CHAPTER 3
RESEARCH METHODOLOGY

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RESEARCH METHODOLOGY

3.1 Introduction

Persons with severe mental disorders, such as schizophrenia and bipolar affective disorder, represent a heterogeneous group with different problems and varying levels of need. Severe mental disorders figure among the ten leading causes of disability and burden in the world (WHO, 2001). More often, severe mental disorders tend to run a chronic course and have a devastating impact on the person’s functioning. Due to this global impact, it affects not just the individual, but also his family and, in turn, the community at large. The deficiency in care facilities and families neglect forces many of the mentally ill to lead life in the streets. The homeless lack the basic care and are alienated from the mainstreams of society. There has been isolated efforts from charity based organizations and religiously oriented families in the care and rehabilitation of the homeless mentally ill. This study aims at exploring the care and rehabilitation efforts undertaken by these facilities for the homeless mentally ill.

The issues in the care of the mentally ill who do not have any immediate relatives are many. There is no accurate data on the magnitude of the mentally ill who do not have relatives or abandoned by the family. Approximate and indirect evidences suggest that this is a serious issue. One percent of the population suffers from serious
mental disorder and at least 50% of them need continuous long-term care. Further there are adults with mental retardation and associated behavioural disturbances. Similarly 48% of the population in mental hospitals are long stay patients with no family members willing to get them discharged. The mental health care of the homeless mentally ill has been a major challenge for the mental health care system. They have been neglected in the society and by the care system due to a number of reasons.

As with most problems, we have learned that there are no simple and universal solutions to the problems of homelessness and there have been no efforts from the govt. to tackle this menace. The homeless not only require medical and basic care but warrants a comprehensive psychosocial care. When the institutional care and rehabilitation facilities failed to address this there have been less visible efforts from the community and few charity oriented individuals.

Several individuals and families in Kerala have been involved in providing food, clothing, shelter, medicine and occupational therapy free of cost for the homeless mentally ill. These are largely charitable efforts sustained by the active support, in cash and kind, of the local community (Murali, 2002). However, theses facilities existed in the community for many years no attempts have been made to systematically review the modus operandi and outcomes. These services need to be further examined with regard to the quality of care.
This study has raised seven pertinent questions for enquiry. What are the rehabilitation processes used by these care facilities? What are the facilities provided at each center? What is the quality of patient care services? What are the personal profile of the chief functionary of the rehabilitation centers and their motivations for setting up and maintaining such facilities? What is the level of knowledge and attitudes of care providers on mental illness? What is the level of satisfaction of the residents? How much is the quality of life and level of functioning of the homeless mentally ill?

The above posed issues are vital aspects to be reviewed and no efforts have been made to review the same. Hence this study proposes to review the above-mentioned areas to throw light into the different dimensions of care viz. the consumers of care, the care providers, which would supplement knowledge to the mental health care system and to social work literature.

3.2 Objectives and Hypotheses of the Study

Objectives of the Study

General Objective:

To study the facilities for care and psychosocial rehabilitation and rehabilitation outcomes of homeless mentally ill in Kerala.

Specific Objectives:

1. To study the facilities for rehabilitation in the rehabilitation centers for homeless mentally ill in Kerala.
2. To examine the methods adopted for care in the rehabilitation centers.

3. To assess the quality of patient care services offered by the rehabilitation centers.

4. To explore the personal profile of the care providers of homeless mentally ill.

5. To study the knowledge and attitude of the care providers regarding mental illness.

6. To assess the level of functioning of mentally ill residing in the care centers.

7. To assess satisfaction of residents in the care facilities.

8. To explore the quality of life of residents in the care facilities.

**Hypotheses**

1. The quality of life of homeless mentally ill increases with higher level of functioning.

2. Better the quality of patient care services better would be the level of functioning of the mentally ill receiving care.

3. Better quality of patient care services better would be the quality of life of the mentally ill receiving care.

4. Better the orientation to mental illness of the care providers higher will be the quality of life of mentally ill.
5. Better the orientation to mental illness of the care providers higher will be the level of functioning of mentally ill.

### 3.3 Definition of Concepts

**Psychosocial Rehabilitation**

Psychosocial rehabilitation is a process that offers the opportunity for individuals who are impaired, disabled or handicapped by a mental disorder to reach their optimal level of independent functioning in the community. It involves both improving individual competencies and introducing environmental changes (WHO 1995). Psychosocial rehabilitation is a comprehensive process and not just a technique.

**Homeless Persons**

“Homeless” or “homeless individual or homeless person” includes—

1. An individual who lacks a fixed, regular, and adequate nighttime residence; and

2. An individual who has a primary nighttime residence that is —
   
   A. an institution that provides a temporary residence for individuals intended to be institutionalized; or
   
   B. a public or private place not designed for, or ordinarily used as, a regular sleeping accommodation for human beings.
United Nations when it declared the International Year of Shelter for the Homeless. According to this definition, a "homeless" person is not only someone without a domicile who lives on the street or in a shelter, but can equally be someone without access to shelter meeting the basic criteria considered essential for health and human and social development. These criteria would include secure occupancy, protection against bad weather, and personal security, as well as access to sanitary facilities and potable water, education, work, and health services.

**Homeless Mentally Ill**

NIMH program announcements define the homeless mentally ill adult population as individuals, age 18 years or older, who have long-term, severe mental illnesses and no fixed place of residence. In this context, long-term severe mental illness is defined as a severe and persistent mental or emotional disorder (e.g., schizophrenia, schizoaffective disorders, and mood disorders) that disrupts functional capacities for such primary aspects of daily life as self-care, household management, interpersonal relationships, and work or school.

**Rehabilitation Outcome**

Rehabilitation outcome refers to measures used to assess the effectiveness of any rehabilitation programme. The purpose of such measures is to provide the service provider with (a) a clear over-all pre vs post picture of the level of functioning of the individual, (b)
clear evidence of the effects of services on the sense of well being of the consumer and, (c) a means with which to monitor his or her own effectiveness (Ware, 1992). The current study uses quality of life and social functioning as measures for assessing the rehabilitation outcome.

**Quality of Life**

The World Health Organization defined QOL as the “person’s perception of his/her position in life within the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards, and concerns. It is a broad-ranging concept incorporating, in a complex way, the person’s physical health, and psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features of the environment.”

Quality of life is assessed based on four domains physical health, psychological health, social relationships, and environment.

**Level of Functioning**

Level of functioning of a homeless mentally ill person includes a person’s level of performance in the domains of Community Living, Interpersonal Relationships, psychological Functioning and Physical Functioning.
Pilot Study

A pilot study was conducted to test the feasibility of the study, to finalize the universe and to decide the tools for data collection. The researcher gained interest in this topic from his experience as Research Officer in the WHO funded research on rehabilitation facilities for chronic mentally ill. The scope of the study was further expanded through regular interactions with the functionaries of two of these centers, office bearers of Kerala Federation of the care of the Mentally Disabled (KFCMD) and discussion with several experts in the field of rehabilitation. The study formed into this shape after series of interactions with professionals in the field of psychiatric rehabilitation.

3.4 Research Design

The study uses a combination of Explanatory and Quasi experimental – After only design (Post test only) evaluation design. The explanatory study tries to establish cause effect relationship and describe phenomena. The first part of the study tries to delineate the rehabilitation processes adopted and quality of patient care services. The study tried to explore predictive factors contributing to quality of life of the homeless mentally ill by exploring the relationships between quality of life and variables such as level of functioning, and quality of patient care services.

In the evaluation design, the study performed both process and outcome evaluation. The rehabilitation processes were studied
and the outcomes using quality of life, level of functioning and patient satisfaction as the outcome measures. The care providers’ orientation to mental illness also was evaluated. The Quasi experimental – After only design (Post test only) was used as the study was intended to document the processes involved in the unique rehabilitation model in the state of Kerala and unavailability of comparable rehabilitation processes for homeless mentally ill. This design provides factual information about the processes used and outcomes of rehabilitation.

**Universe**

The Universe of the study include all residents with Schizophrenia and Bipolar Affective Disorder, Chief Functionaries and Care Providers of the care facilities registered with Kerala Federation of the Care of the Mentally Disabled (KFCMD) established for the care and rehabilitation of homeless mentally ill in the state of Kerala.

**Sampling**

The researcher collected data from three information sources:

1. Study of Rehabilitation facilities

   The researcher used simple random sampling (lottery method) for the selection of 20 centers providing care and rehabilitation facilities for homeless mentally ill from 42 centers registered under Kerala Federation of the Care of the Mentally Disabled.
2. Study of the knowledge of care providers

All the volunteers working in the centers available on the day of visit were interviewed for assessing the orientation to mental illness among the care providers. Data was collected from 66 care providers.

3. Study of rehabilitation outcomes

The researcher further used Simple Random sampling for selecting 10 residents from each of these centers for the assessment of rehabilitation outcomes and client satisfaction. 181 respondents were selected as sample of the study. Some of the centers were not having adequate number of residents fulfilling the inclusion and exclusion criteria.

The researcher used the following inclusion and exclusion criteria for the selection of the sampling units from the above three sources.

**Inclusion criteria**

1. All care facilities for the care of homeless mentally ill run on a voluntary basis and registered under KFCMD.

2. Persons with mental illness who have been diagnosed with schizophrenia or bipolar affective disorders.

3. Volunteers who have been working in the center at least for a period of 6 months.
Exclusion criteria:

1. Residential facilities available in government agencies
2. Mentally ill who were actively symptomatic
3. Mentally ill persons who have been admitted by family members to the rehabilitation facility.

Pre-test

The researcher conducted pre-test of the tools in three centers. The pre-test gave several insights to the researcher. The tools were modified based on the findings of the pre-test. The first tool with 104 items in the study of the rehabilitation facilities were trimmed to a 60-item instrument. The validity of the translated versions of Orientation to Mental Illness scale and Quality of life scale were assessed.

Sources of Data

The primary data was collected from three sources:

1. Chief functionary of Rehabilitation facilities:
   The researcher interviewed the chief functionary of the rehabilitation facilities with an aim of studying the functioning, facilities and services of the center.

2. Volunteer care providers:
   All the volunteers working in the centers were interviewed for assessing the orientation to mental illness among the care providers. Data was collected from 66 care providers.
3. Persons with mental illness residing in the rehabilitation centers.

The researcher interviewed 181 respondents for assessing the rehabilitation outcomes and client satisfaction. Some of the centers were not having adequate number of respondents fulfilling the inclusion and exclusion criteria.

Profile of the Organizations Selected for the Study

1. Emmanuel Kripa Trust, Kodakara

Emmanuel kripa trust is established in the year 1998 at Kodakara in Trichur district. The center was established by Mr. K.K Pyloth for providing shelter for abandoned and homeless women. The initiation was influenced by his religious beliefs and as an effort of dealing with his boredom after retirement.

2. Piyatha Bhavan, Pothy

Piyatha bhavan is established by Sr. Mary in the year 2004 for providing care for homeless mentally ill. The center is located in Pothy near Thalayolaparambu in Kottayam district. The center was started in the ancestral property of the chief functionary for supporting the homeless mentally ill women.

3. Mariyalayam, Elanji

This organization was established by Mr. Mathew in the year 2000 motivated by his religious beliefs. The organization is located at Elanji in Kottayam district. Care is provided to both men and women.
4. Kunjakkan Missionary Bhavan, Ramapuram

This center was established in Ramapuram in Kottayam district in the year 2002 by Mr. Joseph and is currently managed by Mr. Benoy. The center caters to the needs of homeless mentally ill men.

5. Christuraj Trust, Piravom

This organization is set at Piravom in Ernakulam district in the year 1996 by Mr. Jaison subsequent to his miraculous recovery from a terminal illness. The center caters to the needs of both male and female homeless mentally ill.

6. Jeevanilayam, Vaikon

Adv. Mathew established this center for the rehabilitation of homeless mentally ill in Vaikom in Kottayam district in the year 1998 motivated by his religious beliefs and commitment to society. This center provides care to men.

7. SD sisters, Keerampara

This center was established as part of the missionary activities of Sisters of Destitute in the year 1997 at Keerampara near Kothamangalam in Ernakulam district. The present in charge of the center is Sr. Glory, the Mother Superior of SD convent. The center provides care to mentally ill women,

8. Divyarakshalayam charitable trust, Mailacompu

This center is established in Mailacompu near Thodupuzha in Idukki District. The center was established to provide care to
homeless men in the year 1994. the chief functionaries are Mr. Joshy and Mr. Tomy.

9. Avemaria Rehabilitation Center, Perunilam

This center is established as charity center of religious sisters in Perunilam near Erattupetta. Sr. Rosario started the center in the year 2002 to support the care of homeless mentally ill women brought from a center in Palai. Sr Alons Maria is heading the activities now.

10. Abhayabhavan, Koovappady

Motivated by personal life experiences Ms. Mary Esthappan founded the center in Koovappady near Perumbavoor in Ernakulam district in 1997. this center provides care to men and women.

11. Lovehome, Kadavoor

Mr. Mathappan established this center in the year 1997 at Kadavoor in Ernakulam district for providing rehabilitation facilities for homeless mentally ill women.

12. Snehasadan, Muttom

This center is established at Muttom in Idukki District in the year 2000 as an initiative of Christian prayer group. The center provides care to homeless mentally ill men. Mr. Appachan is the in charge at present.

13. Mariasadanam Charitable Trust, Palai

Established by Mr. Santhosh Joseph in the year 1998 for providing care for one person in his own family. Currently provides
care homeless mentally ill men and women. The center is located in Palai in Kottayam district. The institution also takes up stigma reduction and public education programmes through cultural events. The office of the KFCMD operates in this center.

14. Lourde Bhavan, Pallickathode

This center is set up in Pallickathodu in Kottayam district in the year 1999 by Mr. Jose Antony. The center provides care for homeless mentally ill men.

15. Snehasram, Kummannor

Mr. Thomas established the center in the year 2000 for providing care for homeless men and women. The center is located in Kummannoor in Kottayam district.

16. Navajeevan Trust, Kottayam

The trust was founded by Mr. P U Thomas for providing shelter and care to homeless men and women. The center was established in the year 1997 at Villoonni in Kottayam district.

17. Karunyabhavan, Mallappally

This center is established in Mallappally in Pathanamthitta district. Mr. Biju, Mr. Kunju started this center for the care homeless mentally ill men in 1997.
18. Snehalayam, Thittakkadu

Mr. Joseph started this center at Thottakkadu in Kottayam district. The beginning was motivated by his religious beliefs and is providing care for homeless mentally ill men since 1997.


Mr. Kuriakose motivated by his personal life experiences started the center in 1998 for the care and rehabilitation of homeless men at Kothamangalam in Ernakulam district.

20. Penuel Ashramam, Thambalakkadu

Fr. Sebastian Vechhookarott started this center as part of his religious activities connected to prison ministry in 1998 for the rehabilitation of homeless mentally ill men the center is located in Thamabalakkadu near Kanjirapally in Kottayam district. The center also operates a retreat center for those addicted substances and their families. The center is part of a movement named Emmanuel Love Community.

3.5 Research Instruments

The researcher utilized the following instruments of collecting data

1. Interview Schedule for Rehabilitation Facilities:

A structured interview schedule covering the following areas was prepared, pre-tested and utilized for the study

   a. Information Relating to Organization
b. Profile of the Person in Charge

c. Profile of Physical Infrastructure

d. Staffing Pattern

e. Profile of Services Provided

f. Profile of Rehabilitation Activities

g. Other Services

2. Interview Schedule for Residents of the Centers:

The interview schedule covered the following areas

a. Patient Information Summary

b. Level of satisfaction

c. Level of Functioning Assessment

The level of functioning assessment included five dimensions

a) Community Living: This part included 10 questions related to essential skills for living in a community. This domain provides a score of self sufficiency of the person with mental illness.

b) Interpersonal Relationships: This section included 6 questions on the interpersonal skills of the mentally ill person.

c) Psychological Functioning: this part covers three dimensions of psychological functioning (mood disturbance – 8 questions;
Psychotic symptoms – 4 questions and Dangerous Behavior – 3 questions).

d) Physical Functioning: This section comprised of 8 questions on the skills of the person with mental illness in various dimensions of activities of daily living.

Scoring

The functioning in the above said areas were assessed using a 5 point Likert scale. The scores of 1 and 2 indicate Very Low level of functioning, 3 indicating Low and 4 and 5 showing within normal limits. For analysis the scores obtained in various questions under the different domains are computed and their mean scores were identified. The scores obtained are analyzed using the schema of 1-2.5 Very low, 2.6-4 Low and 4.1 to 5 as Normal levels of functioning.

3. Orientation to Mental Illness Scale (Prabhu, 1983):

This standardized scale was utilized for assessing the volunteers’ orientation towards mental illness. Initially a 235 -item scale in English with a five point Likert format was evolved. Seven experts in the field of mental health each of whom with more than 15 years clinical experience in the field, evaluated and scrutinized these items from a large pool of 900 items with regard to content, structure and suitability of the items. It was administered to 350 individuals who were selected by way of a systematic sample with a random start from three representative residential localities of Delhi. Factor analysis of the responses led to the
evolvement of a shorter, refined and factorially validated, 95 item orientation towards mental illness scale.

The 95 item scale was later reduced to 67 items retaining the originality in its entire efficacy. The scale broadly covers four areas:

1. Causation
2. Perception of Abnormality
3. Treatment
4. Aftercare

These four areas are further subcategorized into 13 factors:

1. Causation
   a. Folk belief
   b. Psychosocial stress
   c. Organic causation

2. Perception of Abnormality
   d. Non restrained behaviour
   e. Weak cognitive control
   f. Fidgety behaviour
   g. Bizarre behaviour

3. Treatment
   h. Folk therapy
i. Psychosocial manipulation

j. Physical methods of treatment

4. Aftercare

k. Hopelessness

l. Hypo-functioning

m. Rejection of the mentally ill

Of the 13 factors, four were found to have resemblance to subscales included in the factorially derived tests in the West (Factors 2, 3, 11 and 13), two factors were found to be unique and culture specific to India (Factors 1 and 8) while the other factors (factors 4, 5, 6, 7, 9, 10, 12) were not unique but were independent in nature when compared to the dimensions in the western tools.

Scoring:

The respondents' degree of agreement or disagreement is scored on a five point scale, ranging from Completely Disagree to Completely Agree. Scoring consists of summarizing the response to each statement. This procedure yields a total score for the entire scale, which indicates the extent of unfavorable orientation held by individual, with higher scores indicting a more unfavorable orientation.


The GAF was developed in the early 1990s to rate Axis V of DSM-IV and provides a measure of overall functioning related to
psychiatric symptoms. The GAF is extremely similar to the Global Assessment Scale (GAS) used for the same purpose in the third edition of DSM (DSM-III) and the revised third edition (DSM-III-R), from which it was derived. The scale is clinician rated on a 100-point scale based on all available information, with clear descriptions of each 10-point interval. Ratings are generally made for the past week, but longer intervals (e.g., highest during the past year) can be used. The GAS has received more extensive evaluation and shows fair-to-good reliability and good validity judged against clinician ratings of the degree of impairment. This scale have been used to track change with treatment in inpatient and outpatient practice and in multiple research studies.

5. **WHO Quality of Life Scale (WHOQOL-BREF)**

The WHOQOL-BREF instrument comprises 26 items, which measure four broad domains: physical health, psychological health, social relationships, and environment. The WHOQOL-BREF is a shorter version of the original instrument.

The WHOQOL-BREF assessment shows good to excellent internal consistency, test-retest reliability, discriminant validity, and construct validity in the healthy population and in different patient groups.

Reliability

The evaluation of the WHOQOL-Bref psychometric properties demonstrated good internal consistency and reproducibility. The
internal consistency of the instrument is consistently high in several countries 0.89. The dimensions of the scale have shown internal consistency of physical (0.80), psychological (0.77), social (0.61), environment (0.71). The instrument also shows high test-retest reliability (0.68).

Scoring the WHOQOL-BREF

The WHOQOL-BREF produces a quality of life profile. It is possible to derive four domain scores. There are also two items that are examined separately: question 1 asks about an individual’s overall perception of quality of life and question 2 asks about an individual’s overall perception of their health. The four domain scores denote an individual’s perception of quality of life in each particular domain. Domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life). The mean score of items within each domain is used to calculate the domain score. Mean scores are then multiplied by 4 in order to make domain scores comparable with the scores used in the WHOQOL-100.

Domains of the Scale

<table>
<thead>
<tr>
<th>Domain</th>
<th>Facets Incorporated in the domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physical health</td>
<td>Activities of daily living</td>
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<tr>
<td></td>
<td>Dependence on medicinal substances and medical aids</td>
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<tr>
<td></td>
<td>Energy and fatigue</td>
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<tr>
<td></td>
<td>Mobility</td>
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<tr>
<td>Category</td>
<td>Examples</td>
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<tr>
<td>---------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Pain and discomfort</td>
<td>Sleep and rest</td>
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<tr>
<td>Work Capacity</td>
<td></td>
</tr>
<tr>
<td>2. Psychological</td>
<td>Bodily image and appearance</td>
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<tr>
<td></td>
<td>Negative feelings</td>
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<td></td>
<td>Positive feelings</td>
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<td></td>
<td>Self-esteem</td>
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<td></td>
<td>Spirituality / Religion / Personal beliefs</td>
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<td></td>
<td>Thinking, learning, memory and concentration</td>
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<td>3. Social relationships</td>
<td>Personal relationships</td>
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<td></td>
<td>Social support</td>
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<td></td>
<td>Sexual activity</td>
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<td>4. Environment</td>
<td>Financial resources</td>
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<td></td>
<td>Freedom, physical safety and security</td>
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<td></td>
<td>Health and social care: accessibility and quality</td>
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<td></td>
<td>Home environment</td>
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<td></td>
<td>Opportunities for acquiring new information and skills</td>
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<td></td>
<td>Participation in and opportunities for recreation / leisure activities</td>
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<tr>
<td></td>
<td>Physical environment (pollution / noise / traffic / climate)</td>
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<tr>
<td></td>
<td>Transport</td>
</tr>
</tbody>
</table>
Methods of Data Collection:

Direct interview was adopted as the method of data collection. The investigator collected data from different sources through interview. The key functionary of the organization was interviewed for collecting data about the agency and its functioning. The volunteers were supplied with a questionnaire to understand their orientation to mental illness. The patients were interviewed to understand the satisfaction and quality of life and level of functioning was assessed with the support of volunteers.

Method of Data Analysis:

The quantitative data gathered was analyzed using Predictive Analysis Software (PASW 17.0, SPSS 17.0) (Statistical Package for Social Sciences). The following statistical tests were performed to analyze the data collected:

- Descriptive Statistical measures: Percentage, Ratios Mean, Median and Standard Deviation
- Inferential statistics: ANOVA, t test, Correlation analysis were used for testing of the hypotheses.

3.6 Ethical Issues

The researcher gave due importance to ethical aspects of the study. An informed consent was obtained from the residents before collecting the data. The names of respondents were kept anonymous and were not used in any level of data analysis. The researcher
prepared a list of professionals who can support the respondents at any time, if any emotional reactions arise during or after the interview. The researcher has obtained written permissions from authors whose materials have been extensively used and duly acknowledged all the citations made in this thesis.

3.7 Limitations of the Study

1. The foremost limitation of the study was absence of a comparison group of homeless mentally ill in other settings such as government or professionally managed, for comparing the rehabilitation outcomes

2. The second limitation was the absence of pre data to compare the rehabilitation outcomes of the rehabilitation facilities

3. The third limitation was that the researcher had to visit some of the organizations more than once as the study had extensive data to be collected from three data sources

4. The fourth limitation was the researchers’ inability to conduct qualitative surveys with homeless persons resettled in to the community.

3.8 Chapterisation

1. Introduction
2. Review of literature
3. Methodology
4. Profile of Rehabilitation Facilities & Quality of Services
5. Profile of the Chief Functionary & Care Providers and their Orientation to Mental Illness
6. Profile of Residents and Rehabilitation Outcomes
7. Discussion and Implications for practice
8. Findings & Suggestions