

## **CHAPTER – III**

### **METHODOLOGY**

#### **SCOPE OF THE STUDY**

Unlike other common diseases, leprosy leads to the development of visible deformities and consequently patients are ostracized by society and the family, which leads to debilitation. Leprosy has posed unique problems in various fields of research, medical and non-medical. Persons affected by leprosy are in double tragedy in that they have to undergo the physical consequences of disease as well as social consequences.

The anthropological method claims to observe and interpret the situation of the study population as they are. There are various methods and techniques, which are used in conducting anthropological research. The present study applied both qualitative and quantitative methods of data collection and data analysis.

Leprosy carries strong stigma, disability and deformity; hence it produces many socio-economic consequences. As a result, the affected one tends to become displaced from his or her previous position in life. Therefore finding out the level of debilitation during the prime of an individual's life and discovering the affecting factors would be important for the management of leprosy induced socio- cultural and economic consequences. Addressing these issues by both qualitative and quantitative approaches will provide a better picture of the problems. Different tools and techniques were used to collect and analyze the data in the present study that has boost up its gravity. The uniqueness of this study is not only in covering a large number of samples but also in its study of the knowledge, attitude and practice (KAP) of the community near to the studied population.

## UNIVERSE OF THE STUDY

Nepal is ranked 5<sup>th</sup> amongst the other countries in the world as far as prevalence and detection rates were concerned (ALH 2002). This researcher being a Nepali citizen and aware of the leprosy problem in Nepal felt the need for this kind of research in Nepal. He would avoid language and other logistic problems being in a familiar environment, which is very important while undertaking this kind of endeavor. Therefore Nepal was selected for the study. The Central Development Region was selected because this region, out of five development region in Nepal, is loaded with roughly 50% of the total registered leprosy cases in the country.

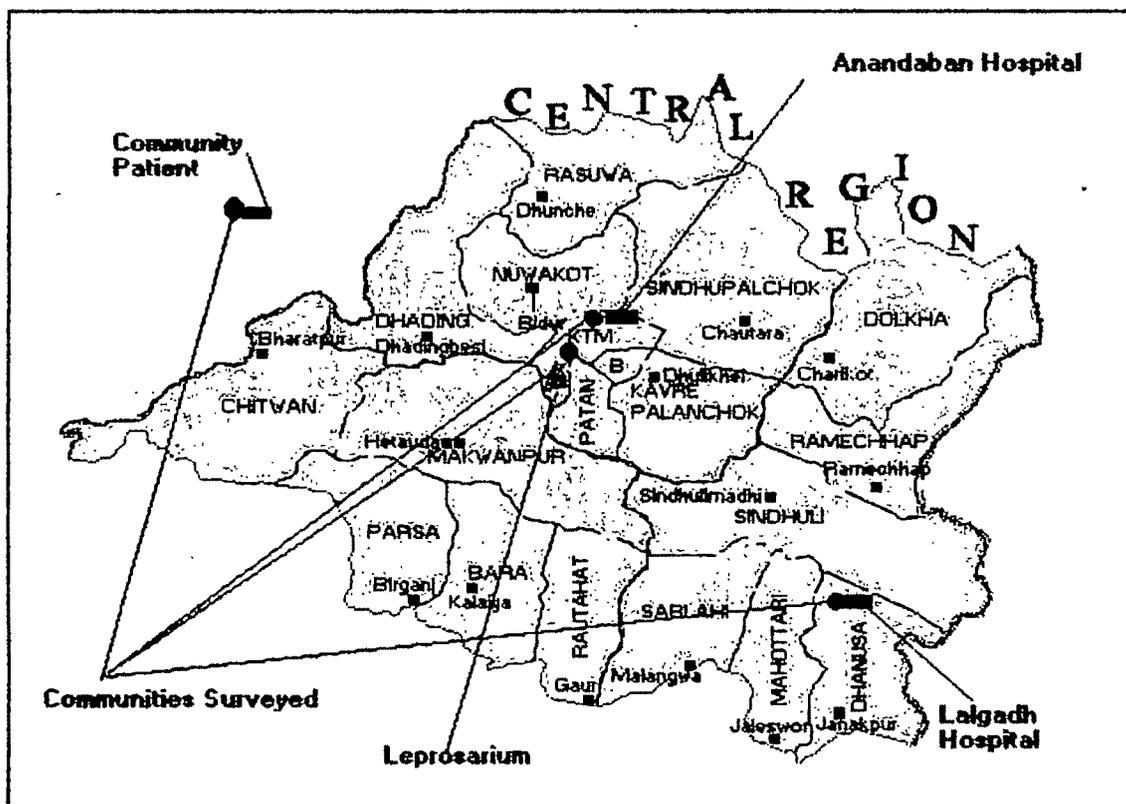
After selecting the geographical location on the basis of high caseload. The second step was to select the respondents. It was not feasible to select a certain geographical area because of availability of patients. Analyzing the circumstances, it was found that patients can be broadly categorized into three groups; hospital based, leprosarium based and community based in terms of availability. Therefore it was decided to take samples from these three mentioned settings. Following this concept, two leprosy hospitals: 1) Anandaban Leprosy Hospital in Kathmandu valley, run by The Leprosy Mission, an INGO and 2) Lalgadh hospital in Dhanusha district, run by the Nepal Leprosy Trust, an INGO were selected. Similarly Khokana leprosarium situated at Chalnakhel VDC of the Kathmandu district was also selected. This leprosarium was established more than 150 years ago.

It was rather difficult to get the third category of patient (patients settled in community) in a cluster. It was not feasible to study scattered patients in different communities due to time and financial constraints. Here, the researcher's involvement and contact with different leprosy worker and organizations facilitated an exploration of the availability of a group of patients in a single community. Following a chain of inquiry with different leprosy workers and organization a community in Pokhara was found. Therefore, this village was selected for the study however, it was out side of the central region. Reason for selecting such village out side of Central Region was due to the unavailability of such a village in the central region.

In selecting a community in order to understand knowledge, attitude and practice towards leprosy and its victims, it was decided to include a ward (a village) of the Village Development

Committee (VDC) neighbouring to the study area (hospital, leprosarium and community where patient were studied). A brief description of the study areas and the background of the respondents are given in the chapter four.

Figure: 3.1 Map Showing Study Areas



### SAMPLING

After fixing the study sites the next step was to select the respondents. Patient below fifteen years of age were deliberately not included in this study because the study required full participation in expressing their opinions and feelings, which was not expected in this age group. However, during the ethnography, they were not ignored. Data were collected regarding this age group as well when available and seemed relevant during observation in field, hospital etc.

Different sampling methods were adopted in the three different settings. There was no problem acquiring the required number of patients in the hospital settings. Therefore stratified random

sampling was done to select the respondents. Stratification was done for sex and treatment status. In this way a total of 320 patients (male-female ratio 1:1 and under treatment- treatment completed ratio 1:1) were selected from the two hospitals (160 from each hospital) for the study.

In the case of the leprosarium, it was attempted to cover all residents. During the period of fieldwork there, it was noted from the *Naike* (leader) of each division that a total of 163 (84 males and 79 females) leprosy affected persons were residing there. Out of 163, 122 patients (65 male and 57 females) were interviewed. The remaining 41 patients (19 males and 22 females) could not be interviewed for two reasons; 1) some of them were unable to speak or were too ill for long conversation and 2) some of them had gone out (visiting relatives, friends etc) during the period of fieldwork there.

Regarding the cases in the community, some information was collected before hand from the Partnership For Rehabilitation (PFR) programme of International Nepal Fellowship (INF) about the patients residing in that particular village. Then patients were approached to identify the other patients residing there, who were not on the list (prepared by of PFR). So from the information chain (one patient to another) all together 60 patients (29 females and 31 males) were identified and they were enrolled in the study.

Another part of this study was to assess the knowledge, attitude and practice of community people. As mentioned in the universe of the study, a nearby village of above mentioned four settings (2 hospitals, leprosarium and community) was selected using the lottery method of random sampling. After the village had been selected, all household heads were invited for interview. In case of absence of the household head (mostly were male) spouses were enrolled. In some cases, the real house owner was not staying in the house and people from outside of that community had taken it for rent temporarily. These cases were excluded from the study.

## **SOURCES AND COLLECTION OF DATA**

This study commenced in March 2000. After the basic preparation, the researcher had a short visits to all study sites between May to September 2000 in order to familiarize himself with the places and collect basic information required. Interviews schedules and debilitation scales were made ready and tested by the end of December 2000. Actual fieldwork started from February 2001 and the data from all sites was collected by the end of April 2002. All 15 months were not fully occupied with fieldwork, refining and entry in the database was also done for the data that had been already collected. Data collected in the later part was refined and fed in computer by the end of June 2002. Then July 2002 onwards, processing, analyzing and writing report started.

The necessary data for this study was obtained from both primary sources and secondary sources. Data regarding socio-cultural and economic impact and level of debilitation were taken directly from the patients under study. Household heads of the selected villages were the sources of information regarding community knowledge, attitude and practice towards leprosy and its victims. Regarding scientific facts about leprosy, data regarding leprosy were collected from secondary sources i.e., reports, books, journal, websites etc. Besides this, some key informants were also the sources of data in both cases (Patient and community).

Case study approach was adopted for the collection of data. The case study approach has been praised as a useful research technique. This approach does not rely on a particular technique. It is an approach which makes use of a variety of techniques for instance, interview (structured and un structured), interview schedule, life histories, personal documents, different kind of observations and so on. Thus in this study, the approach is not based on a given hypothesis or established conclusion but helped in developing a well founded hypothesis for further investigation. The approach in this study is an open ended and objective examination of the sample studied.

This study applied different methods of data collection. Data was collected using both the qualitative and quantitative approaches. Qualitative data regarding the objectives of the study was collected using in depth interview, life history, focused group discussion (FGD), and key

informants. Some sorts of qualitative data were also collected from the structured interview schedule. To gain real understanding of the cultural and social factors at work in connection with leprosy, the traditional anthropological fieldwork method of observation technique was also applied. Observation notes were taken at the spot in short form. Later in the evening all notes were elaborated to make sense. Photographs taken during fieldwork were also used to supplement the missed data regarding the physical situation during observation. Like wise qualitative data regarding community knowledge, attitude and practice towards leprosy and its victims were collected through key informants and informal discussion with the community people in public place (e.g. Tea shop, *Chautara*- resting place in the village). In each community three key informants were approached and two informal discussions were conducted. When taking notes, on the spot no generalization was done to minimize the size of data. Notes were taken as it was and as it was explained. Thus the real situation and explanation were captured with out making any inferences on the field.

Regarding collection of quantitative data, a survey method was used to discover the knowledge attitude and practice of the people towards leprosy and its victims. The educated respondents in the community who were interested to fill it in themselves were given the survey questionnaire. Those people who were not competent enough to write and/or did not want to write themselves were asked each question by the interviewer and the responses noted accordingly. But it must be noted that their response regarding attitude and practice were based on their perceptive response rather than the real one which could only be assured by observation. Therefore, what they said they might not do.

Quantitative data on the patients' part relied on structured interview schedule however the schedule also contained qualitative information. To determine the level of their displacement in four major part of their life (family, social, vocational and self-esteem) a pre tested and statistically reliable debilitation scale (H. Anandaraj 1995) was introduced.

The statements in the original scale were in English. Therefore the scale was translated into Nepali language by doing back and forth translation many times to avoid deviation in the meaning. The scale was then tested in 20 cases (in different strata) before introducing. After

explaining the scale, educated respondents were asked to rate all items independently. For illiterate respondents, the interviewer read every statement aloud and asked to the respondents to select the appropriate response for each item. For the purpose of analysis, the formula (mentioned below) was entered on the computer database in EPI Info 6.04 version to calculate accordingly the level of debilitation. A separate description of the scale is given below. (The scale used is placed in annexes).

## DEHABILITATION SCALE

*“Persons who contract the disease of leprosy suffer mental turmoil and serious social set backs in addition to the physical problems that they encounter. This phenomenon needs no elaboration because often, persons with visible physical deformities are ostracized socially and are reduced to the state of beggars. Both in the past and in several cases even now, leprosy has been considered as a disease that brings debilitation to the person ..... The degree to which a person is debilitated needs to be known particularly by those who deal with him. .... Similarly, with such knowledge, the other members of the professional team such as vocational counselors, physicians, surgeons, physiotherapists and officials belonging to various welfare organization can contribute more meaningfully to the treatment”.*

(H.Anandaraj 1995).

As mentioned earlier, a standard debilitation scale produced by H Anandaraj (1995) was introduced to assess the level of debilitation. This scale contains 52 statements spread over the following four areas:

- |                             |                       |
|-----------------------------|-----------------------|
| 1) Family relations         | 2) Social interaction |
| 3) Vocational condition and | 4) self-esteem.       |

The scale's split-half reliability coefficient ranged high (0.64 to 0.83) in all 4 sub- areas. The item discriminant analysis had a level of significance of 0.001 for 42 statements while the factor analysis explained variance covered over 70%. The statements had a direction in that; they were either positive or negative. In addition, the statements had a five point response category, namely, strongly agree, agree, neutral, disagree and strongly disagree. To each response category weights were given in a descending order, from 5 to 1 to cover the range from strongly agree to strongly disagree. In the case of negative statement, the weights are reversed and given in ascending order, i.e., from 1 for strongly agree to 5 for strongly disagree. The positive and the negative statements were jumbled in order to avoid bias. There are few statements that have dichotomous response category, namely, yes or no. They are given 1 or 2 as the weight depending on the direction of the statement, whether positive or negative.

The scores ranged from 24 to 79. A high score indicated better social integration, i.e., less debilitation, and low score indicated poorer social integration and greater debilitation (Score : Below 75 = High, 76-86 = Medium, 87-100 = Low).

#### Method of Scoring:

Sum up the scores each respondent receives. To find out the actual score-quotient, it is also necessary to calculate the maximum possible score i.e., including the none-applicable statements, wherever necessary. Then divide the score obtained by the maximum possible score and multiply by 100.

#### **DATA ANALYSIS AND INTERPRETATION**

As it has been explained earlier that data collected was of two kinds, qualitative and quantitative. Therefore the treatment of data also followed two approaches in processing, analyzing and interpreting. Let me first explain the process involved for the qualitative data. It is understandable that qualitative data was heavy with text some of which was irrelevant information for the study. To do the analysis more systematically and scientifically, a computer was used with a simple technique. Sophisticated text analyzer software is also available but due

to lack of knowledge on the part of the researcher in using the software an old fashioned technique that was very much time consuming and exhausting was adopted.

Without judging the relevancy of information, all data was typed with some elaboration if required into a simple word processor and saved under some headings. This was done separately in two different folders; one for community and one for patients. In each folder data collected by the same approach was saved in the same file. For instance, all observation notes under file name observation note, all focused group materials under FGD file etc. Then each file was refined again by correcting mistakes (spelling, half sentence etc.). Once data was refined, some headings were created in the same file as per the study interest then the scattered information related to that heading was brought in one place. Finally the same headings merged together from different files and were read repeatedly and become the basis for interpretation and explanation.

In terms of analysis and interpretation, quantitative data was easy to handle. All data was collected in a structured format with some close and open responses. After going through some data, categories with open responses were developed to accommodate the responses. Then a database was designed using EPI Info version 6.04, public domain software produced by WHO, and all data was fed into it. It was found that some parts of the data from twenty community respondent's was missing therefore they were excluded from analysis and also exclude from the sample. Once the data was ready in the computer it became easy to analyze. All the frequency tables, cross tables presented here are the miracle action of this package that could produce these results as soon as it received the command to do so. The cross tabulations show the association between variables in terms of number. Therefore data in this part has been interpreted as per the statistical treatment given to it.

#### **ETHICAL CONSIDERATION**

The ethical principle is a necessary component of research. Ethical issues are particularly serious in human intervention studies. Although, social science research does not intervene physically in the study population, it intervenes in the socio-cultural and personal life of the population under the study. Therefore, social science research is also obliged to regard ethical

consideration in its research process. With this in mind, the present researcher was sincere from the beginning. Ethical and technical clearance was taken from National Health Research Council (NHRC) of Nepal before conducting fieldwork. In every study site, approval was taken from the concerned authority before conducting work. Similarly, respondents were explained the purpose and possible outcome of the research before involving them in interview after it had been made clear to them, consent was taken for their participation.

One woman, during the community survey, did not want to talk further after realizing that she had to give an opinion regarding leprosy. She was so afraid even to talk about leprosy. No argument or convincing was done to persuade her interview. Simply, this respondent was excluded. Similar other incident with patient may be worth mentioning. In one case in the out patient department of a hospital, the researcher started to interview after having the patient's consent. After half an hour, the researcher realized that the patient had become irritated and that he would feel better if he quit the interview. But he was unable to express this to the researcher because he may have had the impression that the researcher was connected with hospital in some way. To make a staff member unhappy might have future consequences for him. This was noted from his body language and from the way he responded. He was just giving a hint that he may miss the bus to go back home. Realizing his situation, after one or two general question (not study related) it was declared that the interview was over. So that he also did not feel embarrassed for not completing the interview. His record (which was already taken) was discarded when he had left.

As the researcher has a long involvement in leprosy work and also has some technical knowledge of the clinical aspect, the researcher intervened in some cases for the sake of the patient. While going through the patient's chart, while taking clinical notes, some mistakes (classification and other management aspects) were observed in some cases. In such cases, the appropriate staffs were approached in a very tactful way so that that they did not feel embarrassed or criticized. Hence the mistakes resolved in the favour of the patients. Some patients who were found desperately in need of economic support were referred to the person responsible for rehabilitation programme of the institution. The researcher had tried his best to

maintain an ethical stance through out the research work if any violation has occurred unknowingly by the researcher he sincerely apologizes for such event.

### **SOME RELEVANT OBSERVATION FROM THE FIELD WORK**

It is said that most of thing carry both the positive and negative aspects together. Researcher also had to face both advantages and disadvantages in this research work due to his previous involvement in leprosy field.

Let me start with advantages first, no hardship had to face for contacting institution, getting information required and to get the approval to conduct the work. One of the study sites was (Anandaban Hospital) belongs to the organization where researcher works. It is obvious that there was no restriction for him to moving around, accessing documents and even use manpower when required. Researcher was equally familiar in other hospital (Lalgadh) as well. Therefore had privileged with the same advantages there as well. Most of the leprosy patients under study (patients in leprosarium and in community) either have visited Anandaban hospital or at least heard about its good reputation. That played a significant role in rapport building with the patients. An important advantage to the researcher, due to the knowledge and experiences gained from the long involvement in leprosy, was that he could sit and even eat with patient with out any fear and hesitation that made respondents feel that they are no more inferior due to disease therefore became friendlier in the interaction. This allowed researcher to dig in depth to take out the hidden facts.

Now, the felt disadvantaged part can be discussed. Despite of researcher consciousness to avoid the possible bias based on previous experience, researcher himself felt a tendency to hasty generalization of the observed phenomena on the basis of previous knowledge and experience. Other disadvantage felt by researcher was that lack of interest in observing small happenings minutely because he had already exposed many times earlier in such situation and likely to ignore the hidden important aspect. Therefore, researcher could be disabled to pick the rich facts in small events.

I am not sure, whether it is appropriate or not to correlate the researcher previous involvement in leprosy with patient expectation. Researchers also felt that once they knew that researcher had come from a big leprosy institution and asking many of their problems and also taking note of it, they tends to develop a kind of expectation to get some thing in future which could led them to response inaccurately i.e., They would be motivated to show problematic and negative part only.

All above-mentioned disadvantages were tried to minimize in possible extent by avoiding biases and by explaining well to the respondents from the researcher side. However, there could be some effects remained despite of all efforts.