CHAPTER 3

METHODOLOGY

The present chapter is an attempt to elaborate the field of study, field work experiences, methods of data collection and analysis, and ethical considerations. The strength of any research study is in the research methodology adopted for carrying out the study. The chapter is divided into two parts;

- First part consist of
  - Background, Significance and Scope of the study
  - Objectives of the study

- Second part comprises of
  - Methodology: meaning of the concepts of the study and conceptual map, the field and participants, process of data collection, techniques and tools, analysis of data, and limitations
  - Ethical considerations
  - Participants profile

1. Background, Significance, and Scope of the study

Living with schizophrenia is a different world. Researchers always show interest in knowing what exist inside that world. Erving Goffman (1961) gives a detailed narration in his work Asylums on how human beings create their own world when they are in an adverse situation over a period of time. His study is an elaborate account of how people living with mental disorder in a mental hospital construct realities of their day to day life. Goffman insists on their potential to create meaning for every situations happening in their life, and the importance of recognizing that human potential. The perceptions of people are highly influenced by whom they interact with, the environment they live in, situations they face in their life, and the experiences and meaning they derive from it.
This study is motivated by the theoretical underpinnings of Goffman’s (1961) work. The premises of this study lay in the fact that people living with schizophrenia are capable to perceive their life and express their views regarding own life. The basic assumption of this study is that, participation of people living with schizophrenia in the community is an imperative aspect that contributes to their quality of life.

Schizophrenia adversely affects daily life functioning, relationships, work, and social involvement. There are debates on whether schizophrenia is a mental disorder or not. There are different perspectives to explain mental health problems (Pilgrim and Rogers 1997). The approach of people living with schizophrenia towards their life may undergo a change and make them to search for various ways to improve their life situations. The illness depicts the ‘subjective experience and understanding of the same problem from the perspective of the patient (sic) and her caregivers’ (Addlakha 2008, 37). A similar viewpoint is adopted in the present study. The aim of medication is to control the distressing symptoms. This is not adequate to lead a social life since schizophrenia disrupts their daily functioning. The focus of rehabilitation is in rebuilding the skills and abilities affected due to schizophrenia. Imparting various social skills may help people living with schizophrenia in social interactions and develop an ability to function in everyday social situations and provide them a confidence in social living. Gradually PLS will be able to maintain a balance in their life and this will help them to regain the productivity impaired due to schizophrenia.

Participation of people living with schizophrenia in the community is rarely explored. Most of the studies are on community participation than on participation in the community of people living with schizophrenia. The present study tries to understand how people living with schizophrenia perceive their participation in the community and quality of life. Literature shows that participation of people living with schizophrenia in the community is limited due schizophrenia. Quality of life of people living with schizophrenia has always gained attention among researchers in India and worldwide. Literature pertaining to quality of life of people living with schizophrenia is available in abundance, but majority of the studies focus on measuring quality of life than trying to capture the perception of PLS on their quality of life. The feeling of productivity varies in
each individual therefore, it is important to understand individual’s perception on her/his quality of life.

Quality of life is a very well advanced area of research, many studies has taken place and many scales and schedules specifically designed to assess quality of life of people living with schizophrenia are in use. The issue here is that most of the studies/scales/schedules concentrate on measuring objective and subjective aspects of quality of life. They do not give an opportunity to explore it from the perspective of the individual about her/his quality of life. Since schizophrenia is that mental disorder which has dire consequences on quality of life of people living with schizophrenia the components of quality of life will be different. The implication of schizophrenia is not just limited to people living with schizophrenia, but to her/his family and society. Therefore, involvement of individuals, families and communities is desirable for mental health care because family and community play important roles in causation, detection and continued care of people living with schizophrenia (National Institute of Behavioural Science 2009). Understanding participation of people living with schizophrenia in the community contributing to their quality of life will contribute to acquire new insights toward rehabilitation.

2. Objectives of the study

The broad objective of the study ‘to understand the various dimensions of participation in the community and the extent to which PIC influences the quality of life of persons living with schizophrenia and the way people living with schizophrenia perceive their own quality of life’ is formulated keeping in mind the research concern and review of literature. Based on the broad objective certain specific objectives are formulated and each objective is supported by pertinent research questions.

1. To understand the perception of people living with schizophrenia on their participation in the community.
   a. How do people living with schizophrenia view their participation in the community?
b. What are the areas of participation in the community?

c. What are the outcomes or consequences of participation in the community?

2. To study the contribution of Non Governmental Organization (NGO) in eliciting participation of people living with schizophrenia in the community activities.

   a. How does the NGO view participation in the community and the reasons for the same?

   b. What are the various activities organised by the NGO for enabling participation in the community?

   c. What are the ways in which the NGO elicits, sustains, and encourages participation in the community?

   d. What role does the professionals’ and other staff in the NGO play part in enhancing participation in the community?

3. To understand the perception of people living with schizophrenia on their quality of life.

   a. How do people living with schizophrenia perceive their quality of life?

   b. What are the various components they consider as part of their quality of life?

   c. How do those components contribute to their life in general?

4. To understand the implications of participation of people living with schizophrenia in the community on their quality of life.

   a. How do people living with schizophrenia view participation in the community as contributing to quality of life?

5. To identify the role of social support system that enables the person living with schizophrenia in shaping her/his perception on quality of life.
a. What are the various sources from which people living with schizophrenia gets support?

b. What are the implications of social support system on their quality of life?

c. How do professionals assist in improving the quality of life of people living with schizophrenia?

d. How do family members view changes in the quality of life of people living with schizophrenia?

3. Methodology

The choice of methodology is as per the objectives of the study, the participants of the study, process of data collection, and analysis of the data. Keeping in mind the scope, objectives, and significance this study has used qualitative methodology to understand participation of PLS in the community and its influence on their quality of life. Since the focus and effort is to understand the experience of person living with schizophrenia from her/his point of view, it is important to know the subjective meaning associated with that experience. For this purpose it is necessary to use the qualitative approach which is flexible enough to respond to the perceptions of the researched and the field of the study.

‘...Qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials—case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts—that describe routine and problematic moments and meanings in individuals’ lives’ (Denzin and Lincoln 1994, 2).

Ethnography was the method chosen for data collection since the aim of the study was to understand the perception of PLS in the context of their everyday life.

‘For Willis and Trondman (2000) ethnography is a family of methods involving direct and sustained social contact with agents, and richly writing up the
encounter, respecting (at least partly in its own terms) the irreducibility of human experience. Crucial elements are: the understanding and representation of experience; presenting and explaining the culture in which this experience is located, but acknowledging that experience is entrained in the flow of history’ (Cited in Karen O’reilly 2005, 3).

Ethnographic method in this study helped in understanding the everyday life interactions of the participants. Ethnography as a method helps to identify the lived experience of the participants. It assist researcher to observe and interact with participants on a day to day basis. In this approach of data collection the researcher is immersed in the field for a longer period of time to understand the participants’ day to day life (Bryman 2008). Ethnographic method of data collection helped me in understanding the everyday life activities of participants. I was able to observe the interaction among participants, between participants and professionals, and between family and participant.

In order to get a comprehensive picture of each participant case study method was also used while gather information regarding the participants. The participant, her/his family, professionals working with her/him, other significant people, and rehabilitation process are considered as single a case. The advantage of case study method is that it helps to assemble data from various sources to get a comprehensive picture (Soy 1996). This method also assisted in organizing the data related to each participant (case) systematically. ‘…case study is defined by interest in individual cases, not by methods of inquiry used’ (Stake 1994, 236). In depth interview and observation were the techniques used to collect primary information from the participants. Key informant interviews were used to gather information from stakeholders (family and professionals). Interview guide and observation guide were the tools assisted in using interview and observation respectively. The case files of participants and diaries (those who maintained one) have also been referred to get a complete picture.
3.1. Understanding the concepts used in the present study

The concepts used in the present study have been defined in different ways. Among the various definitions the definitions which is quite comprehensive is given below. For the purpose of the study it is necessary to understand these concepts.

3.1.1. Schizophrenia

ICD 10 and DSM IV have defined schizophrenia for diagnostic purposes. Various mental health care organizations define schizophrenia on the basis of the disruption it brings in an individual’s life.

‘Schizophrenia….denotes a severe and complex mental disorder wherein the patient loses the ability to think, feel or behave in a normal way. The patient perceives a distorted reality but is usually unaware that he is ill. Patients also suffer from delusions, i.e., firmly held but false beliefs, and begin to act on them. As a result of their faulty thinking and perception, their behaviour becomes abnormal. Nearly 6–7 million Indians suffer from this disorder variously described as the…“Greatest disabler of youth”. It starts in the most productive period of life 15-45 years and is cosmopolitan in its occurrence. It cuts across barriers of gender, educational and social classes…” (SCARF 2007, 1).

This definition shows the impact of schizophrenia on individual’s life. Any person diagnosed as living with schizophrenia for the past three years is considered as eligible to participate in the study. This will help to recognize the differences in the experience of people living with schizophrenia for a longer duration and shorter duration.

In order to identify participants certain criteria were set. Participants must be free of symptoms and well functioning for last six months to one year. During this period she/he must not have encountered any relapse. This is to ensure that participant is not distressed due to the symptoms and is able to respond to the study. She/he should be availing rehabilitation services from the rehabilitation center (NGO) for at least four months. This four month period will help her/him to get acquainted with the activities and structure of the NGO. This criterion was followed on the basis of my work experience as a residential
psychiatric social worker. The study considers both people living with schizophrenia for a longer period and shorter period. Therefore, the number of attempts at rehabilitation was not a criterion, but any PLS who finished four months of rehabilitation process at the NGO fulfilling other criteria as well was considered eligible for the study.

3.1.2. Participation in the community

The term community involves the people with which person living with schizophrenia interacts, organizations they associate with, friends, relatives, family and whoever plays a part in enhancing a better living condition for people living with schizophrenia. Participation in the community may consist of activities helping in effective cognitive, psychological, vocational, and social functioning. For this study, the term participation in the community of people living with schizophrenia has been understood as

- Participant’s understanding on who she/he is
- Ability to have an understanding on what is happening to self
- Ability to carry out daily life activities and face the day to day life stresses and struggles
- Ability to carry out daily activities of living without support from others
- Ability to involve in social activities
- Involvement in decisions regarding treatment and follow up
- Participation in group activities conducted by organisation (NGO) including recreational activities, educational groups, art therapy, and others
- Visits to places such as parks, museums, religious institutions, movies with family or significant others
- Seeking professional help whenever necessary
- Taking part in vocational activities helping in economic independence and the flexibility of these activities as per nature of schizophrenia

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15 I worked as a residential psychiatric social worker for a year in a residential care facility for people living with mental illness. As per my work experience it take four months for the individual living with schizophrenia to fully understand and adjust with the structure, routine, rules, and activities of the facility.
• Maintaining relationship with family members
• Accessing services of the NGO in terms of distance from home, and transportation facilities available
• Ability to afford the services available in terms of the charges incurred in transportation
• And a feeling that all the above mentioned and other activities (if any) are helping to lead a productive life.

This definition is only for understanding the concept it may change as per the perception of the person living with schizophrenia on her/his participation in the community. In short participation in the community may vary from understanding self to participating in social activities. The accessibility and affordability of the services plays an important role in contributing to the better use of the mental health care services. The need to understand how people living with schizophrenia perceive their participation in the community is important to understand their involvement in the community. The value participants give to the activities they perform or take part may contribute to their quality of life. This view depends on the importance participants attribute to their life or Quality of Life (QOL).

3.1.3. Quality of Life (QOL)

Perception on quality of life differs for each person. The concept of quality of life is appropriately explained in the below definition

‘Quality of life is defined as an individuals’ perception of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards, and concerns. This broad concept incorporates the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment. QOL refers to a subjective evaluation, which includes both positive
and negative dimensions and which is embedded in a cultural, social, and environmental context of the person under consideration’ (Rajkumar 1999, 269).

This definition has incorporated both objective and subjective aspects of quality of life. It also points at the significance of considering the individual’s perception on her/his quality of life. Since quality of life should be viewed from the individual perspective, it is the concerned individual who needs to have the final say about her/his QOL (Brown and Brown 2003). This indicates the need for addressing quality of life of each person separately. Generally quality of life can range from emotional aspects to material aspects. This may consists of the ability to maintain personal hygiene to owing a car. QOL is completely dependent on the individual’s perception on how she/he look at own life and try to value it. The question here is regarding the components of quality of life in a person living with schizophrenia. Their perception on quality of life depends on the nature of illness. For people living with schizophrenia quality of life may range from

- Getting rid of distressing symptoms
- Successful maintenance of personal hygiene,
- Helping at home,
- Doing things without help from others,
- Going for a job,
- Ability to maintain regular attendance at work,
- Being part of a support group,
- Completing responsibilities assigned,
- Taking decisions regarding treatment.

The perception of participants on their quality of life may be different from the above mentioned aspects.
3.1.4. Conceptual Map

People living with schizophrenia
- Perception
- Socio cultural context
- Nature of illness

Participation in the community
- Person living with schizophrenia
  - Understanding on self, face and cope struggles, Decision in treatment and follow up, participation in group activities, areas of participation in the community, meaning of participation in the community, relationship with family members and professionals
- NGO
  - Understanding of Participation in the community, activities organised, professionals’ and other staffs’ role
- Family
  - Understanding of participation in the community, support
- Other contributing factors
  - accessibility and affordability of the services provided by the NGO and family’s willingness to send

Quality of Life:
- Perception
  - Goals, expectations, experiences, concerns, level of independence, personal beliefs, psychosocial performances
- Health
  - Physical health
- Subjective well being
  - Happiness, life satisfaction, and morale
- Social support system
  - social relationships, social network

Figure 2: Conceptual Map
3.2. The Field and the participants

The study was carried out in a Non Governmental Organisation (NGO). Reaching out to NGOs working for people living with schizophrenia or severe mental illness was rather a difficult task. Among the many NGOs contacted for data collection only three responded. Organization A\textsuperscript{16} is the only NGO agreed to participate in the present study. The location of study was Bangalore. Selection of the location was based on the openness of the NGO to participate in the study. The participants of the study were availing rehabilitation services at the NGO during the study. Family members and mental health professionals working closely with participants were the other stakeholders of the study. Before the actual data collection phase, it was necessary to ensure that the location and participants were appropriately chosen. Therefore, data collection was preceded by a field visit to ensure the feasibility of the study and availability of participants. This visit helped to get an idea about the working structure of the NGO, and also to meet a few prospective participants.

The data collection started in the month of May 2010. Interviews were conducted after a month of being in the field. This one month gap was to get acquainted with the field. This time period was required to build a rapport with the participants and stakeholders. Since the study demanded close observation of daily life activities, behavior, and participation of PLS in various areas of life ethnography proved to be an appropriate method for data collection. During the initial month I stayed outside the organization. After a month half way home provided me accommodation at the rehabilitation facility till the end of field work tenure. This helped in getting a closer look at the day to day life of people living with schizophrenia. People living with schizophrenia staying at half way home and long stay home (LSH) were referred as residents\textsuperscript{17} since they reside there. PLS attending day care (DC) was referred as clients\textsuperscript{18} since they avail only day care services.

\textsuperscript{16} This is not the original name of the NGO, for the purpose of confidentiality and anonymity a pseudonym has been used.

\textsuperscript{17} The same term may be interchangeably used in this chapter to refer the members (people living with mental illness) at LSH and HWH.
3.2.1. Organizational profile

Organization A started with the objective of providing psychosocial care to people living with mental illness (PLMI). It runs three different rehabilitation centers catering to the diverse needs of PLMI. The centers are half way home, day care centre, and a long stay home. Each of the facility is designed to cater the specific needs of PLMI.

3.2.1.1. Half Way Home (HWH)

Half way home works on the basis of therapeutic community approach and aims to reintegrate participants back to the family. The focus is to improve social skills and reduce self absorption. The activities organised at HWH are meant to increase the level of independence of the resident members. The facility accommodates 21 resident members at a time and the expected duration of stay at the centre ranges from six months to a year or more. Admission is voluntary which begins with the trial period of 10 days. Illness profile consists of schizophrenia, bipolar mood disorder, schizoaffective, psychosis with OCD, and psychosis with epilepsy. Individual and family counseling sessions are part of the intervention programs. Regular psychiatric consultation and follow up is required and pursued to ensure symptom management.

Resident members lived in shared rooms, took responsibilities of maintaining the house, and supported each other. They followed a daily routine at the centre. Resident members’ performed the duties assigned to them and attended group activities at the stipulated time. Participants had issues with the money management in the past. Therefore, they were allotted a certain amount of money for shopping snacks and other daily requirements. After shopping they had to settle the accounts of expenditure. Participants were allowed to go for short vacations with their families to ensure that they were able to adjust well at home.

Residents choose one of the resident members as the chairperson for that week. The duty of the chair person is to supervise and manage the activities at the centre. She/he has to report the requirements and common needs to the professional staff. Chairperson

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18 The same term may be interchangeably used in this chapter to refer the members (people living with mental illness) at day care
prepares a report evaluating the performance of each resident member for that week. Every member in the centre gets a chance to become the chairperson. This has helped in refining the leadership and communicating skills in resident members. The chairperson’s performance is evaluated by other members. The weekly performance of each resident member is evaluated by other resident members and professional staff. Centre organizes various programs such as talents day, sports week to enable participants to demonstrate their talents. There are resident members who continue their education and work, but stays at the rehabilitation facility. Week days are structured and Sunday is a holiday. Professional staffs’ supervise and assist the residents throughout the process of rehabilitation. Paraprofessional staff helps resident members attending day care in vocational sessions.

3.2.1. 2. Day care (DC)

DC mainly offers group activities and vocational training facilities for PLMI. Vocational training is offered in cover-making, book binding, screen printing, plastic molding, computers and typing, hand block printing, craft work, tailoring and embroidery. Group activities include group therapy, recreational activities, and community meetings for the client members. These activities are exclusively for clients, though a few residents from HWH and LSH attends vocational activities at DC. Clients are given individual attention by the staff team consisting of trained mental health professionals and vocational instructors. The centre also functions as a sheltered workshop. Limited bus facility (pick-up and drop) is available for clients who stay nearby the day care facility. Clients with schizophrenia, affective disorders, intellectual disability, psychosis, obsessive compulsive disorder, and personality disorders within the age limit of 18 – 55 years are provided admission at the centre. The facility accommodates 45 clients at one time and the expected duration of stay is decided by the psychiatrist and family. Admission is voluntary and is finalized after the trial period of two weeks.

Programmes at the day care centre include sessions of vocational training and group activities. The vocational activities are assigned on the basis of client’s need. The client member’s interest in pursuing any particular vocational activity is considered once she/he
has achieved stability in the DC routine. This also depends on the suggestions of the psychiatrist and expectations of family members. The current status of illness, educational level, and vocational background of the clients also influence their participation in DC activities. Other activities include group programmes, planned recreations, games, art and craft activities, and basic arithmetic and language classes (based on the need). Individual counseling and family sessions are held on a regular basis. Clients are assigned the responsibility of chairpersonship and assistant chairpersonship for a week or two. All clients get a chance to become chairperson or assistant chairperson. Clients are given various responsibilities which will be evaluated every week by other clients and staff. This helps them to initiate and fulfill responsibilities, also evaluate own performance over a period of time.

3.2.1. 3. Long Stay Home (LSH)

Long stay home is also known as group home. As the name depicts it is a long term residential care facility for people living with mental illness especially people living with chronic schizophrenia. Admission to the centre is voluntary after a trial period of two weeks. The centre can accommodate 12 members at a time with equal number of seats for males and females. The illness profile consists of chronic schizophrenia. All the resident members are aged above forty five. There are complaints of physical ailments such as diabetes, hypertension, and cholesterol. As in half way home there is a routine for residents, but not very intense. The reason for a relaxed routine is that the aim is to promote a routine life rather than sending them back home. Therapeutic programmes include group activity and community meeting held once in a week. Though group activities are not rigorous, counseling services are intense and provided on a regular basis and also whenever resident member asks for it. Relaxed routine does not imply that resident members are sitting idle. Resident members are more relaxed and enter in different activities. They spend time by watching television, doing craftwork, reading newspaper, going for walk, shopping, sleeping, taking rest, going for consultations, and attending classes.

As in day care and halfway home a chairperson is assigned the responsibility of the house activities. A resident member is assigned the responsibility of chairpersonship for a
week or two to take care of the activities at the centre. The performance of the chairperson and other resident members is evaluated during the community meeting. Each resident member is assigned a duty at the centre. Unlike HWH there is no compulsion on the resident member to perform these duties. Resident members have to report to the professionals if they could not fulfill the assigned responsibility. Family meeting is held twice in a year. Some residents attend vocational sessions at day care centre. Group home provides a family atmosphere where resident members help and care for each other. They seek help from professionals whenever required. Professionals’ does not pressurize resident members to do their duties. This helps resident members to perform their duties with ease and at own pace. Resident members are allowed to go out and spend time outside whenever they want to. They have more freedom than HWH residents and DC clients in terms of going out and spending time outside.

These three centers are designed to provide services as per the requirements of residents and clients. Initially I thought of considering only HWH and DC members in my study since the involvement of family is more visible in their rehabilitation process. After observing the structure and functioning of LSH members during the initial month of data collection I understood it is essential to consider LSH members also for the study. The participation of family in the rehabilitation process of LSH members is limited to financial support, but the level of functioning of the LSH members are appreciable. This prompted me to involve them in my research.

3.3 Process of data collection

My work experience with people living with mental illness helped during the data collection period though here my position was of a researcher. I was confident to talk more about my research to PLS once they were ready to trust me. The biggest challenge in studying PLS was to attain their trust. For this purpose I had to spend a considerable amount of time with them. It was here the ethnographic method of data collection helped me to break that barrier of entering into their space. Since I was staying with them in the rehabilitation facility they could see me on a daily basis. This visibility helped to gain their confidence in me. The reason for adopting ethnography was to understand the lived experiences of participants as closely as possible. This approach helped in observing the
everyday life of PLS without disturbing their routine. Initially I preferred to listen to resident members and observe their activities. This was necessary to understand their routine and relationship with one another. Interviews were started after a month when a participant agreed to give the interview. The process of data collection started at HWH, moving to DC, and eventually winding up at LSH.

3.3.1. Staying at HWH

I stayed at the halfway home and followed the routine at the centre. This helped in building rapport and accepting me as part of the centre. Living in the same place helped me to observe the daily routine of people living with schizophrenia, their interaction with other resident members at the centre, their communication with family, interaction with staff, performance of various duties assigned, and the way they sort out their differences. I also participated in the group activities and other house activities such as vegetable cutting and helping in the kitchen. The nature of participation differed as per the requirement of the study. I used observation method in group activities and the interaction between resident members. They were familiar with students coming for internships and fieldworks at organization A. Therefore, building rapport did not take much time since they considered me as a student initially. Access to secondary sources was allowed without any hesitation. This helped in identifying the people living with schizophrenia and getting acquainted with the structure of HWH.

Interviews were started once participants\(^{19}\) agreed to give interviews. Once the rapport was established participants did not hesitate to open up. After a month they were friendly and started sharing even their day to day experiences. I slowly started to approach people living with schizophrenia to tell about my research. They agreed to participate in the study and signed the consent form. Interestingly a few participants initiated to give interview without approaching them. This was when they came to know about it from those who already gave interviews. After confirming their diagnosis I took their interviews. Since the confidentiality of information shared was assured in advance

\(^{19}\) Participants are people living with schizophrenia who took part in the study. Resident members are all people living with mental illness at HWH.

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participants did not hesitate to take part in the study. Another reason for participating in the study was that someone was there to listen to what they wanted to say.

The first participant was Malleshwaran; he agreed to participate when I told him about my actual purpose of stay at HWH. The only request he made was regarding the use of voice recorder. He did not want me to use a voice recorder, but write down the interview. After the interview he asked me to read the interview to him which I did. He suggested small corrections, but was happy with the interview. The same way other participants also agreed to participate in the study. I made a conscious effort to sit with the resident members during breakfast or lunch or dinner as much as possible. Therefore, I was able to observe how they interact with each other during these occasions. Usually, resident members were served first, and then the professionals and other staff at the centre. Professionals distributed food for resident members to ensure that their food intake was adequate. Everyone was allowed a certain amount of food. Those resident members who had physical ailments such as diabetes, blood pressure, cholesterol were allotted accordingly for health reasons. I was also allowed to serve food to resident members. They were quite jovial during breakfast, lunch, tea, or dinner. Resident members’ sometimes shared their food with each other (while professionals and other staff were not noticing). Most of the time resident members with diabetes found it difficult to fight back their craving for sweet dishes, so they sometimes borrowed from other residents. Professionals were aware of this, but ignored until it became frequent.

The center provided enough freedom to the participants. They were allowed to freely move around the centre and go for a walk to the nearby park. The routine ensured that participants go out for shopping once in a week. Phone calls from family members were allowed frequently and participants could call their family whenever they wanted. Resident members were encouraged to take part in activities related to purchasing at the centre. The involvement of resident members in decision making related to house responsibilities were high. The staff interference is less in the day to day life decisions except for therapeutic interventions. This was to help resident members to function independently.
The professionals were supportive and helped to locate the actual diagnosis of the resident members. Later some of them had issues when I hesitated to share the information from participants. Since my interest was to protect the participants’ feelings I never shared any information from participants with the professionals. They also had issues with participants sharing their feelings with me. A few resident members attended day care facility for vocational training. At times I used to go to day care to observe their performance in vocational sessions. These visits helped me to introduce myself to the client members at day care. After a few days they became familiar with my visits.

The client members were in fact more intriguing than resident members. They showed more interest to know about me and my work. Resident members’ interaction with the client members and staff at DC was good. The clients and the residents had mutual respect among for each others. The fact of living with the mental illness never affected their interaction. I never came across any conversations between resident or client members on their diagnosis or treatment. They usually talk about their daily routine, fashion, sports, food, movies, and programs at the centre. Throughout the process of data collection I was amused to observe the same thing across the centers.

Participants and other resident members play games during certain group sessions which were both fun and educational. Professionals put in a good effort to make the sessions enjoyable along with the learning. I used to participate in every group sessions. I also observed their participation during these group activities. I wrote down field notes whenever possible. Every student in the centre carried a notepad, so it was not an issue to write down notes. To a certain extent I did write my observations on the spot, but sometimes due to work or during conversations with the participants I could not. I wrote those observations after reaching my room. In order to avoid doubt I thought it was better to show the note to the participants and gave them my field notes whenever they asked me for the same. This openness helped me to gain their complete trust and cooperation. Though some PLS refused to take part in the study, they never stopped trusting me in sharing their concerns at the HWH.
3.3.2. Data collection at Day care

After finishing data collection at HWH I proceeded to DC. DC routine was different from HWH routine in many ways. Client members attended various group activities and vocational training sessions in day care. Though, I had occasional visits to the facility it took almost a month to establish rapport and start interviews with PLS. I used to travel in the bus of the rehabilitation facility that picked the resident members, professional staff, students, and client members. Client members wished each other in the morning and were happy to be in the company of other members. They never hesitated to wish me or talk to me. Since the purpose of writing down was already been conveyed, they did not find it difficult. The recognition of prospective participants was carried out after referring the case files.

Participants were cooperative and supportive throughout the study. PLS who refused to take part in the study did not hesitate to share their concerns on education and career. The client members at DC were diagnosed with different mental illnesses. These differences did not affect their interaction. Participants viewed each other with dignity and care. Another interesting fact I observed in DC and HWH was that the fights were less common among client members than resident members. I assume that this may be due to the fact that DC clients went home where resident members stay together. Client members were also careful not to let the arguments reach professionals. Therefore, most of the time they tried to resolve issues among themselves. Client members attended the sessions as per the schedule without any reminder from professionals or para professionals. At times some client members felt restless and in such instances professionals had to motivate them.

Client members at the DC shared their food during lunch. They sat in small circles and enjoyed conversation while having the food. During these lunch breaks members make sure everyone had their food. Client members appreciate those members who prepared food by herself. There were client members’ who preferred to eat alone. In such instances other client members did not disturb them. During vocational sessions I used to sit with client members and work with them. This helped in observing their participation and interaction at the sessions. I was allowed to access case files whenever required. This
helped in attaining information regarding participants’ treatment, admission, and history of illness. There were participants who could not speak English, but they were fluent in Tamil. Since I could speak Tamil this did not pose any issues.

Professionals organized talent days where client and resident members could showcase their talents in singing, dancing, poetry, jokes, and skit. Only a few client and resident members volunteered to participate in the programs. Other participants were continuously motivated by the professionals to take part in the programs. Program days were fun filled since everyone performed her/his part without fearing any criticisms. This had a positive influence on their confidence. Client members were closer to para professionals since they spend more time in vocational sessions than with the professionals. In DC family meetings were held once in two months. I attended two family meetings in DC. Family members/caretakers/guardians came and attended classes taken by professionals on mental illness and treatment. During these classes family clarified their doubts regarding various aspects of illness. After the class a personal session with counselor was also arranged to give feedback on the client member’s performance. Client members enjoyed watching movies on the recreation day. They did not mind watching the same movie again and again because that was the only entertainment at the centre.

Client members usually went for picnics and outings with their family members. At times professionals took them to some exhibitions. Client members enjoyed those moments since they were going out with their friends in a group. The data collection at DC finished within three months. The majority of the interviews were written since participants refused to use the voice recorder. This helped in revising the contents of the interview on the same day and go back to the clients next day in case of any need.

3.3.3. Data Collection at LSH

The professionals at long stay home shared my purpose of stay at the centre during the group session and requested them to participate in the study. This helped in LSH members volunteering for interviews. All the resident members were living with schizophrenia for more than twenty years. They had a flexible schedule than the two
other facilities. Resident members were allowed to move around freely. They go out for a walk and shopping whenever they want to (during the day time). The atmosphere was almost like a home since most of the resident members might remain at the centre for the rest of their life. The participants in the study were quite functional and active.

Every day I reached the facility at eight-thirty or nine in the morning. Resident members were friendly and interacted freely with me. They did not hesitate to share their concerns with me. I spent more time conversing and listening to resident members. This helped in establishing rapport quickly and collecting interviews within a month. Though the freedom compared to other two facilities was high, life at facility was slightly dull due to the same routine. The rules were not imposed on the members. They were free to follow the rules or not, provided it did not create any disturbances for others. Participants of the study volunteered to talk whenever they were free. Interaction between the members was friendly, though sometimes arguments occurred. Talking to me was a kind of relief for some members because they felt that someone was listening to their conversation.

I had a good relationship with the professionals at LSH. They were always supportive and gave me all the information they could possibly give. The relationship between resident members was cordial. When any of the resident members turned symptomatic other members adjusted without any compliant. They would actually take care of the disturbed member. They would try not to disturb the individual, but keep an eye on the member to prevent any self harm. Members helped in cleaning the tables and chopping vegetables for cooking. Sometimes female resident members go out together and have some snacks with the money they saved from the shopping money. There were resident members who went for walk regularly in the park or somewhere near the LSH. Even though it was not expressed overtly LSH members missed their home. At the end of the day they stay away from the family and that was really disappointing for the participants.

3.3.4. Organizing the data

After finishing data collection from PLS I approached family members. Interviews with the family members were held at respective centres. Two family members could not
come to the centre due to ill health and work. In that case I went to their house and office to take the interview. This was a good experience as the family was happy to see me and talked freely about the participant. Two other family members promised to give interviews, but kept on postponing the appointment. Later they stopped responding to the mails and phone calls. Interviews with the LSH participants’ family members were difficult since they were all settled outside Karnataka. Only one family agreed to give interview over phone. This was also because participants called their family members and insisted to give me an interview. The participants were ready to give me more time to clarify my doubts and queries. Most of the interviews recorded in the voice recorder were transcribed during the data collection process. After transcription and reading the interviews I organised the field notes and secondary data. This gave me a comprehensive picture on each participant. Case study method helped to organize the data on each individual participant along with interviews from family and professionals, and secondary sources.

3.3.5. Data collection as an experience of personal growth

The whole process of data collection taught me that to fight mental illness medication, psychotherapy, and social support system is not enough. Confidence in self is equally important to recover from mental illness. This confidence occurs only when individual is treated as an individual rather than a patient. This lesson will definitely help me in my work and life. My experience in data collection has brought a change in me as a researcher, a professional, and a human being. As a researcher data collection helped me to observe the details and listen to participants carefully. As a social work professional I started to explore various possibilities to assist people who approach me for help. Data collection taught me that I have something to learn from every individual I interact with. I started to look at life with more meaning and purpose. Living with schizophrenia is a daily struggle with self. A struggle to identify self, to know what is happening with oneself, and to find self. I understood that sometimes participants want family, professionals, or others to listen to them than spending money.
3.4 Techniques and Tools

A background information sheet was used to collect information regarding the illness profile and socio cultural background. In depth unstructured interviews were supported by an interview guide. The intention of using in depth interview was to understand the perception of people living with schizophrenia. This technique helped me to attain a broader perspective on their participation in the community and quality of life. The guide consisted of areas of enquiry such as their perception regarding own life, day to day activities and routine, participation in the community, social support, and quality of life. Though interview guide helped in initiating the interview process further enquiry was based on the information shared by the participants. Key informant interviews were carried out with family members, professionals, and paraprofessionals. This was supported with a key informant interview guide which consisted of areas of enquiry such as process of rehabilitation, participation of PLS in the community, and the quality of life of PLS. Observation was mainly used in group activities, daily routine, other activities, and programme at NGO. The observations were recorded in the field notes for future reference. Secondary sources such as files, various assessment tools, diaries have been referred to unravel the nuances of the data.

‘Wacquant (2003) Social research is based on the close-up, on the ground observation of people and institutions in real time and space, in which the investigator embeds herself near (or within) the phenomenon so as to detect how and why agents on the scene act, think and feel the way they do (cited in Sal Watt and Julie Jones 2010, 109)

Face to face in depth interviews with PLS has been carried out at their respective . Interview sessions took thirty minutes to two hours and three sessions to six sessions. In halfway home among twelve people living with schizophrenia 8 were ready to participate. Among the eight PLS seven were selected since they fulfilled the criteria. Day care consisted of fourteen people living with schizophrenia. Among the fourteen PLS ten agreed to participate, but nine participated and one withdrew. The participant did not give any reasons for the withdrawal. Long stay home had twelve residents living with schizophrenia. Among the twelve PLS five participated. The principles of saturation and
divergence were followed to decide further interviews. Interviews were conducted when participants were free or after five o’clock in the evening to make sure that interview did not interrupt their routine.

Interviews with family members were carried out at their home, or office, or while visiting the NGO. Two family members were contacted through email, and interviewed over phone. Interview sessions with family took maximum of thirty minutes. Interviews with professional were conducted at rehabilitation centre. Eight mental health professionals and three paraprofessionals were interviewed. Total number of interviews amounted to forty-three composing of twenty-one people living with schizophrenia, nine mental health professionals, three paraprofessionals, and ten family members. Field notes were prepared and every day events were recorded in it. I attended all the functions organised by the NGO so that I could get a clear picture on how they ensure participation of PLS in the community. Informal conversations were helpful while organizing the data. Matrix 2 provides an outline of the process of data collection.

Matrix 2: Process of data collection

<table>
<thead>
<tr>
<th>Time line of data collection</th>
<th>Techniques and tools used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Field observation month before data collection (May 2010)</td>
<td>Observation: observation guide</td>
</tr>
<tr>
<td>Survey of documents at rehabilitation centre</td>
<td>Background information sheet</td>
</tr>
<tr>
<td>- Referring case files of people living with schizophrenia</td>
<td></td>
</tr>
<tr>
<td>- Referring dairies maintained by participants</td>
<td></td>
</tr>
<tr>
<td>- Group activity feedback documents</td>
<td></td>
</tr>
<tr>
<td>- Spend a few days at HWH, DC, and LSH</td>
<td></td>
</tr>
<tr>
<td>- Attended activities at the rehabilitation facility</td>
<td></td>
</tr>
<tr>
<td>01-06-10 to 15-09-10</td>
<td>Interview and observation: Interview guide, Observation guide</td>
</tr>
<tr>
<td>- Interviews with HWH resident participants and transcribing</td>
<td>Background information sheet</td>
</tr>
<tr>
<td>recorded interviews</td>
<td></td>
</tr>
<tr>
<td>- Collecting background information</td>
<td></td>
</tr>
<tr>
<td>- Observing group activities at HWH, daily activities, interaction etc.,</td>
<td></td>
</tr>
</tbody>
</table>
3.5. Analyzis of data

Analyzing data in ethnographic study consist of organizing the data and analyzing it (Jones and Watt 2010). The same was followed in the present study. Majority of the interviews were transcribed during the data collection. The remaining was transcribed after the data collection. Two interviews were in Hindi and Tamil. After transcription these interviews were translated to English. Interviews were read many times to ensure
the themes and subthemes. I prepared notes while reading the interviews which helped during the analysis and writing the chapters. Thematic analysis was the basic form of analysis used in the present study. ‘Thematic analysis involves drawing out key themes from the data and then theoretically framing them, in other words making sense of them’ (Watt and Jones 2010, 162). Significant themes and subthemes were identified and substituted with the quotes and the descriptions of participants. Case summaries were used to substantiate the themes. A matrix of the themes and subthemes were prepared as part of thematic analysis.

Research objectives were also considered while cross examining the themes and subthemes. Cross case analysis was used to locate linkages between the themes and subthemes. A matrix of background information of all participants was prepared. This was done with the help of background information sheet. Comparison of existing literature with the themes and subthemes helped in understanding the existing themes and emerging themes. Secondary data was also analyzed along with the primary data. Secondary data was categorized chronologically to get a pattern of living with schizophrenia over the years. Observation guide reports and field notes enriched the data analysis. Field notes and observation notes were arranged as per the themes to support the narratives.

3.6. Limitations

The scope of the study would have been broader if there were a few interviews with the PLS discharged from the rehabilitation centre and living with the family. I tried to contact some of the participants who were discharged from the rehabilitation centre, but they did not respond to the request for an interview. Though one discharged PLS agreed to participate, he could not find time due to his work schedule. Therefore, the study shows the perspective of PLS availing services at the rehabilitation centre. Contacting family members who were residing outside Karnataka was difficult. Some of the family members kept the appointment on hold and finally stopped responding. Therefore, I could not collect interviews from all the families. The findings of the present study cannot be generalized even to a study conducted in a similar setting.
4. Ethical Guidelines

Participants were provided with a full consent form furnishing the details of the study. Confidentiality of the information shared was assured. NGO and participants were assured that their names or any details will not be revealed or used in the final theses. Pseudonyms were used instead of real names. Interview guide and other tools were given to the NGO research committee for scrutinizing. Participants were informed beforehand that they have the right to withdraw from the study anytime till February 2011. Adequate help was taken from professional staff in case of participants’ who could speak only Kannada with the consent and suggestion from the concerned participants. It was made clear to the staff that any information shared by PLS will not be revealed or shared with them or anyone. Interviews were recorded using a voice recorder with the consent of the participants. In case of participants who were not comfortable with the recording interviews were written down.

Matrix 3: Participants’ profile

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Diagnosis and Duration of illness</th>
<th>Period of stay at rehabilitation facility</th>
<th>Educational qualifications</th>
<th>Care taker</th>
<th>Marital status</th>
<th>Social Support</th>
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</thead>
<tbody>
<tr>
<td>HWH participants</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nalini</td>
<td>42</td>
<td>Paranoid schizophrenia, 20 years</td>
<td>8 months (first admission)</td>
<td>Graduate</td>
<td>Sisters</td>
<td>Unmarried</td>
<td>Family professionals</td>
</tr>
<tr>
<td>Sourav</td>
<td>36</td>
<td>Paranoid schizophrenia, 7 years</td>
<td>7 months (second admission)</td>
<td>Masters</td>
<td>Sisters</td>
<td>Unmarried</td>
<td>Family Professionals, employer</td>
</tr>
<tr>
<td>Malleswaran</td>
<td>46</td>
<td>Paranoid schizophrenia, 19 years</td>
<td>1 year (second admission)</td>
<td>SSC</td>
<td>Mother and sisters</td>
<td>Unmarried</td>
<td>Family professionals</td>
</tr>
<tr>
<td>Kavya</td>
<td>28</td>
<td>Paranoid schizophrenia,</td>
<td>1½ years (first attempt)</td>
<td>PUC passed</td>
<td>Father</td>
<td>Unmarried</td>
<td>Family professionals</td>
</tr>
</tbody>
</table>

93
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Illness</th>
<th>Duration</th>
<th>Qualification</th>
<th>Relationship</th>
<th>Marital Status</th>
<th>Professional</th>
</tr>
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<tbody>
<tr>
<td>Shivani</td>
<td>26</td>
<td>Paranoid schizophrenia, 3 years</td>
<td>1 ½ years (first admission)</td>
<td>Graduate</td>
<td>Father</td>
<td>Unmarried</td>
<td>Family professionals</td>
</tr>
<tr>
<td>Varun</td>
<td>33</td>
<td>Paranoid schizophrenia, 17 years</td>
<td>1 year 3 months (first admission)</td>
<td>Medical professional</td>
<td>Father</td>
<td>Unmarried</td>
<td>Family professionals</td>
</tr>
<tr>
<td>Avinash</td>
<td>25</td>
<td>Paranoid schizophrenia, 3 years</td>
<td>1 ½ years (first admission)</td>
<td>PUC</td>
<td>Mother and step father</td>
<td>Unmarried</td>
<td>Family professionals</td>
</tr>
<tr>
<td>LSH Participants</td>
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<tr>
<td>Mynah</td>
<td>45</td>
<td>Chronic schizophrenia, 30 years</td>
<td>16 years (first admission)</td>
<td>PUC</td>
<td>Maternal relatives</td>
<td>Unmarried</td>
<td>Family professionals</td>
</tr>
<tr>
<td>Avni</td>
<td>60</td>
<td>Chronic schizophrenia, 40 years</td>
<td>11 years (first admission)</td>
<td>PUC</td>
<td>Brother</td>
<td>Divorced</td>
<td>Family professionals</td>
</tr>
<tr>
<td>Maria</td>
<td>59</td>
<td>Paranoid schizophrenia, 37 years</td>
<td>15 years (first admission)</td>
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<td>Distant relative/guardian</td>
<td>Divorced</td>
<td>Relatives, professionals</td>
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<tr>
<td>Akhil</td>
<td>54</td>
<td>Paranoid schizophrenia, 40 years</td>
<td>12 years (first admission)</td>
<td>Graduate</td>
<td>Parents</td>
<td>Unmarried</td>
<td>Family professionals</td>
</tr>
<tr>
<td>Navneet</td>
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<td>Chronic schizophrenia, 30 years</td>
<td>7 years (second admission)</td>
<td>PUC</td>
<td>Father</td>
<td>Unmarried</td>
<td>Family professionals</td>
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<td>DC participants</td>
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<td>Ammal</td>
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<td>Paranoid schizophrenia, 20 years</td>
<td>12 years (first admission)</td>
<td>PUC</td>
<td>Parents</td>
<td>Divorced</td>
<td>Family professionals</td>
</tr>
<tr>
<td>Prema</td>
<td>40</td>
<td>Paranoid schizophrenia, 19 years</td>
<td>2 years (first admission)</td>
<td>PUC</td>
<td>Elder brother</td>
<td>Unmarried</td>
<td>Family professionals</td>
</tr>
<tr>
<td>Hasini</td>
<td>43</td>
<td>Paranoid Schizophrenia, 10-15</td>
<td>2 years (first admission)</td>
<td>Masters</td>
<td>Father and brother</td>
<td>Unmarried</td>
<td>Family professionals</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Diagnosis</td>
<td>Duration (first admission)</td>
<td>Education</td>
<td>Relationship</td>
<td>Marital Status</td>
<td>Other Details</td>
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</tr>
<tr>
<td>Arathi</td>
<td>36</td>
<td>Paranoid schizophrenia, 20 years</td>
<td>1 year</td>
<td>Graduation</td>
<td>Maternal uncles</td>
<td>Divorced</td>
<td>Family Professionals, family friends, Caste group</td>
</tr>
<tr>
<td>Rani</td>
<td>36</td>
<td>Paranoid schizophrenia, 19 years</td>
<td>7 months</td>
<td>PUC</td>
<td>Sister-in-law</td>
<td>Unmarried</td>
<td>Family Professionals</td>
</tr>
<tr>
<td>Kumar</td>
<td>42</td>
<td>Paranoid schizophrenia, 19 years</td>
<td>4 years</td>
<td>PUC</td>
<td>Mother and siblings</td>
<td>Unmarried</td>
<td>Family Professionals</td>
</tr>
<tr>
<td>Ali</td>
<td>38</td>
<td>Paranoid schizophrenia, 20 years</td>
<td>7 months</td>
<td>PUC</td>
<td>Parents</td>
<td>Unmarried</td>
<td>Family Professionals Religious group</td>
</tr>
<tr>
<td>Virat</td>
<td>36</td>
<td>Paranoid schizophrenia, 20 years</td>
<td>12 years</td>
<td>SSC</td>
<td>Parents</td>
<td>Unmarried</td>
<td>Family Professionals</td>
</tr>
<tr>
<td>Raju</td>
<td>23</td>
<td>Paranoid schizophrenia, 6-8 years</td>
<td>8 months</td>
<td>PUC</td>
<td>Father</td>
<td>Unmarried</td>
<td>Family Professionals</td>
</tr>
</tbody>
</table>