

CHAPTER-III

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METHODOLOGY

This chapter provides the details regarding the methodology that has been adopted by the researcher to carry out the present study. It encompasses the rationale of the study, objectives, research design, types of data, sources of data, tools of data collection, sampling, process of data collection, analysis of data and operational definitions. The limitations of the study are also included here. It is noted that so far there is neither national nor state level study available in the social science discipline on the topic of NGO response to HIV/AIDS. The methodology has been adopted keeping in view the nature of research problem, purpose of investigation, source and availability of data, observation, experience as well as capability of the researcher. The present study has tried to explore an unknown phenomenon.

Rationale of the study

There is a long history of NGO activities in India. But the growth of NGOs is a phenomenon of late 1970s and early 1980s. During the last two decades there has been a shift towards greater reliance on market and NGOs for provision of service in the social sector. Thus inability of the government to invest coupled with the support from international donor agencies provided the impetus for the expansion of this sector in India. The private sector and NGOs are seen as more efficient, less bureaucratic and effective as compared to Government.

These NGOs are varied both in terms of size, level of operation and services provided. In the process of development, they carry out various programmes pertaining to education, income generation, welfare of handicapped, health and so on. Especially in the field of health, NGOs perform different roles. They provide clinical services, health awareness, health care training and at the same time conduct research. The National Health Policy document 2001 also envisages greater role for private sector and NGOs.

As stated earlier, HIV/AIDS is one of the major health issues in India. National AIDS Control Programme of the Government also envisages greater role for NGOs. In India some of the major NGOs engaged in HIV/AIDS care are Lawyers' Collective (Maharashtra), SAHARAN (Delhi), Shalom (Manipur), Durbar Mahila Samanya Committee (West Bengal), etc. These are larger NGOs but there are several

others who work at the grass root level. Review of available literature shows that there are very few state level studies on NGOs in health Care and these include Maharashtra (Duggal, Gupta and Jesani, 1986), Andhra Pradesh (Baru, 1987), Assam (Sarkar, 1998) and West Bengal (Sarkar 2005). We have also seen in the literature review that many studies were conducted on different aspects of HIV/AIDS in India. But no such state level study on the contribution of NGOs in HIV/AIDS care was undertaken so far. Thus, it is pertinent to explore and examine in detail on the responses of NGOs in HIV/AIDS care.

There is a need to generate baseline data through a critical examination of the functioning of the NGOs, the services they provide, organizational pattern, target group, programme components, programme execution strategy, source of funding, people's participation, beneficiaries' perception, impact of globalization, etc. In order to get some insights on these aspects, the present study has been conducted on NGOs engaged in HIV/AIDS care in West Bengal. The reason for selecting West Bengal is that it has a long and rich history of NGO activities. West Bengal is placed in the second group of States by NACO where HIV infection rate has crossed 5% or more among the high-risk behaviour groups. Besides it, West Bengal is one of the five states where Government of India initially started National AIDS Control Programme with the help of World Bank in 1987. Therefore, considering the importance of NGOs in HIV/AIDS care, it is quite relevant to study their contributions, so that beneficiaries may be better served.

Objectives

The specific objectives of the present study are as follows:

1. To get a state-level overview of NGOs engaged in HIV/AIDS care in West Bengal.
2. To study and examine the contribution of NGOs in HIV/AIDS care services through in-depth study in selected NGOs by focusing on organizational set-up, target groups, nature and extent of services, programme execution strategies, involvement of various stake-holders, problem of stigmatization, ethical issues, sources of funding, perception of beneficiaries towards the working of NGOs, etc.
3. To explore the future trends of NGOs engaged in HIV/AIDS care in the context of globalisation.

Methodology

Research Design

There is paucity of data in the proposed area of study. The main purpose of the proposed study was to explore and gain insight into the contribution of NGOs in HIV/AIDS prevention and care in West Bengal. It was necessary to explore different aspects and facts related to the services provided by these NGOs, target groups, intervention strategies, problem of stigmatization, ethical issues, sources of funding, perception of beneficiaries towards the working of NGOs and so on. Hence, the researcher had to do literature review, experience survey and case studies of some selected NGOs. Literature scanning was done to get an understanding on the state level overview of NGOs in HIV/AIDS care and future trends of such NGOs in the context of globalisation. Experience survey was also made through informal interviews and mailed questionnaires for the same purpose. Mailed questionnaires were sent to all NGOs implementing HIV/AIDS programme in West Bengal. Case study was initiated in the selected NGOs to understand and analyze various aspects pertinent to HIV/AIDS programmes. Thus, as already mentioned earlier that no such study was undertaken at the state-level, the present study has used exploratory design.

Types of Data Required

1. In order to fulfill the first objective, data related to geographical location of NGOs, background of organizations, year of starting the programme, target groups, nature and extent of services, source of funding, etc. were essential.
2. To fulfill the second objective, the types of data included were: historical background of NGOs, organizational set-up, target group, preventive and supportive services, programme execution strategies, involvement of various stake holders, problem of stigmatization, ethical issues, people's participation, perception of beneficiaries towards the working of NGOs, etc.
3. For the third objectives, types of data required were: sustainability of funding, nature of demand of the beneficiaries in future, networking with national and international agencies, impact of globalization, etc.

Sources of data

Keeping in view the objectives, the researcher has collected data from the primary as well as secondary sources. First part of the data was collected by using both the sources i.e. through literature (Secondary source: Report of the West Bengal State

AIDS Prevention & Control Society and SAATHII's "Red Ribbon" Directory of HIV/AIDS Services in India.), informal interview with the key officials of Government and umbrella NGOs and mailed questionnaire to NGOs engaged in HIV/AIDS prevention and care (Primary Source) in West Bengal.

Second part of data has been collected by using primary sources i.e. six selected NGOs, selected staff and selected beneficiaries of these NGOs. Information related to organizational profile and HIV/AIDS programme was collected from the Chief and other functionaries of NGOs. Staff members of each NGO were selected from all level to know about their views on different key issues. Similarly, beneficiaries were selected from each NGO to know about their views towards the working of respective NGOs.

Third part of the data has been collected from both primary sources (NGOs and Key Informants) and secondary sources (relevant literature). The same mailed questionnaires were used for this objective and few key informants were also informally interviewed in this regard.

Tools and Technique of Data Collection

Data were collected through observation, interviewing and focused group discussion. Along with secondary data, the proposed study is mainly relied on the following tools for primary data collection:

1. In order to collect data regarding first objective, a mailed questionnaire was used to make a survey of NGOs engaged in HIV/AIDS care in West Bengal.
2. For collecting data on the second objective, an interview schedule was used during case study in the selected NGOs. The data on the basic information and programme activities were collected from the Chief functionaries and Project Coordinators. Similarly, staff and beneficiaries were interviewed. The Interview Schedule consists of following parts:

Part-A: It contains related questions to get basic information about the organization and staff profile of the NGOs.

Part-B: It includes open-ended questions to understand the nature of HIV/AIDS programme and other related aspects of the programme.

Part-C: It incorporates questions for the staff of NGOs to know about their views on the problem of stigmatization and its effect, violation of human rights, ethical issues, major barriers encountered, etc.

Part-D: It includes broad questions to know about the beneficiaries' perception towards the working of NGOs by using focused group discussion and interview techniques.

3. In order to fulfill the third objective, the same mailed questionnaire was used. Besides it, informal discussions with key informants (e.g. Government and Non-Government officials, academicians and experts etc.) were done. No tools were developed for these discussions.

Process of Data Collection

The process of data collection of the present study has been completed in the four phases, which are as follows:

- In the first phase, names and address of the NGOs engaged in HIV/AIDS care was collected from various umbrella organizations (e.g. West Bengal State AIDS Prevention & Control Society, UNICEF, and Action AID) and HIV/AIDS Directory of SAATHII. Having put all names together, a comprehensive list of 60 NGOs engaged in HIV/AIDS care was prepared.
- In the second phase, questionnaires were mailed to all the NGOs from the above mentioned list and followed up with several reminders through e-mail and phone. The response was received from 27 NGOs, which has accounted 45% of total NGOs. This was done to collect necessary data to get a state level overview of NGOs in HIV/AIDS care in West Bengal.
- In the third phase, six NGOs i.e. Durbar Mahila Samanaya Committee (DMSC), Society for Community Intervention and Research (SCIR), Bhoruka Public Welfare Trust (BPWT), Human Development and Research Institute (HDRI), MANAS Bangla (MB) and SPARSHA were selected purposively based on certain criteria and studied in detail. In each NGO, emphasis was given on historical background, organizational structure, present activities, views of staff, beneficiaries' perception towards the working of NGOs, etc. to understand how far NGOs could contribute to HIV/AIDS prevention, care, support and treatment. In this phase, the researcher visited each NGO and their project sites several times and spent on an average 20 days in each selected NGO.
- At the last phase, the researcher had discussed informally with few key informants like academicians, experts, officials from NGOs and WBSAP&CS

to know about their views on the impact of globalisation on NGOs working in the HIV/AIDS field. At the end of this phase, the researcher has done extensive literature review to know more about the impact of globalisation in this regard.

Sampling

Universe

The study was conducted in the State of West Bengal. A comprehensive list of 60 NGOs engaged in HIV/AIDS care in West Bengal was prepared with the help of government and umbrella non-governmental organizations and Directories of NGOs. These 60 NGOs will be considered as universe of the present study.

Sample size and Sampling Technique

- In the first phase of data collection, a comprehensive list of NGOs was prepared. In the second phase, questionnaires were mailed to all the NGOs of the comprehensive list. Therefore, sampling was not required in both these phases.
- In the third phase of data collection, out of the total sixty NGOs engaged in HIV/AIDS care in West Bengal, a sample of maximum six NGOs was selected by using purposive sampling technique. These six NGOs were of six different types based on the target groups. For instance, DMSC is working with Commercial Sex workers (CSWs), SCIR is with Injecting Drug Users (IDUs), HDRI is with Migrant Labourers (ML), BPWT is with Truckers, MB is with Men having Sex with Men (MSM) and SPARSHA is with People Living with HIV/AIDS (PLWHA). Following criteria were used to select each of the six NGOs:
 - (i) NGOs must be located within the territory of West Bengal.
 - (ii) NGOs must be registered, non-profit and welfare organization.
 - (iii) NGOs must be having at least one full-fledged HIV/AIDS related programme, which has specific project proposal, budget allocation and full-time paid staff.

Purposive sampling technique was used to select ten staff members from each selected NGO to know about their views on different key issues like problem of stigmatization and its effect, ethical issues, violation of human rights, etc. Efforts were made to include all types of staff (lower, middle and higher level) as per their availability. Similarly, fifteen beneficiaries were chosen from each selected NGO purposively to understand the beneficiaries' opinion about the contribution of the

NGOs under the study. Except the group of PLWHA in SPARSHA, two groups of beneficiaries from two different places were formed in each NGO and their opinions were collected through focused group discussion.

- In the fourth phase, purposive sampling technique was used to select ten key informants on the basis of their experience and expertise on HIV/AIDS.

Analysis of Data

The present study is heavily relied on qualitative analysis. However, quantitative kind of analysis was also used for explaining some data of the study. For the first objective, quantitative analysis was made. At first available data were reorganized to develop a common framework for examining the same. The data, those were possible to code, were identified and grouped from each questionnaire. Then simple cross tabulation was done to understand the aspects mentioned in the objective.

For the second objective, the typical data analysis procedure of case study method has been used. First, the data have been organized from the interview schedule, field observation notes, annual reports and other relevant documents and all these data of six NGOs were put separately into six master files. Secondly, the data were analysed after careful reading and re-reading of available data. The data of each NGO were discussed qualitatively and presented through four parts. **Part-I** has discussed the profile of selected NGOs on the basis of 11 aspects like historical background, vision, mission, present objectives, area of operation, target groups, organizational structures, infrastructure, present programmes, source of funding and future plan. Nature of HIV/AIDS programme activities of the selected NGOs is discussed in **Part-II** on the basis of 8 factors: (a) objectives, (b) components of the programme, (c) programme execution process, (d) people's participation, (e) monitoring and evaluation, (f) sources of funding, (g) innovative components and (h) local cooperation. **Part-III** has qualitatively analyzed the views of selected staff members of six NGOs on 6 different issues such as stigmatization, ethical issues, violation of human rights, major barriers encountered, major reasons of spreading HIV/AIDS and future AIDS scenario and role of NGOs. The beneficiaries' perceptions towards the working of six selected NGOs under the study have been discussed qualitatively in **Part-IV** by using 4 criteria such as necessity of NGO's HIV/AIDS programme, cost and quality of services, staff's cooperation and scope of

beneficiaries' participation. Simple cross tables were used to highlight the profile of staff members and beneficiaries of six selected NGOs.

For the third objective, data were analyzed both qualitatively as well as quantitatively. A future trend of NGOs in HIV/AIDS care in the context globalization was discussed in terms networking, advocacy, financial sustainability and future demands of beneficiaries.

Finally, the analysis of data were done from social work perspective and presented in a descriptive manner to support the specific objectives of the study.

Operational definitions

AIDS: Acquired Immuno Deficiency Syndrome is a fatal transmissible disease caused by HIV. The term 'acquired' was chosen because the illness was neither genetically determined nor the result of other conditions. AIDS is the final stage of HIV infection, which is characterized by appearance of various opportunistic infections such as tuberculosis, pneumocytis, toxoplasmosis, herpes, cytomegalovirus, etc. A group of various symptoms and signs caused by the HIV is called as 'syndrome'. Till date no medicine or vaccine has been developed to protect people from HIV infection. Death results from the unremitting growth of opportunistic infection or from the body's inability to fight off malignancies. It is an incurable disease.

ART: Antiretroviral therapy is a combination three or more drugs, provided to arrest the spread of virus within the body. Since HIV rapidly builds resistance to any single antiretroviral treatment, combination treatment is necessary for effective viral suppression. ART is not a cure, medicines need to be taken throughout life, expensive and having serious side effects. Some of these drugs are AZT, ddC, ddI, d4T, etc.

HIV: It means Human Immunodeficiency Virus, which causes AIDS. This virus slowly attacks and destroys the human immune system, body's defence against infection, leaving an individual vulnerable to a variety of other infections. HIV is transmitted by the direct transfer of body fluids, such as blood and blood products, semen and other genital secretions, or breast milk, from an infected person to an uninfected person. The pathology of HIV infection involves three stages – primary

HIV infection, the asymptomatic phase and AIDS. HIV infected people can live symptom free lives for years. On an average it takes 8-10 years to develop AIDS after HIV infection, depending on the immune status of the individual.

HIV Positive: It is also known as seropositive or antibody positive. It means a person has developed antibodies to his immune system after HIV infection. An HIV antibody test will give a positive result for the presence of HIV antibodies. The person may look and feel perfectly well but is potentially infectious and can pass the virus on to the others.

HIV/AIDS Care: In the present study, HIV/AIDS care refers to NGO's multitude of services or interventions, which are provided by the NGO personnel to the individuals, families or communities in order to combat HIV/AIDS crisis. It includes all sorts of services such as preventive, curative, supportive, promotive and rehabilitative services.

Immunodeficiency: Immune system protects our body against the attack by bacteria, viruses and other such foreign organisms. Immunodeficiency means any decrement in the ability of the immune system to respond appropriately to foreign substances or organisms. Immunodeficiency results into an increased susceptibility to various infections.

NGO: It is voluntary formed and registered organization working towards development and amelioration of suffering with non-self serving aims and free from the state control in managing day to day affairs. The proposed study will consider those NGOs who execute at least one full-fledged HIV/AIDS related programme, which has specific project proposal, budget allocation and full-time paid staff.

NGO Response to HIV/AIDS: It refers to the contribution of the NGOs in combating HIV/AIDS crisis. Contribution refers to NGO's activity, support or help towards HIV/AIDS prevention, care, support and treatment.

Perception: According to the Encyclopedia Americana (1992), the core meaning of perception is immediate awareness. To perceive something is to become directly or

immediately aware of it. For example, by means of our senses, we perceive or become aware of the objects, events and persons in our environment. As per the New Encyclopedia Britannica (2002), perception is the process whereby sensory stimulation is translated into organized or meaningful experience. Under the proposed study, perception refers to the way of seeing or awareness of beneficiaries towards the working of NGO.

Limitations of the Study

- (i) This study has considered only those NGOs who are implementing HIV/AIDS programme in 2006-2007. Therefore, it has not included other NGOs who had previously implemented HIV/AIDS programme in West Bengal.
- (ii) In the third phase of study, case studies (of six NGOs) have been done. It is important to note that outcome of case study may not be generalized everywhere in West Bengal.
- (iii) The present study attempted to understand the future trends of NGOs in HIV/AIDS care in the context of globalisation. This may not be the real trend in future as the governance of HIV/AIDS is dependent on many national as well as international factors.
- (iv) The study is not comprehensive due to selection of only two DICs/Clinics from the operational areas of each NGO to get the beneficiaries' responses about the contribution of NGOs in HIV/AIDS care. The study has also not encompassed all the beneficiaries in every studied DICs/Clinics.
- (v) This study has been conducted in West Bengal. Hence, the entire findings of the study may not be applicable to other states as the response of NGO is influenced by the prevailing socio-political factors of the state.