); **Or** TB in a patient with one sputum examination positive for AFB and radiographic abnormalities consistent with active pulmonary TB as determined by the treating medical officer; **Or** TB in a patient with one sputum specimen positive for AFB and culture positive for *M tuberculosis*.

Pulmonary tuberculosis, smear negative – TB in a patient with symptoms suggestive of tuberculosis and radiographic abnormalities consistent with active pulmonary TB as determined by a medical officer; **Or** Diagnosis based on positive culture but negative AFB sputum smear examinations.

Relapse – A relapse is defined as a positive culture for *M tuberculosis* in a patient who had previously completed an adequate course of therapy (Weis *et al* 1994).

Treatment After default (TAD) – A patient who received anti-tuberculosis treatment one month or more from any source and who returns to treatment after having defaulted, i.e., not taken anti-tuberculosis drugs consecutively for two months or more.

Failure – Smear-positive patient whose sputum remains smear positive at 5 months or more after the start of chemotherapy. Failure also includes a patient who was initially smear negative but who became smear positive during treatment.; **Other** - patients who did not fit into the above mentioned categories are regarded as ‘other’ category. Specific reasons for categorizing a patient under this category should be indicated (Khatri, 1999).

B) Historical TB Terminology

TB infections have been described under variety of names over the course of history. Some of these historical names include:

<u>Historical Term</u>	<u>Clinical Symptoms</u>
Pott's Disease	– TB of the spine
Phthisis	- The word phthisis was introduced by the ancient Greeks. Phthisis means loss of weight seen with pulmonary TB.
White Plague	- TB especially of the lungs. TB was referred to as white plague because TB sufferers appear markedly pale.
Lupus Vulgaris	– Cutaneous TB.
Koch's Disease	– Named after Koch who discovered the <i>Mycobacterium tuberculosis</i> .
Tabes mesenterica	– TB of the abdomen
Scrofula	– TB of the cervical lymph nodes. Also called 'King's Evil' [It was called as <i>King's Evil</i> , because of the myth that kings of England and France had special healing powers and it could be cured by the touch of a reigning monarch. This custom believed to have originated in the 12 th century and continued until the 18 th century (Madkour, 2004).
Consumption	- English speaking people introduced the term consumption to refer to TB. It was called as consumption because of the weight loss and wasting that characterizes the disease. TB seemed to consume people from within with its symptoms of bloody cough, fever, pallor and long relentless wasting
Tuberculosis	- Johann Lukas Schonlein (1793-1864), Professor of Medicine at Zurich, named the disease 'Tuberculosis'. The word tuberculosis is derived from a Latin word "tubercula" which means a small lump (Waksman 1964). The word TB may have appeared in print around 1840 for the first time, and but it came into popular use only during the last 100 years (Dubos and Dubos 1952).
Romantic Disease	In the nineteenth it was named as a romantic disease. Perhaps because in the nineteenth century a number of best and brightest young writers, poets, playwrights, artists, musicians, courtesans, scientists, and glamorous ladies died from TB. "People dying of tuberculosis became thin, pale, and gaunt, a look that was considered stylish, much like today's "heroine" ,"chic super models", hence, it became a romantic disease (Reichmann & Tanne 2002:18).