CHAPTER - THREE

RESEARCH METHODOLOGY

Research in the area of social sciences calls for strategic planning and implementation of research methods and techniques for the collection and analysis of data.

Most of the studies in social sciences relate to the understanding of human behavior, which is a product of socio-cultural system. Human behavior being highly complex and variable, cannot be studied in isolation or confined to laboratory experiments as in pure sciences, but is to be viewed in totality within the cultural-framework.

In anthropological studies, research methodology involves tools and techniques of data collection, assessment of the data and relating the data to the theoretical framework or propositions.

I. RATIONALE OF THE STUDY:

Leprosy being associated with social stigma and ostracism, provides a wide area for social science research. Leprosy as a disease poses multi-dimensional problems, namely:

i) Clinical: It is communicable, early signs and symptoms not easily detectable, unknown etiology, lepra-reactions and drug-resistance etc.

ii) Physical: It may cause physical deformities, neuritis, disabilities etc.
iii) Social: It generates intense negative reactions. Affected persons are alienated and may be socially ostracized or abandoned by the community.

iv) Psychological: Loss of self-identity, mental trauma, towards a chronic and stigmatized disease like leprosy.

The above factors can contribute to understanding of human behavior towards health and disease, in general, and leprosy in particular.

II. NATURE OF STUDY:

The study is exploratory in nature. Emphasis has been on exploring the people's beliefs, attitudes and practices toward leprosy. Secondly, the study attempts to analyze the differential explanations given by the 3 P's, namely, the people, patients, and providers of the health (leprosy) toward the identification, causation, transmission of the disease, concepts about cure, ulcers and deformities in leprosy.

An appropriate research design was formulated to incorporate the collection of both qualitative, as well as, quantitative data. Flexibility in the research design was permitted to accommodate the varying methods and techniques utilized for data collection, in order to study the problem from different angles.

III. METHODOLOGY:

1. Selection of the Research Area:

The study was carried out in the Rajnandgaon district of Madhya Pradesh, where a special project on community participation was being launched by an international organization known as Danish
Danida Assisted National Leprosy Eradication Programme (DANLEP) is operating in four districts, namely, Cuttack (Orissa), Salem (Andhra Pradesh), Durg and Rajnandgaon (Madhya Pradesh).

Rajnandgaon was selected as the area for the study based on two factors, namely:

1. It is an endemic area for leprosy cases with the prevalence rate of 8 cases / 1000 population (Source: State Steering Committee Meeting 1988, Rajnandgaon).

2. A new approach to National Leprosy Eradication Programme (NLEP) through Community Participation, distinct from the Blue-Print Model of NLEP, was operating here.

The above project was introduced in the district with the implementation of Multidrug therapy (MDT) in 1987.

For an in-depth study of people's perception towards leprosy, Ghumka, a sector under the Rajnandgaon Leprosy Control Unit (LCU) was selected, primarily, for three reasons:

1. It is the first sector where MDT was implemented for the first time in Madhya Pradesh (April 1989).

2. The sector consists of a high number of deformity cases.

3. The presence of a lady leprosy worker, at the sector's Headquarters which made possible the researcher's stay in the field. Most of the field-work at this sector was carried out with her assistance. The Ghumka sector consisted of thirty-one villages.
2. Type of Data Collected:

i) Ethnographic Information on the village community.

ii) Organizational structure of the NLEP.

iii) Prevalence and incidence rates of leprosy cases.

iv) Process of community participation and community action in leprosy control programme.

v) Knowledge, attitude and practices (KAP) studies about people's perceptions towards early signs and symptoms causations, transmission, treatment, cure in leprosy.

vi) Deformity prevention and ulcer management in leprosy.

vii) Chemotherapy and treatment compliance by the leprosy patients.

viii) Health-workers motivation in adopting innovative practice in LCP.

3. Research Tools and Techniques in data collections:

Data was derived both from primary as well as secondary sources.

I. Primary sources:

A. Observation: Participant and nonparticipant observation of the interactions of patients, family members, community members and leprosy workers at the following junctures:

<table>
<thead>
<tr>
<th>Observation Type</th>
<th>No. of Observations</th>
</tr>
</thead>
<tbody>
<tr>
<td>MDT Drug-delivery points</td>
<td>10</td>
</tr>
<tr>
<td>Clinic days</td>
<td>5</td>
</tr>
<tr>
<td>Family visits by leprosy workers</td>
<td>50</td>
</tr>
<tr>
<td>(Paramedical workers)</td>
<td></td>
</tr>
<tr>
<td>Camps (example: Skin diagnosis, Ulcer Care Camps etc.)</td>
<td>3</td>
</tr>
</tbody>
</table>
(v) Anti-leprosy Fortnight programs emphasizing on community awareness campaigns and case detection) 5

(vi) Family visits by Janbhagidars (Community participators) 8

(vii) Monthly meetings 2

(viii) Surveys 6

B. Interviews

(i) Informal Interviews were conducted through the aid of interview guides.

Informal interviews of the leprosy medical officers (4), leprosy - workers (20), patients (70) and community members (140) were conducted with respect to their:

- clinical and social perception of the disease prior to and after the implementation of the MDT.

- concept of cure in leprosy.

- process of change in health services: from drug-delivery to deformity prevention.

- changing roles of leprosy workers, community members and cured leprosy persons in LCR.

(ii) Formal interviews were conducted through the aids of:

(a) Interview schedules: For patients (50) and community members (100), with respect to early signs and symptoms, causation, transmission, treatment and cure, etc.
(b) Questionnaires: For leprosy workers (35) regarding their attitudes toward their work in leprosy, job, satisfaction, motivation, their interaction with patients, community members and other general health-workers etc.

C. Case-studies: were developed of cured leprosy persons under:

1. Monodrug Therapy (30).
2. Multidrug Therapy (40),

These were based on formal as well as informal interviews and observations.

D. Life-histories: were recorded of older leprosy affected persons (5), leprosy workers (5), and community members, highlighting on:

(1) The situation prior to the implementation of the MDT and new approach in LCP.
(2) Their personal life experiences regarding change in perception towards the stigma and misconceptions in leprosy.

E. Focused Group Discussions (8): Of community members, teachers, youths, members of the ladies club, Janbhagidars (community participators), patients and leprosy-workers were conducted. The group discussions centered around the following themes like:

- factors which have led to community participation.
- innovative practies adopted by the leprosy workers for leprosy control activities,
- perception towards early signs and symptoms, causation, spread, treatment and cure in leprosy.
II  Secondary Sources :

It included informations from the following sources :

(a) Monthly and annual Records and reports maintained at LCU, blocks and sectors head-quarters.
(b) Registers and diaries of Non-medical supervisors, and Para-medical workers.
(c) Patient illness records.
(d) Health education materials.
(e) Materials, articles, monthly magazines published by the society of the district NLEP.
(f) State Steering Committee reports.
(g) Government of India reports.

IV. SAMPLING :

For the collection of quantitative data, sample was selected from the universe of the Ghumka sector of the leprosy control unit, Rajnandgaon. The sample included both the members and leprosy affected persons.

The sample size for the community members was 100.

Sampling was done randomly and included two categories of community members :

(1) Those having experience with leprosy affected persons in the family.
(2) Those having no experience with leprosy affected persons in the family.

Two criteria for sample selection was based on the following : 

-------------------
1. Population of the village: ranging between 500-3000 (according to 1990 census).

2. Prevalence rates of leprosy cases: ranging between 10-12/1000.

Four villages were selected from the Ghumka sector based on the above criteria.

Those were as follows:

<table>
<thead>
<tr>
<th>Village</th>
<th>Population Size</th>
<th>Sample Size</th>
<th>Patient Population Size</th>
<th>Sample Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ghumkha</td>
<td>2730</td>
<td>40</td>
<td>40</td>
<td>20</td>
</tr>
<tr>
<td>Botepar</td>
<td>768</td>
<td>22</td>
<td>14</td>
<td>12</td>
</tr>
<tr>
<td>Eraikhurd</td>
<td>528</td>
<td>18</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>Bhaisatarrah</td>
<td>752</td>
<td>20</td>
<td>12</td>
<td>7</td>
</tr>
</tbody>
</table>

Total population = 4778  
Total sample size = 100

The sample size for the leprosy affected persons was 50.

Sampling was done at random and included the following categories of leprosy affected persons:

(i) Cured persons under monodrug/Multidrug therapies.
(ii) Both MB and PB cases under treatment/defaulters /RFT /RFC.
(iii) With/without deformities, nerve damage or ulcers.
Patients' sample was derived from the same four villages as that for community members, belonging only to Ghumka sector.

Sample size of the leprosy workers was 35.

Sample was derived from the entire universe of the leprosy control unit, Rajnandgaon. It also included leprosy workers from other LCUs, like Kawardha and Chowki. The various categories of leprosy-workers included: Health-educators, laboratory technicians, physio-therapists, non-medical supervisors and non-medical assistants.

V. FIELD - WORK

In social science research, field work plays a vital role. Primary data is collected through field-work in the community. Social scientists study about community and its problems. They seek answers to the questions such as: why do people behave the way they do? What is the basis of a person's behavior and attitudes? etc.

Leprosy is a social problem affecting community. People's attitudes toward leprosy cannot be studied in isolation or scrutinized under a microscope. Thus in this context, the field becomes an experimental ground for studying human behavior; community members, the subject of the study.

Field work in social science research requires the researcher to reside with the community members for a certain period of time, establish rapport with them and through the tools and techniques of observations, interviews, group discussions, questionnaires collects primary data on people's perception (knowledge, attitude and practice) toward the problem under study.
In the present study the field-work was carried out in two phases.

(i) Micro-level study: was conducted at Ghumka sector. It highlighted on the processes of change in people's perceptions toward leprosy with regards to causation, early signs and symptoms, transmission, treatment and cure, after the introduction of MDT in 1987, at the grass-root level.

(ii) Macro level study: was conducted at the district level. It gave insight into the historical perspective of the constructive work ("Rachnatmak Karya") adopted by the leprosy workers and community participators (Janbhagidars) for the leprosy control activities. The process has been documented though a number of case studies, formal and informal interviews, focused group discussions, written accounts provided by the community members, leprosy workers and leprosy affected persons.

Initial contact and rapport-establishment:

Rapport establishment is an integral part of field-work. A good rapport establishment with the community members is essential for obtaining reliable data. "When people have confidence they share their beliefs, values and explanations for the things they do".

The first contact person in the field was the lady Non-medical assistant (NMA), of the Ghumka sector (with whom the researcher resided during the field-work period). Through her the researcher was introduced to prominent members of the community like:

Village sarpanch,
Block medical officer of the primary health centre,
High school principal.

------------------------------------------------------------------

-62-
Non medical supervisor of the sector,  
Village police officer, etc.

The researcher was also introduced to the members of different  
social clubs operating at the village level like:

Youth club  
Mahila Mandali  
Ramayan Mandali, etc.

The field-work was carried out in different phases. Each phase  
ranged between one and half months to three months according to  
the nature of the study.

Phase - I : Exploratory studies : One & Half months :

Exploratory studies included data on:

(i) Ethnographic details of the people of Ghumka village,  
Cultural and socio-economic background, religious and health  
beliefs, aesthetic aspects etc.

(ii) Profile of the prevalence and incidence rates of leprosy in  
Ghumka sector.

(iii) Observation of the interaction between leprosy health  
workers, patients and community members

Phase - II : In-depth study : 3 months :

In the second round of field-work, informal and In-depth  
interviews were conducted. Group discussions of the different  
sections of the community like the village school teachers,  
community leaders, leprosy affected and cured persons, health
workers, were undertaken. Their concepts about early signs and symptoms leprosy were probed into.

Phase III: Data collection through formal interview:
Two & Half months.

Formal interviews were conducted through the tools of interview schedules and questionnaires employed for data collection.

Phase IV: Macro-level study: 4 months.

The Macro Level Study, as mentioned earlier, included a district level study which encompassed people's perceptions toward leprosy in a wider framework. It has identified the process by which leprosy workers moved away from the conventional method to innovate new approaches to control activities, by involving the community in the LCP.

The process documentation of the innovative approaches to LCP at Rajnandgaon has been undertaken by a team of a social scientist, a behavioral scientist, a leprologist, a social activist, a research scholar and leprosy workers. It was aimed to evaluate the ongoing leprosy control activity, which has been distinct from the blue-print model of NLEP.

A historical perspective of the constructive work adopted by the leprosy workers has been documented through a number of case-studies, formal and informal interviews, group discussions, and focused group interviews/discussions. Written accounts were supplied by the community members, especially the Janbhagidars (community participators), which related their life experiences centering around fear removal, removal of misconceptions toward cure and infectivity associated with deformity and ulcers, the motivating factors underlying their involvement in LCP, etc.
Written accounts were also compiled by the leprosy workers, highlighting the motivational aspects to their adoption of innovative practices in LCP and detailed accounts of the activities like organization of various leprosy camps, rallies, street-plays, socio-cultural activities based on leprosy themes, etc. A content analysis of all the above written accounts were undertaken by the team which has resulted in the report "Innovative Approaches to NLEP at Rajnandgaon: A Process Documentation", submitted to the Government of Health Ministries, Madhya Pradesh.

The researcher has been a member of the evaluation team and contributed to the process documentation by touring different blocks under the Leprosy Control Unit, collecting base-line data through a case-studies and analyzing and compiling the written accounts. The base line data gathered during this phase of fieldwork forms a part of the present study.

VI. RECORDING OF DATA:

Log-books were maintained for documenting day-to-day events and experiences and a separate data book for recording information collected through observations, informal interviews, group discussions, interview schedules, questionnaires etc. Information from secondary sources like the reports and registers at the LCU, Blocks and sector head quarters were also recorded.

VII. THE ANALYSIS AND INTERPRETATION OF DATA:

Both qualitative and quantitative methods were employed for the analysis of data.

Questionnaires and interview schedules were research tools employed for collecting quantitative data. The responses were
numerically coded and a code-book was prepared. The coded responses were filled out in prepared performas and fed into the computer for analysis using specially designed dBase programming.

Since the questionnaires and interview schedules were semi-structured and not pre-coded (to allow flexibility in the responses) considerable time was required in coding and analyzing the responses.

The data collected through observations formal and informal interviews, group discussions were analyzed qualitatively. The qualitative data are categorised into different themes and analyzed within the cultural framework of the community.

The hypotheses are being tested through selected case-studies, content-analysis and analysis of questionnaires and interview schedules.

VIII. LIMITATIONS OF THE FIELD-WORK : METHODOLOGICAL ISSUES :

1. Initial Rapport :

At the initial stages of field-work, establishing contacts with the community members was done through the local NMA of the Ghumka Sector. The researcher rarely ventured into independent rapport establishment with the community members or the leprosy affected persons. The apprehension of being turned down by the community members when approached with a topic like leprosy for discussion inhibited the researcher from venturing independently. Secondly, NMA’s assistance was needed for knowing the patients in the community. The hurdle was overcome with the passage of time and gaining familiarity with the community members of the village and
later discovering that community members were open to hold discussion upon leprosy, and it was not a stigmatized issue.

2. Identity Crisis:

Community members at certain areas harboured misconceptions about the role of the researcher while conducting interviews, group discussions or a casual visit to the village. At many instances, the researcher was associated with the NMA, a newly recruited ANM, a visiting health-officer and even a social activist (as discussions were upon social issues surrounding a leprosy person). This crisis was solved by first introducing the researcher as a university student interested in leprosy issues concerning the community.

3. Recording of data and maintenance of log-book:

Interview-guides were useful tools in channeling the informal interviews and group-discussions in the right direction. Data was often recorded in points and later elaborated into detailed notes. The flow of information through these techniques were spontaneous. Difficulty was faced in recording the data obtained through formal interviews based on structured interview schedules. It was impractical to carry out a rigorous session of questions running up to ten to fifteen pages (or an interview schedule) directed towards one respondent at a time. Often such sessions were tiresome both to the respondent and the researcher's part. The community member/volunteer or health-worker accompanying the researcher often complained of the lengthy, time-consuming method of interview. Moreover, community members or family members present at the scene of
interview often prompted the respondent or interrupted in the process of interview.

The above obstacles were overcome, first, by condensing the interview schedule and transforming the format as an interview-guide with probing questions, particularly, with regards to the knowledge about the disease etiology and attitude towards leprosy person. Each interview began with preliminary information i.e. the personal and ethnographic details. Secondly, to avoid monologue responses, informal conversations were interspersed to make the respondent feel at ease. Thirdly, accompanying community members or health-workers stopped complaining about the length of interview when they began, to experience that their knowledge was being enriched by various perceptions and life experiences being expressed / narrated by the respondents. Fourthly, the views expressed by the family members or community members present at the scene of interview were recorded as additional information supporting the views presented by the respondent.

Recording of the data was done on small pocket size writing pads which were not very conspicuous. People were often suspicious of their responses being recorded for some ulterior purpose like lodging a complaint against their responses at the police station. Thus, use of cassette recorder or photography was avoided during such in-depth interviews. The sketchy and brief notes were later filled in the interview schedules. Information obtained through observation were also included.

Log-book served as a background information on the data collected. In the field, the researcher was not able to maintain diary writing on a regular basis. Often diary used
to be updated after a gap of two-three days. Under such circumstances the day's events were outlined in short and brief sentences or points. Much of the time was consumed in elaborating the field-notes at the end of the field-work and planning for the next day's work, thus, systematic writing of log-book often used to be neglected.

4. Need of an Interpreter:

Unfamiliarity with the local dialect spoken in the area, i.e. Chhattisgarhi, made the researcher to seek the help of an interpreter. Often health-worker or a community member, (either a Janbhagidar, CHV, Village-guard (kotwar), or an acquaintance of the researcher) played the role of an interpreter. Through the interpreter, the researcher was able to probe into certain underlying issues and concepts regarding community attitudes, beliefs and practices toward leprosy, their philosophy of life, health and disease and personal body image. The health-workers aided the researcher in understanding the medical implications drawn from the respondents' (especially the patients) views and experiences. For example, a patient was relating the different stages of the disease based on the signs and symptoms. The health-worker present during the time of interview analyzed the patient's explanation corresponding to the medical stages of the disease like: patch stage - "D " chakwa"
neuritic/anaesthetic stage - "p"
ulcer and deformity stage - "Sakar" (mukhr)

Thus, the researcher's field-data were often complemented by the health-worker's back-ground information particularly on patient's interviews, and community member's additional information on general concepts and beliefs prevalent in the community.