CHAPTER -III

METHODOLOGY

INTRODUCTION:

A researcher’s overall plan for obtaining answers to the questions are for testing the research hypothesis is referred to as the design. The research design spells out the basic strategies that the researcher adopts to develop information that is accurate and interpretable.

The research design incorporates the most important methodological decisions that the researcher makes in conducting a research study. The research design stipulates the fundamental form that the researcher will take. Other aspects of the research design study include the data collection plan, the sampling plan, and the analysis plan, which involves important decisions.

This study was conducted to examine the variables of physical/psychological/social and spiritual aspects related to the quality of life and the burden of children suffering from AIDS and their principal
care-givers. A holistic approach to HIV is widely recognized as the most appropriate frame-work for maintaining health in children suffering from AIDS and their principal care-givers.

**RESEARCH DESIGN:**

The research design adopted for this study is a descriptive correlational study that uses a cross-sectional design to examine the relationship between the four domains namely, physical, psychological social, and spiritual aspects, which has an impact on the children suffering from AIDS and their principal care-givers. The investigator had utilized the non-participatory observational method.

**SETTING:**

The investigator had conducted the study at the Government institute of thoracic medicine and chest diseases, Tambaram, Chennai-47. The institution meets the child health care needs in relation to children suffering from AIDS and their principal care-givers, in all the three spheres of promoting health, prevention of illness and disease and the curative aspect of child care. This Government institution of thoracic medicine and chest diseases is situated at the outskirts of Chennai, near Tambaram which
is a 1000-bedded hospital and the health care setting is a fully equipped unit with intensive care facilities. This institution consists of an out-patient department as well as an in-patient department, the out-patient department caters to more than 500–800 patients per day, and treatment is provided to patients suffering from different ailments eg. HIV/AIDS, opportunistic infections and chest diseases. The in-patient department consists of male and female and children’s unit exclusively for HIV/AIDS children and their principal care-givers. Each unit consists of 25 beds, with all basic amenities for the in-patients.

This institution is a Government organization, which provides free health care treatment to all the patients suffering from HIV/AIDS and chest diseases.

**POPULATION**: - (Target population)

300 children suffering from AIDS and their principal care-givers were included in this study. These subjects were in-patients of the children’s unit along with their principal care-givers, at the Government institute Of thoracic medicine and chest diseases, Tambaram, Chennai-47.

**SAMPLE**: -
The study included 300 children suffering from HIV/AIDS and their (n=300) principal care-givers admitted in the Government institute of thoracic medicine and chest diseases, Tambaram Chennai-47.

**SAMPLING TECHNIQUE:**

The investigator had utilized non-probability convenient sampling technique for the selection of the children suffering from AIDS and their principal care-givers.

**INCLUSION CRITERIA:**

1. The children aged between 0-15 years and are suffering from AIDS and their principal care-givers aged between 20-60 years. Duly certified by an medical officer regarding the confirmation of their diagnosis.
2. Children suffering from AIDS and their principal care-givers admitted at the Government institute of thoracic medicine, and chest diseases Tambaram-47.
3. Children suffering from AIDS and their principal care-givers who can read, write, speak, in Tamil, English, and in other Languages.

**EXCLUSION CRITERIA:**
1. Children suffering from AIDS and their principal care-givers who were not admitted during the period between August 2001 to September 2004 in the Government institute to thoracic medicine, and chest diseases, Tambaram, Chennai-47.

2. Children and their principal care-givers suffering from illness other than HIV/AIDS.

**INSTRUMENT: - VALIDITY AND RELIABILITY: -**

The investigator had utilized W.H.O. QOL-Bref Field Trial Version questionnaire, December, 1996. This instrument was validated with the kind guidance of the guide and the co-guide and further guidance was provided by Dr. Shubha Kumar, Clinical Epidemiologist, India Clan, Chennai.

The burden assessment Schedule scale was a validated tool, which was further guided by the Head of the Department of Psychiatry, and Clinical psychologist, of Sri Ramachandra Hospital and Research Institute, (Deemed University), Porur, Chennai-116.

The Burden Assessment Schedule scale (WHO, SEARO, Thara, et al., 1998), this instrument comprises of 40 items based on integrative framework encompassing subjective components of burden experienced by the
principal care-givers. Qualitative and quantitative methods were adopted in this process for the development of this tool. This instrument was utilized by the investigator to assess the burden experienced by the principal care-givers of children suffering from AIDS.

The investigator further utilized standardized stress related checklist, which consists of components related to an individual’s state of illness, physical and behavioural signs and different modes of adaptation.

Stress related checklist, which includes checklist 1 - is based on behavioural signs of stress with 36 items, checklist 2 and 3 is based on physical signs of stress with 29 items, checklist 4 - is based on stress-prone characteristics related to illness with 16 items. The checklist is rated with 4 point Likert’s scale, with a scoring pattern of, often = 4, sometimes = 3, rarely = 2, never = 1.

The EPQ (J) questionnaire was used to assess the personality needs of children related to their personal and school activities. This questionnaire consists of 81 items.

The investigator utilized the above mentioned standardized tools to assess the psychosocial variables of children suffering form AIDS and their
principal care-givers. The components of the tool used for children includes physical-health functioning, medication, pain assessment, social support, psychological and spiritual. And the components included in the tool for the principal care-givers are physical-diagnosis-health functioning, social support, family, psychological and spiritual. The instrument used for children suffering from AIDS and their principal care-givers were translated into Tamil Language. The instruments were evaluated by experts for content validity. Reliability was established by split-half reliability and by test re-test methods of correlation of 0.87 in one sample with a two week interval and 0.81 in another sample with a one month interval supported stability, / reliability.

**INSTRUMENT:**

**PART-I**

Instrumentation includes socio-demographic questionnaire for children suffering from AIDS and their principal care-givers. The questions included were based on one’s name, age, sex, marital status, number of children, nationality, educational status, of the principal care-givers and
their children, employment status and its type, the monthly in-come, an indicator of socio-economic data, which is in a strata form, indicating the different levels of socio-economic group, types of relationship, types of family, religion, support group involvement, current NON-HIV related illnesses, number of hospitalizations (NON-HIV) and the immune status related to CD4 count of the children suffering from AIDS and their principal care-givers.

**PART.II**

Instrumentation includes questionnaire for children suffering from AIDS which consists of six components related to the variables of: -

a) Physical-health functioning - Consists of 6 questions
b) Medication - Consists of 3 questions
c) Pain Assessment - Consists of 6 questions
d) Social Support - Consists of 5 questions
e) Psychological - Consists of 4 questions
f) Spiritual - Consists of 5 questions
The total number of questions in the questionnaire is 29 questions and the scoring pattern is a 4-point Likert’s scale. In which the score varies from strongly agree-4, agree -3, disagree-2, and strongly disagree-1.

Instrument for principal care-givers suffering from AIDS consists of a questionnaire with five components related to:

1. Physical domain-diagnosis-health functioning consists of 10 questions.
2. Social domain-includes social support, consists of 5 questions
3. Family-family concerns consists of 7 questions
4. Psychological domain-psychological aspects, consists of 5 questions.
5. Spiritual domain-spiritual aspects, consists of 5 questions

Total number of questions in the questionnaire are 32 with a scoring pattern of 4-point likert’s scale, which varies from:

- Strongly agree - Score of -4
- Agree - Score of -3
- Disagree - Score of -2
- Strongly disagree - Score of -1

The term ‘Strongly Agree’ is related to positive feeling which indicates bon adaptation by the individual subject and thus gets the highest score of 4. And the feeling of ‘strongly Disagree’ has a score of 1, which is
the least score related to the negative feeling which indicates maladaptation by the individual subject, as expressed and experienced by the children suffering from AIDS and their principal care-givers.

**SCORING OF THE ITEMS:**

The Mean score was assessed and tabulated as follows:

A score of -4: indicates a tendency to ‘Strongly Agree’.

A score of -1: indicates a tendency to ‘Strongly Disagree’.

The questionnaire related to the principal care-givers suffering from AIDS consisted of psychosocial variables related to the physical domain-diagnosis-health functioning which has 10 questions with a 4 point likert’s scale. The scoring pattern ranges from Strongly Agree-4, Agree-3, disagree-2, Strongly Disagree-1.

The variables included in the social domain are social support consisting of 5 questions and the family component consisting of 7 questions. The instrument has the physical domain with 5 questions related to the psychological aspects of the individual. Lastly, the variables related to the spiritual domain has 5 questions. The instrument used for data collection from the children suffering from AIDS consists of 6 questions
related to physical domain-child-health functioning with a scoring pattern ranging from Strongly Agree-4, Agree-3, Disagree-2, Strongly Disagree-1. The questions related to the medications of the child has 3 questions related to pain component of the child, and also includes 6 questions for pain assessment, the social domain includes social support related to the children suffering from AIDS and their families. Social support was one of the variables included in this component, which has 5 questions. The psychological domain related to the children suffering from AIDS had the psychological aspects with 4 questions. Lastly, the spiritual domain, consists of 5 questions, which includes the spiritual aspects of the children suffering from AIDS. The tool utilized for the children suffering from AIDS consists of 29 questions on the whole.

**PILOT STUDY:**

A pilot study was conducted at the Government institute of thoracic medicine, and chest diseases, Tambaram, Chennai-47. 30 children suffering from AIDS and their principal care-givers (n=30) were included in the study.

The pilot study was conducted during the month of August, 2001, from 1.8.2001, to 31.8.2001. The scoring pattern adopted
by the investigator was 4-point Likert’s scale, wherein, the highest score was allotted for a healthier pattern of adjustment bon adaptation, as experienced by the children suffering from AIDS and their principal care-givers. The impact of their experiences as expressed by the children suffering from AIDS and their principal care-givers were observed by the investigator. Interview schedule consisted of questionnaires related to the four domains, namely, physical, psychological, social and spiritual domain of the individual. After conducting the pilot study, the investigator came to the conclusion that the children suffering from AIDS and their principal care-givers had experienced a severe impact related to their illness which indicated insignificance among the relationship of the psychosocial variables. The investigator had to further explore their impact in the main research study. The results of the pilot study revealed certain modifications and refinement in the questionnaire which was followed by the investigator and the validity and reliability of the instrument was established.

**PROCEDURE FOR DATA COLLECTION:**

Data collection procedure was conducted from 1st September 2001 to 30th September 2004 in the Government Institute of Thoracic Medicine and
Chest Diseases, Tambaram, Chennai-47. The research proposal was approved on 28.05.2001 by the advisory committee headed by the controller of examination, Sri Ramachandra Medical College and Research Institute (Deemed University), prior to the pilot study and the main study. The children suffering from AIDS and their principal care-givers were selected by convenient sampling technique. The study subjects who met the inclusion criteria and who were willing to participate in the study had been explained about the study. And the subjects oral consent was obtained. An assurance was given to the study subjects that their anonymity and confidentiality would be maintained. Direct interview method was employed, while interviewing the children suffering from AIDS and their principal care-givers. Each study subject was interviewed separately and privately in Tamil by the researcher. Interview was conducted in a private room in the children’s unit. The instrument consisted of questionnaire for the children and their principal care-givers suffering from AIDS. The questionnaire was based on the four domains of the individual namely physical, psychological, social and spiritual. The questions were read to the children suffering from AIDS and their principal care-givers and their responses were marked on the questionnaire. The
interview lasted from 30 minutes to 1 hour. The data regarding the confirmation of the diagnosis and other details of the study subjects was obtained from the patient’s records. Individual counseling and family counseling were provided by the investigator to the children aged between 6-18 years along with their principal care-givers. As the investigator has successfully completed the post-graduate diploma in guidance and counseling at Annamalai University, Chidambaram, Tamil Nadu, India, hence the investigator was able to do the counseling effectively. The data was collected between 8 am to 4 pm. for a period of 3 years from 1st September 2001 to 30th September 2004.

**ETHICAL PROCEDURE:**

1. Written permission was obtained from the Director of Medical Education, Chennai. And from the Medical Director of the Government institute of thoracic, medicine, and chest diseases, Tambaram, Chennai 47.

2. Verbal permission was obtained from the Nursing Superintendent and the Nurses of the Government institute of thoracic, medicine, and chest diseases, Tambaram, Chennai 47. And they were informed about the research study and the related procedures.
3. Concerned consultants/physicians of the children were informed and verbal permission was obtained.

4. Principal care-givers were informed and explained regarding the purpose of the study and their verbal permission was obtained for non-participatory observation.

**PLAN FOR DATA ANALYSIS:**

Data analysis was computed using both descriptive and inferential statistics. The obtained data includes socio-demographic variables. And the assessment of the psychosocial variables of the tool with its total score for an individual, was analyzed as expressed by the children suffering from AIDS and their principal care-givers.

**INVESTIGATOR PLANNED TO ANALYSE THE DATA AS FOLLOWS:**

1. Descriptive statistics would be used to find out the frequencies, percentage of each socio-demographic variables.

2. Statistical analysis was done by computing the Mean and Standard Deviation for four domains related to physical, psychological, social, and
spiritual aspects of children suffering from AIDS and their principal care-givers.

3. Chi-square test was computed to find out the association between the four domains, namely, physical psychological, social and spiritual aspects related to the children suffering from AIDS and their principal care-givers. Independent t-test was used to determine the difference in the mean scores of psycho-social variables.

4. ANOVA test and Karl Pearson’s co-efficient of correlation were utilized to analyze the association between the four domains physical, psychological, social, and spiritual aspects related to the children suffering from AIDS and their principal care-givers. These tests were used to identify the level of psychosocial distress and its impact on the quality of life and the social support among the children suffering from AIDS and their principal care-givers.

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