CHAPTER - III

METHODOLOGY
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This chapter focuses on the research design, procedure, and methodology that are applied in data construction, collection and analysis. The first part of this chapter explains the statement of the problem, rationale of the study, research design and methodology used. The second part discusses the sampling design, methods and sample size; and the last part of this chapter explains the data collection sources. The primary data for this research consists of structured interview schedule, case Studies and focus group discussion. The secondary data was obtained from existing research. Furthermore, this paper elaborates the technique and method of data processing and the procedure of data analyzing using statistical tools for quantitative analysis that include descriptive and analytical analysis, while qualitative analysis was employed by categorizing the responses from the respondents.

3.1 Statement of the problem.

The study of stigma & discrimination faced by women infected and affected with HIV/AIDS is a critical subject which social scientist has to concentrate and illuminate. Though Women may make up half the world’s population, but they do not share it equally. This is especially evident when it comes to HIV. Half of all people living with HIV are women, yet many are underserved or do not know their status.

HIV/AIDS is not only driven by gender inequality, it also establishes gender inequality leaving women more vulnerable than men to its impact. Gender norms and gender inequality, which evident in uneven access and control over resources, low decision making power and the experience of hostility, fuel the growing numbers of women becoming infected with the HIV/AIDS.

The women infected/affected with HIV/AIDS bear the physical and psychological burden of HIV/AIDS care. Women thus carry a ‘triple jeopardy’ of HIV/AIDS, “as people infected with HIV, as mothers of children infected, and as carers of partners, parents or orphans with AIDS” (Paxton and Welbourn 2004). When women care for others their labour is lost, which has a major impact on their own well-being and on that of the household.

The discrimination and stigma surrounding HIV/AIDS also severely affects the ability of HIV positive women to find and keep work. Women whose HIV positive status is known or assumed within the community may find that people are
avoiding them and no longer buy their goods. HIV/AIDS infected Women are sacked by their employers, it the positive status known to them or employers force for compulsory testing. Even women who remain employed may suffer intense discrimination at the workplace by the employers and co-employees.

In many regions women are deprived from inherit property or land, and have limited access to income and resources. Even women who know their legal rights may not have access to independent legal support (ICW 2004). Women’s unequal social, economic, and legal status is increased by a positive HIV status, and vice versa. Violations of women’s social, economic, and legal rights in turn forbid their ability to seek care, treatment and support, and protect their sexual and reproductive health and rights. Despite the many successes we have seen, women still face inequalities that will keep the AIDS response from reaching its full potential.

HIV/AIDS-related stigmatisation and discrimination threaten the effectiveness of HIV prevention and care programs. It creates an environment that negatively impacts on effective prevention by discouraging women from coming forward for testing, seeking information to protect themselves and their family, thus deepening the adverse impact of living with HIV/AIDS. The present study is to reveal the roots of stigma and discriminations, its consequences on women infected and affected by HIV/AIDS, how basic rights has been denied, government and its commitments’ towards protection of human rights of women. The following are the few major questions, which researcher has tried to take up for investigation:

- Analyzes the sources of stigma and discrimination, the ways in which HIV/AIDS-related stigma and discrimination manifests itself, and the contexts in which HIV/AIDS-related stigma and discrimination take place.
- Level of HIV/AIDS knowledge among women.
- Assess socio economic burden of HIV on women in HIV households.
- Nature of Human rights violation.
- To make recommendations for the health Care System to tackle the growing demands for looking after women with HIV/AIDS.
- To find ways and means to ameliorate the condition of women already infected;

The sample HIV/AIDS infected and affected women are drawn from diverse social- economic geographical and cultural backgrounds. Therefore outlook and status
of women infected and affected with HIV/AIDS is dissimilar. The socio economic background, nature of family, gender norms in society, enjoyment of basic human rights, values of women are important factors that decide the nature and consequences of the problems, which faced by HIV/AIDS infected and affected women.

3.2 Rationale of the study.

The stigma and discrimination against women infected and affected with HIV/AIDS has elicited considerable interest in the mind of social scientist and researchers in recent time. HIV/AIDS related stigma and discrimination adversely affect every aspect of life for women living with HIV and their families. In many settings, an HIV diagnosis still can be as devastating as the illness itself, leading to job loss, school expulsion, violence, social ostracism, loss of property, and denial of health services and emotional support. People living in fear are less likely to adopt preventive behaviour, come in for testing, disclose their sero-status to others, access care and adhere to treatment.

During this third decades of HIV/AIDS prevention, care & support many research has been conducted by NGOs and Governmental bodies at national level, where most of it concerned with Socio- economic impacts of HIV/AIDS, very few studies has attempted on specific issue of women and HIV/AIDS, particularly stigma and discrimination faced by women infected and affected by HIV/AIDS pandemic. Hence the present study, which is an attempt to find and analyse root, causes and consequences of stigma and discrimination as well violation of basic human rights faced by women infected and affected with HIV/AIDS. The present study is confined to study of total 100 HIV/AIDS infected and affected women (50 infected and 50 affected).

3.3 Research design.

The design of the present study is exploratory. This study focuses on the experiences / nature of stigma & discrimination associated with women infected & affected by HIV/AIDS. To understand the phenomenon of stigma, discrimination & denial of rights towards WLWHA (Women living with HIV/AIDS) the mixed method of research approach has been applied. The rationale for using multiple methodologies was to combine qualitative and quantitative analyses to enhance the quality and credibility of the data.
I conducted this mixed methods study, at Darjeeling District of West Bengal. The qualitative data was collected through case studies, face-to-face interviews that were guided by open-ended and close-ended questions were used to collect the data to understand the social, cultural, political, psychological, and environmental determinants of HIV/AIDS-related Stigma and Discrimination of WLWHA, it’s also gave scope to the respondents to share their stories and experiences spontaneously.

The quantitative data was collected through structured interview schedule for investigate the social processes of HIV/AIDS related stigma and discrimination in various contexts. Using this quantitative method it allowed me to compare the different social processes and understand the different sources and forms of HIV/AIDS-related stigma and discrimination.

The quantitative part of the study validated the concepts that emerged from the qualitative part and identified opportunities and future priorities for intervention and prevention programs to reduce the factors driving HIV/AIDS-related Stigma and Discrimination

3.4 Objectives of the study.

1. To study the knowledge, attitude, behavior and practices (KABP) level of HIV/AIDS among the women.
2. To study the impact of HIV/AIDS on women of the affected household, in relation to their socio-economic life.
3. To understand the stigma / discrimination implication of HIV/AIDS on women.
4. To assess the nature of human rights violation with reference to HIV/AIDS.
5. To suggest various measures for effective intervention by applying social work methods.

3.5 Research questions.

The following research questions were investigated in this study:

1) What / where / why and impact of the Stigma & discrimination faced by women infected and affected with HIV/AIDS?
2) What is the knowledge level of women in relation to HIV/AIDS?
3) What extent Human Rights violation experienced by the women infected and affected with HIV/AIDS?
In the search for above answer, the purpose of this study is consequently to comprehend the links between HIV/AIDS and discrimination on women infected/affected in HIV/AIDS.

3.6 Area of the study.

Darjeeling district of west Bengal has been selected for the present research study. As per categorization of districts in India based on HIV Prevalence Darjeeling comes under category of B which means Less than 1% ANC HIV prevalence in all the sites during last 3 years with more than 5% HIV prevalence in any HRG site (STD/FSW/MSM/IDU).

3.1 Map of Darjeeling District.

Darjeeling district has a great potential for the spread of HIV Epidemic and if sufficient attention is not given, they may progress to Category A. The geographical location of the Darjeeling district is in the foothills of the Himalayas and one of the northern district of West Bengal. Darjeeling district touches three international boundaries with Nepal, Bhutan and Bangladesh, also the district is bounded state and district on the north by Sikkim, on the south by Kishanganj district of Bihar state, on the east by Jalpaiguri district of West Bengal.
The district and its role in the inter-state and international trade are crucially important with regard to transmission of HIV. At one side the hill area is attracted for tourism & tea and another side the plain area is the gateway of all the North Eastern states of India.

The HIV/AIDS scenario is quite unique in the district as drug addiction and alcoholism, which encourages risk behaviours is very prevalent in the hills and commercial sex in plain. Female drug addicts, though far less in number than their male counterparts, are more susceptible to being infected by HIV as they face the double danger of being infected through needle sharing as well as sexual intercourse.

Table – 3.1 Scenario of Sample District - General Clients counseled and tested for HIV and sero-positivity detected during 2013-14

<table>
<thead>
<tr>
<th>District</th>
<th>Number of General clients tested for HIV</th>
<th>Number of General clients testing Positivity sero-positive for HIV</th>
<th>Positive Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Darjeeling</td>
<td>21186</td>
<td>448</td>
<td>2.11</td>
</tr>
</tbody>
</table>

District-wise performance of the PPTCT programme during 2013-14

<table>
<thead>
<tr>
<th>District</th>
<th>Number of pregnant women tested for HIV</th>
<th>Total no. of pregnant women testing seropositive for HIV</th>
<th>Positivity</th>
<th>Number of MB pair receiving NVP</th>
<th>Percentage of MB pair Coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Darjeeling</td>
<td>18960</td>
<td>41</td>
<td>0.22</td>
<td>34</td>
<td>82.93</td>
</tr>
</tbody>
</table>

Source: ANNUAL REPORT 2013-14 West Bengal State AIDS Prevention & Control Society

A range of socio-economic factors in the region along with weak regulatory measures have lead to burgeoning human trafficking across these borders, particularly in women and children.

The collapse of tea industry and in and out migration, poverty pushes some women into risky behaviour or dangerous situations. (Subba 1992). Darjeeling has today developed into a major tourist hotspot and has been connected with the larger global scenario. This exposure to the outside world has also had its negative fallouts. The youth are indulging in drug abuse and the past years have also witnessed large scale migration among them. Due to the poor socio economic condition and a growing consumerist culture people want to earn money by any means. Commercial sex and drug abuse are on the rise. This situation has made Darjeeling highly vulnerable to HIV / AIDS.
3.7 Sampling.

In this study purposive sampling methods has been adopted. Parahoo (1997:232) describes purposive sampling as “a method of sampling where the researcher deliberately chooses who to include in the study based on their ability to provide necessary data”.

As per base line survey conducted by West Bengal State Prevention and control society and TI (Targeted intervention) proposal of both the PLHA network Sangabadho from Siliguri (423 members) and Shankar Foundation from Darjeeling (70 members) the total universe was 493 PLHA (380 male and 113 female) in 2007.

Through purposive sampling method total 100 respondent has been selected which include 50 HIV/AIDS infected and 50 HIV/AIDS affected (either partner infected / or died by HIV/AIDS related illness) women from the district.

3.8 Frame of analysis.

Table : 3.2 Frame of analysis.

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Indicators Studied</th>
<th>Method used</th>
<th>Tools Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stigma / discrimination implication of HIV/AIDS on women.</td>
<td>Nature/forms of Stigma &amp; discriminations faced, places where such stigma and discrimination held, reason of such discrimination.</td>
<td>Observation, one to one Interview of WLWA</td>
<td>Filling up of Interview Schedule / Case studies.</td>
</tr>
<tr>
<td>Impact of HIV/AIDS on women of the affected household, in relation to their socio – economic life.</td>
<td>Number of affected people, occupation of members, monthly income, expenditure (past &amp; present), and burden faced.</td>
<td>Observation / one to one Interview with WLWA</td>
<td>Filling up of Interview Schedule / Case studies.</td>
</tr>
<tr>
<td>Knowledge, attitude, behavior and practices (KABP) level of HIV/AIDS among the women</td>
<td>Mode of transmission, misconception, prevention methods, treatment procedure, care and support.</td>
<td>Observation / Interview of WLWA</td>
<td>Filling up of Interview Schedule / Secondary data review.</td>
</tr>
</tbody>
</table>
3.9 Method of data collection.

The study employed both qualitative and quantitative techniques. In-depth personal interviews and case studies have been carried out among the women infected and affected with HIV/AIDS. In order to conduct the interviews, standardized interview schedule has been developed to get insight information and data from the respondents.

Moreover, the interview schedule was also designed based on not only stigma and discrimination experience but also the current situation / issues related to WLWHA socio-economic condition of women affected with HIV/AIDS. The researcher had opportunities not only to collect data but also to investigate directly and examine the situation and circumstances faced by respondents through direct observation.

The researcher personally reached the sample population and collected all information by himself only. Interview schedule were pre-tested prior to data collection in the non-sampled areas to ensure clarity, validity, correct understanding and translation of questions.

Respondents were identified through non-probability, purposive sampling techniques, the CBO of PLHA from the district helped to get participation through its membership base, and respondents being asked to endorse the study to eligible respondents in their social networks. Inclusion criteria for respondents in this study were being women either HIV positive or HIV affected. All the respondents received an oral and written explanation of the content/objective of the study and were asked to read and sign the consent form.

3.10 Tools of data collection.

Primary data was collected through fieldwork from the respondent members of PLHA networks functioning in both the places of the district. Structured interview schedule and case studies were used to gather primary data during the field research. With the above techniques, the researcher had the opportunities not only to collect data but also to investigate directly and examine the situation and circumstances being faced by respondents.

The whole interview schedule was divided into five segments which includes, i) Social-Demographic Characteristics, ii) Knowledge, Attitudes, Behaviour and Practices (KABP) level of HIV/AIDS among the respondents, iii) Impact of

The interview schedule was originally written in English and later translated into Bengali and Nepali which are the most widely spoken languages of the area. The researcher had the advantages of communication skill in Nepali language apart from Bengali.

The researcher was also collected important Case Studies based on forms and severity of stigma and discrimination faced by the respondents, incidence of violation of human rights and positive stories of women’s fight against HIV/AIDS.

Secondary data was collected from desk to review, a range of sources including books, journal articles, previous research, previous thesis, reports of UNAIDS, NACO, State AIDS Control and Prevention Society, unpublished data from ICTC centers, and online articles.

3.11 Data analysis.

The questionnaires included both closed end and open ended questions, therefore quantitative and qualitative procedures were applied. After completing the field visit and in-depth interview the interview schedule were immediately and carefully cross checked in order to make sure that given information had been responded properly. All the case studies were documented.

Data tabulation sheet has been prepared in Microsoft Excel 2007, quantitative data has been entered and statistical analysis has been done through central tendency measures and tables, charts, and graphical representation has been done.

The whole Excel sheet has been divided in five sections. Section one dealt with demographic profile of the respondent question range in tabulation sheet is from 101 – 112. Section two dealt with HIV/AIDS Knowledge, attitude, behavior and Practices (KABP) level among the respondent, question range from 201 to 224. Section three dealt with Impact of HIV/AIDS on women of the affected household, in relation to their socio-economic life question range from 301 to 322. Section four dealt with stigma and discrimination implication of HIV/AIDS on women, question range from 401- 422. Section Five dealt with Human rights violation in relation to HIV/AIDS, question range from 501-507.
A qualitative analysis of case studies has been done used to understand respondents’ behavior, perception, and reasons regarding stigma and discrimination. Not only WLWHA were interviewed but also key informants or stakeholders from CBOs and Government (ICTC, ART centres) were consulted for in-depth information and perception about the WLWHA.

3.12 Ethical consideration.

Women living with HIV/AIDS are a particularly vulnerable population, both due to gender-based inequality and the stigma associated with HIV/AIDS. It was therefore important that the researcher ensured that the rights of this vulnerable population were protected (Polit & Beck, 2012). The following measures were taken to ensure the protection and confidentiality of the participants.

The study was approved by the Visva-Bharati University, formal communication had been done and consent has been taken from PLHA network before conducting data collection. Full disclosure and the right to self-determination were ensured by providing participants with comprehensive information, verbally and in writing, in their mother tongue, about the study before they volunteered their participation and completed written informed consent forms. They were also informed that they could refuse to participate or could withdraw from the study at any time without compromising their healthcare programme. The right to privacy (Polit & Beck, 2012) was ensured by removing all names from transcripts, and not connecting or storing the informed consent forms with the transcripts or biographical information of the participants. Biographical information was limited to ensure anonymity, confidentiality and privacy. Only questions relevant to the research were asked and participants were informed that they had the right to choose whether to respond to all the questions. Interviews were conducted privately and the identities of the participants were kept confidential.

3.13 Operational definitions:

Human Immunodeficiency Virus (HIV). HIV is the virus that weakens the immune system, ultimately leading to AIDS. Since HIV means human immunodeficiency virus, it is redundant to refer to the ‘HIV virus’.
Acquired Immuno-Deficiency Syndrome (AIDS). Syndrome: set of symptoms or signs; Immuno: the defence system of the organism; Deficiency: what is no longer efficient because of inadequacy to defend; Acquired: non-hereditary. AIDS is the consequence of an attack of the immune system during HIV infection. It is the most serious stage of the disease.

Stigma: ‘Stigma’ is derived from the Greek word meaning a mark or a stain. Stigma can be described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others. Within particular cultures or settings, certain attributes are seized upon and defined by others as discreditable or unworthy.

Discrimination: Discrimination refers to any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived belonging to a particular group—in the case of AIDS, a person’s confirmed or suspected HIV-positive status—irrespective of whether or not there is any justification for these measures.

Human Rights: Human rights are universal legal guarantees protecting individuals and groups against actions and omissions that interfere with fundamental freedoms, entitlements and human dignity. Human rights law obliges Governments (principally) and other duty-bearers to do certain things and prevents them from doing others.

GIPA: An acronym for the ‘greater involvement of people living with HIV/AIDS’. In 1994, 42 countries called upon the Paris AIDS Summit to include the Greater Involvement of People Living with HIV/AIDS Principle (GIPA) in its final declaration.

The above chapter was mainly discussed about the whole research process including Research problem, research design, research objectives, questions, explanations of the population and sampling method as well as detail analysis process. Mixed methods research design was the most appropriate for my study by using an structured interview and Case studies. The next chapter presents the key findings and discussion of the study.