

CHAPTER IV

RESEARCH METHODOLOGY

4.1 INTRODUCTION

HIV is culturally a very sensitive issue because in the societies like in India; there is a taboo to talk about the sexual issues. In a report published in a medical journal in January 1986, it was stated that:

“Unlike developed countries, India lacks the scientific laboratories, research facilities, equipment, and medical personnel to deal with an AIDS epidemic. In addition, factors such as cultural taboos against discussion of sexual practices, poor coordination between local health authorities and their communities, widespread poverty and malnutrition, and a lack of capacity to test and store blood would severely hinder the ability of the Government to control AIDS if the disease did become widespread.”

- Ghosh. T.K, JIMA (Jan, (84) (1)

Like in any other country in the world, the disease had first appeared in the HRGs³² in India and gradually spread in Low Risk Groups (LRG)³³ of population. HIV was believed to be the problem of someone else', *i.e.* who were considered to be from the marginalized groups of society, persons whose behavior was believed to be illicit and immoral.

PLHIV in India come from incredibly diverse backgrounds, cultures and lifestyles. The vast majority of infections occur through unsafe heterosexual sex (NACO, UNAIDS), and most of those who become infected would not fall into the category of 'high-risk groups'. Members of such groups, including sex workers, men who have sex with men, truck drivers and migrant workers, do face a proportionately higher risk of infection.

With cultural and religious taboos, on behavioural aspects of society, the topic is very sensitive. This chapter highlights the procedure and techniques employed to conduct this study. To conduct a study on this topic both quantitative and qualitative methodologies were employed. Although, the most tedious task was to approach the people living with HIV, due to stigma and discrimination attached to HIV, it was a

³² High Risk Groups consist of Commercial sex workers (CSW) and their client, intravenous drug users (IDUs), male having sex with male (MSM)

³³ Low risk Groups consist of housewives, general population etc

very challenging task to build confidence in PLHIV for sharing their experience. Ethical issues regarding the research were well taken care of during the whole field survey.

4.2 STUDY DESIGN

This study is an amalgam of quantitative and qualitative research. An intensive research was done to identify the sources of data related to Pune city. Pune is one of the high HIV prevalence districts in India and majority of HIV cases are identified in PMC and PCMC region of the district. Various government, private and international bodies are engaged “in response to HIV” (intervention strategies for HIV epidemic) in the district. Government of India had established National AIDS Research Institute (NARI), in 1992 in the city, after realizing the multi-disciplinary research need involving virology, immunology, microbiology, clinical research, epidemiology, along with field based trails as well as social and behavioural research. Several meetings were arranged with the national research institutes and state level Non Governmental Organizations (NGOs), working particularly with and for the welfare of PLHIV. In the initial phase of study, we had discussions on various aspects of HIV related socio-economic studies with prominent scientists of NARI. NARI, itself is engaged in various studies related to social and behavioral aspects. However, people registered with NARI studies are predominantly coming from lower socio-economic strata of society. Hence, the idea of drawing a sample from PLHIV involved in NARI studies was ruled out. Various other [state, national and international] agencies, are engaged in response to HIV. However, most of the agencies are working with high risk behaviour groups of society or working for prevention and awareness related issues. It was difficult to approach HIV positive patients of private doctors because of the confidentiality and social stigma attached to HIV infection. We were fortunate to locate, Network of Maharashtra People with HIV (NMP+), an organization formed by people with HIV to enhance quality of life among PLHIV. Membership of NMP+ is open to all people living with HIV in the state of Maharashtra, irrespective of gender, caste, religion or social group. NMP+ was founded in 1997, registered in 2001, and now has over 30,000 members. It is an affiliated body of Indian Network of People Positive (INP+).

NMP+ has district networks in the whole of Maharashtra. At present, 34 District level networks of positive people are established and these networks are making efforts to

reach maximum number of positive people for treatment, education and adherence. There was a great help of Network of Maharashtra People Living with HIV (NMP+) and its district level branch, District Level Network of People Living with HIV (DLN+) during the whole research work and their co-operation during the whole field survey is highly commendable. As there is no bar of membership with respect to caste, creed, economic status, race, gender, religion and social group, we had selected NMP+ as the strong base to be taken as a representative sample of population with HIV. PLHIV were contacted and interviewed at the office of Positive Living Center (PLC), MangalwarPeth (earlier) and now at Nehru Nagar (PCMC region), an initiative of NMP+ under the Adherence, Counseling and Treatment (ACT) project. Quantitative information is collected with the help of a well structured questionnaire and qualitative information was collected from the case studies. To conduct a field survey, sample size was designed a priori. The list of people enrolled with DLN+/ PLC till December 2007, was obtained. Nearly, fourteen hundred PLHIV were enrolled with DLN+/ PLC. To draw a sample, we had taken into consideration two dimensions:

- Average household monthly income- an indicator of economic well being
- CD4 cell/ μ L- an indicator of disease progression

On the basis of these two dimensions, the expected sample was drawn from a population of 735 observations. Although, fourteen hundred PLHIV were registered with PLC till date, our main focus was adults with identified CD4 count status. So the list was filtered. Distribution of 735 adult PLHIV registered with PLC based on above two dimensions is shown in table 4.1.

Table 4.1: Distribution of Adult PLHIV registered with PLC CD4/ μ L and Average Monthly Income

CD4/Income	<2000	2000 - 4000	4000-6000	>6000	Total
<200	226 (30.7)	98 (13.3)	28 (3.8)	4 (0.5)	356 (48.4)
200-499	179 (24.4)	90 (12.2)	27 (3.7)	6 (0.8)	302 (41.1)
\geq 500	53 (7.2)	17 (2.3)	5 (0.7)	2 (0.3)	77 (10.5)
Total	458 (62.3)	205 (27.9)	60 (8.2)	12 (1.6)	735 (100.0)

Source: Based on Data from Positive Living Center (PLC), NMP+ Pune.

It was decided that a sample of 400 PLHIV would be adequate for the purpose of our study. Table 4.2 shows an expected distribution of a sample of 400 observations to be drawn from 735 adult PLHIV as follows, based on the two dimensions mentioned.

Table 4.2: Tentative sample based on CD4/ μ L And Average Monthly Income

(Round up)

CD4/Income	<2000	2000 - 4000	4000-6000	>6000	Total
<200	123 (30.7)	53 (13.3)	15 (3.8)	2 (0.8)	194 (48.5)
200-499	97 (24.3)	49 (12.2)	15 (3.7)	3 (0.8)	164 (41.0)
\geq 500	29 (7.2)	9 (2.3)	3 (0.7)	1 (0.2)	42 (10.5)
Total	249 (62.3)	112 (28.0)	33 (8.2)	6 (1.7)	400 (100.0)

Source: Positive living Center (PLC), Pune

From Table 4.2 it is clear that most of the people are coming from the lower economic strata (62.25%) of society and most of them are struggling with the full-blown AIDS (48.5%).

4.3 STUDY AREA

Pune city and its suburban region were selected, to investigate the impact of HIV/AIDS at household level. Pune district is one of the high HIV prevalence district in India and most of the cases of HIV infection are concentrated in the region of PMC and PCMC. Pune city is the second most populous city of Maharashtra state with a growing population of more than 40 lakhs (4 million). It ranks among top five HIV prevalence cities in Maharashtra state. Forty percent of Pune's population lives in urban slum conditions, where a lack of education and access to health information means that people are typically uninformed about HIV. It was estimated that most of the cases of HIV infection in Pune are concentrated in the slum areas only. In 2006, 0.5 percent ANC attendees and 0.5 percent ANC attendees in rural Pune region were found to be HIV infected. Similarly, the HIV prevalence rate was found to be as high as 23.6 percent in MSM and 50 percent in FSW, of those who were tested for HIV (NACO). Pune has notched another dubious distinction as a city with the highest prevalence of HIV-infected MSM population.

Most of the respondents enrolled in the study belong to PMC, PCMC region and Pune metropolitan suburban region.

4.4 CHARACTERISTICS OF RESPONDENTS

The status of respondents was carefully examined. Keeping in mind the expected sample size, respondents from different categories were given due consideration. All the respondents were well informed about the study, its objectives and limitations. An informed written consent was taken from the respondents, before the interview. Face to face interviews were conducted with the help of a well-structured questionnaire.

Respondents were assured that the information provided by them would be used for academic and research purpose only and their status would not be disclosed to anyone. Taking into account the ethical issues regarding the confidentiality of status of respondents, their name and addresses were not put on the questionnaire.³⁴ Four hundred PLHIV were contacted during the field survey and detailed information regarding their economic well being, social background and psychological mind set was collected. Most of the interviews were conducted at the PLC office. Some interviews were also conducted at the residence of the respondent. For that, prior permission of the respondent was sought, whether they can be visited at home or not. As most of the people have not disclosed their status in their neighbourhood due to stigma and discrimination, interviews in the community were taken as informal discussion and notes were taken down regarding the same.

The following table gives the actual distribution of the surveyed respondents by income and CD4 count.

Table 4.3: Actual PLHIV Respondents interviewed, based on CD4 Count and Monthly Average Family Income

CD4 / Income	< 2000	2000 - 4000	4000 - 6000	> 6000	Total
< 200	94 (23.4)	30 (7.5)	10 (2.5)	7 (1.7)	141 (35.2)
200 - 499	105 (26.2)	63 (15.7)	16 (4.0)	14 (3.5)	198 (49.4)
≥ 500	23 (5.7)	21 (5.2)	11 (2.7)	7 (1.7)	62 (15.4)
Total	222 (55.3)	114 (28.4)	37 (9.2)	28 (6.9)	401 (100.0)

Source: Based on Primary Survey

There exists a marginal discrepancy in the expected sample size and actual number of respondents in each cell. This is mainly due the non-availability of the respondents in the particular cell. As far as CD4/ μ L is concerned, the one reason behind the gap is that, most of the respondents are on ART, which has effectively enhanced the CD4/ μ L level. However, importantly, the distribution by income is quite close to the expected distribution.

4.5 QUESTIONNAIRE AND SENSITIVE QUESTIONS

Drafting the questionnaire was very tedious. While keeping in mind all the dimensions of life and particularly, the socio-economic aspects of household in general and individual in particular, it was really a challenging task. Major factors taken into account were socio-economic implication and psychological well being of

³⁴ For ethical consideration and related issue check appendix I of ethical consent

PLHIV. The focus was set, “how the HIV infection has affected the life of household in general and individual in particular”. Data related to CD4/ μ L count, medical history of individual and their demographic characteristics were cross checked from their medical card.

Major reference for drafting the questionnaire and its important content was taken from the study conducted by UNDP (2005) in six high HIV prevalence states of India³⁵ Questionnaire was divided into two main parts³⁶:

1. Details regarding the household
2. Details regarding the PLHIV
 - i) Details regarding WHOQoL HIV-BREF for the individual

There are ten sub-sections of the interview schedule. Part I comprises the detailed information on household characteristics, possession of durables goods and access to basic amenities, death of any earning member in household, death of any earning member in household due to AIDS, income sources and consumption pattern and level. Part II of the interview schedule comprises detailed information of PLHIV individual in the family, namely – details regarding HIV/AIDS status (instances of stigma and discrimination at various set ups of society), impact of HIV/AIDS on employment, impact of HIV/AIDS on the health status and expenditure, coping up strategies and bearing HIV/AIDS economic burden, information on caregiver, empowerment status of HIV positive women in the household, and details regarding impact of HIV on quality of life.

While designing the questionnaire, maximum care was exercised to use common and easy words, so that respondent can grasp the meaning of the question easily. Questionnaire was translated into the local language Marathi to make comprehensible to the respondents. Sensitive questions, like the death of any family member due to HIV related illness, questions regarding sexual behavior, were asked with due consideration, so that the feeling and emotions of the respondents were not hurt.

4.6 SEQUENCE OF QUESTIONS

The sequence of questions in the questionnaire matters a lot. Sensitive questions were placed in the questionnaire with due consideration. General information on demographic characteristics and socio-economic well being was placed in the initial

³⁵ Socio-Economic impact of HIV in India, UNDP(2005)

³⁶ Interview schedule attached in appendix V

section of the questionnaire. Great emphasis was laid to get the involvement of the respondent and the ease and comfort to create interest, so that maximum information could be extracted in the minimum time.

4.7 RELIABILITY CHECK

Great care was taken not to repeat the same question, to avoid monotony during interview sessions. Similarly, to check the reliability of the response, several checks were placed in the questionnaire. For example, for the question “do you think precautions should be taken to avoid transmission of infection from one person to another?” The question that provides the check to that question is “if yes, what precaution have you taken so far to avoid transmission of infection?” The respondent, who has replied “yes” to the earlier question, would be probed to answer the latter question.

4.8 FEATURES TO IMPROVE DATA QUALITY

While drafting the questionnaire, standard norms were kept in mind. Coding, sequence of questions, sensitive questions, mixing of open ended questions and dichotomous questions, pilot study, criterion for interview selection and editing of interview schedules was done with great care and concern.

4.9 PRE-TEST

A pilot study was conducted to ensure the sensitivity and workability of the questionnaire. It was pre-tested on five PLHIV respondents, to examine the workability of the questionnaire. Workability refers to the understanding of questions by the respondents and the prompt desired response of the questions. After the pre-test, a few questions were modified for easy understanding and some questions were added in response to that.

4.10 FIELD EXPERIENCE

The topic of study being sensitive one because of involvement of behavioural aspect of the individual, at the first instance, respondents were reluctant to provide any information. A rapport was built up and respondents were ensured of the confidentiality. Most of the interviews were conducted in the office of PLC, which is

primarily an initiative of NMP+ for the well being of PLHIV. Respondents were more relaxed and comfortable to respond there. It was experienced that most of the respondents belong to deserted poor socio-economic background. After developing rapport, their co-operation was highly remarkable. For interviews conducted at the home of PLHIV respondents, prior permission was sought from responding PLHIV, if he /she felt comfortable to be interviewed at home. At home, interviews were conducted in a casual manner and notes were taken down to encapsulate all details. This practice was followed to ensure the confidentiality. Respondents were asked if they could be traced again to seek any clarity with respect to certain issues later at PLC office.

4.11 DURATION OF INTERVIEW

There was a mix of pre-coded and open-ended questions throughout the questionnaire. Maximum questions were pre-coded in the questionnaire to save the time. Descriptive types of questions were dealt with great care. Face to face interviews were conducted for an hour, whereas another hour was consumed to administer the questionnaire and edit the responses. Almost all the questions were used in the data analysis.

4.12 DATA EDITING AND ENTERING

After completion of interview schedule, questionnaires were edited the very same day of interview, to maintain transparency and to bring all hidden information into light. There was a complete checking of questionnaire for errors, omissions and discrepancies. This is the foremost requirement for the quality of data. All the data was entered in Statistical Package for Social Science (SPSS).

4.13 DATA ANALYSIS

Statistical techniques were applied to get a better adherence to the problem and to know the deep root cause of the problem at hand. Different statistical techniques were applied. To examine the impact of demographic and socio-economic and clinical indicators on quality of life of PLHIV, sophisticated econometric techniques [described later in the relevant chapter] were applied. A descriptive analysis of data was carried out by simple statistical techniques of mean, percentage distribution, and range. With the help of these techniques, data analysis became more conclusive.

4.14 HOUSEHOLD CHARACTERISTICS

This section provides the demographic profile of surveyed HIV households. Information on Household characteristics provides a context for understanding the demographic, health, dependency, social and economic life of the population. Table 4.4 depicts the age sex distribution of population of households with PLHIV members, interviewed in Pune city.

Table 4.4: Household Population by Age and Sex

Age Group	Gender		All
	Male	Female	
0-4	59 (7.7)	58 (6.8)	117 (7.2)
5-9	115 (15.1)	107 (12.5)	222 (13.7)
10-14	125 (16.4)	103 (12.0)	228 (14.1)
15-19	78 (10.2)	43 (5.0)	121 (7.5)
20-24	49 (6.4)	58 (6.8)	107 (6.6)
25-29	31 (4.1)	128 (15.0)	159 (9.8)
30-34	74 (9.7)	108 (12.6)	182 (11.2)
35-39	85 (11.1)	68 (8.0)	153 (9.5)
40-44	36 (4.7)	40 (8.0)	76 (4.7)
45-49	24 (3.1)	27 (3.2)	51 (3.2)
50-54	14 (1.8)	24 (2.8)	38 (2.3)
55-59	21 (2.7)	27 (3.2)	48 (3.0)
60+	53 (6.9)	64 (7.5)	117 (7.2)
N	764	855	1619

Source: Based on Primary Survey

Age and sex are the basic demographic characteristics and play a vital role in the study of family health, nutritional status, mortality, morbidity, other demographic issues and socio-economic well being. Table 4.4 depicts the age and sex distribution of surveyed HIV household population. Of all the respondents nearly 35 percent are below 15. Hence, there are serious threats to potential human capital if parents are HIV positive or have died due to HIV related illness. Those who are in the age span of 15 to 59 are the most productive and economically active age group. Due to HIV infection, economic participation of this age group is curtailed, resulting in economic deprivation.

4.15 HOUSEHOLD COMPOSITION

Household composition depicts the headship of household, size and structure of the household, religion and caste of the head of the household. These dimensions are important in determining the social status of the household. Table 4.5 shows the distribution of HIV households based on these dimensions.

Table 4.5: Percentage Distribution of HIV Households and Household Composition and Structure

Characteristics	Headship		All
	Male	Female	
Household Headship	253 (63.1)	148 (36.9)	401 (100.0)
Composition of Household			
Less than or equal to 2 members	24 (9.5)	32 (21.6)	56 (14.0)
3-4 members	135 (53.4)	81 (54.7)	216 (53.9)
More than or equal to 5 members	94 (37.2)	35 (23.6)	129 (32.2)
Mean Household Size	4.23	3.63	4.01
Household Structure			
Joint /Extended	82 (32.4)	40 (27.0)	122 (30.4)
Nuclear	171 (67.6)	108 (73.0)	279 (69.6)
Religion			
Hindu	218 (86.2)	134 (90.5)	352 (87.8)
Muslim	11 (4.3)	4 (2.7)	15 (3.7)
Christian	3 (1.2)	1 (0.7)	4 (1.0)
Buddhist/ Neo-Buddhist	19 (7.5)	9 (6.1)	28 (7.0)
Any Other	2 (0.8)	0 (0.0)	2 (0.5)
Caste			
SC	83 (32.8)	46 (31.1)	129 (32.2)
ST	35 (13.8)	20 (13.5)	55 (13.7)
OBC	27 (10.7)	23 (15.5)	50 (12.5)
Others	108 (42.7)	59 (39.9)	167 (41.6)

Source: Based on Primary Survey

Table 4.5 shows that nearly 37 percent of HIV households are headed by females. This is unusual in a patriarchal society like India. However, among HIV households, it is quite evident from earlier studies that due to the death of main bread earner, females have to take charge as the head of the household. Mean household size is 4.01, close to an average Pune city average household size. However, the average household size is greater in male headed households (4.23) than female headed households (3.63). This differential is attributed to death of any member in female headed household due to HIV related illness. Nearly 70 percent of households are nuclear. This also depicts the urban culture of society in a city like Pune. An observation emerges from this structure, namely, that in HIV households, due to higher percentage of nuclear families, probability of an ailing HIV member to be looked after, is lower.

Distribution of HIV households by religion (determined here by the religion of head of household) is more or less similar to that of NFHS-III findings for HIV prevalence with majority of households belonging to Hindu religion (87.8%). Nearly, 60 percent of households belong to categories SC (32.2%), ST (13.7%) and OBC (12.5%) respectively. As per census 2001, 58.1 percent of total population of Pune district is residing in urban setup, 10.5 percent and 3.6 percent of total population was identified

as SC and ST population in Pune district. This comparison indicates that our sample has a larger percentage from the lower social strata of the society.

4.16 BACKGROUND CHARACTERISTICS OF PLHIV RESPONDENTS

Demography, education and occupation are important catalysts for health, economic and psychological wellbeing among PLHIV respondents. Socio-economic differentials are of particular importance while drafting intervention strategies for HIV or for health policies concerning PLHIV. This section explores the background characteristics of PLHIV respondents in Pune city. Table 4.6 shows the demographic and socio-economic characteristics of PLHIV respondents by sex.

Table 4.6: Background Characteristics of PLHIV Respondents

Characteristics	Gender of PLHIV Respondents		All
	Male	Female	
Age			
15-19	1 (0.6)	2 (0.8)	3 (0.7)
20-24	5 (3.2)	19 (7.8)	24 (6.0)
25-29	18 (11.5)	73 (29.9)	91 (22.7)
30-34	38 (24.2)	72 (29.5)	110 (27.4)
35-39	47 (29.9)	47 (19.3)	94 (23.4)
40-44	25 (15.9)	18 (7.4)	43 (10.7)
45+	23 (14.6)	13 (5.3)	36 (9.0)
Educational Status			
Illiterate	25 (15.9)	65 (26.6)	90 (22.4)
Primary	33 (21.0)	39 (16.0)	72 (18.0)
Secondary	69 (43.9)	112 (16.0)	181 (45.1)
Senior Secondary	16 (10.2)	17 (7.0)	33 (8.2)
Sen Sec Plus	14 (8.9)	11 (4.5)	25 (6.2)
Marital Status			
Currently married	112 (71.3)	61 (25.0)	173 (43.1)
Separated/divorced/abandoned	9 (5.7)	19 (7.8)	28 (7.0)
Widowed	14 (8.9)	161 (66.0)	175 (43.6)
Unmarried	22 (14.0)	3 (1.2)	25 (6.2)
Occupational Status			
Work Status			
Non- worker	39 (24.8)	78 (32.0)	117 (29.2)
Worker	118 (75.2)	166 (68.0)	284 (70.8)
Type of Work			
Marginal worker	53 (33.8)	108 (44.3)	161 (40.1)
Main worker	65 (41.4)	58 (23.8)	123 (30.7)
Nature of Work			
Regular	51 (32.5)	45 (18.4)	96 (23.9)
Casual	53 (33.8)	108 (44.3)	161 (40.1)
Own Account	14 (8.9)	13 (5.3)	27 (6.7)
N	157 (100.0)	244 (100.0)	401 (100.0)

Source: Based on Primary Survey

Nearly, 75 percent of PLHIV respondents are in the age span of 25-39 considered as most productive and economically active years of the age span of any individual. Likewise, in female respondents these years are of vital importance as per the reproductive health matters. Twenty two percent of PLHIV respondents are non-literate and percentage of illiterate female PLHIV (26.6%) is higher than that of male PLHIV (15.9%). As per 2001 census, in urban Pune 80 percent of women and 91.6 percent of men were literate. Likewise, as per RCH-III the sample for Pune shows that 75 percent of female (age 7+) are literate and 92 percent of male (age 7+) were literate. This highlights the somewhat compromised educational status of PLHIV under consideration when compared with general urban Pune (census 2001), also depicts social status of women in society. Though percentage of currently married and widowed is almost equal, a vast difference as per the gender of PLHIV respondents was observed. More males currently married (71.3%), where as it is female PLHIV who are categorized more as widow (66.0%). Percentage of regular workers is higher among male PLHIV than female. This depicts the socio-economic differentials among PLHIV respondents.

Moreover, as per the occupational characteristics, it is evident from Table 4.6 that most of the PLHIV individuals are working in unorganized sector. There are more marginal workers among women than their male counterparts. As per the 2001 census, out of total female workers in urban Pune, 12.5 percent were marginal workers and about 5 percent males were categorized marginal workers. This depicts the divergence in occupational categories of local Pune urban population in general, and prevailing gender differentials in specific. This also highlights the compromised socio-economic status of PLHIV individuals when compared with Pune urban individuals.

Data on these background characteristics (age, sex, educational, marital and occupation status) of HIV households and PLHIV respondents will help us to analyze the economic profile of PLHIV households, socio-economic consequences of HIV infection at household level and emotional and psychological stress among PLHIV respondents, which is explored in the consecutive chapters.

