CHAPTER-I

Introduction
Anthropologists, medical scientists and biologists collaborate in recent time on research topics ranging from epidemiology of different diseases (Trostle, 1986) to socio-cultural beliefs in relation to disease and illness (Foster and Anderson, 1978; Lambert, 1996). They have uncovered significant etiological links between the social milieu and health status, employing social categories such as bereavement (Jacobs and Ostfeld, 1977), marital status (Gove, 1973), social class (Antonovsky, 1967; Syme and Berkman, 1976) and social dislocation (Neser et al., 1971). Moreover anthropologists have made important contribution to the medico-cultural knowledge through their research (McCracken, 1971). Contemporary research on the impact of disease on economy, social structure, cultural adaptation and social ecology is a fascinating dimension of anthropology. Anthropological knowledge plays a pivotal role in minimizing the burden of diseases and developing strategies for the prevention and eradication of communicable and infectious diseases. The issues related to bio-cultural dimension of different diseases have been studied under the umbrella of medical anthropology (Landy, 1977; Sommerfeld, 1998). Hence, the present study is an humble attempt to understand both the biological and socio-cultural dimensions of mosquito borne lymphatic filariasis (hereafter LF) and the study area is quite endemic for the same disease. The study attempts to understand the epidemiological trend, economic loss, social burden and socio-cultural beliefs relating to LF in an endemic population.

Biomedical anthropology is a newly emerging discipline, which combines the theoretical and methodological concepts of biological anthropology and medical anthropology in the study of health of human populations. It tries to integrate knowledge of biology, human genetics, molecular medicine, human growth, development and nutrition, health behaviour, medical care (intervention) systems, health planning, phychosomatic illness, etc. within its ambit (Johnston and Low, 1984; Balgir, 2004). Biomedical anthropology is based upon the application of anthropological theory to problems of health disease. The theoretical orientation of anthropology that has developed over more than a century of investigation, comparison and generalization, includes both biological
and cultural components. While useful research may focus exclusively upon either component, the deepest understanding of medical problems and the greatest likelihood of successful interventions come from the inclusion of both as well as their integration into an analytic model, i.e. bio-cultural. It is this characteristic that distinguishes biomedical anthropology from human biology, epidemiology, or medical ecology (Johnston and Low, 1984).

Biomedical anthropology is disease-centred and its investigations enquire into the impact of the disease (or condition) upon biological processes of individual or the population to which they belong. This characteristic distinguishes biomedical anthropology from medical anthropology and medical sociology (Johnston and Low, 1884).

The domain of biomedical anthropological study incorporates both biological and cultural explanations of the health, illness and disease processes. This is based upon the facts that many of these process are understandable primarily within the context of culture and that biological causality may play only a minor role (Johnston and Low, 1984). The present study covers both biological and cultural dimensions of mosquito borne LF.

**Presentation of the Problem**

Anthropologists study different human-related problems in a holistic manner. The problem of disease, disease-related perception, knowledge, attitude, the impact of disease, different man-made coping mechanisms to overcome biological disorders, etc. are interwoven with one another. We cannot understand the disease and its impact upon the community without understanding the indigenous knowledge system of the disease, history of the disease, health infrastructure of the concerned geographical area and human behaviour towards the disease as a whole. Therefore, the anthropological approach is quite practical and logical for understanding a problem.

As the disease filariasis is a cause of concern in rural coastal Orissa, it is essential to undertake socio-economic studies on filariasis from this part of Orissa. The
public health significance of the disease should be quantified covering aspects such as loss of income due to acute attacks, chronic manifestations, direct costs of medical care, etc. There is also an urgent need to understand the socio-cultural practices, knowledge, beliefs and perceptions of people towards the disease, their health seeking behaviour and health infrastructure available in the endemic area for better health management and disease control. This information can be utilized to formulate advocacy strategies to control the disease. Further, this information can be useful to design Information, Education and Communication (IEC) materials to educate the people of the concerned area in relation to LF. Further, this bio-cultural study of the disease has a greater practical utility. The findings of the research may go a long way in evolving effective policy measures to tackle various problems related to the disease at the grass-roots level.

**Objectives of the Study**

The study has the following objectives:

- Understand various socio-cultural practices related to LF and the treatment seeking behaviour of people with reference to morbidity control in different conditions of LF in the study area.

- Discuss the existing knowledge, attitude and perceptions (KAPs) of the ethnic communities regarding LF that do not always receive the support of established medical practices.

- Examine the impact of LF on individuals in the forms of societal reaction, intangible social stigma and psychological impairment.

- Analyze the physical impairment of individuals with various forms of the disease and its influence on the patients' participation in different economic and social activities.

- Offer various suggestions for tackling the problem effectively in the study area, in view of the non-going filariasis control programme in Orissa.
Methodology

Enumeration and Sampling

Chronic Patients

Rural area of Khurda district is selected for the study due to endemicity of the disease in the area. A total number of 12 randomly selected villages from different blocks of the district are covered for the study (Table-1). Door-to-door census is conducted and all the subjects are investigated. Information such as total number of family members, their gender, age and occupation is collected during the enumeration. Each individual is examined for chronic signs of lymphatic filariasis, i.e. lymphoedema/elephantiasis, scrotal swelling (hydrocele), breast swelling and hand swelling. The details of these symptoms are given below.

1. Lymphoedema/elephantiasis/breast swelling and hand swelling: Continued and prolonged presence of worms, particularly in the inguinal group of nodes results in chronic pathology of lymphatics culminating in lymphoedema. This commonly affects lower limbs, rarely upper limbs and genitals in both sexes (lymph scrotum, penis, vulva) and female breast. These patients suffer from repeated attacks of adenolymphangitis ADL. Progressive lymph stasis is believed to increase their susceptibility to bacterial infections. Episodes of ADL attacks continue with proliferation of lymphatics and increase in oedema volume, which is replaced by fibrosis, resulting in the consolidation of oedema and fibrous tissue formation. Thereafter, the progression of the local pathology results in skin thickening, disfiguration, ulceration and nodule formation. The lymphoedema of the lower limb is classified into four grades (WHO, 1992).

   Grade 1  Early oedema completely reversible on elevation
   Grade 2  Oedema of the limb, which is partially reversible on elevation of the limb without thickening of the skin.
   Grade 3  Irreversible oedema of the limb with skin thickening.
   Grade 4  Irreversible oedema of the limb with papillary and nodular growth.

2. Hydrocele: Hydrocele is the commonest manifestation of bancroftian filariasis in the male population. When the parasites are lodged in the testicular
lymphatics, it results in accumulation of fluid in the tunica vaginalis testis causing hydrocele. A majority of these patients do not give any history of ADL attacks in their lifetime therefore, the progression seems to be a passive phenomenon. During the enumeration altogether a total number of 377 patients with different overt chronic filarial manifestations are identified. From this a cohort of 62 patients (12 male elephantiasis + 22 female elephantiasis + 21 hydrocele + 7 elephantiasis and hydrocele) is selected for the study following stratified random sampling method.

**Acute Patients**

Of the 12 villages, the people of two villages consisting of 1329 (685 male and 644 female) members are monitored for one year (March 2000-February 2001). Initially, demographic data like age, sex, occupation, etc. of these two villages are collected along with personal identifications of all individuals. All the households of these two villages are visited every fortnight to identify individuals suffering/suffered from an acute attack during the fortnight. An acute ADL episode is defined as the presence of local signs and symptoms such as pain, tenderness, local swelling and warmth in the groin, with or without associated constitutional symptoms such as fever, nausea or vomiting (WHO, 1992). The symptoms of acute episodes, which are common in this endemic population, were explained to the people. As there are no other diagnostic tools to identify ADL episodes, the present method of symptomatic diagnosis is used. This method of diagnosis through local terminologies is found to be highly specific (specificity = 0.980) and sensitive (sensitivity = 0.978) for diagnosing ADL (Gyapong et al., 1996).

For individuals identified as affected with acute attacks during last fortnight, the details including clinical symptoms, duration, etc. are recorded. The affected individuals are tested for microfilaraemia. A finger-prick thick blood film is prepared, using blood collected after 10 PM, stained with Leishman's stain and entire film is examined for microfilariae.
Collection of Data on Knowledge, Belief and Treatment Seeking Behaviour

Data on knowledge, beliefs and treatment seeking behaviour are obtained from the affected people and the community. For examining these aspects among affected people (patients), a case control design is adopted. Age, sex and occupation matched controls are selected for all the 63 chronic and 73 acute patients from the nearby households. Care is taken to see that the controls have no history of either chronic or acute filariasis. Interviews are undertaken among both cases and control with the help of a pre-tested interview schedule. In order to assess KAP of the general community, 362 individuals are sampled and interviewed with the help of structured interview schedule. The practices related to morbidity management among lymphoedema patients are assessed among 100 lymphoedema patients by in-depth interviews using a semi-structure interview schedule. These 100 patients are sampled separately from these villages. Standard methodology is adopted while undertaking in-depth interviews (Pelto & Pelto, 1978).

Collection of Data for Economic Burden among Chronic Patients

Selected cohort of 62 chronic patients were studied for estimating direct and indirect costs resulting from chronic LF. For examining some aspects of costing, age, sex and occupation matched control are selected for all the 62 patients from nearby households. All cases controls are visited of at interval of 4 months continuing for a year (total three visits: July-October 1999, November 1999-February 2000, March-June 2000) in order to cover all the seasons in a year. Of the 62 patients, only 58 are available in all the three visits. The control cases are visited accordingly. The data on expenditure on treatment are collected from cases only, whereas the data on the loss of work time are collected for both cases and control. The respondents (both patients and control) are made to understand the purpose of the study in order to win confidence and achieve cooperation.

Direct Costs (Expenditures on Treatment): Direct cost to chronic filarial patients includes the expenditure made on the medical treatment for the chronic condition. The expenditure made by patients includes various components of the
treatment like consultation fee, cost of medicines, expenditure on travel, stay and food and expenditure incurred on the accompanying persons (escort). These details are obtained at each visit to get the total expenditure made by patient for the last 4 months. Care is taken to exclude the expenditure made on other diseases including acute filariasis. The expenditure pattern is shown in Indian currency i.e. India rupees (INR) along with its approximate value in U.S. dollars (US$). Approximately, INR 1 is equivalent to US$ 0.022.

Loss of Productive Work: Data on daily activity pattern of the 24 hours of the previous day of the visit are collected from both cases and control for every month. The data contain chronological list of activities performed by him/her along with the time spent. The daily activities include economic activities related to their occupation such as working in agriculture fields, cattle herding, working in stone-mines, grass cutting, etc; domestic activities like cooking and related activities, cleaning of house and cattle-shed and collection of firewood; personal works like toileting, bathing, eating and health seeking activities; leisure activities like gossiping, sleeping, watching television, listening radio and religious activities. Of all these, the time spent on occupational related and domestic activities is considered as working time, as those activities are productive.

Collection of Data for Economic Burden among Acute Patients

Expenditure on Treatment: For individuals identified as affected with acute attacks during last fortnight, the details of expenditure on treatment are collected. The expenditure on treatment of ADL episode made by patients includes consultation fee, cost of medicines, expenditure on travel, stay and food, expenditure incurred on the accompanying person (escort) and on self-medication. Care is taken to exclude the expenditure made on other diseases including chronic filariasis. The information collected from the respondent pertains to the ADL episode occurred during last fortnight. The patients' prescriptions, hospital documents receipts of pharmacy shops, etc. are examined, wherever available. The expenditures are shown in Indian currency, i.e. Indian rupees (INR) along with its approximate value in US dollars (US$).
Loss of Productive Work: Data on daily activity pattern of the 24 hours of the previous day of the visit are collected both from the cases and their controls. In this case control design, age, sex and occupation matched controls are selected for the patients from nearby households. Care is taken to see that the controls had no history of either acute or chronic filariasis. The data contained chronological list of activities undertaken by him/her along with the time spent. The daily activities include economic activities related to their occupation such as working in agriculture fields, cattle herding, working in stone mines, grass cutting; personal activities like toileting, bathing, eating; leisure activities like gossiping, sleeping, watching television, listening radio; domestic activities like cooking and related activities, cleaning of house and cattle shed and collection of fire wood; health seeking activities; religious activities, etc. Of all these, the time spent on economic activities both by men and women and domestic activities by women and men (if any) are considered as working time as these activities are productive.

Social Burden

In-depth interviews and focus group discussions are conducted among various categories of people in our study villages for assessing social burden of the disease. The different categories of people covered are: agriculturalists, labourers, educated group and filariasis patients (both acute and chronic). In-depth interviews and focus group discussions are conducted by using a checklist. The checklist consists of questions on various facets of LF and the impact of diseases on them. The standard instructions are followed while conducting in-depth interviews and focus group discussions (Pelto and Pelto, 1978; Hudelson, 1994). The study also record and analyze indigenous people voices concerning LF and its treatment. Those voices reflect people's perceptions of and attitude towards LF.

Analysis and Data Management

Quantitative Data: The quantitative data are entered into computer through MS Excel, and analyzed through SPSS for Windows V.8.0. The schedule consists of both open-ended and closed-ended questions with two to eight alternative
responses. Percentages are computed for different responses. For open-ended questions also, equivalent narrations are pooled and percentages are calculated. Arithmetic mean along with standard deviation is calculated in case of continuous variable. The statistics used for the present data analysis includes geometric mean, arithmetic mean, standard deviation, Z-test, pared t-test, student’s t and $\chi^2$ tests of significance and F-test.

Qualitative Data: All the in-depth interviews and focus group discussions are conducted in Oriya, the local language of Orissa. The entire proceedings of interview/discussion are recorded with the help of a tape recorder. The audiocassettes are played back and transcribed in to Oriya with field notes used as an adjunct. Later the Oriya scripts are translated to English. During transcription and translation of qualitative data the guidelines of Mergenthaler and Stinson (1992) and Mclellan et al. (2003) are followed. These notes are entered into personal computer in MS Word and are analysed by using ATLAS/ti for Windows V.4.1. This programme supported the qualitative data analysis by facilitating the analysis of unstructured and semi-structured transcripts. ATLAS/ti facilitated the activities involved in qualitative analysis of in-depth interviews and focus group discussions, specifically selecting, coding, annotating and comparing noteworthy text segments. It also featured to allow visually connecting, browsing and analyzing selected text passages, memos and codes.

Organization of Data

The thesis, consisting of seven chapters, presents a biocultural perspective of LF in rural coastal Orissa. The introduction chapter deals with the presentation of the problem, objectives and methodology. Second chapter provides the significance of medical anthropology from a biocultural perspective. The next chapter throws light on various facets of LF. It covers aspects such as burden of LF, history of LF, biology of the disease, morphology and symptomatology of filiasiasis, clinical manifestation of LF, treatment and control measures of the disease and an overview of literature on LF. The fourth chapter gives a description of the sample area and people. In the following chapter an attempt
has been made to analyze various biological dimensions of LF. Chapter six presents knowledge, attitude and perceptions (KAP) of the sample population relating to LF. In this chapter various socio-cultural beliefs and practices have been analyzed in the context of health seeking behaviour. The same chapter also examines the social burden of LF. The concluding chapter presents a summary of the findings of the study.