Chapter: One

INTRODUCTION

1.1 Introduction:

Disease or infirmity is as old as human civilization. Its connotations and explanations have been changing according to the prevalent theoretical paradigms and the ongoing shifts in social relations. Developments in the field of health and disease have remained surrounded by debates and 'contradictions'. The debates have been around several issues: whether disease is caused by vector or host; whether increase in life expectancy and reduced death rate is the outcome of 'medical victories' or whether they are outcome of changes in the levels of food and nutrition and whether solutions lie in social epidemiology or in investment in biomedical advancements.

There was a time when disease was considered as the vengeance of the gods or nature, which belief also provided the explanation for its prevalence in particular settings. Initially, good environmental conditions, which mean sufficient amount of water, adequate hours of sunshine and so on, were considered a precondition for good health. With the colonization of different countries located in different climatic zones of the world, this idea was carried forward and schools of tropical medicine came into existence, throughout the western countries. In these circumstances, the study of immediate environment of the individual and of epidemiology became an integral part of health and disease related studies. After the establishment of the Germ-theory, pathogens such as viruses and bacteria were identified as causes of disease. However, exposure to pathogens, while necessary, is not sufficient to cause disease. The growth or decline of the pathogens depends on the environmental conditions including the level of living of

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The study of the triad of 'agent-host-environment' gradually became more comprehensive and disease came to be understood as a consequence of the interactions between the pathogens, the host, and the environment. It is this conception of disease that legitimises the geographer's claim that 'ecology of disease', is a branch of geography, though disease ecology has been considered a branch of ecology and not of geography. Epidemiological studies, which are as old as Hippocrates, in their current sense began with investigations of the Cholera outbreaks in London by John Snow around the mid-1800s. However, the dominant explanatory paradigm during the eighteenth and the nineteenth centuries adopted a mechanistic view of the human body and considered that disease is like a snag in a machine and it can be corrected by repairing the machine.

The next change came with the introduction of the idea of political economy in the field of health and disease. Marxist political economy approach considered disease as an outcome of the larger economic system, which is based on class relations and operates in a dualistic framework of exploiters and exploited. Health-profile of a population according to the Marxist approach depends on many factors and is a combination of existing environmental risks (physical, biological and social), the proportion of the population facing these different risks and the socio-cultural-demographic profile of the region. Besides, health-profile gets affected by the availability and accessibility to health services and by the groups within a particular region or country that utilize or are supposed to utilize these services. The relative poverty and inadequate access to basic services and opportunities are some of the fundamental reasons for the existing pattern of health in the developing countries. Political economy, with its insistence on the need to

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2 For details on this debate see, F. A. Barrett (1986) 'Medical Geography: Concept and Definition', in M. Pacione (ed.) Medical geography: Progress and Prospect, Croom Helm, New Hampshire, pp. 1 - 35.
link the distribution of power with productive activity emphasizes the need to analyse things including health and disease in a framework of social constructions.

The availability and accessibility of good environment is not only an ecological factor but is conditioned by the political decisions made locally and globally. Political ecology is a new approach rooted in political economy and cultural studies. It tries to critically understand the relationship between society and the natural world. Political ecology use ecological analysis with its broader vision of bio-environmental relationship. From the perspective of the political ecologist the environment ranges from the very large cultural (epidemiology of disease in urban settings) through intensely political (resource endowment) to fairly significant natural environment. This study uses the political ecology approach that expands ecological concepts to include cultural and political activities within an analysis of ecosystem that are significantly but not entirely socially constructed. It is imperative for a political ecologist to study the society before seeing its relationship with the natural environment. It is also equally important to examine how natural is the “natural world”. With changing times, the nature of health (physical), economy, polity and space has got transformed. Hegemonic and capillary forces have replaced the use of naked, brutal and coercive forces. Under present day capitalist system, various artefacts of the socio-cultural setting including health and education and various other promises are offered by the modern liberal democratic state. Health, under this proposition, is amenable to all the laws of wealth. In fact, wealth has been the basis of all power and an invincible force of governance, and health too has become an effective instrument for the accumulation of wealth in different ways in different times. Not surprisingly, the health and physical well-being of the population has become one of the essential objectives of contemporary political power.
1.2 Context of the study

With the study of the ‘agent-host-environment’ triad, disease is understood as a consequence of the interaction between the pathogens, the host, and the environment. Good health of a population largely depends on many factors like existing environmental risks (physical, biological and social) in the region, demographic, cultural and economic conditions. Many earlier studies have identified the macro-level socio-cultural, economic, and political influences that are important in contextualizing ‘political ecology of disease’. Some of the earlier studies can be broadly categorised into medical, ecological, socio-economic and political. The dominant stream of medical studies falls under the medical tradition. Many scholars have discussed the growth and maturity of the agent (pathogens, virus, bacteria etc.) and the susceptibility of host (human) to these agents. These kinds of studies started with Harvey’s ‘Blood Circulation Theory’ and later developed as ‘Germ Theory of disease’. Some of the scholars were more concerned with the role of environment than the status of agent and host. They argued that environment plays a dominant role in the susceptibility of the host and maturity of the agent. They highlighted the role of various factors like sunlight, direction of wind and the amount of precipitation. Scholars like Pavlovsky (1962) and Meade (1977) have discussed the role of soil types, acidity of soil, and precipitation in the occurrence of particular diseases. The role of altitudinal mobility and the cycle of disease have also been studied.

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Researches related to the vitality of biological factors developed in epidemiological studies. Scholars like Kaufman, Cooper (1999), Zielhuis, Kiemene (2001), Krieger (2001), Kaufman (2001), Kawachi (2002) gave importance to social factors and highlighted the importance of social epidemiology. They considered that social conditions were dependent on many socio-economic factors like quality of drinking water and housing in a city. Hippocrates (4th Century B.C.), Petermann (1852), Snow (1855), Howe (1968), Finke (1792) in Barret (2000), Greeks and Romans in Johns and Moon (1987) tried to demonstrate the role of these factors in the occurrence and control of a particular disease over space. Dubos has been instrumental in the development of public health and social medicine as an area of interest. Illich (1975), Cleaver (1977), Turshen (1977) and Doyal (1979) highlighted the importance of standard of living, food and water deficiency in the occurrence of diseases and healing of these infirmities. Availability of healthcare facilities and affordability of the same to the common people is another determining factor for the status of health in a population. Foucault (1975), Navarro (1977, 1996, 1999, 2004), McKinlay (1984), Wilkinson (1986, 1999) and Blane (1996)}
have tried to analyse issues related to inequality in the distribution of medical facilities in different contexts of social and political power relations existing in a society.\textsuperscript{11} The impact of political factors especially related to the State on the issues that are indirectly related to the prevailing social and physical conditions that shape the health of the population is not widely studied. However, scholars like Fonaroff (1968), Meade (1977), Turshen (1977), Rosenberg (1988), Navarro (1992, 1996) and Mayer (1996) have tried to highlight the importance of political factors at various levels.\textsuperscript{12}

Studies and researches under different traditions and in various disciplines are not integrative in nature. The two major traditions of medical geography viz. disease ecology and health services research have tended to be mutually exclusive streams of work. Though, during the 1970s the political economy approach was introduced to study inequalities in the health care delivery system, studies of disease ecology remain aloof from these developments except in a few cases like Turshen (1977) and Meade (1977), who analysed the role of state in the prevalence of certain diseases in Africa. This distinction continued and gaps widened between the researches related to the prevalence of disease (a major area of study under disease ecology tradition) and the researches related to distribution of health services (a major study area approached through political economy), as identified by many like Mayer (1982), Johns and Moon (1987). However, Bentham and Colleagues (1991) argue that the dichotomy is becoming increasingly


blurred as experience has shown that important research problems straddle the boundaries. Therefore, it is important to develop a theoretical framework, which incorporates political and economic interests into the ecological framework and human-environment interaction. The present study has tried to identify these gaps and has attempted to intertwine the two traditions so that the parameters of 'political ecology of disease' can be identified with greater clarification.

The study of disease and health in India started during the colonial period. It was Europeans who started drawing maps of various diseases like malaria, plague and disease prone areas like Bengal delta. Probably the first scientific attempt to identify regional factors associated with the prevalence of disease in India was made by McClelland in 1859.\textsuperscript{13} In the last decade of 19\textsuperscript{th} century some other scholars like Macnamara, Moore, Fayer, and Chevers undertook geomedical studies for various diseases in different parts of India.\textsuperscript{14} The work of Hesterlow on environmental factors and disease in Southern India is considered as the foundation of modern medical geography in India.\textsuperscript{15} Later, Geddes (1942) and Learmonth\textsuperscript{15} (1958) provided scientific base to researchers and planners in India for the study of disease ecology. A more comprehensive literature review about the developments in the field of health and disease is done in the next chapter.


\textsuperscript{15} A. M. V. Hesterlow (1929) quoted in R. Akhtar (1992) op. cit.

1.3 Relevance of the Research

It is evident that though a few referral works discuss the ecology of disease in India, no serious attempt has been made to understand ‘disease ecology’ in the context of political economy. In spite of the wealth of information and interpretations of ecological history of Indian medicine and disease, an enormous gap has remained in the critical examination and analysis of disease and its ecological frontiers. Available studies in the field of disease ecology have remained detached from the political structure and have hardly been considered in planning. Two distinct approaches rather branches of medical geography—‘disease ecology’ and ‘geography of health and nutrition’, are normally identified. The role of economy finds sporadic mention in the second one that is broadly concerned with the distribution of health and medical facilities. Nevertheless, the study of disease ecology in India makes very little reference to economic, social, political, and cultural factors that constitute a far more important component in the study of disease ecology and the phenomena of disease occurrence.

Political ecology examines the politics—in the broadest sense of the word—of the environment. It is also often referred to as ecological politics. Political ecology examines the historical role of economic systems, science, language and discourse, ideology, gender, property systems, social movements and resistance, and the everyday politics of the community and the household in shaping human relationships with nature. Political ecology approach to medicine and disease suggests that considerations of power, class and politics can be incorporated easily into the ecological framework so that they can be

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subsumed under the broader category of culture and society.\textsuperscript{19} Turshen proposed that "political ecology ... gives central importance to human agency in the transformation of the complex, interacting web that characterizes the environment".\textsuperscript{20} Some kind of disease ecology – either a biological\textsuperscript{21} or an environmental or a correct conception i.e. of political ecology; has been a prerequisite of any kind of planning exercise, as without knowing the cause it is not possible to offer a solution to minimize or mitigate it.

In this context, the present study also tries to use the concept of deconstruction. Deconstruction is a method of analysis that tells us that we should not assume that the way we perceive the world is the same way the world actually is and there is no limit to the task of deconstruction. Deconstruction in this study is used to probe into the limitation of the current curative practices. It also tries to propose that ecology can be harnessed for benefit of the people and not for the advantage of the powerful. This is contrary to the prevalent conception, as stated by Evernden,

"In choosing to ignore this somewhat dark side of ecology, even well-intentioned authors in advertently create a new ecology to better serve the purposes – that is to better substantiate their arguments. ... So far I have spoken of the use of ecology only by those in support of social reforms. There is, however, a much heavier reliance on ecology by those who defend the status quo."\textsuperscript{22}

Here, the use of deconstruction does not mean negation of the structures of different kinds rather it is an attempt to think through the complexities of 'political ecology of disease'. Deconstruction of disease ecology, therefore, does not involve dissolution of disease ecology \textit{per se} but implies a rigorous consideration of the social

\textsuperscript{19} J. D. Mayer (1996) op. cit.
\textsuperscript{20} Turshen (1984) op. cit., p. 17
\textsuperscript{21} This refers to the reductionist view point and talks about specific etiology of disease
and political systems, which make ‘disease ecology’. It is similar to McQuillan’s\textsuperscript{23} deconstruction of the binaries, where he does not postulate dissolution of binaries but a rigorous consideration of the system of thought which makes the binary logic possible. Political ecology does not amount to a new programme for intellectual cleansing; rather it is a historical outgrowth of the central questions about the relations between human society that is viewed in its bio-cultural-political complexity, and a significantly humanized nature.\textsuperscript{24}

In this study, political ecology approach is being used to study tuberculosis as a disease that occur in a particular environment, which is shaped by various social, economic, and political factors. Tuberculosis (TB) is an infectious disease, responsible for the great number of deaths worldwide. Most of these deaths are in developing countries, which lack the resources for adequate drug treatment.\textsuperscript{25} Though the prevalence of TB has been declining in recent years, certain pockets of population are particularly susceptible to some very serious forms of the disease. Interestingly, the intersection of itinerant population, homelessness, poverty, and migration provide a challenge for TB control in the developed world which is also true for countries like India, where people find it difficult to complete course of prescribed medication.\textsuperscript{26}

In India, tuberculosis is not a simple disease as the social taboo attached to it specially in the rural areas makes it more complex. Many people not only in the rural areas but also in the urban areas do not declare their affiliation to the disease for fear of being alienated. NHFS data puts the prevalence rate of tuberculosis as 60 per ten thousand of population in the rural India and 50 per ten thousand of population in the

\begin{itemize}
\item[\textsuperscript{23}]M. McQuillan (2000) "Deconstruction: A Reader", Edinburgh University Press, p. 19.
\item[\textsuperscript{26}]ibid
\end{itemize}
urban areas. The prevalence rate is higher among the poor, scheduled caste and scheduled tribe population. With this background, we have identified the objectives of this study.

1.4 Objectives

The objectives of the study are to

- Contextualize the ‘political ecology of disease’ in India;
- Assess the attitudes of the government, of the professionals, and of the people towards tuberculosis as a disease and to analyse the policy and planning towards combating it;
- Analyse the interregional and interpersonal differences in the prevalence of tuberculosis and the correlates that determine the treatment seeking behaviour; and,
- Explore the causes of the failure of ‘active efforts’ in public health programme for tuberculosis.

1.5 Research Questions

Flowing from the above mentioned objectives following research questions are posed in this study:

1. What are the physical, socio-economic, and political determinants of disease ecology and disease planning and how have they varied?

2. What has been the political ecology of tuberculosis in India during the pre-independence and post-independence periods in India?
3. How has the prevalence of tuberculosis varied over ecological space and among individuals of different socio-economic strata over time?

4. What causes and correlates explain the variance in the prevalence of tuberculosis and the treatment seeking behaviour among different sections of society in Delhi?

1.6 Conceptual Framework

Tuberculosis, an infectious disease, is responsible for the greatest number of untimely deaths in the developing countries, which lack the resources for adequate drug treatment. The silent nature of the disease attracted little attention towards it in spite of its severity. Generally the incidence of tuberculosis is associated with a) the existing climatic conditions, and b) prevailing precarious living conditions of the certain section of population. The conceptual framework in this study derived from the review of previous studies attempts to show the linkages between various factors that affect incidence of tuberculosis and the treatment seeking behaviour of the patients (Figure 1.1). The framework comprises of three major domains.

- The left side of the diagram describes the various factors namely historical factors, environmental factors and socio-political factors that affect the incidence of the disease. Good environment was considered a pre-condition for treatment during the 17th and 18th century and this helped the disease to reach to the ‘virgin regions’. Most of the sanatoria set up for the seclusion and treatment of the patients were opened in virgin salubrious regions and this led to the disease spreading to these regions. The differential longevity of the agent (bacillus) in a particular environment made certain regions more vulnerable. The effectiveness of the bacillus in poorly fed body made certain people more vulnerable to the disease than other in similar environmental
conditions. The role of state is important in securing or providing adequate food to the masses and also to make the treatment accessible to the people.

• The right portion describes the actual affect and perceived affect of the disease on the individual. It includes physiological changes, occupational changes, social changes and psychological changes.

• The middle portion is related to the incidence of the disease and its treatment. It shows that not all affected people go for treatment. The treatment seeking behaviour is dependent upon the socio-economic profile of the population and also is affected from the cultural and political factors. Those who do not know the disease or do not reach the doctor are bound to die, but mortality does not restrict to this group itself. Several patients die during the course of treatment especially if they develop Multi-drug resistance (MDR).
Figure 1.1
Conceptual Framework of the Study

Environmental and Historical factors
- Temperature
- Rainfall
- Altitude
- Sanatorium

Socio-economic factors
- Income
- Employment
- Nutrition
- Education
- Living conditions
- Accessibility to healthcare
- Cost of treatment

Cultural and Political factors
- Habits like spitting
- Cloths / dressing sense
- Availability of hospitals
- Cost of treatment

Physiological Changes (symptoms)
- Weakness
- Bleeding
- Chest pain
- Fever

Social Changes
- Taboo
- Alienation
- Worry for children
- Desertion

Occupational Changes
- Loss of work
- Compulsion of changing work
- Delay for the work

Psychological Changes
- Sense of Alienation
- Dissatisfaction from life
- Fear of dying
- Uncertainty about being cured
1.7 Study Area

The ecological approach\textsuperscript{27} is very appropriate to study a country like India with its diverse physical and socio-cultural landscape. One of the factors that give rise to various diseases of different kind is environment, which is directly or indirectly an outcome of the existing physical as well politico-economic milieu. India is a country of not only the celebrated environmental diversity but also dissimilar socio-political and varied historic-cultural landscape. The state response to disease has varied greatly over time and space. During the colonial period, the state was concerned with the spread of various diseases and recurring epidemics. Different measures were taken to combat these diseases. However, the impact of these efforts was limited. A considerable number of men (and later women) were trained in medicine, hospitals and dispensaries were opened up that attracted considerable numbers of patients; and issues of disease prevention and public health provision were addressed with enthusiasm. Nevertheless, many of these measures were restricted in their impact to a relatively small section of population, firstly to the European civil and military servants and their families and later to those, who had access to urban facilities. The local population in the pre-Independence times, however, did not adopt the sanitary reforms, which swept Europe in the nineteenth and early twentieth centuries. The varying administrative and political status of various regions like 'princely states' of the country resulted in different health policies across the country. Even after independence the situation has not changed as health is still a state subject means different provinces are free to prioritise the areas of interest and implement them through different administrative set up. Against this background, the present study tries to analyse the incidence of tuberculosis, the factors that led to the variance in morbidity rate and the

\textsuperscript{27} Ecological not in the classical sense of species-habitat and energy flow but in revised sense of cultural, political and social ecology which looks at the creating and modifying forces with greater emphasis.
treatment seeking behaviour in different parts of the country. The country started the combative measures way back in 1908 in the form of sanatorium treatment. The current combative strategy is DOTS (Direct Observed Therapy short course) under RNTCP (Revised National Tuberculosis Control Programme). Delhi is the first administrative unit, to achieve full coverage. It is for this reason that Delhi has been selected as a case study to analyse the treatment seeking behaviour and the perception of the people towards the provided treatment.

1.8 Data Sources

It is important to have information about the components that construct the ecology of a disease. Several data sources provide this information. As the present work starts with deconstruction, it proceeds with an open mind towards the concept of data. It has utilized literature also as data, as it is believed that information in any form - numerical or verbal including philosophical; are part of data base and they provide thoughts for consideration and therefore should not be overlooked. However, the study has not remained exclusivist in approach and has used the available statistical information from various sources like old health reports, data of Sample Registration System and NFHS to strengthen the arguments at the required places. The data has been analysed according to analytical needs with the help of available statistical techniques. Most of the work has been done on the basis of historical records that are available at National Archive of India and National Institute of Communicable Disease (NICD).

The following data sources have been used:

1. Historical Records from the National Archive of India and different State Archives
2. Data from National Institute of Communicable Diseases

3. Data from 28th round (1973-73) and 52nd round (1995-96) of NSSO

4. Sample Registration System (Survey of Causes of Death (Rural) and Medical Certification of Cause of Death (Urban))


6. Information generated from Primary Survey of the people affected from tuberculosis from the six hospitals in Delhi.

1.9 Methodology

Geography as a science of distribution has tried to study the incidence and causal factors of disease over space. This study tries to embrace the population health framework; questions of the interaction of individual level biological and behavioural variables with social and environmental factors. This study has tried to combine the ecological approach to disease and political economy approach to health and medicine in one framework. The prime concerns in this study of tuberculosis are:

- The spatial patterning of mortality and morbidity from tuberculosis
- The diffusion of the disease through time and space
- The spatial analysis of health care behaviour and planning related to tuberculosis

This study has tried to integrate these areas of research, as they are not mutually exclusive. Some of the factors that determine these concerns can be quantified but many

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of them not. This research has used both quantitative and qualitative techniques to analyse these determining factors. The conceptualization of 'meaning in illness and treatment' has been done from the data collected during the primary survey. This is related to the adaptation to tuberculosis by the patients and their perception of the disease and of society. There is an increase in the analysis of health and health-care towards a perspective that considers the broader global political economy and ecological concerns. Sociologists and critical medical anthropologists point towards the inadequacy of existing work in building theory that explains health in totality. However, there are serious limitations of studies, which try to link the local and perceptive based research to the global political processes. They fail to present an account of life and social action at the grass roots level to substantiate their theoretical claims and broad generalisations.

The details of data-base and methodology for each research question are discussed here.

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31 File has referred to several work in his article on meaning in illness; Cantor has tried to analyse the coping by patients suffering from cancer, R.C. Cantor (1978) "And a Time to Live: Towards Emotional Well-being During the Crisis of Cancer", Harper and Row, New York; C.O. Simonton and et. al. (1978) "Getting Well Again", Bantam Books, New York;

Figure 1.2
Diagram showing Philosophy behind Methodology

- **Community and Household**
  - Cultural Practices
  - Participation
  - Field discretion
  - Mapping History
  - Informal Interaction

- **Health Services**
  - Technological Advances
  - Historical Processes
  - Mapping Availability
  - Affordability

- **Programmes/Policies**
  - Historical processes
  - Stake-holder
  - Semi-structured Interviews

- **Treatment**
  - Income
  - In-depth Interviews
  - Group Discussions
  - Perception
1.9.1 **Research Question 1**: What are the physical, socio-economic, and political determinants of disease ecology and disease planning and how have they varied?

**Data Base and Methodology**

Here attempts have been made to conceptualise the Political Ecology of Disease in the existing literature and its implications for India. Political ecology here has been taken as a concept as well as a method. As a concept it deals with the historical growth of environmental concerns for health management and spread of disease over space. In methodological sense it tries to combine the concerns of ecological approach and political economy approach. Political ecology goes further than the political economy approach and proposes that disease is not completely class based and each member of a particular class is not suffering from a particular disease. Similarly all members of any class have never been free from that particular or any other particular, which in this study is tuberculosis, disease. It hence suggests that we should attach some importance to individuals as an entity. We should not generalize the cases; rather we should also consider the exception with concern. It is, however not to advance that political economy approach was wrong or political ecology approach answers all the problems of existing doomed condition of health in society. Rather, it is an attempt to address certain concerns differently.

1.9.2 **Research Question 2**: What has been the political ecology of tuberculosis in India during the pre-independence and post-independence periods in India?

**Data Base**

Various historical records and literature have been used to answer this research question. Different Government records, proceedings, reports of various committees constituted for
the study of particular diseases, etc. available in the archives have been used for the analysis of the disease during the colonial period. For the post-colonial period historical records and reports like

- Report of the Expert Committee on Public Health System
- Health Information of India for different years published by Directorate General of Health Services, etc., have been used along with several Annual reports of different health institutes and associations like
  - New Delhi Tuberculosis Centre,
  - Tuberculosis Association of India, New Delhi,
  - National Institute of Communicable Disease, New Delhi, and its research centres for different diseases located in other places,
  - National Tuberculosis Research centre, Bangalore, etc.

Methodology

For the conceptual analysis of political ecology of disease in India, the attitude of the colonial government towards (i) health and disease and (ii) planning, policy, and practice during the colonial period have been studied. The levels of technological know-how, understanding of biomedical tradition and social epidemiology have been analysed in the context of money available. For the colonial period comparative inferences have been drawn from England, where the same government was operating and taking up policies and practices at variance with its policies in its colonies like India.

The analysis is based on archival records and has been presented at two levels. The first is concerned with the various explanations of the disease that includes climatic
explanation theory, genetic explanation, contagious theory of the disease etc. The second is concerned with the measures that have been taken by the colonial government or by society to combat the disease and their suitability or unsuitability for the existing situation.

1.9.3 Research Question 3: How has the prevalence of tuberculosis varied over ecological space and among individuals of different socio-economic strata over time?

Data Base and Methodology

India after independence has witnessed many developments in health sector including the available health statistics. The available data between 1951 and 1970 is not sufficient to analyse the pattern of disease. However, the number of tuberculosis patient and the success rate of treatment process are available from various sources like Indian Medical Gazette and records of National Institute of Communicable Disease. Data is available for the period between 1971 and 1990 from the 28th round survey of NSSO (1972-73) and also from Sample Registration System (Survey of Causes of Death (Rural) and Medical Certification of Cause of Death (Urban)). A detailed study is possible only for the last decade between 1990 and 2000 since for this period data form two rounds of NFHS (1992-93 & 1998-99) and 52nd round of NSSO is available.

Data for this section of the study have been drawn from The National Family Health Survey (NFHS-2), India, carried out between 1998-99 by the ORC-Macro and the International Institute for Population Sciences, Mumbai. It collected information from a nationally representative sample of 92,486 households (consisting of 517,379 individuals, 161,857 in urban areas and 355,133 in rural areas) during 1998-99. This survey asked questions about each member of the households concerning the occurrences of four important diseases, namely, asthma, tuberculosis, malaria, and jaundice. For the reference
periods for chronic diseases like tuberculosis, the survey asked if the person is currently suffering from this disease. Besides, information on age and sex, religion, caste, educational attainment of household members and standard of living of the household (composed by NFHS) were also included.

Selection of Variables

Predictor variables influencing level and pattern of morbidity selected for the study are: age, sex, religion, caste, educational attainment, and standard of living of the household. Since NFHS did not collect data on household income or expenditure, a proxy, standard of living, as calculated by NFHS on the basis of housing conditions, land holding and consumer durable goods has been incorporated in the analyses. Therefore separate variables related to these aspects have not been used. SLI is used as a categorical variable and the categories used here three – ‘low’, ‘medium’ and ‘high’ for all India level and two – ‘low’, ‘medium and high’ for different ecological zones. Education has been used as a categorical variable and the categories used here are two fold: for the analyses at all India level three categories – illiterate, educated up to middle standard and higher educated has been used. While for different ecological zones only two categories – illiterate and literate has been used, as number in each category becomes less. Besides, the socio-economic analysis of the diseased person has been done on the basis of the NHFS data. A total of 3,001 cases (2, 264 in rural areas, and 737 in urban areas) of tuberculosis have been identified among 5, 17, 319 individuals during 1998-99.

Identification of Ecological zones

In order to study the pattern of tuberculosis, thirteen broad agro-ecological zones have been identified according to various ecological parameters as identified by Indian
Council of Agricultural Research. Only rural areas have been considered in rationalisation scheme due to constrain posed by sampling stratification of NFHS. The survey has divided states into different regions by taking certain districts on geographical basis. This has been done only for the rural areas while; urban areas in the respective regions are kept out of this particular sampling scheme. In order to overcome this lacuna, another parallel analysis has been done for the urban areas of India as a whole. A multivariate analysis have been done for the country as a whole, because if we consider any geographical unit smaller than that, the number of identified cases (which are 737 only in total cases of 161857 in urban areas) becomes very small and it would be difficult to carry out regression or similar statistical exercises. Based on the above available information of each household member, the data files for each region have been created.

To observe the regional variations of level and pattern of morbidity all the thirteen regions have been considered in the analysis. Within one selected inter-state ecological region, variations among different parts of states have also been analysed for different social and economic groups as identified earlier. Multivariate technique has been applied to analyse the regional variations in the causal factors, level and pattern of morbidity.

1.9.4 Research Question 4: What causes and correlates explain the variance in the prevalence of tuberculosis and the treatment seeking behaviour among different sections of society in Delhi?

Data Base

Data for this section has been collected primarily through a primary survey. Nevertheless, secondary sources have been used to identify the population group i.e. information from selected hospitals in Delhi.
Methodology for the Primary Survey:

Selection of hospitals and variables:

Predictor variables or correlates that influence the level and pattern of morbidity can be as wide as ecological, social, economic and political. It is very difficult to study the factors of morbidity. At the same time it is extremely important to look into the reasons of prevailing disease like tuberculosis which kills 1000 persons a day in India. The approach in this study is to try and identify the correlates through studying the behaviour of patients towards disease and the attitude of the government, of the professionals and of the people towards the patients and towards the disease. This also included the socio-economic characteristics of the affected person. An attempt has been made to identify and analyse the treatment seeking behaviour of the diseased. The variables identified are

- Initial identification of disease,
- Place of first treatment (like quacks, private clinic, government hospital, charitable outlets),
- Change in the pattern of treatment,
- Circumstances that led to this change,
- Frequency of change,

On socio-economic issues, variables chosen were as following:

- Caste,
- Educational attainment,
- Mobility,
- Standard of living, which include working and living circumstances and possessions of the household
Quality of water and the housing conditions in a city have been considered important for this kind of disease as highlighted by scholars like Hippocrates (4th Century B.C.), Petermann (1852), Howe (1968), Snow (1855), Johns, Moon (1987), etc. Standard of Living and food and water deficiency (as pointed out by May (1954, 1958), McKeown (1976), McKinlay (1984), Mayer (1986), etc.) has also been included in the analysis. An assessment at the household level has been done for the availability of goods and facilities. The working and living conditions of the patients have also been taken into consideration.

Public Health is amongst the most important issue that may determine the recovery of the affected persons. Dubos (1959) has shown the importance of this and other correlates. Questions regarding inequality in distribution and availability of medical facilities (Foucault (1975), Navarro (1977), McKinlay (1984), Wilkinson (1986), Blane (1996), etc.) have also been considered. Now the availability is not the only important issue as physical access to the health care facility is not a problem in the urban areas. However, the way patient is treated, as an individual is important for this study and attempts have been made to include this aspect of health care delivery system. Questions have been asked about

- Availability of free treatment including medicines,
- Reasons / Ground for denial of the facility (if so)
- Cost of medicine etc.
- Assessed cost of nutrition, which is required to continue with the treatment process,
- The hours and timings of work, and its impact on the visiting of the health care centre.
These variables often do not operate at the individual level and get affected with social and political decisions. The importance of political influence and power relations of the above-mentioned variables is analysed with political ecology approach. The issue has been touched in different parts of world by Fonaroff (1968), Meade (1977), Turshen (1977), Rosenberg (1988), Navarro (1992, 1996), Mayer (1996), etc.

The present study has been done on the basis of semi-structured questionnaires that include questions related to above-mentioned variables. Surrogate variables have been used to analyses some of these issues. For example, the attitude of the government can be judged by the economic condition of the patients, their education level, his occupational conditions, availability of free treatments of the disease, gap between the required fund per capita and actual availability and so on. Direct questions on the attitude of the people and of the professionals have been asked.

**Sampling process and its basis:**

It becomes often arduous for an individual researcher to conduct survey in various parts across the country though that would have been the ideal situation. This aspect of the study has been analysed with the help of the sample survey done by NFHS, which gives us information about 5 lakh population in rural areas from different states. Besides, tuberculosis is a rare disease when compared at the level of population (only 0.5 percent), and this also makes a countrywide survey by individual researcher more difficult.

Delhi is the first administrative unit, to achieve full coverage under DOTS. Delhi is also considered one of the better places in terms of availability of health-care facility. It is supposed that people staying in Delhi have better option to access the state-provided treatment. The behaviour and perception of the people towards treatment can be studied if they have the access to these services. Keeping this in mind, the primary survey for this
study was done in Delhi. The patients for the study have been selected through a multi-stage sampling. There are more than 120 outlets including 21 Tuberculosis hospitals in the five zones of Delhi. In the first stage of sampling five hospitals from each zone of Delhi were selected on the basis of random sampling. Besides the five hospitals, one charity hospital was also added to the study. Hospitals that have been included in the study are:

- North Delhi – Chest Clinic, Jahangirpuri
- Central Delhi – New Delhi T.B. Centre
- East Delhi – Chest Clinic, Shahadra
- West Delhi – Chest Clinic, Jhandewalan
- South Delhi – Chest Clinic and hospital, Nehru Nagar.
- Charity Hospital – R.K. Mission Tuberculosis hospital, Karolbagh

In the second stage 40 patients from each hospital have been selected on the basis of the information given by the DOTS provider at each hospital. As full information of the patients is kept in each hospital the selection has not been a problem. The basis of selection was again random and any forty patients were selected. Their names and address were noted. These patients come every alternate day for the medicine, so tracking them was not very difficult. However, I had to adjust with their timings as many of them reported that they would get late for their work (due to the time taken during interview). Some of the patients were also approached at their residence to check the differences in their reply regarding “treatment-seeking behaviour”, if any. It was noticed during the study that patients were more comfortable at the hospital rather than at their residences. The reason behind this was the prevalence of social taboo in the patients. They were

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33 Recently a new zone has been added in the central zone, however, the latest zone has only one hospital. This study considers the five zones only.
interviewed with the help of semi-structured questionnaire (about 50 percent of questionnaire being close ended and rest as open ended questions). After completion of interviews, categorisation of the patients has been done on the basis of age, sex and migration status of the patients in different regions of Delhi. Accordingly, following categories have been identified:

- Children (0 to 14 years)
- Adult or working population (15 to 59 years)
- Old or retired from workforce (60 + years)
- Men in each of the above categories
- Women in each of the above categories

The individuals for whom information was collected has been categorised in various economic strata. The role of various correlates (variables identified earlier) has been analysed. A deeper investigation has been done regarding the attitudes of the people, of the government and of the professionals. Children (11 out of 240) have been kept out of this analysis as it was felt that they modify the result of the analysis because they are not the active actors in the society. So the analysis is based on the responses of 229 patients from different parts of Delhi.

1.10 Organisation of the Thesis

The present thesis consists of six chapters. Chapter one is introduction. This chapter introduces the research theme, its importance, relevance, objectives and research questions. It also explains the methodology and the rationale behind choosing this methodology and Delhi as the case study for the analysis of treatment seeking behaviour. In chapter two the theoretical Framework of Political Ecology of Disease has been given. Political ecology here has been taken as a concept as well as a method. Before
approaches to study health and disease, philosophical foundations of various conceptions of disease and health have been discussed. In chapter three we have analysed the pattern of disease ecology in India and the time-space relationship of the determinants. In chapter four using various secondary sources including the NFHS, pattern of tuberculosis has been analysed. This chapter has also tried to analyse the impact of ecology and the role of political set-up on the occurrence of the disease in India. In chapter five we have analysed the disease history and the treatment seeking behaviour of Patients and the causes and correlates, which explain this. The treatment seeking behaviour of the patients and their perception towards the treatment has been discussed. An attempt has also been done to analyse the social, economic and psychological impact of the disease on the individuals. Last chapter of the thesis presents the conclusions of the study.