CHAPTER II
Research Methodology

Methodology

The present study is partly exploratory and partly descriptive in nature to gain in-depth knowledge into the stigma and discrimination faced by the People Living with HIV/AIDS (PLWH/As) of the Chandigarh.

It incorporates both quantitative and qualitative research methods. Methodology in a wider sense means the process by which the approach a phenomenon under study and seek answers. It enables the researcher to construct and conduct the research in a systematic manner. Here, an attempt is made to outline the choice of theoretical framework selected along with the rationale for it, as well as, the major procedures, tools and techniques used in collecting and analyzing the data. A brief note has also been added to highlight the experience and problems faced during the course of research. However, before going on to the above-mentioned topics, a brief discussion on the issue of quantitative versus qualitative research methodology is offered.

Qualitative versus Quantitative Research

There are two types of methods that are used to conduct a social research, namely quantitative and qualitative. Quantitative research assumes an objective world, where researchers act in a value-free and unbiased manner and seek finely calibrated descriptions. It uses impersonal, formal and rule-based text and a detached orientation towards the data. The quantitative research uses deduction, limited cause-effect relationships, and context free, rule driven methods and is, therefore, more generalizable. It is, also a theory testing method. Qualitative research on the other hand, assumes that multiple subjectively derived realities coexist and the researchers must interact with their studied phenomena, and the researchers explicitly and overtly apply their own subjective interpretations to understand the phenomena. This research is, non-
positivist in its approach. The qualitative researchers favor greater personal investment in the data, overtly act in a value laden and biased fashion and most frequently use personalized, informal, and context based language and methods. They often encourage substantial flexibility in research procedures and do not enter with strong prototypical models to follow and want to be maximally responsive to the constraints imposed by their immediate situation and empirical data. They focus more on understanding the phenomena at hand than on predicting outcomes and are grounded within the local context; in which the phenomenon of interest occurs and are also more explicit about participants' reactions. In short, the quantitative research is assumed to be dealing primarily with statistics while qualitative research is less concerned with numbers. According to Cassell and Symon (1994) it is thus, quantification versus interpretation.

There is, however, a move towards synthesizing the two approaches. Lee (1999), for instance, recognizes a middle ground theory by blending qualitative and quantitative research. According to him by selecting multiple techniques, the researcher creates a set of complementary data gathering that compensates for the weakness of individual tactics. The data thus collected are descriptively rich and quantitatively meaningful. Similarly, Creswell (1994) also advises blending of the quantitative and qualitative research, as both are desirable for understanding multiple realities. Keeping this in view the researcher too, have used both the methods of research in this study, as according to the study of this nature, both methods by themselves provide only a partial description and analysis of the social phenomena. Therefore, the researcher have combined the two research techniques, in an effort to provide a more comprehensive picture of the trials, pain, despair and hope - in short, the whole life experiences of the persons living with HIV/AIDS.

**Theoretical Framework**

In this study, although functionalist and conflict perspectives have been used to some extent to study the HIV/AIDS infected persons, yet, it is the phenomenological perspective, dealing with the life world and everyday
experiences of the PLWH/As which is being concentrated upon. Phenomenological interpretive research attempts to make the world of lived experience directly accessible. The focus of interpretive research is on those life experiences that radically alter and shape the meanings persons give to themselves and their life projects. Because of its emphasis on lived experience, this approach suggests that social phenomena must always be judged by and from the point of view of the persons most directly affected by them.

Phenomenology desires not to study social facts, but instead, the processes through which social facts are created by man. It strives to study ongoing process of reality construction in society. Thus, while the social factists study social facts as being coercive on man, the phenomenological sociologists study how men engage in the process of creating and maintaining social facts, which are coercive on them. To do this, they must uncover the process through which social order emerges from the negative behaviors of everyday settings. It is from these settings that the appearance of paramount reality is constructed, upheld and through which constraint is experienced. It, thus, brings out those subjective experiences and aspects of social life, which are ignored as mundane and banal, but may provide vital insight into the interactants' definition of the situation. Hence, although the researcher find the other two approaches useful, yet, the emphasis is on the phenomenological analysis of the people afflicted with this illness.

**Methods of Study**

Keeping in mind the major theoretical framework selected for this study, the obvious choice for a research methodology also seems to be qualitative. However, as the researcher known to all, that due to difficulties in gaining access to respondents relating to mental illness, homosexuality, rape etc., and present research has promoted innovative and pragmatic methodological approaches. Similarly, depending upon the particular health hazard being investigated, epidemiology also draws upon the knowledge and techniques of several scientific fields. Since use of a single approach can lead to certain rigidity of research strategies and in understanding the phenomenon. It is,
therefore, considered essential to combine a variety of methodological approaches, both quantitative and qualitative in nature. Lee (1999) advocates this middle position between firstly, the assumption of an objective reality and Secondly, an ongoing and constant process of interpretation, sense making, and social construction of the life world. According to him, a researcher should ask, whether the best method has been applied and not, whether qualitative or quantitative designs are used. He favors the blending of qualitative and quantitative research, which the researcher have also followed.

**Location of Study**

This study was carried out in famous city of north India, namely, Chandigarh. Chandigarh is popularly known as the City Beautiful, is capital of Haryana and Punjab, and of Union Territory in the Northern region of the country, spread over a 20 sq. km it has a population 1.6 million. Chandigarh is a model of architectural grandeur in modern India, which is named after the local presiding deity ‘Chandi’-the goddess of power. It owes its birth in 1950 to the vision of Pt. Jawaharlal Lal Nehru- the first Prime Minister of India who envisaged ‘Chandigarh- the City Beautiful’ as an ‘expression of the nation’s faith in the future’. It is located at the foothills of the Shivalik range with two rivulets – Patiali-ki-rao on the North –West and Sukhna choe on the South-Eastern edge.

Le-Carbusier – the French architect planned Chandigarh for a finite population of half a million; 1,50,000 in Phase –I in sectors 1 to 30 and 3,50,000 in Phase – II in sectors 31 to 47. However, in 1966, there was a division of joint Punjab into Punjab, Haryana and Himachal Pradesh. Both Punjab and Haryana had their capital in Chandigarh, thus it was retained as a Union Territory, thereby leaving a limited space for expansion.

Scholars have indicated that the negation of some of the basic objectives of Chandigarh’s master plan began from the very start of its construction. Obviously, majority of those who were the first to arrive at the site were construction workers, with no provision for housing at all. Failure was evident, by not making any provision for such workers (approximately 30,000) in the Chandigarh project estimates. Consequently, large clusters of thatched huts adjoining major construction work
started sprouting and thus began the genesis of the slums (Dubey, et al. 1999) most of these slums are encroachment on government land or on private land in connivance with the land owners, who have converted the agricultural land on the outskirts of city to build temporary accommodation (mostly jhuggis). Many of these migrant labourers erected these huts with the hope that they would be provided permanent accommodations under some rehabilitation scheme.

The Union Territory of Chandigarh comprises of 52 sectors, 27 villages and 43 colonies. These colonies are slum dwellings with a population of approximately three lacs. As already stated, the dwellers of these slums are migrants, majority of whom have migrated in the search of better job prospects. About 64 percent of these people are from states with very high morbidity and mortality indices (BIMARU states viz. Bihar, Madhya Pradesh, Andhra Pradesh, Rajasthan, Uttar Pradesh and Orissa) in comparison to general indices of India. Out of these 43 colonies, 20 are authorized and rest, 23 are unauthorized. There are 26084 households in the authorized colonies with approximate population of 1.25 lacs, whereas in the unauthorized colonies, there are 29586 households with a population of about 1.75 lacs (Dubey, et al 1996). Once a quaint little town, Chandigarh today is vibrant metropolis with cosmopolitan population. The industrial base of the city is broad. Chandigarh is well known for its well-structured and growing hub of education and Information Technology. But its expansion has brought with it unplanned development disparities in living standards, and large-scale migration. Slums have appeared at several areas of the city. Chandigarh has no well-demarcated red-light area. The sex trade is spread all over the city and is mainly street-based.

Chandigarh was selected for this study because its HIV prevalence rate is increasing and because recognition of the epidemic locally has led to AIDS-related interventions, the mobilization of HIV-positive people, networks among individuals and organization associated with AIDS-related activities, and a growing interest in research on AIDS-related topics.

This study was conducted with people living with HIV/AIDS (PLWHA). In the initial stages of the research an effort was made to extend the study to Haryana and Punjab. However, in spite of being promised co-operation by NGOs
in contact with people living with HIV/AIDS, we were unable to obtain any help from them. After spending six months trying to establish contact through hospitals and other networks in these cities, the research was then taken up in. However, this doesn't make the relevance of this study any less significant because this city is important referral centers for health facilities due to prestigious medical institutes like Post Graduate Institute for Medical Education and Research (P.G.I.M.E.R), Government Medical College and Hospital, Sector- 32 and Community Care Centre (CCC). Thus, this city attracts people from all over India, which provided with a better opportunity of contacting PLWH/As from various cities. Also, as the researcher has already been working in the field of HIV/AIDS in Chandigarh, so his practical experience in the research area has facilitated research. The researcher has good contacts with the in service providers (i.e., NGOs, ICTCs, etc.) which helped in data collection.

**Target Population**

The target population consisted of all the People Living with HIV/AIDS residing in Chandigarh city.

**Sampling**

The respondents of the study were People Living with HIV/AIDS (PLWH/As), both men and women. The number of respondents, whether male or female could not be pre-determined by the investigator, but it was researcher endeavor to interview a proportionate number of male and female respondents in the city. This was done to gain insight into the varied experiences of both the sexes. The snowballing method was used to identify respondents, as that was the only method through which the respondents could be identified due to the nature of the subject. A total of 132 respondents were interviewed. The respondents were only adults. However, few cases of prenatal transmission (mother to child) were also identified; but, interviews could not be conducted with them, as they were infants. Nevertheless, their parents who were also HIV positive were interviewed and have been included in the sample. It would have been interesting to study all the People who are living
HIV/AIDS of the target population. But owing to the time and personnel constraint, the sampling was essential. For this study, simple random sampling technique was used.

A number of all the PLWH/As was procured from the Chandigarh AIDS Control Society, Sec- 16, HIV Positive People Network Sector-15, Community Care Centre, Khuda Ali Sher, and various NGOs which are working with HIV Positive people of Chandigarh. Respondents were selected according to their availability. Some of them were with relatively good accessibility to health care facilities and the other one with low or no care facilities.

Development of Tools

The interview schedule was developed by review of relevant literature, work experience of the investigator in the community, consulting experts in the field of sociology and HIV/AIDS, community medicine obstetrics and Counselors and nursing staff. Their suggestions and comments were incorporated for the validity of the instruments. There were a total of seven experts to assess the content validity of the interview schedule, based on the expert’s opinion necessary modifications were made.

The reliability of tools was ensured by test- retest method, which was obtained by administering the tool two times with fortnightly time gap to 10 subjects. Hence the tool was reliable enough to use for collecting data. The interview schedule was suitable modified again after the pilot trial done on 10 respondents belonging to city itself.

The interview schedule comprised of five parts to collect information pertinent to various aspects of the study:

A) Household characteristics schedule to gain insight into the background of the study population. It collected information of respondents’
Demographic – Age, Sex, Education, occupation, Income etc.
Family – Size, composition, marital status etc.
B) Awareness level of HIV/AIDS among the respondents. The respondents were interviewed for knowing their awareness level how this disease spread (mode of transmission), knowledge of symptoms, the reason of separation and causes etc.

C) Sources of transmission to them i.e., unsafe sex, multiple sex partner, commercial sex partner, unsafe needle, mother to child transmission and blood transfusion etc.

D) Reaction of the respondents when they come to know about their status, what was their family, spouse, peer and employer reaction to them and gain insight into their attitude, knowledge and practices relating to their status.

E) Types of stigma and discrimination respondents faced at the various level i.e. hospitals, family, work place, community, educational institutions were measured to see the variations on the different level i.e. age, sex, educational level, income level, state etc.

F) Coping mechanism they are adopting for overcome the situation and disease (doing mediation, taking medicine regularly, discontinue the high risk activities etc.) and how family and peer group is helping him/her in coping the situation.

Tools, Sources and Method of Data Collection

The choice of research methods that are available to social scientists has been summarized by de Vaus (1986) in terms of experimental methods, survey methods and case study methods. To these could be added the documentary and historical methods. The researcher may use a combination of the different approaches available in order to deal with issues concerned with validity through methodological triangulation (Denzin, 1970).

Investigators can use different approaches to social research but can use
similar methods. Interviews, questionnaires, observation, case study and documents are appropriate in many forms of social research. Interviews may be structured with specific questions, which may include closed or open-ended responses or unstructured where similar topics are raised through an interview agenda. Structured interviews often involve the use of interview schedules, while unstructured interviews are frequently tape-recorded and subsequently transcribed (Burgess, 1984; Hammersley and Atkinson 1983). Similarly, observation includes systematic observation, which involves the use of particular schedules or may be participant or non-participant. The case studies may involve the use of observation, particularly participant observation, together with structured or unstructured interviews and conversations. In particular, observation of people forms a large part of this approach, in conjunction with conversational style interviews. The methods to record data can thus, be field notes or tape-recorded interviews later transcribed. The collection of documentary evidence may take a variety of forms including written material and oral histories (Scott, 1990). Documents are produced in all organizations; they are therefore a major source of evidence for a social researcher. They can take a variety of forms and are often classified as primary and secondary source material.

Accordingly, there is no benefit in considering one technique superior to the other. Instead, there is a need to focus on research problems using as wide range of methods of research as are available. In the present study, the researcher have used all the above said techniques. For ascertaining the general trend of HIV/AIDS, secondary information was collected through sources such as National AIDS Control Organization (NACO), UNAIDS, State AIDS Control Society (SACS), Union Territory Chandigarh, media clippings and government statistics obtained through the use of internet, as well as, documents produced by the above mentioned organizations. Structured interview schedules were used to get specific responses such as profile of the respondents. These were supplemented by in-depth interviews in order to gain insight and develop case studies. The interview schedule was intended to serve as broad guidelines while extracting maximum structured information. However, the interviews were carried out in, a flexible manner as far as sequencing of questions were concerned in order to be sensitive towards the circumstances of the PLWH/As and to make them comfortable to answer personal questions and narrate their experiences. The respondents were given ample time to narrate the important
instances of their lives after their knowledge of their sero positive status. Observation was also a tool used during the interviews and specific reactions of the respondents were noted. The tape recorder was used wherever the respondent consented, which were later transcribed. In other cases, field notes were taken. Data collection was guided throughout by the principle of informed consent and also to maintain confidentiality of their identity, the names of the respondents have been changed. For the data collection main method will be used during the research; interviews of the respondents who are HIV positive and AIDS patients.

Data Sources

The data was collected both from primary and secondary sources. The information from published and unpublished sources like monthly reports of NGOs, registers with ICTCs, Newspapers cuttings, magazine of National AIDS Control Organization, monographs, etc. was used as secondary sources. For the primary data, the information was collected directly from the study subjects with a help of a pre-tested semi structural interview schedule.

Data Collection

Data collection was done from Dec 2007 to Oct 2008, by the investigator, himself. After self-introduction and explaining the purpose of the study, demographic data was collected. The procedure was then explained to the respondents and then they were asked to give their verbal consent for the participation. The interview was conducted with complete confidentiality. For conducting interview sessions, home visits to the respondent’s house were also made, but sometimes due to unavailability of the subject in daytime, evening or non working day interviews were also conducted. If a respondent was found to be unavailable in 4 consecutive visits he/she was dropped from the study. In case of minor subjects mothers were allowed to accompany the respondents, but they were made to understand the importance of respondent’s responses. So that they do not intervene in-between the interview process.

The total numbers of houses surveyed were 132 to get a sample of People
Living with HIV/AIDS (PLWH/As). Average time spent for conducting an interview was 30-50 minutes. Taking into account the time taken to reach a house and building rapport for the interview an average of half an hour was spent on each respondents. Therefore, six hundred hours were approximately needed to collect the data.

The liaison was established with the Government dispensary medical officers, wherever applicable. The subjects who were found to have some morbidity were referred. Many of the subjects were very cooperative, and had many queries, once the interview was finished. Since, the researcher himself was a program manager; he gave health education and referred the respondents with health problems as and when needed.

Analysis and Report Writing

After the collection of data, the processes of coding, tabulation and analysis were undertaken. Field notes were also translated if these were in local language. Data were coded and tabulated manually. The quantitative data has been presented in the form of simple, as well as, cross tables. The qualitative data is presented in the form of case studies, as well as, in the form of relevant portions of narratives of the respondents, in order to bolster or counter the quantitative findings.

Ethical Consideration

Respondents were first explained the purpose of the study and then, their verbal consent was obtained. Whenever the respondents refused, the researcher tried to convince them, but no undue pressure was exerted. Twelve respondents were dropped because they could not be contacted, inspite of repeated visits to their houses. Full confidentiality was maintained, during the interview was conducted and the subjects were also given an assurance about confidentiality.

Experiences during Research

In view of the nature of the research of people living with HIV/AIDS,
difficulties were expected to come forth. It seems appropriate to mention these difficulties in order to understand the limitations under which the study was conducted. In the initial stage, there was a problem of identifying the people living with HIV/AIDS. Since the investigator is already working in this research area professionally, the researcher began with the assumption that it would facilitate the data collection. But in spite of all connections, it took one and half years to conduct the interviews, since it was still difficult to identify PLWH/As. In starting of the research, it being a sensitive area, the hospital authorities and non-governmental organizations involved in working with PLWH/As had their reservations in revealing the identity of such persons as they were bound to maintain secrecy and confidentiality of these people, but later on as the investigator made them realise the importance of the study they agreed to provide valuable information, but just like them investigator of this research is also ethically and legally bound to maintain the full confidentiality.

Secondly, once contacted, the PLWH/As were skeptical in opening up and therefore, a lot of time had to be spent to gain their confidence. A number of respondents, because of time constraint for them, had to be contacted two or more times over a period to gain their trust and fetch important information from the respondents.

Thirdly, the methodological difficulties were compounded by the inadequacy of theoretical background in this field. Whereas, there is a prior tradition of sociological work on other health-related issues, but the researcher found little evidence of detailed theoretical work on stigma and discrimination attached to HIV infected population, which combines both quantitative as well as qualitative approach. Most studies related to HIV/AIDS are concerned with the issues related to public knowledge and public responses to the 'epidemic' and to the preventive behaviors. Thus, the researcher faced problem of getting repetitive and restricted research procedures and findings. It was, therefore, extremely difficult to provide an exhaustive account of research approaches and theories in this case. However, despite researcher limitations, an effort has been made to get insight into the traumatic lives of people living with HIV/AIDS and becoming victims of stigma and discrimination of society, which is not only lowering their worth in society but also leading to more
HIV/AIDS transmission as these people view them worthless part of society and feel revengeful towards society because of which they are facing social, psychological humiliation. Therefore instead of going for safe behavior they feel that they should give back the society, what society has given them.