Chapter III

Methodology
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The topic is highly sensitive one because of its highly personalized and stigmatizing nature. For conducting the study both the qualitative and quantitative methods were employed. The most important task was to reach the HIV patients this however was made possible by selecting the patients who were attending the NACO ICTC centers. As the patients were already in contact with the investigator it was easy to develop rapport and confidence with the patients. For data collection standardized questionnaires and personal interviews were used. The subjects for the study were chosen partly from Haryana and partly from Delhi. It is pertinent to mention here that the cultural values, socio economic conditions and the living standards of the people living the area are almost same. The most important criterion for the inclusion in the study was the CD 4 level. The interviews for the study were conducted after the confidentiality was ensured and rapport was established. The initial visits therefore were to build confidence and rapport with the patients. As suggested by Fischer, (1983) for design the coding scheme, sequence of questionnaire, sensitive questions, mixing of open ended and dichotomous questions and pilot study etc were taken into consideration by using the standardized questionnaires. The subjects were not only informed but informed consent was obtained from each and every participant in writing. As the investigator worked as counsellor and therefore had sufficient training and experience in interviewing the HIV patients and their caregivers and the experience was a great help in working for this study. During the pilot study investigator obtained sufficient training to administer various questionnaires.

DESIGN

As the study aimed to explore the psychosocial problems in the HIV/AIDS patients and also attempted to see the impact of counselling on these variables. The study was conducted in two phases, in the first phase a multi group design was used to examine/ assess, suicidal ideation, depression, family burden, health and quality of life in HIV negative, HIV positive and AIDS cases and their care givers. There were three
groups of HIV/AIDS patients and three groups of their care givers. There were 50 participants in each group. As shown in table 3.1

Table 3.1 showing the design of the study- distribution of subjects in different groups

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<tbody>
<tr>
<td>HIV negative</td>
<td>Care Givers of HIV negative</td>
<td>HIV positive</td>
<td>Care Givers of HIV positive</td>
<td>AIDS patients</td>
<td>Care Givers of AIDS patients</td>
</tr>
<tr>
<td>n= 50</td>
<td>n=50</td>
<td>n=50</td>
<td>n=50</td>
<td>n=50</td>
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For the second phase of the study i.e. for examining the impact of counselling on depression, suicidal ideation, family burden and health and quality of life in HIV positive and AIDS cases and their caregivers, a pre-post design was used.

SAMPLE

The samples of the study consisted of HIV negative, HIV positive and AIDS cases and their care givers. In all a total number of 300 participants were included in the study. There were 50 participants in each group i.e., 50 HIV negative, 50 HIV positive and 50 AIDS cases and their care givers (50 in each groups).

The HIV negative, HIV positive and AIDS cases and their care givers were selected on the basis of non random purposive sampling bases from ICTCs of Delhi, Haryana and (India).

In the first group 50 HIV negative participants were selected and their age range was 24 years to 48 years out of this total number of males were 25 and females were also 25. The second group i.e. care givers of HIV negative participants were in the age range of 28 years to 46 years, out of this total number of males were 25 and female were also 25. In the third group there were 50 HIV positive participants (as tested.
and certified by ICTC Centers) the age range was 30 years to 48 years. There were equal number of males and females. Majority of cases were laborer/drivers and many of them were multiple drug users (more than 50%). The fourth group represented care givers of HIV positive participants. Total numbers of care givers were 50. The age range was 28 years to 49 years, with an equal number of males and females. In the fifth group there were 50 AIDS cases in the range of 32-48 years with an equal number of males and females cases. Majority of participants were laborer/drivers and multiple drug users (more than 50%). In the sixth group there were 50 care givers of AIDS cases. There age range was 28 years to 49 years.

TOOLS USED

The following tools were administered uniformly and individually to each subject by investigator himself:

1. **Hamilton Depression Rating Scale** (Hamilton,1967)

2. **Suicidal Ideation Questionnaire** (Reynolds,1988)

3. **Family burden scale** (Pai and Kapur,1981)

4. **PGI health questioner N-1** (Wig and Verma,1985)

5. **WHO Quality of Life – BREF** (WHO,1998)

1. **Hamilton Depression Rating Scale (HDI):** It was developed by Hamilton, (1967). This scale has 23 questions in MCQ format that clinician may use to rate the severity of a patients depression. The Questionnaire rates the severity of symptoms observed in depression such as low mood, insomnia, anxiety and weight loss. HDI is presently one of the most commonly used scale for rating depression in medical research and is a self report measure of the severity of depressive symptomatology in adults. The HDI may be administered individually or in a group formats it requires approximately 10 minutes to completes, although greater time may be required by elderly persons or persons who are slow readers. There are 3 versions of the paper and pencil form of the HDI, including the full
scale HDI which consists of 23 items, the HDI 17 i.e. compressed of the first 17 items of the HDI and is designed to be equivalent in content and scoring to the 17 items, clinicians administered HDRS and HDI-SF, a 9 items short forms of the HDI. The HDI does not include reverse scored items, although it does include several sets of items that are directly opposite in their symptom expression. The response formats for individuals items varies in scoring from 0-2 or 0-4. Internal consistency reliability estimates for the HDI, HDI-17 and HDI-SF based on total HDI development samples. The reliability for the psychiatric sample was high, with a co-efficient alpha reliability of .89 for the HDI with the total psychiatric sample all forms of the HDI demonstrated very high levels of test re-test reliability. The re-test reliability co-efficient for the HDI total was.95 where as it was .93, respectively for HDI-17, HDI-SF and HDI-MEL.

Scoring procedure for the HDI is simple. The form HS answer sheets are located in the inside sheet of the two page carbon less answer sheets. Tear the perforating at the top of the answer sheet and peel away the top page. The responses to each of the 40 questions transfer through to the bottom page. The number that corresponds to a respondents answer to an individual question is the score for that question. Each individual HDI items measure a circumscribed depressive symptom domain. Some symptom domains are adequately measured by only one question while others required multiple questions for adequate sensitivity of measurement. Therefore, several HDI items comprise only one question. Item 2,3,8,9,12,14,16 and 19 through 23 each comprise a single question. All other items (i.e. 1, 4, 5, 6, 7, 10, 11, 13, 15, 17 and 18) comprise multiple questions and therefore require special weighted scoring procedures. Although based on a single question item 16 also requires special scoring procedures.

The HDI is scored in a pathological direction such that higher item scores indicate higher levels of depressive symptomatology. Scores on items that comprise multiple questions are rounded to one decimal place (i.e. a score of 2.2857 on item 1 is rounded to 2.3). Raw scores for all summary indexes are rounded to the nearest half point (i.e. 5). The possible range of raw scores is 0 to 73 for the HDI, 0
to 52 for the HDI 17, and 0-33 for the HDI –SF sometimes, an adult may skip or otherwise leave one or more HDI items blank. In case where five or more of the items are left blank, the HDI result should be considered invalid. In order to consider on HDI protocol as valid at least 19 of the items on the 23 items HDI must be completed. An item is considered incomplete if any question that should have been answered was left blank, thereby making the calculation of the item score impossible. The scales items are appended in appendix –A.

2. **Suicidal Ideation Questionnaire (SIQ):** The suicidal ideation questionnaire is a self reported measure designed to assess thought about suicide ideation in adolescents and young adults. The SIQ is developed by Reynolds, (1988). The SIQ consist of 30 items and the respondents need to rank each of the items on a 7 point scale, which assess the frequency with which the cognition occurs. For scoring purpose, items are scored from 6 to 0. Items are scored in a pathological direction, so that a high score is indicative of number of suicidal cognitions occurring with significant regularity. The maximum possible score on the 30 items SIQ is 180, and lowest possible score is zero which indicates that none of thoughts indicated by the items have ever occurred.

The internal consistency reliability of the SIQ and SIQ-JR across development samples and for various sub samples by age and sex was completed using Cronbach (1951) co-efficient alpha (rd). Reliability co-efficient by grade were uniformly high and ranged from .969 to .974, with a total sample reliability coefficient of .971 for the SIQ. In the study reported by Klastermen – Fields, (1985) with 156 female college students (primarily 18 and 19 years old) a reliability coefficient of .964 was found. The test re-test reliability of the SIQ was examined in a large sample of adolescent from a high school in the mid –West. Subjects were 80% youngsters from research sample B who were represented on the SIQ on the SIQ approximately 9 week after the initial assessment. On the initial assessment a mean of 17.79 (SD=20.76) was obtained and 4 week later a mean SIQ score of 17.49 (SD=23.82) was found. The test retest reliability based
on these two assessments was .72, which is moderate and consistent with the status of the SIQ. The scale is given in appendix -B.

3. **Family Burden Scale (FBS):** For measuring family burden a structured interview schedule developed by Pai and Kapur, (1981) was used. The scale assesses both the objective and subjective burden. It has to be rated by the interviewer on three point scale i.e. Severe burden (score-2), moderate burden (score-1), and no burden (score -0). It measures the perceived burden on the family in six areas namely (1) financial burden (2) disruption of family routine activities, (3) disruption of family leisure, (4) disruption of family interactions, (5) effects on physical health of others and (6) effects on mental health of others. The burden score can be obtained by adding the rating for each of the 24 items and may range from 0 to 48. The cronbach alpha was.90, indicating the homogeneity of the items in measuring burden. The Spearman- Brown coefficient for split half reliability was high (r=0.92) as reported by Pai and Kapoor, (1981). Convergent validity was shown are significant positive correlation (=.78) between the objective burden and subjective burden scores of FBIS in the studies of Pai and Kapoor, (1981). The Hindi version of the scale was given to five experts to re-translate into English. The discrepancies were removed and then the final draft was administered to 30 parents (15 fathers and 15 mothers) twice with a gap of 31 days. The correlation coefficient between the first and second testing score was .83. The Hindi and English version of the scale were administered to 30 parents (15 fathers and 15 mothers).

The coefficient of correlation between the Hindi and English version was found to be .73. (Kavita, 2010). The Hindi version of the scale is given in appendix -C.

4. **PGI Health Questionnaire N-1:** This tool was developed by Wig and Verma, (1985). It is used as best screening tests that can be used with ease on unsophisticated and low literate group of subjects. The basic focus for the development of this questionnaire was need for a simple neuroticism scale which can be used in clinical settings. The authors of this test opined that in
functional psychiatric illness and more specifically in neurotic illnesses in India, where insight and ego strength is retained, disturbances are expressed more through physical complaints rather than psychological complaints. It consisted of 38 items divided in to two sections – Physical and Psychological section. It is so because of the concepts of illness deep rooted accepted mode of manifestation of it through somatization. Nevertheless psychological disturbances and behavioral dysfunctions which are concomitants of such illnesses are considered to follow it. Cornell Medical index health questinnare which contains 195 items of somatic and emotional complaints, is more acceptable in clinic population in India as compared to any other currently available measure of nuroticisum (Wig, Parshad and Verma, 1973). This is particularly true because of its two main characteristics viz (a) emphasis more on physical and (b) items are simple and brief and more or less in colloquial language.

Finally it consists of 38 items divided in to (a) Physical distress and (b) Psychological distress sections with 16 and 22 items respectively. Most of the patients are able to finish this test within 5 minutes. The numbers of ticks on section “a” and “b” indicate the respective scores, which can be then added up to give a total score also. The questioner is appended in appendix -D.

5. WHO Quality of Life – BREF: This tool was used to measure the quality of life in patients and control group as well. The WHO QOL BREF (1998) is a 26 item instrument consisting of 4 domains: Satisfaction with Physical functioning (7 items) Psychological dimensions (6 items), Social dimension (3 items) and satisfaction with environment (8 items) and one item each for overall QOL and QOL general health items. The physical health domain includes items on mobility, daily activities, pain, energy and sleep.

The psychological domain measures self –image, negative thoughts, positive attitudes, self esteem, learning ability, religion, and mental status. The social relationship domain contains questions on personal relationship, social support and sex life. The environmental health domain covers issues related to safety,
health, and social services and knowledge, reactions, transportation (World health Organization -1995). All scores are transformed to reflect a score of 4 to 20 for each domain with higher scores corresponding to a better quality of life.

Table 3.2 Total items and domains in WHO-QOL Brief.

<table>
<thead>
<tr>
<th>Items</th>
<th>Representing</th>
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<tbody>
<tr>
<td>(1) 1 and 2</td>
<td>Overall Quality of life and general health</td>
</tr>
<tr>
<td>(2) 3,4,10,15,16,17, and 25</td>
<td>Satisfaction with physical functioning</td>
</tr>
<tr>
<td>(3) 5,6,7, 11,18,26</td>
<td>Psychological dimension</td>
</tr>
<tr>
<td>(4) 19,20,21</td>
<td>Social dimension</td>
</tr>
<tr>
<td>(5) 8,9,12,13,14,22,23 and 24</td>
<td>Satisfaction with Environment</td>
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The internal consistency of the WHO QOL- BREF, as assessed by Cronbach alpha coefficient for the responses of all subjects for physical health in the healthy individuals was .70 and for unhealthy individuals was .73, for psychological health in the healthy individuals was .73 and for the unhealthy individual 0.55, for social relationship in the healthy individuals .55 and for the ill individual .84, for environmental health in the healthy individuals .84 and for the ill individuals .72. For convergent construct validity, the correlation of four sub scales of WHO -QOL-BREF and the four sub scales of GHQ -28. Discriminate construct validity was tested by difference between genders and age groups. All sub scales WHO-QOL-BREF questionnaire were significantly higher at male elderly respondents. Differences between young elderly (60 to 74 years) and old elderly people (75 to 90 years) among sub scales score were significant. The scale is given in appendix -E.
PROCEDURE

Each participant was administered measures of depression, suicidal ideation, family burden, health and quality of life, after building rapport. Everyone was briefed about the purpose of the study and informed consent was obtained. Those who volunteered for the study were included for the final testing. The testing was done under uniform and standardized conditions and all the measures were administered individually to each participant by the investigator himself. For the second phase of the study before and after design was used to examine the impact of the counselling on psychosocial problems of HIV/AIDS patients and their care givers. The base line scores were taken from the first testing in the first phase and all the subjects in all groups were taken up for the second phase of the study. For this study the counselling module for HIV positive and AIDS cases and for their care givers were taken of as such for the counselling, the counselors training modules develop by National AIDS Control Organization, Department of AIDS, Ministry of health, Government of India, New Delhi.

The HIV positive, AIDS cases as well as their care givers were given counselling individually by the investigator every week for three months. Every case were called in ICTC Center once a week and it continued for three months, after the completion of three months, measure of depression, suicidal ideation, family burden, health and quality of life were administered again to each subject under stander test condition uniformly by the investigator. The sorted format of standard counselling module for HIV positive, HIV negative, AIDS cases and their care givers are given in the Appendix -F.

ADMINISTRATION AND SCORING

All the participants were interviewed at the intake after developing rapport and building confidence. Informed consent was obtained from the each participant after explaining the purpose of the study and the procedure. It was followed up by standardized AIDS counselling in the groups. The counselling was done by the investigator himself. For the second part of the study a post counselling assessment was done after three months of intake.
STATISTICAL ANALYSIS

The obtained data were analyzed by applying ANOVA, t-test besides the measures of central tendency and depression. Post hoc Duncan’s test was used wherever required.